

Improving Shared Decision Making in End Stage Renal Disease in Saudi Arabia

Nuha Ayad H Alatawi

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Abstract

Background: End-stage renal disease remains challenging to manage in the Saudi Arabian context. Patients with end-stage renal disease and their families are faced with incrementally more complex decisions throughout their treatment journey. There is potential to address this complex decision making through the use of the patient decision aids. However, Saudi Arabia lacks such patient decision aid tools for use in the renal context.

Aim: This thesis explores the educational needs and experiences of patients with end-stage renal disease and/or their family caregivers regarding current advance care planning and shared decision-making practices in a dialysis unit in Tabuk, Saudi Arabia. Subsequently, the study culturally adapts and translates a patient decision aids tool relevant to Saudi Arabian patients with end-stage renal disease and their family caregivers.

Methods: The data were collected in two phases using a pragmatic qualitative research design. Phase 1 involved semi-structured interviews with five end-stage renal disease patients and/or their family caregivers, recruited from a dialysis unit in Tabuk, Saudi Arabia, to explore their educational needs and experiences in communication issues such as advance care planning discussions and the shared decision-making process. Additionally, a modified systematic review in the Muslim context was conducted for an in-depth exploration of these issues. Data from Phase 1 were used to select an evidence-based patient decision aid suitable for adaptation to the Saudi Arabian context. Phase 2 consisted of semi-structured interviews with nine renal care experts and formal discussions with the original authors of the chosen tool Yorkshire Dialysis and Conservative Care Decision Aid into the Saudi Arabian context. The adapted tool was then translated into Arabic using a forward-backward technique. Three additional semi-structured interviews were held with experts to assess the content validity of the translated tool and to develop a preliminary implementation plan.

Findings: The findings from participants' interviews and the modified systematic review indicated that Saudi end stage renal disease patients, and their family caregivers' as well as other Muslim renal patients' education needs were unmet. Hence, these findings were incorporated in the sense that they reinforced the point that an educational intervention was

needed, such as a patient decision aids tools. Such a tool can facilitate communication, improve information reception, and foster informed decisions. Additionally, they can improve shared decision-making practices within Muslim contexts. Consequently, the evidence-based Yorkshire Dialysis and Conservative Care Decision Aid intervention was chosen for cultural adaptation to the Saudi Arabian context. A cultural adaptation of Yorkshire Dialysis and Conservative Care Decision Aid unpase 2 by combining the expert data and discussions with its authors. Translation was done using a forward-backward technique. Adaptation and translation involved a six version and six subversion iterative process. The content validity test and expert feedback indicated that the adapted Yorkshire Dialysis and Conservative Care Decision Aid was culturally appropriate and acceptable for Saudi Arabian contexts, but the Arabic translation needed to be revised. A preliminary implementation plan was developed in response to all input.

Conclusion: In Saudi Arabia, end-stage renal disease patients and their family caregivers have limited knowledge of end-stage renal disease prognoses and alternative management options for end-stage renal disease. Decision-making around conservative management of end-stage renal disease in Saudi Arabia is insufficient, rendering the shared decision-making process complex and challenging. To facilitate the decision-making process, the Yorkshire Dialysis and Conservative Care Decision Aid intervention was adapted successfully to the Saudi Arabian context. However, the findings suggest that further testing of validity and acceptability should involve a larger sample size that includes renal patients, caregivers and healthcare providers to confirm the reported findings. Moreover, further research is needed to examine how the adapted tool is implemented and delivered, as well as the barriers that may arise within healthcare settings.

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List of Abbreviations

Applied Social Sciences Index and Abstracts	ASSIA
Advance Care Directive	ACD
Advance Care Planning	АСР
Advance Care Planning -Sharing Patients' Illness Representations to	ACP-SPIRIT
Increase Trust	
Advance Directives	ADs
Cardiopulmonary Resuscitation	CPR
Central Intelligence Agency	CIA
Central Statistics and Information Department	CDSI
Chronic Kidney Disease	СКД
Chronic Kidney Disease–Mineral and Bone Disorder	CKD-MBD
Communication and Bioethical Training	CoBIT
Complementary and Alternative Medicine	САМ
CPR-Video Decision Aid	CPR-VDA
Cumulative Index to Nursing & Allied Health Literature	CINAHL
Decision Aid	DA
Decision-Making	DM
Do Not Resuscitate	DNR
End-of-life	EoL
End-Stage Renal Disease	ESRD
Established Kidney Disease	EKD
European Association for Palliative Care	EAPC
Evidence-Based Medicine	EBM
Focus Group Discussions	FGDs
Glomerular Filtration Rate	GFR
Gross Domestic Product	GDP
Haemodialysis	HD
Healthcare Providers	HCPs
Home Haemodialysis	нн

International Society of Nephrology	ISN
Joanna Briggs Institute	JBI
Kidney Disease Improving Global Outcomes	KDIGO
King Faisal Specialist Hospital and Research Centre	KFSHRC
King Salman Armed Forces Hospital, North-western Region	KSAFHNWR
Life-sustaining treatments	LSTs
Medical Literature Analysis and Retrieval System Online	Medline
Medical Order for Life-Sustaining Treatment	MOLST
Metastatic Colorectal Cancer	mCRC
Ministry of Health	МОН
Mixed-Method Systematic Review	MMSR
Muslim-Majority Countries	MMCs
National Institute for Health and Care Excellence	NICE
National Kidney Foundation	NKF
National Kidney Foundation–Kidney Disease Outcomes Quality	NKF-KDOQI
Initiative	
National Transformation Program	NTP
Ottawa Decision Support Framework	ODSF
Participant-Phenomena of Interest-Context	PICo
Patient decision aids	PtDAs
Patient-Centred Advance Care Planning	PC-ACP
Per Million Population	pmp
Peritoneal Dialysis	PD
Preferred Reporting Items for Systematic Reviews and Meta-	PRISMA
Analyses	
Primary Healthcare	РНС
Provider Orders for Life-Sustaining Treatments	POLST
Quality of life	QoL
Randomized Controlled Trials	RCTs
Renal Replacement Therapy	RRT
Renal-specific Advanced Communication Training	REACT

Saudi Centre for Organ Transplantation	SCOT
Saudi Commission for Health Specialties	SCFHS
Saudi Society of Nephrology and Transplantation	SSN&T
Shared Decision Making	SDM
Shared End-Stage Renal Patients - Decision Making	SHERPA-DM
The Renal Physicians' Association/American Society of Nephrology	RPA/ASN
United Kingdom	UK
United States of America	USA
Virtual Private Network	VPN
World Health Organisation	WHO
Yorkshire Dialysis and Conservative Care Decision Aid	YoDCA
Yorkshire Dialysis Decision Aid Booklet	YoDDA

Preface

In 2011, I graduated from a nursing school in Jeddah, Saudi Arabia. I interned at the King Salman Armed Forces Hospital, North-western Region in Tabuk city for my internship year. The last rotation for me was a month in the adult intensive care unit. After that, I chose to spend two months elective training in this area, which was one of the obligatory rotations for interns. During that time, I gained a lot of experience under close supervision from another experienced nurse. I cared for patients who had different life-threatening conditions, conscious patients, unconscious patients, and patients with do-not-resuscitate orders, as well as some renal patients. At that time, it was the first time I had heard of palliative and end-of-life care terms, and my mind blanked out due to these new terms and my lack of experience dealing with them. Although overall, I had a wonderful experience, there were some challenges. The main challenge was cultural and language differences between patients and healthcare providers.

Saudi Arabia is a Muslim country, and at that time, most of the nursing staff members were non-Muslims. In particular, providing care for dying patients and respecting patients' family beliefs are important. Another concern was involving patients and their families in end-of-life care decisions, such as do-not-resuscitate decisions. It was a great experience, but because of my student status and limited experience, I left that area with many questions. Subsequently, I worked as a lecturer in the nursing department at Tabuk University in Saudi Arabia. Undergraduate nursing curricula at that time did not include any subject related to palliative and end-of-life care. Further, my master's degree in Nottingham involved a completely different subject, and an elective subject related to palliative care and end-of-life care was not available. These gaps motivated me to consider palliative care and end-of-life care and to explore relevant studies. Thus, a specific interest arose as I recognised that exploring renal patients' and their families' experiences in the field of end-of-life care communication issues is an under-researched area.

Declaration

I, the author, confirm that the Thesis is my own work. I am aware of the University's Guidance on the Use of Unfair Means (<u>www.sheffield.ac.uk/ssid/unfair-means</u>). This work has not previously been presented for an award at this, or any other, university.

Chapter 1: Introduction and Background

1.0 Introduction

This chapter provides a brief overview of the current study, and an outline of this thesis is also presented. A comprehensive overview of the study context is presented. Saudi Arabia's healthcare system and an overview of end-stage renal disease, available treatment options, and alternative treatments are described. The chapter also discusses palliative care in the Saudi Arabian context and its limitations and approaches.

1.1 Study Overview

End-stage renal disease (ESRD) is defined as stage five chronic kidney disease (CKD). Due to their heavy symptom burdens and reduced life expectancies, ESRD patients require palliative care (Feyi *et al.*, 2015). Western countries have broadened palliative care's scope to address the needs of non-cancer patients (Chambers, Germain and Brown, 2010). Palliative care support for ESRD patients can include symptom management, advance care planning (ACP), decision-making (DM), and patients and their families' education (Kane, Vinen and Murtagh, 2013). Patients with ESRD face several choices about treatment and end-of-life (EoL), and many choose life-sustaining treatments (LSTs), such as dialysis or shifting from curative measures, over palliative care (which treats advanced renal disease without dialysis). Shared decision making (SDM) can be beneficial to patients facing such difficult choices. Patient decision aids (PtDAs) have emerged as effective educational interventions for improving ACP discussion and SDM in many conditions, including ESRD.

ESRD patients and their families are likely to have palliative care needs, yet in Saudi Arabia, non-cancer patients, especially renal patients facing life-threatening conditions, have very limited or no access to palliative care. Further, cultural differences, particularly language gaps between patients and their healthcare providers (HCPs), are major barriers that negatively affect EoL care. Furthermore, no PtDAs have been developed or evaluated to improve care and SDM for Saudi Arabian ESRD patients. This thesis, therefore, aims to improve SDM for ESRD in the Saudi Arabian context by exploring the educational needs and experiences of ESRD patients and/or their family caregivers regarding current ACP and SDM practices in a dialysis unit in Tabuk, Saudi Arabia. Subsequently, the study culturally adapts and translates a decision aid tool to be relevant to Saudi Arabian patients with ESRD and their family

caregivers. Participants include ESRD patients, their family caregivers, renal HCPs, and academic scholars with renal expertise. To this end, the thesis employs an exploratory, pragmatic qualitative research design using multimethod qualitative studies, conducted in two phases.

1.1.1 Thesis Structure

This thesis comprises eight chapters. It begins with the current chapter, an introduction and background chapter that provides an overview of the study and describes the context that informed the research. The chapter introduces Saudi Arabia, the country in which the study was conducted, and describes its healthcare system. In addition to discussing ESRD, its alternative treatments, and palliative care, the chapter offers insight into palliative care's nature and limitations within the Saudi Arabian context. The other chapters are described below.

Chapter 2: This chapter describes a scoping review of current educational interventions relating to renal palliative care, especially communication regarding ACP and DM around ESRD. The chapter concludes by identifying gaps in research in the field.

Chapter 3: In this chapter, the key findings of the scoping review are revisited, which helps explain the rationale for the current thesis. Following this, the thesis aims and objectives are outlined. Then, the study's research methodology and the philosophical background of the chosen research method are described. This chapter concludes with a discussion of the pragmatic qualitative research design and the reasons for choosing it.

Chapter 4: In this chapter, an explanation of the methods is presented. The chapter then discusses the planning prior to data collection. Two phases of collecting data are discussed next, each of which included setting, participants, recruitment process, and data collection method and procedure. Next, it describes the importance of cultural adaptation to an intervention and the chosen adaptation intervention, including the reasons for its choice. It also describes the adaptation model used. An overview of techniques for data analysis is provided, as well as the challenges associated with managing, collecting, and writing data. This chapter concludes with an evaluation of the quality of the qualitative study.

Chapter 5: In this chapter, the key findings of phase one of the study are presented in detail. There are two parts in this chapter, each exploring different findings. Part 1 presents Phase 1A findings that emerged from a qualitative exploratory study of ESRD patients' and/or their family caregivers' needs and experiences related to ACP and SDM in Saudi Arabian contexts. Part 2 presents Phase 1B findings that emerged from the modified systematic review, which focuses on ESRD patients' and/or their families' experiences related to ACP discussion and the DM process. The chapter then presents a synthesis and integration of the findings.

Chapter 6: This chapter contains the findings from qualitative interviews conducted with a diverse range of renal care experts working in clinical and academic research roles, which is the first step in the cultural adaptation of the Decision Aid (DA) tool, which is Yorkshire Dialysis and Conservative Care Decision Aid (YoDCA). A summary of the results of the interviews is presented in two parts. In the first part, the data concern the experts' experiences providing care for renal patients. The second part presents patients' views on the cultural adaptation of the selected DA tool.

Chapter 7: This chapter presents the additional steps used to culturally adapt and translate the YoDCA and considers the aspects that need to be considered in making the intervention relevant to Muslims, particularly Saudis. It also presents the content validity testing of the adapted and translated tool and the developed preliminary implementation plan.

Chapter 8: This chapter presents a discussion of this study's findings. A brief summary of the study is provided, and then each phase's key findings are presented and contextualised within relevant literature. This chapter discusses how this study contributes new insights and contrasts with previous research. The study's strengths and limitations are evaluated, and the implications of the findings for future research, clinical practice, and policy are described, followed by the thesis conclusion and a personal reflection.

1.2 Background

This section discusses Saudi Arabia's healthcare system and ESRD to establish the context for the proposed research study.

1.2.1 Saudi Arabia's Demographic and Economic Context

Saudi Arabia is located southwest of the Asian continent, on the Arabian Peninsula. The country has a land area of two million square kilometres, making it the largest in the Middle East. The Saudi Arabian population grew significantly from 1980–2015 and is expected to reach 77.2 million by 2050 (Colliers International, 2018). Its estimated population was 37 million in mid-2023, and its annual growth rate was 1.48% in 2023 (Worldometers, 2023). Urban populations exceed 85%, and Saudi Arabia's society is very young, with 51.1% of the population under 30 years old (General Authority of Statistic, 2022). The average life expectancy for men and women is predicted to increase from 73.1 and 76.1 to 78.4 and 81.3, respectively, by 2050 (Colliers International, 2018). The Saudi Ministry of Health (MOH) (2020) estimates that the number of elderly people (ages 60–79) will increase from 1.96 million in 2018 to 4.63 million by mid-2030. The lengthened lifespan has a significant effect on the need for quality healthcare and the types of facilities used to provide it, such as long-term care facilities, geriatric care services, rehabilitation centres, and home healthcare (Colliers International, 2018). A crude death rate of 2.4 per 1,000 Saudis was reported by the MOH in 2021.

Regarding literacy levels, the World Health Organization (WHO) (2013) indicated that the overall population with secondary and tertiary education qualifications in Saudi Arabia has increased over the years. Saudi Arabia's economy is strongly founded on its massive oil wealth. However, other industries, primarily in the private sector, also contribute significantly to its stability. Almasabi (2013) stated that 45% of Saudi Arabia's gross domestic product (GDP) is derived from oil, while 55% comes from the private sector. The stabilised Saudi Arabia economy has had positive effects on healthcare financing, thus promoting residents' healthcare outcomes. The provision of medical equipment has grown by 10% annually since 2018, and public awareness of health-related issues is increasing (Global Health Exhibition by Informa Markets, 2019).

1.2.2 Saudi Culture

Culture, beliefs, and norms have a significant influence on Saudi Arabian people. Culture is defined as a set of beliefs, behaviour patterns, values, customs, and symbols that are shared between generations (Cortis, 2004). Sobo and Loustaunau (2010) defined culture as a system of norms, values, and beliefs that guide and influence behaviour. Al-Shahri (2002) identified several factors that contribute to a society's culture, including religious, racial, educational, economic, and environmental factors. Thus, it is important to connect religion to culture. Islam is the most practiced religion in Saudi Arabia and the most important factor responsible for shaping Saudi culture. Saudi culture is characterised by a blend of Arabic tribal traditions and customs, as well as a worldview rooted in Islam that informs attitudes and behaviours (Almutairi and McCarthy, 2012) and evidently affects healthcare delivery. Islam promotes healthy lifestyles; it encourages cleanliness, breastfeeding, moderate eating, and regular physical exercise—all positive influences on quality of life (QoL) and health outcomes (Almasabi, 2013). Islam's influence, however, is not always positive. As an example, Saudi Arabia's male guardianship system and gender segregation affect women's access to, quality of, and outcomes from healthcare.

Culture and religion have a major influence on the health context. Cultural influences on perceptions and experiences of health and illness are numerous (Sobo and Luostuana, 2010). Al-Shahri (2002) indicated that Muslims claim sickness is caused by immoral behaviour and is not a punishment from Allah (other name of God), but it is a way of atonement for one's sins. Although the Islamic faith encourages the seeking of medical treatment and help, it is essential for Muslim patients to pray and exercise patience so that Allah can help and forgive them (Almutairi and McCarthy, 2012). Therefore, prayer is considered vital during sickness; most Saudis would appreciate medical and nursing interventions being postponed during the 'prayer hour' (Al Mutair *et al.*, 2014). Such beliefs, when not fully incorporated into healthcare service delivery, may impede care and eventually affect the overall quality of health and healthcare outcomes.

Another cultural norm is traditional practices and beliefs about spiritual healing and traditional medicine. Saudi people practice spiritual healing for a variety of illnesses, such as incurable diseases, poisonous stings, Jinn possession, and evil-eye symptoms (Al-Shahri, 2002;

Al Mutair *et al.*, 2014). Conditions such as these can be treated by reading the Noble Qur'an and listening to the words of the Prophet Mohammed (peace be upon him), eating honey and black sesame, drinking Zamzam water, and taking traditional herbal remedies (Al-Shahri, 2002). It has also been suggested that cultural differences may affect the type of information shared between clinicians and clients when informing them of their diagnoses (De Pentheny O'Kelly, Urch and Brown, 2011). Muslims, for instance, would not expect to discuss medical information with patients directly but rather with relatives. Thus, it is very important to promote cultural awareness and encourage culturally sensitive attitudes and practices among HCPs to contribute to providing quality healthcare to patients with different cultural backgrounds.

Islam also affects family structure and the essence of family relationships. In Islam, family members are encouraged to visit one another, celebrate, provide money, support one another when in need, and show appropriate respect (Al-Saggaf, 2004). The Saudi family operates as a unit and is involved in all aspects of individuals' lives (Al Mutair et al., 2014). Silbermann et al. (2012) described the family's strong supportive role in a patient's psychological adjustment and adherence to treatment during and after active illness. Yet, despite their central care-providing role, families may also influence quality care delivery. In Saudi society, patients' decisions may be changed by their families (Al-Shahri, 2002), and familial authority often overrules patients' autonomy. Additionally, women may feel uncomfortable making important medical decisions without their husbands or fathers present (Hollins, 2009). Often, those who depend on their families for care are hesitant to seek healthcare, especially preventive care. Due to Saudi cultural concerns, conventional medical approaches must be modified to accommodate all patient and family needs. Thus, Saudi Arabia's healthcare system should aim to meet both patients' and families' needs while promoting family-centred care and family inclusion (Al Mutair et al., 2014). Thus, understanding culture can help us understand the social group as well as how culture influences illness-related behaviours.

1.3 Overview of the Saudi Arabia Healthcare System

1.3.1 Healthcare Facilities and Structures

Both governmental (MOH and other governmental agencies) and private healthcare facilities exist in Saudi Arabia, which operates 497 hospitals, with 77,224 beds. Most healthcare services are currently provided by the MOH (MOH, 2021). Notably, about 60% of the services provided by the public sector are free (Alharbi, 2018). Healthcare is structured into three major tiers: primary, secondary, and tertiary care (Almalki, FitzGerald and Clark, 2011). Primary care includes the most basic healthcare services: preventive care, rehabilitative services, and general health education (Almasabi, 2013). Secondary care entails a second tier, to which primary care patients are referred for further treatment (Almalki, FitzGerald and Clark, 2011). Tertiary care provides specialist services via state-of-the-art facilities, offering services to patients across a spectrum of advanced-level diseases (Albejaidi, 2010). However, there are no clear communication channels or referral processes among multidisciplinary HCPs at these levels. No communication channels exist between secondary or tertiary care and primary care, preventing patients from returning to primary care after such referrals (Asmri *et al.*, 2020). Thus, the result is a waste of healthcare resources and duplicate efforts on the part of the government when providing healthcare services to the population.

1.3.2 Challenges Facing the Healthcare System

As in all countries, Saudi Arabia's healthcare system faces challenges. Among the challenges facing the healthcare sector are an increasing population, high healthcare costs, inequitable access, concerns over quality and safety, an increase in chronic diseases, an ineffective electronic health system (eHealth), a lack of coordination and cooperation between other areas of care, and a highly centralised system (Almutairi and Moussa, 2014; Yusuf, 2014). One of the most apparent is the rising turnover of expatriate HCPs and the lack of Saudi HCPs to replace them (Almasabi, 2013). Saudi Arabia largely relies on its foreign workforce to provide healthcare services (WHO, 2013). Saudi physicians comprise only 49.6% and Saudi nurses comprise 63.1% of all those in Saudi Arabia (MOH, 2021). Non-Saudi HCPs arrive with a limited understanding of Saudi society and Islam. In this situation, communication barriers and cultural tensions may arise, posing a threat to patient safety and the quality of care. To overcome this, there has been an increased emphasis on the 'Saudiisation' of non-Saudi HCPs over the past decade (Almalki, FitzGerald and Clark, 2011). Another challenge is that of

increased costs; healthcare services are a huge burden on Saudi Arabia's financial resources. Saudi Arabia also receives more than five million pilgrims each year and ends up providing them with free healthcare services. This has huge implications for the healthcare system's financial stability (Almasabi, 2013). Meanwhile, Saudi Arabia's own dramatic population growth means that patients may face long waiting periods to see HCPs (Almasabi, 2013).

The Saudi Arabia government implemented a comprehensive strategic plan called 'Vision 2030' in 2016, which aimed to address these issues (Kingdom of Saudi Arabia Vision, 2030). Among the executive programmes to achieve the vision was the National Transformation Program (NTP) – 2020, which encourages privatisation and private partnerships (Alasiri and Mohammed, 2022). In line with the Vision 2030, three major healthcare transformation objectives are set out in the NTP: the three elements of improving healthcare are improving access to care, enhancing quality and efficiency, and promoting disease prevention. To achieve the three main healthcare transformation objectives by 2030, the NTP anticipates that a 40% contribution to GDP from the private sector will grow to 65% (Global Health Exhibition by Informa Markets, 2019; Alasiri and Mohammed, 2022). It has been allocating increased financial resources, with the MoH expected to spend approximately 71 billion US dollars for the year ending 2020 (Global Health Exhibition by Informa Markets, 2019). Another important point to mention is that Saudi Arabia has largely invested in the training of human resources in healthcare (Albejaidi, 2010). Evidently, increased investments in modern medical equipment coupled with highly qualified staff will help the country realise its goals towards improved healthcare outcomes over the coming years.

1.4 Chronic Kidney Disease

CKD is identified when the glomeruli of the kidney have a filtration rate below 60 mL/min/1.73 m² and/or the kidney displays damage indicators lasting for more than three months (kidney disease: Improving Global Outcomes (KDIGO) chronic kidney disease–Mineral and Bone Disorder (CKD-MBD) Update Work Group (KDIGO), 2017). CKD is graded in five stages, from 'moderate' to 'severe', based on the filtration rate according to KDIGO (KDIGO, 2017; see Table 1). According to the National Institute for Health and Care Excellence (NICE) (2021), CKD is not static but may progress into established renal failure or ESRD. In the literature, ESRD is an older term used to describe stage 5—the last stage—of CKD (Cohen *et al.*, 2006). It is

necessary to replace the kidneys of patients with ESRD with either dialysis or transplantation to allow them to survive (Thomas, 2014). According to the National Kidney Foundation (NKF) (2023), dialysis patients have an average life expectancy of 5–10 years, which is influenced by their health status and other factors.

Stages of	Glomerular Filtration Rate	Description	
CKD	(GFR) (ml/min/1.73m2)		
Stage 1	90 or higher	Kidney damage with normal function of the kidney and other	
		evidence of kidney damage*	
Stage 2	89 to 60	Kidney damage with mild kidney function loss and other kidney	
		damage evidence *	
Stage 3 a	59 to 45	Kidney damage is mild to moderate	
stage 3 b	44 to 30	Kidney damage is moderate to severe	
stage 4	29 to 15	Severe loss of kidney function	
stage 5	Less than 15	Kidney failure	
* Chronic kidney damage evidence includes chronic microalbuminuria or proteinuria, haematuria, structural			
defects, and confirmed glomerulonephritis biopsy (KDIGO, 2017).			

Table 1: Chronic Kidne	y Disease Stages
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1.4.1 Epidemiology of End Stage Renal Disease

The prevalence of CKD is growing worldwide, posing a significant threat to public health. CKD grew from 18th place on the list of leading causes of death in 1990 to 11th place in 2016 (Vos *et al.*, 2017), with predictions for it becoming the 5th greatest cause of death by 2040 (Foreman *et al.*, 2018). There are more than 750 million sufferers worldwide (Kassebaum *et al.*, 2016; Crews, Bello and Saadi, 2019). Approximately three million people worldwide are currently receiving renal replacement therapy (RRT) (Moura-Neto, Divino-Filho and Ronco, 2021). The incidence of CKD in Middle Eastern countries is largely unknown (Shaheen and Souqiyyeh, 2010; Farag, Kari and Singh, 2013). This is due to a lack of population-based studies (Shaheen and Souqiyyeh, 2010), the lack of a registry system for recording prevalence and incidence, and poor access to healthcare (Farag, Kari and Singh, 2013). Thus, the exact number of patients with CKD and ESRD is unknown in the Middle East.

Hence, ESRD prevalence and incidence may be higher than reported, which may result in an underestimation of its effects (Farag, Kari and Singh, 2013). Therefore, early detection and prevention of the disease are crucial. ESRD incidence, however, has been estimated to be between 100 and 140 cases per million population (Shaheen and Souqiyyeh, 2010). In a recent systematic review (Malekmakan *et al.*, 2018), the prevalence of ESRD was reported as 360 per million population in Middle Eastern countries. ESRD prevalence is highest in Saudi Arabia (Abboud, 2006). According to Almutairi *et al.* (2017), the incidence and prevalence of ESRD in Saudi Arabia have increased by an estimated 513 cases per one million people over the last three decades.

Many factors may be contributing to Saudi Arabia's significant increase in the prevalence of ESRD, including increasing life expectancy, urbanisation, changing age demographics, the prevalence of diabetes and hypertension, and lifestyle risk factors such as obesity, smoking, and a lack of exercise (Hill *et al.*, 2016). In Saudi Arabia, chronic diseases such as diabetes and hypertension have become more prevalent, which may explain the rising risk of ESRD (Narres *et al.*, 2016). Saudi Arabia shares some factors with other countries; however, certain factors are unique to the country. For instance, in Saudi Arabia, consanguineous marriages are common; therefore, kidney diseases inherited through recessive mutation inheritance are common (Kari *et al.*, 2014; Mousa *et al.*, 2021). Hassanien *et al.* (2012) predicted that ESRD in countries of the Gulf Cooperation Council, including Saudi Arabia, will cause increased hospitalisations, morbidity, and a greater need for RRT in the future due to the prevalence of the disease. With limited resources, this increase in healthcare service demand may affect the quality of care. Although these factors have led to a marked increase in CKD burden (Xie *et al.*, 2018), little is known about the burden of CKD in the Arab world (Oyouni *et al.*, 2020).

1.4.2 Management of End Stage Renal Disease

CKD management depends on the stage of renal disease. It is recommended that patients at stages 1 and 2 receive no special interventions. Patients at stages 3a and 3b are treated by primary care, patients at stages 4 are referred to renal teams (pre-dialysis phase), and patients at stages 5 or ESRD require RRT or conservative management (Thomas, 2014). RRT includes haemodialysis (HD), peritoneal dialysis (PD), and kidney transplants. The conservative management of ESRD involves managing symptoms, monitoring renal function

and electrolyte levels, and managing medication and diet (Combs and Davison, 2015). The conservative management approach can be described as part of palliative care. However, according to the Saudi Centre for Organ Transplantation (SCOT), there are two treatment options available for patients with ESRD in Saudi Arabia: dialysis and renal transplantation (SCOT, 2017c). In Saudi Arabia, conservative management is not available as a treatment option for ESRD patients (MOH, 2014) due to the lack of official guidance for offering conservative management, along with religious and cultural factors.

Although there is no official guidance for offering conservative management, nonetheless, some patients receive conservative management for various reasons. These include elderly people who are admitted to the intensive care unit with comorbidities and patients with a do-not-resuscitate order. Kidney transplantation is the preferred treatment for ESRD (Abecassis *et al.*, 2008; Nath and Fervenza, 2018). However, in Saudi Arabia, kidney transplantation accounted for only 4.5% of the total RRT in 2016 (SCOT, 2017c). Due to shortages of donors and medical facilities and recipients' ineligibility, kidney transplants are not always possible (Abecassis *et al.*, 2008; Alobaidi *et al.*, 2021). Dialysis is therefore the treatment of choice for most patients. Al-Syyari and Shaheen (2011) traced the history of dialysis and renal transplants in Saudi Arabia to 1971 and 1979, respectively. Since the inception of these services, Saudi Arabia has progressively improved the coverage of patients accessing dialysis. Saudi Arabia had 322 dialysis centres in 2020 (MOH, 2021).

There are three main dialysis types: in-centre haemodialysis (HD), home haemodialysis (HH), and peritoneal dialysis (PD) (Thomas, 2014). Each has its own pros and cons, and the choice depends on each individual's clinical, and lifestyle needs. According to SCOT's latest annual statistical report, 18,270 (62%) RRT patients are on HD, and 1,389 (5%) are on PD (SCOT, 2017 a, b). The prevalence of HD is due to many reasons, including a lack of access to veins or arteries, or cardiovascular instability that may prevent some patients from receiving PD (Dahlan *et al.*, 2016). Some patients in Saudi Arabia are poorly educated and have low treatment compliance, and some nephrologists believe that PD is unsuitable for such patients in Saudi Arabia and Paul, 1994; Dahlan *et al.*, 2016). Consequently, the majority of ESRD patients in Saudi Arabia undergo HD. The number of patients on dialysis has gradually risen over the past few years, with over 21,609 patients receiving dialysis services in 2020 (MOH, 2021).

Furthermore, in Saudi Arabia, the mortality rate among HD patients was 6% in 2017 (SCOT, 2017c).

1.4.3 Symptom Burden and Quality of Life

Globally, haemodialysis prolongs many patients' lives. Although dialysis is lifesaving, dialysis patients have a poor QoL, greatly reduced life expectancy, and a high symptom burden (Nath and Fervenza, 2018). According to Cruz et al. (2011), patients in any of the stages of kidney disease experience poor QoL as dictated by reduced physical functioning. Thus, the QoL of patients with kidney disease decreases over time. There is a range of exhausting symptoms for patients with HD, including fatigue, dyspnoea, insomnia, pain, anxiety, depression, itchiness, nausea, and vomiting (Davison, Jhangri and Johnson, 2006). Although dialysis may relieve some symptoms, the overall symptom burden for dialysis patients remains high (Murtagh et al., 2007). Moreover, the symptom burden in advanced CKD disease is substantial and similar to the symptom burden in advanced cancer, congestive heart failure, and chronic obstructive pulmonary disease (Solano, Gomes and Higginson, 2006; Kane, Vinen and Murtagh, 2013). These symptoms negatively impact a patient's health related QoL. Due to the devastating impact of symptom burden on patients' lives in all aspects, patients may perceive symptom control as more significant than survival (Jhamb et al., 2008). In many cases, these symptoms go unnoticed and untreated because providers are unaware of the symptoms, perceive them to be difficult to treat, or feel symptom control is not their responsibility as providers (Feldman et al., 2013).

Moreover, the dialysis population is mainly elderly (median age: 65) (Mallappallil *et al.*, 2014). It is estimated that 893.7 per million population of ESRD cases occur among those over 65 years old, while they account for only 3.2% of the total Saudi population (Al-Syyari and Shaheen, 2011). According to Al Sayyari *et al.* (2021), Saudi Arabia's elderly population will increase by 13% by 2030, resulting in four times more people suffering from ESRD in this age group. CKD is a significant concern among elderly people with an increased risk of multiple adverse outcomes. According to Wachterman *et al.* (2017), ESRD mortality rates among older adults are as high as twice that of patients with cancer. According to Kim, Kang and Woo (2018), the QoL of many patients with ESRD does not improve after they begin HD. There is growing evidence that RRT does not benefit every patient with CKD who progresses to ESRD.

The life expectancy of patients over 75 years old, those with multiple conditions, and those who are frail may not be increased by starting dialysis. However, it can increase the risk of other comorbidities. Dialysis is unlikely to improve these patients' symptoms, and it may negatively affect their functional status and health related QoL (Carson *et al.*, 2009; Chandna *et al.*, 2011; O'Connor and Kumar, 2012).

Thus, ESRD patients undergoing dialysis usually have low QoL and poor body function, and dialysis may be discontinued if no improvement occurs (Chambers, Germain and Brown, 2010). As the disease advances, decisions may be made either to withdraw dialysis or to follow a conservative management pathway. The Renal Physicians' Association/American Society of Nephrology (RPA/ASN) also offers guidelines for best practices in planning and implementing dialysis initiation and withdrawal (Renal Physicians Association, 2010). According to these guidelines, patients with multiple comorbid diseases and the very elderly should be afforded the right to decline dialysis, since the burden of dialysis exceeds the potential benefit. The withdrawal of dialysis is commonly associated with death in dialysis patients throughout the world, reflecting their low health related QoL (Davison *et al.*, 2015 a). A growing interest in non-dialytic alternatives is due to the complex needs of elderly and frail patients who have heavy symptom burdens and a reduced life expectancy associated with ESRD (Thomas, 2014). This led to the development of conservative management pathways—that is, a palliative approach in which dialysis is not commenced.

1.4.4 Conservative Management for End Stage Renal Disease

Conservative management is now developed as the fourth treatment option alongside RRT in most renal units in the United Kingdom (UK) (Alston and Burns, 2015). This provides ongoing support and follow-up for patients who do not wish to start dialysis due to ESRD as well as those who are undergoing dialysis and wish to stop. Although conservative management is widely recognised and administered (Murtagh *et al.*, 2009), there is no typical universally accepted term. It has been described in various ways as 'maximum conservative management', 'conservative management', 'conservative management', 'non-dialysis treatment', 'palliative kidney care', 'renal supportive care', 'palliative renal care', 'supportive care', and 'palliative care' (Carson *et al.*, 2009; Alston and Burns, 2015; Murtagh *et al.*, 2016). This group of terms is currently used in the UK (Okamoto *et al.*, 2015) in relation to non-

dialysis care for ESRD, although they are not clearly defined. This has led to large variations in practice. These terms are also used variably in the literature, leading to inconsistent findings and difficult comparisons of findings and conclusions. Section (1.5.1) discusses misconceptions about these terms.

Beyond the lack of a consistent definition of conservative management for ESRD or a clearly established care pathway, a limited understanding of this patient population's healthcare needs also prevents better care and outcomes. In a recent consensus conference aiming to describe the full extent of conservative management in patients with ESRD, Davison *et al.* (2015 a) introduced the concept of comprehensive conservative care. The authors described comprehensive conservative care as holistic patient-centred care designed for stage 5 CKD. Comprehensive conservative care involves interventions to minimise complications, control symptoms, increase communication (including ACP and SDM), and promote physiological, social, familial, cultural, and spiritual care. Comprehensive conservative care clearly involves palliative care interventions and principles; thus, palliative care plays a role in comprehensive conservative care in different countries. This is important to consider, and the description of different conservative care populations can help clarify these perspectives. However, clinicians and researchers will benefit from this standard definition, as it is widely agreed upon in terms of its definition and what it encompasses.

Despite these initiatives, concerns remain regarding comprehensive conservative care, including the limited awareness of how to best provide conservative management renal care (Davidson *et al.*, 2015 a). Murtagh *et al.* (2016) reported that ESRD evidence has been limited to those with RRT in national and international renal registries. In the Saudi Arabian context, for example, the SCOT annual report provides data for those managed by dialysis and transplants, yet no figures are given for the conservative management pathway (SCOT 2017a, b). The number of ESRD patients who choose conservative management is, thus, unknown, highlighting the extent to which Saudi Arabia neglects this vital issue. This may be because an alternative option can be considered only if a patient is ineligible for another treatment (Ziebland, Chapple and Evans, 2015). Veberen *et al.* (2019) noted that patients perceive limited alternative choices to dialysis; thus, dialysis is most chosen by default. However, it is

unclear which models of care or interventions would be the most beneficial for those who are managed conservatively without dialysis, indicating a need for further research.

The survival and QoL of dialysis patients versus conservative populations are also considered. A few smaller studies have compared the outcomes of these patients (Burns and Carson, 2007; Da Silva-Gane *et al.*, 2012; Brown *et al.*, 2015). For example, Brown *et al.* (2015) compared survival, symptoms, and QoL among patients on RRT and conservative management. Despite longer median survival rates among dialysis patients, 57% of non-dialysis patients had stable or improved symptoms, and 58% of non-dialysis patients had stable or for patients with comorbidities (Bristowe *et al.*, 2019). Patients with ESRD must receive palliative care as part of their routine medical care regimen to improve their QoL.

1.5 Palliative Care

The WHO coined the earliest definition of palliative care in 1990, referring specifically to cancer patients. However, it is now understood that palliative care is also an essential care modality for patients with other life-threatening conditions (Chambers and Brown, 2010; Lupu *et al.*, 2018). According to the WHO's expanded definition, palliative care enhances the QoL of patients and their families by preventing and managing suffering through early diagnosis, efficiently evaluating and treating physical pain, and addressing mental and emotional issues (WHO, 2002).

1.5.1 Misconception about Palliative Care and Other Terms

Prior to the mid-1980s, palliative care was considered to be EoL care in the UK and US (Chambers, Germain and Brown, 2010), which created uncertainty among patients and HCPs regarding the scope of these two terms (Payne *et al.*, 2002; Von Roenn, Voltz and Serrie, 2013). The terms palliative care, EoL, and hospice mean different things in different countries (Holley, 2005; Rome *et al.*, 2011), yet they are confused with each other. The WHO definition of palliative care is widely used, and this definition is generally acceptable in Saudi Arabia. EoL care refers to the treatment, care, and support provided to people in their final year of life (Marie Curie Organization, 2023a). In the Saudi Arabian context, the term 'EoL care' refers to the phase of a person's life during which they live with a disease that will eventually worsen

and ultimately lead to death; however, it is not limited to a brief period in which the person is moribund (WHO, 2018, cited in the National Cancer Centre, 2019). These terms are very similar to each other. Further, both the UK and Saudi Arabia consider EoL care to be one component of palliative care, as palliative care is much broader and includes EoL care.

In the UK, hospice and palliative care can begin at any time after diagnosis and provide physical, emotional, psychological, spiritual, and practical support (Marie Curie Organization, 2023b). However, in the Saudi Arabian context, the situation is different. Hospice care is a form of palliative care that is provided for patients with a limited life expectancy, especially six months or less, who want to focus on QoL and comfort rather than life-prolonging care (Institute for Clinical Systems Improvement (icsi), 2020). Additionally, numerous related terms with vague meanings have emerged (Cherny, 2009), such as 'comprehensive care', 'terminal care', 'total care', 'holistic care', 'care of the dying', 'continuing care' and 'comfort care', as well as 'supportive care' and 'best supportive care' (Fadul *et al.*, 2009; Dalal *et al.*, 2011).

Hui *et al.* (2013a) identified similarities and differences between palliative care, supportive care, and hospice care within an oncology context. Although these terms are similar in controlling symptoms and enhancing QoL for patients with life-threatening conditions, there are major differences in these terms regarding the scope of service, number of patients, and perception in clinical settings. According to the authors, supportive care includes services that address survivorship to bereavement, while hospices are now considered part of palliative care, which, in turn, is under the umbrella of supportive care, as illustrated in Figure 1 (Hui *et al.*, 2013b).


Figure 1: A conceptual framework toward understanding "supportive care," "palliative care," and "hospice care."

Although the term palliative care is frequently used, it is used differently in different contexts. For example, palliative care refers to supportive care, which is synonymous in the renal context. This is because supportive care seems to be more socially acceptable and changes people's perceptions of palliative care, and patients and HCPs prefer it (Dalal et al., 2011). Another term commonly used in the field of nephrology is conservative management (Noble et al., 2007). Previously, in ESRD, the terms palliative care and conservative management were synonymous, and for many years, the literature used palliative care to predominantly describe selecting a non-dialysis pathway and withdrawing from dialysis (Fassett et al., 2011). However, Murtagh et al. (2016) argued that palliative care or supportive care should not be used synonymously with non-dialytic care, as supportive care or palliative care can be provided in conjunction with and without dialysis. Thus, the concept of conservative management is incorporated into palliative care. Chambers, Germain and Brown (2010) suggested that optimal management of conservatively treated patients is likely to be achieved by integrating renal and palliative care services. Palliative care principles are combined with interventions to delay CKD progression and minimise complications in patients with ESRD when conservative management is used with a planned, comprehensive, patientcentred approach (Thomas, 2014; Combs and Davison et al., 2015). Davison et al. (2015a) identified similarities between palliative care, supportive care, and hospice care within the renal context. Although hospice care, which is also called EoL care, shares the same

philosophy as supportive care, it is classified under it. Supportive care or palliative care for CKD is a comprehensive umbrella that provides patients with an adequate perspective on coping with life and death, regardless of how long they live, as shown in Figure 2 (Davison *et al.*, 2015b).



Figure 2: A conceptual framework for supportive care in Chronic Kindy Disease.

1.5.2 Palliative Care Service Implementation

In Western countries, the scope of palliative care has widened to incorporate non-cancer diseases. For many reasons, palliative care is complicated for patients with chronic heart failure, chronic obstructive pulmonary disease, and ESRD (Siouta *et al.*, 2016; Rogers *et al.*, 2017). Although extensive information is available regarding these diseases, their trajectories differ from those of cancer. Understanding these different trajectories can aid in planning more appropriate services to meet patients' and caregivers' needs (Murray *et al.*, 2005). For example, cancer-focused palliative care may not suit people whose decline is gradual and progressive, as their needs differ. Varied palliative care approaches are thus required in these non-cancer conditions. The UK has comprehensive national strategies to enhance palliative care (Marie Curie Organization, 2014), which are applied across most countries. The UK thus led a 2007-2013 ranking of the highest levels of palliative care development in Europe (Woitha *et al.*, 2016). The UK's National Renal Service Framework (2005) includes an EoL care

component focused specifically on improving comprehensive palliative care services for people with CKD (Lewis, 2012).

In Saudi Arabia thus far, palliative care services apply mostly to cancer patients. These services were initiated by Dr. Isbister at the King Faisal Specialist Hospital and Research Centre (KFSHRC) over 20 years ago (Alshammary et al., 2014). The KFSHRC is a well-developed inpatient palliative care unit; it is widely considered a regional training centre and offers costfree care, including hospital stays, procedures, and medications (Al-Zahrani, Eldali and Al-Shahri, 2014). Through KFSHRC and other cancer centres, palliative care is implemented by groups of interdisciplinary professionals delivering inpatient, outpatient, and home care services (Al-Zahrani, Eldali and Al-Shahri, 2014). In Saudi Arabia, palliative care services have increased to 20 institutions, including 42 palliative care programmes within different sectors (Osman et al., 2017). These services include consultations within hospitals, outpatient clinics, home healthcare programs, and outreach programs, in some cases (Abusanad et al., 2022). The atlas of palliative care in the Eastern Mediterranean Regions (2017) provides a systematic and comprehensive analysis of palliative care development in these regions. Palliative care remains undeveloped in the majority of 15 countries, and among these, Saudi Arabia has the highest number of total palliative care programmes (Osman *et al.*, 2017). Despite significant achievements in the area over two decades, palliative care services in Saudi Arabia are insufficient. They are still in their nascent stages, and progress to meet Saudi Arabia's growing palliative care needs is slow (Zeinah, Al-Kindi and Hassan, 2013; Osman et al., 2017), which requires several steps for success.

In Saudi Arabia, patients are referred to palliative care services later than they should be (Osman *et al.*, 2017). The services are not widely available across Saudi Arabia (Alshammaray *et al.*, 2019); only a handful of hospitals and care centres in a few cities offer cancer-related palliative care. Meanwhile, patients with other serious illnesses have been excluded (Ghanem *et al.*, 2011). Gray, Ezzat and Volker (1995) stated that in Saudi Arabia, 90–95% of palliative care patients in practice have cancer. Although their research is dated (at least 20 years old), more recent evidence shows that the situation remains unchanged. Ghanem *et al.'s* (2011) study found that only 20 (4.22%) of 474 patients receiving palliative care were non-cancer patients. This means that only a small proportion of the number of non-cancer patients in

need of palliative care receive it. According to Al-Zahrani, Eldali and Al-Shahri (2014), the palliative care programme in Saudi Arabia accepts non-cancer referrals; however, most patients who are referred have a symptom burden associated with malignancy. Along the lines of the evidence suggests that early referrals to palliative care can benefit patients, even those with good functional status. However, this is not a common practice in Saudi Arabian contexts. All age groups are admitted to palliative care, and most are cancer patients (about 95%), but there is also heart, pulmonary, neurological, and renal patients (Osman *et al.*, 2017). ACP has not yet been implemented in Saudi Arabia (Osman *et al.*, 2017). More importantly, the literature shows that there is a gap in implementing palliative care services among Saudi Arabia's non-cancer patients, which must be addressed at the national level. This is due to pre-existing barriers.

1.5.3 Barriers to Palliative Care in Saudi Arabia

There are various barriers to delivering palliative care in Saudi Arabia, which can be categorised at the organisational, HCPs and patient and family levels. At the organisational level, the main problem has been the way policymakers have failed to prioritise palliative care. Another barrier is that effective healthcare policies to support palliative care are lacking (Silbermann *et al.*, 2012; Fadhil, Lyons and Payne, 2017). Almobarak (2016) reported that Saudi hospitals' palliative care systems are inadequate for meeting patient needs. Poor access to palliative care drugs is also an impediment (Alshammaray *et al.*, 2019), as is the deficiency of family health services that are integrated with tertiary and secondary care to warrant continuity of community care (Alshammaray *et al.*, 2019). Similarly, government support for public palliative care literacy through awareness campaigns is insufficient, as is government delivery of high-quality palliative care (Alkhudairi, 2019).

At the HCPs level, the lack of physicians interested in palliative care as a treatment option is a barrier (Alshammaray *et al.*, 2019). HCPs lack knowledge and have limited awareness of palliative care. Alasiry *et al.* (2012) noted that Saudi Arabia's nurses also express concerns about poor public awareness of palliative care. Almobarak (2016) supported this, highlighting that Saudi practitioners' lack of palliative care knowledge may lead them to prescribe or carry out practices that are harmful to patients' palliative care. Alshaikh *et al.* (2015) found that most nurses were unfamiliar with the concept, role, and delivery of palliative care in Saudi Arabia. Perhaps this can be attributed to a lack of palliative topics in nursing programs at the undergraduate level. Silbermann *et al.* (2012) and Alamri (2012) argued that there is a gap in HCP training around palliative care. This is due to the poor quality and quantity of the training material. HCPs show palliative care knowledge, as do nursing students (Khraisat, Hamdan and Ghazzawwi, 2017). The effects of insufficient awareness of palliative care will affect the quality of nursing care in Saudi Arabia in the future. Another rising concern is a lack of awareness regarding the use of pain medication for palliative care, including the possibility that patients may become addicted (Zeinah, Al-Kindi and Hassan, 2013). Cultural barriers, especially language gaps, can also have a negative impact on the palliative care of Saudi patients by non-Saudi providers (Almobarak, 2016; Swetz *et al.*, 2011). Other obstacles, such as providers' unfamiliarity with Islamic practices around death, may negatively impact patients' and families' EoL encounters (Gatrad and Sheik, 2002). Silbermann *et al.* (2012) stated that most clinicians in Saudi Arabia rely on their personal experiences to deliver palliative care. Moreover, providing culturally safe palliative care is crucial.

At the patient and family level, public awareness of palliative care is limited due to a lack of materials and human resources, reducing public interest in seeking palliative care. Alkhudairi (2019) reported that palliative care knowledge and awareness are still low among Saudis; most respondents believed this is due to a lack of information. There is a lack of public awareness about EoL cancer care, which includes palliation, and the focus is mostly on curing (Alshammaray et al., 2019). Patients are often unwilling to discuss death and dying, further hindering their awareness. Culturally, according to Gustafson and Lazenby (2019), the family has a powerful impact on healthcare outcomes for patients seeking palliative care. Patients are generally not talked about their cancer diagnosis and have no idea of their prognosis (Alshammaray et al., 2019). The Saudi family is clearly vital to treatment decision making. Yet, lack of familial communication may adversely affect both treatment and the patients' and families' coping and grieving processes (Joarder, Cooper and Zaman, 2014). Providers must understand these dynamics and put patients and their families at the centre of palliative care decision making. Many other developed countries face similar challenges (Lynch et al., 2009; Mahtani-Chugani et al., 2010; Aldridge et al., 2016; McIlvennan and Allen, 2016; Diop et al., 2017; Siouta et al., 2019). This thesis, however, considers the Saudi Arabian context, which differs culturally from Western countries where palliative care originated and where recent developments are most apparent.

1.5.4 Role of Palliative Care in Chronic Kidney Disease

Many have called for the introduction of palliative care standards into ESRD patient care (Davison, 2003; Chambers, Germain and Brown, 2010). Palliative care must be integrated early and continued to be discussed throughout the course of the disease (Davison, 2012; Grubbs *et al.*, 2014) to treat symptoms and improve QoL (Davison and Jhangri, 2005). The value of palliative care and EoL care are increasingly recognised for patients receiving dialysis and those withdrawing from or opting out of dialysis (Murtagh *et al.*, 2016). Palliative care also aims to outline patients' EoL treatment preferences and can aid family and patient management of ESRD symptoms, ACP, psychological assistance, and education (Kane, Vinen and Murtagh, 2013). Kane, Vinen and Murtagh (2013) and Davison *et al.* (2015a) noted that palliative care and supportive care can help three major groups of patients: (1) those who forgo dialysis and follow the conservative management pathway; (2) those who start dialysis in relatively good health but become symptomatic over time and less able to tolerate dialysis, changing treatment to symptom management; and (3) patients with chronic renal dysfunction due to serious, poorly managed diabetes and at least two of the conditions listed in Box 1.

Box 1: Indicators for Identifying Chronic Kidney Disease Patients Approaching End-of-Life.

- Blood tests revealed that patients will usually need dialysis or that blood dialysis tests are regularly suboptimal.
- In 6 months, weight loss more than 10 %.
- Hypoalbuminemia (<24g/L).
- Complex symptoms which are difficult to control.
- A mobilising assistant needed or on bed for more than 50 % of the time.
- Two admissions (nonselective) or more in the previous 3 months.
- Patients have expressed a willingness to avoid treatment.

Adopted from Lewis and Noble (2012)

The decision to commence dialysis or conservative management, which is part of the palliative care approach, becomes more difficult and challenging for older patients due to the added complexities of increasing age, comorbidities, a reduced overall lifespan, and the effects of dialysis on QoL. This remains a very personal choice; therefore, treatment decisions require balancing risks, benefits, and patient goals. To enable patients and their families to make a shared decision about moving towards a conservative management and palliative care approach, they must engage in a process of ACP, and they reach ACP through a process of shared decision making. Engagement with ACP is one way to enable this complex decision-making process.

1.6 Palliative Care Approaches

1.6.1 Advance Care Planning

ACP is a crucial element of palliative care, and its implementation has become one of the indicators of high-quality palliative care (WHO, 2016). It may be useful to implement an ACP in this context to promote shared decision making among patients who need palliative care, their families, and care providers. Thus, nephrologists caring for ESRD patients should be enabled to develop an approach to ACP based on patients' and families' expectations, as well as dialysis treatment goals (Davison, 2010; Rosansky *et al.*, 2017).

ACP is defined as 'a process which enables individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and health-care providers, and to record and review these preferences if appropriate' (Rietjens *et al.*, 2017, p. 546). It is designed to elicit patient preferences regarding future care, including preferences regarding EoL care (O'Halloran *et al.*, 2018). ACP involves discussing and preparing for future decisions related to EoL treatments, discussing place of care or death, and conversations about future scenarios. The process also included nominating decision makers, completing physician orders for life-sustaining treatments (LSTs), and completing legal documents, which are advance directives (ADs) (Kim and Choi, 2017). Kim and Choi (2017) defined ADs as legal documents that offer guidelines on the forms of care that a patient wishes to receive in the future. In these written documents, the individual communicates his or her personal preferences for future medical treatments if he or she is unable to do so later (Orentlicher, 1990).

In the literature, there is much debate regarding whether ACP is effective and under what circumstances. A substantial number of systematic reviews and research studies have been published showing the effectiveness of ACP on various patient and family outcomes in the general population, as well as for renal patients. These outcomes include: ACP improving QoL and quality of EoL care; improving documentation of care preferences and completion of advance directives; enhancing patient-HCP communication on EoL; enabling patients to talk about EoL with family and friends; bringing preferred care into alignment with what is delivered; improving patient-family and concordance about care preferences; enhancing DM process, reducing family members' anxiety and depression, improving patient and family satisfaction and decreasing hospitalisation; and increasing uptake of palliative and hospice care services (Detering *et al.*, 2010; Brinkman-Stoppelenburg *et al.*, 2014; Holley and Davison, 2014; Luckett *et al.*, 2014; O'Hare *et al.*, 2014; Davison and Moss, 2016; Jimenez *et al.*, 2018).

However, other studies have demonstrated that the ACP process and intervention may not be effective in achieving positive outcomes for patients and their families. For instance, ACP does not influence communication quality or EoL care quality, patient-family satisfaction with EoL care, hospital admission, use of life-prolonging treatment, decision-making confidence, patient communications, or completion rate of advance directives (Perkins, 2007; Curtis *et al.*, 2013; Luckett *et al.*, 2014; Lim *et al.*, 2016; Michael *et al.*, 2022). Further, it has no impact on anxiety and depression among family decision makers (Carson *et al.*, 2016) or on family involvement in decision making (Vandenbogaerde *et al.*, 2022).

Although the use of ACP is recommended as a good practice for ESRD patients and improves palliative care among haemodialysis patients (Davison, 2009; Renal Physicians Association, 2010; Song *et al.*, 2015), it is infrequently implemented. Researchers have estimated that only 6–49% of CKD patients participate in ACP globally, and only a limited number of treatment options are considered (Weisbord *et al.*, 2003; Morton *et al.*, 2016; Tamura *et al.*, 2017). The implementation of ACP is challenging and complicated, and it entails several obstacles, including two major types: barriers faced by patients and families and barriers faced by HCPs (Box 2) (Davison *et al.*, 2010). A systematic review by O'Halloran *et al.* (2018) also highlighted similar barriers to ACP discussions in renal disease patients.

In the Muslim context, ACP is rarely discussed (Biondo *et al.*, 2017). Most people in Muslim countries do not discuss EoL issues—for example, whether they would like to be admitted to intensive care, referred to palliative care services, withdrawn from RRT, or resuscitated—with their HCPs (Al-Jahdali *et al.*, 2013). Findings from Muslim contexts demonstrate cultural, social, and religious reasons for these situations. For example, Heirali *et al.*'s (2021) study, which aimed to understand current Islamic views on ACP and EoL care for multi-ethnic Muslim patients and HCPs in a Canadian context, revealed that ACP is an unfamiliar concept for many Muslim patients. These factors are also reported in Western countries, such as the US (Hong *et al.*, 2018) and the UK (McDermott and Selman, 2018), and non-Western countries, including China (Low *et al.*, 2000), Korea, and other Asian countries (Kim and Choi, 2017), as culture and religion influence patients' perceptions and attitudes towards discussing ACP, EoL care, and SDM.

Box 2: Barriers to Advance Care Planning in Renal Context

Patient and family- Related barriers

- Inadequate knowledge about ACP.
- Cultural differences among HCPs and patients in terms of patient's freedom, treatment preferences and DM process which raise conflict among them.
- Unwillingness to discuss their EoL planning and issue of death.
- Believe that the HCPs responsible to initiate the ACP discussion.
- Lack of insight about their health status and prognosis hence feel the ACP not relevance to them.
- View that ACP in unnecessary because the caregivers will know what to do.

HCPs- Related barriers

- Lack of skills and training among HCPs in introduce and implement the ACP discussion.
- Diagnostics uncertainty and lack of familiarity with suitable alternative treatment.
- Believe the ACP discussion not needed.
- Believe the patient and their family do not ACP discussion.
- Concern that discussion of EoL issues can destroy hope while embarking on life-sustaining treatments (LST) such as dialysis.
- Time constrains.
- Delay conversation until patients are too sick to be completely interested in the discussions.

1.6.2 Shared Decision Making

According to Davison et al. (2015a, p. 5), SDM is:

'A process of communication by which physicians and patients agree on a specific course of action based on a common understanding of the patient's treatment goals, taking into account the benefits and harms of treatment options, and the likelihood of achieving the outcomes that are most important to individual patients'.

The SDM model is considered a preferred approach to helping patients with ESRD understand their treatment options, be involved in their treatment decision making, and make informed treatment decisions aligned with their values and preferences (Moss, 2010; Stiggelbout, Pieterse and De Haes, 2015). Patients and clinicians must collaborate to make decisions to achieve SDM (Winterbottom *et al.*, 2014). It is important that the SDM process includes deliberation, in which the patient is aware of their choices, understands all their options, and determines what is important to them. These steps can be used to introduce shared decision making to patients with ESRD when discussing treatment options, so they can be involved in the decision. However, in the Saudi Arabia, no evidence exists regarding shared decision making in relation to dialysis treatment or EoL care decisions.

Although the main purpose of SDM is to make informed choices, the process can also be employed for educational purposes (Elwyn *et al.*, 2012). It is essential that the healthcare provider explain that there are treatment options and that patients have a choice, as outlined in Elwyn *et al.*'s (2012) model for SDM. HCPs facilitate SDM by providing appropriate materials considering the patient's context. However, SDM is poorly incorporated in daily practice (Couët *et al.*, 2015), especially in CKD care (Morton *et al.*, 2010; O'Hare *et al.*, 2014). Many nephrologists have difficulty implementing SDM, especially with older patients who are facing dialysis decisions (Hussain *et al.*, 2015). This is due to limited time, the clinical situation, some patients' lack of desire to participate in SDM, and difficult patient reactions, and HCPs often neglect decision aids (Gravel, Légaré and Graham, 2006). Various factors influence patient DM, according to Murray *et al.* (2009), including family, friends, disease status, patient sense of well-being, QoL, control needs, and personal preferences about benefits and risks. Other aspects include patients' information needs about the disease, uncertainty regarding treatment options, and treatment side effects. SDM posits that patients should have a voice in the decision-making process, but culture and customs play a significant role in major treatment choices, particularly in the Saudi Arabian context. Elwyn et al. (2012) stated that if patients come from cultural backgrounds that tend to limit autonomy, SDM can be a problem. Typically, patients in Saudi Arabia consult with their families before deciding on treatment management or options. Family member involvement in treatment decision making is emphasised, particularly in the case of women's health and informed consent (Aldosari, 2017). In Saudi families, males are regarded as the primary decision makers due to cultural expectations regarding gender roles. Family members are therefore important in the decision-making process in Saudi Arabia. Moreover, Al-Jahdali et al. (2009) and Baharoon et al. (2010) examined ACP preferences and EoL decision making in Muslim dialysis patients. Among HCPs, hindrances to ACP included limited time and training, unwillingness to discuss EoL care with patients, and the belief that patients would not accept these issues. Factors influencing patient decisions included a lack of knowledge about LSTs (Al-Jahdali et al., 2009; Baharoon et al., 2010). Additionally, some patients rely on their doctors to make decisions, while others rely on their families. Morton et al. (2010) argued that HCPs generally do not provide patients and families with the knowledge required to ensure appropriate care.

Several instruments have been designed to support deliberation, facilitate the SDM process, and improve the patient's ability to choose the best option. These include educational programmes and decision support interventions, such as PtDAs and prognostic tools (Elwyn *et al.*, 2012). PtDAs are tools to help structure and increase SDM (Hulin *et al.*, 2017) by initiating ACP discussions and recording healthcare decisions. They include information about the condition, the treatment options available, and the associated advantages and uncertainties. They also encourage patients to recognise and share their preferences with HCPs and others involved in DM (Spatz and Spertus, 2012; Elwyn *et al.*, 2012). More than 86 randomised trials have recently been performed to determine the efficacy of PtDAs in supporting SDM for different diseases (Stacey *et al.*, 2017; Hess *et al.*, 2012). Decision aids, however, appear to have no difference in general health outcomes or QoL when compared to usual care (Stacey *et al.*, 2017).

1.7 Chapter Summary

ACP and SDM are key to implementing effective palliative care; they should ideally be implemented early in a serious disease. The literature demonstrates different experiences of care, type, and access to services for people with ESRD between Western countries (e.g., the UK and the US) and non-Western countries (e.g., Saudi Arabia). This shows the profound advantages that patients with cancer and non-cancer conditions can draw from seeking palliative care services in Western countries. Since the introduction of palliative care in Saudi Arabia, very few articles have discussed this subject, especially regarding Saudi Arabia renal disease patients' perceptions, needs, and attitudes towards palliative care service implementation. It is important to note that there are many barriers to palliative care, ACP, and SDM. In Saudi Arabia, many of these barriers are heightened, and there are other cultural, social, and religious challenges to overcome. Across all these barriers, an overarching priority is to improve patient and family education in order to support informed decision making, which can lead to ACP and receipt of palliative care. Chapter 2 reviews the existing literature and identifies key gaps in educational interventions for the ESRD population.

Chapter 2: Scoping Review

2.0 Introduction

The previous chapter reviewed the literature about ESRD in Saudi Arabia, particularly its incidence and management strategies. It also reviewed the availability of alternative treatment options, such as palliative care -based services and their approaches (ACP and SDM practices), and their limitations, particularly renal-related limitations. It was concluded that an insufficient amount of education, training and resources constitute the main barriers to introducing palliative care and its approaches into the renal setting. Thus, this chapter reviews the literature on palliative care educational interventions, particularly ACP and DM, for ESRD. This informed my conducting a study to develop an educational intervention—a 'decision aid' tool for Saudi patients with ESRD and their families—that improves SDM practice in the Saudi Arabian context.

This chapter provides a scoping review of all available evidence-based studies about educational interventions that support palliative care communication issues, such as ACP and DM, in renal contexts and an appraisal of the methodologies used in those studies. It also examines other relevant aspects of intervention characteristics, including mode of delivery, content and evaluation of patients and their families, and HCPs outcomes. This chapter begins with the review question and an overview of the search strategy. This is followed by a review of the literature related to different educational interventions. Next is a discussion about how these interventions support ACP and DM processes in both patients and HCPs, followed by a discussion of the findings in relation to previous literature, the identification of gaps in the literature and the justification for the study. Considering the lack of research in this area, the literature regarding educational intervention for renal patients in Saudi Arabia is limited.

2.1 Methods

2.1.1 Design

Scoping reviews are conducted to determine the nature and extent of available research evidence to provide a preliminary assessment of their potential sizes and scopes (Grant and Booth, 2009). The methodology followed the Joanna Briggs Institute's (JBI's) approach for scoping reviews (Peters *et al.*, 2020). In this study, a scoping review was carried out based on the steps described in Arksey and O'Malley (2005) and Levac, Colquhoun and O'Brien (2010).

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Several steps were involved, including the development of a question, identification of relevant articles, selection of those articles, data extraction and charting and analysis and reporting of the results.

2.1.2 Review Aim and Question

The aim of the proposed scoping review is to collect and synthesise literature on educational interventions to support renal palliative care communication issues, in particular ACP and DM. The objectives of this review are as follows:

- To map all educational interventions related to palliative care approaches–ACP and DM–in the renal context.
- 2) Evaluating the evidence of their reports, use, and study results.
- 3) To explore and define knowledge gaps on the topic.

A standard approach, the PCC framework (Peters *et al.*, 2020), was employed to identify the main element of the question and keywords for focusing on the search strategy. Three components of PCC contribute to the creation of review questions and search strategies: the population (P), the concept (C) and the context (C). Based on the PCC framework, a scoping review of peer-reviewed and grey literature (Peters *et al.*, 2020) addressed a broad proposed review question, 'What evidence is available on how educational interventions support palliative care approaches via communication, ACP and DM in the renal context?' The goal was to find current literature on palliative care approaches and impacts, summarise and disseminate research results and establish study gaps (Booth, Sutton and Papaioannou, 2016). The population was 'HCPs, ESRD patients and their family caregivers', the concept was 'educational intervention on palliative care and approaches' (covering all types of interventions and outcomes) and the context was 'renal healthcare settings, hospital-based'.

2.2 Inclusion Criteria

To narrow the results of the literature searches, inclusion and exclusion criteria must be incorporated. The inclusion and exclusion criteria according to the PCC framework are summarised in Table 2.

Criterion	Inclusion	Exclusion
Population	 Adult patients with ESRD/CKD stage 5 >18 years and/or their family caregivers Patient on dialysis >3 months/long-term dialysis or conservative management Studies with mixed participants' medical conditions include those in which CKD is more than half of the population and their results are reported separately. HCPs in renal units who care for patients with renal diseases. 	 Study population consisted of children or adolescents. Studies describing educational interventions for patients with CKD stages 1–4 or not on dialysis treatment or transplant patients. Studies describing educational interventions for students and healthcare professionals not working with ESRD patients, palliative care nurses and home care nurses.
Study Design	 All existing literature reporting empirical, qualitative, quantitative or mixed methods studies and literature reviews (systematic/scoping) and dissertations/theses. Any perspectives of patient and family caregivers and healthcare professionals regarding educational interventions. Studies written in English between 2000 and 2019. 	 Conference abstracts, case studies, professional opinion papers, guidelines, papers on expert panel meetings and published research protocols to study not yet completed.
Concept	 Studies focused on educational interventions related to palliative care communication issues (ACP and DM). More details are provided in Section 2.2.1. 	 Studies describing educational interventions that focus on treatment modality decisions or interventions regarding a switch between treatment modalities. Studies describing educational interventions for pre-dialysis and non-relevant to palliative care approaches.
Context	Studies conducted on renal disease in hospital settings.	Studies conducted in homecare settings.

Table 2: Selection Criteria for Scoping Review

2.2.1 Context and Concept

I included the literature published in English in peer-reviewed journals and studies from grey literature, such as doctoral theses and dissertations, which focused on educational interventions related to palliative care communication issues (ACP and DM) in the context of renal disease in hospital-based renal healthcare settings. I considered all palliative care educational interventions that can support renal patients and/or their families and HCPs to facilitate ACP discussions and engagements in DM or SDM (e.g., educational programmes and patients' decision aid tools), with no limitations imposed on outcome measures in hospital settings. Studies were eligible for inclusion if they focused on the following interventions:

- Advance Care Planning (ACP) interventions are communication processes among individuals, their families and HCPs in order to understand, evaluate, discuss, plan and make future healthcare decisions. ACP may or may not result in a written advance care directive (ACD), a legal document offering guidelines on the forms of care that a patient desires to receive in the future (Kim and Choi, 2017).
- Communication interventions are dialogues about progressive, incurable illness and EoL, for example, ACP, transition to palliative care and/or discussing death (Brighton *et al.*, 2017). Information and education can affect communication processes and outcomes.
- Decision Making (DM)/Shared Decision Making interventions include the DM process, patient enrolment or engagement in DM, decision support tools and DM for medical treatment, e.g., choosing Life-sustaining treatments (LSTs), which are medical interventions/treatments that potentially postpone death (Kim and Choi, 2017). These include cardiopulmonary resuscitation (CPR), mechanical ventilation, haemodialysis and administering drugs, such as antibiotics or chemotherapy (Rodriguez and Young, 2006; Kim and Choi 2017).
- **Other** education interventions not described above were included if they appeared in the literature.

2.3 Type of Sources

The following search engines and evidence-based medicine (EBM) databases were examined by electronic means to identify published sources.

- Cumulative Index to Nursing & Allied Health Literature (CINAHL via EBSCO)
- Medical Literature Analysis and Retrieval System Online (Medline via Ovid)
- ProQuest
- Scopus
- Cochrane Library

Supplementary information was obtained from other search engines, for instance, Google Scholar, Google Web, from citations and reference lists in published and unpublished works (grey literature), and from the *Saudi Journal of Kidney Disease and Transplantation*.

2.4 Search Strategy

The review was performed using the staged approach defined by JBI Reviewer's Manual (Peters *et al.*, 2020), and the literature search was conducted according to the guidelines of Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA (Tricco *et al.*, 2018)). The first step was a limited search of peer-reviewed, published papers on the CINAHL database using initial key terms that were established from the PCC statement. All alternative words for the most important keywords were also incorporated. Furthermore, the keywords were generated after consultation with a research librarian using the titles, abstracts and index terms in the papers. Both British and American English usage and spellings were considered when selecting key words to intensify the prospect of getting all pertinent articles (Table 3).

PCC	Keywords/ terms	Synonyms (alternative search terms)
Population	Healthcare providers caring for ESRD patients. ESRD patients and their families	Nurses, nursing, doctors, physicians, healthcare providers, healthcare workers, health care providers, healthcare professional, Health care professional, patient, family, caregiver, surrogate.
Concept	Educational interventions focused on palliative care and approaches, especially communication, advance care planning and decision-making.	Education, training, learning, educational intervention in nursing, educational programm, educational program, educational sessions, learning intervention, training programm, training sessions, training program, health education, patient education information, pre dialysis education, Palliative care, supportive care, end of life, end- of-life, PC, EoL, SC, Advance care planning, Advance care, plan, plans, planning, preferences, ACP, communication skills, decision, decision making, shared decision making, DM, decision support techniques, decision aids, advance directive.
Context	Renal context	End stage/advanced renal care in hospital-based settings

Table	3:	Scoping	Review	Кеу	Terms
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In the second step of the search strategy, these keywords were used to search through all databases and sources identified in Section (2.3). The identified key terms were used to conduct the searches. 'OR' and 'AND' combined the intervention and outcomes. A grey literature search was conducted at this stage. In the third step, the reference lists of the identified studies were searched for additional studies. The initial searches were conducted in May 2019 among studies in English from 2000–2019. Appendix 1 provides an example of a search strategy (CINAHL). This was done prior to the beginning of the fieldwork for the study. A second search was undertaken in October 2023 to identify any further published papers that met the review-inclusion criteria when the study was underway, and the thesis was being prepared. No new papers were identified.

2.5 Study Selection and Data Extraction

The results included a wide range of studies, filtered based on research and reporting characteristics to meet the inclusion criteria presented in Section (2.2) (Moher et al., 2009). A single researcher (NA) performed the process of study selection and data extraction. After removing duplicates, the results of the second and third searches were exported into a spreadsheet for eligibility screening, which was a two-step process. First, the titles and abstracts of all identified studies were screened for potential eligibility. Second, a full-text screening of the selected studies was conducted, during which a final selection was made for data extraction. The research team was involved in this step to approve the final included studies, and disagreements about selection and inclusion were resolved. Moreover, when there was uncertainty, two other authors were consulted, thus using a team approach to aid rigour, following Levac, Colquhoun and O'Brien (2010). Descriptive analysis was conducted on all included studies. The extracted data were synthesised qualitatively and presented as evidence in written tables and a narrative summary. Data extracted from the chosen studies included citation details, primary author, date of publication, county of origin, journal name, study aim, study design, sample size, settings, intervention type, protocols used to implement interventions, outcome measures, relevant findings and results to the scoping review question, authors' conclusions and possible related reference papers. The results were categorised into tables based on the methodology and methods adopted by the included studies.

2.6 Results

2.6.1 Study Screening

A total of 3,337 articles were found in electronic databases and other sources. Of these, 3,095 articles were identified after 242 duplicates were removed. After screening the titles and abstracts, 73 possibly relevant articles remained. After a full-text review, 19 articles were ultimately included. The following PRISMA chart (Figure 3; Moher *et al.*, 2009) shows the 19 studies that met all inclusion criteria. Appendices 2A, B and C describe the included studies.



PRISMA 2009 Flow Diagram



Figure 3: PRISMA flow chart describing the search process for scoping review.

2.6.2 Characteristics of Included Studies

The scoping review included studies from five countries: Spain, the UK and Malaysia each contributed one study. The USA contributed 14 studies, while Canada contributed two. Based on the study design, there were six randomised controlled trials (RCTs), 12 pre- and post-test designs and one qualitative study. Of the 19 studies, four were identified as theses in the grey literature. The included studies employed a variety of participants, including patients, patients and their family caregivers and HCPs. Four studies involved ESRD patients on dialysis treatment, six studies involved ESRD patients on dialysis treatment and their family caregivers and seven studies involved HCPs. The HCPs included renal nurses, physicians, nephrology consultants, healthcare assistants and nephrology fellows. Two studies involved ESRD patients, their families and HCPs.

2.6.3 Critical Appraisal of Included Studies

Scoping reviews usually do not include quality assessments since they summarise existing evidence (Booth, Sutton and Papaioannou, 2016). However, to enhance the validity and credibility of the outcomes, all articles in this review were assessed to ascertain their methodological quality, using different tools from the JBI for each study design. High quality studies scored high on the JBI critical appraisal checklist, used relatively large sample sizes and had limited bias. Weak studies did not meet the criteria for high quality studies; they scored poorly on the JBI critical appraisal checklist, used small sample sizes, had weak study designs, exhibited bias and were not specific to ESRD. Overall, 15 studies were reported as high quality, while 4 were reported as moderate quality. Appendix 3 shows the critical appraisals for all studies.

2.7 Intervention Characteristics

Appendix 4 lists educational intervention characteristics by individual study.

2.7.1 Mode of Interventions Delivery

Three interventions were delivered via online educational materials (Hing *et al.*, 2016; Oarde, 2017; Simpson, 2017). Kapell Brown, Kryworuchko and Martin (2018) used videos as the delivery mode. Five interventions were delivered via interview sessions (Kirchhoff *et al.*, 2012;

Song *et al.*, 2009, 2010, 2015; Amro *et al.*, 2016). Five studies used training workshops and programmes with HCPs as a delivery mode (Bristowe *et al.*, 2014; García-Llana *et al.*, 2017; Schell *et al.*, 2013; Cohen *et al.*, 2016; Schell *et al.*, 2018). One study's mode of delivery was peer–mentor telephone calls and three face-to-face meetings with video support (Perry *et al.*, 2005). Two interventions were delivered via printed material (Corbett, 2017; Courtright *et al.*, 2016). Gross (2015) used three modes: printed materials, online sessions, and classroom sessions.

2.7.2 Interventions Contents

Hing *et al.* (2016) and Kapell Brown, Kryworuchko and Martin (2018) designed ACP education materials for CPR decisions. Oarde (2017) provided general information about palliative care benefits and services for patients. Amro *et al.* (2016) studied an intervention delivered by researchers and HCPs, educating patients on EoL care as ACP-informed DM. In three studies, communication skills-focused training workshops were conducted for HCPs. The course content involved learning to give bad news, acknowledge individuals' emotions, discuss treatment priorities for ESRD patients when prognosis is unclear and discuss dialysis therapy aspects, such as EoL treatment and withdrawal (Schell *et al.*, 2013; Cohen *et al.*, 2016; Schell *et al.*, 2018). Song *et al.* (2009, 2010, 2015) presented three interventions delivered by trained HCPs, focusing on five elements: describing illness, exploring gaps between illness and progress, examining thoughts about death and dying, presenting EoL information for seniors to clarify goals and summarising the values of discussion and future discussion. Corbett's (2017) intervention educated nurses and nephrology providers about guidelines supporting DM, ACP and correct palliative care referral.

Simpson (2017) focused on patient engagement and DM guidelines. The participants for Bristowe *et al.* (2014) developed a Renal-specific Advanced Communication Training (REACT) programme, and García-Llana *et al.* (2017) administered a Communication and Bioethical Training (CoBIT) programme to physicians, nurses, and HCPs. These programmes focused on improving communication skills and confidence. Gross (2015) implemented a Provider Orders for Life-Sustaining Treatments (POLST) programme. To serve as programme facilitators, the project coordinator, and dialysis nurse received 14 hours of training in a Provider Orders for Life-Sustaining Treatments communication. They also learned to screen dialysis patients for a Provider Orders for Life-Sustaining Treatments conversations. Kirchhoff *et al.* (2012) provided patients with information about available treatment options and their potential benefits and risks. Perry *et al.* (2005) and Courtright *et al.* (2016) focused on ADs. One intervention was delivered by trained patient mentors (Perry *et al.*, 2005), and in the remaining studies, the research team delivered interventions.

2.8 Outcomes

The review's findings were categorised according to different participant groups, and the key findings of these educational interventions were presented for each group. There were three types of outcomes: outcomes focused on patients and their families, outcomes focused on HCPs and other outcomes.

2.8.1 Outcomes Focused on Patients and their Families

This section examines the patient and family-reported outcomes of palliative care communication issues (ACPs and DMs) in educational intervention. Overall, the noted outcomes were identification of patient preferences; addressing patient needs; patient/surrogate decisional conflicts, congruence and confidence in decision making; completion of advance directives; patient, family caregivers and healthcare providers communication and interactions, and patient and family well-being, anxiety and quality of life.

2.8.1.1 Identification of Patient Preferences

Identification and addressing the goal of care of ESRD patients' preferences towards EoL care was reported as an outcome in six studies. Results varied, as some studies reported improvement in patient outcomes with EoL preferences, particularly after exposure to intervention, while other studies found no significant difference among them.

For example, using the Provider Orders for Life-Sustaining Treatments (POLST) paradigm, Amro *et al.* (2017) showed that clinical ACP face-to-face encounters identified haemodialysis patients' preferences for LSTs following the dedicated encounter to discuss ACP and an over 50% increase in patients adopting the DNR code status. According to the study findings, 42% of patients did not wish to receive CPR and mechanical ventilation, 22% did not wish to receive artificial nutrition and 2% did not wish to be transferred to a hospital following cardiopulmonary arrest. These encounters also led to the completion of approximately 90% of medical orders for life-sustaining treatment (MOLST) forms. In addition, Gross's (2015) POLST programme helped meet ESRD patients' EoL preferences, including EoL treatment options. The study reflected that the post-exposure to interventions improved patient outcomes with EoL preferences, particularly LSTs. A study by Kapell Brown, Kryworuchko and Martin (2018) found that a CPR-video decision aid (CPR-VDA) tool helped patients and their families elect their preferences towards CPR treatment during their EoL care. In the study, most patients (43/49) had an order for CPR in their physician's orders before the intervention, and only seven patients (7/49) did not have an order. Following completion of the value clarification worksheet and viewing the CPR-VDA, 28/49 chose to have CPR, while 13 did not.

The ACP intervention implemented by Hing et al. (2016) enhanced patients' autonomy in CPR treatment and their access to patient-centred care. The educational brochure positively affected patients' understanding of ACP's importance and subsequently altered their intentions to prepare ACPs. However, statistically, there was no significant effect of the plans for ACP after exposure to the educational brochure on patients' preferences and decisions regarding EoL care. There was no statistical difference between pre- and post-educational brochures in CPR or intubation decisions when cardiorespiratory collapse occurred outside of a dialysis centre. Moreover, the ACP intervention, as administered to ESRD patients by Kirchhoff et al. (2012), positively altered patients' and surrogates' preferences to receive care according to their wishes. Following the ACP intervention, patients demonstrated an increased willingness to discuss their preferences with trained facilitators. The experimental groups chose less aggressive care than the controls; however, there was no statistically significant difference between the two groups. A significantly higher number of experimental groups ESRD patients chose dialysis withdrawal, although the interviews did not address that decision. Furthermore, Song et al. (2010) showed that patient-centred advance care planning (PC-ACP) interventions enhanced patients' and their families' preferences for EoL care treatments, particularly LSTs.

2.8.1.2 Addressing Patient Needs

Four studies reported that the ACP educational intervention addressed patient needs in different outcomes. These include improved knowledge of EoL care decisions and EoL care treatment options, as well as improved confidence in communication and palliative care-available services. For example, Kapell Brown, Kryworuchko and Martin (2018) found CPR-VDA to be beneficial to patients and their families, providing information and facilitating DM processes for CPR. Patients considered the CPR-VDA easy to use, even in situations in which illness made it difficult for them to attend to critical aspects of the DM process. The CPR-VDA enhanced patient knowledge of CPR decisions. According to Amro *et al.* (2016), using the POLST paradigm reflected ESRD patients' understanding of EoL treatment options. A study by Oarde (2017) found that online palliative care educational materials provided to ESRD patients enhanced their awareness and confidence in using palliative care services. It also taught them how to help their families manage the burdens associated with ESRD. The REACT programme, developed by Bristowe *et al.* (2014), effectively addressed ESRD patients' needs. REACT helped them share their feelings and emotions with other patients and improved their confidence in talking about their issues.

2.8.1.3 Patient/Surrogate Decisional Conflict, Congruence, and Confidence in Decision

Making

Outcomes such as patients' decisional conflict, patient-surrogate congruence in care goals, and surrogates' confidence in decision-making were reported in five studies. The results varied. For example, Song *et al.* (2009, 2015) used the ACP intervention—Sharing Patients' Illness Representations to Increase Trust (ACP-SPIRIT)—designed to enhance communication regarding EoL care, preparation for EoL decision-making between patients and their surrogate decision-makers and surrogate's bereavement outcomes. Song *et al.* (2010) used a PC-ACP intervention designed to improve knowledge about illness course and benefits and risks of LSTs needed at EoL among patients and their decision-maker surrogates. Patients' decisional conflict was assessed by their level of difficulty in making EoL care choices. The studies found that both groups showed difficulty in making EoL choices but did not find significant differences among them, although the studies collected data at different intervals ranging from baseline to 12-month follow-up.

All three studies assessed patient–surrogate congruence EoL in treatment preferences regarding the goal of care and whether LSTs and CPR are continuous in situations with a low chance of survival. The studies found that the intervention group showed greater concordance in treatment preferences regarding continuing LSTs at EoL between patients' wishes and surrogates' knowledge of those wishes over time. However, Song *et al.* (2009, 2015) indicated that the results were not significantly different between the intervention and control groups across all time points. Moreover, the studies assessing surrogate's confidence in DM reported that although surrogates in both groups showed higher confidence in making decisions for their loved ones compared to baseline, they were not significantly different in all three studies.

Furthermore, Kapell Brown, Kryworuchko and Martin (2018) found that CPR-VDA intervention improved patients' and families' decision self-efficacy and confidence in making decisions. The decisional conflict was also assessed when uncertainty about the best treatment existed among patients and their families in terms of feeling uninformed, being unclear about personal values regarding treatment options and feeling unsupported in DM. The study reported that the intervention reduced DM conflict and uncertainty about the best treatment among patients and their families and documented physicians' orders and patients' choices about receiving CPR. Alternatively, Courtright *et al.* (2017) assessed satisfaction with the decision-making process measured immediately following patients' decisions using a standard or expanded choice set. The study found that patients were highly satisfied with the decision-making process, but there were no differences between the standard and expanded groups.

2.8.1.4 Completion of Advance Directives

Two studies, Perry *et al.* (2005) and Courtright *et al.* (2017), focused on improving EoL care planning and decisions in terms of examining how ACP intervention influences completion of advance directives (ADs) among ESRD patients who were exposed to educational interventions.

Perry *et al.* (2005) found that peer mentor-facilitated ACP intervention improved AD outcomes and reported a high proportion of participants' completion of ADs and a willingness to complete them compared with other groups that received written and routine care. It also

indicated that patients in the peer-intervention group had a significantly greater level of confidence and comfort in discussing ADs compared to the other two groups; the intervention group showed significant differences. This influence was most prominent among African Americans who completed ADs and were more comfortable discussing them. To achieve successful AD education, specific cultural factors must be addressed. Moreover, Courtright *et al.* (2017) offered more ADs options for completing a brief advance directive form and expanded options, including a brief, expanded or comprehensive form. The study found that although there was a substantial rise in the proportion of patients who decided to complete an ADs and took one home, proposing alternative forms was not associated with higher completion rates.

2.8.1.5 Patient, Family Caregivers and Healthcare Providers Communication and

Interactions

Two studies, Song *et al.* (2009, 2010), focused on improving communication and interaction among patients, families and HCPs towards discussion of EoL care and decisions in terms of examining how ACP educational interventions influence the communication process. Song *et al.* (2009, 2010) found that ACP-SPIRIT and PC-ACP interventions significantly affected patient–HCP interactions and communications related to EoL care among both patients and their families and patients and their HCPs.

2.8.1.6 Patient and Family Well-being, Anxiety and Quality of Life

The effect of the ACP interventions on patients and/or their family (surrogates) psychospiritual well-being and the in terms of adaptive well-being with current illness, anxiety, depression and QoL were assessed in five studies. The studies reported varied results. Two studies (Song *et al.*, 2009, 2010) found that patients or surrogates in both groups improved over time on well-being but found no significant effect among the groups. However, Perry *et al.* (2005) found that the ACP peer-mentor intervention effect on ESRD patients' psychological well-being was associated with a significant improvement in subjective well-being and reduced anxiety among African Americans compared to their counterparts, while death acceptance was slightly higher but not statistically significant. Conversely, Song *et al.* (2015) assessed surrogates' bereavement outcomes in terms of symptoms of anxiety, depression and posttraumatic distress and revealed a significant effect of the ACP-SPIRIT

intervention on these outcomes in African Americans. Compared to their normal treatment peers, African Americans engaged in peer-mentor-facilitated ACP and SPIRIT sessions showed greater change in subjective well-being, anxiety and depression. Courtright *et al.* (2017) also found not statistically or clinically significant difference in QoL between standard and expanded choice set groups over the course of their study.

2.8.2 Outcomes Focused on Healthcare Providers

This section examines the HCPs-reported outcomes of palliative care communication issues (ACPs and DMs) in educational intervention. Overall, the identified outcomes were improved communication skills, competence, and confidence, and healthcare providers' knowledge and needs.

2.8.2.1 Improved Communication Skills, Competence, and Confidence

Six studies reported an improvement in communication skills, competence and confidence among renal HCPs after exposure to intervention. The results varied, as some reported no significant increase following exposure to the intervention, while others had significant increase in these outcomes.

Thus, Bristowe *et al.* (2014) used Renal-specific Advanced Communication Training (REACT) to meet renal professionals' needs for communication training before holding ACP talks with patients. Although HCPs' confidence improved in communicating with patients about EoL issues, there was no significant increase over a 3-month period. The level of confidence increased slightly, providing information on treatment efficacy and discussions of death and dying between pre-training and 3 months. However, the results were not statistically significant. This is the only study that reported a piloted process of REACT programme development before its implementation. Gross's (2015) POLST programme also improved HCPs' communication with patients about EoL care strategies and their wishes regarding EoL treatments.

Similarly, Cohen *et al.* (2016) developed an interactive one-day workshop for nephrology fellows, in which participants explored how to deliver bad news, discuss care goals in dialysis decision-making, respond to emotions, discuss uncertainty, elicit patients' goals, discuss

conservative therapy and address withdrawal and EoL issues related to dialysis therapy. This positively impacted their skills and attitudes, and they showed improvement in all eight communication skill domains mentioned above at different periods of time.

Schell *et al.*'s (2013, 2018) training also enhanced nephrology fellows' communication skills regarding complex discussions about dialysis DM, helping patients define EoL care goals and preferences and delivering bad news. This improved their preparedness to provide effective bedside education. Across all areas, including delivering bad news, empathetic communication and dialysis initiation, the level of preparedness significantly increased. The fellows unanimously agreed to recommend this training to their friends and colleagues. Moreover, García-Llana *et al.* (2017) determined that the CoBIT programme increased HCPs' self-confidence when conducting communication and bioethical tasks—managing patients' medical and personal needs, expressing empathy, motivating patients and coping with patient aggression, all of which significantly improved after the intervention.

2.8.2.2 Healthcare Providers' Knowledge and Needs

In two studies, the intervention improved HCPs' knowledge of different aspects of care. Simpson (2017) found an increase in HCPs' knowledge and awareness regarding patient engagement and that this learning was helpful in clinical practice after an education session on the Shared End-Stage Renal Patients-Decision-making (SHERPA-DM) tool. Corbett's (2017) 'Facilitating ACP' project reported on four renal patients' referrals to palliative care services and on 22 ACP discussions, over four months, from a baseline of zero after HCPs educated them about DM, ACP and correct palliative care referral guidelines.

2.8.3 Other Outcomes

Acceptability and feasibility of the interventions, HCPs' satisfaction with educational intervention and evaluation of educational sessions were reported as outcomes in six studies. Of the 18 interventional studies, four measured the interventions' acceptability and feasibility. Song *et al.* (2009, 2010) quantitatively assessed patients' and their surrogates' experiences with ACP-SPIRIT and PC-ACP interventions. In their studies, feasibility was assessed by tracking the proportion of patients who completed the intervention and those who completed the entire study. Acceptability was assessed by the quality of communication

interactions among the participants and HCPs and by a clinical cultural sensitivity questionnaire. Kapell Brown, Kryworuchko and Martin (2018) examined the acceptability of the CPR-VDA via a questionnaire for patients and their families (leaving out HCPs) focusing on amount of information, clarity, length, balance in presenting information, willingness to recommend to others and overall stability for decision-making.

Bristowe *et al.* (2014) provided qualitative feedback on the REACT programme's acceptability among HCPs, showing that future sessions should include more role-playing and patient experiences. Although there were differences in feasibility and acceptability outcomes related to different interventions, all these studies found the interventions to be positively acceptable and feasible to facilitate discussions about EoL care preferences and the DM process. Another reported outcome by García-Llana *et al.* (2017) was the satisfaction of healthcare professionals. The study evaluated HCPs' satisfaction with the CoBIT programme in an advanced CKD unit. They determined that the HCPs were satisfied, and they recommended this training for all other HCPs. Simpson (2017) evaluated the overall education session using a survey. HCPs reported that the educational presentation was good and that it would help other clinicians learn about patient engagement.

Only one qualitative study met the inclusion criteria, which was to obtain surrogates' perspectives on the process and the impact of SPIRIT by comparing African American and Caucasian participants (Song, Metzger and Ward, 2017). The participants agreed that the intervention helped them focus on and discuss issues that had been ignored and helped surrogates and patients express their thoughts. African Americans more frequently expressed feeling prepared for the EoL DM experience due to the intervention than Caucasian participants. Song *et al.* (2009) conducted semi-structured interviews to obtain further information about how patients perceived the ACP-SPIRIT intervention, which was part of an RCT. Most of the feedback regarding the intervention was positive. ACP-SPIRIT was not difficult for 27 patients and 23 surrogates, but two patients and four surrogates reported that it was difficult to hear that the illness would not be cured. According to four surrogates, a subsequent session would be helpful in determining what needs to be done to ensure that others are aware of a patient's wishes.

2.9 Discussion

Educational programmes are vital interventions that allow ESRD patients to decide informally on their preferred care. This scoping review sought to understand more about how educational interventions work when applied to palliative care and their approaches, and EoL issues in an ESRD context. This is the first scoping review focused exclusively on studies concerned with educational intervention for palliative care and its communication issues (ACP and DM) in a renal context. 19 studies were identified that evaluated a broad range of educational interventions and outcomes for ESRD patients, patients and their families and HCPs. Most interventions were developed between 2015 and 2018 and took place in Western countries. There might be differences in preferences, priorities and practices in clinical settings, and there might be less emphasis on ACP discussions and DM processes among countries. The only study that described an intervention occurring in a Muslim country was by Hing *et al.* (2016). This study modified a pre-published survey and educational brochure and translated it forward and backward to meet the needs of the Malay people. However, modifications and the translation_process were not entirely reported.

Although all included studies generally reported positive findings, in some studies there was no significant difference between the pre- and post-tests, and the control and experimental groups. This is attributed to variations in the interventions included in their designs, contents, delivery and finding outcomes. Most interventions used multiple educational modalities, such as written online or printed materials, audio materials, face-to-face interviews, training workshops, peer mentors, role play and follow-up sessions. Moreover, only a few studies reported the development process of the intervention based on the assessment needs of the target population. The diversity of intervention approaches, measures and findings outcomes mean that it is not yet possible to draw conclusions about the most appropriate and effective way to conduct educational interventions focused on palliative care and its approaches for ESRD patients, their families and HCPs, to facilitate ACP discussion and the SDM process. There has been no comprehensive educational intervention regarding ACP that addresses caregiver, health professional and system-related factors. This finding is consistent with Myers *et al.* (2018), who conducted a systematic review to find evidence of either tools or practices that demonstrate how HCPs can effectively facilitate ACP conversations and/or discussions regarding goals of care. According to the study, despite several studies reporting positive results, there are no consistent patient outcomes to support any one clinical tool for use in ACP. As a result, the study suggested that more research needs to be done on documentation and best practices for ACP and goals of care discussions.

Previous systematic reviews have demonstrated that research on palliative care approaches, such as ACP and DM, in ESRD patients is limited, particularly intervention studies and it remains uncertain whether educational interventions focused on ACP can improve ESRD patients' outcomes (Lim *et al.*, 2016; Lopez-Vargas *et al.*, 2016). Luckett *et al.* (2014) conducted a systematic integrative review of seven ACP-evaluated interventions offering valuable information for future practice regarding CKD patients. These interventions trained nursing staff and doctors in discussing EoL care, completing documentation, addressing patients' EoL care preferences, improving patient–doctor communications, encouraging patients to express their requests and familiarising them with ACP as part of a long-term care programme. However, Luckett *et al.*'s (2014) study focused on a group of patients with mixed CKD stages.

This is the first scoping review to examine palliative care educational interventions related to renal context in patients with stage 5 CKD or ESRD. This review reported different outcomes regarding ESRD patients and their families, renal HCPs and other outcomes. The outcomes with regards to patients and their families, include election of EoL care preferences, increased knowledge about EoL treatment options, facilitation of discussion, DM, and completion rate of ADs and ACP, improved decision confidence, reduced DM conflicts among patients and their families, their families, reduced anxiety and improved QoL and AD and ACP completion rates. These results align with other studies that showed the impact of ACP intervention on ACP documentation, identified preferences for EoL care and decisions in a dialysis context (Sellars *et al.*, 2019; Lupu *et al.*, 2022) enhanced congruence in terms of care goals and surrogate decision confidence, reduced patients' decisional conflicts and reduced surrogates' bereavement distress (Song *et al.*, 2005; Detering *et al.*, 2010).

Another important observation was the focal nature of ACP intervention focused on patient preferences in their EoL decision and care in relation to LSTs, particularly CPR. Surprisingly, no studies have examined ACP for patients with CKD who are considering or have chosen a conservative (i.e., nondialytic) approach to care or initiation dialysis as prolonged life treatments. ACP has been widely studied in dialysis patients and conservatively managed patients, although such research has resulted in limited evidence (Holley *et al.*, 1999; Murtagh and Sheerin, 2010). A review of outcomes among HCPs indicated that educational interventions improved completion rates of AD and improved communication confidence and skills particularly when delivering bad news and discussion about EoL care. This review supports evidence from previous observations (Cheung *et al.*, 2021) which reported that the communication workshop intervention was improved in all communication skills domains: demonstrating empathic behaviours, responding to emotion and EoL concerns, eliciting family's concerns at EoL and patient's goals and discussing spiritual concerns.

In addition, SDM, a decision aid is a tool designed to support performance of SDM in clinical encounters between HCPs and patients. As a result of their difficulty in producing, they often do not reflect current evidence and show limited uptake in practice. In this review, only one study used a DA video for patients and their families, promoting SDM in EoL CPR treatment preferences (Kapell Brown, Kryworuchko and Martin, 2018). Some initiatives aim to develop tools to help patients make treatment decisions. Winterbottom *et al.* (2016) evaluated the acceptability, feasibility and effectiveness of the Yorkshire Dialysis Decision Aid Booklet (YoDDA) in usual pre-dialysis practice. YoDDA has been valued and useful for patients with deteriorating kidney disease as part of the pre-dialysis education. Some current initiatives aim to develop and use such DA tools in renal disease, helping patients choose amongst different dialysis modalities (Fortnum *et al.*, 2015; Finderup, Jensen and Lomborg, 2018; Finderup, Jensen and Lomborg, 2019; Subramanian *et al.*, 2019) and amongst RRT (Ameling *et al.*, 2012; Patzer *et al.*, 2016). Such DAs are also being developed to improve patients' satisfaction, knowledge and communication (Subramanian *et al.*, 2017). However, few educational tools have been established to inform patients' choices of the conservative management pathway.

Only three studies used a DA tool that focused on conservative management. A recent RCT conducted by Wong *et al.* (2023) assessed the feasibility and acceptability of a decision aid on conservative management among patients with advanced CKD and their family members. conservative management decision aids were feasible and acceptable, and they increased discussions about this treatment option with HCPs. This finding was also reported by Saeed

et al. (2023). However, these interventions were focused on conservative management as treatment options for renal patients without palliative care-based decision aid and focused on feasible and acceptable outcomes among dialysis and non-dialysis patients in stages 4 and 5. Additionally, Eneanya *et al.* (2020) conducted an RCT to test the effectiveness of a video decision aid on knowledge of supportive kidney care among older patients with advanced CKD. The study reported that after receiving education, the knowledge of supportive kidney care increased significantly, but there was no difference between the study arms. The study arms did not differ in their preference for supportive kidney care. More importantly, 96% of respondents were comfortable watching the video, 96% found the content to be helpful and 96% said they would recommend it to others. Some ESRD patients may opt out of dialysis treatment (Nobel, 2008). Therefore, patients should know from the start that non-dialytic management is a viable option for ESRD. No DA tool currently exists in the Saudi Arabian clinical context. Only one RCT study has been conducted in Saudi Arabia to evaluate the effect of a decision-aid tool on patients with metastatic colorectal cancer (mCRC) (AlSagheir *et al.*, 2020).

Many PtDAs developed for ESRD patients have been reported in scoping reviews. This consists of scoping reviews of pre-dialysis educational programmes, a scoping review of the information clinicians can use to counsel older patients with kidney failure, a systematic review of PtDAs that support SDM between dialysis and conservative care management pathways, and a scoping review of interventions for treatment modality decisions in ESRD supporting SDM (Van den Bosch, Warren and Rutherford, 2015; Raj *et al.*, 2019; Winterbottom *et al.*, 2020a; Engels *et al.*, 2022). Despite multiple efforts to foster SDM across the international healthcare community, it seems that patients still encounter low levels of SDM (Haesebaert *et al.*, 2019). This may be because there is no conclusive evidence regarding which intervention is most effective in supporting SDM for treatment modality decisions in ESRD. Moreover, these interventions are underreported in terms of their impact on SDM (Engels *et al.*, 2022). Thus, more research is required in this area.

Several literature gaps were identified from this scoping review. One is the insufficient focus on conservative management and SDM educational interventions among ESRD patients, their families and HCPs, about dialysis withdrawal and the palliative care approach. Most research focused only on EoL treatment and ACP regarding LSTs, including dialysis, CPR and DNR. Some educational interventions discussed in the literature, such as communication, mainly concerned opting out of dialysis. Proper communication among HCPs, patients and patients' families is vital during the SDM process. Studies should also discuss physicians' perspectives on engaging in SDM processes with patients regarding dialysis withdrawal.

Importantly, no educational intervention studies addressing palliative care have been carried out for ESRD patients in Saudi Arabia. One previous study evaluated multidisciplinary educational classes for CKD patients in Saudi Arabia (Elhassan *et al.*, 2019), yet it did not measure their impact on patients' EoL issues, such as improving ACP discussions, planning for EoL care or enhancing DM. Alhameedi (2016) reported that approximately 20% of Saudi ESRD patients received no or delayed treatment options and that 60% were unsatisfied with their treatment options. She recommended that pre-dialysis education be improved in Saudi Arabia's clinical settings. To support the rights of patients to be informed about appropriate care choices, more informational resources need to be provided and more time needs to be spent on patient education. The Saudi population's awareness of CKD manifestations is low (Alateeg *et al.*, 2018). Thus, educational intervention areas in Saudi Arabian clinical context were neglected in both pre-dialysis and dialysis patients.

Another gap is qualitative research that assesses the participants' perspectives on the educational interventions. Qualitative research explores people's opinions, behaviours and attitudes towards the research topic. A few studies have collected data from HCPs to understand their perspectives on the potential benefits of educational interventions, yet qualitative data focusing on patients are minimal. More research must collect sufficient primary data assessing patients' educational needs and showing the advantages of educational interventions in the renal-care context. The emotions, values and situations that may affect the implementation of educational interventions among patients have similarly not been studied. Even as educational interventions aim to ensure quality of care is given to patients and understand the care process, some patients may refuse to cooperate with their HCPs due to such emotions, values and situations. Existing studies assume that, once educational interventions are in place, they will immediately benefit patients, their families and HCPs. Future studies must also explore HCPs' emotions, values and situations, and how these affect their implementation of educational interventions in the renal care context.

2.10 Chapter Summary

This review highlighted the growing interest in educational intervention related to palliative care and its communication issues (ACP and DM); however, these interventions varied in their assessment for effectiveness and implementation. Most studies in this review focused on ACP and EoL treatment preferences particularly LSTs and the DM process, including decisional conflict, patient-clinical communication and DM participation. Not many studies focused on interventions that improved SDM, such as using decision aid tools. Educational interventions enhance and facilitate ACP and EoL discussion, but their impact may be influenced by the healthcare environment where they are delivered. Therefore, it is vital to consider specific cultural factors. In Saudi Arabia, family is intrinsic to patients' DM, and communication among patients, their family caregivers and HCPs is a major challenge. As noted, Saudi Arabia has no existing educational interventions for renal palliative care communication issues, such as ACP and DM. Therefore, researchers should assess the educational needs and experiences of Saudi Arabia's ESRD patients, their family caregivers and HCPs for palliative care communication issues. Researchers should also evaluate how a shared DA tool might improve ACP discussions—and the SDM process for ESRD patients, their families and HCPs—addressing challenges of renal EoL care, including the emotional and ethical dilemmas of dialysis withdrawal. This would fill the research gaps and help develop/adapt specific educational interventions in the Saudi Arabian context. Next, the following subsections present the goals and objectives of this thesis.
Chapter 3: Methodology

3.0 Introduction

This chapter describes the study's methodology. The first section outlines the study rationale based on the scoping review of current educational interventions relating to renal palliative care, especially communication regarding ACP and DM around ESRD. The next section articulates the research's aims and objectives, followed by the study overview. Following that, the study's methodology, philosophical assumptions, theoretical underpinnings, and approaches to qualitative research are discussed, including pragmatic qualitative research design and the reasons for choosing them. The final section provides a summary of the chapter.

3.1 Study Rationale

The literature review presented in the previous chapter referred to a variety of palliative care educational intervention approaches, measures, and findings. Most studies in the scoping review focused on delivering interventions to improve ACP discussion, EoL treatment preferences, and DM. The main aspects involved were enhanced communication regarding EoL care, preparation for EoL decision-making, participation in EoL decision-making, and preferences, in particular LSTs. Only one study used the DA tool as an educational intervention to improve knowledge and facilitate CPR decision-making. Some initiatives were aimed at developing and using DA tools to help renal patients make treatment decisions, initiatives which have been implemented with good results in countries such as the UK, the USA, and Australia (Ameling *et al.*, 2012; Fortnum *et al.*, 2015; Winterbottom *et al.*, 2016). These initiatives assist patients in choosing between different dialysis modalities and RRT. In some cases, these interventions were developed locally, while others were imported and adapted to local cultures. Even so, few educational tools are available to help patients choose conservative management.

As noted, Saudi Arabia has no existing educational interventions for renal palliative care communication issues such as ACP and DM. It is worth noting that limited research has been conducted on these issues within the Muslim context for renal patients and their family caregivers, particularly in the Saudi Arabian context. Saudi research regarding renal educational intervention is still in its infancy. The previously identified interventions of ACP and SDM experienced by ESRD patients and their family caregivers in different parts of the world may differ from those that may be appropriate in Saudi Arabia due to the country's different religious, cultural, and social structure. Saudi patients' DM is intrinsically linked to their families, and communication between patients, their families, and their HCPs is a major challenge. Therefore, researchers should assess the educational needs and experiences of Saudi Arabia's ESRD patients, their families, and HCPs relating to palliative care communication issues.

Currently, no DA tool exists in the Saudi Arabian clinical context; however, evidence suggests that Saudi Arabia would likely benefit from one of the currently available interventions. As Saudi Arabia has a unique culture, it is likely that such an intervention would need to be culturally adapted. Saudi Arabia is a conservative Muslim country where local Arabic is the main spoken language and Islam is the religion of most citizens. While Saudi society has traditions that are historically rooted, the prevalence of ESRD is high in comparison to global averages, and patients have little awareness of ESRD and its management. Thus, based on the success of such interventions elsewhere, a culturally adapted educational intervention such as a DA tool will likely achieve some success in managing renal disease. It would address research gaps and assist the development or adaptation of specific educational interventions for the Saudi Arabian context. The following subsections describe the aims and objectives of this thesis.

3.2 Study Aims and Objectives

3.2.1 Study Aims

This thesis aims to explore the educational needs and experiences of patients and/or their family caregivers regarding current ACP and SDM practices in a dialysis unit in Tabuk, Saudi Arabia. It also aims to culturally adapt and translate a decision aid tool to be relevant to Saudi Arabian patients with ESRD and their family caregivers.

3.2.2 Study Objectives

This research study has the following study objectives:

1. To understand and describe current ACP and SDM experiences and practices in the dialysis unit from the perspective of people with ESRD and/or their family caregivers.

- To systematically explore, synthesise, and describe evidence on the preferences and experiences of ESRD patients and/or their families regarding ACP discussions and the DM process in the Islamic context.
- To conduct an expert discussion with a broad multidisciplinary range of healthcare providers and people working in clinical, academic, and research settings to explore their views and perspectives on the cultural adaptation of a decision aid tool.
- 4. To undertake the cultural adaptation and translation of a decision aid tool for the Muslim context, specifically the Saudi Arabian context.
- To assess the content validity in terms of acceptability and understandability of the culturally adapted and translated decision aid tool and develop a preliminary implementation plan.

3.3 Study Overview

This study was intended to employ a mixed-methods, exploratory, sequential three-phase design. However, due to COVID restrictions and changes that were required within the PhD time limit, a qualitative research design was chosen, namely a pragmatic qualitative research design, consisting of a variety of methods. The study was conducted in two phases, which are described in more detail in the next section as well as in Chapter 4. Figure 4 illustrates the study overview flowchart.

Research Aim: To explore the educational needs and experiences of ESRD patients and/or their families' caregivers about current ACP and SDM practices in a dialysis unit in Tabuk, Saudi Arabia, and to culturally adapt and translate a decision aid tool to be relevant to patients with ESRD and their family caregivers in Saudi Arabia.

Phase 1A comprised a qualitative exploration study: Individual interviews were conducted with Saudi ESRD patients and their family caregivers to identify their experiences, problems faced, and education needs in communication issues, such as ACP discussions and the SDM process.

Phase 1B comprised a modified systematic review focused on the experiences of ACP and DM of Muslims dialysis patients.

The findings from Phases 1A and 1B were analysed and combined, leading to Phase 2.

Phase 2 comprised cultural adaptation of an intervention: Individual interviews were conducted with experts in renal care from Muslim countries to inform cultural and linguistic adaptation of a DA tool.

Phase 2: Experts' findings were combined with a series of meetings with developers of the chosen DA tool in the UK and this research team to refine modifications to the tool.

Described cultural adaptation and translation process, and developed pre-final versions of the culturally adapted and translated DA tool.

Seek tool copyright.

Tested the content validity of the chosen DA tool that was adapted and translated to fit the culture of Muslims, particularly Saudi Arabia. Feedback from consultation interviews with three previous renal care experts.

Developed final versions and report the adaptation process.

Figure 4: Study Overview Flowchart

3.4 Qualitative Research

A qualitative study employs a research approach built on a broad understanding of inquiry as a humanistic or idealistic exercise. An important aspect of qualitative research is understanding participants' experiences, opinions, attitudes, and social interactions and the phenomena that they encounter within their natural settings (Denzin and Lincoln, 2013). An advantage of qualitative research is that it concentrates on the context and meaning of human experience and allows researchers to gain an in-depth understanding of phenomena (Creswell and Poth, 2018). Moreover, as qualitative research is primarily inductive, it offers opportunities to explore previously unknown phenomena and to understand why and how they occur (Peter, 2015; Creswell and Poth, 2018). Guest, Namey, and Mitchell (2013) pointed out that qualitative research seeks to answer questions such as 'what, how, and why' from the perspective of the participant rather than that of the researcher. The researcher should not predetermine the study outcome to ensure that participants have a voice and to minimise bias (Colorafi and Evans, 2016).

The qualitative method has increasingly gained attention across different disciplines including clinical research to view data extensively and strengthen clinical trial outcomes. Qualitative research in healthcare settings is described as exploring and understanding participants' experiences of phenomena of interest in order to explain their behaviour and actions within a specific context (Cleland, 2017). A healthcare professional's work typically takes place within social, interpersonal, or clinical contexts where statistical methods are usually inadequate to investigate stakeholders' (particularly patients, their caregivers, and HCPs) perceptions of the quality of healthcare services provided (Renjith *et al.*, 2021). Qualitative research focuses on collecting experiential information that is difficult to obtain using quantitatively oriented methods of data collection. Thus, from a generalized approach, the qualitative method seeks to understand the meaning individuals construct and how they attach perceptions to the world and experiences within personal surroundings.

A qualitative research design was chosen for this research because meeting the aim of this study requires an in-depth understanding and exploration of the experiences, needs, priorities, and problems faced by ESRD patients and family caregivers in communication issues such as ACP discussion and the SDM process. Furthermore, this methodology was used

due to the nature of the output sought from the research because this study provides a detailed analysis and interpretation of culture-related issues that are difficult to quantify. A further resonant reason is that a qualitative design was appropriate because the evidence base in this area in Saudi Arabia is very limited and qualitative methods are well suited to exploratory research.

3.5 Philosophical Assumptions of Qualitative Research

The research paradigm plays a major role in shaping research direction, since it comprises the presumptions of researcher when starting a project. It provides investigators with a set of beliefs that would guide their actions and determine how and what they learn during their investigation. It entails four philosophical assumptions, namely, ontology, epistemology, axiology, and methodology (Creswell and Poth, 2018). Ontology refers to the nature of reality. During research, investigators assume the existence of multiple realities on the study topic, which helps in the identification of various themes that may arise during the research. For instance, when conducting a phenomenological study, one may indicate how the respondents view their experiences in different ways (Creswell and Poth, 2018). Epistemology refers to knowledge, how one knows knowledge, and the relationship between the subject and researcher (Creswell and Poth, 2018).

Axiology refers to the role values play in research. The investigators affirm that there are principles that influence their actions, for example, ethical concern for privacy leads to the requirement to conceal the identity of the participants. Most researchers indicate the values that play a key role in shaping their work, interaction with participants, and the reporting of findings. Methodology refers to the process of studying the identified research topic. The chosen strategy guides the type of data to be collected and the mode of analysis; for example, a qualitative strategy employs the collection of data based on the understanding of the research questions among the participants. The researchers may sometimes ask further questions for the purpose of clarity. On the other hand, quantitative strategy depends on theory and the perspective of the researcher heavily determines the findings (Creswell and Poth, 2018).

3.6 Research Paradigms

The assumptions that were explained in Section (3.5), in turn, are often applied in research through the use of paradigms, which may also be referred to as a 'worldview' (Creswell and Creswell, 2018), and theories, called an interpretative framework. A research paradigm includes philosophical concerns of ontology and epistemology and presents itself in different interpretive frameworks, including post-positivism, social constructivism, transformation and pragmatism (Creswell and Poth, 2018). Post-positivism embraces the assumption that, although cause and effect may occur, this is not a guarantee that a relationship exists, since every situation has multiple realities. A post-positivism, where cause and effect must occur. Social constructivism involves seeking an understanding of the world, which advocates qualitative approaches and inductive reasoning. Researchers construct complex views of situations based on a collection of varied responses rather than narrow meanings constrained by the researchers' understanding and perspective (Creswell and Creswell, 2018).

In transformative frameworks, information is not neutral; its distribution depends heavily on social classifications (Creswell and Creswell, 2018). Unlike post-positivism, which upholds structural 'laws', this paradigm tries to include marginalised groups like the indigenous peoples. Pragmatism is defined as a worldview in which one focuses on what works best in terms of addressing research problems and questions using pluralistic approaches (Creswell and Poth, 2018). As there are no strict philosophical constraints, researchers are free to use any method, procedure or technique appropriate to their field. The data can be collected in any way, and assumptions and analyses can be used. Moreover, according to Morgan (2014), pragmatism embraces both post-positivism and constructivism extremes and offers a more flexible and reflexive approach to research design. As Kaushik and Walsh (2019) explained, pragmatism is part of a researcher's worldview, so it can have an impact on how research is conducted. A more detailed account of the reflexivity and subjectivity of the researcher is given in the following section.

3.6.1 Subjectivity in Qualitative Research

The researcher's subjectivity is intimately involved in qualitative research (Ratner, 2002). Subjectivity influences the choice of topic, formulation of hypotheses, methods and interpretation of data. Qualitative methodology encourages researchers to reflect on their values and objectives and on how they influence the research (Ratner, 2002). Researcher subjectivity is very important in this thesis. As a researcher, I shared a similar cultural background with the participants and my pre-existing knowledge and experiences about my thesis research topic. As will be discussed later in Chapter 4, Section (4.4.7.4), it was important for me to consider how previous experiences and my cultural background might affect the participants' responses. It was also worthwhile to note that all qualitative interview participants were from the same cultural background as me. It is possible that my pre-existing knowledge and background influenced what participants chose to say or not say and even extended to tacit knowledge and making assumptions about shared understandings that may not be explicitly captured. However, because I shared the same cultural background as the participants, they may have communicated more willingly to share information than they would have. For this reason, I possibly obtained richer and more authentic data. It was also apparent to me that my subsequent interpretation and analysis of the findings could have been affected by my previous experience and shared cultural background.

3.7 Pragmatism as a Research Paradigm or Design

Pragmatist research philosophies have been adopted or influenced by many research methodologies. These include mixed-methodology, Q-methodology and a generic qualitative approach. Consequently, qualitative research can be conducted based on pragmatism as a philosophical underpinning for researchers. However, according to Kelly and Cordeiro (2020), a pragmatist approach that emphasises enquiry and practicality is more useful than research philosophies which focus solely on abstract concepts or philosophical theories. According to the paradigms, what works best to understand a particular phenomenon is more important than the methodologies' philosophical bases, and what works both functionally and practically is valid (Long, McDermott and Meadows, 2018).

Because a paradigm is a conceptual and practical "tool" that enables the solution of specific research problems, there is an increased need to be pragmatic when considering current challenges in healthcare, health education and public health (Glasgow, 2013). For example, adapting evidence-based interventions, which was the aim of my study, requires a different approach and different methods to determine how to improve adoption and usage by the populations that are most in need. It is anticipated that research in these areas using pragmatic design will result in more rapid and relevant findings that can be applied immediately in the field (Holtrop and Glasgow, 2020). Thus, pragmatism underpins the present thesis as the philosophical bedrock of generic qualitative enquiry in the methodology.

Moreover, according to the pragmatism approach, human actions cannot be separated from the experiences of the past or from the beliefs derived from them (Kaushik and Walsh, 2019). A pragmatist views social problems from the perspectives of the individuals who experience them, thus leading to the development of actionable research questions (Kaushik and Walsh, 2019). Pragmatic research aims to build an understanding of the world primarily through human experience rather than relying on absolute truths (Allemang, Sitter and Dimitropoulos, 2022). According to Dillon, O'Brien and Heilman (2000), a pragmatist defines a genuine problem within the context of a real social situation and then initiates the enquiry to resolve it. Consequently, pragmatic studies begin by identifying a problem and viewing it within its broadest context. This leads to research enquiry, which aims to better understand the problem and ultimately resolve it. Dillon, O'Brien and Heilman (2000) suggested that, once the problem has been identified and its dimensions have been defined, it should be investigated from various perspectives, depending on the purpose of the enquiry.

A pragmatic paradigm is based on the premise that real-world problems are best examined using the most effective methods, including multiple sources of data and knowledge to answer questions (Brierley, 2017; Allemang, Sitter and Dimitropoulos, 2022). Therefore, the pragmatic design is suitable for mixed methods studies, in which quantitative and qualitative data are collected and integrated into a single study, as well as multimethod studies, which utilise multiple forms of quantitative or qualitative methods (Creswell and Poth, 2018). As a result, this paradigm encourages the adoption of different methods of enquiry to discuss problems in an appropriate way, acknowledging that methodologies can contribute to our understanding of the world. This thesis employed multiple methods and the intermixing of qualitative studies and data to achieve the research aim. Thus, as a researcher, I decided to address my thesis aims with any methodological tool available, using the pragmatist credo of "what works". The thesis was therefore designed as a two-phase, multimethod, qualitative study, which was elaborated on in more detail in Chapter 4.

3.7.1 Reasons for Adopting Pragmatic Qualitative Research Design

The pragmatic research is used in a variety of ways, either as mixed-methods studies using a combination of both qualitative and quantitative approaches in a single study or as a multiple form of quantitative or qualitative approach, to advance a specific piece of research in the best possible manner (Morgan, 2014). An important reason for using a pragmatic research design is that, originally, this thesis was intended to be a mixed-methods study, and ethics approval and protocol were written for a mixed-methods study. Unfortunately, due to the pandemic, it was not possible to employ a mixed-methods study, but I had already started to design the qualitative side of the study, which suits pragmatic qualitative research as the thesis is designed as two phases of multi-method qualitative studies.

As explained previously, qualitative research can also be conducted based on pragmatism, since it tends to be adopted when using generic qualitative inquiry methods. Generic qualitative research employs a descriptive methodology (Sandelowski, 2000) to understand how individuals interpret phenomena and situations, using 'what works' for finding answers (Kahlke, 2014). Thus, my thesis using pragmatism approach as the philosophical underpinning generic qualitative inquiry as the methodology. The rationale for the pragmatic study is that it offers researchers a straightforward description of the participants' perceptions and lived experiences. Qualitative description ensures the researcher has a direct grasp of a subject's nature, and the lived experiences guarantee results that align the expected solution to the identified problem (Allemang, Sitter, and Dimitropoulos, 2022).

Moreover, the process of pragmatic studies begins with identifying a problem and viewing it from its broadest perspective. As a result, research inquiry is conducted, with the goal of understanding the problem better and resolving it. Returning to the thesis research topic particularly as little is known about the topic due to limited research on ESRD patients and their family caregivers' experiences in ACP and SDM, pragmatic qualitative research design was chosen (Kahlke, 2014). Thus, my thesis was therefore designed as a two-part multimethod study to include examining the educational needs and experiences of ESRD patients and their family caregivers within a Saudi Arabian context regarding current ACP and SDM practices in a dialysis unit. Subsequently, I adapted and translated a patient decision aid tool to make it more relevant to them. I adopted the pragmatism paradigm, using a multimethod qualitative approach to achieve my study aims, since pragmatism is a practiceoriented philosophy derived from real-world experiences (Creswell and Creswell, 2018).

Notwithstanding the above, pragmatic design does not rely on assumptive ideologies of reality and philosophy of a problem but is more focused on addressing research problems and questions using whatever methodology and methods achieve this (Creswell and Creswell, 2018), which offers real evidence to inform changes in practical health settings (Holtrop and Glasgow, 2020). Accordingly, this thesis utilised the pragmatism paradigm in order to value and prioritize understanding over methodological purity or theoretical purity. The limitations of a research study are a key factor driving reliance on a pragmatic design so that the researcher can anticipate a problem and its likely solution. Pragmatic design offers an excellent approach to avoid relying on conceptual knowledge to solve issues. Quality description in this approach contributes to change and quality improvement in practice, which is the main aim of this thesis, namely, to improve SDM for renal patients and their families in the Saudi Arabian context. The foundation of the pragmatic design has always ensured that the researcher uses the tangible evidence of lived experiences in solving nursing issues. Although some researchers regard the design as simple and inappropriate for complicated scientific research, its strength is that it offers a tailored intervention.

Furthermore, conducting a study that explores a particular cultural context as a phenomenon relating to a particular health situation helps the researcher explain the issue. According to Kahlke (2014), a generic qualitative research design is justified to understand why a phenomenon occurs together with a particular belief or societal context. However, before exploring the occurrence of a phenomenon, integral answers to various questions have to be developed. The researcher must have clear answers to 'what', 'how', and 'when' before developing an understanding of the 'why' question. The aim of this study is 'to culturally adapt

and translate an existing DA tool' for those with kidney disease to fit the Muslim context, particularly in Saudi Arabia.

Thus, in utilising the pragmatic design to address the present subject, the researcher should answer the 'what' question by assessing the nature of kidney diseases among Muslims. The design will also offer a clear direction on where, how, and when dialysis and conservative care decisions are taken to help those diagnosed with kidney diseases, based on Islamic beliefs. With this question addressed, the pragmatic design provides an opportunity to understand 'why', for example, in the Muslim context dialysis and conservative decision-making on kidney disease are different than in other religious faiths. Lastly, the pragmatic design may also become a basis for future research on dialysis and conservative care decision-making for those with kidney disease to fit the Muslim context by obtaining a comprehensive understanding of the research question to offer appropriate answers. Considering these reasons, my overarching worldview is most closely aligned with pragmatism, thus, I chose a pragmatic-pragmatism as overall paradigm for my thesis.

3.8 Chapter Summary

This chapter provided a brief summary of the findings of the scoping review and study rationale, which the research aims, and objective based on these findings. This chapter discussed the definition, philosophical assumptions, theoretical underpinnings, and approaches of qualitative research. Lastly, this chapter explained the pragmatic qualitative research design as the methodology of this thesis and the rationale for choosing it. The following Chapter 4 describes the methods that were used to conduct the two phases of this exploratory pragmatic qualitative study.

Chapter 4: Methods

4.0 Introduction

This chapter presents the study's research methods, which were applied to examine the research aim and objectives, as outlined in Chapter 3, Section (3.2). This chapter is divided into five parts. Part 1 (4.1) presents and discusses the pragmatic qualitative research methods employed and the reasoning behind these choices, including sampling strategy and sample size. Part 2 (4.2) discusses planning prior to data collection. Part 3 (4.3) describes the data collection methods employed in two phases. Section (4.3.1) describes the Phase 1A research context, participants, recruitment process and data collection method and procedure. Section (4.3.2) reports on the Phase 1B methodology for a modified systematic review. Section (4.3.3) outlines Phase 2, the cultural adaptation of an intervention, the chosen intervention and its process. It describes the research context, participants, recruitment progmatic qualitative research, data analysis and the challenges of data collection and writing up a report. Furthermore, processes were used to ensure study quality. The chapter concludes with a summary, which is presented in Part (4.5).

4.1 Pragmatic Qualitative Research Design Methods

As discussed in Chapter 3, this study employed a pragmatic qualitative research design that used a variety of methods to achieve the study's aim. The study was conducted in two phases. Phase 1 comprised interviews with ESRD patients and/or their family caregivers at a dialysis unit in Tabuk, Saudi Arabia (Phase 1A) and a modified systematic review in the Muslim context (Phase 1B). This was followed by Phase 2, which involved interviews with a wide range of experts in renal care within the Muslim context. The techniques used for qualitative data collection in the present study, the reasoning behind their choices and the sampling strategies are described below.

4.1.1 Individual Interviews

Qualitative individual interviews were chosen as the most appropriate method for this study. A qualitative interview is viewed as a rich source of detailed information that thoroughly helps understand participants' experiences with phenomena of interest, as well as how they describe them, and is particularly valuable when examining sensitive topics (Clarke and Braun, 2013; Holloway and Galvin, 2016; Renjith et al., 2021). Therefore, individual interviews were conducted during this project, which allowed the researcher to examine renal patients and their family caregivers' delicately complex and personal experiences. Furthermore, most previous research in Saudi Arabia on this topic has been quantitative, and a qualitative approach to evaluating ACP and SDM processes has not been used in Saudi Arabia. A semi-structured interview method was chosen instead of structured interviews to give participants more freedom to express their feelings. A semi-structured interview can be viewed as an opportunity to gain insights into interviewees' perceptions, experiences and feelings and as an interactive process in which a question or probe aims to uncover unexpected information (Holloway and Galvin, 2016; Silverman, 2017). Moreover, it provides the flexibility to elaborate on or avoid certain topics, while its structure ensures that the research aim also is discussed (Clarke and Braun, 2013). It was selected for use in this study because it allowed for direct examination of real-life experiences. Furthermore, it helped the researcher maintain consistency and control over what was discussed. By doing so, new ideas and themes could be introduced, and participants were able to examine issues and speak about what was important to them (Holloway and Galvin, 2016).

4.1.2 Sampling Strategies and Sample Size

Sampling is a term given to a process in which individuals from a population are chosen to answer a research question from a practical and theoretical perspective, following ethical principles (Holloway and Galvin, 2016). One of the main strategies in qualitative research is purposeful or purposive sampling (Gentles *et al.*, 2015), a procedure for selecting specific respondents or groups of respondents who are most likely to provide insights into the study's aim (Holloway and Galvin, 2016). The technique begins with a purpose in mind; therefore, sample selection is designed to select people of interest and exclude people who do not suit the aim. A purposive sampling technique was used in this study to sample all study participants, as the researcher aimed to access a specific subset of participants.

Moreover, a purposive sampling technique was employed to ensure that the sample was diverse in age, gender, ethnicity, education background, work and experience background, co-morbidity, duration of treatment and different renal disease experiences. A variant of purposive sampling is chain referral or snowball sampling, which is used when previous participants are asked to suggest other potential participants relevant to the chosen subject (Holloway and Galvin, 2016). According to Renjith *et al.* (2021), it is advisable to adopt snowball sampling whenever participants are likely to be difficult to obtain through ordinary methods. I initially used the purposive sampling technique to select participants, then shifted to snowball sampling due to slow response rates. Thus, this research was conducted using a combination of purposive sampling and snowball sampling techniques.

As for sample size, the study's nature determined it. Qualitative research entails collecting rich data; therefore, sample sizes are small compared with quantitative research. Furthermore, qualitative research is conducted until data saturation has been reached, i.e., no new themes are being identified in subsequent interviews (Saunders *et al.*, 2018). However, time constraints and other barriers to sample saturation often make it difficult to reach data saturation. A small sample size is recommended for individual interviews due to the level of detail required for data analysis (Holloway and Galvin, 2016). According to Creswell and Plano Clark (2011), qualitative research typically employs small samples to study a few individuals or cases. Moreover, Creswell (2014) recommended that 3–10 participants be recruited to understand the phenomenon's central concept. Thus, due to the nature of this qualitative research and previous researcher suggestions, the sample for each phase of the study was limited to 10 participants.

4.2 Planning Prior Data Collection

This section explains several steps that need to be considered in the data collection process. These include preparing the research documents required for submission with an ethics application, filling out and submitting ethical application forms to seek ethical approval and gaining access to the study site. More information about the study site and access to it can be found in Section (4.3.1.1).

4.2.1 Research Documents

Research documents were developed for data collection and include a study invitation letter, participant information sheet, consent form, interview guide and interview questions. These documents were developed in English and submitted to the Sheffield Ethics Committee. Part of the data in this study was collected from patients and/or family caregivers in Saudi Arabia.

Most Saudis speak Arabic as their mother tongue, which is the country's official language. Thus, participants might have poor English language skills, i.e., they may have only a basic knowledge of the language in which the research was conducted. Therefore, all documents mentioned above that were provided to patients and/or their family caregivers were translated into Arabic. Prior to obtaining ethical approval from the King Salman Armed Forces Hospital North-Western Region (KSAFHNWR) in Saudi Arabia, as I am a principal researcher in this study who speaks both Arabic and English, I translated the documents into Arabic. The Arabic versions of all these documents were revised, then approved by the Saudi Arabian hospital's ethics committee.

4.2.2 Ethical Approval

Before data collection, ethical approval for the study had to be obtained. Developing the research documents, completing the ethics application forms and getting the ethics committee's approval took almost six months. Two applications were submitted. First, approval was obtained from the Health Sciences School's (HSS) ethics committee at the University of Sheffield in the UK (Reference Number: 035156) on 26 June 2020 (Appendix 5A). Second, approval to undertake the study in Saudi Arabia was obtained from the King Salman Armed Forces Hospital North-Western Region (KSAFHNWR) research ethics committee (KSAFH-REC-2020-352) on 8 September 2020 (Appendix 5B).

4.2.3 Change in Research Method or Protocol

This study was conducted during the COVID-19 pandemic; consequently, considerable changes were made because of the crisis, which required further ethical approval from the UK and Saudi Arabia regarding these changes. Modifications were made to the study project, including the research plan, study context, participant inclusion and exclusion criteria, recruitment methods and data collection methods. This was mandatory to continue my research project during the pandemic and is explained in detail in Part 4, Section (4.4.6), and on the COVID-19 Impact Form (see supporting document).

4.3 Data Collection Methods

The data were collected in two phases. Phase 1 comprised a qualitative exploratory study that focussed on renal patients and family caregivers' experiences with ACP and SDM practices.

During this phase, data were gathered from various sources. Phase 1A, primary data were collected from ESRD patients and/or their family caregivers at a dialysis unit in Tabuk City, Saudi Arabia. Phase 1B involved a deeper examination of the issues under investigation in Phase 1A by conducting a modified systematic review in the Muslim context. Phase 2 involved primary qualitative data collection from a wide range of experts in renal care within the Muslim context to aid in the cultural adaptation of a chosen DA tool, as explained below.

4.3.1 Phase 1A: Qualitative Study

This phase aimed at conducting a qualitative exploratory study to explore the educational needs and experiences of ESRD patients and/or their family caregivers concerning communication issues, such as ACP discussions and the SDM process in a dialysis unit in Tabuk, Saudi Arabia.

4.3.1.1 Research Context and Gaining Access

This phase took place in Tabuk, the capital city of the Tabuk Region in North-Western Saudi Arabia. Tabuk region has a population of 687,000 (as of 2023) (World Population Review, 2023) and was chosen because it is the hub of the region's healthcare management system. Furthermore, most research conducted in Saudi Arabia occurs in the largest cities. Tabuk City contains three dialysis centres with different capacities: Two are affiliated with the Ministry of Health (MOH), and one is at Prince Sultan Kidney Diseases Centre, located at King Salman Armed Forces Hospital North-Western Region (KSAFHNWR). King Salman Hospital was chosen as the context for the study because although palliative care is available for cancer patients, palliative care services for renal patients are lacking. Furthermore, KSAFHNWR was chosen for practical reasons, including the researcher's familiarity with the hospital and the system. The hospital provides facilities for a full range of primary, secondary and tertiary patient care for both inpatients and outpatients, with a capacity of more than 800 beds.

The kidney/dialysis centre in this hospital has been affiliated with the Saudi Centre for Organ Transplantation since 1992. Moreover, it is the second-largest centre in terms of the number of kidney transplantation operations conducted there. This centre includes HD, PD and kidney transplantation departments, as well as nephrology clinics. Approximately 215 HD patients visit the dialysis centre each week. The centre is open seven days a week, with three shifts of HD sessions per day: morning; afternoon and evening.

After approval to conduct the study was granted, the hospital assigned a co-researcher, who was a nephrology physician who worked as a gatekeeper. Gatekeepers are responsible for ensuring the safety of vulnerable populations, such as patients, and for ensuring that researchers follow ethical requirements (Creswell and Poth, 2018). The co-researcher and the dialysis unit's head nurse worked together as gatekeepers, and an initial meeting was held with them to discuss the study's aim, method and potential participants. They agreed to help with participant recruitment and explained to me that adult patients undergoing peritoneal dialysis PD could be difficult to reach. I was careful about keeping in regular contact with both, seeking their input and explaining my progress to maintain a good working relationship.

4.3.1.2 Target Population

The population of this phase consisted of two types of participants: ESRD patients and/or patients' family caregivers at the kidney diseases centre at KSAFHNWR in Tabuk, Saudi Arabia.

4.3.1.2.1 Inclusion and Exclusion Criteria

Participants were included if they were patients and/or family caregivers aged >18 years or older who had received ESRD diagnoses and were on dialysis for at least three months. ESRD is defined under Stage 5 of the CKD classification by the National Kidney Foundation-Kidney Disease Outcomes Quality Initiative (NKF-KDOQI), which refers to individuals with an estimated GFR of <15 ml/minute /1.73 m2 who require dialysis regardless of GFR (Abbasi, Chertow and Hall, 2010; KDIGO, 2013). Thus, patients with either an ESRD or CKD Stage 5 diagnosis were included. Families play an important role in Saudi society, particularly in providing patient care and supporting treatment adherence. Thus, the decision was made to include patients' family caregivers as participants in this study. Each patient with ESRD was eligible to identify one family caregiver who provided support and with whom they attended dialysis sessions. Caregiver refers to a person who helps care for a person suffering from a chronic illness (Ramsay *et al.*, 2012). In my study, caregivers were defined as informal caregivers who generally were relatives of the individuals requiring care. In my thesis, I referred to them as family caregivers.

Interviewing patients and/or their family caregivers at the advanced stage of the disease provided an in-depth examination of their lived experiences, including what the disease might mean to them. It also allowed patients who have lived with their disease condition and made various decisions on treatment over time to acknowledge their needs. While Saudis and other Arabs have some cultural similarities, they also differ in certain aspects, including language dialects, necessitating adaptation of interventions so that they are relevant to all Arab groups – a considerable challenge. Thus, only Saudi patients and/or their family caregivers were included. Although the Saudi population's literacy level is rising, some remain illiterate, particularly adults. Those who have reading and writing literacy or who are illiterate were allowed to be participants, but potential participants were excluded if they lacked the capacity to provide consent, such as if they had a psychological or neurological disorder. While the intention was to exclude patients with a kidney transplant history or who were on a waiting list, this was changed because most ESRD patients at the chosen dialysis unit either had a history of transplantation or were on a waiting list.

4.3.1.2.2 Recruitment Process

Recruitment for a study requires access to potential participants who meet the inclusion criteria (see 4.3.1.2.1). Participants who were ESRD patients and/or their family caregivers were recruited purposefully from the dialysis unit at KSAFHNWR in Tabuk city, Saudi Arabia. I did not secure permission to make direct contact with potential participants due to COVID-19 restrictions, so I met with the co-researcher and the dialysis unit's head nurse to discuss the research project and criteria for potential participants. Following this initial meeting, copies of the Arabic study invitation letter were provided, which included the study's title, aim, invitation to participate and the researcher's contact details (Appendix 6A). Copies of the Arabic participant information sheet also were provided (Appendix 6B). The KSAFHNWR provided the researcher with a bilingual Arabic and English consent form to be used during data collection (Appendix 6C).

Thus, information about the study was circulated through the dialysis unit's head nurse, who screened prospective participants, both patients and their family caregivers, to determine whether they met the inclusion criteria. When patients attended the dialysis unit during their routine haemodialysis sessions, she used a screening and identification process with potential

participants. None of these prospective participants at the clinics were contacted. She then gave them an invitation letter. If they were interested in taking part, prospective participants contacted me via email, phone or even social media platforms, such as WhatsApp, to express interest. If they agreed to participate, I sent them a copy of the participant information sheet and a consent form. We then agreed on a time when I could contact them via phone to introduce myself briefly and discuss the study's aim and information sheet. This also allowed participants to ask questions in advance before the interviews. One of the prospective participants was illiterate, so I read the information sheet and consent form aloud to them over the phone.

During the calls, I indicated that the interview was comparable to a phone call, would last approximately 60 minutes and would be recorded digitally. Moreover, it was reiterated that their participation was entirely voluntary and that if they chose not to participate, this would not pose any implications in terms of services and care that they or their families were receiving. Recruitment of family caregivers was difficult in this study due to COVID-19, which required the hospital to discourage family caregivers from accompanying patients unless it was necessary. Thus, during the calls, each participant was asked whether they had a family caregiver, and if so, whether they were willing to participate. At the end of phone calls with those who wished to take part, we agreed on a convenient interview date and time. Written informed consent was obtained from both patients and/or their family caregivers, which the head nurse collected at their next dialysis sessions, prior to the interviews. I phoned potential recruits 24–48 hours before the scheduled interviews to confirm their interview date, time and availability.

Recruitment commenced in November 2020 and ended in May 2021, with 60 out of 215 HD patients meeting the inclusion criteria. Furthermore, 22 ESRD patients and three family caregivers were approached initially and invited to take part in the study via gatekeepers. Time and access constraints were challenging at that point because of the COVID-19 pandemic, as I could not visit the unit directly, and I was allowed limited face-to-face interactions because of the pandemic – factors that were out of my control. Even though I asked the dialysis unit's head nurse to approach everybody, she decided to approach only those whom she thought would be willing to participate because of her own time constraints

and other pragmatic reasons. This gatekeeping issue has been discussed widely in the literature. It has been argued that gatekeepers may significantly impact not only the study's sample, but also the results (Groger, Mayberry and Straker, 1999; Rankin and McFadyen, 2016). Subsequently, I recruited three ESRD patients and one family caregiver from the original 22, then an additional family caregiver was recruited via snowball sampling. Thus, the final overall number of participants recruited was five: three patients and two family caregivers.

4.3.1.3 Data Collection Method of Phase 1A

4.3.1.3.1 Interviews Method

Qualitative interviews are conducted in several ways, and face-to-face interviews are the gold standard (Saarijärvi and Bratt, 2021). In this study, it was preferable for data to be collected through face-to-face, semi-structured interviews, but under COVID-19 restrictions that were in place, it was impossible to conduct face-to-face interviews. Thus, I used phone interviews to collect all data. Phone interviews have their own advantages. First, they make interviews possible in places that are difficult to reach (e.g., war zones or areas with unstable Internet connections). Second, due to the relative anonymity of a phone call, participants feel more comfortable sharing sensitive information. Third, it facilitates participation by people who are less confident speaking face-to-face. Finally, a phone call allows subjects to participate in the comfort of their own homes (Clarke and Braun, 2013; Saarijärvi and Bratt, 2021).

4.3.1.3.2 Interview Schedule

Semi-structured interviews comprise a list of open-ended questions to guide the interviewer through the issue under investigation. One set of interview guides was developed for both patients and their family caregivers in the context of 'patient-family interviews' (see Table 4). However, minor modifications were made to suit only family caregiver interviews. The subjects covered in the topic interview guide were developed through:

- Previous literature reviews
- The validated Ottawa Decision Support Framework (ODSF) (Jaconsen et al., 2013)
- Support from the study's supervisors

Using topic guides helps ensure consistency in the data collected between interviews while allowing the interviewer to discuss topics that are particularly important to participants (Holloway and Galvin, 2016). Accordingly, the questions' sequence varies from participant to participant based on the interview process and each participant's responses. The topic guide included two kinds of questions: demographics and open-ended questions.

Interview Sections		Interview Questions	
A	General knowledge about disease	1- Please could you tell me briefly about you and what you understand about your disease?	
		- Tell me a little bit about yourself: how are you at the moment?	
В	Communication with healthcare providers	 2- Can you tell me about a time that you had discussion with member of healthcare providers about treatment and start your current treatment (dialysis) 	
		Probes:	
		 Who explained dialysis treatment to you? (doctor, nurse, health educators, social worker)? How did you fool about this discussion? 	
		 How did you feel about this discussion? How did you feel about the timing of this discussion? Do you think that discussion about dialysis was started at the right time - Why? 	
		- Was there enough time to make an adequate decision – Why?	
		- Discussion future care with your healthcare providers	
		Probes:	
		 What have your healthcare providers told you about what might happen with your health in the future? What concerns do you have about your future care? 	
		 Have any of your healthcare providers given you an opportunity to discuss a care plan? (future plan) 	
		 Is there any other information you would like to receive about your health – What? 	
С	How decisions were made	4. How were the options for the management of your disease presented to you?	
	about management	Probes:	
		 What information was shared with you/were you given? How did you feel about the information you were given? (useful- 	
		relevant)	
		 In what way did you receive information about dialysis? (oral information; written information; video or other) 	

Table 4: Patient and Family Caregiver Interview Topics Guide

		 Have you discussed the option of not having dialysis or alterative treatment- please describe?
		5. Who made the decision
		 Probe: Who was involved in the decision? What were the reasons you chose to have dialysis? What did you think the benefits might be? Have you experienced anything which you did not expect since starting dialysis? What factors contributes to make a decision easy/most difficult for you – why? What support did you have to make a choice - how? (is it enough?) 6. Can you tell me about any concerns that you have now about the decision that was made? Probes:
		 How well do you feel you understood what was involved at the time? Did you feel you were involved enough in the decision- why? Did you feel you were able to ask questions- why? Did you feel your family/significant others were able to contribute to the decision-why?
D	Suggestions for care plan discussion, decision making process and materials.	 7. What do you think could have improved the discussions you had about planning for your future care, and decision-making? Probes: How do you think care plan should be introduced to you - why? Would you change any things about discussion -Why? What types of source you need to support you to make a decision? (printed written martials- video listening)? How do you think the decision making process could be improved/changed?
E	Closing	8. Are there any other relevant issues we haven't covered that you would like to mention?9. Are there any questions you that would like to ask me?

4.3.1.3.3 Interview Procedures

I conducted all interviews via phone. The interviews were intended to be conducted together as 'patient-family interviews' because in the Saudi Arabian context, families play a significant role in psychosocial adjustment and adherence to treatment. Their role is to accompany the patient to the hospital for treatments and medical appointments. However, it was decided that the interviews would be conducted either together or separately based on participant preferences, difficulty in recruiting participants, and time constraints. As a result, four interviews were conducted: two patient interviews; one patient-and-family caregiver interview; and one interview with a family caregiver. Each interview was conducted in Arabic and lasted between 59 and 130 minutes. At the start of the interview, the research purpose was reiterated, and verbal consent was obtained. Participants also were assured that all data provided would remain confidential. I gave each participant a pseudonym due to their limited numbers and to ensure anonymity. Participants once again were informed that the interviews would be recorded using a research phone, and the reasons for this were explained. Semi-structured interviews were conducted following collection of demographic data (using an interview guide, presented in Table 4). The demographic data included age, gender, education background, medical history, type of dialysis treatment and number of years on dialysis. For family caregivers, additional questions were asked about their relationship with patients and number of years caring for patients. During each interview, I took notes to assist with reflection and data analysis (Creswell and Poth, 2018). Furthermore, following each interview, a summary was written to ensure credibility.

4.3.2 Phase 1B: Modified Systematic Review

This section describes the design and methods used to conduct a modified systematic review to examine, synthesise and describe systematically evidence on the preferences and experiences of ESRD patients or their family caregivers regarding ACP discussions and the DM process in the Muslim context. This method was used due to COVID-19 pandemic challenges. A limited number of participants was recruited for qualitative interviews in Phase 1A, so this review was conducted to supplement qualitative data collected directly. I chose this approach of using systematic review data to supplement my qualitative data after a discussion with my supervisors. Essentially, I recruited fewer participants than I expected during the qualitative phase and did not feel that the data I collected was rich enough or appropriately answered all my research questions. As Page *et al.* (2021) pointed out, systematic reviews can address questions that individual studies cannot answer otherwise. Moreover, this modified systematic review can help assess the transferability of findings from small-scale qualitative research studies. Thus, I needed to supplement the qualitative data with other evidence, and the most effective way to do so was to conduct a systematic review. Furthermore, this review focussed on the Saudi context, but due to the scarcity of Saudi literature in this area, the review was expanded to include other Muslim countries. Islam is followed by 24% of the world's population—an estimated 1.8 billion people in 2015, according to Lipka (2017). This makes Islam the world's second-largest religion. Most Muslims live in Northern and Central Africa, the Middle East and Southeast Asia, where they comprise more than 90% of the population. Currently, the world contains approximately 50 Muslim-Majority Countries (MMCs), of which 14 are low-income countries, and 25 are middle-income countries. In this review, MMCs are defined as those in which more than 50% of the population is Muslim (Lugo *et al.*, 2011).

4.3.2.1 Review Design

This review was intended to use a modified mixed-method systematic review (MMSR) design. MMSR combines both quantitative and qualitative data from primary studies and integrates them formally (Aromataris and Munn, 2020). It employs multiple methods (e.g., intervention trials and in-depth interviews) and integrates these methods to draw on the strengths of each type of evidence (Pearson *et al.*, 2015). Therefore, this type of review was chosen to gain broader knowledge by including studies investigating patients and their families' preferences from different angles. To understand how a modified systematic review works, a traditional systematic review must be defined first. Bettany-Saltikov (2016) defined a systematic literature review as a process that involves identifying, evaluating and interpreting all available research relevant to a particular research question, topic area or phenomenon of interest.

Other authors have emphasised the rigour and transparency of procedures used in systematic reviews by including the use of an explicit study protocol; addressing pre-specified, highly focussed questions; appraising studies to determine their scientific quality; and using explicit methods, such as a descriptive summary or meta-analysis (where appropriate), to combine findings across a range of studies (Booth, Sutton and Papaioannou, 2016). A modified review might not include all the universal steps involved in a systematic review (Dixon-Woods *et al.*, 2006). Dixon-Woods *et al.* (2006) stated that a modified systematic review usually is conducted in an area where only a few published studies are available for analysis, whereas a full systematic review often is conducted where many quantitative studies are available. In

the modified review, some systematic review processes are modified to suit the available research (e.g., the pre-planned search strategy and the method for appraising the literature).

4.3.2.2 Review Question

To search for all relevant papers on a topic, the review question must be both comprehensive and specific. The participant-phenomenon of interest-context (PICo) framework is used in mixed-methods review questions (Lizarondo *et al.*, 2020). By using a PICo framework, a modified review was conducted in the present study to address the following broad review question: What evidence is there about ESRD patients or their families' experiences and preferences with ACP discussions and related decision-making processes and communication with HCPs in the Muslim context (see Table 5)?

Table 5: The PIC	o Framework for	Muslim Cult	ure Review
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Population	Phenomena of interest	Context
End Stage Renal Disease (ESRD) patients /and their family caregivers (family members)	Advance care planning discussion, decision making process/shared decision making.	Muslim countries

4.3.2.2.1 Review Aim and Objectives

This modified review aimed to identify, synthesise and describe systematically the evidence on practices, preferences and experiences of ESRD patients or their families regarding ACP discussions and the DM process in the Muslim context. This aim has the following objectives:

- To examine ESRD patients and/or their families' perspectives and preferences about ACP and the DM process in the Muslim context.
- To describe how discussions about ACP and DM are held between HCPs and ESRD patients and their families in the Muslim context.
- To identify factors that either prevent or facilitate initiation of ACP and DM in the Muslim context.

4.3.2.3 Inclusion and Exclusion Criteria

The selection criteria for including and excluding studies were determined before the literature search, and they reflect this review aim. The study inclusion and exclusion criteria are summarised in Table 6.

Table 6: Selection	Criteria f	or the Sv	<i>v</i> stematic	Review

Criterion	Inclusion	Exclusion
Participants	Patients:	
	 Adult over 18 years of age. Diagnosed as ESRD or CKD stage 5. Received either treatment dialysis, kidney transplant or conservative management. Family caregivers*: Over 18 years of age Identified by the patients. 	 Paediatric studies. Studies focused on HCPs' experiences. Mixed participants group (patients and HCPs): if the results are mixed and cannot be separated. Mixed participants' medical conditions: if the results are mixed and cannot be separated
Phenomena of interest	 Studies on patients and/or their families' experiences and preferences of ACP discussion, DM process, and communication with HCPs 	 Studies focusing on euthanasia, brain death, assessing the quality of life, palliative care priorities and organ transplantation were excluded because each topic deserves its own investigation. Studies that focused on patients' experience of ACP as an educational intervention were excluded because this objective has a different investigation aim. These studies were identified as a part of the scoping review, see chapter 2.
Study design	 Quantitative, qualitative, and mixed method studies. Experimental and none-experimental design, observational and descriptive studies, questionnaire/survey, phenomenology, grounded theory, ethnographic studies. PhD Thesis 	
Context	 Consider a study conducted in any of the Muslim-majority countries where Muslim's account for more than half of the population. Any other country with a smaller Muslim population could conduct a study if they recruited a majority Muslim sample, but only if the results for Muslims were presented separately. Studies conducted in Muslim countries' hospital-based settings 	 Studies either were conducted in non-Muslim countries or included non-Muslim participants. Studies conducted in homecare settings
Language	English and Arabic*	Other languages
Type of research report	Full research report from inception onward	 Poster, abstract, editorials, comments, study protocol

*Family caregivers who attend treatment with their patients are defined as non-professionals who care for and support the patient most often.

* The inclusion of studies was not restricted by language. Because this review focuses on Muslim countries, it was important to conduct reviews of literature that were not written in English as excluding studies based on their language will have an impact on the scope and completeness of the review. Many papers in languages other than English are abstracted in English, from which a reviewer can decide whether to retrieve the full paper. Whenever possible, non-English studies that were eligible were translated by a professional.

4.3.2.3.1 Phenomena of Interest

For this review, I did not limit the types of studies included. Studies using any methodology were accepted if they focussed on ACP or DM processes or addressed one or both elements of ACP as defined by the European Association for Palliative Care (EAPC) (Rietjens *et al.*, 2017). This definition of ACP includes (1) discussing the patient's goals and/or preferences for future medical treatment with their family and/or health care providers; or (2) recording patients' preferences. The preference record may include the appointment of a personal representative and ADs; patients and their families' discussed preferences in terms of place of death and their DM for EoL treatments; documented preferences regarding completion of AD; decision-making related to LSTs; and DNR orders. This review also considered studies using different ACP terminologies, particularly EoL discussions or decisions related to ACP, as used in some studies globally. Table 7 defines the key terms used in this review.

Key term	Definition
Advance care planning (ACP)	Defined as the communication processes among individuals, their families, and HCPs to understand, evaluate, discuss, plan, and make future healthcare decisions. ACP may or may not result in a written advance care directive (ACD) (Rietjens <i>et al.</i> , 2017).
Communication	Defined as dialogues about progressive, incurable illnesses and EoL, for example, ACP, transition to palliative care, and/or discussing death (Brighton <i>et al.</i> , 2017). Information and education can affect communication processes and outcomes.
Decision-making (DM)	Includes the DM process, patient enrolment or engagement in DM, decision support tools, and DM for medical treatment, e.g., choosing Life Sustaining Treatments (LSTs), which are medical interventions or treatments that potentially postpone death (Kim and Choi, 2017). These include cardiopulmonary resuscitation (CPR), mechanical ventilation, haemodialysis, and administering drugs like antibiotics or chemotherapy (Rodriguez and Young <i>et al.</i> , 2006; Kim and Choi, 2017).
End-of-life (EoL) decision-making	Refers to any decision concerning the care provided to critically ill patients currently or in the future. This included decisions regarding admission to the intensive care unit (ICU), cardiopulmonary resuscitation, and other specific interventions to prevent or treat critical illness (Frost <i>et al.</i> , 2011).
Patient experiences	Refers to occurrences and events that take place independently and collectively across the continuum of care. Individualised care is strongly tied to patients'

Table 🛛	7: Kev	Terms l	Jsed	within	the S	Systematic	Review
						,	

	expectations and is integrally associated with patient-centred and family-centred care (Wolf PhD, and Jason, 2014).	
Patient preferences Refers to preferences about the context in which care is delivered, care		
	relationships, involvement in care, and outcomes of care. These may include	
	decision-making, psychosocial support, the place of care, and the place of death.	
	(Sandsdalen <i>et al.,</i> 2015).	

4.3.2.4 Review Methods

This modified systematic review was conducted in accordance with the JBI methodology for MMSR (Lizarondo *et al.*, 2020).

4.3.2.4.1 Search Strategy

The literature search was conducted using PRISMA guidelines (Tricco *et al.*, 2018). A specialist librarian was consulted when developing the search strategy to ensure rigour in the search process. Using this guidance, I developed a systematic search strategy based on the predetermined research or review question and employed the following electronic databases: CINAHL; Medline via Ovid; PubMed; Scopus; ProQuest via Applied Social Sciences Index and Abstracts (ASSIA) (a premium social science collection and dissertations and theses) and Cochrane Library (only for Cochrane reviews and protocols). Other resources were obtained using keywords and search engines such as Google Scholar. Moreover, I did keyword searches of articles from these journals to find articles relevant to my study: the *Saudi Journal of Kidney Disease and Transplantation*, the *Saudi Medical Journal*, and the *Saudi Journal of Medicine and Medical Sciences*. The searches were conducted between August 2021 and February 2022.

An example search strategy (CINAHL) is provided in Appendix 7. The keywords were chosen using the PICo statement, and all alternative words for the most important keywords were incorporated. Both British and American English usage and spelling were factored in when selecting keywords to intensify the likelihood of obtaining all pertinent articles. The keywords used are presented in Table 8. The identified keywords were used to conduct the searches with 'OR' and 'AND' used to increase exposure and improve outcomes. The search not only contained words for ACP and AD decision-making, but also was designed to retrieve articles on EoL decision-making. To ensure a comprehensive search, the researchers scanned the reference lists from the relevant existing literature review and the included studies. Although no date restrictions were placed on searchers, the concept of ACP increasingly has been recognised since the 1990s (Seymour, Almack and Kennedy, 2010; Brinkman-Stoppelenburg *et al.*, 2014).

Table 8: Key	words for	Systematic	Review

PICo	Keywords/ terms	Synonyms (alternative search terms)
Participants	ESRD patients and their families	Renal disease, kidney disease, renal Failure, kidney Failure, end stage renal failure, end-stage renal failure, end stage renal disease, end-stage renal disease, ESRD, chronic kidney disease, CKD, Chronic renal Failure, established kidney disease, EKD, established renal failure, ERF, advance chronic kidney disease or advanced chronic kidney disease or haemodialysis or hemodialysis or dialysis or renal replacement therapy or RRT or peritoneal dialysis or kidney transplant or renal treatment. patient*, family*, family members, relatives, carers, caregiver, surrogate*, informal carers, informal caregivers, family caregivers, family carers.
Phenomena	Participants experience of	Plan*, advance care, "Advance care planning", Advance care plan*,
of interest	communication, advance care planning and decision-making.	Advance health care plan*, Advanced health care plan*, Advance health- care plan*, Advanced health-care plan*, Advance healthcare plan*, Advance medical plan*, Advanced medical plan*' "Patient care planning", patient care plan*, ACP, advanced medical plan*' "Patient care planning", patient care plan*, ACP, advanced medical directive*, advanced directive*, Advance medical directive*, Advanced medical directive*, living will*, "end of life planning", "end-of-life planning", "Future care goals", "end of life wishes", "end-of-life wishes", Communication*, Conversation*, discussion*, document, decision*, choice*, decision making, decision- making, decision making process, decision-making process, DM, shared decision making, shared decision-making, SDM involvement*, participation, engagement, decision support techniques, decision aid*, decision tool*, or patient decision aid*, pad, "patients decision making", PtDAs, healthcare proxy*, health care proxy*, power of attorney. Palliative care, End of life, terminal care, life support care, death, dying, life sustaining treatment*, life-sustaining treatment*, LST, hospice care, resuscitation, CPR, cardiopulmonary resuscitation, haemodialysis, mechanical ventilation, conservative management or cm or non-dialytic treatment or non-dialytic management or stopping dialysis or withholding dialysis or withdrawal from dialysis
Outcomes	Experiences and impact of ACP discussion on patients' communication and DM process	Experiences*, perception, opinions, attitudes, views, feelings perspectives, preferences or values, personal autonomy, qualitative*, grounded theory, ethnography, phenomenology, narrative*, interview*, focus group*, questionnaire*, survey*, "participant observation"
Context	Middle Eastern countries and other Islamic nations' healthcare settings	Islam, Muslim, Islamic, Islamic countries, Islamic communities, Muslim countries, Muslim communities, Persian, Arabic, Arab, East-Asian communities, East-Asian countries, Saudi Arabia or United Arab Emirates or Kuwait or Bahrain or Egypt or Iraq or Qatar or Jordan or Oman or Lebanon or Syria or Iran or Yemen or Turkey or Algeria or Cyprus or Morocco or Tunisia or Palestine or Libya or Pakistan or Sudan or Djibouti or Afghanistan or Somalia or the Comoros or Brunei or Bangladesh or Indonesia or Kyrgyzstan or Maldives or Malaysia or Tajikistan or Turkmenistan or Uzbekistan or Albania or Kosovo or Mayotte or Burkina Faso or Chad or Gambia or Guinea or Mali or Mauritania or Niger or Senegal or Sierra Leone or Western Sahara or Azerbaijan or Kazakhstan.

4.3.2.4.2 Study Selection

Study selection was conducted based on inclusion criteria in Table 6 mentioned earlier, which were informed by using the PRISMA flow chart that Moher *et al.* (2009) developed. A single researcher (NA) manually screened the titles of returned search hits from individual EBM resource databases against the inclusion and exclusion criteria. At this stage, irrelevant citations and duplications were excluded. Abstracts were screened for eligibility based on inclusion and exclusion criteria after duplicates were removed. Full-text articles of all potentially eligible papers identified were retrieved and read to determine eligibility for PICo element consistency. For studies that did not meet the inclusion criteria, the reasons for the exclusion of full texts are provided in Figure 7, Chapter 5, Section (5.2.1.1).

4.3.2.4.3 Quality Appraisal

Methodological rigour refers to an assessment of a study's internal and external validity based on the use of various tools. The appraisal aims to determine the overall quality and degree to which a study addresses potential biases in its design, conduct and analysis. Studies with low methodological quality are likely to have limited validity, reliability and generalizability, resulting in limited clinical implications. A single reviewer (NA) assessed this review's data quality, rather than the two reviewers usually required, because the study was part of a doctoral thesis. In the current modified review, each included study was assessed for quality using the eight questions from the JBI critical appraisal checklist for cross-sectional studies (Moola *et al.*, 2020). For each question, the reviewer marked the study as 'Yes', 'No', 'Unclear' or 'Not applicable' and awarded one point for each of the questions marked 'Yes'. The total number of points was recorded and used to determine study quality. However, studies were not excluded based on their methodological quality. Instead, the quality appraisal was used to inform the weight given to each individual study within the overall analysis. This modification was informed by the dearth of research available on this topic. The results from the quality appraisal for individual studies are provided in Appendix 8.

4.3.2.4.4 Data Extraction

A single researcher (NA) extracted data from the studies included in the review using the standardised JBI data extraction tool (Lizarondo *et al.,* 2020). The extracted data included specific details regarding the publication and study, participants, contexts, phenomena of

interest and outcomes relevant to the review objectives, study design, statistical analysis results, and all other relevant data. The quantitative data comprised data-based outcomes of descriptive or inferential statistical tests.

4.3.2.4.5 Data Synthesis

Although this was an MMSR examining the different methods available to synthesise quantitative and qualitative data or integrate quantitative and qualitative evidence, all included studies were quantitative studies. Therefore, this review took a quantitative approach, synthesising quantitative psychometric data related to the review objectives. After extraction of common tables, the heterogeneity of context, population, design and outcomes across included articles precluded meaningful meta-analysis. Therefore, a descriptive synthesis of experiences and preferences was undertaken. A narrative synthesis of extracted data was undertaken using tables with emerging thematic headings.

4.3.2.5 Integration and Triangulation of Findings from Phases 1A and 1B

This section presents a description of the approach to integrating the findings from the qualitative study, Phase 1A, and modified systematic review, Phase 1B, after data collection. The integration of findings within the literature has been described in various ways within various contexts: in general research (Heale and Forbes, 2013); in mixed-methods research (O'Cathain, Murphy and Nicholl, 2010) and in systematic reviews (Lizarondo *et al.*, 2020). These techniques often are used to integrate data for a mixed-methods approach, but little direction can be found in the literature about triangulation between primary and systematic review data. In line with using different methods to examine the needs, preferences and experiences of ESRD patients or their families regarding ACP discussions and the DM process, the findings then were combined, a process known as triangulation. According to Heale and Forbes (2013), research triangulation involves using more than one approach to investigate a question, which typically is associated with research design and method. The triangulation technique's purpose in this thesis was to confirm suggested findings and determine the data's completeness.

The most common type of triangulation is methodological triangulation, in which more than one methodological approach is used to collect data. I employed methodological triangulation by collecting data from interviews and the modified systematic review. The triangulation occurred at the interpretation stage of this thesis. Several authors have pointed out how complex and problematic triangulation and integration are, and how little is known about how they can be conducted (Farmer *et al.*, 2006; O'Cathain, Murphy and Nicholl, 2010). The 'triangulation protocol' developed by Farmer *et al.* (2006) informed my approach to triangulation and integration. The idea is to identify themes from different data sources and methods, then group them based on shared characteristics. However, my approach was not to group both data sets into similar themes, but rather to identify themes from each data set and compare the findings. According to Farmer *et al.* (2006), the data were compared to determine the degree of convergence based on two criteria: 1) a description of the meaning and prominence of the presented themes, and 2) detailed coverage with specific examples provided in relation to each theme.

Themes and subthemes then are used to analyse the data to identify degree of convergence in terms of complete agreement, partial agreement, silence and dissonance in data from different sources. Complete agreement means that both sets of results agree in both elements of comparison, e.g., meaning and supported examples (Farmer *et al.*, 2006). Partial agreement refers to agreement in one or some, but not all, subthemes. Silence means one set of results covers the themes or subthemes, whereas the other set of results is silent on the themes or subthemes. Dissonance means disagreement between result sets (Farmer *et al.*, 2006). The data comparison based on these terms was explained in more detail in Chapter 5, Section (5.3).

4.3.3 Phase 2: Culture Adaptation of an Intervention

This phase of the study aimed to adapt and translate a decision aid tool to be relevant to Saudi patients with ESRD and their family caregivers. It also aimed to develop a preliminary implementation plan. For this reason, examining renal care experts' views and perceptions of a decision aid tool and identifying aspects that aid in its adaptation to the Muslim context, particularly Saudi Arabia, by employing a pragmatic qualitative research design are appropriate for this study. This section first discusses the importance of adaptation in an intervention, then the intervention selected for adaptation, followed by cultural adaptation processes. Second, it discusses the adaptation process in terms of each phase's contexts and target population, recruitment process and data collection method, then discusses the translation steps and reporting process.

4.3.3.1 Cultural Adaptation of Intervention

As discussed in Chapters 1 and 2, the treatment journey of patients with CKD is complicated incrementally by increasingly complex decisions. The progression of their disease to ESRD requires that patients make treatment modality decisions (Jayanti et al., 2015), which are difficult to make due to uncertainty regarding their eligibility for treatment options and these treatments' impact on their lives. SDM helps patients make such decisions. PtDAs are evidence-based interventions designed to help patients and their families make deliberate, informed choices from a variety of health care options (Stacey et al., 2017), as well as make decisions about their future care. PtDAs emerged as effective education interventions that improve ACP discussions and SDM. PtDAs also support decision-making procedures in contexts in which multiple factors and uncertainties may influence outcomes, but little information is available on disease trajectories in those with ESRD (Murtagh, Murphy and Sheerin, 2008). Several current initiatives are using DA tools for renal patients, which have been successful in helping patients discuss their treatment options with HCPs and make informed decisions (Ameling et al., 2012; Winterbottom et al., 2016; Subramanian et al., 2019; Wong et al., 2023). However, these interventions were implemented in Western countries, and no PtDAs exist for Saudi Arabia's ESRD patients.

Due to cultural and health system differences, Middle Eastern countries cannot simply implement interventions developed in Western countries. Notably, culture exerts significant influence on health, i.e., complex cultural constructs shape a group's actions and decisions. Culture can be defined as a set of values and beliefs that influence national or ethnic group behaviour (Barrera and Castro, 2006). If an intervention fails to consider a cultural group's beliefs, customs, traditions and lifestyles, it will be ineffective (Castro, Barrera Jr and Holleran Steiker, 2010). Thus, adapting an existing decision aid tool to a different cultural context could be a solution due to the complexity, effort and costs involved in designing and developing an entirely new intervention (Coulter *et al.*, 2013).

Bernal, Jiménez-Chafey and Domenech Rodríguez (2009, p. 362) defined cultural adaptation as 'the systematic modification of evidence-based treatment or intervention protocol to consider language, culture and context in such a way that it is compatible with the client's cultural patterns, meanings and values'. As part of the development process, adaptations are made in response to the characteristics of the targeted community and environment. This typically involves participants from the target population for whom the adaptation is being developed and results in optimal outcomes. Cultural adaptation is used to generate a culturally equivalent version of the intervention. An additional requirement for intervention adaptation is translation from one language to another (Beaton *et al.*, 2000). Thus, the phase aims to adapt and translate a DA tool for ESRD patients and their family caregivers culturally in the Saudi Arabian context.

4.3.3.2 Intervention Selected for Adaptation

Many PtDA tools are available to the public online for people with advanced illnesses, particularly renal patients. These tools aim to support dialysis decisions, but their decision focus is different. Thus, I conducted a scoping review of the literature focussed on the DA tool to identify existing patients' DA tools used for patients with ESRD. I identified 19 DA tools, of which 12 were general tools for any related health conditions and seven were designed specifically for renal disease. I worked with my supervisor and data from my qualitative interviews to narrow that down to four potential tools, including three more specific to renal patients. The fourth is broader but can be adapted slightly for renal care and dialysis. I had planned to conduct a focus group with HCPs to decide which tool to use, but had to cancel it due to the pandemic, leaving me with a short list of four tools (see Appendix 9). As an alternative, my supervisors and I reviewed all four tools and discussed their merits and

drawbacks based on the study's requirements. Consequently, the Yorkshire Dialysis and Conservative Care Decision Aid (YoDCA) was chosen (Winterbottom *et al.*, 2020b). This tool discusses ACP issues in a way that the other tools did not. The YoDCA provides balanced information regarding CKD treatment options available to patients and their families.

Moreover, it was chosen because it offers information about three RRT options, conservative treatments and future care options, particularly palliative and EoL care. These options can be used with various types of CKD patients in Saudi Arabia. Furthermore, this tool was developed as a theoretically driven, evidence-based resource to help CKD patients choose between conservative management and dialysis treatment options in consultation with health professionals, compared with other resources. The YoDCA research group at the University of Leeds developed the YoDCA decision aid tool, which was designed for people with CKD who are getting worse and making decisions concerning conservative care or dialysis pathways. A primary goal of this tool is to provide individuals and their families with information about these different pathways and how they can choose the one most suitable for them. It can be used independently by patients, family caregivers, and/or with their HCPs. At 28 pages, it starts with an introduction on how to use YoDCA, followed by these sections: Section A – chronic kidney disease and established kidney disease information; Section B – Conservative care and dialysis treatment information; Section C – Decisions about conservative care and dialysis pathways; and Section D – The next step in care. It also includes a glossary, further information and research used.

4.3.3.3 Cultural Adaptation Models

A cultural adaptation model proposes guidelines and methods to help implement interventions in a culturally sensitive manner. In the 1990s, several guidelines were developed regarding culturally appropriate and valid health questionnaires (Guillemin, Bombardier and Beaton, 1993; Beaton *et al.*, 2000; Wild *et al.*, 2009). Traditional guidelines for adapting health-related questionnaires have failed to consider the content and purpose of patients' decision aids. (Chenel *et al.*, 2018). Several resources exist that provide clear instructions on how to develop PtDA and assess existing decision aids' quality (Elwyn *et al.*, 2009; Elwyn *et al.*, 2011; Coulter *et al.*, 2013). The phases or guidelines on the development of PtDA are described in these models. The phases include defining the decision aid's scope and content
and creating a prototype and field-testing it in different contexts. However, these guidelines are of little help in identifying concrete ways to adapt decision aids for different cultural contexts even though they consider some cultural aspects in relation to decision aids under development. No current guidelines exist to help researchers adapt and validate decision aids, so Chenel *et al.* (2018) conducted a scoping review to identify existing procedures for cultural adaptation and validation of PtDAs. The authors identified 11 main procedures for adapting and validating patients' decision aids, including appraisal of the original DA, assessment of the new cultural context, translation, linguistic adaptation, cultural adaptation, usability testing, examination of DA acceptability, test-retest reliability, content validity, construct validity and criterion validity. In accordance with the size and complexity of the decision aid materials to be adapted, these procedures can be structured to match resources and timelines. Chenel *et al.* (2018) reported that these procedures were applied differently among widely published studies (Lawrence *et al.*, 2000; Akl *et al.*, 2007; Coudeyre *et al.*, 2009; Orlando *et al.*, 2013; Price *et al.*, 2013; Ko *et al.*, 2014; Lau *et al.*, 2014; Volk *et al.*, 2014; Berry *et al.*, 2015; Jull *et al.*, 2015; Fatima *et al.*, 2016).

Through their review, Chenel *et al.* (2018) suggested four core iterative phases or steps to structure the adaptation process, which include: 1) exploring the original DA and the new cultural context; 2) adapting the original DA to the new cultural context; 3) testing the preliminary version of the adapted DA and 4) field-testing the adapted DA in a real-life use context. Chenel *et al.*'s (2018) first three Steps were the focus of this thesis, but Step 4, which entailed testing in the real world, lied outside the scope of this thesis. I added another step that focusses on developing final versions and reporting adaptation process, coded as Step 4 in my thesis. Translation of the chosen tool is part of the cultural adaptation process, so WHO's recommendations (2017) were used to guide translation, which recommended a forward-backward translation technique. Chenel *et al.*'s (2018) steps alongside WHO recommendations were modified to fit the research process conducted during the pandemic. As a result, four main steps were involved in culturally adapting the YoDCA tool. Each step contains substages, which are explained in more detail in the next section. Figure 5 illustrates the four YoDCA cultural adaptation steps used for Phase Two following Chenel *et al.*'s (2018) steps.



Figure 5: Illustration the YoDCA cultural adaptation in line with the four steps adopted by Chenel *et al.* (2018).

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4.3.3.4 The YoDCA Tool's Cultural Adaptation Process

4.3.3.4.1 Step 1: Exploring the Original Tool and the New Cultural Context

This stage begins by examining and identifying the tool's content, as well as establishing correlations between sections. The aim was to determine which sections of the tool would need to be adapted to the new cultural context and how this could impact the tool. For example, written information or graphic sections may be modified based on the target population (Chenel *et al.*, 2018). In this stage, a diverse range of renal care experts participated in individual semi-structured interviews that focussed explicitly on their views about the tool and identified the key aspects to focus on in the cultural adaptation of the YoDCA tool. The target population (4.3.3.4.1.1).

4.3.3.4.1.1 Research Context and Target Population of Experts

Experts were recruited from the following Muslim countries: Saudi Arabia; Kuwait; Yemen; Egypt; Eritrea; Malaysia and Pakistan. Although this research was intended to be conducted in the Saudi Arabian context, a low response rate from Saudi Arabia (due to COVID) necessitate including participants from other Muslim countries.

4.3.3.4.1.2 Inclusion and Exclusion Criteria

Participants included during this phase were from a broad multidisciplinary range of HCPs and people working in academia and research fields. They were experts in renal care, ACP and SDM discussion, palliative care and EoL care from Saudi Arabia, the Middle East and other Muslim countries. In this study's context, HCPs include nurses, doctors, health educators, head nurses and senior managers. Including such varied types of participants from different cultural backgrounds was important to enrich the data by eliciting different views and perspectives from people who deal with renal patients directly, particularly those in academic roles who conduct research to improve care practices. Despite differences in cultural backgrounds, their shared traits and religious practices persist across geographic and political boundaries. Thus, including participants relevant to the Saudi Arabian context, as well as other Muslim contexts, aided the adaptation process. The inclusion and exclusion criteria for recruited participants are explained in Table 9.

Table 9: Inclusion	and Exclusion	Criteria for	Expert	Participants
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Inclusion Criteria	Exclusion Criteria
 Healthcare providers in renal or academic with experts in renal Healthcare providers who are Saudi, Arabic speakers or with Muslim backgrounds from other Middle East countries Healthcare providers with a non-Saudi non-Muslim background who have experience working in the Saudi Arabian context with the target population currently or previously. Healthcare providers who are experts in renal care, ACP, SDM, palliative care or end-of-life care Healthcare providers who are experts in patient communication Nursing or medical personnel working in an academic and research field. People willing to participate in adapting a decision aid tool for the renal context. 	 Healthcare providers with no experience in renal care, ACP or SDM Healthcare providers without experience of working in the Saudi Arabian context or not from a Muslim country

4.3.3.4.1.3 Sampling and sample size

A purposive snowball sampling technique, as discussed earlier (4.1.2), was employed during this phase to recruit experts (Etikan, Musa and Alkassim, 2016) in kidney disease, ACP discussions, SDM processes and palliative care. A maximum variation sample, including healthcare providers and doctors or nurses working in academia or research, offered different perspectives, backgrounds and experiences (Holloway and Galvin, 2016). As discussed before, this type of research requires a small sample size. Therefore, no more than 10 participants were sought for this phase based on specific criteria explained in the previous section.

4.3.3.4.1.4 Recruitment Process

The Initial recruitment process used an invitation letter sent via email to a potential list of personal contacts of the researcher and two professionals working in the dialysis unit at the KSAFHNWR. I then reviewed the most recent literature to identify potential participants who published articles relevant to renal disease or practices, or palliative and end-of-life care in the Saudi context and other Muslim countries. This helped identify a list of 42 potential participants who were invited to participate in the study via email using their publicly available email addresses. The email included invitation information, a participant information sheet and a consent form (Appendices 10A, B). The individuals were told that

their participation would be voluntary. Moreover, I used snowball sampling by asking identified experts to suggest and forward the email to other eligible health professionals at their place of employment or elsewhere in the Middle East whom they felt might be interested in this topic. Furthermore, I used different methods to improve the recruitment process to identify and select eligible external participants in the following ways:

- I developed an invitation for a call for experts via Twitter for Saudis or those with a Muslim background working in other countries or healthcare providers with experience working in Saudi Arabia.
- Sheffield Hospital nursing staff were contacted via email seeking Muslim HCPs who work in renal/dialysis units.
- I attended an online conference focussing on renal care and ACP to identify participants.

Participants were recruited between July and September 2021 for an online semi-structured interview. Altogether, 42 potential participants were approached via these various techniques, and 15 replied. Six out of the 15 refused to participate for various reasons, including lack of interest, lack of experience in palliative care or renal care, or time constraints. A follow-up email was sent to 27 participants who did not reply. This was sent approximately one month after the initial email.

Thus, nine respondents ultimately agreed to participate. They then were asked to fill out and sign the consent form and return it, as well as indicate dates and times when they would be available for interviews. Once interviews were scheduled, online interview links were created and sent to participants. Before convening for the interviews, scheduled at least a week in advance, prospective participants were sent a copy of the decision aid tool and interview questions, which asked them to provide their opinions verbally during the interviews following an in-depth evaluation of the content and structure, the parts that needed to be translated and adapted, and the elements that should be retained, added or eliminated. A reminder email was sent to potential recruits 24–48 hours before their scheduled interviews to confirm the time, date, and their availability. Eight interviews were generated from the nine participants, whose roles and experiences with renal care varied (see Chapter 6). The

participants represented the following Muslim regions: Middle East; Greater Middle East; East Africa and South Asia.

4.3.3.4.1.5 Data Collection Method of Phase 2

4.3.3.4.1.5.1 Expert Interviews

Online semi-structured interviews were chosen as the most appropriate method during this phase instead of phone interviews. A video conferencing system (Google Meet) was used to collect data remotely, allowing two or more people at different locations to communicate in real time with audio and video imaging (Gray *et al.*, 2020). As participants in this phase were recruited from different Muslim countries, the main purpose of using video conferencing was that it economically supports research aimed at interviewing participants who are geographically dispersed populations and typically is used to reduce phone costs (Gray *et al.*, 2020).

4.3.3.4.2.5.2 Expert Interview Schedule and Piloting

An interview schedule was used (see Table 10) to facilitate interviews. The interview topic guide and questions were developed based on previous studies and amended based on this project's research aim, with some suggestions from the main researcher, followed by supervisory team discussions to reach consensus. Participants initially were asked icebreaker questions to build comfort and ease them into the interviews, followed by main topic questions that focussed on the study's objective. Probes and prompts also were utilised. The interviews then were concluded with closing questions that offered participants a chance to express any concerns or issues they may have had.

The interview schedule was piloted through the first interview, after which the researcher evaluated the questions to ensure accuracy, understandability and relevance. Meetings with supervisors were used to discuss the summary of this pilot interview, and no changes were suggested to the schedule. Therefore, this pilot data was included in the study's analysis. Only one concern surfaced regarding participants' role and the questions to be asked. For example, for participants with an academic role, some questions were not appropriate, specifically those related to their experiences caring for renal patients, as well as prior experiences with patient discussions.

Table 10: Expert Interview Topics Guid	able 10: Ex	opert Inte	rview To	pics G	uide
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Inter	view Sections	Interview Questions
Α	Introductory	1. Please could you tell me briefly about what your role or experience of caring
	question	ESBD patients or your role in the research field?
	4	
		2 Please could you tell me what are your thinking of the top challenges are in
		renal care?
D	Conoral	2 In general, what did you like or not like about this DA tool? Is anything
В	foodback on	s. In general, what did you like of not like about this DA tool: is anything
	expert s	
	evaluation of	Probes:
	the original DA	
	tool	- Does the DA tool scope and structure seems organized? Why/why
		not?
		A Do you think that this DA would be useful when considering a decision
		about your nationts' health? Why/why not?
		about your patients health? why/why hot?
		Probes:
		 Do the topics seem right? Why/why not?
		- Do you think the DA is acceptable in the Saudi Arabia dialysis care
		context or not and if not what changes they would recommend?
		context of hot, and if hot, what changes they would recommend.
		5. Are there any parts needed to be adapted, which part?
		6. Are there any elements would like retain, add, eliminate of the DA? Please
		specity?
С	Translation and	7. Who are the users of the DA tool? Patients, their families or healthcare
	linguistic	providers?
	adaptation of	8. What language might the DA tool presented in? Arabic or English or
	the DA tool	bilingual?
		Probes:
		- Does the DA tool need to be translated as whole resource? Yes/ No?
		Why/why not?
		If no is there any parts peopled to be translated into Arabia language?
		- If no, is there any parts needed to be translated into Arabic language?
		which part?
		9. Literacy level, content comprehension and comprehensiveness
		Probes:
		 Are there any words or expressions questionable? What is the
		alternatives and Why?
		- Is it understandable by the care provider/ How would you modify it
		according to people with low literacy.

D	Cultural adaptation of the DA tool.	10. Back to question 3; I will now go through each part on the DA. Do you think that part makes sense?						
		Probs:						
		 Is it sociocultural appropriate? If a concern is raised: What do you like/not like? What would you change/ modify? 						
		- How would you change it?						
		- How would you use the DA tool with your patients?						
		 Do you have any other comments or suggestions that I should consider that would make the DA easier for Saudi Arabia patients to use? Topics, ideas: particular words? 						
E	Closing Questions	11. Those are all the questions I were going to ask; would you like to ask me about anything? Is there anyone else you think I should talk with about this topic?						

4.3.3.4.2.5.3 Expert Interview Procedures

As the principal researcher, I conducted all interviews online via the Google Meet platform using the audio or audio-visual function. Nine experts participated in eight interviews, as one interview comprised two interviewees. The interviews were conducted in the English language, as English was the second language for all of them. Interview length varied depending on how much detail the participants were willing to provide. The interviews lasted between 25 and 90 minutes each. The research purpose was reiterated, and consent was obtained verbally at the beginning of each interview. The participants were assured that all data provided would remain confidential and that a pseudonym would be used to ensure each participant's anonymity. The participants were informed that the interviews would be recorded over the phone, and the reasons for this were explained.

Following this, demographic data were collected, including age, gender, nationality, religion, education background and level, their job role, experience working in Saudi Arabia, experience with patient discussion and prior experience in palliative care education and practices (using the interview guide; see Table 10). Open-ended questions were asked. Generally, all participants were asked the same questions, but each interview's direction varied based on the information provided. The researcher took field notes during each interview, and a summary of each interview was provided to assist with reflection and data

analysis. Following data collection, the experts' initial data analysis was conducted using reflexive thematic analysis (Section 4.4.5) to inform the second step of the cultural adaptation process, which is explained below.

4.3.3.4.2 Step 2: Adapting the Original DA to the New Cultural Context

Chenel *et al.* (2018) described this phase as a way of consolidating findings from the previous phase and planning procedures for developing an adapted version of the DA. DAs generally are transformed to fit new cultural contexts through cultural and linguistic adaptations. The adaptation procedure in this step comprised three stages: Stage 1, preliminary adaptation; Stage 2, first adaptation; and Stage 3, second adaptation. All these stages were discussed in detail in Chapter 7.

4.3.3.4.2.1 Stage 1: Preliminary Adaptation

This adaptation was informed heavily by the experts' findings from Step 1. This stage started by modifying each YoDCA segment based on suggestions and themes emerging from the experts' interviews. Data from these interviews, summarised in Chapter 6, were analysed, and initial adaptation aspects were identified. Based on the data gathered, aspects of the YoDCA content were modified to improve its cultural appropriateness and acceptability in Muslim contexts, particularly Saudi Arabia. As this was adapted and developed, Version 1 was released, which was called preliminary adaptation Version 1. Based on Resnicow *et al.'s* (1999) definition, cultural sensitivity of health promotion programmes is measured by surface and deep structures. The surface structure of interventions relates to how well they fit within a particular culture. Materials could be matched with the target population's superficial characteristics to achieve this. Using familiar and preferable target people, places, languages, food, locations, and clothing is part of the surface structure (Resnicow *et al.*, 1999). However, deep structure sensitivity involves understanding cultural, social, historical, environmental, and psychological forces that affect the target population's health behaviour (Resnicow *et al.*, 1999).

At this stage, input, and perspectives on YoDCA adaptations fall into two categories: cultural adaptation and clinical adaptation. Thus, changes were made at both the surface and deep structural levels. Aside from surface-level elements, such as people's language, images, and

resources familiar to and preferred by the target population, this draft also considered values and beliefs at deep levels. Moreover, Kreuter *et al.* (2003) suggested five strategies to make intervention material more culturally appropriate: peripheral; evidential; linguistic; constituent-involving and sociocultural. Kreuter *et al.* (2003) suggested that socioculturalbased materials must demonstrate an understanding of cultural normative practices and belief systems, particularly cultures' inner workings, rather than just outward appearances.

Moreover, in accordance with WHO (2006), which developed a technical adaptation guide for a decision-making tool for family-planning clients and providers, adaptation can be divided into two types: recommended adaptations and possible adaptations. Recommended adaptations are changes recommended by either experts or the tool's original developers to make it more usable for both patients and HCPs in the Muslim context. This adaptation was advised in the following areas: treatment method adaptation; local terminology and consistency with national standards and procedures. Possible modifications may require more time or significant modifications in terms of the tool's sections or components when adapted to a specific cultural context. It might be possible to change these elements: references; illustrations; adapting to different patient groups; and production and implementation issues (WHO, 2006). When adaptation processes were conducted for Version 1, all these adaptation types were considered, i.e., both surface-level changes related to clinical adaptations and deep-level changes related to cultural adaptation were included in this preliminary stage of adaptation and developed in Version 1.

4.3.3.4.2.2 Stage 2: First Adaptation

At this stage, the adaptation was informed heavily by both the interviews with experts and discussions with YoDCA's original authors, who created the tool. The original authors reviewed Version 1 of the preliminary adaptation. The adaptation's preliminary aspects were discussed during a formal videoconference meeting with YoDCA's original authors. This stage aimed to examine the original authors' perceptions towards the preliminary draft of the adapted YoDCA tool Version 1 and seek their approval of the adaptations. This was an iterative process in which the English version of YoDCA was redrafted, reviewed, and revised until it was ready for the translation and then testing step. The main focus of this stage was on cultural adaptation, i.e., tailoring the tool materials to national Saudi standards and

protocols. Thus, this stage considered adaptations related to the tool's cultural relevance, not clinical content. Any clinical adaptations lied outside the scope of my thesis, as the clinical content already had been validated in a UK context. Making clinical adaptations was not the primary focus. Numerous versions were created during this stage, starting with Version 2, and progressing to Version 5. Figure 6 illustrates differences among developed versions at this stage, and more complex versions were developed in Chapter 7. Penultimate English Version 5 of the culturally adapted YoDCA tool has been approved.

Version 1	 Informed by previous interviews with experts.
Version 2	 Informed by previous interviews with experts and discussions with the original authors.
Version 3	 Informed by discussion with the original authors regarding consistency with national Saudi standards and protocols.
Version 4	 Informed by discussion with authors who approved English version 4.
Version 5	 The penultimate version of the adapted English version, which includes illustrations adapted by a medical illustrator.

Figure 6: Illustrated versions of the YoDCA developed through the First Adaptation at Stage 2 of the Cultural Adaptation Process

4.3.3.4.2.3 Stage 3: Second Adaptation

As part of cultural adaptation, translating YoDCA into the local language for the target population prior to testing and clinical use was another important step in the adaptation process. According to WHO (2007), which developed the principles and a process for adapting and implementing sexual and reproductive health guidelines and tools, the translation process of health communication materials or WHO guidance into the local language can be conducted either before or after adaptation and field testing, depending on needs and context. As a result, for me as a researcher, it was best to develop the adapted English version

of the tool and obtain the original author's approval before beginning the translation because a penultimate English Version 5 of the culturally adapted YoDCA tool has been approved. This adapted and approved version is easier to translate and helps ensure that the translation process is more efficient. Thus, the translation process was followed by the adaptation process, and the adapted penultimate Version 5 of YoDCA was translated into Arabic in this study. The methodology was based on translation and back translation procedures, which are standard procedures for adapting questionnaires (Beaton *et al.*, 2000) and patient information documents (Guillemin, Bombardier and Beaton, 1993; Wild *et al.*, 2005). This is the most widely used and accepted method for achieving effective instrument translation equivalence.

4.3.3.4.2.3.1 Preparation for Translation Process

Translation guidelines usually neglect the preparation step, but Wild et al. (2005) recognised that a lot of work must be done before translation can commence. For these reasons, the following steps were included as an outline of the preparation work. Initially, permission to use the culturally adapted penultimate Version 5 and translate it into Arabic was obtained from the original authors (see Appendix 11). Then forward and backward translators were recruited, and the cost to produce translated versions was estimated. During the whole forward-backward translation process, three independent translators were used, and each translator had different tasks. For example, the first was me as a researcher (who is bilingual but not a professional translator), who is familiar with health concepts and worked on forward translation from English to Arabic. The second was a professional bilingual translator called 'Translator 1', who worked on editing the Arabic version and producing the version that I approved of the translation. The third was an independent professional bilingual translator, called 'Translator 2', who worked on backward translation and was blind to the original English version of the YoDCA booklet. More details on these independent translators' roles are explained in the following translation process, as well as in Chapter 7. After that, a summary of the translation process flow and timeline is developed (see Table 11).

Table 11: Summary of the Translation Process Flow

Process flow	Time
Forward translation One forward translator	Two weeks for the researcher to translate into Arabic and release the initial Arabic version which begin on May 23 and will end on June 6, 2022.
(researcher NA)	
Editing One professional translator or editor (Translator 1).	One week for Independent Translator 1 to review the initially translated Arabic version began on June 7th and will end on June 13, 2022.
Synthesis of forward translation (Researcher NA)	The researcher spent three days reviewing both the initial and edited translated versions, as well as discussing with the editor, to reach Arabic version 6, which was released on June 17, 2022.
Back translation One backward translator (Translator 2).	Two weeks, beginning June 18 and ending June 30, 2022, for independent translation work, discussions, and the release of the back-translated version.

4.3.3.4.2.3.2 Translation Process

When used in other cultures, languages and countries, an instrument's translation, adaptation and cross-cultural validation require comprehensive, rigorous and wellestablished methodologies (Beaton et al., 2000; Jones et al., 2001; Beaton et al., 2002; Sperber, 2004; Wild et al., 2005; WHO, 2017). In the health care literature, even though methodological approaches exist for translating, adapting, and validating instruments for cross-cultural health care research, wide variation persists in their application. Due to variations among these approaches, I used the most recommended ones: WHO's guidelines. To ensure cross-cultural adaptation and translation of an instrument, WHO's guidelines offer a clear, comprehensive and systematic approach. Furthermore, several WHO studies have refined the WHO process of translating and adapting instruments for cross-cultural use (Shajrawi et al., 2020). Thus, in this study, it was intended to develop the Arabic Version 6 of the YoDCA tool based on WHO recommendations (2017), which focussed mainly on forwardbackward translation. As WHO recommended 4 steps for the translation of an instrument, due to the COVID-19 pandemic, document length, budget, availability of human resources, and the PhD study's constraints, deadlines, and timing during the pandemic, these steps were modified and combined with Chenel et al.'s steps, which are illustrated in figure 5. The translation process was conducted as explained below:

Forward Translation: The researcher NA, whose mother tongue is Arabic, translated the penultimate English Version 5 to Arabic Version 6, with an eye towards retaining as much of

the English text's meaning as possible. Others, including a professional translator and editor called Translator 1 whose native language is Arabic, were hired to review and edit YoDCA's Arabic Version 6. I discussed questionable or unclear text, phrases and terms with the translator 1. Then, I reviewed and compared the two versions (the initial forward translation Version 6 and the edited translation version 6A), highlighted any differences between them and discussed them to reach a consensus. I then synthesised the Arabic-translated texts into a single document, which I coded as the penultimate forward-translated Arabic Version 6B.

Backward Translation: Back translation involves translating a target language version (the penultimate Arabic Version 6B of the YoDCA booklet) back into the source language version (English language version) to verify the translation of the research instrument or document (Maneesriwongul and Dixon, 2004). The primary goal of back translation was to enable comparisons between the original source language Version 5 after adaptation and the version that was back-translated into the source language. Back translation comprised three processes: translation; comparing; and reconciliation of back translation, as described below.

Process One: Translation. Translating back into the original language is the first process, also referred to as a 'back translation'. This process aims to produce a document with an accurate translation and identify any inconsistencies in the translation process. A bilingual certified translator 2 who is professional, competent and has a medical background conducted the back translation. The translator 2 understood that this was a back translation intended to be compared with the original. This makes for a somewhat more literal translation than typically would be the case, which improves its effectiveness and makes it easier to compare. The back translator was not involved in the original translation process and did not have access to the source text for the initial translation to ensure that the original text could not influence how the back translation was worded. Version 6C was developed.

Process Two: Comparison. The comparison process involves comparing the back-translated text with the original text. This step is crucial to the success of the back translation process because it distinguishes between differences that matter and those that do not. I conducted this step because it was time-consuming and resource intensive. I compared and identified any discrepancies between the forward 6B, backward-translation 6C and original adapted Version 5 and wrote a report documenting this process (see Chapter 7). This process aimed

to detect any differences in meaning between the original and back-translated texts. Such issues were investigated and resolved during the next step, 'reconciliation'. It was not expected that the two texts would be exact equivalents. It was possible that the terminology and grammatical construction would differ, but this was viewed as a superficial difference. Therefore, I looked for places where meaning, concept, function, or effect were significantly different, i.e., differences that mattered and may affect meaning in the document.

Rather than conduct the comparison using a computer, I used side-by-side hard copies, as it is much easier to miss things on a screen, i.e., hard-copy comparisons are far more reliable. I worked through the two documents (back translated and original texts), systematically comparing small chunks of text, typically one to two sentences, which are not too long to retain in short-term memory. Any potential differences were highlighted on the hard copies, which are called a 'potential issue report'. If no potential issues were identified, the researcher confirmed the translation as accurate. Otherwise, it was on to the reconciliation step. After I identified potential differences and highlighted them on the hard copies, they were transferred to a spreadsheet.

Process Three: Reconciliation. This process aimed to produce an accurate translation. The focus here must be solely on the translation itself, its essential meaning and function, and whether it accurately reflects the source text because different languages can express ideas in multiple ways. The 'compare' step produces a set of apparent differences in the meaning between the source text and back translation. Some of these are superficial differences in sentence structures and use of alternative terms compared with the original. These differences have no need for modification. I and the translator 2 discussed discrepancies until consensus was reached on which translation was closest to the original wording, would be better understood by the intended audience and used better grammar and syntax. Therefore, the final backward-translated version (6C1) was developed and approved as a certified back translation (see Appendix 12).

4.3.3.4.3 Step 3: Testing Prefinal Adapted YoDCA Tool Versions (Expert Consultation)

During this step, a penultimate or pre-final versions of the YoDCA was presented to potential users who represented the target population. As part of this step, additional information also was gathered to improve fit between the DA and cultural context (Chenel *et al.*, 2018).

Consultation with experts is an important stage to ensure clarity, detect linguistic mistakes and ensure cross-cultural equivalence (Chaboyer *et al.*, 2012). Three previous experts in renal care were recruited from Step 1 of the adaptation process (4.3.3.4.1.4) to take part in assessing content validity. Consequently, I conducted three additional semi-structured interviews to assess the culturally adapted tool's validity, as well as its acceptability within Muslim culture, particularly that of Saudi Arabia. The experts were selected purposively to represent different professional backgrounds: one nephrology doctor; one nursing staffer; and one academic nursing staffer. The experts represented different genders, comprising one male and two females. One spoke English, while the other two spoke Arabic. The recruited participants received an invitation email that included the aim of the research and a copy of the consent form and participant information sheet for this step (see Appendices 13A, B).

Following their approval, the penultimate culturally adapted and translated versions of YoDCA (Versions 5 and 6B) and interview questions were sent via email, and availability for interview times and dates was confirmed. The interview topic guide for this step was developed based on this step's goals, suggestions from the main researcher and supervisory team agreement (see Table 12).

One English speaker reviewed the adapted penultimate English Version 5, and two Arabic speakers reviewed the adapted and translated penultimate Arabic Version 6B to ensure that the adapted YoDCA version retained its equivalence in an applied situation with target endusers. All interviews were conducted online via Google Meet in the English language. Each interview lasted between 40 and 60 minutes. The interviews were audio-recorded with the experts' permission. At the beginning of the interviews, participants were reminded about the study's purpose, and verbal consent was obtained.

During the individual interviews, either penultimate Versions 5 or 6B were assessed in terms of clarity, readability, linguistic appropriateness, grammatical structure and comprehension, and cultural equivalence. The experts were asked to evaluate the tool's overall content and suggest improvements for future tool versions. They also were asked whether they thought the adapted content would be appropriate in Muslim healthcare contexts. They then were asked about the information's clarity, including whether they had difficulty understanding it, as well as its relevance. They also were asked to consider the alternative wording for a specific

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translated term. Finally, they were asked about the tool's utility and implementation plan in clinical contexts. Although otherwise asked the same questions, the English-speaking experts did not address linguistic issues. Part 2 (7.2), Chapter 7, examined this point in more detail.

Inter	view Sections	Interview Questions
B	Cultural	 What was your first impression and reading experience of this booklet? Probes: How valuable was the information? Are there any topics that you would like to see in a future version of this tool? If yes, what do you think should be added? Please share your thoughts about the way it is presented in terms of the layout or design, e.g., the colours, the images, and the size of the writing? Please describe what you like and do not like about it.) Do you think the content of this booklet is socioculturally appropriate for
	appropriateness	the Muslim context? (Why or why not do you think that)
		 Probes: Is any of the information offensive or inappropriate in a Muslim context? If yes, please describe it. How would you change this information?
С	Linguistic appropriateness	 3. How understandable was the information?? (Is the booklet easy to read or confusing?) 4. Was the translation and language used clear? Probes: Were there any (Arabic or English) sections, sentences, or words in the tool that were unclear or confusing? If yes, please specify. How would you change this information?
D	Utility and implementation of the booklet	 How do you feel about using this booklet as a tool to assist in your patients' renal treatment decision-making? How would you use it with patients?
		 Who would you recommend this booklet to? (Specific staff, septic patients) What do you think is the best way to implement this in a clinical setting? (Time and place) 7. Do you have any advice on how to introduce it to hospital management? Please specify. 8. Are there any barriers to using it in clinical settings? Please specify.
E	Closing	9. What other suggestions do you have to improve on this decision-making

Table 12. Tool content valiancy interview ropics duide
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Question

tool as a whole?

4.3.3.4.4 Step 4: Developing Final Versions and Reporting the Adaptation Process

Based on experts' comments, which were summarised in Chapter 7, Part (7.3), the researcher synthesised the pre-test results from both the English and Arabic versions, refined and developed the final versions (5A and 6B1) and wrote a summary of future changes suggested in the culturally adapted and translated versions of the tool. Furthermore, a preliminary draft of an implementation plan was developed, and a cultural adaptation and translation steps was reported. All adaptation and translation stages were completed and documented successfully in Chapter 7.

4.4 Data Collection Management

4.4.1 Time Frame

The data collection period was between November 2020 and July 2022. All interviews and other research activities, such as a modified systematic review and cultural adaptation and translation processes, were conducted within this time frame. During this period, my data collection was suspended twice, then resumed, due to the COVID-19 pandemic. This was explained in more detail in Section (4.4.6).

4.4.2 Interviews Transcription and Translation

During Phase 1 of my study, data were collected in Arabic, then analysed and reported in English. The challenges that the qualitative researchers faced included maintaining the accuracy of participants' perspectives, particularly with a study conducted in one language during data collection but conducted in another during data analysis (Regmi, Naidoo and Pilkington, 2010). For practical reasons, the data were translated into English at an earlier stage to avoid the risk of lost meaning. The literature suggests two distinct methods of translating research interviews. The interview can be translated verbatim, but this approach is tedious and time-consuming (Regmi, Naidoo and Pilkington, 2010). Other methods include interpreting key themes or a few quotes and adding them to the context of the report (Regmi, Naidoo and Pilkington, 2010). However, in my study, the first method was employed.

Extant research has suggested that translation directly impacts study findings' validity (Chen and Boore, 2010), so researchers should be aware of translation and interpretation concerns. Therefore, I followed strategies to ensure rigorous translation, a move that many authors

suggested (Chen and Boore, 2010; Santos Jr, Black, and Sandelowski, 2015). These included analysing all transcriptions and transcribing all digital audio-recordings into the original language in which the data were collected. One professional translator then received copies of original Arabic transcripts and was asked to translate the written transcripts verbatim (word for word). Thus, I transcribed the audio-recorded interviews into Arabic, then had a certified bilingual translator translate them into English. The translator signed a nondisclosure form to ensure participant data anonymity.

To ensure the translation's validity, I reviewed the translation several times to ensure it reflected words' actual meaning and avoided misinterpretation. Moreover, translated transcripts were given to supervisors, and their comments on the translations were considered. Due to the direct verbatim translation of the text, very few corrections were made, such as sentence editing or choosing the correct words to match meaning. For Phase 2, a practical decision was made when choosing an outside agency (transcriber). This was an appropriate procedure, considering interview length, PhD study time frame and the transcription's time-consuming nature. The transcriber signed a nondisclosure agreement form to ensure participant data confidentiality (see Appendix 14).

4.4.3 Computer Software

During Phase 1 of the study, the transcripts were managed and organised based on two main considerations. First, organising data manually, either with pen and paper or by cutting and pasting documents using word-processing facilities. As a second method of managing interview transcripts, software packages were available. Data were stored electronically to support data coding and analysis through NVivo qualitative data analysis software, Version 14, on license from the University of Sheffield. I only used it during the initial stages of the analytical process. As a researcher with experience using it, I decided to conduct manual coding and analysis on printed paper transcripts to engage with the data personally. It was also more practical for me to create a chart to organise some of the initial headings. This provided a visual representation of how the study findings were organised. Manual coding was used in data that emerged from Phase 2.

4.4.4 Ethical Considerations

Ethical concerns have been raised that are associated with all empirical research studies. A qualitative researcher must be aware of and account for ethical concerns when conducting research that involves understanding people and using their voices and perceptions. The following ethical principles are critical in research and were applied prior to data gathering to ensure respect for participants, which included ensuring their anonymity and data confidentiality, preventing harm and protecting privacy (Creswell and Poth, 2018). One ethical concern was respect for participants. This means that the recruitment process was conducted on a voluntary basis, i.e., no participants were coerced into participating in the study. Participants provided written informed consent and were told that they were free to withdraw from the study at any time without providing any reasons. The patient participants also were informed that their participation in the project would not affect the quality of service or care that they received. Furthermore, the period between providing information about the interviews and signed consent was more than 24 hours to allow time for participants to reflect on and discuss participating in the study with others. Afterwards, verbal consent was obtained at the beginning of each interview.

In terms of confidentiality, I handled the data in a confidential manner. The research findings did not identify any participants in the study; pseudonyms were used in line with ethical principles. Moreover, a clear explanation of the confidential and anonymous nature of the study and data storage was provided on the information sheet and consent form (see Appendices 6, 10 and 13). All recorded data were transferred as soon as possible and deleted from the voice recorder (phone). Furthermore, all collected data were transferred to the University Drive by Virtual Private Network (VPN) when working remotely. All research data collected on paper were copied, scanned and stored in a folder on the university's secure X: a drive with a secure password. As part of the research process, discussions with my supervisory team and publications were based only on coded data and direct quotes that were anonymised to ensure that the speakers could not be identified. All steps were taken to ensure that participants' confidentiality and privacy were not breached.

Regarding prevention of harm, the study was not expected to pose any harm to participants, but sharing experiences with the researcher may be uncomfortable or distressing. To avoid this, participants were reminded that they could choose not to answer questions if they felt uncomfortable and could withdraw from the study at any time. Moreover, participants were given contact details for a social worker at the dialysis unit if they felt stressed during the study and wanted to talk to someone. I also checked participants' well-being after they participated in the study and engaged in informal conversations with them. Ethics approval was obtained from the University of Sheffield and Saudi Arabia.

4.4.5 Data Analysis

In this thesis, the data were analysed using Braun and Clarke's reflexive thematic analysis approach, which encourages researchers to contribute actively to the analysis (Braun and Clarke, 2019, 2022). This method was well suited to the research aims and to the exploratory, pragmatic, qualitative research design because it allowed me to interpret patterns of meaning across the dataset that were consistent with descriptive information analysing a particular phenomenon (Braun and Clarke, 2006, 2019). Using the reflexive thematic analysis approach was suitable for understanding the current practice of ACP discussion and the SDM process for ESRD patients and their family caregivers at the Saudi Arabian dialysis unit. Furthermore, it was used in the present study to examine participants' views about the cultural adaptation of the YoDCA tool to inform the general adaptation of the tool, thereby achieving this study's principal aim. Moreover, it provided flexibility, acknowledging my own perspectives and biases when interpreting the data. It is therefore very appropriate in the context of pragmatic assumptions and design.

Consequently, it allowed me to ensure that qualitative data were collected and analysed in a way that respected participants' subjectivity to their attitudes while also being aware of and embracing the reflexivity and subjectivity influence of my interpretations as a researcher. Researchers' subjectivity is not seen as problematic in this approach but rather as an integral part of analysis (Braun and Clarke, 2022). In addition to complying with the underlying research philosophy, reflexive thematic analysis allows for both semantic and latent meaning to be identified within data and offers tools and techniques that are either atheoretical or theoretically flexible (Braun and Clarke, 2019). In this study, thematic analysis was carried out inductively, analysing the semantic meanings generated from the data without predetermined theoretical foundations, using the six recursive stages described by Braun and

Clarke (2019, 2022). The following steps describe the phases of the analytical process utilised for this study.

The first step entailed dataset familiarisation, which developed the opportunity for a researcher to familiarise themselves with the dataset (Braun and Clarke, 2022). This was done by reading and rereading participants' transcripts, beginning to note my reactions and reflections and obtaining an early impression of the body of research (Braun and Clarke, 2022). In this phase, I set about familiarising and immersing myself in the data by listening and relistening to each audio recording of the interviews. My next step was to transcribe the patient interviews verbatim, which was a helpful strategy to familiarise myself with the data (Smith and Sparkes, 2016). In a reflexive discussion with my supervisory team, we discussed our understanding of the data set as we began the reflexive thematic analysis process. Then, after I reviewed and read each transcript, I considered potential meanings and patterns and made reflective notes as I became more familiar with the data. As a result of data familiarisation, I was able to make sense of what the interviewees were saying. Thus, a broad code was generated, and key quotations were labelled to assist in the following steps.

The second step entailed data coding by organising the data in a meaningful and systematic way that made sense to the researcher (Braun and Clarke, 2022). This step involved coding the entire dataset to ensure that a large amount of collected data was placed into small, meaningful chunks. Well-structured data coding helps to capture particular themes that directly address the developed research questions (Braun and Clarke, 2022). Researchers generally use inductive approaches in qualitative research, but deductive approaches can also be employed or use a combination of both (Braun and Clarke, 2019). In this study, I used inductive approaches that emerged from the data, in which the researcher used words or concepts as stated by the participants (Howitt, 2019). Thus, I coded based on my research aim. The initial codes were derived by reading the transcripts several times and identifying commonalities or important expressions. The goal here was not just to identify themes but to begin to understand how my perspectives and biases might affect the results. After two rounds of coding, a table of three columns was created: one column for the codes, with definitions of each code; a second column for the number of occurrences of each code; and a third column for direct quotations, references or evidence from text. A colour-coded system

was used to avoid errors. For example, for patients and/or family caregivers' interviews, an initial analysis produced 100 codes. As I continued coding the interviews, I moved between them, and I noticed that the coding had decreased.

The third step entailed generating initial themes embedded in the text (Braun and Clarke, 2022) to ensure that the detected patterns were significant to the identified and explored data. While no clear rules have been established on theme generation, any search should reflect a character of significance. This step involved examining how different codes may be combined to form a subtheme or even an overarching theme. Furthermore, any overlapping statements shared by multiple participants required linking to generate potential themes that informed a particular attribute. After the initial codes were generated, I reviewed the codes of the four interviews. Some initial codes formed potential themes and subthemes, while others were discarded. Based on that review, 80 codes were grouped into 32 categories or subthemes, and seven preliminary themes were developed. My research aim acted as a guide for preliminary theme development.

The fourth step involved developing and reviewing themes, in which the researcher examined, modified and developed preliminary themes identified in the previous step (Braun and Clarke, 2022). The review was undertaken centrally to gather all information with relative meaning to each identified theme. The researcher extensively evaluated all collected data to ensure that all developed themes were addressed exhaustively by participant responses (Braun and Clarke, 2022). Through this step, I ensured that my analysis was both grounded in the data and shaped by my reflexive engagement. The data associated with every theme identified, and all transcripts were colour coded differently to ascertain whether they supported the entire context. Several processes were conducted at this step, including discarding an existing theme if not enough data was found to support it, combining themes into one theme, dividing themes into two themes or forming subthemes (Braun and Clarke, 2022). After the initial subthemes and themes were generated, the supervisory team discussed how they could be refined into subthemes based on their similarity and contextual ability to address the main research questions. Based on the discussion, the final refinement process ended with 65 codes grouped into 28 subthemes that developed six themes. One theme was combined into another.

The fifth step was refining, defining and naming themes (Braun and Clarke, 2022). This required me to identify the essence of what each collective attribute shared by the participants was all about. My contribution during this step entailed writing a brief synopsis for each theme. Moreover, I examined whether the narrative was an all-embracing theme that explained the entire study context. The narrative ensured that specific comments developed from the participants' responses indicated the strengths and limitations of the research. Based on feedback from my supervisory team, only one subtheme was renamed to be consistent with the accompanying narrative. The final step in reflexive thematic analysis is writing up. This was the research endpoint by compiling a report on themes and coding statements from the participants' direct quotes. Then, a summary of the entire analytical process was written to provide a reliable report that depicted the addressed problem and recommendations, offering a long-term solution (Braun and Clarke, 2022). This was done by developing a first draft of the findings chapter. Finally, six overarching themes were identified. The same process was applied to code the experts' interviews.

4.4.6 Challenges to Research during Recruitment and Data collection

I faced considerable difficulties due to the COVID-19 pandemic, which forced me to suspend data collection twice. Several challenges arose during data collection, particularly during the recruitment process. The main problem was that I did not have permission to visit the hospital and recruit participants personally. Saudi culture views face-to-face communication as more respectful; therefore, it is more likely that patients will participate if they are invited verbally rather than via written invitation. Pandemic restrictions and cultural norms made it very difficult to recruit both patients and HCPs from the hospital in Saudi Arabia, resulting in a lower recruitment rate than I had hoped and forcing me to change my methods to address this problem. For example, I changed the inclusion and exclusion criteria for patients and family caregivers. I employed different recruitment methods, such as snowball sampling. Furthermore, I expanded the recruitment process for experts to include other Muslim countries and used their direct publicly available emails. I also used social media and other sampling strategies to improve recruitment. Due to this delay in the recruitment process and the PhD time limit, my research plan had to be modified, and some phases were not completed (see the COVID-19 Impact Form supplementary document).

4.4.7 Rigours of Qualitative Research

High-quality research depends on adherence to what may be described as rigorous processes. Trustworthiness in qualitative research was established based on five criteria: credibility; transferability; dependability; confirmability and reflexivity (Denzin and Lincoln, 2018). However, qualitative research quality does not have universally agreed-upon standards because different methods and epistemologies are employed (Brooks *et al.*, 2019). Therefore, the following section discusses some established ways and steps undertaken throughout the research process to evaluate the reliability and validity of this qualitative research, as well as how these were applied to the present study (see Table 13).

Process	Steps	Rationale		
Ensuring informed consent	Once consent was obtained, information relating to the study, interview process, and outputs was reiterated to participants, who were offered the opportunity to ask questions immediately prior to interview commencing.	To ensure participants decided to participate of their own accord		
Data collection	Digitally recorded in-depth one-to-one interviews	To focus on the individual and their responses and to preserve verbal communication as far and as accurately as possible		
	Notes made immediately after interviews	To preserve a sense of context, e.g., background noises		
	Personal reflexive journal maintained	As the research instrument, the researcher could not be separated from the data		
Data management	Digital recordings transcribed verbatim by one researcher as soon as possible post-interview.	To become immersed in the data and facilitate dependable analysis		
	Interjections, hesitations, pauses, and intonation, derived from interview notes highlighted.	To aid analysis		
	Audio-check of transcript	To check for transcription error		
Data Analysis	Careful reading and rereading of transcripts	To begin to code raw data of relevance to the research aim and facilitate dependable analysis		
	Handwritten line-by-line initial coding of data.	To think about the data in different ways and open the possibility of further and different dimensions of analysis		
	Comparison of findings with recent research.	To determine whether findings substantiated or refuted findings reported by other researchers		
Final Report	Extended data extracts used in presentation of findings.	To provide evidence to support analysis		

Table 13: Trustworthiness Steps Used in Research Process

4.4.7.1 Credibility

In qualitative research, credibility means that the study findings are credible and based on appropriate methods (Shenton, 2004). Thus, credibility can be described as accuracy. To achieve credibility, I conducted all interviews, and enough time was allocated for each interview (Graneheim and Lundman, 2004). Restating participants' answers is also an effective technique for validating answers (Partington, 2001) to avoid misinterpretation. Another approach to enhancing credibility is applying the triangulation technique (Silverman, 2017). In the present study, data from patients' interviews and data from a systematic review were drawn together to develop a deeper understanding of Muslim renal patients' experiences with ACP and DM practices. Moreover, to enhance credibility further during the data analysis process, my supervisors and I had meetings to discuss themes and subthemes. In presenting the findings, I highlighted and discussed responses that contrasted with the majority.

4.4.7.2 Transferability

Transferability refers to how far the findings can be applied or transferred beyond the project's scope (Shenton, 2004). A detailed description of the study context allows readers to judge findings' transferability (Korstjens and Moser, 2018). As described in Chapter 1, this chapter provides an overview of the local context in which the study was conducted. Transferability of the findings to other contexts is difficult due to seclusion practices' cultural and contextual nature. However, it is hoped that the findings will be of interest to similar organisations and individuals. Findings from the present study could be useful to Arab Gulf Cooperation Countries with similar cultural structures.

4.4.7.3 Dependability and Confirmability

Dependability refers to the audit process, also known as an audit trail, which ensures that all methodological and analytical decisions are documented properly (Bryman, 2008). For example, this thesis contains a complete record of all the study's phases, including details about the formulation of problems, concepts that motivated this topic, details about participant selection and decisions made about data analysis. Confirmability was achieved through an audit trail. A transparent data analysis, according to Korstjens and Moser (2018),

is one in which the findings are based on data, not researchers' preferences. Therefore, supervision, which comprised discussion and reflection with both supervisors, functioned as an independent check. A researcher also can achieve confirmability by being reflective about their own role throughout the research process, which is explained below.

4.4.7.4 Reflexivity and the Researcher's Role

The researcher's background can impact their interpretation of the study's information and what they have achieved from the research (Creswell and Poth, 2018). In qualitative research, this is termed reflexivity. Thus, reflexivity and the researcher's role in qualitative research are a very important issue. Reflexivity refers to critical reflection on engagement and the researcher's subjective contribution in a research project (Creswell and Poth, 2018). The researcher who conducts the study also analyses how their social location and interaction with participants affect the findings. Therefore, reflexivity considers a researcher's positioning in a study. Positionality refers to a researcher's worldview and position about a research task and its social and political context (Creswell and Creswell, 2018). Creswell and Creswell (2018) also asserted that the researcher's background, experiences and culture build on the researcher's interpretation of a theme and the data's meaning.

I am a Saudi who shares a similar culture with the participants; therefore, I may be able to better understand the participants and interpret the data. Furthermore, I must understand the participants' perspectives and how I affect their interactions and data. Supervisory teams from different contextual backgrounds engaged with me regularly in discussions about data analysis, providing a deeper reflexivity level by raising issues and asking questions that explained and addressed taken-for-granted meanings that I overlooked, being from a different cultural background. Thus, I must be aware of the difference that personal background and position can make in the data. The researcher's role is to make decisions on the study's focus, type of data to collect and type of analysis to embrace. From the beginning of the study, with the establishment of researcher positionality and transparency concerning personal assumptions and beliefs, I adopted a reflexive stance throughout the investigation. The study and key research points were conducted with a reflexive stance. Reflectivity requires that I consider my preconceived notions and prior interests as a researcher. Through

regular meetings with supervisors and by writing reflective updates following interviews, I acknowledged reflexivity during the study.

4.5 Chapter Summary

An overview of the study's research methods and reasons for using them is presented in this chapter. An overview of prior data collection planning was presented. The chapter then discusses the data collection process in two phases. During Phase 1, ESRD patients and their families were interviewed qualitatively, and a modified systematic review was conducted due to the limited number of participants. This was followed by Phase 2, which outlined the YoDCA adaptation process in four steps. Ethical considerations when conducting a qualitative study were reported. The data analysis methods used also were described, along with the COVID-19 pandemic's impact on researchers' plans. Finally, the chapter ended with an evaluation of the qualitative study's quality.

Chapter 5: Findings of Phase One Qualitative Study and Modified Systematic Review

5.0 Introduction

This chapter presents data from two research streams: qualitative interviews with ESRD patients and/or their family caregivers, plus a modified systematic review. The findings from both were analysed and presented separately, but both studies' findings were integrated at the end of this chapter. The chapter begins with a report on a pragmatic qualitative methodology that employed in-depth interviews with Saudi ESRD patients and/or their family caregivers. These interviews aimed to explore experiences, needs, priorities and problems that ESRD patients and/or their family caregivers face with communication issues, such as ACP discussions and the SDM process. This is novel because until now, only quantitative approaches have been used to investigate knowledge and perceptions of CKD, as well as ACP and DM preferences among ESRD patients in the Saudi context. In this chapter, I refer to ESRD as CKD because this is what the participants called it during the interviews.

This chapter also reports on a modified systematic review conducted to synthesise and describe evidence on ESRD patients and their families' experiences in a Muslim cultural context with ACP discussions and DM processes. This systematic review complements the qualitative data gathered directly and was necessary due to the limited number of participants recruited for qualitative interviews, largely due to COVID pandemic challenges. This chapter is divided into four main parts. Part 1 (5.1) presents qualitative study findings (Phase 1A), including an overview of study participants, followed by a presentation of key themes and subthemes derived from participant interviews. Part 2 (5.2) comprises a modified systematic review (Phase 1B) that discusses the themes that emerged from the review. The chapter concludes with Part 3 (5.3), which integrates the findings, and Part 4 (5.4), which summarises the chapter.

5.1 Phase 1A: Qualitative Study Findings

5.1.1 Participant Details

Recruitment of interview participants took place between November 2020 and May 2021. The process is outlined in detail in Chapter 4, Section (4.3.1.2.2). Of the 215 patients in the dialysis unit, 60 met the inclusion criteria. Altogether, 25 participants were approached (22 ESRD patients and three family caregivers) via two gatekeepers: the dialysis unit's head nurse and a co-researcher who is also a nephrology doctor. However, poor response rates once again made it difficult to recruit a representative sample. Only seven participants (five patients and two family caregivers) agreed to participate based on the invitation letter. They contacted the researcher by phone to provide their initial approval and proceed to the next step. They then were sent the participant information sheet and discussed the study with the researcher via phone. Two patients refused to participate after reading the participant information sheet; thus, the final sample comprised five patients: three patients and two family caregivers. Four interviews were conducted: two patient interviews; one patient-and-family caregiver interview and one family caregiver interview. The data were anonymised using pseudonyms due to the small sample.

5.1.1.1 Demographic Data Analysis

All the participants recruited in the study were Saudi Muslims who spoke Arabic and were either CKD Stage 5 or ESRD patients, or family caregivers for such patients. Most participants were females between 25 and 40 years old (see Tables 14 and 15). The participants had a wide range of education backgrounds, from illiteracy to higher education. Two had higher education degrees, one had a high school diploma, one had an elementary education, and one was illiterate. Most were unemployed, had undergone haemodialysis for between six and eight years, and acknowledged uncertainty regarding their haemodialysis treatment duration. Some had a long history of the disease and experienced different treatment modalities of RRT, while others were on the waiting list for a kidney transplant. All participants were asked about their family medical history, with most reporting hypertension in their families, two reporting diabetes but only one reporting a family history of kidney failure.

The family caregiver participants were asked about their relationship with their patients who participated in the study. The family caregivers comprised one spouse and one sister, who both have been providing care for approximately five to six years or since their loved ones' diagnosis. Both described their relationships with the patients as 'strong'. Heterogeneity was evident among study participants regarding their sociodemographic characteristics and experiences with CKD disease and its treatment. In qualitative research, heterogeneous samples produce more transferable results than homogeneous samples, particularly if the case samples differ (Robinson, 2014). In this study, diverse case samples involved patients of different ages, genders and education levels. Furthermore, they involved patients with varying disease diagnosis and treatment experiences. Tables 14 and 15 present the patients and family caregivers' demographic characteristics. A summary follows that provides background information on each participant and links to the findings, in which pseudonyms were used in accordance with ethical standards.

Table 14: Phase 1A: Patients' Characteristics

Participants	Gender	Age	Educational level	Employment status	Patient Medical history	Type of dialysis	Year on treatment
P1: Reem	Female	25 Years	Higher education	Not employed	Has turner syndrome and Blood clotting	Haemodialysis	8 years
P2: Noor	Female	38 Years	Secondary school	Not employed	Has a history of hypertension	Haemodialysis	6 years
P3: Sara	Female	38 Years	Elementary school	Not employed	Has hypertension and multiple sclerosis	Haemodialysis	7 years

Table 15: Phase 1A: Family caregivers' Characteristics

Participants	Gender	Age	Relationship to the patient	Educational level	Employment status	Family Medical history	Year of providing care	Knows causes of CKD	Patient involvement in DM
Family caregiver 1: Malak	Female	33 Years	Sister	Higher education	Not employed	Has a history of kidney failure, diabetes and hypertension	5 years	Unsure	Patient was involved
Family caregiver 2: Ahmad	Male	40 Years	Spouse	Illiterate	Employed	Has a history of diabetes	6 years	Unsure	Patient was involved

5.1.1.2 Participants' Background Summaries

Participant 1: Reem, a 25-year-old Saudi female with a bachelor's degree, is an ESRD patient who was diagnosed with genetic kidney disease when she was 3 months old. She also has a history of Turner syndrome and blood thrombosis. Her treatment began in 2006, when she was 10 years old and received a kidney transplant that failed after just one day. She waited two years without dialysis after the operation failed. In 2008, she began peritoneal dialysis (PD) treatment for five years because she was a student at school. After several complications, she switched to haemodialysis (HD) for eight years. Thus, she was on dialysis for 13 years. Currently, her name has been on the kidney transplant waiting list for almost seven years.

Participant 2: Noor, a 38-year-old Saudi female with a high school diploma, is an ESRD patient who was diagnosed with a developed kidney disease seven years ago. She has a history of hypertension but does not take medication currently. She also has a history of lupus erythematosus and pulmonary embolisms. She does not have a long ESRD history and has received HD treatment for seven years. She currently is looking for a donor and has completed paperwork for a kidney transplant, but her name is not on the waiting list yet.

Participant 3: Sara, a 38-year-old Saudi female with an elementary school degree, is an ESRD patient who was diagnosed with a developed kidney disease at age 15. She has no previous medical history but has a present history of multiple sclerosis and is now in a wheelchair. Furthermore, she has a hypertension history. She began dialysis at age 15 and chose PD the first year because she was in school, but due to several complications, she switched to HD for the following eight-and-a-half years. After 11 years, she had a kidney transplant, but it failed after 13 - 15 years. She then resumed HD treatment for seven years. Currently, her name is on the kidney transplant waiting list.

Family caregiver 1: Malak, a 33-year-old Saudi female with a university degree, has cared for her ESRD sister for five years. Before that, her mother cared for her sister for 20 years. During her sister's disease journey, she has supported her physically and emotionally. Her duties include looking after her medications, managing her diet, accompanying her to dialysis appointments and clinic appointments, and providing psychological support. **Family caregiver 2:** Ahmad, a 40-year-old Saudi male, is illiterate, but employed. He has cared for his ESRD wife since she was diagnosed seven years ago. During his wife's disease journey, he has provided psychological support and has accompanied her to dialysis and clinic appointments. Due to his other responsibilities, he cannot attend all appointments.

5.2.1 Themes

Six overarching themes were identified, each with associated subthemes: (1) participants' experiences living with kidney disease; (2) perceptions of chronic kidney disease; (3) participants' experiences communicating with healthcare providers; (4) opportunities to discuss future care plans; (5) decision-making regarding dialysis or renal replacement therapy and (6) recommendations to improve the decision-making process. Detailed descriptions of these themes, plus quotes from participants' interviews, are provided below.

Theme 1: Participants' Experiences Living with Kidney Disease

This main theme presented a comprehensive picture of participants' lived experiences with CKD. The focus was on these experiences' major aspects in relation to the patients' varying diagnosis stories and timing of diagnosis; attitudes towards chronic kidney disease diagnosis; reaction to dialysis and the role of Islamic faith in coping with chronic kidney disease and its treatments. These represented the first main theme's subthemes.

Diagnosis Stories and Timing of Diagnosis: This subtheme describes how patients learned of their diagnosis for the first time and at what stage of their disease. Participants had different stories and experiences, with varying paths to diagnosis. For example, Reem reported that she had genetic forms of kidney disease and was diagnosed at birth with CKD due to Turner syndrome, but Noor and Sara were diagnosed with CKD after visiting the emergency department for a variety of symptoms. Initially, Noor and Sara recalled that when they first experienced symptoms, they viewed them as symptoms of common illnesses, such as colds, abdominal pain or dyspnoea. They also viewed them as nonspecific symptoms. Due to this, the CKD diagnosis was unexpected for them and their family caregivers. They were confused and surprised and did not know how they contracted the disease because they had other medical conditions without associating them with a particular disease. For them, their CKD

was so advanced at the time of diagnosis that they already lost most of their kidney function and required immediate dialysis. As they described:

> "One day, I felt sick, so I visited the hospital with my husband, but he had to leave. When I entered the Emergency room, the doctor told me directly that I need to be on dialysis ... He told me that I had toxins, and these toxins are increasing in my body, I asked him "What do you mean by that?". He told me that your body is swollen now, and you can see that... they did the x-ray and informed me that I had to be started on dialysis" (Noor, female ESRD patient, 6 years on HD)

"That day, I was tired, I had a cold, chest pain and fever. When my mother saw that the fever and chest pain lasted for a while, she told me to go to the hospital. We went there and when I went into the emergency room, they informed my mother that I had renal failure... the doctor told us that there was no choice except dialysis... They inserted a temporary catheter and started first session of haemodialysis ..." (Sara, female ESRD patient, 7 years on HD)

"Suddenly she (his wife) had a dyspnoea, a normal one... the doctor saw her in the emergency department, told her that she must be on renal dialysis ...The doctor came and told us without any tests nor anything, he just put the stethoscope on her chest and said, "Should be on renal dialysis" (Ahmad, male family caregiver, provides care for 6 years)

In Sara's case, her mother had cared for her since her diagnosis until five years ago, so she provided some input during the interview. She explained that the first time she heard about her daughter's CKD diagnosis was when she took her to the emergency department because she was very sick, complaining of nose bleeding, shortness of breath and vomiting. They then admitted her daughter to the medical ward, where they told them her daughter had kidney failure. When she discussed it with the doctor, he told her that dialysis was the only option.

Attitudes Towards Chronic Kidney Disease Diagnosis: This subtheme examined participants or their loved ones' experiences after CKD diagnosis, which varied. They reflected on their experiences with a range of emotions after CKD diagnosis, including fear, disbelief, doubt and denial. Fear is one of the most common emotions patients feel when hearing about their diagnosis for the first time. For example, Sara felt fear when she heard she was diagnosed with CKD in the emergency department. Another common reaction was disbelief and doubt, which Malak, Noor, Reem and Ahmad felt when they heard for the first time that they or their loved ones had been diagnosed with CKD. Various reasons may account for disbelief and lack of understanding of the CKD diagnosis. One reason that Noor and Ahmad, her caregiver, cited was that because Noor had existing minor conditions, it was difficult to accept a more serious diagnosis. She had similar symptoms in the past, and they were nothing serious. They both felt shocked and disbelief when Noor found out she had CKD, possibly because they recalled that when she had been ill with similar symptoms before, it was treated using diuretics. Thus, they were shocked to realise that on this occasion, that treatment plan was not going to work. Furthermore, Noor, Malak and their loved ones refused to believe their CKD diagnoses, i.e., their doctors did not convince them during discussions about their diagnoses. In such circumstances, they sought another opinion or advice from a different country or hospital. As they described it in the following statements:

> "... To be honest, at that time (meaning when she was on the emergency room) I was afraid of the speech I heard (I have renal failure) ... That day I was afraid because I was young, and my mother was with me" (Sara, female ESRD patient, 7 years on HD)

> "... My mother felt confused and did not believe that her daughter had kidney failure and she was not convinced and went to another hospital, and the other hospital told us she had kidney failure and needed dialysis quickly (as soon as possible)" (Malak, female family caregiver, provides care for 5 years)

> "I have a feeling my diagnosis was mistaken (laughing) ... Before that my body was swollen and when I was admitted to hospital, they gave me diuretics and when I took them, I returned home thanks to Allah ... After that, I left the kingdom and travel to Jordan, I did not tell the doctor that I was started on dialysis and told them I just needed to do some laboratory tests. They told me that my lab results were good, and I asked them about the
result of the x-ray I did. The doctor told me it was fine, then I told him that the physician in Saudi Arabia told me that I needed dialysis. He told me that I did not need dialysis but Alhamdullah on everything" (Noor, female ESRD patient, 6 years on HD)

However, doubt and denial over the CKD diagnosis could persist for many years, according to Ahmad, who denied that his wife Noor had CKD when she was diagnosed, which led him to seek another opinion even after his wife had been on HD for years:

> "... Two years ago, she had this condition (the dyspnoea), and she was admitted to the hospital, and I mean I say that her kidneys did not work, suddenly she suffered from a dyspnoea, they gave her a diuretic, her kidneys began to work as normal for two years, she became healthy and not suffering from anything ... It has been six years and she is still on renal dialysis and until now I am not convinced that she has Renal failure" (Ahmad, male family caregiver, provides care for 6 years)

Reaction to Dialysis: This subtheme described how participants reacted differently towards starting dialysis, particularly when they were first informed about it. The participants' experiences with commencing dialysis, particularly HD treatment, were associated with fear of treatment failure, rejection dialysis treatment, and denial, and fear of death. For example, Reem had a negative perception of HD treatment before starting it due to her previous negative experience with PD. However, that perception changed over time. In Sara, Noor and Ahmad's cases, they refused to start dialysis at the beginning after diagnosis. Noor and Sara rejected HD treatment due to the sudden diagnosis, whereas Ahmad rejected it partly due to his denial and disbelief about his wife's diagnosis. Moreover, Sara and Noor had the same thoughts about facing mortality after being diagnosed with CKD, but expressed or manifested their death feelings differently. Sara began fearing death after her dialysis sessions began, but Noor expressed her fear of death due to her family, particularly her children, who influenced her decision to undergo dialysis. Meanwhile, Noor, Sara and Reem reported accepting dialysis after recognising the importance of HD treatment and experiencing treatment over time. This perception was not shared by Ahmad, who continued to deny the CKD diagnosis and HD treatment for his wife. As described in the following statements:

"I remember that time (when the doctor told us about starting dialysis), me and my mother refused. My mother said no to haemodialysis" (Sara, female ESRD patient, 7 years on HD)

"My wife went there (emergency department) not even thinking about the dialysis, she did not consider it, and when the doctor came and discussed with her, the dialysis started – I have not accepted and I am not convinced ... I am not convinced that she should be on dialysis ... she does not need dialysis, in my opinion..." (Ahmad, male family caregiver, provides care for 6 years)

"... I was also afraid of dying (I ask forgiveness of my God) (laughing) since I have my husband and kids ... so, I made my decision to speed it up ..." (Noor, female ESRD patient, 6 years on HD)

Patients who accepted treatment frequently were motivated by the progression of their condition and their treatment experience over time:

"Now, when I discuss my health condition with the doctor, he tells me that my kidneys are shrinking (became smaller in size), and it is necessary to remain on renal dialysis. Now, I feel better than before thanks to Allah" (Noor, female ESRD patient, 6 years on HD)

"... Even if the experience was harsh at first (meaning when started HD treatment), and my mood was a bit tired, but with the passage of seven years since the start of the experience, I got used to it" (Reem, female ESRD patient, 8 years on HD)

The Role of Islamic Faith in Coping with Chronic Kidney Disease and its Treatments: This subtheme emerged from participants' descriptions of how they accepted and coped with CKD to handle the long dialysis journey. Participants discussed coping with the disease through the Islamic faith as a strategy. The participants were all Muslims who professed that Allah (Allah is another name for God) is the source of all power in the universe, and they have strong faith in Allah. For example, being in a stressful situation led them to use their faith as a coping mechanism by thinking and trusting in God. Sara believed that CKD was a test from God, while Noor and Ahmad believed that HD was a blessing from God. In Ahmad and Noor's cases, they

described some acceptance of the disease as they believed that everything that happened was caused by Allah, the creator, and must be accepted. The participants expressed further insights as follows:

> " The doctor told me that it was not the first nor the last disease, but God put me in an exam. In addition, I must be patient and God will help me to find a donator ... My mother said the same too. She consolidated me and told me to trust God and do it (meaning dialysis)" (Sara, Female ESRD patient, 7 years on HD)

" Of course, being on dialysis is exhausting but it is a blessing from Allah". (Noor, female ESRD patient, 6 years on HD)

"... That is because this is a chronic disease. Therefore, there is no solution but transplantation after Allah Almighty is capable of everything..." (Ahmad, male family caregiver, provides care for 6 years)

Moreover, during the interviews, participants described other ways they coped with and accepted CKD. All participants responded with the words 'Thank God' and 'Alhamdullah' when asked about themselves or their loved ones. This can be translated to mean praising and thanking God for everything and acknowledging acceptance of everything happening to them. Saudi culture emphasises this attitude, and Allah rewards it. All participants were familiar with this religious language, which had been used during consultations at every stage in their disease journey, such as when they were diagnosed, tried dialysis for the first time, experienced complications, switched modalities and made decisions, even while experiencing fear or concerns about their future care, plans or death.

Theme 2: Perceptions of Chronic Kidney Disease

This theme represents the participants' level of knowledge and awareness about chronic kidney disease, symptoms, causes, risk factors and treatments, and includes three subthemes: (1) participants' knowledge about chronic kidney disease; (2) awareness and perceptions of chronic kidney disease's causes and (3) participants' prior knowledge of chronic kidney disease and its management.

Participants' Knowledge about Chronic Kidney Disease: In this subtheme, the participants described their level of knowledge and awareness of CKD. When the participants were asked what they knew or understood about CKD or its symptoms, they generally all had limited knowledge of CKD and its symptoms and treatment. Varying knowledge and awareness levels were found among the participants. For example, Noor believed CKD meant her body contained toxic fluid that wasn't being expelled. As for Sara, she only knew about the CKD symptoms that she experienced and their treatments. Ahmad's knowledge was limited to dialysis, and he thought CKD was an asymptomatic condition. Reem, whose CKD was congenital, had a better understanding of her condition and knew about the causes and treatment. As they reported:

"The information is that the dialysis is intoxication in the body. I mean regarding urine; I am still capable of that, but I cannot get rid of everything in my body (toxins). The collection of fluids does not all leave the body. I mean I have toxins in my body, that is all I know" (Noor, female ESRD patient, 6 years on HD)

"To be honest, I was young, and I did not know anything... Renal failure means...silence... But when I grew up a little bit, I knew that when my feet are swollen and my pressure is high, I am not well. In addition to the low pressure that tells me that I am not in good health ... I only know about dialysis is that there are two types, and that transplantation is the best solution" (Sara, female ESRD patient, 7 years on HD)

"I swear, kidney failure what do I know about it? – I know about dialysis only ... Kidney failure has no symptoms" (Ahmad, male family caregiver, provides care for 6 years)

"Kidney failure, of course, is a chronic disease, which is a congenital defect that occurs from birth or due to Turner syndrome. As for dialysis, it is a bit tiring and includes complications just that. There are two types of disease treatment or dialysis treatment: peritoneal dialysis and haemodialysis" (Reem, female ESRD patient, 8 years on HD) Awareness and Perceptions of Chronic Kidney Disease's Causes: In this subtheme, participants' varying knowledge about CKD causes was examined. When participants were asked specifically about their awareness of CKD causes, Sara, Malak, and Ahmad stated that they were unsure about the main causes of CKD. This concerned themselves or their loved ones. Only Reem knew the cause of her CKD – in her case, genetics. However, Ahmad had a misconception about CKD causes, believing that the doctor and medication were the main reasons why his wife has CKD. As stated in the following statements:

"I did not know the main reason at that time, but they told my mother that it was due to high blood pressure and high temperature ... they told me that I had urinary tract infection which affected that kidney, until the kidney failure happened ..." (Sara, female ESRD patient, 7 years on HD)

"... Turner syndrome causes many diseases, but I got kidney disease because of it ... Turner syndrome is a birth defect that causes kidney failure, especially in females, as it causes a chromosome deficiency that affects the kidneys ..." (Reem, female ESRD patient, 8 years on HD)

"Regarding the causes of kidney disease, only the God knowing that, but it is caused by doctor ... Most of the kidney failure is from medications and drugs. Nowadays, they say herbal medications cause kidney failure. I swear, our ancestors took these medicines a lot and used them to treat their diseases, and no one of them had renal failure, nor did they complain about the kidneys. Kidney failure occurred because of chemicals and various drugs" (Ahmad, male family caregiver, provides care for 6 years)

However, Noor and Ahmad neither were convinced nor accepted the explanations when their HCPs told them about CKD causes because of their lack of awareness of CKD risk factors:

" (I swear) they told me it was hereditary. Even though none of grandparent had renal failure or even underwent dialysis before ... No one in my family was on dialysis except for me. In the hospital, they told me that renal failure was due to hereditary factors, but some doctors told me it was due to Lupus erythematosus which affected my kidney functions" (Noor, female ESRD patient, 6 years on HD)

Participants' Prior Knowledge of Chronic Kidney Disease and its Management: In this subtheme, all participants, both patients and family caregivers, reported that they had limited knowledge of CKD and its treatments prior to starting RRTs despite all patient participants being at high risk of getting CKD. For example, Noor, Ahmad, and Sara stressed that they received no information about CKD and treatment options, particularly HD, prior to starting treatment. Due to sudden diagnoses and the start of emergency HD, their first encounter with HD was in the emergency room. However, Reem reported that she did not have enough knowledge or understanding of the dialysis process prior to the first session, particularly PD and transplantation options, due to her young age at the time. Consequently, these participants did not receive enough knowledge or education before starting their treatment to make informed decisions. As explained below:

"... When I went to the ER, they suddenly and directly told me about haemodialysis ... As I underwent haemodialysis for the first time, and I had no idea what the machine looks like... I did not know that dialysis worked like this since no one told me anything about dialysis before. I thought it was just two or three days and I would not have to do it again, I did not know that" (Noor, ESRD patient, female, 6 years on HD)

"In my first experience in the department (Peritoneal dialysis), I was not aware of the dialysis mechanism that fills my peritoneum with water, and this water stays for a long-time causing pain. I did not know that or why my peritoneum was full of water, why the water stays in it and then comes out. I had no idea, and they did not explain to me enough information..." (Reem, ESRD patient, female, 8 years on HD)

Theme 3: Participants' Experiences Communicating with Healthcare Providers

For this theme, the participants described their positive and negative experiences communicating with HCPs in both the emergency department and dialysis unit. The theme comprised three subthemes: (1) participants' reflections on initial discussions around

treatment options with healthcare providers; (2) information provision from healthcare providers and (3) missed conversations and information gaps.

Participants' Reflections on Initial Discussions around Treatment Options with Healthcare Providers: All participants stated that the main focus of their first discussion with their HCPs after diagnosis focused on the importance of dialysis, with the HCPs encouraging them to start treatment. Participants' initial discussion experiences were diverse. For example, Noor and Ahmad reported having negative feelings about their first conversation with their doctor, whom they felt was not honest with them. However, the situation differed for Sara and Reem, who expressed more positive feelings about their first discussions with their HCPs, either when they started treatment for the first time or when they shifted to another treatment modality. Sara had positive thoughts and felt more comfortable during her initial discussion with her doctor about CKD and dialysis. This relieved her fear and made her more accepting of her diagnosis and treatment. In Reem's case, she was satisfied after her discussion with her doctor. She also was satisfied with his decision to switch her from PD to HD treatment due to her PD complication. As mentioned in their statements:

> " For me it was not good (discussion) because it is an illness ... when I went to the (ER) the physician told me that the beginning when we were discussing the importance of the dialysis that I needed renal dialysis urgently and I need to agree otherwise complications could occur or even die... He told me about that the dialysis will be for 3 days after which the kidneys will get back to normal as they were. ... A week later, the doctor met me and informed me that it is necessary to continue haemodialysis for life. Silence ... It was bad discussion because they did not tell me the truth and lied to me" (Noor, female ESRD patient, 6 years on HD)

> "When he was discussing and talking to me about disease, I felt that it is not the most difficult thing, and it can be the easiest disease ... It was a very good discussion this doctor used to make me feel that I was doing well and that he did not make things difficult. ... That doctor helped me a lot at this time, and I became not afraid of dialysis. Everything was very good regarding that discussion. I do not know how he makes me feel comfortable with the words

he tells me every visit, every visit, not just one" (Sara, female ESRD patient, 7 years on HD)

Information Provision from healthcare Providers: In this subtheme, the participants reflected on the amount of information they received from their HCPs during their initial discussions about treatment options, their comprehension of that information and their interaction with HCPs. Regarding receiving information from HCPs, particularly doctors, Noor, Ahmad and Reem reported negative experiences receiving information from doctors. They alleged that their doctors gave them inadequate information about CKD and its management during their initial discussions about the decision to commence RRT. Furthermore, Reem reported receiving insufficient knowledge about PD due to her very young age. However, Sara argued that she obtained enough information about her CKD and dialysis from her first discussion with her HCP despite her young age. In their descriptions, they said:

"It was insufficient. They did not tell me any information. They just asked me to head to the dialysis unit and I did. They asked me to head to the operations room for the central catheter and I did with no information ... It was insufficient or no information at all (laughing). They just cared that I start haemodialysis (I swear) I benefited nothing from that discussion" (Noor, female ESRD patient, 6 years on HD)

" He (doctor) explained everything about the dialysis machine, and I saw the machine (HD). After that, I underwent the first session, and the nurse started the dialysis procedures to make sure if the catheter was working or not. At that time, I remember everything, despite my young age, he explained and did everything for me regarding haemodialysis" (Sara, female ESRD patient, 7 years on HD)

In terms of information sources, the participants described varying experiences while seeking information related to RRT. These included receiving detailed information via verbal communication from doctors, as well as written material, particularly on transplants. They also received practical training from watching videos of other patients, particularly for PD treatment. Aside from these, Noor, Sara, and Malak tended to use other sources, such as shared information from other HD patients concerning their own experiences during dialysis sessions, information from websites and information obtained for their loved ones from previous experiences with the disease:

"It was an oral discussion with my father and me. He did not give me any written information regarding haemodialysis and previous kidney transplantation. All the information we received was oral during a discussion with the doctor" (Reem, female ESRD patient, 8 years on HD)

"I learnt about the dialysis, its types and how it works from the other patients who started it before me ... I learnt everything regarding the dialysis from them not from the physician as he did not explain anything to me ... When I walked into the dialysis unit and saw the other patients next to me (during the dialysis session). That is how I became aware of the dialysis, and I learnt from the patients through discussions with them and with everyone what they felt or what they had" (Noor, female ESRD patient, 6 years on HD)

"As for peritoneal dialysis, I received information from one of the nurses responsible for peritoneal dialysis through experience or training ... I saw the nurse doing the peritoneal dialysis... I also watched videos...Before I started dialysis the nurse left me to watch a video of people installing the peritoneal device, but their faces are not clear, only their hands. How they hold the tools, put them on the table, clean them, and the nurse told me that you must clean the table that you will use. How to put the empty tube and explain how to install the tubes before the start of the dialysis session" (Sara, female ESRD patient, 8 years on HD)

Regarding interactions with HCPs, participants were asked whether they were able to ask their HCPs questions during their discussions. For example, Reem and Noor did not feel free to ask questions or share information during consultations with their doctors because of their health conditions at that time. However, Sara said she asked questions and interacted with her doctor. As they expressed all these experiences in the following statements:

> "I could not exchange information with him because I did not see the doctor. I did not see him because there was a curtain between me and him. I was on

the bed and my ECG was connected to me and I was tired at that time. I was tired at the time. My sister was with me, and he was supposed to talk to my sister and tell her everything (regarding dialysis), but he did not talk to her at all nor explain anything to us. He did not tell me what was going on with me, but he said to me quickly, you are sick. You have fluids on your chest, and you need to start haemodialysis now" (Noor, female ESRD patient, 6 years on HD)

"I was asking him questions; I was sitting with the doctor and ask him why this is happening and why that is happening. If this happens, what should I do, and if that happens, what should I do? In fact, until now I am asking about dialysis. For example, I ask if I experience knee or body ache on the second day (the second dialysis session). I ask the doctor why I felt pain in my knee or body. Ask during the dialysis or during the days when I do not have a dialysis session" (Sara, female ESRD patient, 7 years on HD)

Missed Conversations and Information Gaps: In this subtheme, some participants reported that shared information between them and their HCPs was lacking. Furthermore, they perceived missed opportunities for conversations. As a result of these missed opportunities, patients had difficulty thinking about and making informed decisions, as well as maintaining effective professional patient-health relationships. Noor, Ahmad and Sara reported several information gaps, including CKD management, dialysis types, catheterisation, dialysis complications and CKD's impact on their daily lives. Sara reported receiving no information about HD complications, but she did received information regarding PD, which was explained to her before she started her treatment. Only Reem reported receiving all the relevant information about CKD management and its complications. As described below:

"Our doctors do not explain to the patient. Regarding the treatment plan, for presenting the treatment plan, the doctor is supposed to explain everything (about their state of health and treatment) to them (patients). They are supposed to state the options; good and bad (treatment-wise), and what suits their condition ... He did not explain or provide me with any information but told me about the urgent need for haemodialysis and to go to the OR. I mean they did not explain what dialysis is or what I am washing off my blood, they just told me I have a haemodialysis session now and to go to the OR.... The doctor did not tell me that I can be hypotensive during the session, no he did not explain anything to me. ... Only when I refused the dialysis at the beginning, he told me what would happen if I did not start it immediately, that is all he told me ... he did not explain anything regarding its effect on my daily activity" (Noor, female ESRD patient, 6 years on HD)

"He (doctor) did not (explained the renal dialysis treatment type). He just told me that three sessions of haemodialysis and did not explain anymore. He did not talk about anything (dialysis type) he just told us that it was necessary to undergo catheter insertion in the same day or day surgery. Then, she would undergo another surgery for catheter which required to admitted to surgical ward department in hospital. This is what he told us.... No, he (doctor) did not discuss anything with us and did not tell us anything (complication of the HD)" (Ahmad, male family caregiver, provides care for 6 years)

"No, they were not explained to me (complication of HD) before starting but after a while of starting it. That time, I was at the emergency department and the doctor rushed me to get admitting to the hospital directly. I learnt it after starting dialysis and no one taught me anything before it ... He explained what it is (PD), and told me that it is very easy, I can do it anytime, and I do not have to go to hospital three time weekly to renal dialysis centre. He said that it was very easy and showed me a video from hospital" (Sara, female ESRD patient, 7 years on HD)

"He (doctor) told me that there are complications, but they are milder than the complications of peritoneal dialysis that I have tried... He told me that there are complications that will occur during haemodialysis such as low blood pressure, feeling dizzy and having convulsions" (Reem, female ESRD patient, 8 years on HD)

Theme 4: Opportunities to Discuss Future Care Plans

This theme appeared while asking participants about their opportunities to discuss their future care or treatment plans with their HCPs throughout their disease trajectories. This theme comprised two subthemes: (1) discussion about prognosis, future care plans and treatments and (2) anticipated or current concerns regarding future care plans.

Discussion about Prognosis, Future Care Plans and Treatments: This subtheme emerged when participants were asked about their opportunities to discuss disease progression and future health effects. They also described their experiences thinking about and discussing their future care plans and alternative treatments. Their responses were varied, as three participants highlighted the issue of not talking about disease prognosis and not thinking about future care plans and alternative treatments. Ahmad, Noor and Sara reported a lack of opportunities to discuss their disease prognoses in relation to themselves or their loved ones with their HCPs. They stated that their HCPs did not share any information with them about their conditions' progression or any impact on their health in the future. Furthermore, they indicated that they had not thought about future care plans, nor talked about them. However, they discussed the possibility of a kidney transplant as an alternative treatment option for their future care or treatment plans. Reem had the opportunity to discuss with HCPs her disease prognosis indirectly and consider her future care plan, including the possibility of kidney transplantation due to her current health condition while undergoing dialysis. As they expressed all these points in the following statements:

"None of the doctors told me anything about her (meaning his wife) future condition, how it would affect her health condition, or how her kidney failure would develop in the future" (Ahmad, male family caregiver, provides care for 6 years)

"He (doctor) did not tell me or ask me about anything in that regard (meaning future care plan), he only asked me to bring or (look for) a donor. He told me that at the same day I was started on haemodialysis or the second or third day on haemodialysis – to bring a donor and that is because I am young. I told him I agreed on that" (Noor, female ESRD patient, 6 years on HD)

"My condition was no longer the same as before due to thrombosis and catheter problems (cannot change its place), as well as almost constant inflammation or infection ... The more years I am on dialysis, the worse my condition gets and the more complications I have, which can affect the heart and many other organs. They told me that my case is an emergency, which means that a kidney transplant is needed as soon as possible. They put my name on the waiting list with the priority because my condition required it" (Reem, female ESRD patient, 8 years on HD)

In terms of alternative treatments, some CKD patients have options available, such as palliative or conservative care. These can be offered instead of RRT for many reasons, including when a patient decides not to accept dialysis, a transplant for kidney failure is not suitable for them or these treatments do not improve their quality of life. When the participants were asked whether they had been informed about or offered alternatives to dialysis, they all stated that they never were informed about nor discussed alternatives to dialysis for their future care plans. They only were informed about and offered RRT, either dialysis or a kidney transplant, with no other alternative therapies offered. As Reem noted:

"No, (doctor) did not discuss with me the option not to undergo dialysis or just gave me medication but he discussed with me and my father about types of dialysis or kidney transplantation, and the choice between them was obligatory" (Reem, female ESRD patient, 8 years on HD)

Thus, all participants, either at the beginning or during their disease course, were offered RRT. Switching between modalities was offered only if one treatment did not work well. No alternative treatment options – such as non-dialytic or conservative care, i.e., palliative or supportive care – were offered if their illness worsened in the future.

Anticipated or Current Concerns Regarding Future Care Plans: This subtheme emerged when the participants were asked during their interviews about the issue of their anticipated or current concerns about their future care or treatment plans, and what information they would ask concerning it. The participants reported varying concerns. Reem, Sara and Ahmad described their future concerns, including failure of treatment or catheterisation and worries about possible kidney transplantation. However, Noor argued that while she had no concerns or fears about future care in general, she did worry about doctors not telling her the truth. The participants experienced all these concerns over many years of receiving treatment. For instance, Reem expressed fear about the future, exacerbated by her previous experiences with dialysis failure and kidney transplantation. She was particularly concerned about the possibility of future kidney transplantation and the use of anticoagulant treatment to protect the transplanted kidney. As she noted:

"I have some concerns now. I am afraid that what happened with haemodialysis and peritoneal dialysis and kidney failure would repeat again in the future. It is true that I would prefer a kidney transplant for a second time as soon as possible, but I am afraid that it will fail as before. My haematologist told me that I should take this anticoagulant treatment for life, even after a kidney transplant. The blood viscosity increases, and does it affect the health of the kidneys or cause failure of a new transplanted kidney?... I am just afraid if I do a kidney transplant and I will not be on dialysis, I do not know, I will miss the anticoagulant treatment dose and cause kidney failure again" (Reem, female ESRD patient, 8 years on HD)

Sara expressed concerns about catheterisation failure because her doctor said her arteries were very weak and could not handle HD, as she had no other places to insert a new catheter. She feared the prospect of a second kidney transplant; therefore, she developed a strategy to protect her hand catheterization and chose only gentle nurses to protect her current catheter. As she noted:

> "Many (meaning fears and concerns) to be honest. Thanks to God. I am afraid that the catheter fails, I am afraid that anything unexpected happen. In order not to tell me that I have no choice except transplantation again. The fears increase as my body would not be able to bear catheters and I do not have suitable arteries for catheterization. I try to protect my hand as much as I can from the nurses because I know that I have not another treatment except the

transplantation, and I do not want to enter the OR again ... I pray to God that my catheter that in my hand will last longer. I choose nurses carefully during dialysis sessions, and I know a nurse that deals carefully with it in order not to feel pain during dialysis sessions. It is important to protect it'' (Sara, female ESRD patient, 7 years on HD)

In Ahmad's case, he had concerns about his wife's future care in terms of finding a kidney donor for her, but he also lacked detailed information about the kidney transplantation process. As he noted:

"Regarding the transplant, it has not happened it and we have not got any donors – I did not get donors, nor did I find myself. I applied to donate to my wife, but the tissues did not match, and right now, there are no donors for her... I have some information that I want to know, for example, about the method of transplantation. Or how it fits with the person (tissue match) and how it is done. I have no fear of transplantation, but I would like to know how it is done" (Ahmad, male family caregiver, provides care for 6 years)

However, Noor alleged that they had no fears or concerns about her future care plan and would not ask about or discuss any information with the doctor about her current or future health condition. She recalled previous experiences of not fully understanding her health problems, possibly because she believed that doctors did not tell her the truth about her health condition. Furthermore, each doctor had a different opinion, leading to her becoming confused and feeling mistrust towards doctors during discussions. As a result, she was reluctant to speak with doctors and noted:

"I do not have fears. The most important thing for me is to get cured, I have no fears and Alhamdullah for everything... I have nothing to ask about, but I prefer and want the doctor to tell me the complete truth about my health condition (laughing) when talking to me. I mean each doctor lies and it is impossible for them to tell you the truth (Laugh). For example, my chest operation (central catheter they use for dialysis) each doctor told me a different reason; one told me it is because of my tissues, another one told me I had a problem with my veins and the last one told me I had an inflammation and prescribed some medication for me. I do not know which one of them is lying and which one is telling the truth. I just wish they are lying about what they tell me that is all I wish" (Noor, female ESRD patient, 6 years on HD)

The fundamental issues of the participants' inability to obtain information and explanations about the progression of their health conditions, express thoughts and discuss future care or treatment plans and related concerns were exacerbated by their doctors' absence during their dialysis sessions unless they specifically requested it. Noor and Malak emphasized this issue, noting that even when a doctor was present, the conversations' main focus was on lab test results, rather than conversations about future care plans and treatment options. Furthermore, their concerns were not addressed unless their HCPs initiated a discussion about their problems; otherwise, they had limited opportunities to raise additional concerns. As they stated:

> "Since the start of haemodialysis, I have not seen the physician. He did not come to explain anything to me. No future treatment plans or alternative options aside from the dialysis were explained to me ... The doctor does not usually come unless we ask or request him ... The doctor comes only if it is the time of lab results to inform me about it if it is good or not, or to ask me about shortage of medications or if I medications to be given to me in case I ran out of them" (Noor, female ESRD patient, 6 years on HD)

Theme 5: Decision-Making Regarding Dialysis or Renal Replacement Therapy

This theme emerged as participants described their decision-making processes and experiences around commencing renal replacement therapy, comprising five subthemes: (1) decision-making experiences; (2) opportunities to select preferred treatment options; (3) decision-making preferences; (4) perceptions of influences regarding decision-making and (5) feelings towards decisions made.

Decision-Making Experiences: This subtheme examined participants' varying experiences with decision-making types that the patient was exposed to and their degrees of involvement in their decisions, which varied. For example, in Reem and Sara's cases, they were very young or in adolescence, respectively, when they were diagnosed, and they reported how their

families made treatment decisions for them. However, this was different in Noor's case, having been diagnosed as an adult. She reported that the decision to start dialysis was her own responsibility, but that it was shared with her family. Ahmad, Noor's husband and caregiver, echoed his wife's views and felt responsible for her treatment decisions:

"I did not make any decision regarding peritoneal dialysis or kidney transplantation, but my father made the decision on my behalf because of my young age at the time" (Reem, female ESRD patient, 8 years on HD)

"Only me and my sister who made the decision (meaning start HD) quickly that time" (Noor, female ESRD patient, 6 years on HD)

Furthermore, Noor and Sara commenced dialysis because of emergency decision-making when they suddenly discovered they had CKD in the emergency department. As Noor noted:

"All (meaning patients) who undergo haemodialysis, undergo the process in the emergency department" (Noor, female ESRD patient, 6 years on HD)

Moreover, during their disease journey, Sara and Reem were exposed to situational decisionmaking. This decision was made either by the patient or their family, or by the doctor based on their health condition because their current treatments were not working effectively, and the patient suffered from complications. Therefore, their HCPs discussed switching to another modality. As Sara reported, her decision to switch RRTs was shared by family members who accompanied her during discussions with HCPs. However, Reem reported that the treatment decision, particularly when she switched to HD after suffering from PD complications, was her doctor's decision, not hers:

> "The decision, I told you, came when I became ill. After I got tired of peritoneal dialysis, I told the doctor that I wanted haemodialysis ... The hospital (doctors) left me completely responsible for the decision – they would make me sign the papers, so they were free of responsibility. I mean, they let you decide on your own, either you choose this, or you choose that... doctor does not help you make the decision easily, he gives you the options and asks

you to choose and puts the responsibility on you ... the doctor does not interfere in my decisions..." (Sara, female ESRD patient, 7 years on HD)

"Because I got an infection from peritoneal dialysis, and I am suffering from It ... As a result, the doctor told me a forced decision that there was no other solution, he said now, you must be on haemodialysis...It was a right decision from the doctor who decided the haemodialysis for me, and I always say alhamdulillah he decided the haemodialysis for me, because I feel more comfortable now...The decision for haemodialysis was obligatory from the doctor, but alhamdulillah I felt comfortable, and I always thank Allah that there is haemodialysis" (Reem, female ESRD patient, 8 years on HD)

The extent to which participants' involvement in HCP discussions and decision-making was varied. For example, Sara felt completely involved in the decision to start dialysis and switch between RRTs, but Reem felt that she had not been involved in the kidney transplant and PD decisions due to her young age at the time. However, she was involved when she switched to HD treatment later. However, Noor felt that she was not fully involved due to time constraints:

"Yes, I was involved enough (meaning in making decision)" (Sara, female ESRD patient, 7 years on HD)

"Regarding peritoneal dialysis and the first kidney transplant, I did not attend those discussions ... I was included (in decision making for HD). Because of my poor health, I wanted any alternative treatment rather than peritoneal dialysis to feel more comfortable" (Reem, female ESRD patient, 8 years on HD)

"I did not feel sufficiently included at the time of the decision, because they did not give me the chance to think, make my decision and none of that" (Noor, female ESRD patient, 8 years on HD)

All participants had family members involved in their decision-making on treatments, but they took different positions on issues or had different experiences with decision-making. **Opportunities to Select Preferred Treatment Options:** In this subtheme, participants' experiences having the opportunity to select their preferred dialysis modalities varied. For example, Noor and Sara reported that they did not have the opportunity to select among dialysis options and viewed dialysis as inevitable, not merely one option among many. Ahmed, Noor's family caregiver, expressed views similar to those of Noor and Sara. Their HCPs did not offer treatment options, and they had limited decision-making opportunities. In Reem's case, the situation was different. She reported that her family was able to choose between HD or PD because she was young and studying at school. As they described:

"No, he did not set the options, the doctor settled on haemodialysis, because I was sick, and I was not able to breathe well... The doctor was in rush, and the only available option was haemodialysis to get better.... After month or more after I got better, the doctor told me about the second option which is peritoneal dialysis" (Sara, female ESRD patient, 8 years on HD)

"The doctor discussed it with my father, and he was given a choice between haemodialysis and peritoneal dialysis. He stated that peritoneal dialysis is the best option for me at this time due to my young age... my mother and father discussed with the doctor about dialysis, and he told them to start peritoneal dialysis. Because of my study conditions, we agreed to do the peritoneal dialysis at home, so that I could be with them at home..." (Reem, female ESRD patient, 8 years on HD)

Decision-Making Preferences: This subtheme expressed the participants' preferences for collective or individualistic decision-making. In Saudi culture, family members play a significant role in discussing treatment options and supporting and understanding each other. All the participants reached their decisions by sharing them with their families, which they preferred, particularly when it came to deciding on dialysis. Families' involvement and influence in decision-making varied considerably, but the family always played some role in supporting the patient and/or making decisions about care and treatment. Family influence on decision-making includes decisions made with family members and/or for family members. As for decisions made with the family, Sara, Ahmad and Malak stated that the decision to start dialysis was made with the help of a family member who shared their

decision. Although Noor was supported by her sister in her HD decision, she added another family involvement level because she made her decision for her family. She explained that she was afraid of death, as she would not be with or see her children, so she chose dialysis to be with her children. As they described it in the following statements:

> "The decision I took was between my family, my mother and the doctor were not a difficult decision ... if I said I wanted this thing or chose something, and they felt that this matter is good for me, they agree with me, but if they see that it is not good, they convince me, explain to me, and discuss it with me ... my mother and my family made the decision as we think that dialysis is better" (Sara, female ESRD patient, 7 years on HD)

"I joined her (his wife), and her sister as well to start dialysis. Only her sister was with her that time" (Ahmad, male family caregiver, provides care for 6 years)

"... I was too scared and afraid from death (as the doctor told me) I thought I would not see my kids or I would not be able to see them again, so I made my decision quickly and agreed to haemodialysis" (Noor, female ESRD patient, 6 years on HD)

Moreover, the participants agreed that families have played an active role in their decisionmaking processes and in providing care. The following statements are examples of taking responsibility for enacting patients' wishes, which encompass decision-making shared with family members, attending medical appointments to ask questions by accompanying patients and supporting them throughout their illness journey, and assisting in decision-making and supporting these decisions. As illustrated below:

> "My father was the person who was with me the most and the one who knew the most about my medical condition. ... My mother was the one who helped me during the peritoneal dialysis at home" (Reem, female ESRD patient, 8 years on HD)

> "My sister was the one to support me until I made my decision, but this support was because of fear. So, she spoke to me and advised me not to keep

thinking until the next day. She advised me to start haemodialysis as soon as possible, and after 3 days I would be healthy and there would be no need for haemodialysis again. Her support was not enough, but she told me that it was a must to start haemodialysis, and she would be my side" (Noor, female ESRD patient, 6 years on HD)

These interviews clearly indicate that families exerted a powerful influence over patients' decisions as a result of negotiations between them. The family plays another critical role in the decision-making process by providing emotional and psychological support to help reassure and comfort patients. Unlike HCPs, who mostly only provide information, families offer substantial emotional support. As Sara noted:

"I was young (when diagnosis), my mother was with me and used to tell me to be patient... She told me that it would not be difficult if I underwent dialysis. My mom consolidated me and told me to trust God and do it (dialysis) to relieve my symptoms ... She told me to put my trust in God and wait for someone ...we would talk to them (doctors and the family) and get you a transplant or a donor (undergo a kidney transplant), ... She comforted me with these words" (Sara, female ESRD patient, 7 years on HD)

Perceptions of Influences Regarding Decision-Making: This subtheme emerged from participants' experiences when confronted with the decision to begin treatment. Participants were exposed to a wide range of factors that influence decision-making, including factors that either facilitated or hindered it.

Facilitating Factors: Various factors helped participants decide to begin treatment, including HCPs' role and external pressures on decision-making. Furthermore, their families' role was examined in the previous subtheme. In terms of HCPs' role, Sara, Noor and Reem noted that their doctors' role was to help them make decisions not only about starting HD treatment for the first time, but also when they considered switching to another RRT, as they relied on discussions with their doctors and the trustworthiness therein. However, Noor and Ahmad made negative comments about their doctors' role during discussions in terms of how they

perceived that the doctor frightened the patient so they would decide quickly. As stated in the following statements:

"... The doctor helped me at the beginning. I mean, when I had dialysis for the first time, in the transplantation and in switching between types of dialysis ... He made things easier for me" (Sara, female ESRD patient, 7 years on HD)

"The fear was the only factor that pushed me to reach my decision quickly, and to start haemodialysis. Only fear, when the doctor frightened me, I decided to undergo haemodialysis till I recover... I mean they frightened me, and I did not expect that. They frighten us to agree quickly, and because of that I agreed ..." (Noor, female ESRD patient, 6 years on HD)

In terms of external pressures on decision-making, in this study, some participants reported a variety of perceived pressures influencing their decision-making, while others did not. This study examined two pressure subcategories: situational and social. In terms of situational pressure, Noor, Sara and Ahmad reported how the doctor in the emergency department pressured them to accept dialysis, so they did not have enough time to make informed decisions. They perceived that this pressure forced them to accept dialysis without sufficient time to consider options:

> "I was at the Emergency department and the doctor rushed me to get admitting to the hospital directly...the doctor was in rush, and the only available option was haemodialysis to get better, lower blood pressure, and decrease fluid overload. The shortness of breath does not relieve except by dialysis... I was sick and my mother was saying "quickly, quickly", she agreed, and I had the catheter operation carried out immediately" (Sara, female ESRD patient, 7 years on HD)

"In fact, there was pressure, I mean the doctor said there are toxins, and it is imperative to start dialysis ... tells her that if you do not start dialysis and do the dialysis session, you will lose yourself. That is what the doctor said. It was a rush. It was a rush on dialysis decision, signed papers and started the dialysis session" (Ahmad, male family caregiver, provides care for 6 years) In one case, a mother family caregiver who was the decision maker for Sara when she was very young found herself obliged to accept dialysis. She knew that Sara's condition would be critical without it and said the doctor explained Sara's situation this way: Without dialysis, either she gets dialysis or fluid will build up, and she could fall into a coma. The caregiver felt that this left her with no other choice but to accept dialysis for Sara, who then started her HD treatment. Furthermore, Sara and Reem experienced other situational pressures due to their various other health conditions. This made such decisions even more crucial, particularly when they considered switching treatment modalities. As they expressed:

"... My health condition helped me make the decision (because of infections or inflammation due to peritoneal dialysis) ... It was a short time, as my father decided and agreed at the same time as the discussion ... It was almost an obligatory decision... I would have preferred a new treatment method other than peritoneal dialysis based on the experience. I mean I would have preferred there was another method other than peritoneal dialysis because I was really tired and wanted to rest" (Reem, female ESRD patient, 8 years on HD)

From the perspective of social pressure, in Ahmad's case, societal obligations affected his sense of responsibility. Generally, in the Saudi context, decision-making previously was viewed as a gender issue. The guardianship system had permeated the Saudi culture, in which women's autonomy remained limited when it came to health care provision because health care facilities required permission from male guardians to administer care to women. In Saudi culture, most women relied on their male relatives for such decisions, including fathers, brothers, sons and/or spouses, who were responsible for making such decisions and signing medical papers. However, this situation recently has changed, as women now can make their own decisions and sign consent forms except with invasive procedures. In Ahmad's case, I got the impression that he was experiencing pressure to accept dialysis due to social factors. His wife asked him to sign a consent form for her to start HD, which led to him blaming himself later. He viewed it as his responsibility to sign the consent form because he was her spouse. As he stated:

"They (my wife and her sister) returned to me, asked me to sign the dialysis paperwork and I said no. The doctor informed me that he would sign that he was out of responsibility, or I signed on my responsibility (I did not agree to start dialysis) and that the doctor is not to be held responsible... But my wife signed and convinced me... She informed me and asked me to sign the papers to start the dialysis... and I came back and agreed and signed" (Ahmad, male family caregiver, provides care for 6 years)

However, Sara noted that she did not feel any pressure when she made her decision, either when she started dialysis for the first time or when she switched treatment modalities. As she stated:

"No, there was no pressure at all. On the contrary, all decisions were in my favour. I told you there is no solution except for dialysis, and the only solution after dialysis is transplantation" (Sara, female ESRD patient, 7 years on HD)

Barriers to Decision-Making: This was examined when participants were asked about their experiences with hindering factors that caused them to feel hesitant about making decisions. Participants' experiences with hindering factors varied. For example, Noor and Ahmad stated that a lack of knowledge about dialysis options, symptoms, benefits and risks made them hesitate or postpone deciding whether to start treatment. Reem said that although she did not report any hindering factors, their lack of knowledge about dialysis generated unrealistic expectations about what it would involve. However, Sara stated that she did not encounter any factors that made decision-making difficult. The following statements clarify this:

"... The lack of information regarding treatment options which makes decision-making more difficult.... They (doctors) are supposed to tell you, they are supposed to sit with me, explain, provide me with all the information and then decide. They are not supposed to freak me out, ask me to go to the operating room and have the catheter directly" (Noor, female ESRD patient, 6 years on HD) "Yes, this is what the doctor is supposed to say. There are supposed to be four or five doctors participating and conducting tests for the patient, and then determining whether the patient needs dialysis or not" (Ahmad, male family caregiver, provides care for 6 years)

As Ahmad stated in the preceding quote, when asked whether he thought information from their doctor was lacking about dialysis types, side effects and risks that might contribute to this difficult decision, he answered yes.

> "No, there were not any factors that made the decision difficult. Just in the beginning, the dialysis catheter was a rough experience. I had a local anaesthetic, so I was observing how the catheter worked and how the blood moved through it...But when I had the catheter procedure in the neck and skin, I felt a severe pain, I did not expect that there would be pain and suffering psychologically, and I used to say I was for how long, but I feel that I did not expect that" (Reem, female ESRD patient, 8 years on HD)

"No, there were no factors that made it difficult for me to make a decision. I do not have factors like I told you unless Allah allows something to happen. I am afraid something might happen, and I made a decision that was more difficult than the first one" (Sara, female ESRD patient, 7 years on HD)

Feelings Towards Decision-Making: This subtheme was generated from participants' descriptions of their feelings towards the decision to initiate dialysis. Participants described different emotions and feelings before and after such decisions were made, expressing a sense of shock, fear, hesitation and regret associated with making dialysis decisions.

Prior to or During Decision-Making: Noor reported feeling shocked when informed that she must begin dialysis. She expressed her feelings at the time she made her informed decision to start treatment, noting that she was afraid, shocked and started crying when she saw the dialysis unit. Sara was terrified during dialysis sessions because she did not understand the purpose of dialysis and was worried and cried during every session. However,

Reem experienced different anxieties, as she worried about complications from HD treatment based on her negative experiences with PD treatment. As they expressed:

"... The decision to start dialysis was shocking to me because I only went to the hospital for my Lupus erythematosus ... I was scared, and I wanted to cry that time. I was scared because I do not know what dialysis is, how they are going to wash my blood, how the blood comes out of my body and how the blood goes in. I was wondering what they put (insert) in my chest. At first, I did not know anything, and I got shocked when I walked into the dialysis unit" (Noor, female ESRD patient, 6 years on HD)

"Before the start of dialysis, I had great fear. My mother will tell you that we hesitated a lot after we spoke and discussed with the doctor... I had a fear. I mean, I wondered why I was there on dialysis, why I came to the hospital, why I was on haemodialysis and suddenly got sick, I used to cry every day " (Sara, female ESRD patient, 7 years on HD)

"I was only afraid that the complications of haemodialysis that the doctor had told me would get more severe, and my body would not accept haemodialysis like peritoneal dialysis" (Reem, female ESRD patient, 8 years on HD)

Post-Decision-Making: Some participants expressed regret over their decision to start dialysis. For example, Reem stated that she felt it was not the right decision and that she had not had enough time to think about the decision. She then blamed herself for agreeing to begin HD. Furthermore, Reem expressed regret over her previous decision to undergo PD after her negative experience with it. Another example was Ahmad, who expressed severe regret over his wife's decision to begin HD treatment. Other participants, such as Noor and Sara, did not explicitly express regret, but they expressed themselves in ways that indicated regret, such as talking about God, deep sighs, changes in voice tone and laughing during their interviews. The participants' regretful feelings were assessed indirectly through qualitative data collection, but the researcher avoided using the word 'regret' to minimise any influence on the participants. As illustrated in the following statements:

"... I almost thought at first that I had made a mistake in deciding to start the haemodialysis, and I blamed myself for agreeing with the doctor even though the discussion with him made it easier for me ... I did not have enough time to make the decision and it was obligatory decision. So, I did not make the right decision" (Reem, female ESRD patient, 8 years on HD)

"If I had refused this thing at first, maybe she would not have needed dialysis. If I just refused this from the start but it was a doctor's order. Maybe she did not need dialysis... if the decision was up to me, I would have said no to the hospital and to the doctor, and maybe she would not have needed dialysis until this day...This decision was imposed upon us from the beginning. We should not allow her to start dialysis" (Ahmad, male family caregiver, provides care for 6 years)

Theme 6: Recommendations to Improve the Decision-making Process

This theme emerged when participants were asked about how the decision-making process could be improved. The participants offered several recommendations, which comprised the following six subthemes: (1) Who should lead and be involved during the discussion?; (2) improvement of communication and relationships with healthcare providers; (3) improvement of patient knowledge and type of information; (4) improvement of sources of information; (5) improvement of the decision-making time frame; and (6) improvement of care practices.

Who Should Lead and be Involved During the Discussion?: In this subtheme, participants expressed their opinions on how to improve their previous experiences with DM in terms of who should hold the discussion, who should be present and who should be consulted. Noor believed that a dialysis consultant or someone with experience with dialysis should lead discussions with patients. Reem agreed, noting that a specialist must consult with the patient so that the patient is less afraid of dialysis. Furthermore, both asserted the importance of involving their family members to discuss and consult with them on their decisions. However, Ahmad had a different view, preferring to discuss his wife's case with more than one doctor prior to making decisions. As described in the following statements:

"It needs to be with a dialysis consultant. I mean, someone who knows about dialysis. It is better to be someone who has experience with dialysis. I mean, they ask him, and he responds (Laughing). I mean, now I am supposed to undergo haemodialysis, they are supposed to tell me that somebody else underwent haemodialysis, go to this person, and ask him how this go, and about everything related to it ... It is better to be with family members. ... The patient is not supposed to make the decision himself, but it is necessary that he consults someone (meaning the family), I mean, family would be better than me in making the decision" (Noor, female ESRD patient, 6 years on HD)

"I do not listen to only one or two doctors, but there are supposed to be 5 or 6 doctors, and then I think about using this treatment ... the most important point is that we do not make our decision based on only one doctor (but we consult more than one doctor)" (Ahmad, male family caregiver, provides care for 6 years)

Improvement of Communication and Relationships with Healthcare Providers: This subtheme presented the participants' recommendations from the perspective of patients and their family caregivers regarding communication and relationships with HCPs. Malak and Noor made a few suggestions on how to improve patient-HCP communication, as well as the relationship between patients and HCPs in general. They also recommended that a doctor be present during dialysis sessions so that they can discuss their conditions and express concerns. Malak also indicated that how nurses and doctors handle patients' needs improvement, such as being an active listener, persuading patients and considering their psychological conditions. Furthermore, Sara stressed the importance of discussions with doctors to help her with decision-making. As she noted:

"I mean the problem is communication only ... I mean, honestly, my sister knows that if she asks to see some doctors, she will not benefit, so she does not ask them, even if she is tired and her condition is bad, because if he comes, he tells her something that is not persuading. This is the problem in communication that we want to improve ... The nurse or the one who deals with the patient must consider the patient's circumstances ... She is supposed to try to listen to the patient in a good way, to pay attention to the patient's opinion and to be able to convince him" (Malak, female family caregiver, provides care for 5 years)

"The doctor should come to us (the patients) and evaluate our condition. I mean, we need to discuss our health condition with him, and tell him what is wrong with us. He should come anytime, not only when we are sick. I mean, at the time of haemodialysis. I wish that the doctors attend the haemodialysis session" (Noor, female ESRD patient, 6 years on HD)

"Everyone makes his own decision. But imagine that doctor does not help you make the decision easily, he gives you the options and asks you to choose and puts the responsibility on you. But some doctors make it easier for you to choose by discussing it with you, as I told you earlier about Doctor A. I mean, make things easier for you, say things like do not be afraid, this is a test from Allah, everything is a mercy and do not be afraid, Allah willing everything will be fine. But some doctors, for example, only give me options and tell me that you have nothing except this option" (Sara, female ESRD patient, 7 years on HD)

Improvement of Patient Knowledge and Type of Information: In this subtheme, participants suggested increasing the amount of knowledge shared with them about CKD disease, particularly information about dialysis, its benefits and complications. Noor, Ahmad Reem asserted that receiving such information must be and done prior to undergoing dialysis. This would help convince them more effectively about such treatment and facilitate their decision. As Sara recalled, there was enough information at the time the decision was made. The information provided to her was not sufficient for her to make an informed decision after experiencing RRT for more than seven years now. As she noted:

> "Provide us with good and enough information, because I did not understand the information, they provide us with. I mean, they should tell us everything necessary before starting dialysis ... I mean to make the decision and I am confident of the sincerity of their words. I make my right decision, agree to it,

and start treatment. The doctor is supposed to explain to me what is going on, the time of haemodialysis, the machine of dialysis, and everything. He must explain to you what this needle is, this needle, and the fluids mixes here. He is supposed to explain everything. This is the most important thing I mean'' (Noor, female ESRD patient, 6 years on HD)

"I need the discussion itself to be improved. The doctor should explain in detail without rush. He should not make the patient to make his decision quickly... The doctor should explain to me the different ways of treatment, the different type of dialysis. For example, what is haemodialysis, what are its advantages and disadvantages, does it affect the patient, does it affect the patient's energy, does it affect organs other than the kidneys, does it affect the heart and more or less complications ... He must give the patient a detailed explanation, explaining in detail whether haemodialysis or peritoneal dialysis is better" (Reem, female ESRD patient, 8 years on HD)

"At that time (meaning make the decision to start dialysis treatment), the information was enough for me – I told you but now you are asking me again of I would say no" (Sara, female ESRD patient, 7 years on HD)

Improvement of Sources of Information: This subtheme emerged when participants were asked about resources that they preferred when seeking information about CKD and its treatment. The participants' modes of seeking information differed. For example, Ahmad, Noor and Sara preferred verbal consultations with doctors as their main source. Despite this, Noor noted that some patients were illiterate, and that their needs should be considered. Sara and Noor preferred using the Internet instead of more traditional methods, such as verbal explanations from doctors and printed materials, including educational booklets. However, Reem preferred printed resources. Furthermore, Noor sought information about dialysis from other people or patients who had experienced dialysis before:

"Haemodialysis specialist or another patient, or someone who underwent haemodialysis before who talks about dialysis and its benefits. Someone who talks and teaches us everything, explains everything about haemodialysis, and talks about the side effects haemodialysis causes, talks about your illness, and talks about everything ... For me, I can read. I mean written sources are good, I appreciate them. But some patients cannot read. So, it is supposed to be oral words, they need someone who talks to them'' (Noor, ESRD patient, female, 6 years on HD)

"Regarding the methods of education, the first thing that gives you an explanation about kidney failure was the doctor, in addition to the educational books at that time... Now, you can learn through a website the complications and the benefits of dialysis or what is peritoneal dialysis, its complications, these are all known by pressing a button. Previously, we mainly depended on booklets or doctor's speech..." (Sara, female ESRD patient, 7 years on HD)

" I prefer to be written, the brochures explain to me in detail about the pain and complications that occur to me, but I have not tried the videos before" (Reem, ESRD patient, female, 8 years on HD)

Improvement of the Decision-making Time Frame: This subtheme emerged when participants were asked whether they would increase the time between discussions with HCPs and deciding on dialysis. Reem and Noor preferred a longer decision-making period so they could contemplate and consult with others to make an informed decision. However, Sara stated that she had enough time to reach a decision and that she would not change the discussion with her HCPs due to her previous positive experiences with HCPs when discussing dialysis. She also had prior decision-making experience. Ahmad disagreed with this view, emphasizing that the most important thing was that the doctor should not start dialysis until everything is explained to patients sufficiently to convince them that dialysis was necessary. As expressed below:

"By giving me time to make the decision and tell me everything honestly. I mean, to give me the correct information. He should not tell me it is urgent without giving me an hour or two to think. For example, he should give me time to decide and talk to someone. He should not talk to me alone, but talk to any of my relatives, like my husband or my brother. He should give me a chance to discuss with them. They supposed to make the decision with me, not only me who make the decision alone and quickly ... I mean, the thing I want to improve the most is the time, to have a longer duration to think about the decision and to make it and to consult my family'' (Noor, female ESRD patient, 6 years on HD)

"No, (meaning she would not change time duration) I had enough time to make a decision ... my doctor was good, he was the best. I used to sit on the chair every time I came to visit him, he explained to me, trained me on how to use my medicines and told me not to come to the appointment without the medicine bag so he can check it. I mean, I do not wish to change anything because every time it was a first-time experience" (Sara, female ESRD patient, 7 years on HD)

Improvement of Care Practices: This subtheme illustrated participants' suggestions on how to improve care by standardising care practices for the patient prior to commencing dialysis. Reem and Ahmad believed that the doctors rushed through the discussion and decision process about dialysis, either for themselves or for their loved ones. Therefore, they called for HCPs to discuss alternative treatment options with patients, instead of merely pushing dialysis. Furthermore, they suggested conducting pre-dialysis tests and procedures to provide adequate clinical information to support decision-making. As Reem noted

> "The doctor should not make his decision quickly, nor should he rush without considering the necessary procedures and tests ... Somehow, doctors rush chooses the dialysis when the kidney fails, while there are other solutions like kidney transplant procedures. There must be a procedure. I mean to make an assessment to decide if the patient is eligible for dialysis or not. In addition to perform medical tests. I mean pre-dialysis tests.... They should confirm if the patient's body will accept haemodialysis or not. Also, the decision should not be made quickly, as there are two types of dialysis. What do you choose? You choose and start the dialysis. There must be a procedure." (Reem, female ESRD patient, 8 years on HD)

5.2 Phase 1B: Modified Systematic Review

The method of conducting the modified systematic review is described in Section (4.3.2) of Chapter 4. This section presents findings from a modified systematic review to examine, synthesise and describe evidence on ESRD patients or their families' preferences and experiences regarding ACP discussions and the DM process in the Muslim context. This review was necessary to provide a deeper examination of the issues under investigation in Phase 1A. This additional evidence synthesis was required to complement the limited number of participants recruited for interviews due to the COVID pandemic, providing complementary data to support the qualitative data gathered directly during Phase 1A. This was intended to be a systematic mixed methods review, but no qualitative evidence was uncovered, so the review included only quantitative data.

5.2.1 Review Results

5.2.1.1 Search Process Results

Altogether, 4,779 potential studies were identified through a systematic search of databases, including published and unpublished material. Furthermore, 201 publications were extracted from other sources through manual search techniques and reference lists. After removal of duplicates, 4,474 studies remained, which then were screened based on their titles and abstracts. Another 4,386 studies were excluded, primarily because they did not examine ACP in the Muslim renal context. This large number of excluded studies indicates the inherent challenges and difficulties in the search process, particularly in the area of renal disease in the Muslim context. The 88-remaining full-text studies were retrieved and assessed. Of these, 83 were excluded based on participants, study context and/or study objectives not meeting inclusion criteria. Exclusion reasons are provided in the PRISMA flow diagram below. Ultimately, five quantitative studies met all inclusion criteria and were included in the synthesis (see Figure 7; Moher *et al.*, 2009).





Figure 7: PRISMA flow chart describing the search process for Modified Systematic Review

5.2.1.2 Description of Included Studies

The five included studies were published between 2009 and 2022 and were conducted in three countries: Saudi Arabia (n = 2); Malaysia (n = 2) and Pakistan (n = 1). The term 'advance care planning' was used in one study (Saeed *et al.*, 2020). Other studies used terms such as 'end-of-life decisions' (Al-Jahdali *et al.*, 2009; Baharoon *et al.*, 2010) or 'end-of-life care' (Maniam, Tan and Chong, 2021; Azahar and Ibrahim, 2022), which were related to ACP. All five studies were conducted in hospital-based settings and were quantitative, although they varied in design and methodology. One study, conducted by Maniam, Tan and Chong (2021), employed the Q methodology, whereby 37 opinion statements were listed based on their relevance in a unimodal grid, and the data collected were analysed using varimax rotation and centroid factor extraction. Three studies used cross-sectional observational descriptive questionnaires (Al-Jahdali *et al.*, 2009; Baharoon *et al.*, 2010; Azahar and Ibrahim, 2022). Excel and SPSS software were used to analyse the data collected.

Baharoon *et al.* (2010) also undertook a descriptive analysis of the collected data. Saeed *et al.*'s (2020) study in Pakistan used an existing survey tool and translated it into Urdu and later English, then used descriptive statistics to describe the findings and establish research objectives. Four of the studies focussed on ESRD patients as participants, and only one study (Azahar and Ibrahim, 2022) included both patients and their relatives or family members who were involved in the patients' EoL decision-making as participants. The methodological quality of the included studies was assessed using the JBI critical appraisal checklist for cross-sectional studies (see Appendix 8). One study (Azahar and Ibrahim, 2022) was classified as high quality, another (Maniam, Tan and Chong, 2021) as moderate quality and the final three (Al-Jahdali *et al.*, 2009; Baharoon *et al.*, 2010; and Saeed *et al.*, 2020) as low-quality. A descriptive summary of the included studies is provided in Table 16.

Study/ Author	Aim	Method & Sample	Result	Conclusion
/year/ Country				
Title: Advance care planning preferences among dialysis patients and factors influencing their decisions Author: Al-Jahdali <i>et</i> <i>al.</i> (2009) Country: Saudi Arabia	To study the preferences for CPR and end of life medical intervention among Saudi haemodialysis patients.	 Method: A cross-sectional, observational, and descriptive (quantitative). Using questionnaire composed of 4 sections. The fourth section contained different scenarios and questions on personal and preferences such as end of life decisions, medical interventions, CPR, ICU admission, and the decision maker in these events. Sample: 100 HD patients (67 Saudis, 33 non-Saudis, 28 Arabs, and 5 non-Arabs). Main outcomes: Knowledge about CPR, mechanical ventilation, and ICU admission. End-of-life preferences about these outcomes. Factors that affect their decision. 	More than 95% of patients had little or no knowledge about cardiac resuscitation, intubation, and mechanical ventilation. The majority, 77%, authorized their treating physician to decide for them about cardiac resuscitation in case they did not make advanced directives/ or unable to make the decision and only 22% believed that this decision should be made by their family members. If their physician believed their condition was hopeless, 77% preferred to stay at home.	Most patients had limited awareness about cardiac resuscitation measures. Most of the patients trust their physicians to decide about the futility of resuscitation. Patients were able to decide reasonably well when they are well informed.
Title: Factors associated with decision-making about end-of-life care by haemodialysis patients	To determine the preferences of the ESRD patients on dialysis about end-of-life care and differences of certainty regarding the	Method: A cross-sectional, observational, and descriptive (quantitative). Using questionnaire. The third section contained different scenarios followed by questions on personal wishes and preferences related to these scenarios that address: end-of-life decisions, medical interventions,	Most were willing to make their preferences on end-of-life care decisions, and 67% were certain on answering CPR questions. More than two thirds of the surveyed patients were willing to make decisive decisions. Having more than 5 children was the only factor significantly associated with the ability to make decisive decisions; there was an insignificant association with factors such as marital status or non- Saudi nationality. Factors such as self-perception or disease curability, previous admissions to hospital or	There was a significant lack of knowledge in study patients of cardiopulmonary resuscitation, mechanical ventilation, and disease outcome.

Table 16: Descriptive Summary of Included Studies
Author: Baharoon et al. (2010) Country: Saudi Arabia	application of cardiopulmonary resuscitation and life sustaining measures in case of cardiac arrest	CPR, ICU admission, and who should be the decision maker in these events. Sample : 100 HD patients (67 Saudi, 33 non-Saudi). Main outcomes: Knowledge about CPR, mechanical ventilation, and ICU admission. Personal preferences related scenarios address about end-of-life decisions, CPR and LSTs in case of cardia arrest.	intensive care units, prior knowledge of mechanical ventilation, or cardiopulmonary resuscitation did not have any influence on making certain decisions on end-of-life care.	
Title: Dialysis decision making and preferences for end- of-life care: perspectives of Pakistani patients receiving maintenance dialysis Author: Saeed <i>et al.</i> (2020) Country: Pakistan	To study informed dialysis decision-making and EoL attitudes and beliefs in Pakistani patients receiving dialysis	 Method: using survey was adapted from the study of Canadian dialysis patients by Davison Sample: 522 dialysis patients (93% are Muslim patients) Main outcomes: perspectives about dialysis decision making, end -of-life care attitude, knowledge of palliative and hospices care. 	Less than one-quarter of the respondents (23%) felt informed about their medical condition, and 45% were hopeful that their condition would improve in the future. More than half (54%) wished to know their prognosis, and 80% reported having no prognostic discussion. Almost 63% deemed EoL planning important, but only 5% recalled discussing EoL decisions with a doctor during the last 12 months. Nearly 62% of the patients regretted their decision to start dialysis. Patients' self-reported knowledge of hospice (5%) and palliative care (7.9%) services was very limited, yet 46% preferred a treatment plan focused on comfort and symptom management rather than life extension.	Pakistani patients reported a need for better informed dialysis decision making and EoL care and better access to palliative care services. These findings underscore the need for palliative care training of Pakistani physicians and in other developing countries to help address communication and EoL needs of their dialysis patients.
Title: End of life care preference among hemodialysis population: Revisit Q methodology	To understand the diverse subjectivity of opinions on end- of-life care preferences, feelings, needs,	Method: The Q methodology was used where 37 opinion statements were ranked in order of importance in a unimodal shaped grid.	Forty-three persons living with haemodialysis, mean age ± SD= 56.58 ± 10.22 years, participated in the study. Five- factors were identified: living in the present, family preference, self-preservation, power vs. control and autonomy in decision making. The participants rank 37 statements from the most important to the least important. Eleven participants ranked significantly positive	End-of-life discussions are potentially inhibited by preferences to live for the present which should be explored in future studies.

Author: Maniam, Tan and Chong (2021) Country: Malaysia	value and goals in life among a haemodialysis population.	Sample: 43 HD patients living in Malaysia, with different ethnicities (Malay = 9, Chinese = 22, Indian = 12). Have varying levels of piety (religious = 18, nominal = 15, freethinker = 10). Main outcomes: opinion in end- of-life care preferences, feelings, needs, values and goal in life.	on living in the present. Four participants ranked significantly on family preference. Four participants ranked significantly positive on self-preservation, two significantly positive on power versus control, and three significantly positive on autonomy in decision-making.16 participants were not ranked significantly, and two were confounded. Preferences for remaining positive in the face of illness through a healthy lifestyle and preserving relationships and autonomy were demonstrated.	
Title: Differences in Attitude towards End-Of-Life Care among Haemodialysis Patients and their Family Members in Two Malaysian Hospitals Author: Azahar and Ibrahim (2022) Country: Malaysia	To explore attitudes towards EOL care among haemodialysis patients and compare them with the patients' family members.	 Method: A cross-sectional, observational, and descriptive (quantitative). Using questionnaire. The questions regarding EOL care started with a scenario that required participants to imagine themselves or their loved ones becoming completely dependent in self-care. The questions explored preferences in EOL care, including the place of death, the use of cardiopulmonary resuscitation, intubation, nasogastric tube feeding, use of restraints, and antibiotics. Sample: 164 ESRD patients and their families (participants consisted of 82 pairs of patients and their relatives). Main outcomes: attitude toward EoL care among patients and their families. 	Patient' and 'family' groups demonstrated differences in their preferences regarding EOL care options. Family members group favoured cardiopulmonary resuscitation (81.7% vs 41.4%) ($p < 0.001$), endotracheal intubation (80.5% vs 43.9%) ($p = 0.989$) and nasogastric tube feeding (87.8% vs 67%) ($p = 0.001$) more than patients themselves. The physician was the most nominated surrogate decision - maker by the patient (91.5%). Majority of the patients (57.3%) felt uncomfortable discussing EOL care options. There was significant correlation between duration of dialysis and patients' EOL preferences where patients less than 5 years on haemodialysis favoured CPR (55.9% vs 31.3%; $p = 0.026$), intubation (55.9% vs 35.4%) and nasogastric tube feeding (82.3% vs 56.3%; $p = 0.013$) compared to patients who had been on haemodialysis for 5 years or longer.	This study demonstrated significant differences between the attitudes of the patients and their relatives regarding EOL care preferences.

5.2.1.2.1 Sampling

The five studies included in this review employed a variety of sampling methods. Saeed *et al.* (2020) used convenience sampling methods. Maniam, Tan and Chong (2021) and Azahar and Ibrahim (2022) used purposive sampling, while the other two studies were unclear about their sampling methods (Al-Jahdali *et al.*, 2009; Baharoon *et al.*, 2010). Sample sizes varied considerably across the included studies. For example, Saeed *et al.* (2020) accepted 522 participants, which was the largest sample, while Maniam, Tan and Chong (2021) had the smallest number, at 43. The average number of participants was 186. A common methodological issue was apparent in the included studies in that they did not specify how many participants they required or justify their sample sizes. If the sample size is not correctly justified, it may not be possible to draw valid conclusions, which might affect the study's credibility.

5.2.1.2.2 Participants

Altogether, 847 adult renal patient and 82 family caregivers/ members were participants in the five studies included in this review. Al-Jahdali et al. (2009) investigated resuscitation preferences among Saudi HD patients using 100 participants who had been undergoing dialysis for at least two years and who were not on a transplant list at King Abdul-Aziz University Hospital or King Abdul-Aziz Medical City. Baharoon et al. (2010) examined the factors associated with decision-making about EoL care among 100 patients who had been on HD for more than two years at King Faisal Specialist Hospital and King Fahad National Guard Hospital. Saeed et al. (2020) sought perspectives from Pakistani patients on dialysis decisionmaking and EoL care attitudes and beliefs, as well as palliative and hospice care knowledge. The study employed convenience sampling to gather 522 surveys from dialysis patients from seven dialysis hospitals within Pakistan. Maniam, Tan and Chong (2021) investigated the diverse subjectivity of views on EoL care preferences, needs, feelings, goals and values in life among the HD population in Malaysia. Azahar and Ibrahim (2022) examined attitudes towards EoL care among HD patients and compared these with those of their family caregivers, as the latter may be involved in future EoL care decision-making. The study employed purposive sampling to gather 164 surveys from dialysis patients and their family members in two major tertiary hospitals in Malaysia – Hospital Kuala Lumpur and Hospital Serdang.

5.2.1.3 Synthesis of the Review Findings

This review's findings were synthesised using a narrative synthesis approach, which can help synthesise quantitative research findings from several studies but should be considered only when a meta-analysis is not viable (Popay *et al.*, 2006). A meta-analysis was not possible for this review because the quantitative studies reviewed were heterogeneous regarding the design of the studies, measured outcomes, and participants' experiences and backgrounds. The ACP discussion and decision-making process was the main outcome investigated in this review. The studies' results varied, with only one using the term 'advance care planning' to investigate patient preferences, while others used 'end-of-life care discussion', 'end-of-life care decisions' and 'end-of-life care' to refer to ACP. The review's findings were categorised based on different participant outcomes. This review comprises five outcomes: (1) patients' advance care planning and end-of-life discussion preferences; (2) patients' preferences for end-of-life care; (3) patients' perspectives on who makes advance care planning and end-of-life decisions; (4) patients' knowledge about their chronic kidney disease and (5) patients' knowledge about end-of-life decisions and palliative care. Each outcome was explained in more detail as follows:

5.2.1.3.1 Patients' Advance Care Planning and End-of-Life Discussion Preferences

ACP is a processual event focussing on one or more conversations. A discussion of ACP may result in different outcomes, including an advance directive (ADs) that names the person who decides for the patient whether the patient can or cannot make decisions (preventive power of attorney, proxy), the patient's view on EoL decisions, and opinions on general preferences and values. Therefore, it is necessary to examine patients' preferences and attitudes regarding ACP, as well as related decisions that influence their engagement and AD completion.

Perceived Value of Advance Care Planning and End-of-Life Discussion: Regarding patients' agreement with the importance of ACP and EoL planning, this was reported in only one of the included studies. Saeed *et al.* (2020) reported on the importance that HD patients place on ACP and found that 63% of the Pakistani participants viewed EoL planning as essential. However, less than 5% remembered having a discussion with their physician regarding EoL

care choices over the previous year. Furthermore, only a small percentage had completed a living will (17%).

Attitudes Towards Advance Care Planning and End-of-Life Care Discussion: In terms of patients' willingness to discuss ACP and ADs, Saeed *et al.* (2020) reported that almost two-thirds of participants were comfortable discussing and engaging in EoL care with their nephrologist and family members, and about half wanted their nephrologist to discuss quality of life and attend to their spiritual, social and psychological concerns. However, Azahar and Ibrahim (2022) found that more than half (57.3%) of the 82 HD participants felt uncomfortable discussing EoL care, and only 53.7% were comfortable. Furthermore, Maniam, Tan and Chong (2021) discovered variations in attitudes towards discussions of ACP and EoL care among HD participants in Malaysia. This study found that some participants were not keen on discussing their EoL care with HCPs or setting up a living will, while others wanted to discuss it.

Discussion Partner Preferences: Saeed *et al.* (2020) found that approximately one-third of participants preferred to discuss EoL issues with their nephrologist (37%), compared with 22% who wished to have this discussion with their family physician. The research also has emphasised patients' preferences at the time of initiating ACP and EoL discussions. Saeed *et al.* (2020) indicated that most patients wanted to discuss EoL care issues only when the need arose (56%). However, Malaysian patients in Maniam, Tan and Chong's (2021) study would consider discussing EoL issues when the opportunity arose and would like HCPs to initiate the discussion.

Attitudes Towards Talking about Death: Two studies in this review investigated the possibility of discussing death among HD patients. In Maniam, Tan and Chong (2021), they examined Malaysia's population perspective when discussing EoL care and death with HCPs. Some preferred to discuss death and dying with their HCPs, while others strongly opposed discussing such issues with HCPs, although they wanted direct, honest information about disease progression. However, Saeed *et al.* (2020) found that most of the Pakistani participants viewed it as essential to plan for their death in advance.

5.2.1.3.2 Patients' Preferences for End-of-Life Care

The participants in the studies included in this review were asked about their personal wishes, including the type of EoL care they wished to receive; admission to an intensive care unit; medical interventions such as CPR, intubation and other LSTs; and their place of death.

Care Preferences: In terms of type of EoL care that they wished to receive, some studies asked respondents whether they preferred their treatment plan to focus on extending life or relieving discomfort. Saeed *et al.* (2020) found that 47% preferred to focus on comfort and symptom management rather than life extension (19%) and 34% remained unsure. Likewise, Maniam, Tan and Chong (2021) examined EoL care preferences among Malaysian participants and found that their control of symptom burden appeared to be important to them. However, the study discovered that some participants were opposed to receiving LSTs or professional EoL care (the authors did not define what they meant by 'EoL professional care') or were concerned with living the best life possible.

Terminal Care Location or Place of Death Preference: Al-Jahdali *et al.* (2009) investigated Saudi HD patients' preferences in relation to their personal wishes and setting for terminal care. They found that 73% preferred to remain at home if their condition deteriorated rapidly to the point of impending death. Furthermore, 77% would prefer to remain at home if a physician ruled that the patient's situation was hopeless, while 20% favoured being admitted to a hospital ICU even if it was not possible to improve their condition. In the same vein, in Saeed *et al.* (2020), most (68%) preferred home to be their place of death rather than a hospital (12%). Maniam, Tan and Chong (2021) similarly found that Malaysian participants preferred to spend their last days at home with their families.

Attitudes Towards Cardiopulmonary Resuscitation: In terms of medical intervention, such as resuscitation preferences, Saeed *et al.* (2020) reported that more than half of survey participants (56%) wanted full resuscitation in the event of cardiac arrest. Unlike Saeed *et al.*, Al-Jahdily *et al.* (2009) argued that the percentage of patients who would undergo CPR was determined by the expected outcome of the resuscitation: 79% were in favour of resuscitation if they would recover fully from their acute illness and become independent after recovery. However, the percentage in favour of resuscitation decreased to 35% if they would be left with chronic brain damage after resuscitation.

In Azahar and Ibrahim's (2022) study, the Malaysian participants were asked about their attitudes towards EoL care in terms of CPR and intubation. They found significant differences between different groups of respondents. For example, middle-aged adults (ages 45–65 years; p = 0.309) were less likely to favour CPR than young adults (ages 18–44 years) and the elderly (ages > 65 years). However, all groups were more likely to prefer minimal and non-invasive techniques, such as nasogastric tube feeding, physical restraint and antibiotic administration. Furthermore, the study reported a significant correlation between the duration of dialysis and patients' EoL preferences, with patients on HD for less than five years favouring CPR (55.9% vs. 31.3%; p = 0.026), intubation (55.9% vs. 35.4%; p = 0.066) and nasogastric tube feeding (82.3% vs. 56.3%; p = 0.013), compared with patients who had been on HD longer.

Support Preferences: One study (Saeed *et al.*, 2020) focussed on patients' perception of ACP and EoL care in terms of receiving support, finding that more patients relied on family and friends (40%) for support for emotional and social matters than on their doctors or nurses (29% and 18%). Only 4% of patients sought emotional support from religious leaders/imams. In another study, patients who believed they were a burden to their families or themselves accounted for 28% of the total (Al-Jahdali *et al.*, 2009).

Patient vs. Family's Attitude Towards End-of-Life Care: Interestingly, Azahar and Ibrahim (2022) compared patients' attitudes towards EoL care with those of their family members, finding that patients favoured CPR (p < 0.001) and intubation (p < 0.001) significantly less than their relatives did for them, i.e., relatives were more likely to opt for CPR and intubation on the patient's behalf than the patients would themselves.

5.2.1.3.3 Patients' Perspectives on Who Makes Advance Care Planning and End-of-Life

Decisions

Patients' involvement in clinical decision-making is important and can improve quality of care, yet little is known about ESRD patients' preferences in a Muslim context. Therefore, it is important to examine their perceptions and preferences in the decision-making process.

Decision-making Preferences: This subtheme expressed the level of involvement in decisionmaking by patients themselves or by those they preferred to include in their decision-making, such as relatives or HCPs, as well as preferences in decision-making styles, either individualistic or collective DM. Participants' preferences on who should be involved in decision-making varied in the review, ranging from preferences for autonomy to shared choices. Some were identified as being passive treatment decision-makers, though most preferred a shared approach to decisions, with difficult ones made either with their physician or their family. Saeed *et al.* (2020) found that approximately two-thirds of the Pakistani participants wanted their families to be actively involved in decisions on their care management plan. However, Baharoon *et al.* (2010) established that more than 60% of the Saudi participants expressed a willingness to make decisions. Furthermore, Maniam, Tan and Chong's (2021) examination of Malaysian participants' perspectives indicated that some did not view involvement in the decision-making process as a priority, preferring that their family members make EoL decisions. However, other participants in the same study stressed that their individual autonomy was a priority in decision-making and emphasised making their own EoL care choices.

Decision-Maker Preferences: This subtheme concerns who would be the main decision makers in ACP and EoL care on behalf of patients if they cannot communicate and make their own decisions. In the context of Saudi HD patients making care decisions, Al-Jahdali *et al.* (2009) found that most preferred that their treating physician decide on their behalf whether to perform CPR if they are unable to make the decision. Only 22% thought that their close relatives should make such a decision. Similarly, according to Azahar and Ibrahim's (2022) study in Malaysia, most participants (91.5%) would choose their doctor as the decision-maker instead of a family member if they ever became noncommunicative.

However, Saeed *et al.* (2020) found that nearly half (47%) wanted their families to make medical decisions for them if they were unable to make decisions for themselves, while 27% preferred that their physicians make decisions on their behalf. Similarly, in Furthermore, Maniam, Tan and Chong's (2021) examination of Malaysian participants' perspectives indicated that some did not view involvement in the decision-making process as a priority, preferring that their family members make EoL decisions' (2021) study, some participants were found to prefer to use a proxy such as a family member in treatment decision-making events if they were unable to make their own decision. Surprisingly, Al-Jahdali *et al.* (2009) found that when they posed the question more directly ('Would you agree with your

physician deciding to not perform resuscitation if your heart stopped?'), they found that only 26% believed that their doctors should refuse CPR in the event of cardiac arrest.

Previous Decision-Making: Only one study (Saeed *et al.*, 2020) examined previous patients' experiences making decisions about starting their HD treatment. In the case of Pakistani HD patients' involvement in decision-making regarding their dialysis, 54% agreed to start dialysis because their doctors advised it, while less than 28% claimed it had been their own choice. The study further established that almost 62% expressed regret over the decision to start dialysis.

Perception of Influences Affecting Decision-Making: This systematic review examined how different factors mediated choices about EoL treatment among HD patients in a Muslim context. Two studies examined factors influencing decision-making in ACP. One of these (Al-Jahdali *et al.*, 2009) did not find any close correlation between patients' demographic characteristics and their EoL decisions, neither did it report significant correlations between patients' EoL decision preferences and religiosity, quality of life, dialysis duration, family size, number of children, working status, gender, age or marital status. However, Baharoon *et al.* (2010) found that having more than five children was connected to having the ability to make firm decisions. Their study also found that other factors, such as non-Saudi nationality and marital status, played a role in making firm decisions. Their research ruled out factors such as disease curability, self-perception, last admission to the intensive care unit, exposure to CPR and knowledge of mechanical ventilation influencing the patients' decisions concerning ACP and EoL care.

However, Azahar and Ibrahim (2022) reported that age and dialysis duration were influential factors in patients' decision-making about EoL care. Maniam, Tan and Chong (2021) identified factors contributing to EoL care preferences, such as self-preservation, living in the present, power vs. control, family preference and autonomy in decision-making. The participants preferred to remain positive during their illness by living a healthy lifestyle and preserving their independence and relationships. The researchers concluded that EoL discussions are hindered by patients' preference to live 'in the moment' and a lack of interest in discussing the future or preparing for death. Choosing their EoL care preferences seemed important for

the participants, but they preferred to appoint surrogate decision-makers, while decisions on EoL treatment and care were left to family members.

5.2.1.3.4 Patients' knowledge about their Chronic Kidney Disease

Patients' knowledge of their disease and its prognosis is one of the most important factors for improving health outcomes and making informed decisions.

Awareness of Disease Condition: Two studies investigated patients' knowledge about their condition and prognosis. In Saeed *et al.* (2020), over half (59%) of the Pakistani HD patients said that they believed they were somewhat informed about the disease, and 23% said they were completely informed. However, less than a quarter (12.3%) suspected that their condition could worsen during the subsequent 12 months, and 45% thought their situation would get better in the future. Al-Jahdali *et al.* (2009) reported that although most participants had been on HD for many years, 72% expected to recover from their kidney disease, whereas only 14% admitted knowing that their condition was incurable, and 14% claimed they did not know their chances of recovery. The study further revealed that only 14% were aware of their prognoses.

Information Preferences: In terms of patients' knowledge about their disease prognoses, most patients (68%) in Saeed *et al.* (2020) felt it was critical to attain additional information regarding their medical condition, while 54% wished to be informed about their prognoses. Similarly, in Maniam, Tan and Chong (2021), the Malaysian HD patients preferred to know about their medical condition, and in Saeed *et al.* (2020), 80% preferred to receive medical information directly from either their nephrologist or family physician. These studies concluded that the participants could make informed decisions if they were given sufficient information. Thus, the reviewer pointed to a need for culturally appropriate education and counselling programmes for patients that improve their level of knowledge and disease management.

5.2.1.3.5 Patients' Knowledge about End-of-Life Decisions and Palliative Care

Palliative care addresses EoL matters, such as resuscitation and ACP; therefore, it is important to understand patients' perceptions, preferences and levels of knowledge regarding it.

Knowledge about Cardiopulmonary Resuscitation: Two studies examined HD patients' knowledge of ACP preferences and EoL decisions. In Al-Jahdali *et al.* (2009), over 95% of the patients in Saudi Arabia were found to have very little knowledge of CPR, mechanical ventilation or intubation. These results are similar to those reported by Baharoon *et al.* (2010), who found that most Saudi patients had limited knowledge of their disease outcomes, CPR, mechanical ventilation and intubation.

Knowledge of Palliative and Hospice care: Only one study examined patients' knowledge of hospices and palliative care. Saeed *et al.* (2020) found that knowledge of both was limited among Pakistani HD patients. Moreover, in Saeed *et al.* (2020), authors investigating ESRD patients' preferences in terms of EoL care reported that only 61% of the patients expressed a preference for more information about ACP in terms of management options, such as alternative ways to manage physical symptoms or dialysis withdrawal.

5.2.1.4 What this Review Adds

The review findings contribute to understanding Muslims with ESRD and their families' preferences regarding EoL communication issues, ACP discussions and the DM process. This understanding is necessary in developing services and conducting clinical practice in a way that ensures patients and their families' preferences are met. This review also suggests that an ACP model that is culturally sensitive to Muslims needs to be developed. Muslim communities rely heavily on relatives for decision-making, so ACP should emphasise communicating openly and establishing a connection with patients and their families to gain a better understanding of their values. The review findings also may be relevant to the practice of ACP in Western countries, particularly in engaging patients or family members of Muslim descent. HCPs also should avoid stereotyping Muslims' collectivist culture and bear in mind that these patients may prefer active involvement in it.

5.3 Triangulation of Findings from Phases 1A and 1B

As explained in Chapter 4, Section (4.3.2.5) Phase 1 employed the triangulation protocol technique, which Farmer *et al.* (2006) originally described, to integrate the findings. The triangulation protocol drew upon the findings from qualitative interviews with ESRD patients and/or their family caregivers (Phase 1A) and the modified systematic review (Phase 1B). A

list of identified themes between the two data sets, the type of agreement and its explanation can be found in Table 17. The themes were presented and ordered based on Phase 1A, then Phase 1B, and the degree of convergence was noted.

Themes	Qualitative study: interviews	Modified systematic review	Degree of convergence	Comments		
Participants' Experiences Living with Kidney Disease	Х		Silence	This theme was covered in interview data.		
Perceptions of Chronic Kidney Disease	Х		Silence	This theme was covered in interview data.		
Participants' Experiences Communicating with Healthcare Providers	X		Silence	This theme was covered in interview data.		
Opportunities to Discuss Future Care Plans	Х	X	Partial agreement	There was an agreement on component which is supported by examples		
Decision-making regarding Dialysis or Renal Replacement Therapy*	X		Silence and Partial agreement	This theme was mainly covered in interview data but has partial agreement in one point		
Recommendations to Improve the Decision-making Process	Х		Silence	This theme was covered in interview data.		
Patients' Advance Care Planning and End-of-Life Discussion Preferences	X	X	Silence and Partial agreement	This theme was mainly covered in review data but has partial agreement in one point.		
Patients' Preferences for End-of- Life Care		х	Silence	This theme was covered in review data.		
Patients' Perspectives on Who Makes Advance Care Planning and End-of-Life Decisions*		X	Silence and Partial agreement	This theme was mainly covered in review data but has partial agreement in one point.		
Patients' Knowledge about their Chronic Kidney Disease	Х	Х	Partial agreement	There was an agreement on component which is supported examples		
Patients' Knowledge about End-of- Life Decisions and Palliative Care		X	Silence	This theme was covered in review data.		
"Although two themes related to decision making were silenced, there is some partial agreement.						

 Table 17: Summary of Identified Themes and Agreement among Research Methods

In Phase 1, six themes emerged from the qualitative interviews, and five outcomes emerged from the literature review, as presented in Table 17. Following identification, themes and subthemes were analysed and compared based on agreement, partial agreement, silence and dissonance levels. The degree of convergence was silence on most themes. The term 'silence' refers to instances when data are covered in one data set, but not the other. For example, three themes emerged from the systematic review: patients' ACP and EoL discussion preferences; patients' preferences for EoL care; and patients' Knowledge about EoL Decisions and Palliative Care. All data that focussed on ACP and EoL care preferences and decisions emerged from the review data. Due to religious and cultural factors, it was difficult to discuss disease prognosis and future care plans with patients during the interviews. Patients were asked briefly whether they had the opportunity to do so. Thus, the topics discussed included ACP preferences, and EoL care topics were identified only from review data.

In another example of silence, three themes emerged from patients' interviews: participants' experiences living with kidney disease; participants' experiences communicating with HCPs and recommendations to improve the decision-making processes. These themes emerged only from the interviews, whereas the review data were unable to elicit such themes because of the review objectives. Furthermore, silence was presented under two themes: Perceptions of chronic kidney disease and patients' Knowledge about their chronic kidney disease. Although in the first instance, the two themes could be similar to each other, they encompassed different data in terms of meaning and supporting evidence. The qualitative study found that participants had limited knowledge of CKD, causes, symptoms, risk factors and management. The review data did not include such research and focussed on participants' awareness of their condition and how they would prefer to know about their condition.

Regarding partial agreement, five themes with agreement on only one comparison criterion emerged. This is related to detailed coverage with specific examples provided in relation to each theme. One example of partial agreement was evident with the following themes: opportunities to discuss future care plans that emerged from the interviews and themes that emerged from the review; patients' Knowledge about their chronic kidney disease and patients' ACP and EoL discussion preferences. Based on the interviews and review data, participants generally reported limited knowledge about their CKD prognoses. They also had no discussions with their physicians about their wishes for their future care plans, and their ACP was documented poorly.

Another example was partial agreement on the following themes: decision-making regarding dialysis or RRT emerged and patients' perspectives on who makes ACP and EoL decisions.

Some agreement was observed, particularly in terms of participants' preferences in the decision-making process, their previous experiences in DM and their perception of factors influencing DM. Both interviews and the review revealed that participants preferred SDM, and they shared their decisions with their families. However, data from the review indicated that some preferred that their families or physicians make difficult decisions related to EoL care. Despite this, partial agreement was evident among these themes, with the two themes silenced in meaning and supporting evidence. One theme emerged from interviews focussing on RRT decision-making, while the other theme emerged from the review focussing on EoL care decision-making.

Partial agreement also was found on previous experiences with DM between both participants in the two data sets, specifically when HD treatment was started. The participants indicated that they regretted their decision to start dialysis after their physician urged them to initiate treatment. The data comparison between these two themes on participants' perception of factors influencing decision-making revealed some dissonance. In both data sets, various factors influenced their decision-making concerning RRT and EoL care. A review found that marital status and nationality influenced their decisions. While data emerged from interviews, it was found that doctors and the presence of external pressure played an important role in facilitating DM, and that a lack of knowledge was the main barrier to the DM process.

Data triangulation was achieved by using information gained from both the patient interviews and modified systematic review. I identified important differences in the data collected using both methods. The data from the interviews were focussed on participants' experiences living with CKD, experiences communicating with HCPs about CKD and its management, their experiences in making decisions regarding the use of RRTs and their options to discuss future care planning. The review focussed mainly on patients' preferences regarding ACP and EoL care, as well as their preferences in relation to EoL care decisions. Both data sets were complemented to address the study's objective: to identify patients and/or their family caregivers' education needs and their experiences with current ACP and SDM practices.

5.4 Chapter Summary

This chapter explored experiences, needs, priorities and problems that ESRD patients and/or their family caregivers have faced with communication issues, such as ACP discussions and the SDM process. This objective was achieved through qualitative interviews with ESRD patients and/or their family caregivers in Saudi Arabian contexts, in addition to a modified systematic review in a Muslim context. The data gathered from these sources were used to complement each other. The study's findings add additional evidence supporting ESRD patients and family caregivers' experiences in ACP discussions and SDM processes in the renal Muslim context, particularly Saudi Arabia. This study also provided insight into how current ACP and SDM practices were established, and patients' education needs were identified within the context of Muslim culture and Saudi Arabia. Six overarching themes emerged from the interviews. ESRD patients and/or their family caregivers had varied experiences with CKD diagnosis and in making decisions regarding starting dialysis, as well as a lack of opportunities to discuss their prognoses and future care. The present study reported that Saudi ESRD patients, and their family caregivers' and other renal Muslim patients' education needs were unmet, although they had been on HD for many years. These needs were focussed on improving patients and their families' knowledge not only about CKD and its management, but also on alternative treatments and palliative and EoL care, which facilitate ACP discussions and enhance the SDM process. They were willing to improve their knowledge – including information about all options and potential benefits, harms and side effects from each option, the effect of lifestyle changes and disease prognosis – to make an informed decision. They wanted more time to think about and consult with their families before deciding on dialysis. Despite some differences between the data sets, the data from the interviews and modified systematic review reinforced the need for a decision aid tool in ESRD that addresses the needs of those in a Muslim (particularly Saudi Arabia) context.

Chapter 6: Findings of Phase Two Cultural Adaptation Process Experts' Interviews

6.0 Introduction

The purpose of this chapter is to describe the initial adaptation process used to develop a culturally adapted version of the YoDCA tool for ESRD patients and their families. More information about the tool is described in section (4.3.3.2) of Chapter 4. This chapter was designed to contribute to the achievement of the following research objectives: to explore views and perceptions of the YoDCA decision aid tool from a broad multidisciplinary range of healthcare providers and people working in academia and research, and to identify aspects that aid in the adaptation of the YoDCA tool to the Muslim context. This chapter describes step 1 of Chenel *et al.* (2018), which examines the original DA and the new cultural context, as discussed in Chapter 4, section (4.3.3.3). This step contains the findings from qualitative interviews conducted with a diverse range of renal care experts working in clinical and academic research roles, which were intended to inform preliminary cultural adaptation.

This chapter describes qualitative interview study that included semi-structured one-to-one interviews with renal care experts. The chapter starts with a brief overview of the study participants, after which the findings from the interviews, divided into two parts, are presented. Part 1 (6.2.1) reports data around the experts' experiences providing care for renal patients, while Part 2 (6.2.2) focuses explicitly on their views about the cultural adaptation of the YoDCA tool. However, there is a degree of overlap between these two parts, and one informs the other. Finally, the chapter concludes with a chapter summary. In this chapter, I use a range of terms such as ESRD, CKD, renal care, and kidney care because this reflects how the participants described the care of ESRD patients.

6.1 Step 1: Exploring the Original DA and the New Cultural Context (Expert Interviews) 6.1.1 Participant Details

The original intention was to recruit study participants from Saudi Arabia. However, I had to expand my recruitment base due to COVID crisis restrictions and a low response rate. Thus, the participants come from Muslim countries in the Middle East, the Greater Middle East, East Africa, and South Asia. Participants were recruited for semi-structured interviews between July 2021 and September 2021. To obtain a maximum variation sample, a purposive

snowball sampling method was used to select participants with experience in providing kidney disease care, ACP discussions, SDM processes and palliative care. Chapter 4, section (4.3.3.4.1.4), describes this process in detail. A total of 42 potential participants were approached via various techniques, including directly via publicly published email, snowball sampling, social media (via a Twitter study advertisement) and the gatekeepers, who were the co-researcher nephrology doctor and the head nurse of the dialysis unit at KSAFHNWR. All those approached were sent an invitation email that included a study explanation, participant information sheet, consent form and interview guide.

All potential participants were encouraged to forward the email to other eligible health care providers who they felt might be interested in this discussion, whether at their place of employment or elsewhere in the Middle East and other Muslim countries. All potential participants and were emailed an invitation to participate in the study. Fifteen experts replied. Six out of fifteen refused participation for different reasons, including: lack of interest, lack of experience in renal or palliative care, and time restrictions. A follow-up email was sent to non-responding participants approximately one month after the initial email, but these did not reply. The final number of participants recruited was nine from eight interviews. Those nine participants varied in their roles and experiences of renal care; their details are captured in Table 18. Due to COVID-19, all interviews were conducted online via Google Hangouts (Google Meet), using either the audio or audio-visual function. The summary that follows provides the background of each participant, including demographic information and experience caring for renal patients. It also links to the findings, where pseudonyms are used in keeping with ethical principle.

Table 18: Phase 2: Experts' Characteristics

Participants	Age	Gender	Nationality	Educational level and background	Current job or role	Work experience	Work experience in Saudi Arabia	Experiences in patient's discussion	Training or education in palliative care	Experience in providing palliative care
Khalid	50 years	Male	Yemeni	PhD University level, Biochemistry	Academic role	8 years	8 years	No	No	No
Tala	37 years	Female	Malaysian	PhD University level, Nursing	Academic role	14 years	No	No	No	No
Ali	49 years	Male	Eritrean	University level, Medical	Clinical role	17 years	17 years	Yes	Yes	Yes
Layla	35 years	female	Kuwaiti	Master university level, Nursing	Nursing clinical role	15 years	No	No	No	No
Rami	61 years	Male	Saudi	PhD University level, Medical	Academic role*	12 years	22 years	Yes	No	No
Hasan	65 years	Male	Saudi	PhD University level, Medical	Clinical role	37 years	37 years	Yes	No	Yes
Sami	42 years	Male	Pakistani	Master University level, Medical	Clinical role	9 years	9 years	Yes	No	No
Rana	44 years	Female	Egyptian	PhD University level, Nursing	Academic role	20 years	9 years	No	Yes	No
Maha	39 years	Female	Egyptian	PhD University level, Nursing	Academic role	15 years	No	No	No	No

6.1.1.1 Participants' Background Summaries

Expert 1: Khalid is a 50-year-old Yemeni male whose educational background is in biochemistry. He has had an academic and research role for eight years in Saudi Arabia. He is a lipidologist whose research focuses on lipid disorders in ESRD, and he has published a paper in the renal area. He is also interested in the co-relationships between cardiovascular disease, ESRD and mortality rates.

Expert 2: Tala is a 37-year-old Malaysian female whose educational background is in nursing. She has worked at a nursing school for fourteen years as an academic and researcher and teaches undergraduate nursing students in Malaysia. She has conducted and published approximately six studies about CKD patients and nursing students. Thus, she has a comprehensive understanding of CKD trends in Malaysia.

Expert 3: Ali is a 49-year-old Eritrean male whose educational background is in medicine. He is a nephrology doctor and has 17 years of clinical experience working with ESRD patients in Saudi Arabia. He has experience of renal patients' discussions around RRT. Although he does not have any prior formal training or education in palliative care, he does understand the subject through attending a certified session. He has only six months' experience in palliative care, providing assistance to cancer patients.

Expert 4: Layla is a 35-year-old Kuwaiti female whose educational background is in nursing. She has clinical experience working with renal or urologic patients. For seven years her work focused on post-operative nursing care, such as caring for dialysis wounds, but she is not an expert in using dialysis machines. She then worked in a nursing administrative role as an incharge nurse for patients with renal problems. She has 10 years' experience as a member of the health education committee at the hospital. Currently, she has a scholarship to study for a nursing PhD.

Expert 5: Rami is a 62-year-old Saudi male. His educational background is in medicine, and he received fellowship training in family and community medicine. He was a family physician in a governmental primary health care centre in Saudi Arabia and for ten years served as the volunteer director of health care at a non-governmental dialysis centre. He was responsible for administration of the dialysis centre, which provides free healthcare for the poor and

serves paediatric, adult and geriatric patients (male and female). He has experience with renal patient discussions, informing them about diagnosis and management, mainly haemodialysis treatment. He has no prior formal training or education in palliative care and only limited experience in this area. He has been a professor at the medical college for 12 years, teaching family medicine courses, including communication skills and delivering bad news, to undergraduate medical students. He has a senior academic role at a Saudi Arabia university.

Expert 6: Hasan is a 65-year-old Saudi male whose educational background is in medicine, and he has fellowship training in nephrology and transplantation. He is a nephrology consultant and has 37 years of clinical experience working with ESRD patients in Saudi Arabia. He is an internal medicine professor. He usually discusses RRT treatment options with patients. He is not certified or educated in palliative care, and only practiced during his studies, but does have experience providing palliative care for renal patients. He has conducted considerable research and published several studies, mostly focusing on kidney transplantation and organ donation.

Expert 7: Sami is a 42-year-old Pakistani male. His educational background is in medicine, and he has a master's degree in nephrology. He is a nephrology consultant and has worked with ESRD patients for nine years in Saudi Arabia. His role is typically to discuss dialysis initiation with patients. He has no prior formal education in palliative care nor any experience providing palliative care for renal patients.

Expert 8: Rana is a 44-year-old Egyptian female. Her educational background is in nursing. She has a doctorate in medical-surgical nursing, with a focus on colorectal cancer, as specified in colostomy care. She has performed an academic and research role for 20 years, including 9 years' working in an academic field in Saudi Arabia. She teaches medical-surgical and critical care courses in both theory and practice to undergraduate nursing students. She has worked as a clinical instructor for six years.

Expert 9: Maha is a 39-year-old Egyptian female whose educational background is in nursing. She has a doctorate in medical-surgical nursing, with a focus on burn rehabilitation. She has taught undergraduate nursing students, particularly in nephrology. She has also had a clinical role for 15 years training students in the hospital. Through her work, she teaches undergraduate nursing students fundamental nursing courses and helps students learn how to deal with renal patients.

6.2 Introduction of Themes

This section reports the main themes identified regarding the initial cultural adaptation process of the YoDCA tool. In total, eight themes emerged from the interview data, divided into two parts: part one includes four themes relating to the experts' experiences of renal care, and part two includes four themes concerning their perceptions of how to culturally adapt the YoDCA tool to fit the Muslim context. These eight themes and their subthemes are discussed in turn and illustrated with quotes. The participants engaged in a narrative as they spoke in detail during the interviews. Hence, in this chapter, quotes were carefully selected. In order to adhere to the 'ethos and aesthetics' of qualitative research reporting (Sandelowski, 1994), it was necessary to select quotes that were relevant to each section and make further editing adjustments for brevity (Lingard, 2019). The quotes I selected and edited retained the general message of the transcripts they were taken from. As part of the coding process, I kept detailed information to assist with selecting appropriate quotes. Throughout this chapter, interview quotes are written in italics and have been adjusted for readability by removing repeated words, correcting or replacing incorrect words, and removing minor hesitations ('hm', 'uh', 'yeah'). Moreover, a few minor grammatical changes were made to the verbatim quotes to make them more understandable (Corden and Sainsbury, 2006).

6.2.1 Part One: Interview Themes

This part identifies the four themes regarding experts' experiences providing and improving renal care: (1) perception of influences on renal care quality; (2) experiences in caring for renal patients; (3) Muslim context and perceptions of the decision-making process; and (4) understanding of and perspectives on palliative care.

Theme 1: Perception of Influences on Renal Care Quality

This theme emerged when participants were asked to reflect on current challenges in renal care. The participants identified factors that influence renal care quality in the Muslim context, and these are influenced by the interplay between the macro, meso and micro domains. From the perspective of the participants, the main challenges of renal care can be divided into these 3 different levels, as described below.

The Macro-Level Perspective: Participants discussed factors that represent the external context, focusing on factors related to national and government policies. Several issues were identified. For example, as reported by Sami, a key macro influence is the failure to integrate care among the different national health care settings, particularly in the Saudi healthcare context. Ali, Rana and Maha similarly indicated a lack of coordination or collaboration among the multidisciplinary team of HCPs within the same health organization. According to them, renal care lacks care coordination among local healthcare settings and primary healthcare (PHC). In addition, there is a lack of communication and collaboration between HCPs, leading to a disconnect between hospital services and those provided by PHC and community HCPs. Participants considered this a major systematic barrier to mitigating the risk of progression to kidney failure and providing optimal care. As they stated:

"Coordinated care between different (healthcare settings), especially in the context of Saudi Arabia, where we have different ministries. Unfortunately, it is not very well connected. We have a problem with coordination and connection ... There is no single system in the country where we can access the record of the patient. For instance, the Ministries of Health and Defence, there is no connection between them, and their systems are totally different. So, we cannot access the patient's record unless we ask for it" (Sami, a Pakistani male nephrology consultant, has 9 years of experience)

"We do not have integrated or holistic renal care. When you talk about integrated renal care, it means that if a patient is diabetic and is at a stage, he may have the good fortune to be diagnosed at stage one. Then, as part of integrated renal care, you need to provide him with several visits with the nephrologist. Also, he needs to be seen a cardiology clinic after neurology, psychiatry, a parathyroid physician, a vascular surgeon, a social worker, and a dietician make recommendations. He must go through all of them as a whole ... I mean, whenever there is no holistic approach to treatment or holistic management for CKD patients, we will miss the patients" (Ali, an Eritrean male nephrology physician, has 17 years of experience).

Another source of issues was the growing demand for RRT in a context of limited resources. As Sami, Hasan, and Ali reported, this is one of the main challenges of renal care, and they identified different reasons. For example, Sami reported that the growing number of elderly renal patients with comorbidities was one of the main sources of increased demand. In the same vein, Hasan indicated that the increased numbers of expatriates in Saudi Arabia, which range from 10 to 12 million, with many having ESRD, had put pressure on health services in the Saudi Arabian context, particularly to find a place to dialyze them. This limited access to RRT for a substantial number of expatriates. Moreover, Ali stated that a labour shortage, particularly among nephrologists in rural areas of Saudi Arabia, is another factor influencing the quality of renal care provided. Hassan echoed this view. Furthermore, Hasan revealed that among the top challenges in renal care are transplantation and an insufficient supply of donors. Additionally, he stated that the second challenge is the limited number of settings where dialysis is available, and limited suppliers of dialysis, making this one of the major changes in renal care in the Saudi Arabian context. As they stated it:

"I would say the biggest challenges, of course, growing number of patients, especially the elderly of course comorbidities, of diabetes, hypertension, then we will move on also our life expectancy increasing as long as the kidney diseases in the face" (Sami, a Pakistani male nephrology consultant, has 9 years of experience)

"Lack of the nephrologist in some rural areas, we do not have a tertiary hospital, and it is very rare to find a nephrologist. Whenever we talk about stages one and five, it will never be managed solely by an internal medicine physician, and it is a big mistake to assume that internal medicine or a general practitioner will manage a renal deterioration situation" (Ali, an Eritrean male nephrology physician, has 17 years of experience)

"The top challenge actually is the transplantation. The ideal treatment for renal failure is a transplant, but the donor is not optimal. So, we have to look to increase the donor pool in order to save those patients with end-stage disease. The place of dialysis we have enough dialysis units and now we have three companies running outsourcing, but they cannot accommodate all the patients'' (Hasan, a Saudi male nephrology consultant, has 37 years of experience)

Another factor affecting high-quality renal care, and one that has a negative impact on health outcomes, is late diagnosis of CKD, which is a major reason for delayed referral. Ali explained why primary care HCPs in Saudi Arabia fail to monitor and follow up on diabetics and hypertensives, adding that they also have inadequate knowledge about CKD management. As a result, these patients and their families are often denied a CKD diagnosis, thus delaying dialysis treatment. This causes sudden presentations to the emergency room in the late stages of CKD. Rami identified different reasons that lead to a late-stage diagnosis, including the fact that early detection of CKD is difficult because it is an asymptomatic disease, as well as a lack of regular check-ups in the general population. They stated:

> "In Saudi Arabia, we have a problem that we cannot figure out the patient in their earlier stages of disease. Due to lack of follow-up and monitoring renal progress, it is very rare to pick up a patient at an earlier stage, particularly stages one or two ... Also, a lack of knowledge for our primary care physician. Very rarely find a doctor in an emergency department or in primary care requesting a renal function panel" (Ali, an Eritrean male nephrology physician, has 17 years of experience)

"Most of the patients were diagnosed at the late stage of the disease. Because most of the patients did not feel or believe they had a problem, except those who were having a regular examination or follow-up. There is not much done for the routine check-up. A regular check-up for everyone, a yearly check-up, can help catch cases early" (Rami, a Saudi male academic medical staff, has 22 years of experience)

Rana and Maha identified another set of macro-impact factors. Rana discussed the COVID-19 pandemic and its challenges to the healthcare system. She considered renal patients

vulnerable to COVID-19. Maha believed that a lack of understanding of palliative care services affects renal care quality, asserting that dialysis patients are widely underserved in palliative and hospice care. She was the only participant who made this point. However, when asked about the top challenges in renal care, Rami emphasised that, from his point of view, renal care in Saudi Arabia is fully supported by donations. The country has contracts with companies to provide dialysis machines and maintenance. As he described:

> "Renal care in Saudi Arabia, getting the top priority, Alhamdulillah. There is a society called 'Kilana' which supports all dialysis centres around Saudi Arabia. If we look at the hospitals who have the dialysis centre, they can also support from the administrative part of the hospital themselves and from the Ministry of Health because they need continuous disposables for the patients as well as businessmen, who donate to the centres" (Rami, a Saudi male academic medical staff, has 22 years of experience)

The Meso-Level Perspective: In this subtheme, the participants described organisational factors and their relationship to care quality. These factors, which focus on barriers that arise organisationally in healthcare settings, centre on standardising patient education. Ali and Sami indicated that the lack of standardised patient education and pre-dialysis education is considered the main organisational factor affecting care quality, and they identified some reasons for this lack of standardisation. Ali considered that the lack of pre-dialysis education is due to patients' reaction to the diagnosis, which is denial, thus making them reluctant to discuss their treatment. Also, he reported that they trust Islam for medical treatment more than hospitals. Sami and Ali also noted that health care at the primary level is not very developed, particularly the role of family medicine in educating patients to improve their health outcomes. Many CKD patients do not receive such education, and there are disparities in the information they receive when they do receive it. This issue affects their ability to accept the diagnosis and make an informed RRT decision. On the other hand, Tala, who has an academic and research role, discovered from her research studies that several factors affect patients' education in clinical settings. For example, she reported that patients are concerned about their disease and know all information related to it. However, there are currently no standards for patient education, and it lacks a multidisciplinary team. In addition,

HCPs have limited time to spend with their patients due to their increased workload and increased number of patients. As they described:

"There is absolutely a lack of patient education and pre-dialysis education when I talk about the denial phase. Nobody will be ready to discuss or educate him about dialysis if he is in denial. The patient believes in faith (Allah), so they are not thinking in preventive measures; they will never visit the hospital for a regular check-up, unless emergency ... In Saudi Arabia, we have failed to have a solid family physician role. This is supposed to be addressed by a family physician. If we do not have the family physician role, patients will be referred to a tertiary care provider. The doctors in the tertiary will not be able to track all family history" (Ali, an Eritrean male nephrology physician, has 17 years of experience)

"There are no standardization methods of teaching. Patient sometimes worsen from initial to latest stage may be because they did not know how to self-manage at home because they were only educated by nephrologists, not by others multi-disciplinary. I can assure you that a comprehensive education cannot be given because doctors are busy. The numbers of patients attending the clinic are growing and I believe it Is a trend and definitely a close contact session cannot be done" (Tala, a Malaysian female academic nursing staff, has 14 years of experience)

The Micro-Level Perspective: In this sub-theme, participants explored the factors that affect renal care quality from the perspective of patients and HCPs and identified several factors that impact the care provided. For example, Tala mentors her clinical student and discovers trust and communication issues between HCPs and patients. Another communication problem was identified by Layla, who emphasised the language barrier between HCPs and Arabic patients, especially in Gulf countries. This is because most HCPs are migrants for whom Arabic is not their native language. As they stated:

"Patients tend not to disclose certain sensitive questions because they expect not to get treatment. They are scared because they believe if they present certain information to the HCPs, they might not receive the appropriate treatment due to their negligence in taking this substance which deteriorate their health. This is a taboo or misconception'' (Tala, a Malaysian female academic nursing staff, has 14 years of experience)

"I think those patients were mainly old people. I think there were struggles to communicate with the nurses because in my country, nurses were Indian or Filipino, who worked with dialysis patients. So, I have noticed like the patients they were like struggle to communicate in Arabic with those nurses" (Layla, a Kuwaiti female clinical nurse staff, has 12 years of experience)

Moreover, Ali believes that cultural attitudes, beliefs or perceptions may be a challenge affecting care quality. He reported that some renal patients with diabetes and hypertension think that dialysis and medication will solve these problems without adhering to other management strategies. Tala supported this view and stressed another challenge: Arab people have misconceptions about food and medication. As they described:

> "It is a matter of culture. Even if we have a large workforce, if the culture is not changed, I could not imagine one of my patients. It was more than seven years ago, and he never gave up smoking. Despite being on dialysis, he was continuing smoke and he gets told me what will happen more than my kidney fail. I told him you still have a lung; you have a heart. If you do not care about them, we care only about your kidneys. He then discovered that his lungs had changed after a few years. And once he realized that he started to get mad and he was unable to control himself, even quitting smoking at that level will not help" (Ali, an Eritrean male nephrology physician, has 17 years of experience)

> "I was wondering do people in Arab countries have cultural and nutritious food while receiving treatment for CKD. Because they believe medication can solve their problems. So, I would perhaps you might look at this angle as well, because I believe that misconceptions about certain procedures. They think that after taking medication, they feel okay, but all though they are on

medication, they still need to control their diet" (Tala, a Malaysian female academic nursing staff, has 14 years of experience).

Theme 2: Experiences in Caring for Renal Patients

This theme was identified by experts based on their earlier experiences and knowledge of providing renal care and emerged from the perspective of both clinical practice and academic research. The different cultural and educational backgrounds of the experts shape their experience and role in caring for renal or ESRD patients. They have extensive experience providing and improving patient care. This includes the academic role of teaching nursing or medical students, their research role to improve renal care, and their clinical role. This theme includes two subthemes: (1) academic, research and educational influences on the provision of renal care; and (2) an understanding of renal care from a clinical perspective.

Academic, Research and Educational Influences on the Provision of Renal Care: In this subtheme, the participants reported that their experiences and role in providing care for renal patients had been gained through direct or indirect involvement, including knowledge gained from their educational background, work as academic staff members teaching undergraduate students and involvement in research to improve healthcare. For example, Rana and Maha reported that they first provided renal care to patients during their education, when their responsibilities focused on bedside nursing care and patient education. Rami's academic experience, which includes teaching undergraduate medical students, focused on teaching skills to communicate with renal and other patients in clinical settings, particularly how to communicate bad news to a patient. On the other hand, Tala discussed her role in improving renal care from the point of view of her research. She stated that her academic and research roles involve gaining experience and improving kidney care in the Malaysian context. As they described:

"I have taught for 20 years. I worked as a clinical instructor role for six years ... In the dialysis unit, my role with those patients were to assess a patient's condition as a whole and provide care before, during and after dialysis. I taught theoretical lectures and, I have a role in clinical areas including chronic renal disorder was particularly applied in the hospital in the haemodialysis *unit'' (Rana, an Egyptian female academic nursing staff, has 20 years of experience)*

"Basically, I was a principal investigator of ward internal grad and I have managed to study several studies that is conducted among CKD patients among the students itself, so that I can have a broad picture what is actually the trend of CKD in Malaysia" (Tala, a Malaysian female academic nursing staff, has 14 years of experience)

An Understanding of Renal Care from a Clinical Perspective: In this subtheme, the participants described their clinical experiences and roles as nephrology consultants and nursing staff providing renal care in the hospital. For example, Ali, Rami, Sami and Hasan worked at Saudi dialysis centres and had varying levels of clinical experience dealing with ESRD patients. However, overall, they had expertise working with patients across the disease trajectory. Furthermore, Layla, who worked in the Kuwaiti surgical unit, indicated that she cared for renal patients, providing postoperative nursing care focused on wound care. They described their experiences in the following statements:

"I am mainly focusing over managing stage five and especially in dialysis or to be specific I can say haemodialysis patient or in-centre haemodialysis patient. This is where will be my bulk of my experience since 2008 up to date with some exposure over pre-dialysis care. I can focus mainly over stage three to stage five" (Ali, an Eritrean male nephrology physician, has 17 years of experience)

"We receive very poor patients who are in the final stage of CKD from our colleagues in the hospital. The patient came to us after being referred by the nephrology department. We told them that you need to do a small operation which the A-V shunt. We explained to him the pre and during the dialysis process. We told them, it is beneficial for you. Your life will continue, which is good for you. You can continue your work yes; you will be a little bit weak for some time but at least you will maintain your life" (Rami, a Saudi male academic medical staff, has 22 years of experience)

Theme 3: Muslim Context and Perceptions of the Decision-Making Process

This theme reflects participants' perceptions of renal care practice in Muslim contexts. It involves communicating with patients to explain the different treatment options available to them. It also explores Muslim cultural perspectives in the decision-making process in terms of who is involved in the DM and who is responsible for the decision, as well as who speaks with the patients regarding the decision and their preferences for involvement. This theme included two subthemes: (1) healthcare providers' communication with renal patients about chronic kidney disease treatment options; and (2) responsibility for making decisions.

Healthcare Providers' Communication with Renal Patients about Chronic Kidney Disease **Treatment Options:** In this subtheme, some participants described their prior experiences communicating with renal patients about treatment options and the choices available to them within the Muslim context, and particularly in the Saudi Arabian context. Those participants with a medical background are Rami, Ali, Sami and Hasan, all of whom have a clinical role as they work directly with renal patients in a dialysis centre. Despite their different cultural backgrounds (two Saudis, one Eritrean and one Pakistani), their experience of providing renal care was in a Saudi Arabian and Muslim context. This influenced the care they provided and their communication with patients. Some practices and decisions in Saudi Arabia's healthcare system were shaped by Muslims and Islamic influences. It is clear from the interview data that, in the Muslim context, and particularly in Saudi Arabian clinical settings, patients are primarily offered RRT after being diagnosed with CKD; they are not usually offered conservative management or withdrawal from dialysis. For example, Hasan, Rami and Sami focused their discussions on dialysis initiation, dialysis re-initiation, and switching between RRT for patients with renal disease. Due to religious and cultural norms in the Muslim context, not all of them discussed withdrawal or stopping dialysis. According to Hasan, Saudi Arabia has guidelines for conservative management of intensive care patients who are very sick. As Hasan and Sami explained, they do not discuss conservative management (non-dialytic) or withdrawal from dialysis treatment with every patient but only with a specific group of patients. Those patients that include critically ill patients in intensive care units, patients with comorbidities, patients with short life expectancies and patients with Do Not Resuscitate (DNR) orders. As they described:

"We only offer RRT in clinical practice. We had always was to put the patient to choose, between dialysis or transplantation. Rarely, you will have some patients who will withdraw ... So, there is till now, especially in Saudi, we do not discuss with the patient that he cannot either the options of not dialyze him or let him die. But if we have someone who is critically ill in ICU, and he is DNR usually such patient will discuss with the family not to perform dialysis because it is not necessary to be done for nothing, no hope" (Hasan, a Saudi male nephrology consultant, has 37 years of experience)

"Up to our knowledge in treating kidney failure is having either the haemodialysis or peritoneal dialysis or continue transplantation, the medicine, till now, does not have more pure options than this one (meaning stop dialysis treatment) ... I did not see in my life, but we give him this option" (Rami, a Saudi male academic medical staff, has 22 years of experience).

According to the experts, renal patients in the Muslim context rarely discuss or are approached with conservative care as a treatment option due to religious, cultural and medical factors. These include patients, family caregivers or communities who do not accept conservative care as a treatment option. Hasan and Rami believe that patients and their families, as well as patients who cannot afford dialysis sessions, do not request conservative management; they may not accept it as a treatment option. As Rami explained, this is due to religious instruction that encourages people to help the poor and those who cannot care for themselves. In addition, Rami asserted that discussing the discontinuation of dialysis treatment is a difficult decision that is not usually encouraged within a Saudi context because it could have a negative impact on patient health outcomes and possibly lead to death. However, Ali stated that few patients are approached or conferred with about this treatment option. As they stated:

> "Very rare to have some people who said do not initiate dialysis for their patient if they know that it is a terminal case... It is very rare, but usually the family takes the decision. Because the family, the patient himself is very sick to get the decision" (Hasan, a Saudi male nephrology consultant, has 37 years of experience).

"It is very rare in Saudi health care system even in the Middle East country, very rare patient to approach the conservative management ... I did not see any case, he asked for withdrawal. I will tell you what, the patient himself he will not say, "No, it is difficult for me not doing my dialysis, it is not easy." He will be unfortunately going for death ... It is a religious instruction encouraged us to help each other, to help poor people ... Especially those kidney failure people who we know that their kidney is not working so that life will be stopped at any time. We rush to help them to do the dialysis ... they will have people who can donate for them to help them to do his treatment by dialysis but no conservative" (Rami, a Saudi male academic medical staff, has 22 years of experience)

"I doubt you will find such statistics (patient approach conservative management pathway in Saudi Arabia) it is very rare. It happens usually not because the doctor convincing the patient it happens all the time because the patient is not convinced with the dialysis. I had one patient who refusing the dialysis totally and he was not convinced to initiate it, but he is being forced by the family ... we tried with him even one to two sessions per week, he says that he gets sick with the dialysis and he having to continue. Then again, he got some on and off on dialysis. But honestly, it has been enforced by the patient himself" (Ali, an Eritrean male nephrology physician, has 17 years of experience)

On the other hand, Maha and Ali stressed respecting all patients' choices and preferences. Maha stressed that patients should know from the start all the treatment options available to them. However, Ali argued that although they give patients the right to choose their treatment, in some cases it is not the patients' decision. As they described:

> "We should concern about patient code of ethics that a person should know all their option, even if that option is not suitable or recommended for them and respect the patient choice. For these reasons, the conservative care and transplant care are included, and the patient should choose after increased

his health awareness about the disease" (Maha, an Egyptian female academic nursing staff, has 15 years of experience)

"It is the freedom of the patient to choose the proper tool of management after getting all the options. But I do not think it is a simply for me ... you give these choices to the patient you are helping the patient not to be forced. An example, of a young guy, 20 years and he end up with renal failure. Suppose the first choice for him is transplant, but he does not have this choice. He does not have a donor. Then he will be forced to go for haemodialysis." (Ali, an Eritrean male nephrology physician, has 17 years of experience).

Responsibility for Making Decisions: The participants indicated that this sub-theme incorporates Arabic and Western cultural values and beliefs in the DM process. This leads to differences in terms of who makes the decision and who is involved in the process, as well as who speaks with the patients regarding the decision. For example, Layla and Tala believe that patients in Arab Muslim countries do not participate in the decision-making process, while HCPs make decisions without patient involvement. Moreover, Layla emphasised the importance of involving patients in the DM but that the level of patients' involvement in the decision-making process depends on their age and physical and cognitive ability. For example, if patients can make decisions, they should make decisions and participate in discussions. However, some people cannot decide because of their health or age. This view was echoed by Rana, who expresses her experience of caring for and supporting her father through a decision-making process. From her perspective, decision-making is not an easy process, and many medical and psychosocial factors influence decision-making, such as her father's age, health condition, and denial of the disease. As they stated it:

"In the Middle East, Arab countries and the Gulf region were not involving the patient like we are not taking patient confidence about his or her decision. Really, I feel here (in Western countries) they give the patient the ability to decide. It is not as usually you decide on behalf of the patient ... Patients they should decide, and HCPs should discuss with patients, this is his decision not our decision" (Layla, a Kuwaiti female clinical nurse staff, has 12 years of experience). "It was difficult for me and my father and family to make this decision (switching from conservative management to HD). Two years ago, my father had no symptoms, but his renal function test was high. His nephrologist advised us to take the urgent decision regarding RRT. And because the age and health condition have a history of operation of my father, we did not have the opportunity for kidney transplantation. But at the same time, the decision to dialysis was very difficult, especially because he believed there were no symptoms, so there was no need for dialysis" (Rana, an Egyptian female academic nursing staff, has 20 years of experience)

Khalid and Tala also raised the significant point that in Muslim culture there is a preference for the involvement of family, particularly male family members, in decision-making. They argued that the patient's gender could influence his or her right to decide. They reported that the female gender was perceived to lead to less autonomous decision-making and that women were less likely than men to make decisions alone. As they stated:

> "If we are talking about gender, female patients, you know, maybe she has a husband, she has sons or relatives. Therefore, I believe 90% of our females are unable to make their own decisions. They discuss their decisions with their husbands, fathers, sons etc." (Khalid, a Yemeni male academic biochemistry staff, has 8 years of experience)

Furthermore, according to Rami, Maha, and Hasan discussing and resolving a decision is not an individual process; it is a collaborative process involving HCPs, multidisciplinary teams of HCPs, patients and their families. This is called a shared decision-making process. Moreover, Layla emphasised the importance of the nursing role in discussing with and educating patients about their treatment choices. She also emphasised the importance of making decisions alongside other HCPs. As they stated:

> "As soon as the patient knows his diagnosis, we are the medical team, we offer him the information needed about his disease, complication, and the option of management of the disease. Then, of course, he will choose, and he will seek the help from his relatives, from his family and from their health care

team. His doctor's opinion, other doctors' opinions, about which treatment is best for him'' (Rami, a Saudi male academic medical staff, has 22 years of experience).

"Because of the policy like in my country (meaning Kuwait) whereas a nurse, we are not involved in these things (patient discussion). We are nurses only limited to do physical care. I guess also Saudi nurses they also are not involving. It should be involved in between both sides, healthcare provider, nurses or doctors or other departments. Like we nurse, like based on our experience, we have the ability to explain more than the doctors" (Layla, a Kuwaiti female clinical nurse staff, has 12 years of experience).

Theme 4: Understanding of and Perspectives on Palliative Care

In this theme, participants of different backgrounds described their perceptions and attitudes towards palliative care for renal patients. They also described how their personal experiences relate to professional practice, particularly in the Muslim context. The following subthemes are included: source of knowledge about palliative care; prior experience providing palliative care in a renal context; and perceptions of palliative and end of life care.

Source of Knowledge about Palliative Care: This sub-theme emerged when participants were asked if they had prior palliative care training or education. All participants reported no formal education or training in palliative care. However, Ali and Rana stated that they learned about palliative care by attending certified sessions. Hasan indicated that he practiced during his educational process. The sessions they attended were not related to their specialization. As they reported in the following statements:

"Only a certification being attending some of the conferences focusing mainly over a cancer patient" (Ali, an Eritrean male nephrology physician, has 17 years of experience)

"I do not have formal training or education. It is only practice during my education" (Hasan, a Saudi male nephrology consultant, has 37 years of experience) **Prior Experience Providing Palliative Care in a Renal Context:** In this subtheme, the participants described their experiences providing palliative care for renal patients in the clinical setting in a Muslim context, particularly in Saudi Arabia. Their experiences varied according to their different areas of professional practice. Only one participant, Hasan, provided palliative care to ESRD patients as part of his work. Ali had a different view on palliative care for renal patients: if initiation of dialysis was considered palliative, he would do it. However, Sami stated that he had never provided palliative care for renal patients. Ali and Sami had never provided palliative care for renal patients experience of palliative care for other life-threatening conditions, particularly as part of his work as a family physician. Less palliative care is provided for renal patients in the Muslim cultural context of Saudi Arabia. One reason is that it is not commonly practised due to the cultural context. As they reported:

"My experience in providing palliative care is a normal practice not by years. It is you are facing patients who already need palliative care and you give him this one. So, it is a daily practice... With some of my elderly patients, who were DNRs, and with some patients with end-stage CKD, nothing could be done if their heart, kidney, or liver were involved. They can go with that care" (Hasan, a Saudi male nephrology consultant, has 37 years of experience)

"If you consider initiation of dialysis, convincing as a palliative, then yes. Otherwise, the other choices of palliative, especially in nephrology, I did not have an experience... I have been exposed to cancer patient end stage cancer levels; I can say I have an experience of six months" (Ali, an Eritrean male nephrology physician, has 17 years of experience)

"As a family physician, I have a bit of experience with that. A family physician can manage and treat all type of problems. Almost 80% of the community problems can be dealt with a family physician. Palliative care is not part of our job, but we can deal with it... We provided to patients coming to me complaining of what I call it, community problems" (Rami, a Saudi male academic medical staff, has 22 years of experience)
Perceptions of Palliative and End-of-Life Care: In this subtheme, the participants explored their varied perceptions of palliative and end-of-life (EoL) care as treatment options for renal patients in a Muslim context. According to Hasan, patients are unaware of the concept of EoL care as a terminal option for renal disease, so it is rarely discussed with patients and their families. Hasan also reported that, although it is difficult to discuss this treatment with patients and their families because family members first need to be reassured, it is very important for them to know about it. However, Rana and Maha emphasised that Arab patients and Arab culture have difficulty accepting palliative care as a treatment, especially for renal patients. Due to cultural reasons, some patients will reject this treatment. As these views need to be considered when adapting the tool, other words to describe EoL need to be used, rather than expressing it explicitly. As they stated:

"The choice of end-of-life care, it is not clearly for people to hear... I think patients should know about this thing, but maybe you start the first, and this is just the family sometimes with the patient would so. Sometimes it is difficult to discuss the end of life, maybe with the family and some of the patients. I think it is very rare to have it. However, some of the patients can ask you need to discuss it while some patients need to talk to their families first" (Hasan, a Saudi male nephrology consultant, has 37 years of experience)

"Not all people or patients accepted treated or managed with palliative care. There is no need to explain in detail the process of end of life or remember patients, you are at the end of life, and they are. As you know, the brain behaves, believes, and the culture of Arab countries do not like to discuss endof-life with people" (Rana, an Egyptian female academic nursing staff, has 20 years of experience).

"The point of palliative care is meaningful for any patient but in the Arabic culture not ... This issue (meaning palliative and end of life care) makes them more frustrated, sad or unhappy and affect their decision or ability to choose" (Maha, an Egyptian female academic nursing staff, has 15 years of experience)

6.2.2 Part Two: Interview Themes

This part focuses on data that emerged explicitly about participants' perspectives on cultural adaptation of the YoDCA tool. Four main themes surrounding the essential elements of adapting the YoDCA tool or booklet emerged from the data: (1) overall impressions of the YoDCA tool; (2) comprehensiveness and completeness of the informational content; (3) sociocultural appropriateness; and (4) suggestions for the application and implementation of the YoDCA tool.

Theme 1: Overall Impressions of the YoDCA Tool

This theme summarised both the feelings and impressions experienced by participants following their reading of the YoDCA tool in terms of relevance, interest, and what they thought the main message was for their practice. Moreover, their perceptions included the way content was presented, the amount of information, and their suggestions to improve the adapted tool. This theme includes five subthemes: opinion of the purposes and scope of the tool; perception of informational content layout; suggestions for informational layout modifications; perception of informational content amount and length; and suggestions for informations.

Opinion of the Purposes and Scope of the Tool: This sub-theme emerged when the participants were asked for their general perspectives on the YoDCA tool as an educational intervention. Throughout the participants' review and evaluation of the content of the tool, their attitudes towards its content varied. Most participants had a positive attitude, while only one had a negative attitude towards the tool scope and its use in clinical settings. For example, Hasan reported that the tool is helpful for preparing HCPs for discussions with their patients and educating renal patients, as well as HCPs, about conservative management and decision-making processes. Others, such as Rana, Khalid, Layla, Sami and Tala stressed that the tool could be helpful for facilitating the patient's decision-making process and involvement. Only one participant, Rami, had a negative attitude: he rejected using such a tool for his patients to consider their decision making, believing that, compared with dialysis treatment, conservative management would reduce the patient's life expectancy. Thus, he did not consider it as a treatment option for the ESRD patient and would not offer it to his patients. As they described it:

"It is very simple, and I think it is mainly for educations of patients and relative and probably if we have some other to educate the resident and to encourage the resident to join nephrology to be good ... We have to learn our staff about how to deal with the patient and what to speak with them about the future management and it is a good tool for physician and social worker to know about it and to have it in" (Hasan, a Saudi male nephrology consultant, has 37 years of experience)

"This booklet will give a comprehensive picture of CKD and different methods of CKD management and make. It is useful for patients because this information will help the patient to facilitate him to think clearly and freely to take his decision regarding their renal replacement therapy" (Rana, an Egyptian female academic nursing staff, has 20 years of experience)

"I will not give it as a tool to my patients because, Alhamdulillah, we have enough power to give him the right and the good treatment. How come I will give them a choice between (dialysis and conservative management), let them live for weeks or let them live for 10 years? Totally different. From a medical point of view, which I mean the availability of all the medical resources for the patient free of charge, or even if it is with charge, a lot of people will help him to be treated in a private hospital but not offer them a conservative treatment that he will live only for weeks. No, it is totally (not acceptable)" (Rami, a Saudi male academic medical staff, has 22 years of experience).

Perception of Informational Content Layout: In this sub-theme, the participants explored their thoughts about the information itself and the way that it was presented in the tool. Most of the participants had a positive attitude towards the YoDCA tool in terms of its presentation and organisation of disease trajectories and management information. Hasan, Sami and Tala commented positively on the DA tool's structure and organization, as well as the parts of the tool they liked most. However, Rana and Maha reacted negatively towards the organisation of the tool's informational content. Rana reported that some information sequences and arrangements would make it difficult for patients to follow and think about their decision,

whereas Maha believed that the tool should lead patients to their decision through an organisation that moves from general to specific information, and that this needs to be considered during adaptation. As they reported it:

"Very well organized ...What I like is that it takes things step by step and it is very simple. Taking pre-dialysis, dialysis, and the future management, which is good. I like to have such steps to be adopted in CKD patients" (Hasan, a Saudi male nephrology consultant, has 37 years of experience)

"Well, there are a lot of things to be liked about this tool. First, it is a good design layout, for example, if we talk about introduction of the kidney function is very well written and it is quite inaugurated that what are the functions of the kidney in the body. The second part is that the decision map, it is amazing, it is very well written part in the decision tool briefly describes all kinds of treatment options available and different stages of making those decisions for example, at switching units is very simplified, but it is very comprehensive at the same time" (Sami, a Pakistani male nephrology consultant, has 9 years of experience)

"In deeds, the tool was not organized in my opinion because consequence of some paragraphs or the arrangement of the booklet contents, so it is making decisions so difficult ... There is a part of questionnaire came before discussion its related content part. I think in page 13, table four that questionnaire should be placed after they explained or clarified the information, according that the patient will select the appropriate decision or appropriate method of treatment" (Rana, an Egyptian female academic nursing staff, has 20 years of experience)

Suggestions for Informational Layout Modifications: In this sub-theme, some participants suggested improvements to the organisation and layout of the YoDCA tool. Others were concerned about the format; though they did not necessarily have an issue with the way in which the information is laid out, they had concerns about the way the information is communicated. For example, Maha emphasised that the information presented in the tool

needs to be organised systematically from general to specific knowledge, suggesting that the tool might be divided into three informational content sections: physical, psychological and spiritual. This is particularly important for Muslim cultures, as the inclusion of a spiritual component helps improve patients' health outcomes and their decision-making processes. Including such information through tools provides patients with the psychological care they require to heal their feelings and anxiety in relation to psychiatry. In addition, the spiritual and religious realms play an important role in coping with disease distress and when making decisions. This could provide guidance to HCPs on how to use patient-centred interventions to reduce anxiety, improve communication and make better decisions, especially in this context. The data also suggest that there was a difference of opinion regarding the preferred format in which their patients might like to receive this information, which was to use communication channels other than written materials to educate patients. For example, Rami, Layla, and Ali stressed that patient education should include an audible version of the content using short videos and a visual diagram. However, Sami argued that written material is more credible for patients than information presented on the internet or social media. As they described it in their statements:

> "The booklet should be divided into three parts; physical (disease, its sequels and treatment modalities), psychosocial (psychological problems, interpersonal relationships that affect patient's ability to take decisions) the psychological support the patient in every stage to enable to take a choice, depend on his belief. Then, spiritual care integrates it with palliative care (praying, reading Quran, my God will help me, my God has put me in this difficult situation and asking the god to make me patience and so on ...This makes the patient able to choose" (Maha, an Egyptian female academic nursing staff, has 15 years of experience)

"There are many ways to get information, not just reading. The reading is the best way, if it is coming from respectful reading material and it would make it more trustable. Now we are in an era of social media. No need to make it only a reading material. It can be simplified in a diagram or in a simplified video. You can use many tools that are easy for the patient to understand. If you only focus on reading, you will be stuck and you will not give enough information. You will not get enough people to get the information" (Rami, a Saudi male academic medical staff, has 22 years of experience)

"When something is written, it is easier to believe and use in other parts of the world. Hence, that is not we cannot say that this is maybe this doctrine is saying only for known listeners. So, I think more than understanding it is always the belief that makes decisions easy because if they trust their doctor or if they trust the information, their decisions become straightforward. In these days, age, social media and information on the Internet are available, but how to believe it that is the problem. So, here this tool has a place when something is solid, written, presentable and reproducible then of course, it is easy for any level of accuracy" (Sami, a Pakistani male nephrology consultant, has 9 years of experience)

Perception of Informational Content Amount and Length: In this sub-theme, the participants described their thoughts about the amount of knowledge and information included within the tool, as well as its length. While Layla, Ali, and Khalid described the tool as being very informative, noting that it includes helpful and important information relevant to their clinical practices, they reported that the tool was very long. Taking into consideration patients' preferences for learning styles other than reading, they recommended that tool length be considered during adaptation. Tala, on the other hand, holds the opinion that one could retain the current number of pages or limit certain information. However, Rana and Maha have different perspectives on the amount of information, arguing that the amount of information provided in the YoDCA tool is insufficient to facilitate patient decision-making. They believe that Arab patients have lower health awareness, which could have a negative impact on their health, leading to the need to provide a lot of information. Laila similarly stated that patients in Arab countries are not involved in their healthcare and have limited knowledge of health care conditions and management. Thus, from their point of view, this tool needs to be improved by adding some information. As they stated:

"It is very useful and informative to me, but I told you that healthcare providers, including myself and patients, have little time to read all these booklets. Because I believed this based on my experience, I have 10 years'

experience of Health Education Committee and I am talking based on my experience like patient they do not like to read at all ..." (Layla, a Kuwaiti female clinical nurse staff, has 12 years of experience)

"In terms of length, it is also good not too much information and this is very reasonable for a layman person to read it. Patients, they might have a lot of things they are doing, at their home. So, they might not really read the whole books at one time, and they might read it portion by portion. So, I have tried to act myself as the patient. I want to read this one first and I put it back and continue. So, this is the booklet is already, in terms of page number remain with the current pages, or you just can limit certain information" (Tala, a Malaysian female academic nursing staff, has 14 years of experience)

"Important information that the patient need is not enough to make a decision ... We need more information and more knowledge related to the patient condition and that type of treatment" (Rana, an Egyptian female academic nursing staff, has 20 years of experience)

"...The booklet has valuable information can be used as a guideline for nurses. How to deal with a dialysis or renal patient or nephrology patient. But for the Arabic patient, those patients have a lower health awareness that need to more information and need more details about this disease to add it to the booklet" (Maha, an Egyptian female academic nursing staff, has 15 years of experience)

Suggestions for Informational Content Modifications: In this sub-theme, the participants suggested some modifications and strategies to improve the content of the YoDCA tool. These strategies focus mostly on reducing the length of the tool, and changing the format is one way to reduce the amount of information and number of words. Layla, Ali, and Khalid suggested improving it by reducing the number of pages or employing alternative educational methods. Hasan, Khalid and Sami took into consideration patients with low literacy and suggested ways to make it easier to use with the target population. As they described it:

"In my country, we provide some videos for patient like to give them health education to instruct them about some procedures. So, I will suggest this one, if we can make in Saudi, something like that, and make some videos, more videos like around four minutes, three minutes ... it would be much easier" (Layla, a Kuwaiti female clinical nurse staff, has 12 years of experience)

"I think the booklet must be reduced, I think we do not need the section one and two. Only the main points to help them to read shortly. Focus on the main points ... It will be possible and acceptable for the low literacy people, about three or five minutes maximum to read the booklet and in clear Arabic and English language" (Khalid, a Yemeni male academic biochemistry staff, has 8 years of experience)

"... Generally, I would like to a little bit shorter a smaller number of pages, and of course, we should not talk about the services which are not available, for example, hospice care, which is not available" (Sami, a Pakistani male nephrology consultant, has 9 years of experience)

Another strategy suggested to reduce the length and amount of information was to modify the content, making it more concise. Sami, Rana, and Tala noted that, while the information related to kidney transplants is useful, it needs to be more concise. As they stated it:

> "I have a little bit concerned about the part, for example, the transplant section in this tool. When we liberated the transplant, I did not particularly I would like it to be shorter for example, not this long because my understanding of this tool when we compare conservative treatment versus dialysis ... we should introduce a little bit about transplant but not like one page two pages, we want to make it brief. So, that it is not a lot of information creates confusion, so I will try to be short" (Sami, a Pakistani male nephrology consultant, has 9 years of experience)

> "Kidney transplant option section needs major revision. I believe because I can see that this section is very difficult and repetition. So, like this sentence, most people have transplants, have a better quality of life. Maybe need to

revise the sentence ... This paragraph needs to be simplified, because of a lengthy introduction too much" (Tala, a Malaysian female academic nursing staff, has 14 years of experience)

Furthermore, some participants were concerned about Table 2, which relates to managing the symptoms of kidney disease. Concerns were raised about the content and information included, which elicited diverse responses from participants. Rana and Maha reported that this table omits important information about the pathophysiology of each symptom and that treatment of the symptoms is not clear and needs more detail. They believe renal patients must know this important information. However, Sami argued that this table needs to be concise because it contains general information. On the other hand, Tala liked the table but suggested some modifications. As they reported it:

"In page 8 regarding managing the symptoms of chronic kidney disease. There is no mention about causes of each symptom. Or what is the pathophysiology of each manifestation or why this manifestation arise with a patient with establish kidney disease. Also, in the treatment of symptom not clear and not understandable for the patient, what mean, using tablet for what or what is the type of tablet? What it is the action there, and so on, for all the managing it" (Rana, an Egyptian female academic nursing staff, has 20 years of experience)

"In a table where different symptoms are listed, and then we write them down, and to my liking, maybe unnecessary. We can just say two lines, for example, that these are the usual symptoms, and they are managed, according to doctor's advice with tablets, injections, and fluid because this is too long. As this is a very general information, it gives the impression that this is like that. We are not telling anything specific giving an impression to the patient that maybe this is all what is required that the dialysis or transplant or peritoneal dialysis, they are unnecessary know this is everything is there. I think two to three lines is enough" (Sami, a Pakistani male nephrology consultant, has 9 years of experience) "I guess this is more suitable to go to anemia because between established. Shortness of breath the immediate treatment definitely not tablet should be oxygen. So that is why I think, if you think this can be controversial, that you can remove than repeats with managing anaemic symptoms or that perhaps if this is just some suggestion. And this one, this statement is not clear need to urinate more often? Or perhaps the patient is having problem in difficulty for you urinate" (Tala, a Malaysian female academic nursing staff, has 14 years of experience)

The participants' responses varied when asked if they would eliminate some parts of the YoDCA. Rana suggested removing the decision map presented in each section, while Sami suggested removing the section that focuses on the kidney transplant option. They believe that including it in the tool is pointless because the decision map is repeated, and that each section repeats the same things. Another way of reducing the length of the YoDCA tool is by focusing on its scope and main message. Layla and Sami explored the main message of this tool as it focused on dialysis treatment and conservative management. They believe that information about the kidney transplantation option that is included on page 5 of the YoDCA tool should be in a separate tool. However, Tala argued that no parts need to be removed, and that the focus should instead be on modifying and improving some parts. As they reported it:

"In my opinion decision map in each section of booklet they repeat it many times. We can put it one time at the first previous section. No need to repeat the decision map in each section of the booklet if there is no new content include. But really it is without any purpose for the patient" (Rana, an Egyptian female academic nursing staff, has 20 years of experience)

"It is a very nice topic found to be very useful to apply in Saudi or Middle East, from this perspective, honestly not necessarily to include kidney transplant because the content itself for patients to read about all this conservative or dialysis but for sorry kidney transplant, I think is okay if it is not included. Like it is enough. This one, it is transferred, it is it sounds like something that it needs a lot of information on the different booklet I think, better to keep it separate" (Layla, a Kuwaiti female clinical nurse staff, has 12 years of experience)

"That there was no part of this tool that would be removed from this tool. So far you just stick with the current content, however, improvise in terms of limiting, rephrasing words so that it would not become too lengthy, that is why I say as much as possible, if you can explain by using graphic. That is more interesting actually because people's love graphic nowadays, because during this pandemic people are very tired" (Tala, a Malaysian female academic nursing staff, has 14 years of experience)

Theme 2: Comprehensiveness and Completeness of the Informational Content

Through this theme, participants explored how they perceived the information in the YoDCA tool in terms of its readability level, how they translated it into their own words, and how they thought about and constructed meaning from what they saw. Additionally, they explored their perceptions of the linguistic appropriateness and completeness of the informational content and their suggestions to include new content. This theme includes four subthemes: clarity of the information, linguistics, difficult concepts or expressions, and missing content and new content that are required.

Clarity of the information: In this sub-theme, the participants were asked about the clarity of the information presented within the tool and its readability level. Participant responses varied. Layla, Rana, Maha and Khalid reported that the content of the YoDCA education materials is consistently written at a level that is too high for many patients to understand, even for patients with a higher level of education. They indicated that the tool is not applicable to all patients as the dialysis population includes different groups of people in terms of their age and educational level. Moreover, Layal and Rana stressed the importance of family involvement in the patient education process, which helps patients with low literacy read and understand the tool. However, Tala asserted that the information is written for the patient in a straightforward manner. As they stated it:

"I feel it was like effective and it is giving explanations in the case for healthcare provider, and in a simple way. But as a nurse, I am talking like, it was very easy for me to understand, but I just that maybe it will be a little difficult for patient to understand in detail. Not all patients are educated, and even educated, it is difficult for them to understand some medical terminology" (Layla, a Kuwaiti female clinical nurse staff, has 12 years of experience)

"If the patient is illiterate, his family or his friends or even the kidney professionals can help him in or assisting him to transfer this booklet information to the patient" (Rana, an Egyptian female academic nursing staff, has 20 years of experience)

"What do I like about the booklet is that the information is delivered in a very simple manner. This is great because you are trying to use more layman terminology rather than medical terminology ... It is very direct for work. I will say most of the contents are very direct forward it is not confusing at all" (Tala, a Malaysian female academic nursing staff, has 14 years of experience)

The participants focused on the presentation of the information within the tool as they thought it would improve the level of readability among users. Thus, all participants stated a strong preference for pictures and diagrams to be included in the tool or booklet to enhance their visual attractiveness. Khalid, Layla, Maha, and Rana noted that figures are easily and correctly interpreted and help convey information. In terms of a useful tool within Muslim countries, Tala thought that the addition of more colourful pictures would make it more appealing to patients and their families. As they reported it:

"I think using figures with short phrase or sentences will be attractive for the patient and relatives. If you can add some pictures or attractive figures, it will be nice" (Khalid, a Yemeni male academic biochemistry staff, has 8 years of experience)

"I like I think in terms of content, language, page number is great. Somehow, I still have room of improvement that I would like you to add because I have found this booklet less graphic or used perhaps pictures downstairs in groups, more graphic rather than lengthy explanation... you would like to improve it so that you can utilise it in Muslims communities so I would say the content not bad, but I did have suggestion, to some area (meaning within the booklet itself)" (Tala, a Malaysian female academic nursing staff, has 14 years of experience)

Linguistics: This sub-theme emerged when the participants were asked about the language that should be presented within the new adapted tool: Arabic, English or bilingual. They were also asked about the amount of translated information and language presentation in either the same tool or a separate tool. All participants agreed that, to accelerate the YoDCA's development and adaptation, the tool must be translated into the local language of Arabic and have an adapted English version before it can be used in clinical settings. Some participants, such as Hasan, Layla, Sami and Khalid, preferred that the tool be produced bilingually, taking into consideration patients' level of education, age, preferences, and the ethnic diversity among Arabic-speaking countries. Rami, Rana, Ali and Tala suggested that either Arabic or English should be the language presented in the tool, depending on its main or target users, whether patients with their families or HCPs. As they described it:

"It should be bilingual because we have really Saudi population is around 32 million and the expatriate around 12 million, which is significant number and most of them, they do not read Arabic. So, probably bilingual is important" (Hasan, a Saudi male nephrology consultant, has 37 years of experience)

"I think it depends on the audience group. For example, if the patient, our patient is speaking Arabic, 90% of them then you have to do it in Arabic. You can convey the message in the right way, and they can understand it if you want to for the patient and their family. For the doctors or health team, you can give it bilingual, to make it more understandable if he wants in Arabic but he can understand in English. so, make it bilingual" (Rami, a Saudi male academic medical staff, has 22 years of experience) On the other hand, Maha considered that translation should be for a targeted group, not just the basic Arabic language, because Arabic-speaking countries include a variety of ethnic groups. As she reported it:

> "The tool or booklet should be translated into Arabic, but you should translate it according with culture you will collect the data from it (meaning testing the tool among them). I mean in Saudi Arabia; you should translate in different method than Egyptian language. I mean that the general Arabic or the basic Arabic not suitable for each patient from a different culture" (Maha, an Egyptian female academic nursing staff, has 15 years of experience)

Participant responses varied when they were asked their preferences concerning the style or presentation of the languages within the tool (layout). Khalid, Hasan and Sami suggested and preferred—that one booklet include both languages (Arabic and English). However, Tala preferred that two separate versions of the tool be developed or produced, one in Arabic and one in English. Her view is based on previous research, which reveals that including both languages in the same booklet would be very cluttered and wordy in terms of presentation. Thus, instead of reading 28 pages, they now must read 56 pages, increasing the chances that the reader is not going to read it. As they described it:

> "I think the best choice both Arabic and English. I think you can divide each page to right side for Arabic and left side for English. It will be not big book and it is acceptable. I think the final for will be 30 papers it will be acceptable" (Khalid, a Yemeni male academic biochemistry staff, has 8 years of experience)

> "It is not recommended that even one booklet, you have both languages altogether it is not reasonable to have a bilanguage in one single booklet. So, make it separate the English version and the Arabic version. Then you may ask your patients to make a choice, which one do they prefer to read the English or the Arabic version" (Tala, a Malaysian female academic nursing staff, has 14 years of experience)

Difficult Concepts or Expressions: In this sub-theme, the participants were asked to identify any difficult words, phrases or concepts used in the YoDCA tool and how they would improve it. Some participants claimed that some terms are difficult for non-healthcare providers, including patients and their family caregivers, as well as educated people who are not specialists. While evaluating the whole tool, Rami, Rana and Layla indicated that while the medical terminology is understandable for HCPs, patients need simpler language. Khalid reported that, as the terms 'established kidney disease' and 'conservative care' were not familiar to everyone, patients would not understand them. Tala noted that some expressions or sentences need revising to be more understandable for readers. As they reported it:

> "For me all terminology is understandable. I read it and I know it before. For example, the eGFR, Estimated Glomerular Filtration Rate. I know it from the beginning. It is all understandable. If we simplify it for patients, they will understand. If you find a translation for it, and you will find, it is easy" (Rami, a Saudi male academic medical staff, has 22 years of experience)

"For me it was commonly used term in end stage renal failure and the first time I faced with this in many terms in the tool maybe like conservative care. I left for Wikipedia, and I was reading about this care. This is new for me because I am not a specialist ... Other term established kidney disease is new for me. I am familiar with chronic kidney disease, end-stage disease, acute, but I have never used it or read it before. This is only for me, but maybe it will be accepted by others" (Khalid, a Yemeni male academic biochemistry staff, has 8 years of experience)

"In terms of content, I have no objection it is a very good. An example, I noticed some area need just double-check the sentence, the regular check-ups include could, I guess that right here you read blood pressure, urine and blood test not urine and blood pressure test. I think that is in terms of the location just have to look back here" (Tala, a Malaysian female academic nursing staff, has 14 years of experience)

Missing Content and New Content that are Required: In this sub-theme, the participants identified some information that was missing in the tool and recommended adding this

information to the new adapted version. They believe that some information is necessary for renal patients to read and understand from various perspectives. For example, Ali believes that patients need to be educated about diet because conservative management includes not only medication but consideration of patients' diet and lifestyle, and these could be culturally specific. In another instance, participants felt that information about psychological and spiritual support is missing, particularly in the Muslim context. Khalid and Maha emphasised the importance of adding information to help improve patients' psychological status. Moreover, Tala indicated that the Muslim context must include information that focuses on the spiritual needs of ESRD patients. On the other hand, Ali stated that ESRD patients need to read and know about the importance of the psychiatric consultation services that are available to them. As they described it:

"I think it is a well-recommended tool, but maybe you need to add something about the diet because conservative is mainly focusing on his diet and his lifestyle and not only the medication. Some of food, is not combinable with our culture and whenever you told the patient, you need not to eat more than 80 grams of beef every day, then how are you going to understand the 80 grams of beef. He only knows 'Mufatah' and 'Mandy' (traditional Saudi food). He needs to understand how much he needs to eat simply" (Ali, an Eritrean male nephrology physician, has 17 years of experience)

"The common psychological problems associated with ESRD and fear from death, you should provide psychological care for each problem and how patients deal with negative feelings ... In this booklet I feel that you need physiological and spiritual support for the patients in every stage to take a decision. Needs a psychologist to support the patient and psychologist Muslim to guide the patient or support the patient with Quran to assist them..." (Maha, an Egyptian female academic nursing staff, has 15 years of experience)

"I thought this book is not focused at all on spirituality. But later only I notice in a few last portions of the section then only I noticed this issue of spirituality. So, I believe that there is one graphic should be added over here (meaning in picture 3) on spiritual needs ... I will see all of sections here are relevant, but for here you can edit up one more content on my ability to perform my daily spiritually. For example, just one heading like this, might focus on lifestyle another one heading my ability to perform my spiritual needs (meaning in Box 2)" (Tala, a Malaysian female academic nursing staff, has 14 years of experience)

Theme 3: Sociocultural Appropriateness

The original DA tool was targeted towards those of Western culture, whereas the new target audience is of Muslim culture. Significant differences exist between the two cultures in terms of religion, decision-making processes (particularly family inclusion) and, as explained in the preceding part, the patients' level of knowledge about disease. This theme investigated the participants' views as to whether the original tool is culturally appropriate for particular cultural groups, such as Muslim groups, and how they would improve the tool to be more acceptable in the Muslim context. This includes two subthemes: (1) sociocultural acceptability and applicability of the YoDCA tool and (2) Muslim cultural attitudes and cultural differences.

Sociocultural Acceptability and Applicability of the YoDCA Tool: This subtheme emerged when participants were asked whether the original tool is acceptable and applicable to Muslim cultural settings. Participants' attitudes towards the social acceptability of the YoDCA tool, in particular its main scope of conservative management in Muslim clinical settings, varied. Some participants found it unsuitable for a Muslim context for various reasons, while others found it suitable. The participants explored their perceptions towards the acceptability of the entire tool, assessing conservative management as a treatment option for renal patients from Islamic, cultural and medical perspectives. From the perspective of religion, some participants believe that the tool would not be acceptable in a Muslim dialysis care setting. Some policies and guidelines in a Muslim healthcare setting may be influenced less by religion, and others more by religion. For example, Hasan emphasised that the religious authority's view of conservative management as a treatment option in the Muslim clinical context could influence the tool's acceptability in the Muslim dialysis centre.

In Muslim culture, any management that includes treatment withdrawal or discontinuation is deemed questionable by the religious authority within the Ministry of Health prior to implementation based on Islamic rules. For example, a DNR order is approved for practice within the SA clinical setting by the religious authority. As conservative management is considered a non-dialytic treatment option, it must be reviewed and approved according to Islamic rules prior to being introduced to renal patients. He also emphasised that we could discuss the tool, including conservative management, once the Ulama (Muslim authorities) have given their approval. Moreover, both Layla and Ali felt that, in some circumstances, the tool is not applicable for patients in a Muslim culture. Specifically, they found some aspects of the informational content to be offensive and insensitive, and any adaptation would need to remove these words. Further, as discussed in Part 1, Muslim patients believe in Allah and thus have different perspectives on palliative and end-of-life care management; indeed, they avoid discussing such topics. Rana and Maha expressed concern about the use of such terms in the adapted version and suggested modulating these words. As they reported:

"From an Islamic point of view, no patient has offered to stop dialysis or medication for the patient. However, we struggled to get DNR accepted from Ulama, and they accepted that. Since they accept DNR, I think this will come in the future (accept conservative management). So, either patients will go for palliative or not to enter the dialysis because they are very sick and, in court in sharia, there is permission that if you have someone who you cannot, who you think as a doctor that cannot be regained his effectiveness and his health do not do anything. This is, we have it, but still, we must push further for high Ulama opinion but not one not a single one ... Once we get a green light from Ulama we can discuss that (meaning the tool)" (Hasan, a Saudi male nephrology consultant, has 37 years of experience)

"... There are some parts and sections I think we should change, some words, some sentences that do not apply to us in our Muslim country. Page seven and eight, the patient, they will lose their ability to drink alcohol and six drive. In Kuwait, we do not use this sentence, we do not write it on any paper because we know it is offensive for the patient to use such words, I think it is better to remove them" (Layla, a Kuwaiti female clinical nurse staff, has 12 years of experience)

"... In our culture, end-of-life care is better avoided because this discussion makes the patient think they are near death, makes them more depressed, and may complicate their condition. The part that discusses end-of-life treatments need to be omitted because our culture does not accept such discussions. But you can present it differently. Just when talking with your patient if they refuse or stop the treatment you will face complications like that" (Rana, an Egyptian female academic nursing staff, has 20 years of experience)

From a cultural standpoint, some of the participants had a negative attitude towards conservative management as a treatment option in the Arab Muslim context. Khalid, Ali and Rami argued that the conservative treatment pathway is not suitable for the Middle East context and that this treatment cannot be broached with patients for cultural and religious views or reasons. Additionally, Rami was concerned about the tool's main message. He believes it was more appropriate for the tool's main target group, people of Western cultures, but not suitable for new populations, such as those living in a Muslim culture, due to differences in cultural attitudes and family roles. As they reported it:

"I think this conservative management is new method, not widely used, not word we use here in Saudi Arabia or in the Middle East country... the conservative care, I think, need to clarify because, as you know, we are Muslims. We trust in Al qadha wa al qadar you know is (Divine will and decree)" (Khalid, a Yemeni male academic biochemistry staff, has 8 years of experience)

"It is very hard in our culture to convincing the patient to stop the treatment and be in the conservative management ... I tried once to convince one of the patients to stop the dialysis because the patient was terminally ill. Then when we decide that he needed to go for a conservative, suddenly of no-how, all the family is coming, and they start blaming that you want to kill him. We still did not have this gap of understanding of the people. For example, if I am convincing my patient today to stop the dialysis and he needs to go because the life expectancy from the conservative versus the haemodialysis is almost the same. But if you try to convince those nominated patients or those selected patients, you will end up with blaming of the culture and the regulation of the law, the medical law does not prevent/protect you" (Ali, an Eritrean male nephrology physician, has 17 years of experience).

"This topic conservative management are not seeming right for patient in Saudi Arabia and other Muslim culture as we are throwing him to the hell ... It is not found in our society leaving a patient who need a treatment. We are leaving him ... Our families, they are so connected, not only the first-degree relatives but also the extended relatives, they can donate for you" (Rami, a Saudi male academic medical staff, has 22 years of experience)

As a result, Rami proposed that, to be more acceptable and applicable in the Muslim context, conservative management be removed from the entire tool as a treatment option for renal patients in the Muslim context:

"... If we need to adapt this tool to fit to Saudi culture or Muslim culture, we need to remove the conservative management as an option for those patients of course, because this conservative management here, they are talking about medication. I know I am a doctor, that only medication to relieve his pain, and the diet and fluid only. This is the conservative treatment they are talking about. I will not say it is not acceptable. I will say it is not there. We do not have it. We do not let the patient (choose it) even the health professional people, the doctors, they will not tell the patient'' (Rami, a Saudi male academic medical staff, has 22 years of experience)

From a medical perspective, Sami, Hasan, Rana and Maha believe that the tool is applicable and suitable for Muslim patients in terms of presenting other treatment options, such as conservative management, for CKD patients. In contrast, Rami believes that conservative treatment is very risky for patients with renal disease because it may negatively impact their health outcomes. As they described it: "Generally, it is acceptable to the law it is acceptable to Muslim culture and Saudi culture. It is generally acceptable because it is giving you all the options as we discussed earlier, which is giving all the options and describing them and teaching them regarding different modes of treatment. So, there is no for example, because this is not something like asking about, get average donation, which is accepted even in Muslim culture only still there is a debate and there is a section which may have different thoughts, but regarding to this tool, it is acceptable to Muslim worlds should not have any problem adaptation of any culture" (Sami, a Pakistani male nephrology consultant, has 9 years of experience)

"I think it is suitable at the moment since still the patients had to take the maximum management before, they die. I think this concept now is still there and very rare to have some people who still do not initiate dialysis for their patient if they know that it is a terminal case" (Hasan, a Saudi male nephrology consultant, has 37 years of experience)

"Because I'm a family medicine and I'm going to the preventive part, I have to treat the patient and improve his health. This will not improve his health; it is only releasing the inside pain. I mean, what I feel now, but what I am needed to relieve from. For example, now, the dialysis can extend the life of a patient 10 years to 15 years. If he is not doing the dialysis, I cannot guarantee how many days he will live, and put on that, the conservative treatment also, he will live for weeks. I am, by help of God, can give 10 years. So, it is very risky for patients to choose such treatment" (Rami, a Saudi male academic medical staff, has 22 years of experience)

Muslim Cultural Attitudes and Cultural Differences: The participants in this subtheme reported that differences between Muslim and Western cultures in terms of preference in decision making need to be taken into consideration throughout the adaptation process. Khalid and Tala stressed that Muslim cultures prefer family involvement in decision-making, and they recommended that this be taken into consideration when adapting the tool. As they reported, families in Muslim cultures are usually involved in the DM process, and the family

plays a central role in the decision-making process of their relatives. For example, for users from Asian or Muslim cultures, Tala suggested additions to page 5, noting that preferences in the DM process include: 1) family involvement (e.g., their next of kin as children, siblings, or immediate family members or in-laws); and 2) spouses or husbands assisting in the process. Moreover, Hasan indicated the importance of the family's role in supporting, caring for and educating their family member patients. However, Rami raised another point, noting that the cost of treatment is another difference that may influence the acceptance of conservative management within the Muslim context. Thus, the family should be involved in an adapted version of the tool. This could be accomplished by including the phrase "patients and their families" in the instructions or information written for the patient. As they reported it:

> "You know in Great Britain different conditions exist here in Saudi Arabia. This is not only the patient here in Arab countries who decides, but also his relatives, especially if the patient is young. I think here in middle East countries helping from the relatives maybe play role for the deciding how to treat. I think any haemodialysis or renal disease patient cannot decide alone. He needs supporting from relatives or friends" (Khalid, a Yemeni male academic biochemistry staff, has 8 years of experience)

> "... That is why the family is important. Usually, you choose the educated one from the family and the wisest one, and all and so you can speak with them to understand your language. Otherwise, it will be difficult for the patient. And some are emotionally related to the patient, very emotional, so it is difficult for them" (Hasan, a Saudi male nephrology consultant, has 37 years of experience)

> " ... if I am thinking in Western country. I am an old man and I do not have family. My son or my daughter, they are away, and they are engaging their lives, so I need a lot of money. I need a lot of care to go in dialysis. This has cost me a lot. There is another option, which is the conservative treatment, which is less cost of money. I think is not suitable for us because in our Islamic society, especially in Saudi Arabia, the health management is free of charge for all people in the Ministry of Health hospitals and primary health care

centres" (Rami, a Saudi male academic medical staff, has 22 years of experience)

Theme 4: Suggestions for the Application and Implementation of the YoDCA Tool

This theme summarised participants' suggestions for a preliminary plan to implement the YoDCA tool in routine clinical practice. Participants had different perspectives on implementing a new educational intervention in their clinical practice that includes a new treatment pathway, such as conservative care. Some participants indicated that certain steps or processes need to be followed before introducing a tool into clinical practice. Other participants reported a road map of suggestions for the implementation of the YoDCA into clinical settings. Thus, this theme includes two subthemes: the essential preliminary steps prior to tool introduction in the clinical setting and suggestions for the implementation of the YoDCA into the YoDCA in clinical settings.

The Essential Preliminary Steps Prior to Tool Introduction in the Clinical Setting: Participants in this sub-theme discussed the idea that a new tool, such as YoDCA, should go through several steps or processes and require specific consideration before being used in a clinical setting. According to the participants, three main steps and considerations should be followed before introducing the YoDCA tool into their clinical practise within a Muslim context: public health and religious authority policies, community or cultural authority policies, and organisational authority policies, as described below. In terms of public health and religious authority policies, the participants indicated the importance of seeking approval from both religious authorities and public health policy at a national level before implementing any educational intervention material that includes new treatment options. As a result, because conservative management is not widely used in the Muslim Arab context, it is included in this tool as a third option for ESRD. Khalid insisted that health policy organisations such as the Ministry of Health in Saudi Arabia must approve the new adapted YoDCA tool and its conservative management treatment option before it is introduced into daily practice in clinical settings. On the other hand, Hasan stressed that, in addition to health policy approval, this sort of 'conservative management' treatment requires approval from the Council of Senior Muslim Scholars. Thus, before such a tool can be implemented, it must be approved by the country's religious authorities. As they reported in their statements:

"I think this is new method, not widely used in Saudi Arabia or Middle east countries. So, in all steps (of implementation) you must follow the Saudi protocols for the introduction of new methods for that and hospitals or healthcare section. Because I think even the doctor or specialist 100% accept your (tool) but without written consent for the Ministry of Health, I think they cannot use this in the unit... I advise you to contact with any person from the Ministry of Health about this new method to get approval...after you are getting approval from them you can started with patients" (Khalid, a Yemeni male academic biochemistry staff, has 8 years of experience)

"... Broadly, this can be given to high to Ulama and the Ulama agree about it We have such Islamic rules should be in there before implementing it. I think they will agree because they agree about DNR. So, this is a good tool to be given to them and to agree upon ... I think it should go through the minister of health, the minister of health should go to, there's a committee to raise it to higher to the Ulama (Senior Muslim Scholars) and to get the permission from there ... Once we get a green light from Ulama that we can discuss that, but it should be also, as a policy of the hospital" (Hasan, a Saudi male nephrology consultant, has 37 years of experience)

Regarding community or cultural authority policies, Ali raised the issue of community or culture as an issue that can influence the implementation of such a new tool, including a new treatment. Great effort needs to be made to develop community engagement by persuading people, including HCPs and family caregivers, to become engaged and agree to its incorporation into their daily clinical routines. Therefore, according to Ali, the healthcare provider and family members should first be convinced of this treatment before it is offered to patients. He was the only participant who made this point:

"The patient part is easy, whenever you tell the patient, I will stop your dialysis he would be more than happy. The second very important, part is the family culture and physician, how you can convince them that this is the right option of treating the patient and it will never change the life expectancy. I think it is good to start up with the nephrology field or nephrology society, you need to link with like to be implemented you need to link with Saudi Nephrology Society. Then, you need to go to the second level, to the culture, to the people, and that's you are not able to approach them without using right stakeholders and use the influencer in the society the social media. My expectation, this will be a new modality which is being old in the world, but it will be new life in Saudi Arabia. Thus, you need the get the health care specialist which is a big journey and it's not easy" (Ali, an Eritrean male nephrology physician, has 17 years of experience)

Regarding organisational authority policies, Hasan, Khalid and Ali emphasised that once public health and religious authorities grant approval to introduce the tool, it needs to be introduced to the hospital administration and then to a specific HCP and a specific group of patients. As they indicated in their statements:

> "First, if you have a permission to introduce the tools and if I implemented it as the head of the department, I would distribute for the service provider and the social worker and the hospital, I will speak with my staff for each patient, we should do this, each one categorized, uh, we should do it. And it should be even in the policy of the hospital that if you have terminal case what to do with them or patient who need that treatment. Usually, this is within the policy of the hospital and if it is there, everyone should implement it" (Hasan, a Saudi male nephrology consultant, has 37 years of experience)

"The best approach is to, first of all, you need to select your health care provider. And whenever you go with that health care provider, you can ask them for a selective criterion for the patient" (Ali, an Eritrean male nephrology physician, has 17 years of experience)

Suggestions for the Implementation of the YoDCA in Clinical Settings: In this sub-theme, the participants reported and proposed ways to introduce this tool in clinical settings. They agreed on some points that must be considered when implementing such a tool, including who is involved in the implementation, the delivery method, and implementation location and time. In terms of who is involved in its implementation, the YoDCA tool focuses on SDM. Therefore, patients and clinicians need to discuss the options using the best available

evidence and make informed, shared decisions that consider the patient's context, values and preferences. All participants stated that both HCPs and patients, along with their families, should be included in this tool as the main or target audience involved in its implementation. Moreover, Tala indicated the priority of users—that is, the patients themselves and then the HCPs—and considered the cultural preferences in Muslim countries, such as family involvement in the decision-making process. However, Sami argued that patients' health conditions may influence the extent to which they can be involved in decisions. As such, their representative quotes are as follows:

"The main target audience is still patients. Nevertheless, the healthcare professionals treat, the patients also must read the content or else he, or she might not know what the patient's expectation is from first they have the professionals. We are part of Asia or middle east country; we are very close to our family members. Sometimes if you are not well as with the content, you still need to seek help from your family members that are available in your house. So, I will say, if you ask me in terms of priority, you should go to the patients and to the healthcare professionals make to equally be the next of kin who really take care of these patients" (Tala, a Malaysian female academic nursing staff, has 14 years of experience)

"I would say all of them. HCPs, Families definitely and in many situations, patients as well some patient unfortunately, when we talk about conservative care or dialysis, maybe they already have low conscious level, or they are not really able to read and understand. But some patients will be able to read and understand. So, I would say all three of our patients, families and healthcare worker is the target audience for this tool" (Sami, a Pakistani male nephrology consultant, has 9 years of experience)

On the other hand, Hasan and Maha emphasised that multi-disciplinary HCPs, including doctors, nurses, social workers and psychologists, should be involved when implementing this tool. As they reported it:

"I think it is the healthcare provider- plus social worker, plus-patient and the family of the patient. So, I think all of them are involved. Even the physician

himself, he should know about it... So, it is multi-dispensary people together in order to get the patient or the family to understand what's going'' (Hasan, a Saudi male nephrology consultant, has 37 years of experience)

The participants had different views about which patients would be eligible to use the YoDCA tool when it is implemented in their daily routines. Hasan, Ali, and Sami insisted that the tool could not be used with all ESRD patients. There are specific criteria for selecting patients who will benefit from the tool, such as the elderly, patients with comorbidities, and patients with terminal illnesses for whom dialysis is not beneficial. Additionally, Ali and Sami argued that there are many applications of the YoDCA tool in terms of its implementation with patients in clinical settings. Each scope, according to them, determines which participant can approach and use the tool. For example, they indicated that one of the scopes could be that using the tool with a newly diagnosed patient is easier than with a patient on treatment. However, Rami expressed a negative attitude towards such tools; he refused to implement the YoDCA tool, which includes conservative management in daily practice in a clinical setting in a Saudi Arabian context. As they described it:

"This tool cannot provide like a decision-making tool for all patients who are reaching end stage renal failure. This tool applied for those who are terminal case and for patient who could shift between treatment modalities" (Sami, a Pakistani male nephrology consultant, has 9 years of experience)

"There is a lot of scope for this decision aid tool. This tool could be useful for newly diagnosis patients as well as young patient. This tool cannot provide decision making to everyone, because as I said if the patient is young, and he doesn't have a lot of comorbidities ... For him, it would be between three options, dialysis, haemodialysis, peritoneal dialysis and renal transplant. So, the tool should mainly focus on these three options, and explaining their benefits and risks and according to his lifestyle and availability of doner as well. This tool is also talking about conservative treatment, palliative and end of life care that is relevant for elderly people, in some patients this is one of an option" (Sami, a Pakistani male nephrology consultant, has 9 years of experience) "I will not introduce it, especially this tool. It is not suitable. I will not introduce it from the beginning" (Rami, a Saudi male academic medical staff, has 22 years of experience)

The participants made a variety of suggestions regarding mode of delivery and time and place of implementation, such as timescales during the disease journey and identifying specific places to deliver the YoDCA tool in clinical settings. For example, Maha recommended introducing tools via the development of an education programme. Rami recommended that they introduce the tool during a consultation session for their patients. On the other hand, Sami suggested that the tool should be introduced to patients in the nephrology clinic, while Tala suggested that the nephrology clinic's waiting area and day one of admission would be a better place and time for its implementation. As they reported it:

> "After preparing educational material or booklet, you should prepare an educational program make 12 or 10 sessions. I will divide it into theoretical and practical session. I will use media such as PowerPoint of booklet, posters and I will use video... Educational program should be start early at inpatient or outpatient clinic according to patient's status in a specific time suitable and comfortable for patients to help them a long their disease journey to take decisions independently not affected by other opinions" (Maha, an Egyptian female academic nursing staff, has 15 years of experience)

> "The other option how to make the patient decide about his treatment. If we have a direct contact with the patient, we will give him the information through a face-to-face meeting and let him come to my clinic and explain the situation to him" (Rami, a Saudi male academic medical staff, has 22 years of experience)

> "It has to be induced in the clinic, there are in the clinic where we follow the patient from earlier stages and sometimes there is a referral in the late stages where the sometimes you receive from primary health care patient is advancing period and is coming to you. We call as a low clearance clinic. So, because clinic scenario, we don't have unlimited time, unfortunately, address all the questions. So, we can introduce that tool there for the patient to read

and have some information regarding this and then answer their question in the next visit'' (Sami, a Pakistani male nephrology consultant, has 9 years of experience)

"I will say that looking at this tool it is actually relevant to be disseminate at clinic setting and because while waiting for their turn, you can give this too, and almost the patients too tick, certain information, like the boxes that you want them to tick perhaps while waiting. Just introduce and ask them on this. Then it is actually relevant as well to be given for the patient at the ward setting particularly during the first day of admission, because their stay will be a little bit longer" (Tala, a Malaysian female academic nursing staff, has 14 years of experience)

6.3 Chapter Summary

In summary, this second stage of study—interviews with the renal experts—were crucial in supporting the need for decision support for renal patients undergoing renal treatment and in informing the content of the culturally adapted draft of the YoDCA tool. The first part helped to determine the factors that influence the quality of renal care provided and explained how the Muslim context particularly Saudi Arabia influences the care provided for renal patients. Further, as shown by the data of the two participants who had clinical and academic/research roles, the lack of knowledge and practice of palliative care for these patients further supports the idea that additional support should be provided for individuals faced with such healthcare decisions. These findings enable us to conclude that meeting the needs of Muslims with renal disease requires educational interventions that increase their level of awareness about the disease and its management and facilitate their decision-making process. Additionally, part two explored participants' perspectives on the changes required to adapt the YoDCA tool. Following the initial ideas that guided the decision aid adaptation, the next stage of the research will incorporate experts' views in its preliminary adaptation. The culturally adapted tool will be reviewed in the next chapter.

Chapter 7: Cultural Adaptation and Translation Processes of the YoDCA Tool

7.0 Introduction

The main goal of the YoDCA adaptation and translation processes described in this chapter was to provide English and Arabic versions that were socioculturally acceptable to Saudi patients with ESRD and their family caregivers. The previous chapter described step 1 of Chanel et al.'s (2018) cultural adaptation process, which explored the original DA and the new cultural context by reflecting experts' views and input. This chapter reports Steps 2, 3, and 4, which adapt the original DA to the new cultural context, test the adapted tool, and develop the final versions and reporting adaptation process. Furthermore, it describes stages of crossculturally translating the tool from its original English version into Arabic, as well as the rationale for each stage's content adaptation. This chapter is divided into five parts. Part 1 (7.1) presents step 2 of culturally adapting the YoDCA, which went through different versions, from the preliminary adapted draft (Version 1), section 7.1.1, to the penultimate English variant (Version 5), section 7.1.2. It also provides information on the translation process in Section 7.1.3, which used the forward-backward translation technique to produce the Arabic version of the tool (Version 6 and its subversions). Content validity evaluation findings are reported in Part 2 (7.2), followed by Part 3 (7.3), which describes step 4: developing final versions and reporting on the adaptation process. Part 4 (7.4) describes the preliminary implementation plan. This chapter concludes with a summary in Part 5 (7.5).

7.1 Step 2: Adapting the Original Decision Aid to the New Cultural Context

This section discusses the aspects of the YoDCA tool that were adapted in accordance with the data collected. The findings from the interviews with the patients and/or their family caregivers as well as the findings from the modified systematic review (summarised in Chapter 5), were incorporated in the sense that they reinforced that such a tool was needed and guided decisions about choice of DA tool. The adaptation process described in this chapter was heavily informed by the findings of the expert interviews (summarised in Chapter 6) and discussions with YoDCA's original authors: Dr Anna Winterbottom and Professor Hilary Bekker, both working at the University of Leeds (Winterbottom *et al.*, 2018).

These discussions took place in videoconference meetings held over Google Meet and numerous follow-up e-mails to ensure that the original authors approved the adaptation process and resulting tool. Chapter 4, Section (4.3.3), explained the methodological basis for the adaptation. This process was time consuming because the cultural adaptation and translation required six versions and six subversions (see Figure 8), beginning in November 2021 and ending in May 2022. Appendix 15 presents the timeline of the adaptation process.

These versions are presented in three stages in this chapter:

- Stage 1 the preliminary adaptation integrated the findings from the interviews with experts (Version 1).
- 2. Stage 2 the first adaptation involved discussions with a team composed of the original authors of the tool and a medical illustrator (Versions 2–5).
- 3. Stage 3 the second adaptation was the translation into Arabic (Version 6 and subversions).



Figure 8: Versions of the YoDCA Tool Developed through Cultural Adaptation

7.1.1 Stage 1: The Preliminary Adaptation

Version 1: Input and guidance from experts guided the major content adaptations as to how the recommendations related to each emerged theme could be applied in the adaptation of a YoDCA variant for the Saudi context. There were two levels of adaptation: clinical and cultural; some adaptations were considered recommended, while others were considered advanced, as described in Chapter 4, Section (4.3.3.4.2.1). The changes made to the YoDCA content were based on the three themes that emerged from the interviews with experts. These themes – overall impressions of the YoDCA tool, comprehensiveness and completeness of the informational content, and sociocultural appropriateness – are described below. Table 19 summarises the key modifications to the YoDCA tool recommended by the experts, the general themes that these suggestions corresponded to, the specific changes made to each version of the tool, and their rationale.

Theme 1: Overall Impressions of the YoDCA Tool

This theme represents modifications to the YoDCA tool to apply feedback from experts on the layout of the information presented, the length of the tool, and its format. They suggested that the tool should be reorganised and divided into three parts: information about physical care, followed by psychological care, and finally, spiritual care. Since all three parts were already included in the tool, this suggestion to divide it into three sections was not adopted. The experts also pointed out that the tool was very long, which may affect its acceptance or use. Several strategies were identified by the experts to reduce the length, which were considered during adaptation. This included being more concise, removing some parts, and using figures and graphs instead of words. For example, as shown in Figure 9, based on their suggestion, a graphic about kidney functions was inserted instead of using words to describe the five jobs performed by the kidneys.



Figure 9: Differences between the original and adapted tool (Version 1).

The experts also suggested either removing information about the kidney transplant option or making it more concise, as the tool was mainly meant to be used to decide between dialysis and conservative management. This suggestion was incorporated by shortening that section and adding statements, as shown in Figure 10: 'Please note that kidney transplant information is covered in a separate booklet' and 'For more information, please speak with your professional kidney treatment team'. Other parts they suggested reducing or removing are listed in Table 19.



Figure 10: Differences between the original tool and the first adaptation (Version 1): Box 1 on kidney transplant options.

Another suggestion for reducing the length was to use more graphics particularly in such a pandemic era, people are very tired, and figures help convey information better than words while also increasing visual appeal. This suggestion was considered during adaptation (see Table 19). Thus, the original statement was shortened to 'Tips for healthy kidneys', as in Table 1, and colourful visuals were added to explain these tips (see Figure 11). Figure 11 illustrates the changes made to Version 1. I modified Table 1 in the original tool, which included tips for keeping the kidneys healthy. As shown, there was a modification made by shortening the 'tips' statements and adding pictures that explain each tip.

Table 1: Tips For Keeping Kidneys as Healthy as Possible [3]

To slow down the loss of kidney function:

- · Go to your regular kidney unit appointments monitoring your well-being and regular tests can pick up changes to your health before you get symptoms
- · Check your blood pressure at home or get it checked regularly, and take blood pressure medications - high blood pressure damages kidneys
- Ask pharmacists about any 'over the counter' medicines and 'natural' remedies you are planning to take, to check if they can damage the kidneys in people with EKD
- · Follow the instructions for taking all medications your doctors give you
- · Have a winter flu jab every autumn people with EKD are more likely to get infections
- Get advice from a pharmacist, GP or kidney team about treating infections, high temperatures and diarrhoea quickly - getting dehydrated can damage the kidneys
- · If you have diabetes, avoid high blood sugar levels diabetes damages the blood vessels in kidneys
- Give up smoking or at least cut down smoking speeds up kidney damage
- · Give up alcohol or at least cut down alcohol speeds up kidney damage
- Do some exercise 2-3 times a week regular exercise helps keep kidneys healthy
- · Keep a healthy weight being overweight means your body, and kidneys, have to work harder
- · Cut down on salt salt can lead to high blood pressure which damages the kidneys.

Original Tool

Figure 11: Differences between Table 1 in the original tool and adaptation (Version 1).

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Adapted Tool Version 1

Furthermore, the tool was criticised for not being colourful, which may make it less appealing to users. Thus, a coloured background was added to the box to make it more attractive (see Figure 9). In addition, some experts suggested changing the tool's format, either to make an audible version using video or an electronic version. However, due to time and resource



Table 1: Tips For Keeping Kidneys as Healthy as Possible [4]
constraints, this suggestion is currently unworkable. These options will be considered in the future when producing further versions of the tool.

Theme 2: Comprehensiveness and Completeness of the Informational Content

This theme focused on helping users understand and use the information in the YoDCA, implementing the experts' advice about the informational content, and identifying the patients' informational needs. The experts identified some issues related to the content's readability. These included the way the information was presented; difficult words, phrases, and concepts used; and the translation of the original tool. Another issue identified was that the original tool neglected some relevant information that could facilitate users' decision-making. To address these issues, the experts suggested several essential modifications: a) the use of plain, simple language; b) translation into simple Arabic; c) use of colour, pictures, and diagrams to enhance the clarity of the information; d) revision of certain sentences; and e) addition of certain information to ensure the tool's completeness.

Not all these suggestions were implemented in the initial YoDCA iterations version 1, but all were eventually incorporated into subsequent adaptations. For example, plain language and tool translation were addressed in Version 6 (Stage 3). Version 1 used additional pictures to enhance clarity in receiving and understanding the information. A picture of the kidney transplantation process, for example, was added to explain the placement of transplanted kidneys. In addition, a picture of the haemodialysis process and pictures of haemodialysis and peritoneal dialysis access were added (see Figure 12). Figure 12 shows that the researcher added three additional pictures to the adapted version 1 to provide more explanation about dialysis treatments and access.



Figure 12: Dialysis treatment: process and access; changes from the original tool to Version 1.

Furthermore, images representing Muslim patients' spiritual needs and healing conditions were added. Figure 13 illustrates the difference between picture 3 in the original tool and picture 5 in Version 1. Figure 13 suggests that people with established kidney disease (EKD) need to think about what is important in their lives before choosing treatments that suit their values, although this does not specifically address Muslim patients' spiritual needs. Thus, I added a picture representing spiritual values in a Muslim context. Moreover, some of the original images were replaced with ethnically representative pictures in the booklet. For example, the icon that represented pets on the cover page of the original tool was replaced by a prayer symbol icon in Version 1.



Figure 13: Differences between the original tool and Version 1; images representing spiritual values were added.

Another suggestion by the experts was to provide additional information in the adaptation. Some of this additional information was medical and not specific to the culture, such as general information about kidney anatomy, information about CKD and its types, an explanation of its symptoms, a comparison of treatments, and the psychological and psychotherapeutic support needs of patients. There was some disagreement about whether these items should be included in the adapted version. Thus, not all these suggestions were followed, and mainly adaptations related to the cultural relevance of the tool as well as only few clinical adaptations were considered, as explained in Chapter 4. On the other hand, some experts suggested that, instead, they would add information related to psychological and spiritual support. This is necessary for CKD patients, particularly those in Muslim contexts. This suggestion was followed in Version 1 (Figure 14).

Coping with Established Kidney Disease

When people are told they have EKD, it can affect their lives, how they feel, and the lives of those around them. People can feel shock, grief and denial at first. Some people find it difficult to concentrate and think clearly. It is common for people to experience anxiety, depression, concerns about body image, and loss of self-confidence. People suffering from EKD often present with these common psychological problems. Those patients need to be encouraged by their family and kidney professional to visit psychiatric specialists and consult with them. These feelings and problems may go away by themselves as people get used to living with EKD. Some people find sharing their experiences with their kidney team, and their family can be useful [2].

People with EKD have to try to adapt to this chronic physical illness. Some of those people cope with their illness in different ways. Being active in choosing treatments and in managing the illness helps maintain a feeling of being in control and helps people make sure they get the treatment that best suits their lives. Adjustment in cognitive, emotional, and behavioural terms is required by patients and their families.

Many people with CKD need help and psychological support from other people, especially if the disease gets worse. This help can come from their family, friends, and/or health professionals. Psychological support specifically provides an appropriate basis for the incorporation of Islamic spirituality into the healing process of Muslim patients. In the Muslim population, spiritual healing is widely practised by Saudi people for many diseases, including those that cannot be cured. The treatment in such cases entails reading of the Noble Qur'an and sayings of Prophet Mohammad (peace be upon him), Rugya (see picture 4), eating honey, black cumin, and Zamzam water, which is obtained from the well in the Holy Mosque ^[10]. Zamzam water is believed to cure many diseases [11].



Picture 4: Treatment with Rugya [12]



Figure 14: Information for coping with EKD in Version 1.

Figure 14, shown above, depicts an additional page and text added to the original tool that addressed the psychological and spiritual needs of and care for EKD patients, particularly those living in Muslim communities, as this information was not present in the original tool. For more detailed information, see Table 19 for a summary of the changes adopted and declined in Version 1 along with rationales.

Theme 3: Sociocultural Appropriateness

This theme reflects adaptations aimed at enhancing the acceptability and usability of the YoDCA within the Muslim context. In the interviews, some comments were made regarding the cultural relevance of the YoDCA tool. Some of the terminology was deemed inappropriate for Muslims, including words that participants might find offensive or sensitive. These concerned alcohol and sex and were located on pages 6, 7, and 8 in the original tool. The experts recommended removing the word 'alcohol' from the adapted version, as they expressed that some patients may find any assumption that patients drink alcohol offensive. Saudi Arabia prohibits alcohol consumption religiously; therefore, it is also banned legally (Al-Haqwi, 2010). Despite this, it has been shown that alcohol use is not uncommon (Sweileh *et al.*, 2014; Bell *et al.*, 2017), especially among young males (Al-Haqwi, 2010). In the Muslim context, particularly in Saudi Arabia, most ethnic groups are Muslim Arabs. Indeed, there are people who have been alcoholics, but this is not the cultural norm; therefore, the reference to alcohol was removed.

Moreover, pages 7 and 8 discuss, as a symptom, how ESRD patients may lose interest in sex. The expert suggested removing this word, as most HCPs in Arab and Muslim countries are reluctant to discuss taboo subjects, such as sex, with both male and female patients. Their concern was that discussing sex and intimacy would be inappropriate and embarrassing. According to Dupont (2016), in Saudi Arabia, as in the Islamic and Arab worlds, public discussion of sex is taboo. As a result, Version 1 omitted the sentences that mentioned sex.

Another example is the use of the term 'end-of-life care' in box 3 on page 19 of the original tool. The participants stated that Arab and Muslim patients avoid discussing end-of-life care because they are afraid of it; these patients do not accept it as a treatment. Therefore, it is inappropriate to mention it clearly in the tool. As they suggested, it is preferable to omit this

section or express it more clearly by using alternative terms, such as 'psychological and spiritual needs'. Almasabi (2013) reported that Muslims strongly believe that God heals illnesses, both physical and psychological. It is also obligatory for Muslims to seek medical treatment whenever possible and should not end their lives. Patients in the Muslim and Arab communities do not expect their HCPs to provide them with information or reminders about terminal illness (Attum *et al.*, 2018), as for the end of life, it is a matter in God's hands and cannot be think about or accurately predicted. In Islam, people believe that Allah (God) determines the exact time of death for everyone by determining the longevity of everyone (Al-Shahri and Al-Khenaizan, 2005).

In this way, patients and their families can generally be satisfied with life expectancy discussions if this doctrine is referred to (Al-Shahri, 2002). As it is part of renal care, this is an essential component of the YoDCA tool that could not be omitted. However, we could not clearly present and discuss end-of-life care with Arabic patients, as it could influence their psychological well-being. Therefore, this term was replaced in box 3 on page 22 of Version 1 by the term 'supportive care' (see Table 19). Moreover, another example on page 9 presented information about conservative management as an active treatment for renal care. One participant suggested that this section be removed from the adapted version. He believed that this treatment option was more appropriate for Western culture than for Arab or Muslim culture. This modification was not incorporated into Version 1 of the tool, however, as such an adaptation would deviate from its scope.

Another significant concern was addressing Muslim cultural preferences in decision-making (DM). The participants recognised that others could be involved in patients' DM processes at some point. They also recognised that one person's decisions affect others in every situation. The experts suggested acknowledging the importance of family roles in caregiving and their involvement in decision-making. In the Muslim context, particularly in Saudi Arabia, patients' decisions may be changed by their families (Al-Shahri, 2002); familial authority often overrules patient autonomy. Figure 15 illustrates the difference between the original text of page 5 and the text in Version 1 by adding extra lines of text to Version 1 to broaden the concept of family support and involvement in DM, thus making it more culturally relevant to Muslim users.

Making Treatment Decisions with Kidney Professionals

Kidney professionals and people with CKD make decisions together about the treatments that will fit best into their everyday life to a) protect their kidneys, b) slow down damage to their body from losing kidney function, and c) manage any symptoms from their CKD getting worse.

These decisions help people plan their EKD management with their kidney professionals along a care pathway.

The decision maps in this booklet can help people see the different care pathways for people with CKD over time [1,2] (see Decision Map 1).

Decision Map 1: Planning Care Pathway and Treatment Decisions for People with EKD



Kidney professionals use details from people's kidney test results, experience of symptoms, other health problems or illnesses, and any lifestyle changes to give information about different options and care plans.

Some decisions happen often as part of CKD care, such as adjusting diet, medicines, fluid and exercise, to keep kidneys as healthy as possible (see Table 1). Other decisions happen less often, such as a change of care pathway when tests show CKD is getting worse, or treatments are not working as well as they did (see Section B).



Figure 15: Differences between the original tool and Version 1 after adding new text about DM process.

Making Treatment Decisions with Kidney Professionals

Kidney professionals and people with CKD make decisions together about the treatments that will fit best into their everyday life to a) protect their kidneys, b) slow down damage to their body from losing kidney function, and c) manage any symptoms from their CKD getting worse.

These decisions help people plan their EKD management with their kidney professionals along a care pathway. The decision maps in this booklet can help people see the different care pathways forpeople with CKD over time [1,2] (see Decision Map 1).





Kidney professionals use details from people's kidney test results, experience of symptoms, other health problems or illnesses, and any lifestyle changes to give information about different options and care plans.

Some decisions happen often as part of CKD care, such as adjusting diet, medicines, fluid and exercise, to keep kidneys as healthy as possible (see Table 1). Other decisionshappen less often, such as a change of care pathway when tests show CKD is getting worse, or treatments are not working as well as they did (see Section B).

Another consideration includes sociocultural framework influences on preferences and the direction of decisions made. In the Muslim population, culture and family are part of the decision-making process. Muslim culture preference in Decision Making process: a) family involvement (e.g., their next of kin such as children, siblings or immediate family members, in-laws), and b) spouse assisting in the process (husband).

Adapted Tool Version 1

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Furthermore, the original tool materials were created for a Western culture and are inclusive without specifically mentioning religion. Muslim patients want to know how to maintain their spiritual needs while undergoing treatment. As outlined by Mardiyono, Songwathana and Petpichetchian (2011), Muslims have a spiritual obligation to maintain their health, which is essential to the Muslim health belief model. Accordingly, the experts indicated that highlighting the spiritual aspect of patient care in Muslim culture was important in two areas of the adapted version. This coincides with two themes that emerged from the expert interviews: the comprehensiveness and completeness of the informational content and the sociocultural appropriateness of the content. Because of this importance of the spiritual aspect for Muslim users, a graphic concerning spiritual values was added in picture 5, page 12 of Version 1 (see Figure 13). In addition, a new subheading, 'My ability to perform my spiritual needs', was added to box 2 on page 20. These differences between the original tool and Version 1 are highlighted in Figure 16. Moreover, some additional minor alterations were made to make it more appropriate (Appendix 16).

Roy 7: Prompts to help you talk with kidney professionals	Box 2: Prompts to help you talk with kidney professionals
This page is to help you talk with kinney professionals may be a solution of the provide the professionals about your kidney health, experiences of treatment, other health concerns and daily life. Talking to family and friends about the following topics can help you to work out if one option suits you better than another. Use the space below to write notes or questions to help you talk to your kidney professional.	This page is to help you talk with kidney professionals about your kidney health, experiences of treatment, other health concerns and daily life. Talking to family and friends about the following topics can help you to work out if one option suits you better than another. Use the space below to write notes or questions to help you talk to your kidney professional. My kidney function and kidney health:
My kidney function and kidney health:	My treatments and side effects:
My treatments and side effects:	My well-being and self-care:
My well-being and self-care:	My health and other illnesses:
My health and other illnesses:	My hobbies and lifestyle:
My hobbies and lifestyle:	My ability to perform my spiritual needs:
Other:	Other:
Original Tool	Adapted Tool Version 1

Figure 16: Differences between the original tool and Version 1: a new heading was added.

Themes and Subthemes	Adaptation Suggested by Experts	Original Text Revisions	Modifications Made	Changes Made to Culturally Adapted YoDCA (Version 1)	Rationale and Comments
Theme 1: Overall Impressions of the YoDCA ToolChanging the presented information's layoutAdding purpose and objectives to explain why this booklet was developed for patients	Reorganised the whole tool into three main sections: physical care; psychological care and spiritual care.	None	This suggested modification was not made.	Following such a recommendation, I needed to add more information, which led to an increase in the number of pages that the participants cited. This booklet already includes parts on physical care, and I added one paragraph for psychological and spiritual support, particularly for Muslim patients, on Page 8 of Version 1.	
	Placement of Table 4 on Page 13 within the tool	None	This suggested modification was not made.	It might be possible to move this questionnaire to the end of Page 17. However, what I understood is that this Table 4 or questionnaire asks patients to write down their reasons for choosing either of the care pathways. They then can discuss this with their HCPs in Section C to make the decision, then use Table 6 to think about which pathway will suit them best.	
	On the page titled 'About the Booklet'	Reworded the purpose and added the objectives	I adapted and slightly modified this booklet's purpose, and I wrote its objectives (Page 2).	This adaptation was made because it gives the patients a chance to organise their thoughts and provides a broad perspective on the booklet's content.	
	Adding outlines of this booklet's content	Page 3, heading "Contents"	Added	On Page 3 of Version 1, I added one sentence to explain what is included in each section. In addition, a new sentence instructing how to use the booklet was added.	

Table 19: Adaptation of the YoDCA Tool Based on Experts' Suggestions: Version 1

Reducing the tool's length using different strategies	On Page 10, Box 1, 'the kidney transplant option': This part needs to be concisely compared with the basic treatment options of conservative care or dialysis, as they are described in detail compared with the basic treatment presented in the tool.	Concise	I condensed the information about the kidney transplant option into a few sentences. For example, I added these two sentences on Page 11 of Version 1: 'Please note that kidney transplant information is covered in a separate booklet'. For more information, please speak with your professional kidney team.	This modification was made to the newly adapted tool, and it is very helpful in shortening the tool's length.
	On Page 8, Table 2, 'Managing Symptoms of Kidney Disease', this information could be more concise or modified into two lines as the following: 'that these are the usual symptoms, and they are managed according to the doctor's advice with tablets, injections and fluids'.	None	This suggested modification was not made.	Using tables is a good way of presenting information and reducing the number of words. The table makes it easier for users to see each symptom and how it is managed.
	On Pages 14, 15, 16 and 17, my decisions and trade-offs with conservative care are almost identical to those of the three sections on which they are based, like overlapping information. Maybe make one or two sections only, or we can make subheadings like 'A, B and C' in there.	None	This suggested modification was not made.	This might be possible if the information had been repeated needlessly; however, each section has its own purpose, so I retained the information to reinforce key points and to avoid any confusion and deviation from the original.

		Table 1 on Page 6 uses pictures and simple words instead of complete sentences. All of these can be shortened by monitoring your disease's progress regularly and following the appointment schedule. Then paste the graphic.	Added	The number of pictures and figures in the tool was increased to make it more attractive for patients and their families to read, instead of sentences and words (see Figures 1 and 2), or see Figure 9 in this chapter.	This type of modification will be very helpful in shortening the tool's length and enhancing its visual attractiveness. The patient then can be encouraged to read the materials.
		The decision map repeated in each section suggests keeping only one map and removing the others.	None	This suggested modification was not made.	In the original booklet, only Decision Map 2 on Page 9 was repeated on Page 14, while the other decision maps had different titles for different purposes in each section. I retained this on Page 14 because it is going to be reviewed for users and patients so that they can think about which pathways suit them best.
Theme 2: comprehensiveness and completeness of the informational content	Using simple language and avoiding the use of medical terms and abbreviations	The entire booklet	The entire booklet was revised at Stage 3.	This suggestion was made when I adapted the tool. I worked on these changes and sought approval and copyright from the original developer, then I translated it into Arabic.	This was addressed during the development of the newly adapted DA tool, which was translated into simple Arabic.
	Translating tool and languages presented in the tool	The entire booklet set was translated into Arabic and produced in bilingual (with English and Arabic text side-by-side throughout the booklet) languages.	The translation process was completed during Stage 3.	This tool was translated into Arabic, as the new targeted population was Arabic-speaking Muslim patients in Saudi Arabia's dialysis centres.	Due to Saudi Arabia's heavy reliance on its foreign workforce to provide healthcare services (WHO, 2016), for those who cannot speak or read Arabic, this is a major barrier to communication between patients and their HCPs. Therefore, I prefer to make it into two separate versions (Arabic and English versions). This type of modification would be very helpful in addressing the communication barrier problem.

Questionable expressions and words, and suggested alternative words were noted.	 On Page 7 in Table 2, some questionable expressions and words, and suggested alternative words were noted: Questionable term 'short of breath' Questionable word 'tablet' in management of 'shortness of breath'. The dubious expression 'need to urinate more often' On Page 8: 'The regular checkups include blood, urine and blood pressure tests, monitoring of symptoms and changes to everyday life'. On Page 9: 'This booklet is for people who have chosen to manage their kidney disease actively and are not suitable for a transplant'. 	Revised	 These modifications were made on Page 9 of Version 1 as follows: Replaced with 'Anaemia' Replaced with 'management usually based on triggers' Replaced with 'difficulty in urination/to urinate' On Page 9 of Version 1, it says, 'The regular checkups include blood, urine tests and blood pressure, monitoring of symptoms and changes to everyday life'. On Page 10 of Version 1, it says, 'This booklet is for people who have chosen to manage their kidney disease actively and are beyond the scope of transplant management'. 	This type of modification was adopted for clarity.
Providing more medical information	On Page 4, I added the anatomy of the kidney, types of renal failure (acute and chronic), lab investigations, ESRD definition, symptoms, complications and comparisons between treatment options' advantages and	None	This modification was not made because patients who use this tool are already chronic and have reached Stage 5 of CKD. I just added 'CKD is an irreversible condition' in Section A, Page 4, of Version 1.	Although this is a frequently asked question from patients or anyone suffering from renal failure as a result of CKD, this suggested adaptation would be possible to add, but it is dependent on the tool's intended users, who could be newly diagnosed patients or dialysis patients who need to switch treatments. As newly diagnosed patients, they need more information to understand the nature of the

		disadvantages at the beginning.			disease. While patients who are already on dialysis have some knowledge or education about this type of information, this will lengthen the tool, which other participants are criticising.
	In Picture 2 on Page 7, 'Loss of kidney function', changes in kidney disease stages and each stage's symptoms are missing.	None	This suggested modification was not made.	The symptoms of kidney disease are already on Page 9 of Version 1, so they need not be added to Picture 3 on Page 7.	
		On Page 7, the unit of eGFR that gets to about 15 is missing.	Added	On Page 7 of Version 1, it says, 'When a person's eGFR gets to about 15ml/min'.	This type of modification was adopted for clarity.
		On Page 7, information is needed on both how patients obtain support from a psychiatrist and how to improve their psychological status.	Added	The following sentence was added on Page 8 of Version 1: 'Those patients need to be encouraged by their family and kidney professionals to visit psychiatric specialists and consult with them'. Furthermore, some sentences about psychological support for patients during their disease journey were added. This is a vital aspect for these patients, as well as their spiritual needs. A small paragraph about psychological and spiritual coping strategies with EKD for Muslim patients also was added (see Page 8 of Version 1).	This adaptation was made because it is such an important part of Muslim culture and because it elaborates on the need for these patients to see a psychiatrist. This requires much courage from the patient or their loved one, as stigmatisation issues may surface due to depression.

		On Page 8, Table 2, 'Managing symptoms of kidney disease', more information about each manifestation's pathophysiology needs to be added, and its management needs more	None	This suggested modification was not made because the symptoms and their management were provided on Page 9. It is general information, so each symptom's pathophysiology needs not be included, as this was based on the tool's intended use.	This suggested adaptation would be possible to add, but it is dependent on the tool's intended users, who could be newly diagnosed patients or dialysis patients who need to switch treatments. As newly diagnosed patients, they need more information to understand the disease's nature. While patients already on dialysis
		explanation.			this type of information, this will lengthen the tool, which other participants have criticised.
		On Page 12, Table 3, 'Summary of the management of EKD with conservative care and a dialysis pathway', needs to add more information that gives the patient an opportunity to select the most suitable treatment for them and provides data on different types of dialysis, indications, contraindications, advantages, disadvantages and complications from each dialysis type.	Added	Not all the suggestions were implemented. I updated the table on Pages 13–14 with the following information: side effects; nutrition and diet. This information is very important for patients to know to facilitate their decision-making between dialysis and conservative management.	Only information about nutrition and diet was added, while other information-related treatments were left out because they were based on the participants and targeted users' prior knowledge.
Theme 3: Sociocultural Appropriateness	Omitting sensitive and offensive words	 On Page 6, the sentence 'Give up alcohol or at least cut down – alcohol speeds up kidney damage'. 	Removed	All statements containing the words 'alcohol' and 'sex' were removed from adapted tool Version 1.	Alcohol consumption is strictly prohibited in Muslim culture, as is discussing sex.

	 On Page 7, the sentence 'It is common for people with EKD to experience a loss of interest in sex'. On Page 8, Table 2, 'Managing symptoms of kidney disease': 'Loss of sex drive'. 			
Fearing talk about palliative and end-of-life care: Either omit it or use alternatives.	On Page 19, the term 'end of life care' in Box 3 Also, in the document on Decision Map Pages 5, 9 and 14, in Picture 2, on Pages 7 and 13, in Box 3, on Page 19 and on Page 21.	Reworded	The term 'end-of-life care' was replaced with 'supportive care for people with worsening EKD through their illness' in Box 3 on Page 22 of Version 1.	The term 'end-of-life care' could not be changed to 'psychological and spiritual needs' because these needs are viewed as part of end-of-life care alongside physical care. This term also is mentioned several times throughout the document, including on Decision Map Pages 5, 9 and 14, in Picture 2 on Page 7 and Pages 13 and 21. I could not change it on these pages because it would affect the meaning of the sentence and the services provided. This issue needs to be discussed with the main authors.
Omitting conservative management topics	Section B on Page 9 presents information about conservative management as an active treatment for renal care.	None	This suggested modification was not made.	This type of modification could not be adapted into Version 1 of the tool, as such an adaptation would deviate from its scope.
Demonstrating family involvement and its role in the DM process	On Page 5: 'Some decisions happen often as part of CKD care, such as adjusting diet, medicines, fluids and exercise to keep kidneys as healthy as possible (see Table 1). Other decisions happen	Added	I added the following sentence in addition to the main text. 'Another consideration includes sociocultural framework influences on preferences and the direction of decisions made. In the Muslim population, culture and family are part of the	This type of suggestion must be adapted because it is a central characteristic and emphasises the family unit's importance, which is consistent among Arabic and Muslim cultures.

	less often, such as a change in care pathway when tests show CKD is getting worse, or treatments are not working as well as they did (see Section B)'.		decision-making process. Muslim culture preferences in the decision-making process include a) family involvement (e.g., their next of kin, such as children, siblings or immediate family members and in-laws) and b) a spouse assisting in the process (e.g., a husband)'.	
Addressing the aspect of spiritual needs or care	On Page 11, Picture 3 should include a graphic depiction of spiritual needs.	Added	The spiritual values graphic in Picture 5, Page 12, of Version 1 was added, as were examples of ways to satisfy spiritual needs, such as prayer, reciting the Quran and supplication.	This suggestion must be viewed as the addition of a spiritual need that is particularly important for Muslims, especially those who appreciate their capacity to pray and recite the Quran, apart from being physically fit to perform daily activities. For example, the long duration
	On Page 17, Box 2, more content is needed on my ability to perform my daily spiritually. For example, one heading like this might focus on lifestyle, or another on my ability to perform my spiritual needs.		On Page 20 of Version 1, a new subheading, 'My ability to perform my spiritual needs', was added.	involved in haemodialysis may impact one's prayers, particularly if they are unfamiliar with the concept of combining prayers, as permitted by Islam. Thus, it is very important to talk to an expert who appreciates patients/clients' religious practices.

7.1.2 Stage 2: The First Adaptation – Discussion with the Original Authors of the YoDCA Tool

The second stage of the adaptation process is described here. In this stage, the preliminary adaptation, Version 1, was presented to the original authors for further review and development. Final approval of the changes was sought. Their feedback was used to further review and develop the tool. This involved an iterative process in which the English version of the YoDCA was revised until it was ready for the next steps of translation and testing. This process resulted in the creation of numerous drafts, beginning with Version 2 and progressing to Version 5. Research team members (I and my academic supervisors) reviewed the first and subsequent drafts iteratively with authors, until an optimal penultimate variation – Version 5 – was obtained. The changes to each version are detailed below.

7.1.2.1 Meeting with Original Authors and Further Revisions

This section details the main points highlighted in meetings with the original authors. It also details the impact of their feedback on the subsequent refinement of Version 1. In preparation for revising Version 1 and developing Version 2, a summary of the modifications to YoDCA and a meeting agenda were created (see Table 19 and Appendix 17). The meeting between the original authors of the YoDCA tool and the research team was held on December 13, 2021. The supporting documents, which included Version 1, the summary of the modifications, and the meeting agenda, were sent two weeks before the formal meeting. The main goal of that meeting was to discuss the adaptations made in Version 1 and get feedback on and approval of these adaptations. The authors received, during the meeting, summaries of the experts' feedback and the adaptations made in Version 1.

The experts' suggestions were implemented in Version 1, but some conflicted with those of the original authors and could not be incorporated into Version 2. The key issues identified by the original authors in Version 1 were as follows: a) the more text that was added and revised, the more difficult it was to understand, and the more unbalanced the information presentation became; b) the additional pictures were problematic for a variety of reasons, including complexity, unhelpfulness, and copyright issues; and c) the colourful background did not enhance the visual appeal. All these issues were recorded in Table 20, which presents

the modifications that were made, the feedback that was not incorporated into Version 2, and the justifications for declining these suggestions.

Version Two: Following the discussions with the authors and their written feedback, the changes made to the YoDCA booklet in Version 1 focused solely on cultural adaptation rather than clinical adaptation. However, some minor clinical or general adjustments were required to improve its relevance to the Muslim population. This resulted in the creation of Version 2.

Themes Suggestions Made in Version 1 **Reasons for Not Implementing Suggestions for Version 2** Theme 1: Overall On Page 2, the following suggestions were made: • The revised purpose is guite a complex sentence and a little biased, as is adding objective information without adding any of this. It is already Impressions of the YoDCA Tool written in the purpose statement and in the information about The booklet's purpose was revised, and additional sections of the booklet. Thus, I would keep Page 2 as is. This is a objectives were added. booklet for patients, not a scientific report with a 'purpose' and 'objectives'. Certainly, add this to a paper when describing the active ingredients, but not patient resources. On page 3, the following suggestions were made: In terms of readability, more text and explanation will make it more difficult to understand and reduce the added value of short prompts to help people orient themselves to the actual. • More text and explanation were added for the Avoid telling people what is important or to remember what to do. It is contents of the booklet. an empirical question to see how people use it and what they read. It is • A following sentence was added: "It is important to go up to them to think about what is useful to them. I would like people through the sections one by one." to go through each section in order, but we must accept that when people are ill, they may want to be able to dip in and out of sections. In a cultural context, changing words is fine, but adding complex sentences is more difficult to understand, so I would keep pages 2 and 3 as is. The information on Pages 4, 8 and 11 was placed in colourful Text becomes difficult to read when the font size and background colour background boxes. are changed, so this must be considered when dealing with visual impairment issues. Furthermore, breaking up the text in this manner makes it far too easy for people to miss a box and not read all the information. This also distinguishes the information from the rest of the text, which it should not do because it is all standard text. Thus, I would prefer it to be written in standard text with a white background. Hence, the suggested fixes in the graphic boxes were not made. Instead of using words, a picture of a kidney was added to Due to the copyright issue of using pictures, we could ask a medical Page 4. illustrator to create a picture alongside the text. I then would rename this 'Picture 2: Main jobs of the kidneys' to maintain consistency in the wording between the Yorkshire Dialysis Decision Aid (YoDDA) and YoDCA resources.

Table 20: Consultation with Original Authors and their Commentary on Changes in Version 1 of the YoDCA Tool

	This statement follows the original text on Table 1, Page 8: 'You should follow the tips below'.	Using phrases such as 'you should' is a directive, and people may disengage from the information if they are told that they must do something, particularly if they don't want to do it.
	Several pictures were added on Page 6 to help explain the tips for keeping kidneys healthy.	We shortened the information and added pictures, neither of which added anything informative. We followed theoretical frameworks that link action and reaction while creating this table. The original table included explanations to help people understand why it was necessary to follow each piece of advice, such as, 'Give up smoking or at least cut down— smoking speeds up kidney damage'. These statements are very instructional and would not necessarily enhance health literacy. They just make people feel guilty if they do not do these things. Moreover, little symbols next to each point may be more useful than points and may improve literacy, but they need better typesetting. However, this could be an issue if you use copyrighted images. Thus, this table was kept as is.
	The information on kidney transplantation was concise, and a visual explanation of how a new kidney is transplanted was included. Moreover, the following sentence was added: 'Please note that kidney transplant information is covered in a separate booklet. For more information, please speak with your professional kidney team.	The diagram is not needed, as the information did not concern helping people decide about whether to undergo transplant surgery. This resource is not about transplantation, but we need enough information to be informed. Due to the lack of balance in information provision, I would only remove text that is irrelevant to the Muslim population; otherwise, I would leave it as is.
Theme 2: comprehensiveness and completeness of the informational content	All questionable words and expressions related to Table 2 on Page 11 were revised.	Adding more words does not make it easier to understand or come across as instructive. Furthermore, the phrase 'difficulty urinating' was revised. Patients do not find it difficult to urinate; they feel the need to go to the toilet more often. We suggest making revision to the previous wording.
	This booklet is for people who have chosen to manage their kidney disease and lies beyond the scope of transplant management.	This revised sentence was not understandable. Thus, consider revising the original wording 'are not suitable for transplantation'.
	On Page 15 in Table 3, the following sentence was added: 'For more information about dialysis treatment, see the links on Page 26'.	By writing such a sentence, this makes the information unbalanced, as it recommends more information about dialysis, but the equivalent is not mentioned on the conservative management pathway side of the table.

	On Page 17, three pictures explaining the haemodialysis process – 'peritoneal dialysis', 'catheter access' and 'haemodialysis fistula access' – were added.	Including information by using these pictures makes the treatment information unbalanced because no equivalent information is provided in the form of pictures about conservative management. This information is also about people deciding about dialysis vs. conservative management – not about the specific details of dialysis therapies, which are included in the sister resource YoDDA, the dialysis decision aid booklet.
	On Page 10 in the section 'Coping with established kidney disease', the following sentence was added in relation to psychiatric care: 'Those patients need to be encouraged by their family and kidney professionals to visit psychiatric specialists and consult with them. These feelings and problems may go away by themselves as people get used to living with EKD'.	This sounds like a directive. Instead of telling people what they or their family members should do, the information should direct them to services. We suggested that this sentence be removed.
	On Page 10 in the section 'Coping with established kidney disease', another sentence was added in relation to psychological care: 'Adjustment in cognitive, emotional and behavioural terms is required by patients and their families'.	This sentence makes it sound like people are being told what they must do. The terms 'cognitive, emotional and behavioural' are complicated and may be misunderstood. Suggest that this sentence be removed.
Theme 3: Sociocultural Appropriateness	On Page 6, in the context of family involvement in decision making, I added the following sentence: 'Another consideration includes sociocultural framework influences on preferences and the direction of decisions made. In the Muslim population, culture and family are part of the decision-making process. Muslim culture preferences in the decision-making process include a) family involvement (e.g., next of kin, such as children, siblings or immediate family members and in-laws) and b) a spouse assisting in the process (e.g., a husband)'.	This is complicated language, and we would not put this in a patient resource. Thus, we suggest removing it and replacing it with the following sentence: 'They talk with people with kidney disease and their families' members who are important to them in making these decisions.' Furthermore, the phrase 'their family' was promoted throughout the content.
	On Page 10, spiritual care information was added, as well as spiritual need and treatment pictures.	The following text of information was suggested: 'many people speak with their spiritual leaders about coping with illness and supporting families. People with kidney disease talk with their kidney team about which natural and spiritual remedies can be taken with their treatments when coping with kidney disease. Many people find it useful to talk with their families, spiritual leaders, and health professionals about how to fit their EKD treatments around praying times and religious festivals.' With

	regards to the pictures inserted, the pictures are not helpful and are biased. There are other types of psychological support that are not pictured and adding pictures of one type of treatment may be biasing. Also, do you want to endorse Zamzam water as an evidence-based resource? Suggest removal.
On Page 14, a spiritual values image is inserted into Picture 5 alongside other aspects and is labelled 'Thinking about what is important to you in your life'.	They proposed changing the image of daily life to make it more relevant to Saudi Arabia. So, include a prayer symbol as well as other culturally relevant items.
On Page 14, the following text was added: 'aims to keep people well for as long as possible in a way that fits people's values and daily needs, including the capacity to perform spiritual needs, such as prayer, reciting the Quran and supplication'.	This sentence was replaced by' On page 14, the following sentence were added:' aims to keep people well for as long as possible, in a way that fits people's values and daily and spiritual needs".

The following changes were made in response to suggestions about Version 1:

- All the text in the booklet was written in standard font on a white background, taking into consideration issues concerning visual impairment that could make it difficult to read the text.
- All complex sentences were removed on the following pages: 2, 3, 5, 8, and 12.
- All the pictures I added were removed due to their complexity and copyright issues.
- On page 5, for cultural relevance in the DM process, the following phrase was added: 'They talk with people with kidney disease and their family members who are important to them in making these decisions'. Furthermore, the terminology 'their family' was promoted throughout the content.
- I kept Table 1 on page 6 of the original, which includes explanations of tips to keep the kidneys healthy. This helps people understand why it is necessary to follow each piece of advice. For cultural relevance, I only removed the sentences that mentioned alcohol.
- To maintain balance in the information provided in the sources, I kept box 1 on page 11 of the original, under 'kidney transplant option'.
- I kept Table 2, 'Managing symptoms of kidney disease', for readability and to avoid complexity for users. However, keeping it in its original form may confuse patients about which medication tablets they can use to manage these symptoms.

Furthermore, some additional small modifications were made, which are listed in Appendix 18. As a result of these changes, Version 2 was developed. This version and the summary of modifications presented above were sent to the authors for their review. In addition, there were some questions about the final version's status concerning reference inclusion, changes to the publication, and updated dates. In addition, there were questions about the medical illustrator's and costs. This included details on pages 28 and 29 of the final versions. **Version Three:** The focus of the third version of the tool was maintaining equivalence between treatments and service delivery in the two countries (the UK and Saudi Arabia) based on the original authors' comments (Table 21). Feedback on Version 2 was solicited from the original authors, which primarily focused on consistency with Saudi national standards and the protocol for renal treatment. Various characteristics set different countries apart from one another: they may use different terminology or have different standards and guidelines; their services may offer different treatment methods or pathways; and they may have their own policies and laws relating to renal healthcare. Thus, analysing the current situation in the target context is usually an important step in the process of drafting an adapted tool. It was critical to recognise the significant differences between the clinical guidelines and service delivery in the UK and the local practices provided in Saudi Arabia healthcare settings, which must be considered during the adaptation process. It is important for the information and services in the tool to be consistent with the national standards in Saudi Arabia. Adapting teams should focus on adapting to the health systems of particular countries, according to the World Health Organization (WHO, 2006).

To begin with, the UK uses the National Institute for Health and Care Excellence (UK- NICE) clinical guidelines (NICE, 2021) in healthcare settings. After a review of the tool and comparison with the national standards and guidelines, I reviewed differences between the current practices and standards in Saudi Arabia and the UK-NICE guidelines. It was found that Saudi Arabia does not have its own guidelines for CKD but follows the international guidelines for kidney disease: Improving Global Outcomes (KDIGO)- National Kidney Foundation's Kidney Disease Outcomes Quality Initiative (KDOQI)- evidence-based practices (EBP) (KDIGO-KDOQI-EBP), KDIGO CKD Work Group, 2013). Thus, the whole booklet and the authors' feedback were reviewed based on these guidelines. Table 21 outlines the recommended adaptations considered by the main authors and research team. At this point, the authors introduced me to their medical illustrator at the University of Leeds, who would subsequently work on the resource's additional images.

Version 2 Main Text	Original Author's Feedback	Adaptation Rationale Explanation	Adaptation in Version 3	
On Page 4: 'CKD is an irreversible long- term problem where people's kidneys slowly stop working'.	 You do not need this 'long' here; when the kidneys stop working, it's implicitly a long-term problem. I am not sure people will understand what 'irreversible' means in this context. 	The phrase 'irreversible long-term' was removed for clarity's sake.	The sentence was restored with the original text.	
On Page 5: 'They talk with people with kidney disease and their family members who are important to them in making these decisions'.	They suggested using just 'their family' or 'relatives' but avoids using 'members'.	The word 'members' is deleted.	The sentence was revised as follows: 'They talk with people with kidney disease and their families, who are important to them in making these decisions'.	
On Page 6, Table 1: 'Tips for keeping kidneys as healthy as possible'.	Consider reviewing the list of recommendations for these tips with practices in Saudi Arabia clinical settings.	The table was reviewed, and Saudi Arabia has the same list of recommendations.	No changes were made to this table in Version 2.	
On Page 7: 'When a person's eGFR gets to about 15 ml/min…'.	Consider reviewing the eGFR number in Saudi Arabia to ensure it is correct for their clinical guidance.	Saudi Arabia does not have its own guidelines for CKD, but instead follows the international guidelines for KDIGO-KDOQI EBP, and each hospital has its own treatment protocol. Thus, I reviewed all the documents based on these guidelines and added KDIGO clinical practice guidelines (2013) as reference No. 4 in the text citation and final reference list.	The sentence was modified slightly to: 'When a person's eGFR gets to about 15 or lower ml/min/1.73 m ^{2 [4],}	
On Page 8: 'People with CKD may need help and psychological support from other people'.	They suggested replacing the phrase 'psychological support' with 'spiritual support'.	The phrase was replaced.	The sentence was modified to: 'People with CKD may need help with spiritual support from other people'.	
On Page 8, another sentence says, 'Psychological support can include Islamic spirituality in the healing process of Muslims'.	The sentence was not understandable, as psychological support would be something associated with psychologists.	The sentence was removed.	To ensure clarity, this sentence was removed.	

Table 21: Summaries on the Differences between Version 2 and Version 3 Adaptations.

On Page 9: 'These include specialist teams of kidney (sometimes known as renal or nephrology) doctors and nurses, dietitians, occupational therapists, clinical psychologists, counsellors, social workers, primary care physicians (your primary healthcare centre PHC), pharmacists and physiotherapists'.	Consider reviewing whether all these are part of the renal care team in Saudi Arabia clinical settings.	In Saudi Arabia settings, doctors, nurses, dietitians, pharmacists and social workers are the only ones who are part of or included on Saudi Arabia's renal care team.	The sentence was modified to: 'These include specialist teams of kidney (sometimes known as renal or nephrology) doctors and nurses, dietitians, pharmacists and social workers'.
On Page 9: 'Different kidney units organise their EKD care and services in different ways'.	-	Following that sentence, I added another sentence to confirm that Saudi units follow KDIGO guidelines in the text and cite them on the references list.	I added the following sentence: 'All kidney units follow the international guidance about the care they offer' [e.g., KDIGO 2012].
On Page 9, Table 2 presented an explanation of shortness-of-breath symptoms related to anaemia, and how its management is based on triggers and the doctor's advice, modified slightly from the original tool.	 Consider reviewing whether all these treatments were offered in Saudi Arabia settings. We did not explain each symptom's cause in the table, so I would remove the statement that shortness of breath is caused by anaemia. In terms of management, I would stick with the original wording. 	The treatment offered was reviewed, and no changes were made. For its management, I would stick with the original wording.	A minor change was made to shortness of breath and its management, which was restored to the original version.
On Page 12, Picture 4, 'Thinking About What Is Important to You in Your Life', I proposed replacing some symbols with more culturally appropriate ones.	 Consider removing the pet's symbol and replacing it with a culturally appropriate one. Adding more than one symbol related to prayer or religious practice would make the pictures unbalanced, as each smaller bubble is meant to represent a different aspect of a person's daily life. They suggested making changes for culturally appropriate symbols, such 	For the cross symbol, it might be replaced by a capital letter (H), a word such as 'hospital', 'heart rate' or a 'heartbeat' icon. The medical instructor's assistant will complete the work at the University of Leeds, who will introduce it to me via email.	This will be accomplished by producing the final version, and the modified image will be in Version 5.

	as food, drink and health settings. A symbol used to represent hospitals is a cross.		
On Page 13, Table 3, 'Summary of management of EKD with conservative care and dialysis pathways'.	Consider reviewing whether all this information aligns with clinical guidelines in Saudi Arabia.	According to the Saudi Centre for Organ Transplantation (SCOT, 2019), two treatment options are offered to EKD patients in Saudi Arabia: dialysis therapy and renal transplantation. Conservative management is not offered as a treatment option in Saudi Arabia (Ministry of Health, 2014). In Saudi clinical practice, conservative treatment is offered only to a specific group of patients, such as elderly patients with comorbidities who are admitted to the ICU, or DNR patients.	I would leave this table as is, supported by the KIDGO guidelines that 'conservative management should be an option for people who do not wish to pursue RRT and should be supported by a comprehensive management programme'.
On Page 15: 'End-of-life care is total care that helps all those with advanced, progressive, incurable illnesses to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes the management of pain and other symptoms and the provision of psychological, social, spiritual and practical support' [16].	This is a complex sentence containing lots of medical terminology that people reading the booklet are unlikely to understand. Perhaps it would be better to simply state, 'More information is available in Section D about end-of-life care'.	The sentence was removed due to excess complexity.	The following sentence was added: 'More information is available in Section D about end-of-life care'.
On Page 18, it says, 'Medical studies measure a) the life expectancy of people with EKD compared with groups of healthy people; b) kidney treatments' impact on how quickly kidneys stop working, symptom control and side effects; and c)	They suggested replacing the references [17,18,19,20] with research on the Muslim or Saudi population.	Most renal studies in Saudi Arabia focussed on dialysis patients' quality of life rather than life expectancy. I only found studies that focussed on spiritual coping for Saudi and Muslim patients and its effects on improving their health outcomes. I have two references, which I replaced with the original reference.	Two references in a Muslim context were found, which I replaced with 18 and 19 references, which are the numbered references on the list.

different ways people cope with EKD [17,18,19,20]'.			
On Page 21: 'People on both the conservative care and dialysis pathways are asked to make advance care plans when they still feel well. These plans help kidney professionals and families know what treatments to change, start or stop'.	Consider reviewing whether an ACP discussion is considered and offered in Saudi Arabia settings.	Saudi Arabia follows KDIGO guidelines, which emphasise that 'all CKD programmes and care providers should be able to deliver advance care planning for people with a recognised need for end-of- life care, including those undergoing conservative kidney care. 'However, I am not sure if that applies to all patients who are undergoing HD treatment or just those patients with a specific criterion'.	I would leave this original wording as is because the guidelines support it.
On Page 21, Box 3, 'Supportive care for people with worsening EKD through their illness' I suggested that I would keep it as 'end-of-life care' for people with worsening EKD. 'Supportive care' is a term used interchangeably with conservative care, and what is discussed here is distinct from that: end-of-life care for all those with EKD, regardless of which treatment they are on.	They suggested keeping it as is and adding text about 'spiritual leaders' in the last paragraph.	I added the following statement: 'Spiritual leaders' support is vital to encouraging individuals to discuss their needs and preferences at death, to provide support and advice to reduce an individual's anxiety about death and, if possible, to prepare for death and manage it in a dignified manner to prepare for burial'.	I changed the title box slightly and inserted a new statement; see Figure 17.
On Page 25, I listed useful links for people with EKD and their friends and family. For example, <u>Books – SSN & T</u> (<u>ssn-sa.com</u>)	They suggested explaining what SSN&T stands for and perhaps providing the full reference for the names of the leaflets, as you would for a journal publication, followed by a web link. Also, remove brackets from the web link to match the bulleted list of points above.	The changes have been made.	The reference was cited as follows: The Saudi Society of Nephrology and Transplantation (SSN&T) (2019). A Chronic Kidney Disease Guide for Patients and Their Families. Available at: <u>https://www.ssn-</u> <u>sa.com/books/#1557332192280-</u> <u>e0e81bd7-061d</u>

fe expectancy for people with EKD is less than for healthy people. The most ommon cause of death for people with EKD is from another illness they may ave such as cardiovascular disease, cancer or stroke ^[30] . Most people having alysis have a longer life expectancy than people having conservative care.	Life expectancy for people with EKD is less than for healthy people. The most common cause of death for people with EKD is from another illness they may have such as cardiovascular disease, cancer or stroke ^[21] . Most people having dialysis have a longer life expectancy than people having conservative care.
Then people have little or no kidney function left, and are not on dialysis, toxins and excess water build up in their body and they move towards the end of life. For people with no kidney function who stop dialysis, this withdrawal from life appens over about 10 days. For people with some kidney function left, this may appen over a few weeks or months. This stage of EKD manage symptoms people experience, such as aches and ains. This stage of EKD management is known as end of life care . During the last w days at the end of life, people slip into a coma (fall unconscious), and when he toxins have built up in the blood, their heart stops beating, they gradually agin to withdraw from life and death happens.	 When people have little or no kidney function left, and are not on dialysis, toxins and excess water build up in their body and they move towards the end of life. For people with no kidney function who stop dialysis, this withdrawal from life happens over about 10 days. For people with some kidney function left, this may happen over a few weeks or months. Nurses and doctors help manage symptoms people experience, such as aches and pains. The support of the spiritual leaders is vital to encouraging individuals to discuss their needs and preferences at death, to provide support and advice to reduce an individual's anxiety about death, and if possible, to prepare for death and manage it in a dignified manner in order to prepare for burial. This stage of EKD management is known as end-of-life care. During the last few days at the end of life, people slip into a coma (fall unconscious), and when the toxins have built up in the blood, their heart stops beating, they gradually begin to withdraw from life and death happens.

Box 3: Supportive care for people with worsening EKD through their illness

V

F

Adapted Tool Version 2

Adapted Tool Version 3

Box 3: End of life care for people with worsening EKD

Figure 17: Differences between box 3 in Versions 2 and 3 (p. 21).

Figure 17 presents the main differences between box 3 in the original tool and in Version 3. Based on the discussions with the original authors, the researcher kept the box title out of the original tool and added new lines explaining the role of spiritual leaders for EKD patients in the last stages of disease.

Version Four: Following the review of the third version by the authors, a few very small tweaks and suggestions were identified to create Version 4. These were final suggestions concerning minor formatting and language issues. They suggested that page 9 could just have the reference number, like the other references, and that KDIGO could be used instead of the year. On page 21, they suggested that the following sentence be replaced: 'The support of spiritual leaders is vital to encouraging individuals to discuss their needs and preferences at death, to provide support and advice to reduce an individual's anxiety about death, and if

possible, to prepare for death and manage it in a dignified manner in order to prepare for burial'. They suggested, as a replacement, 'Spiritual leaders provide support and advice about any concerns around the management of and preparation for death'. Version 4 was created by implementing all these modifications. Version 4 was sent to the authors to obtain their approval before proceeding to the next steps. Version 4 changes were approved.

Version Five: Following the minor adaptations to the tool text and the release of version 4 of the adapted YoDCA tool, illustrations and icons were added to produce the penultimate English version – Version 5. This level of adaptation – integrating illustrations and icons – is considered advanced, according to the WHO (2006). The illustrations and icons in Versions 1– 4 were generic and developed in a UK context. In field tests with providers and patients in parts of Western countries, they have proved understandable. Nonetheless, it may be necessary to field-test illustrations locally for comprehension and acceptability. Muslim countries and contexts may require, and have the resources for, further adaptation of the tool to make it more acceptable within their services. For example, they may want to insert region- or country-specific illustrations to make them more acceptable and recognisable to users (WHO, 2006). As a result, the original authors reported that some illustrations and icons included in the tool, as well as additional images, needed to be adapted to the Muslim context. A medical illustrator was therefore recruited to work on Version 4. The illustrator worked carefully with me and with original authors to ensure that all changes were made correctly.

The medical illustrator was contacted after Version 4 was approved, and it was explained that I had made some minor alterations to the text and, as part of this adaptation process, would like to include some additional images in the resource as follows:

- On the first page, the pet's symbol was removed from the second circle and a culturally appropriate symbol added.
- On page 4, a picture of the main functions of the kidneys was included.
- On page 12, the pet's symbol was removed from the daily life circle and a culturally appropriate symbol was added. Additionally, the symbol that was used to represent hospitals' cross symbol in the original picture was changed to the use of the letter H.

There was a discussion with the illustrator to clarify what sort of symbol should replace the pets image. Prayer symbols were discussed, such as the Muslim prayer sign, a man praying, or the Islamic religious sign for 'mosque'. Moreover, changing the details on the back cover would help differentiate between this version and the original. These changes were made and then reviewed by the researcher (see pictures 18, 19, and 20). As a result, penultimate Version 5 was developed with a different code number on the back page to differentiate it from the original version. Currently, only an electronic version is needed, so we made all the web links live so people could click on them to access the websites listed.



Figure 18: Differences in the cover pages of the original, Version 1, and Version 5.

Figure 18 above depicts differences in the icons presented on the YoDCA tool's cover page. The icon that represented pets in the original tool was changed to a prayer symbol icon in Version 1 by the researcher, while in the penultimate English draft, Version 5, it was changed to a mosque symbol by the medical illustrator.





Figure 19 depicts differences in the text presented on page 4 of the YoDCA tool. The types of jobs that kidneys performed were written in sentences in the original tool, but in Version 1, the researcher used a picture to describe them. In Version 5, the medical illustrator used both words and pictures that illustrated these words.



Figure 20: Differences in picture 3 (p. 11) in the original tool, Version 1, and Version 5.

Figure 20 depicts differences in the picture titled 'Thinking about what is important to you in your life' in the original tool and Versions 1 and 5. In the original, four important aspects were included, but spiritual values were missing. Thus, I added a picture to describe the spiritual values in Version 1. In the penultimate draft, Version 5, the medical illustrator removed the added image and replaced the pet's symbol, which represented the first aspect of daily life, with a mosque symbol to reflect spiritual values.

After receiving Version 5, it was necessary to carefully review this penultimate adapted version for errors and inconsistencies. Thus, both the researchers and original authors reviewed the tools. The authors then proposed that the wording on the inside cover of the YoDCA be altered to read as follows: 'The booklet was developed by the Yorkshire Dialysis and Conservative Care Decision Aid (YoDCA) study team in the UK. Study details are listed at the end of the booklet (see pages 28–29). Nuha Alatawi and Clare Gardiner (University of

Sheffield, UK) are using this adapted version of YoDCA in a study in Saudi Arabia to improve shared decision-making in established kidney disease'. Following this modification, the penultimate English version, Version 5, was developed. The copyright process began, and permission to use the YoDCA tool in the research project was obtained in May 2022 (see Appendix 11).

7.1.3 Stage 3: The Second Adaptation – Translating the YoDCA Tool

As discussed in Chapter 4, Section (4.3.3.4.2.3), as part of the adaptation process for the penultimate Version 5 of the YoDCA, which was copyrighted, it was translated into Arabic. The forward–backward translation process was used (Beaton *et al.*, 2000; WHO, 2017).

7.1.3.1 Forward Translation (Versions 6, 6A, 6B)

Having been adapted into English and copyrighted, Version 5 was translated into Arabic by me as a researcher to create Version 6. In order to make the tool more useful to other CKD populations outside of Saudi Arabia, I used the formal written Arabic language. A direct translation was not possible due to differences in Arabic and English sentence structures. Right-to-left is the direction of writing and reading in Arabic; thus, the word order sometimes needed to be changed to match the Arabic language and its sentence structure and context. In addition, the different meanings of words in the two languages required some words to be changed. Terms and phrases posing translation problems were highlighted during the translation, including 'conservative care', 'living with kidney disease', 'established kidney disease', 'prompts', 'manage disease', 'treatment and therapies', and 'advanced care planning.' The initial forward translation was then released called version 6.

Once Version 6 was drafted, a professional bilingual translator (Translator 1) with medical language translation experience edited the translated document. A discussion between me and Translator 1 focused on Arabic morphology and grammatical inflection. Arabic sentence structure, for example, differs from that of English, especially in the word order (subject, verb, and object). In Arabic, the core sentence structure is verb, subject, and object; if no such mechanisms are used, words can be arranged in many permutations. Moreover, Translator 1 was told to make sure that during editing, the language used was natural, simple, clear, and acceptable for an Arabic target population. They were also informed about problematic

terms. In this way, Version 6A was produced. I reviewed and compared each modified text element after receiving the edited version, and the differences between the two versions (6 and 6A) were insignificant. Thus, all improvements were made to the penultimate forwardtranslated Arabic version (6B) based on an agreement between me and Translator 1 to produce and accurately translate the full Arabic version of the YoDCA booklet before backward translation was conducted. Table 22 summarizes the forward-translation process, including specific translations and semantic equivalence concerns, and how they were resolved.

I described the modifications in the translated text as 'slight', although the meaning was almost the same, the grammar or synonyms were different. The improvement included three expanded phrasings for difficult-to-translate words or phrases – for example, clarifying words were added as modifiers, while two words were used to capture nuance and form complete sentences. More natural expressions were required in three instances to make the language more understandable and improve the flow. The final wording was nearly identical in three examples, but some modifications were needed for the final phrasing. There were two instances when a literal translation from the original English was chosen because both phrasings were correct, but one was more literal. There was an issue with the accuracy of two translated words. Thus, the wording had to be expanded and more natural phrasing used. Other enhancements were made in four instances: the sentence construction was improved by changing the word order, terms were reworded, and punctuation was used in the correct place to separate and clarify the meaning of sentences. Moreover, Arabic diacritic marks (Taksheel, or vowels) and definiteness were used as required to ensure correct and clear diction.

Consensus was reached between me and Translator 1 on the problematic terms and phrases. For example, because 'established kidney disease' was difficult to translate into Arabic, I translated it as 'مرض الكلى المتفاقم' and 'مرض النهائيه' and 'مرض الكلى المتفاقم'. We then agreed to use ' مرض 'throughout the document and to consider the experts' feedback when testing the tool. Moreover, the word 'prompts' was translated to 'الموجهات' and then retranslated as 'الدوافع'. This led to the production of Version 6B.

Original English	Forward Translation (Researcher), Version 6	Revised forward translation (Translator 1), Version 6A	Penultimate forward translation, Version 6B	Concerns about the two Arabic translations	Reconciliation solution type	Explanation of reconciliation
A Dialysis and Conservative Care Decision Aid: Living with Kidney Disease	الاداه المساعده في اتخاذ قرارغسيل الكلى والرعاية المحافظة:التعايش مع أمراض الكلى	المساعدة في اتخاذ قرار غسيل الكلى والرعاية التحفظية: التعايش مع أمراض الكلى	المساعدة في اتخاذ قرار غسيل الكلى والرعاية التحفظية: التعايش مع أمراض الكلى	I added the word 'אערוס' to the tile that means decision aid. There was an issue with translation accuracy because this word is too narrow in meaning and too focused on a physical item. This may confuse readers.	Better matched the meaning.	The word 'الاداة' was removed from the title. Mostly used the revised translation because the translator chose more appropriate words for the title.
Conservative care	الرعاية المحافظة	الرعاية التحفظية	الرعاية التحفظية	My word is sub-optimal wording for 'الرعاية المحافظة' and translator 1 had better literal wording.	Better literal match	The problematics word' للرعاية المحافظة 'which means 'conservative care' was translated to' الرعاية التحفظية ' to be more appropriate for use in clinical settings.
Five main jobs of the Kidney	خمس وظائف رئي <i>سي</i> ة للكلى	خمس وظائف رئيسية تقوم بها الكلى	خمس وظائف رئيسية تقوم بها الكلى	None	Chose more natural expression, expanded wording	Use translator words: the translator added two Arabic words, 'تقوم بها' to this sentence to make it more readable and complete.
Health professionals who are expert in managing kidney problems care for people with CKD. They might be called specialist kidney, renal or nephrology doctors,	الاخصائيين الصحيين علاج اوادارة مشاكل الكلى يقدمون الرعاية المصابين بمرض	يقدم الأخصائيون الصحيون المتمرسون في علاج أو إدارة مشاكل الكلى الرعاية للأشخاص المصابين بمرض الكلى المزمن، وقد يُطلق عليهم اسم أخصائيو أمراض الكلى	يقدم الأخصائيون الصحيون المتمرسون في علاج أو إدارة مشاكل الكلى الرعاية للأشخاص المصابين بمرض الكلى المزمن، وقد يُطلق عليهم اسم أخصائيو أمراض الكلى	My word order was 'sub- optimal,' which is not easily understood by an Arabic reader, as well as punctuation, which was missing. As a result, the sentence's meaning was unclear. Also changed noun	Grammatical inflection	The translator rewrote the word order by starting with verb and then subject, as well as adding punctuation such as a comma to make it easy to understand and read.

Table 22: Forward Arabic Translation of the YoDCA: Identification of Problems and Resolution
nurses, dieticians, psychologists.	الكلى المزمن و قد يطلق عليهم أخصائي أمراض الكلى أوطبيب أمراض الكلى والممرضات وأخصائيي التغذية وأخصائيي نفسي	أو طبيب أمراض الكلى ، ممرضات، أخصائي تغذية، أخصائي نفسي	أو طبيب أمراض الكلى ، ممرضات، أخصائي تغذية، أخصائي نفسي	statements for a grammatical construction.		Furthermore, replace the noun statement 'أخصائيو 'with 'خصائيو' .
People use this booklet in different ways.	يستخدم الناس هذا الكتيب بطرق مختلفة	يستخدم الأشخاص هذا الكُتيّب بطرق مختلفة.	يستخدم الأشخاص هذا الكُتيّب بطرق مختلفة.	None	Used both for the final wording which nearly identical	The two translations were similar, but to use formal Arabic, the researcher used translator words and replaced the noun 'الناس' with' .
Slow down damage to their body from losing kidney function	إبطاء الضرر الذي يلحق بأجسامهم بسبب فقدان وظائف الكلى	تأخير الضرر الذي يلحق بأجسامهم بسبب فقدان وظائف الكلي	تأخير الضرر الذي يلحق بأجسامهم بسبب فقدان وظائف الكلى	None	Used both for the final wording which nearly identical	The two translations were similar, but to use formal Arabic, the researcher used translator words and replaced the verb' تأخير with'إبطاء'
Go to your regular kidney unit appointments	اذهب إلى المواعيد المنتظمة لوحدة الكلى	اذهب إلى مواعيد وحدة الكلى بشكل منتظم	اذهب إلى مواعيد وحدة الكلى بشكل منتظم	My words were more easily understood as the researcher's translated words needed other minor modifications. Modified it to make it easier to understand by adding 'بشكل'.	Chose more natural expression, expanded wording	Combined both translations: The translator changed the word order and added one Arabic word (بشكل ' to this sentence to make it more readable and complete.
Managing other health conditions like diabetes or problems with the heart and arteries	إدارة الحالات الصحية الأخرى مثل مرض السكري أو مشاكل القلب والشرايين	إدارة الحالات الصحية الأخرى التي قد يعاني منها المريض مثل مرض السكري أو مشاكل القلب والشرايين	إدارة الحالات الصحية الأخرى التي قد يعاني منها المريض مثل مرض السكري أو مشاكل القلب والشرايين	My words were more easily understood as the researcher's translated words needed other minor modifications. Modified it to make it easier to	Chose more natural expression, expanded wording	Combined both translations: The translator and added one Arabic phrase ' التي قد to this sentence to make it more readable and complete.

				التي قد 'understand by adding 'يعاني منها المريض		
Some people find sharing their experiences with a psychologist, mental health professional, their kidney team, and their family can be useful.	يجد بعض الناس أن مشاركة تجاربهم مع فريق الكلى وعائلاتهم وطبيب نفسى وأخصائي صحة عقلية يمكن أن يكون مفيدًا	يجد بعض الناس أن مشاركة تجاريهم مع فريق الكلى وعائلاتهم والطبيب النفسى وأخصائي الصحة العقلية يمكن أن يكون مفيدًا	يجد بعض الناس أن مشاركة تجاريهم مع فريق الكلى وعائلاتهم والطبيب النفسى وأخصائي الصحة العقلية يمكن أن يكون مفيدًا	Grammatical construction to make it more readable	Definiteness, Ar abic grammar rules	The translator's definite object in the sentence is ' الطبيب النفسي 'rather than ' طبيب نفسي '.
Carrying out HD means having needles put into the fistula at each session. A local anaesthetic can be used to numb the arm or leg that the needles go into. The anaesthetic makes haemodialysis less painful. Some people feel dizzy or tired during and/or after a haemodialysis session. Some people say it is uncomfortable having a fistula in their arm or leg.	إجراء الغسيل الدموي هو وضع أبر في الفستيولا في كل جلسة. يمكن استخدام مخدر موضعي لتخدير الذراع أو فيها الإبر. يجعل الساق التي تدخل فيها الإبر. يجعل الكلى أقل الما. الأشخاص بالدوار يقول بعض الأشخاص إنه يقول بعض فستيولا في فستيولا في ماتهم.	يتم الغسيل الدموي عن طريق وضع إبر في الفستيولا في كل استخدام مُخدر أو الساق التي يتم اودخال الإبر فيها. يجعل التخدير غسيل يبعل التحدير غسيل الكلى أقل ألمًا. يشعر بعض الأشخاص بالدوار أو غسيل الكلى أو بعدها. إلى أن وجود أو ساقهم هو أمرّ غير مُريح.	يتم الغسيل الدموي عن طريق وضع إبر في جلسة. يمكن استخدام مُخدر أو الساق التي يتم اودخال الإبر فيها. يجعل التخدير غسيل يبعل التلابر فيها. الكلى أقل ألما. يشعر بعض الأشخاص بالدوار أو غسيل الكلى أو بعدها. إلى أن وجود أو ساقهم هو أمرّ غير مُريح.	This section was the most difficult to translate because it used medical terminology that was difficult to understand.	Chose more natural expression, flow of the phrasing to make it more understandable.	The translator's words were chosen because they are better worded for these statements and are easier to understand by an Arabic reader. The translator rewrote the sentence by changing the word order and using formal Arabic words.

Kidney professionals and people with kidney failure make plans about end-of- life care, often with help from other health professionals and services.	يضع أخصائيين الكلى والأشخاص بالفشل الكلوي خططًا حول رعاية نهاية العمر ذلك بمساعدة المتخصصين والخدمات الصحية الأخرى	يضع أخصائيو الكلى والأشخاص المصابون بالفشل الكلوي خططًا بشأن رعاية نهاية الحياة ، وغالبًا ما يتم ذلك بمساعدة المتخصصين والخدمات الصحية الأخرى.	يضع أخصائيو الكلى والأشخاص المصابون بالفشل الكلوي خططًا بشأن رعاية نهاية الحياة ، وغالبًا ما يتم ذلك بمساعدة المتخصصين والخدمات الصحية الأخرى	I had sub-optimal wording for 'End -of-life care' which was ' بعاية نهاية العمر 'and translator 1 had better literal wording. Also changed noun statements for a grammatical construction.	Better literal match. Grammatical inflection.	The translator's words were chosen because they are a more literal translation of 'end-of-life care,' which was 'قياية الحياة' As used for patients in clinical settings. Furthermore, replace the noun statement ' أخصائيو' with 'أخصائيو'.
The conservative care pathway means a chance to do daily activities (e.g., hobbies, family and pets, leisure and holidays) with fewer regular medical routines, until there is no kidney function left	مسار الرعاية المحافظه يعني فرصة للقيام بالأنشطة اليومية والأسرة والحيوانات الأليفة وأوقات والعطلات) مع المواين الطبي المنتظم، الى ان لا تعمل وظائف الكلى	مسار الرعاية التحفظية يعني فرصة القيام اللونشطة اليومية (مثل والحيوانات الأليفة وأوقات الفراغ والعطلات)، مع القليل من الروتين الطبي المنتظم، إلى أن تتوقف الكلى عن العمل	مسار الرعاية التحفظية يعني فرصة القيام اللونشطة اليومية (مثل والحيوانات الأليفة وأوقات الفراغ والعطلات)، مع القليل من الروتين الطي المنتظم، إلى أن تتوقف الكلى عن العمل	My words lack natural expression in this sentence.	Chose more natural expression.	The words of the translator were chosen because he chose better wording for the phrase ' مع القليل من الروتين الطبي المنتظم، إلى أن The translator's words are more easily understood when read.
When people have little or no kidney function left, and are not on dialysis, toxins, and excess water build up in their body and they move	عندما يكون لدى الاشخاص وظائف قليلة أو معدومة في الكلى ، ولا يخضعون لغسيل الكلى ، تتراكم السموم	عندما يعاني من المرضى من قلة أو انعدام وظائف الكلى ولا يخضعون لغسيل الكلى، تتراكم السموم والمياه الزائدة في أجسامهم ويتجهون	عندما يعاني من المرضى من قلة أو انعدام وظائف الكلى ولا يخضعون لغسيل الكلى، تتراكم السموم والمياه الزائدة في	My words lack natural expression in this sentence. Also changed noun statements and correction punctuation placement for a grammatical construction.	Chose more natural expression. Grammatical inflection.	The words of the translator were chosen because he chose better wording for the phrase ' عندما يعاني من المرضى من قلة أو انعدام وظائف الكلى ولا يخضعون لغسيل الكلى، تتراكم السموم والمياه الزائدة في

towards the end of life.	والمياه الزائدة في أجسامهم ويتوجهون نحو نهاية الحياة.	نحو نهاية الحياة.	أجسامهم ويتجهون نحو نهاية الحياة.			أجسامهم ويتجهون نحو نهاية أجسامهم ويتجهون نحو نهاية 'الحياة' The translator's words are more easily understood when read. Furthermore, replace the noun statement 'يتوجهون' with 'يتجهون'.
The peritoneum acts as a filter when a dialysis fluid (dialysate) is added to the peritoneal cavity.	يعمل الصفاق كمرشح عند إضافة سائل غسيل الكلى (الديلزة) إلى التجويف البريتوني.	يعمل الصفاق كمرشح عند إضافة سائل غسيل الكلى (الديالة) إلى التجويف البريتوني.	يعمل الصفاق كمرشح عند إضافة سائل غسيل الكلى (الديالة) إلى التجويف البريتوني	None	Used both for the final wording which nearly identical.	Combined translation since they were similar. Translator 1 words for final wording, nearly identical. The translator replaced the word' الديالة' with 'الديلزة' as used for patients in clinical settings.
Useful information for people with EKD, and their friends and family	روابط مفيدة للأشخاص المصابين بمرض الكلى المتفاقم\المرحله وأصدقائهم	روابط مفيدة للأشخاص المصابين بمرض الكلى المتفاقم وأصدقائهم وعائلاتهم	روابط مفيدة للأشخاص المصابين بمرض الكلى المتفاقم وأصدقائهم وعائلاتهم	My wording is sub-optimal wording for this sentence. There was an issue with translation accuracy because the words 'family' and 'friends' were missing.	Better matched the meaning.	The translator added the وعائلاتهم ' وأصدقائهم.' ', to match the wording in the original English version.

7.1.3.2 Back-Translation and Reconciliation (Versions 6C, 6C1).

As discussed in Chapter 4, a bilingual translator independently translated version 6B back into English (Translator 2). This provided an additional check to ensure that the translations were semantically equivalent. Translator 2 was not familiar with the original tool but had knowledge of healthcare concepts. Version 6C was then released with the coded back translation. I reviewed and compared the back translation of the YoDCA with the original English and Arabic forward-translated versions. This was done to identify and correct unclear terms and sentences, and to highlight and record any parts that were substantially different. I identified potential differences and highlighted them on the hard copies. There were 22 word-, phrase-, or sentence-level discrepancies, which were discussed among me and Translator 2. This enabled the analysis of differences between the original, translated, and back-translated documents. A consensus was reached regarding which translation was more accurate, better understood by the intended audience, and used better grammar. After the discussion, the necessary modifications were made to achieve a consensus on the final translated document, Version 6C1. Table 23 presents both the back-translation and reconciliation processes carried out by the researcher and Translator 2.

After comparing the translated versions (forward (6B) and backward (6C)) with the original, some of the differences did not require modification, but other words and sentences did. Minor differences in sentence structure and the use of alternative terms from the original were one manifestation of this. For example, there were 14 instances in which the final wording in the back translation was nearly identical to the original. Therefore, using anyone of these words were acceptable, as this was the most common concern in the back-translated version (see Table 23).

However, there were some terms used in the back translation that needed to be revised and modified. I checked whether the terms and sentences used were correct and then contacted Translator 2. There were discrepancies with words and phrases, including five concerns about better matches for a meaning, one concern about a better literal match with English, and one concern about choosing more a natural expression. I, as a researcher, and Translator 2 were able to reach an agreement using alternative terms and phrases which is necessary to clarify the original meaning of the text and ensure that the translation is accurate and satisfactory.

All differences were resolved, and a final translation was produced (see Table 23). The back translation was reviewed for the second time by me after improvements and amendments were made to the translation based on the agreement reached by me and Translator 2. The back translation was acceptable, and the flagged sections were carefully checked to ensure that they matched the source text, that the translation was clear and unambiguous, and that they read well. Subsequently, I confirmed that the translation was accurate and finalised a certified backward translation, Version 6C1, of the YoDCA booklet (see appendix 12).

Final forward Arabic translation, Version 6B	English wording of the original tool	Back translation text, Version 6C	Potential differences among texts	Concern and Reconciliation	Final back translation to version 6C1 after discussion with translator 2
المساعدة في اتخاذ قرار غسيل الكلى الرعاية التحفظية: التعايش مع أمراض الكلى	A Dialysis and Conservative Care Decision Aid: Living with Kidney Disease	Help deciding on dialysis and conservative care: Living with Kidney Disease	In the title of the original text, the word 'decision aid' is used, while in the back translation, the word 'helping decide' is used.	Both English words have the same meaning in the Arabic language. Use one of them in the final wording, nearly identical. Thus, there is no need for modification.	Help deciding on dialysis and conservative care: Living with Kidney Disease
الكتيب	The YoDCA Study Booklet	The Handbook	The naming of this document in the original text used the word 'booklet,' while in the back translation it used the word 'handbook.'	Both English (booklet and handbook) words have the same meaning and effects in the Arabic language. Use one of them in the final wording, nearly identical. Thus, there is no need for modification.	The Handbook
عملية اتخاذ القرارات المشتركة	Shared decision making	Joint decision- making	The original text used the word phrase 'shared decision making,' while in the back translation it used the word phrase' joint decision-making'	Both English phrase (shared and joint) have the same meaning and effects in the Arabic language. Use one of them in the final wording, nearly identical. Thus, there is no need for modification.	Joint decision-making
مرض الكلى المتفاقم	Established kidney disease (EKD)	Advanced chronic kidney disease (ACKD) and Progressive kidney disease	The original text used the term 'established kidney disease,' which is used to describe CKD that is getting worse (CKD stage 4 or 5). The translator used different terms on each page, such as 'advanced chronic kidney disease' and 'progressive kidney disease.'	Concern about the word choice better literal match. Both phrases were accurate but 'Advanced chronic kidney disease' is closer literally to English. Thus, I reached agreement with the translator to use 'advanced chronic kidney disease.' Researchers think this term might not be used in clinical settings in Saudi Arabia. They might use 'kidney failure' or 'end stage renal disease' as defined by KDIGO. This could be resolved by posing the question to the experts	Advanced chronic kidney disease (ACKD)

Table 23: Backward Translation of the YoDCA into Arabic: Identification and Resolution of Problems

				during the consultation and texting interviews.	
مرض الکلی المزمن	CKD is a life-long illness	CKD is a lifelong disease	The original text used the term 'illness,' while in the back translation the word 'disease' is used.	Both English terms (illness and disease) have the same meaning in the Arabic language. Use one of them in the final wording, nearly identical. Thus, there is no need for modification.	CKD is a lifelong disease
القسم الرابع: الخطوات التالية للرعاية.	Section D: Next Steps for Care	Section Four: The following steps of care	The original text used the phrase 'next steps of care,' while in the back translation the phrase 'the following measures of care' is used.	The concern here is the better matched the meaning, The problem with the accuracy of translation. The word 'measures' did not fit with the meaning of the word 'steps' in the original text because measures have lots of different meanings in Arabic, which may confuse readers. Therefore, I reached an agreement with the translator to use 'the following steps of care'. Which is the best phrase to use.	Section Four: The following steps of care
تساعد الدوافع الأشخاص على تدوين أي أسئلة وأفكار مهمة لهم عند اتخاذ هذا القرار.	Prompts help people note down any questions and thoughts that are important to them when making this decision.	Instructions help people write down any queries and thoughts that are important to them when making this decision.	The original text used the word 'prompts,' while the translated text used the word 'instructions.'	Both English words (prompts and instructions) have similar meanings in the English language in terms of encouraging people to do something, which has the same effect in the Arabic language. Use one of them in the final wording, nearly identical. Thus, there is no need for modification.	Instructions help people write down any queries and thoughts that are important to them when making this decision.
التحكم في توازن الماء والمعادن (مثل البوتاسيوم والصوديوم) للحفاظ على أجسامنا بصحة جيدة	Controls the balance of water and minerals (e.g., potassium, sodium) to keep our bodies well	Manage the balance of water and minerals (e.g., potassium, sodium) to keep our bodies well	The original text used the phrase 'control the balance of water and minerals' as the kidneys function. The translator used the phrase 'manage the balance of water and minerals' as the kidneys function.	The concern here is the better matched the meaning, The problem with the accuracy of translation the word 'Manage' has different meanings in Arabic than 'control'. Control means having power, while 'manage' means dealing with it. I	Controls the balance of water and minerals (e.g., potassium, sodium) to keep our bodies well.

تصنيع الهرمونات التى تتحكم فى وظائف أخرى (مثل ضغط الدم وفقر الدم)	Make hormones that control other functions (e.g., blood pressure, anaemia)	Synthesis hormones that control other functions (e.g., blood pressure, anaemia)	The original text used the phrase 'make hormones that regulate other functions' as the kidney's function. The translated text used the phrase 'synthesis hormones that regulate other functions'.	reached agreement with the translator to use the same word 'control.' The concern here is the better matched the meaning, The problem with the accuracy of translation. The word 'synthesis' means the combination of something with a different meaning. I reached agreement with the translator to use 'produce hormones that regulate other functions.' 'Make' is a synonym for 'produce.'	Produce hormones that control other functions (e.g., blood pressure, anaemia)
تساعد هذه القرارات الأشخاص وعائلاتهم وأخصائيّ الكلى على التخطيط لإدارة مرض الكلى المتفاقم الذي يعانون منهم طول مسار الرعاية.	These decisions help people plan their EKD management with their families and kidney professionals along a care pathway.	These decisions help people, their families, and kidney specialists plan to manage their ACKD throughout the course of their course of care.	The original text used the phrase 'care pathway,' the back translated text used the phrase 'course of care.'	The concern here is choosing more natural expression. Both English phrases have similar meanings but may have different effects depending on the sentences, which may be confusing for readers. I reached an agreement with the translator to use the original word 'pathway' in the text. As this chose better wording for (care pathway).	These decisions help people, their families, and kidney specialists plan to manage their ACKD throughout the course of their care pathway.
احصل على لقاح الأنفلونزا الشتوية كل خريف	Have a winter flu jab every autumn.	Get a winter flu shot every autumn.	The original text used the word 'flu jab,' while translated text used the word 'flu shot.'	Both English words (jab and shot) have the same meaning and effect in the Arabic language. Use one of them in the final wording, nearly identical. Thus, there is no need for modification.	Get a winter flu shot every autumn.
الدعم باللياقة البدنية.	Support with fitness	Physical fitness support	The original text used the word phrase 'support with fitness 'in the management of symptoms of kidney disease. The translator used the word phrase 'physical fitness support' in the	The concern here is the better matched the meaning, The problem with the accuracy of translation. The phrase 'physical fitness support' may have a different meaning than 'fitness support,' which may confuse readers. I reached an agreement	Physical fitness support

			management of symptoms of kidney disease.	with the translator to use 'physical fitness support' in the text.	
يحصل هؤلاء الأشخاص على الكلية من شخص متوفي: متبرع متوفي	People are given a kidney from a person who has died: a deceased donor	People receive a kidney from a deceased person: a deceased donor	The original text used the word phrase 'person who has died,' while the translated text used the word phrase 'deceased person.'	Both English words and phrases have the same meaning in the Arabic language. Use one of them in the final wording, nearly identical. Thus, there is no need for modification.	People receive a kidney from a deceased person: a deceased donor
تأثيرات العلاج	Consequences of treatment	Treatments effects	The original text used the phrase 'consequences of treatment of chronic kidney disease,' while the back translated text used the phrase 'treatment effect of chronic kidney disease.'	Both English phrases have the same meaning and effect in the Arabic language. Use one of them in the final wording, nearly identical. Thus, there is no need for modification.	Treatments effects
تناسب إجراءات رعاية مرض الكلى المتفاقم الحياة اليومية،	Fit EKD care routines into daily life.	Advanced chronic kidney disease routines are appropriate for everyday life	The original text used the sentence 'Fit established kidney disease care routines into daily life' when comparing between treatment pathways. In the back translated text, the sentence 'advanced chronic kidney disease routines are appropriate for everyday life.' Was used when comparing between treatment pathways.	The concern here is the better matched the meaning, The problem with the accuracy of translation. The sentences used in the translated text were not clear and not gave the same meaning as the sentences in the original text. Therefore, I reached an agreement with the translator to use this sentence: 'Align everyday activities with advanced chronic kidney disease care practices.'	Align everyday activities with ACKD care practices.
تعديل وتبديل العلاجات	Adjusting and Switching Treatments	Modifying and Switching Treatments	The original text used the word 'adjusting' in 'adjusting and switching treatments,' while the back-translated text used the word 'modifying' in 'modifying and switching treatments.' The translated text used the word 'modifying' in modifying and switching treatments	Both English words (adjusting and modifying) have the same meaning and effect in the Arabic language. Use one of them in the final wording, nearly identical. Thus, there is no need for modification.	Modifying and Switching Treatments
عادة ما يتم اختيار الأشخاص الذين بشاركون	People who take	People who	The original text used the word	Both words (six and gender) have the	People who participate

في هذه الدراسات بسبب خصائص مثل العمر والجنس والعرق والمشاكل الصحية الأخرى و/ أو العلاج.	studies are usually chosen because of characteristics like age, sex, ethnicity, other health problems, and/or treatment	studies are usually selected because of characteristics such as age, gender, ethnicity, other health problems, and/or treatment.	who take part in these studies are usually chosen because of characteristics like age, sex, ethnicity, other health problems, and/or treatment.' In the translated text used the word 'gender' in the sentence: 'People who take part in these studies are usually chosen because of characteristics like age, gender, ethnicity, other health problems, and/or treatment.'	Arabic language. Use one of them in the final wording, nearly identical. Thus, there is no need for modification.	usually selected because of characteristics such as age, gender, ethnicity, other health problems, and/or treatment.
مقايضاتي بين مسارات الرعاية التحفظية وغسيل الكلى	My Trade-offs Between Conservative Care and Dialysis Pathways	My Compromises Between Conservative Care and Dialysis Pathways	The original text used the phrase 'value trade-offs,' While t he translated text used the phrase 'value compromises.'	Both English phrases have the same meaning and effect in the Arabic language. Use one of them in the final wording, nearly identical. Thus, there is no need for modification.	My Compromises Between Conservative Care and Dialysis Pathways
المربع ٣: رعاية نهاية الحياة للأشخاص الذين يعانون من تدهور حالة مرض الكلى المتفاقم	Box 3: End of life care for people with worsening EKD	Box 3: End of life care for people with deteriorating ACKD	The original text used the word 'worsenin,' while the translated text used the word 'deteriorating.'	Both English phrases have the same meaning and effect in the Arabic language. Use one of them in the final wording, nearly identical. Thus, there is no need for modification.	Box 3: End of life care for people with deteriorating ACKD
يتم عمل فحوصات وظائف الكلى المنتظمة مثل معدل الترشيح الكبيبي المقدر ونسبة الألبومين إلى الكرياتينين	Kidney function is worked out from regular tests on estimated glomerular filtration rate (eGFR) and albumin to creatinine ratio (ACR).	Regular kidney function tests are done such as the estimated glomerular filtration rate (eGFR) and albumin to creatinine ratio (ACR).	In the back translation, translator (2) rewrote the sentence, change word order and use synonym.	Both English sentences have the same meaning and effect in the Arabic language. Use one of them in the final wording, nearly identical. Thus, there is no need for modification.	Regular kidney function tests are done such as the estimated glomerular filtration rate (eGFR) and albumin to creatinine ratio (ACR).
يقدم الأخصائيون الصحيون المتمرسون في علاج أو إدارة مشاكل الكلى الرعاية للأشخاص	Health professionals who are expert in managing kidney	Health professionals experienced in treating or	In the back translation, the Translator (2) was expressed the sentence meaning with different words.	Both English sentences have the same meaning and effect in the Arabic language. Use one of them in the final wording, nearly identical.	Health professionals experienced in treating or managing kidney problems provide care

المصابين بمرض الكلى	problems care for	managing kidney	Thus, there is no need for	for people with CKD,
المزمن، وقد يُطلق عليهم	people	problems provide	modification.	and may be called
اسم أخصائيو أمراض	with CKD. They	care for people		nephrologists or
الكلى أو طبيب أمراض	might be called	with CKD, and may		nephrology doctor,
الكلى ، ممرضات، أخصائي	specialist kidney,	be called		nurses, dieticians, and
تغذية، أخصائي نفسي.	renal or	nephrologists or		psychologists
	nephrology	nephrology doctor,		
	doctors, nurses,	nurses, dieticians,		
	dieticians,	and psychologists.		
	psychologists.			

7.2 Step 3: Testing Prefinal Versions of the Adapted YoDCA Tool

This section describes step 3 of Chenel et al. (2018), which was testing the penultimate version of the adapted DA. Following the translation of the adapted YoDCA tool, Version 6, and its subversions, evaluations of the penultimate adapted and translated versions (5 and 6B) were conducted with three experts recruited from the previous phase: Ali, Layla, and Tala. One expert who spoke English reviewed the penultimate adapted English version (5), and two who spoke Arabic reviewed the penultimate translated version (6B). The acceptability and clarity of the contents were assessed through a content validity exercise using semistructured individual interviews. In this phase, user feedback was elicited on how understandable and palatable the information was. Users' informational needs and characteristics, such as literacy levels and linguistic and cultural appropriateness, were also examined. These factors can influence understanding and change behaviours, so solutions were sought to resolve these issues. This phase also included linguistic evaluation of the Arabic version for clarity, intelligibility, appropriateness, and cultural relevance. The experts' comments included their first impressions of the adapted and translated tools as well as the latter's cultural and linguistic appropriateness, utility, and implementation potential. In addition, they suggested further improvements.

Theme1: Overall Feedback on the Adapted and Translated YoDCA (Versions 5 and 6B). Tala and Layla reported that the tool was very informative and well designed. However, they reported that it was quite lengthy, which may limit their ability to use it. They suggested that a future version should use graphics and pictures instead of words and bullet points. However, Ali did not share the same point of view. According to Ali, the tool contained enough information to help patients understand their disease trajectory and make accurate decisions. It is the first tool available in Saudi Arabia healthcare settings for both patients and their families. This is very significant for family inclusion, especially for uneducated patients. As they explained in their statements:

> "It is very informative (English version) ... I will say is very good in comparison to the previous one, this one you detail up with all the proper example choices, and it is actually supported with evidence ... However, if you can translate that into graphic in the future, much better I will say. Because it is

quite lengthy, and you know it is kind of wordy as well" (Tala, a Malaysian female academic nursing staff, has 14 years of experience)

"...It was rich, and I think it is helpful ... You are offering the patient with the right tools to understand to digest to mitigate his decision and not the patient himself and it can also involve the family. Let me speak in about Saudi patients, we have a big portion of the patient they are not educated or not completing the high level of the school. So, they will not have this level of understanding, but you will have this issue with the family, and they will keep asking about all the choices and what we will be the end" (Ali, an Eritrean male nephrology physician, has 17 years of experience)

Furthermore, Ali raised another concern about the tool's presentation and design. He claimed that he had no issues with the presentation or layout, but that patient testing was necessary, as there may be some difficulties in dealing with the Arabic accent among Saudi patients since Saudi Arabia is not a small country. He described the issue as follows:

> "For the time being, it should be tested with real patients. I believe maybe you will face a small challenge that you are not dealing with a small country. The largest of regions and the change of the accent in between the regions might create a minor problem with the understanding of the tool, especially as I told you that the patient is not fully educated. It might need some versions of the translation have a different accent, or it might lead to more pictures to help the patients to understand" (Ali, an Eritrean male nephrology physician, has 17 years of experience)

The experts also suggested that the updated version needed to include some relevant topics missing from the tool to help with both cultural and clinical adaptation. For example, false perceptions about kidney disease and medications. Similarly, Tala recommended that a section on taboos should be included in the booklet, particularly in the Malaysian context. The Malaysian context is very similar to the Muslim/Arab setting in that there is widespread misunderstanding of CKD and its management. For example, once patients get a diagnosis, they may get advice from their family members and other patients that causes more damage

and faster disease progression. Patients may also believe that medical treatment is unsafe and that only alternative treatments or religious practices are safe. This is considered a major challenge to raising awareness in such communities about CKD treatment. As a result, Ali and Tala recommended including such a topic in future versions. Moreover, Tala suggested including a self-monitoring checklist: a daily fluid intake chart, BP readings, and glucose readings. Layla, on the other hand, had a different viewpoint based on her experience on the additional topic, stating that it is critical to emphasise the role of social workers and religious figures in supporting patients in the healthcare setting, particularly those who are anxious or depressed, as those patients should know there are religious and social support services available to them. As they reported:

> "In Arab societies, we have false perceptions about the treatment and the management option. Many of the patient believe that ESRD can be treated for example with herbal or can be treated with changing type of water ... we have majority of our patient before they take a decision to start the dialysis, keep connect with some of a dialysis patient and they ask them how you feel what was the most painful time do you advise us to start or not? For sorry, many of them respond that dialysis is killing them and destroy their life ... So, this all-false perception from the people surrounded by the patient so we need to clear it through the tool" (Ali, an Eritrean male nephrology physician, has 17 years of experience)

> "In one part of the paper (tool) that they will have depression and stress because this stage ... so after you we mentioned the problem, you may suggest that there will be some social care provider, so if you will mention their role as a social worker in this stage, patients they will feel more comfortable when they will feel that there will be support from this perspective. Also, in Kuwait, we have some people like who is coming regularly to visit the patient like Mulla (religious person) like support and encourage their spirit ... they will talk to them, do not worry, they will give them just like some Dua' for the patient usually would really be comfortable" (Layla, a Kuwaiti female clinical nurse staff, has 12 years of experience)

However, Layla indicated that these supportive services are not only for Arab Muslim patients but also for Arab non-Muslim patients. Based on her experience working in hospitals, the religious figure visiting Muslim or non-Muslim patients says a Dua for them and gives them a book to read. Thus, they reassure and encourage patients based on their language. It is, the experts suggested, very important to consider Arab non-Muslims in future versions of the booklet.

Theme 2: Cultural Appropriateness. After reviewing the adapted tool, all experts agreed that it was appropriate for Muslim patients. For example, Tala stated that the content of the adapted version was more appropriate and acceptable in the Muslim context, particularly because family inclusion in decision-making and spiritual and psychological support were added. However, Ali suggested removing alcohol is not a major requirement, and it should be included in a future version. As they reported:

"It is appropriate for Muslim patient ... I can see that your team really works hard to improve the content and you include the family in comparison to the earlier version. I can see that the family element is there. Then some content whereby you apply the spiritual needs ... The second version is much better in terms of the content" (Tala, a Malaysian female academic nursing staff, has 14 years of experience)

"I believe last year we comment about some of the phrases (alcohol). I believe you are getting those point. Anything could be adapted for the Muslims especially that today we are in openness with others. There is nothing is called prohibited. I mean, whenever they are talking about alcohol is alcohol and we have it in our society. Regardless, we are Muslims or not but that is not mean because I am Muslim, I will be ashamed to ask about ... You should ask him regardless or at least in the in the tool, you need to tell him that drinking alcohol is still impacting the kidney" (Ali, an Eritrean male nephrology physician, has 17 years of experience)

Theme 3: Linguistic Appropriateness. The penultimate Arabic version (6B) was tested for linguistic appropriateness by two Arabic-speaking experts, Ali and Layla. During the interview,

they explored how they perceived the Arabic information in the YoDCA tool in terms of its clarity and readability. They also explored how they constructed meanings in their own words based on what they read. Ali and Layla had different views on the Arabic translation, particularly in terms of its clarity and readability. For example, Ali reported that the translation was understandable, but some terms needed to be reviewed, while Layla reported that it was not an easily readable Arabic translation, particularly for non-educated people. As they stated:

" It is clear. I can say that in general, I understand it well ... It has been written or it has been translated in easy language. Might we need to recheck further in some of the terminology, but in general, it was accepted" (Ali, an Eritrean male nephrology physician, has 17 years of experience)

"Although it is in Arabic, but I think it was like little complicated for some terminology. But in general, it was the clear, but I am talking from a patient perspective, I think it is somewhere that was like a little complicated, it is better to avoid them ... It was Arabic but honestly not easy Arabic. Like I am a nurse, and it was difficult for me to understand the word (الكلى المتفاقم) ... some or a few sentences were inappropriate, it was more complicated" (Layla, a Kuwaiti female clinical nurse staff, has 12 years of experience)

Furthermore, during the interview, the experts either identified or were directed towards specific translated terms in the tool. These terms correspond to the original term identified during the translation process. They examined whether these accurately reflected the English meaning and used appropriate words relevant to HCPs, users, and patients in an Arabic Muslim context. They were also asked if they had suggestions for improving the translations or alternative word suggestions. Layla and Ali identified common problematic terms and suggested alternative words used in clinical settings. These included' الرعاية التحفظية وغسيل الكلى ', الرعاية التحفظية وغسيل الكلى ', and ', 'طرق العلاج ',' إدارة أمراض الكلى ', 'المتفاقم . Moreover, Layla identified other phrases that might not be easily understood by patients, especially older patients. She suggested alternative words to simplify it. Layla discussed these distinct words and statements based on her experience as a member of a healthcare

education committee. Table 24 summarises the terms and statements identified, as well as the experts' concerns and suggestions to improve the translation. I reviewed all comments made by the experts and made the necessary revisions to the final version (see Table 24), which was 6B1. The Arabic version I developed in this thesis is only for Saudi Arabia healthcare settings; other Muslim countries would need it translated into their spoken language and might need slight cultural adaptations.

Original English terms and phrases	Forward/backward translation (Arabic terms) version (6B)	Expert	Their comment and concern	Their suggestion	Final version (6B1)
Conservative care	الرعاية التحفظية	Ali	The Arabic language is full of terminology, so you can incorporate it into your Arabic translation. Whatever words you're using, they will be understood by the people, so do not think it is a problem (الرعايه التحفيظيه). When you say (العلاج التحفظي)) or (العايه التحفيظيه), it is now accepted. I mean, both are fine.	It is preferable to use the term 'العلاج التحفظي'.	الرعاية التحفظية
		Layla	The word (الرعايه التحفظيه) also, I cannot, I think it is difficult to understand. It will be confusing for the patient when they read it. Currently I do not have any alternative word but for sure it will be confusing because I was working with a health education committee and patients, they did not prefer to read at all. They do not like to read; they want something very easy if you want to instruct them. I worked with renal patients, and I gave them instructions before and after surgery. But it's only polit points; they only want polit points, but honestly, they want only one page. They will not bother themselves to check another page or other things.	Non	
Established Kidney disease	مرض الكلى المتفاقم	Ali	This word had a wordy and lengthy translation (امراض الكلى المزمنة المتفاقمة). So, we need to translate it into progressive chronic kidney disease. We can mention (تدهور امراض الكلى المزمنه) without describing the phrase (تدهور امراض الكلى المزمنة), but in general, when discussing all diseases, the term 'المتفاقم' may confuse patients. Thus, maybe the word تدهور' would be wordier if you wanted to talk about the progression of the disease itself.	'تدهور' Use instead of' مرض الکلی 'المتفاقم	No change made. We need to do more exploration by testing
		Layal	' it is difficult to understand and complicated word I never heard this word before. I think this one is (الفشل الكلوي) more appropriate because we as Gulf regions, I think we are familiar with the word of renal failure, which is something common, but when we will complicate it, like we are added one- word extra people they will misunderstand, they will get maybe scared. But if you will make it simple (مرض الفشل الكلوي) then underneath you will write that you will explain at the stage I think it will be better. The main thing you write (الفشل الكلوي) then subtitle (complicated stage or end stage) or it can be (المتقدمه المرحله) or (المتقدمه)	مرض 'Use' مرض 'as main term and between brackets we can say (المتقدمه or (المرحله النهائيه).	with HCPs and real patients.
Management of kidney disease	إدارة أمراض الكلى	Ali	It is preferable to translate it into (رعاية امراض الكلى). I think the word 'رعاية' it is better than 'ادارة' since the word 'ادارة' will be more confusing when the patient read that word.	It is preferable to use the	رعاية امراض الكلى

Table 24: Problematic Terms and Expressions Identified by the Experts and their Suggestions for Improvements from Versions 6B to 6B1.

				رعاية ' phrase . ' امراض الكلى	
		Layal	The word 'ادارة' could be confusing, I mean when I say it (ادارة), they are like administration (in meaning). Thus, I think better to say (علاج) only.	lt is preferable to use the word' علاج instead 'ادارة).	
My Trade-offs Between Conservative Care and Dialysis	مقايضاتي بين مسارات الرعاية التحفظية وغسيل الكلى	Ali	The word ''مقايضاتي'' is better than ''مقايضاتي '' is better than ''توازن' in the meaning.	lt is preferable to use the word 'توازن'.	الاختيار بين مسارات الرعايه
Pathways		Layla	what does this mean (مقايضاتي)? I did not understand, so, I do not think, and I am not sure the patients will understand this word. You could say ' الاختيار بين) الاختيار بين المسارات 'or' مسارات الرعايه التحفظيه وغسيل الكلى	اt is preferable to use either " الاختيار بين مسارات الرعايه التحفظيه وغسيل or " الاختيار بين ."المسارات	التحفظيه وغسيل الكلى
Therapist	طرق العلاج	Ali	The phrase 'وسائل العلاج' it can be therapist, or you could use 'وسائل العلاج' it is accepted. So, whatever word you use it is accepted.	Bothe phrases are acceptable	طرق العلاج
Consequences of treatment: Carrying out HD means having needles put into the fistula at each session.	تأثيرات العلاج يتم الغسيل الدموي عن طريق وضع إبر في الفستيولا في كل جلسة	Layla	On (تأثيرات العلاج), page 13, there is sentence (الفستيولا في كل جلسة), page 13, there is sentence (الفستيولا في كل جلسة), they did not (الفستيولا في كل جلسة). they did not know this word. You can say (وضع الإبره في المكان المخصص لها). But if you will wite Fistula, they will read it in fistula the old people maybe they will think what this is 'Fistula' mean. We can understand but I think if you are said (في المكان المناسب فضع الإبره) it will be better.	It is preferable to use either' وضع الإبره في المكان المخصص وضع ' or 'لها الإبره في المكان المناسب	وضع الإبره في المكان المخصص لها
On page 18 it was said " Medical studies measure a) the life expectancy of people with EKD, compared with groups of healthy people, b) the impact of kidney treatments on how quickly	تقيس الدراسات الطبية أ) متوسط العمر المتوقع للأشخاص الذين يعانون من مرض الكلى المتفاقم الأشخاص الأصحاء، ب) تأثير علاجات الكلى على مدى سرعة توقف الكلى عن العمل، والتحكم في	Layla	The phrase 'تقيس الدراسات الطبية' This I do not know it is coming from where when you say (تقيس الدراسات الطبية) is it a new sentence or what exactly? Because it is written a point there was a point like (متوسط العمر) then A, B, and C took place there (تقيس الدراسات الطبية) I was looking for interest so that if patients read it, they will think it is continuous to some paragraph or something like that. So, if you want to write bullet points like this in , use a different colour so they know it's a different point. Also, at the end of this sentence wrote different number 16,17, 18,19, I do not understand what they mean by 16.17.18.19 all these numbers. Do you mean	Make it as bullet points with different colour. Remove reference	No change made. We need to do more exploration by testing with real patients.

kidneys stop working, symptom control and side effects, and c) different ways people cope with EKD [16,17,18,19].	الأعراض والآثار الجانبية، و ج) الطرق المختلفة التي يتعامل بها الأشخاص مع مرض الكلى المتفاقم[١٩،١٨،١٧،١٦].		the reference that you use for this booklet. I think, based on my opinion and my experience, that patients will get confused when you write a number like that. Because if you get this booklet for the patient, they will not care about the reference; however, if you get this booklet for the management, they will care about the reference. But this reference will not go on this small booklet that will be provided to the patient. I know it is important to add the reference, but I do not think the patients care about the reference because, anyway, when it does come from the hospital, they will know that it is appropriate and that all the information is accurate. If you want to include something like, I am not sure, but I believe that people in our society, particularly the elderly, may not be familiar with this number reference, so do not get confused, even if you make it small. So better to remove it.	numbers from the text of the patient booklet.	
An example of a trade-off might be thinking about what is more important to you in your daily life now, as your kidney disease gets worse	قد يكون من أمثلة المقايضة التفكير فيما هو أكثر أهمية بالنسبة لك في حياتك اليومية الآن، حيث أن مرض الكلى لديك يزداد سوءًا	Layla	قد يكون من أمثلة المقايضة التفكير فيما هو `It was written on page 18 in this sentence أكثر أهمية بالنسبة لك في حياتك اليومية الآن، حيث أن مرض الكلى لديك يزداد سوءا understand this sentence `أكثر أهمية بالنسبة لك في حياتك اليومية الآن، . Like what I understand like you are giving example for the patient that they should think about something different, more interesting for them. I think no need to write `just write (من المهم للمريض ان يفكر في اشياء اخرى) instead of writing `autis Interesting to ther ways, not just by giving examples like the right or wrong way, but you can give them examples like, 'Stay with family or watch TV, for example,' or 'Listen to music and the Quran like this.' I mean, give them an example, like a point that the patients will understand.	It is better to change the sentence to ' من المهم للمريض ان يفكر في اشياء ' and then make the examples into bullet points.	من المهم للمريض ان يفكر في اشياء اخرى
Haemodialysis and peritoneal dialysis	غسيل الكلى الدموي وغسيل الكلى البريتوني	Layla	We as HCPs can understand the terms like this (البريتوني وغسيل الكلى الدموي وغسيل الكلى), but I am not sure if patient they understand this term `البريتوني`. To be completely honest, when we are in Kuwait, we do not use these terms; we simply use the term "renal failure," and then we go into detail and explain this, this, this, and this based on the case. Honestly (I do not have any alternative word for `البريتوني` because in my country, we prefer brochures or booklet. We are re not pretending to go into detail and using them to avoid confusing the patient. But, as I previously stated, when it came to explanations and details, we made short videos (four to three minutes) that I believe explained everything about the instructions.	None	No change made. We need to do more exploration by testing with real patients.

Ali and Layla were asked whether they recommended using both Arabic and English adapted versions in clinical settings. They asserted that it would be better to use both versions because there are English-speaking staff and patients. Therefore, each user could choose their preferred language. In contrast, Tala examined the penultimate adapted English Version, 5. She was asked whether she noticed any English words or statements that did not make sense or caused confusion after further review. She reported that while it was simple for her as an educated person, it would be difficult for the undereducated or people with low-literacy levels. As a result, she suggested that once the English and Arabic versions were completed, they be sent to either an English department or an expert. This would enable the experts to check, compare, and review the texts' meanings. Moreover, Tala reported that there were typographical errors to be fixed, particularly on page 8 with the word 'kindy' and page 9 with the abbreviation 'KDIGO'.

"The language use was direct forward simple and easy to understand ... But this English language is uneasy thing to be understood for non-educated or the person who has low literacy level it might be challenging for them ... So, I would suggest you perhaps you can maybe arrange a meeting or send your booklets to English department or literacy department or experts ... So, they checked both versions whether it suits the needs of the community or not, and they can help you in terms of that, because we think it is easy" (Tala, a Malaysian female academic nursing staff, has 14 years of experience)

Theme 4: Utility and Implementation. The experts shared their suggestions on the implementation tool in clinical settings (see Box 3 for details of the implementation plan) in terms of how it should be introduced to hospital management, which patients and staff need to be introduced to the tool, how it should be implemented with patients over time, the challenges that need to be taken into consideration before implementation, and their own suggestions for future improvements of the whole tool. In terms of introducing the YoDCA tool to hospital management, the experts had differing views. Some favoured informal communication channels with hospital directors, while some preferred more formal routes. Other suggestions included working with the national Ministry of health (MOH), undertaking clinical trials, or consulting the Saudi Society of Nephrology and Transplantation (SSN&T) to

more fully assess the tool's effectiveness. Collaboration between the MOH and SSN&T to produce educational material is part of the Saudi protocol for treating CKD. Therefore, involving both organisations at an early stage would be beneficial. As they described in their statements:

"I will say that my first approach if you have to or really insist to introduce to the hospital management, we need a written letter or email suggesting that to let the hospital use or utilise the booklet if the permission is granted. I will see that this is not easy system ... If you are about to use your materials in a different setting in a different country the approaches. Perhaps the first stage is research ... We see how acceptance rate in the HCPs accepted and if the finding shows good or positive outcomes. Then there is a higher chance to utilise your booklet into the setting" (Tala, a Malaysian female academic nursing staff, has 14 years of experience)

"I prefer that not to start with the hospital management, but I prefer to Saudi Society of Nephrology is the best option. It should be part of the protocol of the Saudi protocol that whenever we are starting to educate our patient or start to help them to take the right decision, we need to provide them with this tool" (Ali, an Eritrean male nephrology physician, has 17 years of experience)

The experts discussed the types of patients that could benefit from this tool. They all stressed that the tool is not suitable for all patients. Before introducing tools to patients, they need to carefully choose them. As they insisted, they would either first use it with educated patients and then move on to patients with less education, or they would develop a different version of the tool for undereducated patients. The experts had different views on which patients to use the tool with. They disagreed about whether it would be suitable for all renal patients or just those with CKD. Moreover, Ali stressed the importance of family involvement in the implementation of the tool. This allows patients to facilitate their understanding in making a decision. As they stated:

"I think only educate the patient with honestly who is with bachelor or master or PhD they will be interested to read this much information. Otherwise, like normal people, I do not think they will have interest to read this much especially in their disease they do not have an energy to read ... Another booklet (for non-educated), it is not like booklet, I think something simple if you can simply the form of the content not audio but video" (Layla, a Kuwaiti female clinical nurse staff, has 12 years of experience)

"... This booklet is suitable for those already confirmed that knows by the physician that he or she is having CKD ... They are contemplating what to do, should I start the dialysis, or should not and what will be happening after this stage. That you have is good you highlighted about the palliative care on the transplant option in this booklet in a simple manner ... But we also not necessarily to narrow the scope only to those with disease but because to me I can see this booklet is actually one source of information to create awareness" (Tala, a Malaysian female academic nursing staff, has 14 years of experience)

"I think in the patient who recently have the disease but also does not matter if you will get to that at the end stage and he will see what still in the end stage, but he is not died so still there is chance to receive some support, so it is good for them to read" (Layla, a Kuwaiti female clinical nurse staff, has 12 years of experience)

Ali was asked about the appropriate time to introduce the conservative management option. He was also asked about the choice of switching between dialysis and conservative management as the relevant scope of this tool for their patients. He stated that it is preferable to introduce it at an early stage for newly diagnosed patients who have not started dialysis; the tool would not be suitable for dialysis patients. As a result, he suggested creating multiple versions of the tool, each for use with a specific group of patients. For example, a version for haemodialysis patients would need to focus more on the transplant option, discussing what is involved in a transplant and what happens afterwards. For conservative patients, a version could include more options about dialysis, conservativeness, and the transplant itself. He suggested that every population needs a special tool, which would be coded as blue, yellow, and red. As he said:

"It depends on If you are in an earlier stage, yes you will have the option ... you cannot give it to the patient who are already in dialysis. Unless you are decided to stop them from dialysis and that will kill him ... Mainly the patient who are recently diagnosed as CKD from stage from stage one until the stage five but before deteriorating the kidney to the dialysis requirement the earlier stage will get more benefit in earlier stage is better" (Ali, an Eritrean male nephrology physician, has 17 years of experience)

Moreover, when asked about conservative management in the Saudi Arabian clinical context, Ali emphasised that this type of management is introduced at a later stage of CKD. It comes at a specific time for a specific group of patients – specifically, those who are diagnosed late due to ignorance about screening. As he described:

> "There is a specific timing to have or continue in conservative. So, whenever you talk about conservative in the patient who already in the dialysis, that you mean, you want to give the mercical of this patient. I mean, know he needs to stop the dialysis and stay at home. In some cases, yes, you need to take this decision. Whenever you feel that the patient is not comply well with the dialysis and he has a problem in coming to the dialysis clinic or to receiving the dialysis treatment and you do not have any option for transplant. Then you need to help the family of the patient to take this decision" (Ali, an Eritrean male nephrology physician, has 17 years of experience)

The experts were then asked whether specific HCPs would need to be involved in the implementation of the YoDCA tool in clinical settings. Layla reported that a multidisciplinary team could benefit from the tool, not only nurses. Ail reported that healthcare educators, social workers, and the patient experience department need to be included in the implementation process alongside the HCPs. As Layla reported:

"I think all the medical team, not only the nurses. I think the nurses and doctors on pharmacists, dieticians all of them. Like it is multidisciplinary team. So, all the people whose are involved to give care for this patient they must have a copy of this booklet, all of them" (Layla, a Kuwaiti female clinical nurse staff, has 12 years of experience)

The experts were questioned about the most effective delivery method, location, and timing for introducing their patients to the tool during their daily care routines. One preferred giving it to patients early in their disease process, directing them to sections relevant to their needs, and asking them about their concerns. Another preferred to limit the tool to three to four pages, focusing on the main information. This would ensure that it is discussed with the patient before proceeding to the details. Another preferred to use a combined approach that begins with a simple explanation and progresses to greater detail. By giving people the tool to understand more about their disease, they can make informed decisions. As they described:

> "You must get to know what the need for your patients is because this booklet is prepared in 30 pages ... Some people do not love to read because we have different learning styles ... So, ask them what they want to know and just once they inquiries about treatment choice then, point up and open up of issues in interest and push them to the page mention about the patient's problem, you would not through all, you know we have to catch the needs of the client what want they know and then go directly to the section. It is good if you give the booklet earlier to all patients and ask them to read that ... In the next follow-up or next visit, perhaps ask them to read the book or Paraphs just rias a question for them, do you have anything that you concern about, and you can deliver the information based on the booklet" (Tala, a Malaysian female academic nursing staff, has 14 years of experience)

"I will eliminate the page and I will I explain to the patients then, I will give him each paper individually and I will read with the patient like this ... The other things about like renal dialysis and these things and details I prefer to go after we explain all these things little just simple idea ... I will go through this process that maybe you will have side effects of the dialysis like depression that do not worry we will have social worker will come every day you will make sure that you will be comfortable from and Mullah people they will come they will reassure you we had facility like you know a group discussion'' (Layla, a Kuwaiti female clinical nurse staff, has 12 years of experience)

However, only Tala reported that the appropriate way to introduce the tool is for HCPs to use it in a training module. They should also, she said, conduct trial research to see whether the tool would be accepted in clinical settings in the future. She advocated introducing the tool to patients in a research study.

> "I will recommend, to have a health care professional first. Perhaps we can use it as a training module. Like the continuous medical education session for the doctors or nurses we can have the CME session to introduce this booklet. And it is suitable for training if you are talking about to disseminated among healthcare professionals So, if then once the awareness is there, that perhaps you can talk to the superior to the authority to the gatekeeper, on utilising it 100% of your setting" (Tala, a Malaysian female academic nursing staff, has 14 years of experience)

The experts also recommend locations for administering the booklet in healthcare settings. In addition, they recommend timing for induction throughout the course of the disease. Layla and Ali indicated that the most appropriate location to use the tool would be the outpatient department and nephrology clinic before transferring the patient to the dialysis clinic. Patients in the nephrology clinic would meet all members of the medical team and receive a booklet that would allow them to understand all the information and make a proper decision. This, Alli thought, would be the right place to use the tool. However, Tala had a different view. As she reported, this tool should not be restricted to outpatient and inpatient departments; it can be used in other healthcare settings, such as primary healthcare, community settings, and private settings once permission is obtained. As they described:

"Start with all the nephrology clinics I mean before the dialysis. Before they get involve the patient in the dialysis, they need to help him to take the right

decision. They will give him the booklet and they will give him a time to digest it and read it very well before they come" (Ali, an Eritrean male nephrology physician, has 17 years of experience)

"We can utilise at the clinic wherever In Malaysia we have nephrology clinic or a haemodialysis clinic or outpatient department, a day clinic. Then in hospital we have the medical ward, so we can use at the Medical as well for patients admitted ... this is booklet, is nothing wrong with you to put this in the relevant in surgical clinic or in the community settings, primary healthcare clinics. Because this is one way of creating awareness of CKD treatment, if you have the symptoms not waist until too late. I mean still you can put the booklet in the general practitioner clinic and privet clinic and no issue of restriction as long as I missioned before getting the permission for the gatekeepers" (Tala, a Malaysian female academic nursing staff, has 14 years of experience)

Furthermore, the experts were asked about the barriers to using the tool within healthcare settings, both from patients' and HCPs' perspectives. From the patient's perspective, all experts agreed that undereducated patients may find it difficult to utilise the tool. Another barrier, according to Ali, was visual impairment, so he proposed that we adapt the tool into another format, either audible or braille. On the other hand, Tala explored how culture is considered one of the barriers to using tools, particularly in the Malaysian context, which similar taboos in Saudi Arabia. She stated that cultural influences and taboos are very strong in Malaysia, which may lead to misconceptions about CKD. As she reported:

"The non-educated even if you remove the word and use the picture will be difficult to understand these (meaning the content). If you can make it, I am not sure if you will make English understandable for other people, but if it is not in English, it will be difficult for people who do not speak Arabic" (Layla, a Kuwaiti female clinical nurse staff, has 12 years of experience)

"I think this is the main barrier (written format). But maybe it might be helpful if it is recorded because we have the bulk of the patient, they have a

problem in the vision impairment due to the diabetes. It may be helpful to be in a Braille language or to be audible material'' (Ali, an Eritrean male nephrology physician, has 17 years of experience)

"In Malaysia there are a lot of taboos, I men certain people do not go to the, they do not seek treatment, medical approach first they went to complementary treatment approach of alternative medicine approach and sometimes they want to see religious practitioner. We have religious medicine which something not alighted with medicine or medical treatment that sometime make delay and their condition become more warison ... If you ask me, the taboo element must always be there in our booklet because you are trying to correct our patients' misconceptions about treatment, and patients have severe misconceptions" (Tala, a Malaysian female academic nursing staff, has 14 years of experience)

From the perspective of HCPs, both Ali and Tala believed that there would be no barrier to the tool's use, and that it would be helpful. However, Layla reported that there is a barrier from the HCP's perspective, which is that the workload of HCPs may inhibit their usage of the tool in their clinical daily practices. As she stated:

"The barrier only the work. Workload in the clinic maybe some time the nurse in the clinic they will not have the time to explain it in detail. It is not like the ward's nurses. They will be to have more time to talk with the patient, especially for their initial assessment. So maybe it is one workload" (Layla, a Kuwaiti female clinical nurse staff, has 12 years of experience)

While the experts had differing views on many aspects of implementation, areas of consensus were identified. These led to overall recommendations for future improvement:

 Reduce the amount of information (for example, avoid using paragraphs and only use points or develop another format, whether audio or video).

- Add more pictures related to Muslim society (for example, add a picture of men or women who wear custom Saudi clothing).
- Alternative versions of the tool could be developed, including a version for newly diagnosed patients, which could be more of an educational tool than a decisionmaking tool.
- Develop several further versions of the tool, each focusing on a different CKD stage.
- New versions could introduce taboos and false perceptions about the disease and its management.
- A new version should be considered for Arabic non-Muslim patients, such as Arab Christians.
- A new version could include ideas about group discussion, so patients can discuss and learn from others.

7.3 Step 4: Developing Final Versions and Reporting Adaptation Process

This section described the fourth step of the cultural adaptation process, which was developing final versions and reporting how the adaptation process was done. The penultimate versions of the culturally adapted English version 5, and the translated version 6B, were inspected by the experts. This served as a final check on the accuracy of both the adaptation and translation processes. The experts recommended several minor linguistic corrections and clearer instruction statements. In addition, they recommended a few topics to be included on cultural topics, such as group discussion, false perceptions, and taboos. They also considered including other Arabs who are not Muslims in the future version. They also suggested that different versions of the tool could be used at different stages of the disease's trajectory. However, not all these suggestions were feasible within the scope of the PhD thesis. For example, suggestions related to adding new topics, developing a different version for different patient groups, or developing a different format, such as audio or video, will be considered for future changes and were not undertaken here.

At this stage, all changes made to the penultimate English-adapted version 5 were minor, such as spelling corrections, because I had already received approval from the original authors of the tool. As a result, I could not make major changes to the tool; thus, these suggestions

will be explored in future research. Thus, based on the experts' feedback, the final adaptation and translation had eight revisions. This included two sentences modified to be easier to understand and four instances of word replacements. Additionally, there were two typographical corrections (Kidney, KDIGO). The researcher then reviewed the translation process reported above and developed the final versions (5A and 6B1). All steps of adaptation and translation were successfully completed and documented in this chapter. The final culturally adapted English version (5A) was uploaded as a supporting document alongside my thesis (see supplementary document).

7.4 Preliminary draft of the implementation plan

Prior to implementing a DA in clinical practice, a plan of implementation or draft guidelines for using the tool within the clinical setting needs to be created. This will increase the tool's acceptability and usability, potentially improving its implementation or application, and reveal barriers to implementation. This section of the chapter focuses on the fourth theme that emerged from the in-depth interviews with the experts (summarised in Chapter 6): suggestions for the application and implementation of the YoDCA tool. Their suggestions resulted in the creation of a preliminary draft of an implementation plan or guideline for HCPs looking to use the YoDCA in their daily clinical practices. The implementation guidelines included who would be involved in implementation, where and when it would take place, and how it would be delivered (see Box 3). However, the experts identified some issues to consider prior to the implementation of the YoDCA tool, such as the different requirements of various governmental, health, and religious organisations, and addressed relevant policies of public health, religious, hospital organisation, and community authorities, which are explained below.

- Integrated into policies: Approval is required from public health policymakers (the MOH in Saudi Arabia) to introduce a new DA tool and treatment option (conservative management) into daily practice in clinical settings.
- Religious authority policies: Alongside health policy approval, religious authorities in Saudi Arabia must also approve a DA tool before implementation. Treatment through conservative management requires approval from the Council of Senior Muslim Scholars because it is different than offering dialysis treatment to patients.

- Hospital organisation authority policies: The tool implies changes to current services. The current patient-clinician dynamic needs to be changed so that clinicians can encourage and respond to patients' greater involvement and patients are more likely to get involved. Other challenges include the large number of patients and time constraints. It is possible to have communication difficulties for a variety of reasons, such as language barriers and an incomplete understanding of important cultural or religious beliefs. Moreover, different patient groups have variable and complex needs, often in association with age and lower literacy.
- **Community or cultural authority:** Community engagement is required, including persuading people such as HCPs, patients, and their family caregivers to get engaged and agree to incorporate the tool into their daily routines.

The implementation plan for HCPs to use the YoDCA in clinical settings, presented below, was developed based on the eight original interviews plus the three additional interviews detailed in this chapter (see Box 3). This is only the first draft, which is likely to undergo changes and revisions following piloting, which will form a subsequent phase of research to assess how the proposed plan works in real-life settings. Development of the draft implementation plan was based on expert interviews. However, there were contradictions in the data, and the respondents had different opinions on how to introduce it to hospital management and when and with whom it could be used. In the original eight interviews, the experts indicated that all patients with stage 5 CKD, as well as elderly people with complications that render DNR and dialysis ineffective, are eligible to use this tool. In the second round of interviews, however, the experts reported that it was only suited for educated people who had CKD or did not, those newly diagnosed, patients in the end stage or those in stages 3 and 4, those on dialysis, and patients who would change the modality, but not for conservative management. Conservative management is only available to newly diagnosed patients who have not yet begun dialysis. Differences such as these meant the implementation plan had to be flexible and adaptable, and future iterations may be revised following piloting.

Box 3: Guidelines for Healthcare Providers Using the YoDCA Tool in Clinical Settings

Intervention

The Yorkshire Dialysis and Conservative Care Decision Aid (YoDCA) is an educational intervention that helps people who are choosing between conservative care and dialysis due to chronic kidney disease getting worse. The purpose of the tool is to help people and their families discuss these different options with health professionals and explain why one option may be more appropriate for their lifestyle.

Pre-implementation of the Intervention

- Identify team members who will be trained on how to implement YoDCA with patients.
- Identify suitable patients, encourage them to be involved in shared decisionmaking, and use YoDCA with them.

Who is involved in the implementation?

The purpose of this tool is to facilitate shared decision-making. Therefore, clinical expertise on disease management must be combined with patients' preferences, values, and life experiences.

Which HCPs should introduce the intervention?

Implementing and training involves multi-professional teams – nurses, dieticians, social workers, health educators, counsellors, doctors, nephrology teams, renal wards, and dialysis staff.

Which patients is YoDCA for?

Existing patients who reach stage 5 of chronic kidney disease with the following criteria:

- Being elderly and frail
- Having other serious health problems, such as heart failure, cancer, or terminal illness
- Being referred for consultation about future goal clarification or EoL decisionmaking
- DNR patients in the intensive care unit
- Dialysis has not increased life expectancy or improved quality of life.
- Inability to complete two hours of a dialysis session.

Please note that this tool is not intended for newly diagnosed patients.

When and where might it be introduced?

Inpatient and outpatient clinics should utilise the tool once a patient referral has reached the late stage.

- **Outpatient or nephrology clinics:** The DA should be introduced for the first time in the outpatient clinic alongside discussions about dialysis and future care plans.
- In-patient ward settings: Particularly during the first day of admission.

How might it be implemented?

The YoDCA tool itself can be given to the patient in advance, either in an outpatient clinic to use at home or in the patients' wards. This will give them plenty of time to read it, discuss it with their family, and think about the best treatment and decision for them. They then discuss this with their doctor or nurse to talk through it in more detail in a face-toface discussion or consultation. HCPs then follow up with patients via phone or in person, answering questions. In addition to auditing all dialysis patients, HCPs should highlight those who may be suitable for a change in their dialysis method.

7.5 Chapter Summary

This chapter describes steps 2, 3, and 4 of Chenel et al.'s cultural adaptation process for the YoDCA booklet in five parts. Part 1 described step 2, in which all versions developed from Version 1 until the penultimate culturally adapted and translated drafts, Versions 5 (English) and 6B (Arabic). The adaptation had three stages. In the preliminary stage, the aspects of the booklet brought up in the experts' interviews were recorded, and their input was applied to the original tool. This stage focused on both clinical and cultural expert input, yielding Version 1. The first adaptation incorporated input from the original authors and justified adaptation decisions. This version considered cultural aspects with minor clinical changes. Versions 2–5 were iteratively developed, with 5 as the penultimate English version. The second adaptation stage focused on the forward and backward translation process from penultimate English (Version 5) to Arabic (Version 6) and the sub-versions. The translation was guided by the WHO guidelines, which included forward -backward translation. Part 2 described step 3 which presented the qualitative findings of three additional individual interviews with experts who tested the tool's content for its cultural and linguistic appropriateness. It also described their input concerning the utilisation and implementation of the tool in their daily clinical routines as well as their overall suggestions for improving the tool. Following that step 4 was completed in Part 3, Versions 5 and 6B were modified based on linguistic issues. Hence, the final adapted English version, 5A, and the final adapted and translated Arabic version, 6B1, were developed. Finally, Part 4 presented the preliminary implementation plan or HCPs guideline for using the YoDCA tool in clinical settings based on the experts' suggestions. The findings of this study are discussed in the following chapter.

Chapter 8: Discussion and Conclusion

8.0 Introduction

This study's findings are discussed critically in this chapter in relation to relevant extant literature. This chapter also suggests future research directions, along with identifying new knowledge and implications for clinical care and policy. The study reported in this thesis aimed to explore the education needs and experiences of patients and/or their family caregivers regarding current ACP and SDM practices in a Saudi Arabian dialysis unit. It also aimed to culturally adapt and translate the YoDCA tool for Saudi ESRD patients and their family caregivers. This is the first evidence-based, culturally adapted and translated education intervention for renal patients and their families in Saudi Arabia. In this chapter, the discussion is presented based on the study objectives. This chapter has five parts. Part 1 (8.1) identifies the major themes emerging from Phases 1 and 2 of the study and discussed their relationships to existing research literature. It also examined and critiqued YoDCA's cultural adaptation process. The study's strengths and limitations are discussed in Part 2 (8.2), followed by Part 3 (8.3), in which the findings' implications are examined and future research directions are suggested. A personal reflection on the research process is provided in Part 4 (8.4), and concluding observations are made in Part 5 (8.5).

8.1 Study Findings and Comparison with Previous Literature

Before interpreting my study's findings, understanding its context is essential. As far as culture and religion are concerned, Muslim contexts are distinct from others. An individual's religious and cultural background largely influences their health beliefs, behaviours and attitudes about illness and death (Attum *et al.*, 2018). Thus, both culture and religion have a potential impact on uptake and views about ACP (Boucher, Siddiqui and Koenig, 2017). Muslim and Islamic influences are reflected in some Muslim healthcare practices, policies and guidelines, as well as clinical decisions (Padela and Curlin, 2013). The evidence-based research on palliative and EoL care communication in Muslim countries is limited, particularly for renal patients undergoing ACP and SDM processes. As a result, I have drawn on literature from other countries.
8.1.1 Phase 1: Qualitative Study and Modified Systematic Review

This section discusses data from two literature streams: Phase 1A, qualitative interviews with ESRD patients and/or their family caregivers, and Phase 1B, a modified systematic review. These were employed to address the study's first objective: to identify the education needs of ESRD patients and/or their families' caregivers and examine their experiences regarding current ACP and SDM practices. Similar findings from these two sources are discussed in the qualitative interview section (8.1.1.1) and are described below.

8.1.1.1 Phase 1A: Qualitative Interviews with ESRD Patients and/or Their Families' Caregivers

This phase's findings provide significant and original insights into the experiences of patients and families living with kidney disease, the ACP discussion process and SDM in the Saudi Arabian context. The following themes were used to synthesise the findings:

- Perceptions of Chronic Kidney Disease
- Participants' Experiences Communicating with Healthcare Providers
- Opportunities to Discuss Future Care Plans
- Decision-Making Regarding Dialysis or Renal Replacement Therapy

8.1.1.1.1 Perceptions of Chronic Kidney Disease

Participants in my study demonstrated varying levels of knowledge and awareness of CKD. Most participants had no or scant knowledge of CKD, its causes, symptoms and management, particularly before starting RRT. Furthermore, most first encountered dialysis treatment in hospital emergency departments without any prior education. These findings are in line with those reported in both the Western literature (Finkelstein *et al.*, 2008; Tan, Hoffman and Rosas, 2010) and Middle Eastern literature (Hejaili *et al.*, 2007; Alhameedi, 2016; Al Rahbi and Al Salmi, 2020; Almutary, 2021), namely that renal patients have limited knowledge of CKD and no awareness of their treatment options. For example, Hejaili *et al.* (2007) surveyed 143 ESRD patients in Saudi Arabia on RRT in one hospital to determine how aware they were of their condition and available treatments. The researchers found that patients lacked awareness of kidney disease, risk factors and treatment options. The studies discussed above examined different groups of CKD patients, but none examined family caregivers' perceptions, unlike my study, which has added new insights on ESRD patients and their family caregivers' experiences without restrictions on treatment duration. These studies clearly indicate that the issue of limited knowledge among renal patients is an international one, but it is particularly challenging in the Saudi Arabian context for reasons related to healthcare service organisation and delivery, as well as cultural factors.

Regarding healthcare services, one possible reason why participants in my study had limited knowledge is because these participants' conditions were not detected early or not diagnosed until they reached the end stage and required urgent dialysis. Several potential barriers to timely detection and management of CKD exist in Saudi Arabia, one of which is that patients in the early stages of the disease are often unaware of it because the symptoms are often indistinct. In most cases, patients do not notice CKD symptoms until they reach the fourth or fifth stage, leading to late referrals to a nephrologist. Therefore, most had to start urgent haemodialysis (HD), as they did not receive pre-ESRD nephrology care. As a result, they had fewer opportunities to make clinical decisions about RRT and did not have enough time to prepare for dialysis through an educational programme and psychological preparation. Early detection of CKD can reduce cardiovascular morbidity significantly and give patients enough time to prepare for RRT (Baer, Lameire and Van Biesen, 2010).

Hassanien *et al.* (2013) reported similar findings after conducting a cross-sectional study to examine pre-ESRD care in two HD centres in the western region of Saudi Arabia. Pre-ESRD nephrology care was unavailable for 47.6% of HD patients, and emergency departments referred 50.6% to urgent dialysis. The lack of pre-dialysis education in a clinical nephrology context in Saudi Arabia has been attributed to late referrals to a nephrologist (Alhameedi, 2016; Alhazmi, 2022). Very few CKD patients receive pre-dialysis education and undergo planned RRT because of late nephrologist referrals that have been demonstrated to be a contributor to emergency dialysis initiation (Raffray *et al.*, 2021). Mendelssohn, Malmberg and Hamandi's (2009) international integrative review found that between 24% and 49% of dialysis patients started unplanned dialysis without adequate preparation. Previous research has indicated the importance of referring patients to a pre-dialysis service in a timely manner and involving a multidisciplinary team in the process. These factors can postpone initiation of RRT and decrease the need for emergency dialysis (Heatley, 2009). In line with this, the status of late referrals in Saudi Arabia requires further investigation to better identify and understand ways to reduce late referrals.

Another possible reason is that CKD patients in the early stages and patients with risk factors often are treated in primary care (Thomas, 2014). Primary care physicians may have inadequate training and education in CKD management. Although evidence from Saudi Arabia and other Muslim contexts is limited, a systematic review of the international literature by Neale, Middleton and Lambert (2020) highlighted barriers to effective care in various European countries, namely that the most frequent barriers associated with CKD detection and management in primary care include lack of time, anxiety about diagnosing CKD, dissatisfaction with CKD guidelines and patients' perceptions about the disease and its management.

Regarding cultural factors, Saudis commonly only visit the hospital and request medical assistance in severe cases of ill health. Even though Saudi Arabia has many health facilities, and healthcare is free (Almalki, FitzGerald and Clark, 2011), Saudis tend to delay seeking any sort of healthcare until they experience symptoms of a disease or are at an advanced stage (El Bcheraoui *et al.*, 2015). Moreover, in Saudi Arabia, many people who feel unwell first seek complementary and alternative medicine (CAM) rather than medical treatment. Whilst CAM commonly is used worldwide (between 21.6 and 90% of the Saudi Arabian population) (Posadzki et al., 2013; Sait et al., 2014; Clarke et al., 2015; Alrowais and Alyousefi, 2017), consumers' religious beliefs influence CAM practices in Saudi Arabia, as CAM is related to prophetic medicine and traditional habits. Saudi Arabia was the leading Arab country in terms of integrative and complementary medicine research output, according to a bibliometric study published in 2015 (Zyoud, Al-Jabi, and Sweileh, 2015). Various other studies also have reported that CAM has been used to treat numerous acute and chronic illnesses and conditions among the Saudi population, including diabetes, cancer, hypertension, liver diseases, asthma, digestive disorders, skin diseases and neurological disorders (Alrowais and Alyousefi, 2017).

Few studies have investigated CAM medicine use among Saudi Arabian patients with CKD and on HD. AlAnizy *et al.* (2020) found that 54.9% of their sample were using CAM, of which 88.4% were herbal consumers at different CKD stages. Another study revealed that 50% of ESRD patients undergoing HD were using CAM, of whom 80% were using herbal remedies (Alsayari *et al.*, 2022). Furthermore, most patients did not fully disclose their use of CAM to their HCPs. Consequently, patient education and open communication are needed between physicians and patients regarding the potential advantages and risks associated with various CAM treatments, particularly herbal remedies.

Dialysis urgency and a lack of prior knowledge about treatments were significant issues among most participants in my study, which can be an impediment to patients changing their lifestyles and participating in DM. The aforementioned literature clearly indicated that in the Saudi Arabian context, the issue of inadequate information regarding CKD and its management still exists among renal patients, whether they are in the early or end stages, i.e., having been treated for many years or having just started urgent HD. Thus, in considering international studies' findings (Isnard Bagnis *et al.*, 2015; Goovaerts *et al.*, 2015), it has been suggested that Saudi Arabia should focus on enhancing public awareness of CKD risk factors, symptoms, causes and management. Furthermore, it should offer pre-dialysis education, and dialysis information also needs to be offered to patients, particularly those who undergo emergency dialysis.

8.1.1.1.2 Participants' Experiences Communicating with Healthcare Providers

In my study, most participants reported dissatisfaction with initial communication with their physicians about starting dialysis treatment. In some cases, participants complained that their physicians did not explain their CKD diagnoses and management enough, so they did not understand everything they were told and could not interact during the discussion. Moreover, participants identified information gaps regarding CKD management, dialysis types and complications, and its impact on their lives. Due to an absence of communication, patients were unaware of the symptoms or complications associated with their renal disease, making them anxious about the future. The results from earlier international research indicated that renal clinicians demonstrated poor communication skills and a tendency to avoid discussing diagnoses and prognoses (Bristowe *et al.*, 2014; Llewellyn *et al.*, 2014). This led to late-stage diagnoses and the need for emergency dialysis.

Highlighting similar issues, Mendelssohn, Malmberg and Hamandi (2009) conducted an integrated review of the literature on European dialysis patients. These studies revealed that almost one-third of ESRD patients worldwide experience an 'unplanned' or 'urgent' initiation of dialysis. This situation can be highly challenging, as patients may not have had sufficient time to become educated and make decisions regarding dialysis options and suitable dialysis access, or they may have had to change their decisions because of the unanticipated situation. Therefore, HD is the only option available for these patients. For patients who need urgent dialysis initiation, HD is the most used modality (Javaid *et al.*, 2017). Previous research has linked pre-dialysis care and education programmes to reduced instances of urgent dialysis commencement, decreased use of catheters and improved survival rates (Lacson *et al.*, 2011; Hasegawa et al., 2009). As such, participants in my study reported dissatisfaction with their communication with HCPs and that they failed to receive complete information about CKD and its management. These findings underscore the importance of enhancing communication regarding patient apprehension, treatment plans and decisions. Effective doctor-patient communication plays a vital role in providing top-quality healthcare, eliciting an improved understanding of patients' needs, perspectives and expectations (Ha and Longnecker, 2010). Therefore, HCPs need training to improve their communication skills to address patients' needs.

8.1.1.1.3 Opportunities to Discuss Future Care Plans

Disease prognosis refers to predictions about a condition's progression and includes worsening symptoms, complications and expectations for quality of life and life expectancy. Poor prognosis can initiate discussions about future care plans, preferences and wishes. My study found that most participants reported they had no opportunities to discuss their disease prognosis and future care plans with their HCPs, i.e., they did not know whether their disease would progress or worsen in the future. Notably, in other Muslim studies reported in the modified systematic review (described in Chapter 5, Section 5.2), HD patients in other Muslim contexts also reported having limited knowledge about their prognoses, expecting to recover from their kidney disease, having no discussions with their physicians about their wishes, and ACP being poorly documented. Earlier research conducted in both Muslim (Al-Jahadali *et al.*, 2009; Hing *et al.*, 2016; Ahmed *et al.*, 2022) and United States and Canadian (Division, 2010;

Saeed *et al.*, 2019; Thorsteinsdottir *et al.*, 2022) contexts provide similar findings from patients. These studies also indicate that dialysis patients exhibited a lack of awareness regarding the seriousness of their condition and had limited discussions with their HCPs concerning ACP and documentation. Thus, regardless of whether the extant studies examined Muslim or non-Muslim patients experiencing various RRT methods, the findings still align with my study. One of these studies (Al-Jahadali *et al.*, 2009) was the only study conducted in Saudi Arabia. Although very limited evidence was found in Saudi Arabia, my study builds on these 2009 findings, providing valuable insights into the perspectives and understandings of ESRD patients and their families regarding EoL communication issues. It specifically focusing on the possibilities of discussing ACP, examining treatment alternatives and fostering a collaborative decision-making process among Saudi ESRD patients and their families. Moreover, it examined their education needs in Tabuk City.

Many potential reasons may have contributed to poor communication of prognoses and a lack of discussions about future care among my study participants. From a medical perspective, the absence of discussions may be because of patients, families and healthcare providers' hesitancy to discuss such issues. When patients do not recognise their health condition as progressive, they avoid discussing their prognoses with HCPs until they experience illness symptoms. Although patients should feel comfortable discussing their concerns regarding ACP with their health professionals and expect them to start such conversations (Davison and Simpson, 2006), this does not appear to be happening in Saudi Arabia. Possible reasons for this communication gap include nephrologists' lack of training in communicating bad news and lack of clinical experience in conservatively managing ESRD and EoL care in older patients. Furthermore, time constraints, expectations that their patients may not accept such discussions and a desire to maintain hope can push physicians into avoiding such discussions altogether (Davison, Jhangri and Johnson, 2006; Keating *et al.*, 2010; Saeed *et al.*, 2015; Rosenberg *et al.*, 2017; O'Riordan *et al.*, 2019).

Among the reasons reported in Chapter 5, patients do not trust HCPs who claim they will fully recover after two to three dialysis sessions, thereby contributing to general mistrust. Another reason mentioned during the interviews was that poor communication was exacerbated by the doctor's absence during their dialysis sessions unless patients specifically requested it. Despite the presence of a physician, the primary focus of discussions was to go over results from laboratory tests, rather than discuss future care plans. Most patients in the present study had many years of HD and had experienced many complications, leading them to switch to another RRT. However, the participants reported that they had no opportunity to discuss their future care plan and prognosis. Due to fluctuating disease trajectories associated with CKD (Murtagh *et al.*, 2011), ACP should be initiated earlier in the disease trajectory for each of these patients regardless of their ages. Saudi Arabia's healthcare system has aimed to adhere to global directives for KDIGO-KDOQI EBP (KDIGO CKD Work Group, 2013), which stress the importance of providing ACP for individuals requiring EoL care, including those being provided conservative kidney care (KDIGO CKD Work Group, 2013). One reason for the lack of discussion about ACP may be that ACP is not consistently incorporated into routine care for all ESRD patients in the Saudi Arabian context.

According to the interviews and systematic review, as well as the studies discussed above, the ACP concept in the Muslim context is often relevant to EoL care. To make the concept of ACP more comprehensive and inclusive during the early stages, this thesis supports early efforts to think about and discuss ACP with patients with life-threatening conditions such as CKD at diagnosis and during the illness trajectory. Additional qualitative research could be conducted to address this issue and develop interventions that enhance early physician-patient communication concerning discussions about prognosis, ACP or EoL planning. These interventions should aim to ensure that patients and family members fully understand the implications, express their preferences, and are equipped to help their physicians make timely decisions.

The aforementioned studies clearly indicated that poor prognosis discussion and ACP resistance is an international issue, manifesting in myriad ways in various cultures, e.g., many unique factors contribute to ACP resistance, and these factors rarely are discussed in the Saudi Arabian context. Furthermore, cultural and religious factors deter patients from discussing their prognoses and ACP, including faith or spiritual beliefs, particularly for Muslim patients who believe that only God knows their precise prognoses and death time (Al Mutair *et al.*, 2014). Similarly, in the Muslim culture, Arab patients are reluctant to discuss ACP and advanced planning directives due to their fear of hearing about death (Bahroon *et al.*, 2019).

Cultural factors also may influence a patient's ability to gather information regarding their medical condition, e.g., limited truth-telling, which is common in Muslim communities. In most Muslim cultures, patients' relatives are inclined towards protecting their family members and keeping sensitive information concerning their relatives' illnesses hidden from them (Al-Awamer and Downar, 2014; Martina *et al.*, 2021). Therefore, they are excluded from discussions about their prognoses and health conditions. Nonetheless, it has been demonstrated in numerous studies that notable variations exist in truth-telling approaches and behaviours between Western and non-Western nations (Mobeireek *et al.*, 2008; Khalil, 2013; Rosenberg *et al.*, 2017). For example, Khalil (2013) found that while Western societies prioritise patient autonomy and truth-telling, significant variability exists within and among various Middle Eastern countries concerning patient-physician relations and family structures in truth-telling activities and choices. In both geographical populations, protecting patients from distressing information is a common reason for not disclosing information. Therefore, HCPs' educational activities concerning truth-telling can accelerate changes in attitudes, perceptions and beliefs.

Cultural differences among HCPs and patients also can be another factor, particularly within the Muslim context, including Saudi Arabia. Languages, cultures and religions among Saudi Arabian patients and nurses vary, which can be attributed to the increasing number of expatriate HCPs operating in the Saudi healthcare system (Almutairi and McCarthy, 2012). Alshammari, Duff and Guilhermino (2019) contended that these disparities in language, culture and religion create barriers to clear and effective communication, which then affect Saudi patients' health outcomes negatively. Sanders *et al.* (2019) found that physicians' ethnicity and religion affect their participation in ACP discussions and EoL care decisions. Thus, it is essential in Saudi Arabia to improve communication between patients and healthcare professionals. To increase cultural harmony, training, and education programmes on Saudi cultural heritage (which Islamic teachings heavily influence) could be developed and conducted for HCPs.

8.1.1.1.4 Decision-making Regarding Dialysis or Renal Replacement Therapy

In my study, it was demonstrated that regardless of participant differences in decision-making experiences, all participants reached their decisions by sharing them with their families. All

participants reported that family plays a significant role in the DM process concerning care and support, and that they prefer making shared decisions with their families to commence their dialysis treatment. In the previous section, it was noted that family plays a crucial role in patient care in Saudi Arabia and that patients highly regard their families' views when making significant decisions concerning their health. According to cultural norms, the family should be involved in health education and decision-making, among other matters. However, family involvement sometimes can present challenges to patients engaging in informed decision making, e.g., in Saudi Arabia, patients' decision-making autonomy often has been overruled by family authority, according to Al-Shehri (2002). Consequently, physicians may engage in discussions about significant decisions with the patient's family without the patient present. Likewise, Alzahrani et al. (2023) studied the experiences of middle-aged Saudi CKD patients who had undergone HD and found that all participants reported that their families encouraged them from committing to self-care management and HD processes. Although Alzahrani et al. (2023) did not discuss the family's role in DM, it did report similar findings regarding the family's role in supporting HD in the Saudi Arabian context. Similar findings have been also obtained in earlier research conducted in various regions of the world, emphasising family involvement's significance when making decisions (Covic et al., 2010; Harwood and Clark, 2013; Saeed et al., 2019). These studies suggest that family engagement enhances predialysis education, in which discussions about treatment alternatives should include family members and partners.

My study findings build on previous evidence (AlHaqwi *et al.*, 2015; Alrawiai *et al.*, 2020) and expands the literature about Saudi Arabia preferences in clinical decision making. The findings suggest that renal patients prefer sharing their health decisions with their families, even in critical situations, when it comes to making health decisions in the Saudi Arabian context. AlHaqwi *et al.* (2015) investigated preferences for SDM among patients in Saudi Arabia and identified three distinct decision-making styles. The paternalistic approach is the first, in which a physician or healthcare professional makes decisions concerning a patient without their explicit consent. The second style, informed consumerism, involves patients and possibly their families when determining the best treatment option. SDM is the third style, in which patients and physicians share information, conduct in-depth discussions on medical issues, evaluate different treatment plans and agree on a treatment plan together. A Saudi

Arabia study's AlHaqwi *et al.* (2015) results indicated that SDM was the most preferred style, demonstrating that Saudi patients possess a positive outlook about the SDM process. Further studies are needed to examine the underlying factors affecting patient preferences for SDM.

In my study, the most obvious and significant finding was that most participants felt they had no choice on dialysis options. They viewed HD as inevitable, rather than optional, and some became aware of other RRT options only after spending a year in HD treatment. In my study, most participants were diagnosed with CKD in the emergency department and were required to undergo urgent HD treatment. Due to this critical situation, they were not given treatment options, i.e., the only option available was HD. Marron et al. (2006) reported a similar finding after examining factors affecting planned vs nonplanned dialysis among Spanish patients commencing RRT. They found that most patients started unplanned dialysis, particularly HD, compared with planned dialysis. Furthermore, Mehrotra et al. (2005) determined that 70% of urgent HD patients were not offered peritoneal dialysis as an RRT option, and 30% of the patients reported that nobody discussed treatment options with them until after dialysis had commenced. The interview data in my study clearly indicated that most participants had no opportunity to discuss RRT treatment options and were not educated about all available CKD treatment options. In this situation, in which the patient had no opportunity to learn about dialysis and decide regarding methods, it can be very challenging for the patient. A patient's clinical decision is dependent upon information from HCPs and other sources, according to Jayanti et al. (2015). Aside from improving patients' communication and education, providing this information about CKD treatment options can help them make informed decisions, particularly patients starting urgent HD treatment in Saudi Arabia, a group that comprises many renal patients.

Another finding was reported that some participants in my study regretted their decision to start dialysis, even though they had spent many years on it. Those participants who expressed regret spent a long time reflecting on their decision after they made it. They did not claim that the information was inadequate but blamed themselves due to the limited time they had to make the decision and their doctors' high-pressure approach when making the decision to start dialysis. This finding aligns with other Muslim studies reported in the modified systematic review (described in Chapter 5, Section 5.2) by Saeed *et al.* (2020), who found that

more than half of Muslim Pakistani HD patients regretted their decision to commence HD because it was their doctor's choice, not theirs. Previous research conducted in the USA context (Saeed *et al.*, 2019) supports this finding. Moreover, Song *et al.* (2013) found that most dialysis patients felt unprepared when starting the procedure. These results may not only explain a lack of comprehensive education programmes and decision-support interventions for CKD, but also low education levels among patients, while time constraints during patient visits are also likely to contribute (Morton *et al.*, 2010). However, according to Saudi culture, doctors generally are viewed as having the best knowledge and are highly regarded. Clearly, Saudi Arabian culture exerts a high degree of influence, which may affect patients' satisfaction with their decisions.

The participants in my study also examined factors that affected their decisions, e.g., HCPs' role and external pressure to facilitate their DM process. Others viewed their lack of knowledge about dialysis options as the main factor behind their decision to undergo dialysis. I found that a doctor's recommendation was the most influential factor in my study participants' decision-making to undergo HD. This finding aligns with results from earlier studies conducted in the US (Wuerth *et al.*, 2002; Mehrotra *et al.*, 2005), which indicated that doctors' opinions affect patients' choices. Nevertheless, my study found that patients' health influenced doctors' advice, i.e., doctors gave advice on or influenced treatment choices that were appropriate for their patients. My study found that limited knowledge of dialysis treatments hindered participants' decision-making, as the patients in this group were not preeducated on CKD management options and dialysis sessions. My study's findings are consistent with previous research indicating that many patients with advanced CKD lack sufficient information to make well-informed decisions (Dharmarajan *et al.*, 2017; Chu *et al.*, 2020). The data clearly indicated that doctors exert strong influence on patients' decisions, but that they should ensure patients have enough information to make informed decisions.

8.1.1.2 Phase 1B: Modified Systematic Review

The modified systematic review was conducted due to the limited number of participants recruited for qualitative interviews, which occurred largely because of the challenges associated with the COVID pandemic. A systematic review provides complementary data to support qualitative data gathered directly. Moreover, I encountered a methodological issue

that was extremely challenging regarding how I talked to Saudi patients about ACP and EoL care, decisions and issues: I was unable to address these issues during the interviews due to cultural and religious influences. Thus, I asked them briefly about their future plans. However, by conducting this modified review, I was able to address some of these sensitive issues. This review identified five quantitative articles that met the inclusion criteria, and even though quantitative research is useful for identifying certain aspects, only qualitative methods can answer certain questions. As a result of my review, I found that qualitative research on patients' perspectives and HCPs' perceptions of experiences in decision making. To the best of our knowledge, this is the first systematic review that has addressed preferences and experiences of ESRD patients and their families regarding ACP and decision-making in the Islamic context. In this review, how EoL care choices and decisions are mediated among ESRD patients was explained and examined in a Muslim context under the following themes:

- Patients' Advance Care Planning and End-of-Life discussion Preferences
- Patients' Preferences for End-of-Life Care
- Patients' Perspectives on Who Makes Advance Care Planning and End-of-Life Decisions
- Patients' Knowledge about End-of-Life Decisions and Palliative Care

8.1.1.2.1 Patients' Advance Care Planning and End-of-Life Discussion Preferences

One of the most significant findings from the review is that Muslim HD patients' attitudes towards ACP and EoL care values and their willingness to discuss them, including discussing death, varied. Along the lines of the qualitative study (patients and/or their family caregivers' interviews), participants did not talk about future care planning, citing a lack of opportunities to discuss any plans with their HCPs, and for religious and cultural reasons, I did not discuss their plans with them. In this review, some studies revealed that some Muslim participants preferred to engage in ACP and EoL care discussions, particularly those discussing death. Other studies highlighted that some participants were uncomfortable discussing EoL care issues, particularly discussions about death and dying, with their HCPs. The varying ethnic and cultural backgrounds of participants within this review help explain the varying results. Attum *et al.* (2018) argued that Muslims are not homogeneous and that different groups may have

different cultures despite sharing the same religion. Diverse ethnicities within the Muslim context hold diverse views on health and illness that affect their attitudes and behaviours. These findings are consistent with those reported within a Muslim context: older people feel emotionally distressed when discussing death and dying and are reluctant to speak about the topic (Htut, Shahrul and Poi, 2007; Bahroon *et al.*, 2019).

One possible explanation is that Muslim patients believe that only God knows the future and their exact day of death (Al-Shahri, 2002), so they feel uncomfortable talking about death. This may create a barrier between HCPs and patients when initiating the ACP process in this culture. Thus, ACP rarely addresses this within a Muslim context. An interesting correlation exists between this review's findings and those found in the broad literature from Western countries, which found variations in patients' perspectives on death discussions. For example, Collins and Lehane (2013) found that in Ireland, 78% of HD patients felt comfortable discussing death with their doctors. However, death and dying remain taboo subjects in some cultures, including those in the US (Bullock, 2006; Carrese et al., 2002) and East Asia (Bowman and Singer, 2001). Thus, this phenomenon can be seen in both Western and non-Western contexts. As a result, the ACP discussion needs to be formulated on both individual and faithbased levels. Furthermore, this review indicated that Muslim patients were willing to talk about ACP, but that it was discussed and documented rarely because it was a new concept in the Muslim context, according to Biondo et al. (2017). This may account for discussion reluctance on both sides—physician and patient. Other factors are explained in more detail in this chapter in previous Section (8.1.1.1.3).

8.1.1.2.2 Patients' Preferences for End-of-Life Care

This review found that Muslim HD patients have a variety of EoL care preferences. Some preferred care that focussed on symptom management rather than prolonged life. Extant studies also have noted this variation, for example, a study by Htut, Shahrul and Poi (2007) was conducted in a Muslim context in Malaysia and examined Malaysian participants' attitudes towards prolonged treatment procedures in relation to different life-threatening conditions. Most viewed CPR, dialysis and mechanical ventilation as aggressive and invasive procedures and did not wish to accept them. Moreover, Ahaddour, Van den Branden and Broeckaert (2018) examined Moroccan Muslim women participants' attitudes towards

withholding and withdrawing LSTs and found variations among participants based on age. The middle-age group was opposed to prolonging treatment, whereas elderly women supported continuing LSTs. A possible explanation for this shared resistance is the limited availability of information on prognosis, treatment options, survival rates and families' role in healthcare decisions within the Muslim context. Furthermore, patients undergoing dialysis may not perceive their condition as fatal, which is why they rarely consider issues related to death unless they experience a crisis (Al-Arabi, 2006).

Another explanation could be that participants' religious beliefs influence their opinions. Participants took comfort from religious or spiritual services or people. They possibly were scared or very determined not to die, or perhaps they had a very strong will or desire to live regardless of circumstances. This review found that participants' decisions to accept CPR varied depending on several factors, including age, dialysis duration and expected outcomes from resuscitation. Extant studies from non-Western countries supported this finding—e.g., Japan (Miura *et al.*, 2001), Malaysia (Hing *et al.*, 2016) and Saudi Arabia—indicating that participants had different attitudes towards CPR, and whether to accept it. Furthermore, in a previous study, improved CPR knowledge was associated with greater preference for comfort care near EoL (Volandes *et al.*, 2013).

8.1.1.2.3 Patients' Perspectives on Who Makes Advance Care Planning and End-of-Life Decisions

In Section (8.1.1.1.4), I present and discuss data related to Saudi ESRD patients' experiences and their families regarding decision-making for dialysis treatment. This section discusses issues in more detail, focusing on Muslim patients' perspectives and experiences with DM for ACP and EoL care decisions.

Significantly, this review highlighted different involvement levels in decision-making related to ACP and EoL care. Some participants preferred to have active engagement and involvement in EoL decision-making processes, whereas others involved their families. In studies conducted in East Asian countries, Ivo *et al.* (2012) and Hui *et al.* (2016) reported the same findings, most likely because those who prefer to make their own decisions worry that the family will not honour them. Others preferred passive involvement, which preserves their autonomy by delegating decision-making to their families or HCPs and involving them in that

process. Interview participants in Chapter 5 generally preferred SDM, which was most common among these participants. The interview data indicated that participants were involved to a degree in decision-making when initiating the first dialysis session and that they preferred family involvement in the DM process. They reached their decisions by sharing them with their families. This was related to their belief that they had made the right decision and that their family would honour their wishes. Cultural beliefs are particularly strong in EoL. Differences in autonomy emphasis may be influenced by cultural and spiritual beliefs or religion, in addition to age and family, in perceived decision-making. This is discussed in more detail in Section (8.1.1.1.4).

Another important result that emerged concerned factors influencing patients' ACP preferences and EoL care decisions. This review demonstrated religion and culture's role in influencing patients' ACP preferences and EoL decision-making. Despite most respondents in all the studies being Muslim, one study (Al-Jahdali *et al.*, 2009) reported that religion did not influence how patients handled their EoL-care-related decisions. The other studies pointed out, through indirect interpretation of their results, that religion and culture may influence patients' preferences in ACP discussions, including EoL decisions. These differences in EoL approaches can be explained by several factors peculiar to Muslim societies, e.g., patients' sociocultural and religious views might influence their attitudes towards ACP discussions and EoL decisions (Badawi, 2011; Al-Jahdali et al., 2013; Al-Awamer and Downar, 2014; Shabnam et al., 2020). As previously discussed, concerning patients' attitudes towards ACP and EoL discussions, as well as their decision-making preferences, these factors have been explained. However, Saeed et al. (2015), which examined Muslim physicians' beliefs and attitudes towards EoL care in the US and other countries, found that religion can play a significant role in judging and deciding how to provide EoL care, but also that religion usually exerts less influence than country of origin and prior experience with EoL care issues. Ramalingam et al. (2015) reported similar findings. A diverse array of interconnected cultural factors influences preferences for ACP discussions and EoL decision-making among the studies included in this review. Therefore, understanding culture and religious implications for ACP is paramount to improving discussions.

8.1.1.2.4 Patients' Knowledge About End-of-Life Decisions and Palliative Care

This review found that most Saudi HD patients have no or limited knowledge of EoL care, including CPR and mechanical ventilation. A recent study conducted in Saudi Arabia by Baharoon *et al.* (2019) identified results similar to those of Al-Jahdali *et al.* (2009) and Baharoon *et al.* (2010). Although a long-time frame separates these two studies, their results were still similar, indicating that patients in Saudi Arabia still face the same problem, thereby limiting their knowledge of CPR intervention. This likely is caused by an ineffective approach to delivering enough medical knowledge on mechanical ventilation and CPR in relation to patients' medical conditions. The SDM process can be improved by assessing whether all patients understand EoL decisions, particularly regarding CPR and mechanical ventilation. Charles, Gafni and Whelan (1999) emphasised the importance of sharing CPR/resuscitation information as an essential component of SDM.

This review also found that Pakistani HD patients lack adequate understanding of palliative and hospice care, supporting evidence from previous observations of different US and Canadian populations (Davison *et al.*, 2016; Saeed *et al.*, 2019). One possible explanation for this result may be that HCPs are unsure of palliative care and hospices' relevance for CKD patients due to poor knowledge, HCPs' discomfort discussing palliative referrals and a lack of education about palliative care services among HCPs, patients, and religious believers (Davison *et al.*, 2016). As a result, educating dialysis patients, their families and HCPs about palliative care and other services can improve patients' quality of life and EoL care discussions and decisions significantly.

8.1.1.3 The Need for a National Education Intervention

This section brings together the data from the interviews and the modified systematic review to consider the need for a national education intervention. During the interviews, participants reflected on their experiences living with CKD, discussing issues such as future care plan discussions and decision-making processes. From this reflection, their education needs were identified. Furthermore, the modified systematic review identified a similar need among other Muslim renal patients. As a result, from this research phase, insights can be gained into ESRD patient and family needs within a Muslim context, particularly in Saudi Arabia. The discussion in the previous section clearly indicated that many patients started urgent HD, and that participants missed valuable opportunities to make informed decisions and select the best treatment option. They experienced their first treatment session without adequate communication with physicians and had no prior education, so they were not adequately prepared to initiate treatment. Accordingly, these participants had no clear understanding of their condition or prognosis and did not know how to manage it. Therefore, these participants hoped to improve their experiences communicating with HCPs and their decision-making process.

All participants agreed that better communication with physicians and more information about their condition and treatment were necessary, particularly before making decisions, e.g., participants recommended that doctors be present during dialysis sessions, thereby allowing them to discuss their condition and future concerns. They suggested increasing the amount of information provided, particularly before starting dialysis, including all information related to dialysis treatment, e.g., dialysis types, catheterisation, dialysis machinery and processes, benefits, complications of each type and dialysis treatment's effect on patients' health and quality of life. Furthermore, the interviews indicated that patients wanted more general information about CKD, symptoms, causes, management, medication, alternative treatments and their condition and prognosis. Having this information would help them accept their situation and make their decisions. This study supports previous observations by Lewis, Stabler and Welch (2010) in the US and Sowtali et al. (2020) in Malaysia. According to these studies, which assessed the education needs of participants at different stages of CKD, patients sought the same information about CKD, catheterisation, medications and treatment options. Although these studies focussed on assessing patients' education needs at different stages of CKD, the present study focussed on patients' experiences with ACP and SDM, and the education needs of ESRD patients on HD. These studies emphasised that all CKD patients, whether they are on RRT, have nearly the same type of information needs. Lewis, Stabler and Welch (2010) found that different groups of patients need different information based on their CKD stage. However, in my study, patients also expressed interest in discussing alternative treatment options, possibly because they had reached the end stage.

Furthermore, participants in my study suggested using different communication channels, instead of only written information, to accommodate people with poor reading skills.

Participants also recommended giving patients enough time to think about their treatment type and make their decision, thereby allowing them to digest all the information given and consult other people, e.g., family members or other HCPs. Finally, patients recommended improving standard care practices prior to dialysis treatment, e.g., discussing alternative treatment options instead of starting dialysis, or conducting a pre-dialysis diagnostic test that provides them with clinical information that supports their decisions.

My study reported that Saudi ESRD patients, and their family caregivers' as well as other Muslim renal patients' education needs were unmet, although they had been on HD for many years. These needs focussed on improving patients and their families' knowledge not only of CKD and its management, but also alternative treatments and palliative and EoL care, which facilitate ACP discussion and enhance the decision-making process. Furthermore, their recommendations outlined above reinforce the need for a national education intervention, e.g., a decision aid tool for renal patients. Such a tool would improve information provision and decision-making processes. European guidelines recommend that patients and their families should be offered unbiased information about various RRT modalities as part of implementing a structured education program at all RRT centres (Covic et al., 2010). This applies to dialysis patients who are referred late or who start dialysis unexpectedly. Furthermore, the Renal Physicians Association (2010) from Europe countries developed a recommendation for initiating and withdrawing dialysis for patients with acute kidney injury, CKD and ESRD. They recommended that in addition to being informed of their diagnosis and prognosis, all treatment options should be made available to renal patients, including RRT, avoiding dialysis and continuing medical management, or stopping dialysis and transitioning to EoL care.

After identifying education needs, it is possible to determine whether and how education interventions can be effective in Saudi healthcare settings. Assessing education needs and developing an education intervention to address these needs are critical, as they might help slow CKD progression to ESRD. ESRD's prevalence and its complications will continue to rise without education interventions for renal patients. This will burden Saudi Arabian healthcare systems, individuals and families. Establishing an education intervention in Saudi Arabia, with educators available in PHC settings, can relieve enormous pressure on secondary healthcare

facilities. It also could reduce unplanned dialysis, improve patient outcomes, boost survival rates and enhance care quality provided to these patients. Several studies have found that CKD patient education, often in conjunction with disease management strategies, slows CKD progression, promotes patients' engagement, decreases mortality and enhances QoL (Levin, 2005; Richards *et al.*, 2008; Bagnis *et al.*, 2015). To consider which tool is required, the priorities and key adaptations required for each of the currently available decision aid tools should be identified. This is needed to match the chosen tool with the culture of Saudi ESRD patients, their families and HCPs. This will be covered in the next two sections.

8.1.2 Phase 2: Cultural Adaptation and Translation of the YoDCA Tool

8.1.2.1 Qualitative Interviews with Experts in Renal Care

The second objective was to examine experts' experiences providing care for renal patients and their views about the cultural adaptation of the Yorkshire Dialysis and Conservative Care Decision Aid (YoDCA) tool (Winterbottom *et al.*, 2020b). The tool presents all available options for CKD patients, including RRT and non-dialytic options, e.g., conservative and palliative care. This helps patients and their families make decisions about which treatment ideally suits their lives as their kidney disease worsens. The objective was addressed by conducting in-depth interviews with renal care experts, including people working in clinical, academic and research settings described in Chapter 6. The following are some of the key themes which emerged from the data:

- Muslim Context and Perceptions of the Decision-Making Process
- Overall Impressions of the YoDCA Tool
- Comprehensiveness and Completeness of the Informational Content
- Sociocultural Appropriateness

8.1.2.1.1 Muslim Context and Perceptions of the Decision-Making Process

This section discusses Muslim renal care experts' experiences, particularly in communicating with renal patients about CKD management. This study found that experts in Muslim contexts who work in with their patients. Moreover, the experts said they discussed the DM process in Saudi Arabian healthcare settings, which only recommended RRT for renal patients and rarely discussed or approached non-dialysis options from a Muslim perspective, asserting that

patients usually are not involved in DM in Muslim countries and that HCPs make these decisions. Family involvement is highly preferred in DM, particularly for women.

Regarding available CKD management within the Saudi Arabian context, the present study indicated that Saudi HD patients are unlikely to be treated using non-dialysis treatments, e.g., palliative care or conservative management. However, in UK healthcare settings, it is recommended that a choice between RRT and conservative management should be offered to patients who need RRT in accordance with NICE guidelines (2021). According to these guidelines, patients and their families must be provided with balanced and accurate information about all RRT modalities and conservative management options available to them. The present study found that participants were given only RRT treatment options for their conditions, possibly because Saudia Arabia has no recommendations or guidelines in place concerning conservative management as an active treatment option for renal patients. Saudia Arabian follows international guidelines for CKD management (KDIGO-KDOQI EBP) (KDIGO CKD Work Group, 2013), which recommend educating and counselling patients with progressive CKD about different RRT modalities and transplant options. Moreover, the Saudi Ministry of Health (MOH) has stated that conservative management is not an option for renal patients (MOH, 2014). This treatment is considered only for patients with chronic conditions that meet specific criteria, mainly those admitted to intensive care units, primarily elderly cases with comorbid conditions and do-not-resuscitate orders (DNRs).

Consequently, Saudi renal patients rarely consider conservative management. This finding aligns with Van de Luijtgaarden *et al.*'s (2013) research, which reported that conservative treatment was provided to only 15% of their ESRD patients in 11 European countries. Among the specific barriers associated in the latter study with conservative management were patients with limited literacy, misconceptions about treatment and limited training in conservative management among nephrologists, insufficient pre-dialysis education, limited availability of renal services, nephrologists lacking experience selecting eligible patients for conservative management and nephrologists lacking confidence to communicate with patients about conservative management. De Jong *et al.* (2021) conducted an international study in which these obstacles were highlighted. As part of the systematic review of De Jong, the authors identified nonmedical obstacles that nephrologists face when determining

whether conservative or RRT care is the most appropriate course of treatment for ESRD patients. The barriers were classified into three groups: patient level (e.g., attitude, motivation, role perception, sociocultural background and knowledge); healthcare professional level (e.g., fears and apprehensions, communication skills and working approach) and healthcare system level (e.g., financial obstacles, practice organisation and supportive staff). Saudi Arabian healthcare settings might face the same barriers; however, the Saudi Arabian context has a unique explanation for why conservative management is usually not practised in Saudi healthcare settings for renal patients, which is related to religion and cultural norms. I expand on this in section (8.1.2.1.4).

Regarding how decision-making processes are perceived, in Subsection (8.1.1.1.4), I discuss data related to preferences in the Muslim context, particularly in Saudi Arabia, concerning the family's involvement in decision-making. This study's participants placed significant emphasis on the family's role in decision-making; thus, in this section, I examine this issue further, focussing on preferences in relation to family involvement in DM, particularly among female patients. This came from experts' responses when they were asked about the YoDCA tool and whether it was useful in considering patients' decisions. Evidently, cultural and sociological factors influence the decision-making process in Saudi Arabia (Al-Shahri, 2002; AlHaqwi et al., 2015), which has a unique culture based on a particular interpretation of Islamic Sharia law that determines gender roles and expectations. In Saudi Arabia, health services may be inaccessible, unavailable or governed by some cultural or gender norms. Gender was an issue in decision making. Guardianship permeates Saudi culture, limiting women's autonomy in healthcare, thereby affecting quality, access and outcomes. Traditionally, a male guardian is required to give permission for women to use healthcare facilities; thus, women accept less responsibility for decisions (AlHaqwi et al., 2015). However, this situation recently has changed, and women now can make their own decisions and sign consent forms. The Ministry of Health announced in 2012 that female patients 18 and older can sign admission or release forms without a male guardian present, except for abortions and sterilisations (Aldosari, 2017). Despite these changes, some women and healthcare facilities still struggle with this issue because of cultural traditions.

Another significant finding that experts reported is that DM usually is handled by HCPs without patients' input in Muslim countries. However, the present study's findings do not support previous research. Alrawiai et al. (2020) examined patients' perceptions during clinical encounters in research viewed as a landmark study on shared decision-making practices in Saudi Arabia. Patients are highly involved in shared decision-making in Saudi health systems, the study found. However, ESRD patients' involvement in decisions about dialysis treatment options has not been examined in any study in Saudi Arabia. Therefore, no data were available on how Saudi patients make health decisions. Nevertheless, my study offers context regarding how patients participate in shared decision-making within Saudi Arabia. Mobeireek et al. (2008) conducted other research in Saudi Arabia, in which an extensive survey was administered to evaluate physicians and patients' perspectives on involving patients vs. the family when conducting diagnosis disclosure and decision-making. The questionnaire employed in this survey had been created earlier in a collaborative manner to compare Japanese and US physicians' attitudes. Saudi Arabian physicians expressed a greater inclination in their study towards favouring patient autonomy, while patients favoured family involvement. Mobeireek et al. (2008) noted that the responses fell between those observed in the US, in which a patient-centred model was favoured strongly, and those in Japan, where a family-centred approach was preferred. Different priorities are attached to patients' rights, their families' needs and society's interests as a whole. Obviously, in the same culture, one rigid model is not appropriate for all patients and relatives, and practising physicians must be flexible and skilled in various ways. Furthermore, patients' preferences regarding patient participation in treatment decisions may vary depending on the condition being treated.

8.1.2.1.2 Overall Impressions of the YoDCA Tool

In this section, experts' opinions on cultural adaptation of the YoDCA tool are discussed. Overall, this study's participants viewed the YoDCA tool positively, except that they found it to be quite lengthy, which potentially could impact its use. Thus, they suggested decreasing content by modifying the format and content—either by removing some parts or summarising them. Earlier studies have noted that healthcare resources containing excess information can overwhelm patients, who then cannot focus on crucial details (Zikmund-Fisher, Fagerlin and Ubel, 2010; Fagerlin, Zikmund-Fisher and Ubel, 2011). Peters *et al.* (2007) examined three studies on healthcare information provision and determined that limited information elicited better comprehension and improved decision-making about hospital service quality and healthcare choices. However, a comprehensive literature review has reported contrary findings, suggesting that more in-depth decisions help enhance knowledge and decrease decisional conflicts compared with less-extensive information presentations (Feldman-Stewart *et al.*, 2013; Stacey *et al.*, 2014,2017). Nevertheless, debate continues the definition of a detailed or simple decision aid, as well as what is the bare minimum of information that should be provided. Furthermore, a research gap appears to exist regarding how the amount and length of information presented in decision aids can affect the tool's attractiveness, as well as patients and their families' engagement levels. This is particularly relevant during the DM process.

8.1.2.1.3 Comprehensiveness and Completeness of the Informational Content

The most obvious finding is that most experts found that the YoDCA tool was written for HCPs, not patients, and suggested strategies to facilitate users' comprehension and understanding. These included using plain language and translating tools into Arabic. Furthermore, experts suggested adding additional content to the original tool, including general information about CKD and its management, and specific content about psychological and spiritual support for Muslim patients. Language preference played a critical role in the present study, as the targeted users were Arabic patients, posing difficulties associated with the English language used in the tool. The importance of using 'plain language' when sharing healthcare information has been emphasised in earlier studies (Fagerlin, Zikmund-Fisher and Ubel, 2011). The basis of these recommendations is mainly the research highlighting the advantages of using 'plain language' to enhance the understanding of healthcare literature among individuals with low literacy levels (Clement *et al.*, 2009). This was considered during the translation of the tool into Arabic. Notably, the YoDCA tool, even after being translated into Arabic, requires users to be literate. Recent research has indicated that low-literacy patients' needs frequently are overlooked when considering decision aids for these populations, with only three relevant decision aids identified (McCaffery et al., 2013; Muscat et al., 2021). This indicated that more studies are needed to develop decision aids that can be more widely applicable, particularly for individuals with low literacy levels.

According to experts, adding information related to spiritual support for Muslim patients is an important aspect that can help patients cope with their illnesses. Spirituality is a major part of the sickness and recovery experience in Saudi Arabia because religion plays a central role in the social and cultural context. According to several scientific studies (Reig-Ferrer *et al.*, 2012), religious coping mechanisms and spirituality elicit a therapeutic effect on HD patients' spiritual health, their ability to manage the disease (Patel *et al.*, 2002) and their health-related quality of life (Fradelos *et al.*, 2021). Therefore, a comprehensive care plan needs to be developed that specifically addresses Muslim patients' spirituality, as well as their physical and emotional needs (Koenig, 2009). This was one of the most important considerations during the cultural adaptation of the YoDCA for the Saudi Arabian context.

8.1.2.1.4 Sociocultural Appropriateness

My study found that the original tool's social acceptability in the Muslim context was influenced by religious and cultural factors. These factors need to be considered during adaptation. Cultural and religious barriers, along with medical barriers, which are explained in Section (8.1.2.1.1), contribute to the limited practice of conservative management in Saudi Arabian healthcare settings. Culturally, conservative management is a new treatment option in the Middle East. As reported in the Global Kidney Health Atlas (Amouzegar *et al.*, 2021) by the International Society of Nephrology (ISN), the Middle East has limited capacity for RRT services, with conservative kidney management available in 82% of countries but only 18% of countries having specific conservative care or recommendations. Despite this, 27% of countries have easy access to conservative care. HCPs are reluctant to discuss conservative management due to patients' negative attitudes towards it, which they view as giving up on the patient. Therefore, conservative management is never accepted as a treatment option.

From religious perspectives, in a Muslim healthcare setting, some practices and guidelines may be influenced more heavily by religion, for example, conservative management for renal patients. In Muslim culture, religious authorities within the Saudi MOH are sceptical about terminating treatment according to Islamic rules (Sharia law), possibly because doctors are uncomfortable withdrawing care if the patient's quality of life is poor without dialysis. Dialysis withdrawal can result in patients' deaths, so HCPs may view conservative management as a sign of suicide or euthanasia, both of which are forbidden in Islam (Saaed *et al.*, 2015). Similarly, religious authorities can approve a DNR order to be practiced in Saudi Arabia clinical settings. No explicit reference to 'DNR' is made in the Quran, Sunnah or Hadith, as it is a product of modern medicine, but Islamic scholars have issued a fatwa regarding it: 'Life-supporting machines may be withheld or removed if three knowledgeable and reliable physicians agree that the patient's condition cannot be improved' (Saeed *et al.*, 2015). Despite public debate, most Muslims accept this DNR policy (Sachedina, 2005). Another example is organ donation. Muslims' religious beliefs do not support transplants (Laouad *et al.*, 2011). Instead of conservative management, dialysis withdrawal and palliative renal care are discussed most often in most religion-influenced literature (Elliott *et al.*, 2012; Cervantes *et al.*, 2017). In light of the fact that religion appears to exert little influence on patients' modality choice (Chanouzas *et al.*, 2012), most Muslim jurists and followers accept organ donation because of Islam's principle of saving lives. The experts reported that conservative management can be used in the Saudi Arabian context for renal patients if Muslim authorities approve it.

Experts found that the original version of YoDCA, a tool for renal patients and their families, contained offensive and sensitive information about alcohol, sex, and end-of-life care. The tool was developed in a Western country, and the new target users are renal patients and their families in Saudi Arabia. Saudi society is traditionally conservative, and religious and legal restrictions prohibit alcohol possession or consumption (Bassiony, 2013). Muslim patients often avoid discussing sex-related issues (Attum et al., 2018), and palliative and endof-life care treatment options are not accepted for religious reasons. Therefore, discussion topics like alcohol and sex could discourage readers and influence tool use. The study builds on Alabdulbaqi's (2019) adaptation of the Diabetes Self-Management Programme to type 2 diabetes patients' needs in Saudi Arabia. The diabetic patients requested that sections about alcohol and sex be removed, but the dialogue about sex was omitted for males. Adapting a decision aid tool culturally to Muslims was also undertaken in Malaysia with diabetic patients (Tan et al., 2020). The investigators reviewed the content and layout of the DA tool with HCPs and provided iterative feedback. In my study, I used expert opinions directly in adapting the decision aid for a Saudi Arabia audience to add to the body of evidence concerning decisionmaking for renal patients and their families. Furthermore, the adapted versions of YoDCA were tested for their cultural and linguistic appropriateness. Other novel aspects of the study included expert suggestions for how to implement the adapted YoDCA tool in clinical settings. As a result, a draft of this plan was developed, which will be discussed next.

8.1.3 The Process of Culturally Adapting and Translating YoDCA Versions

The third and fourth objectives were to describe the cultural adaptation and translation process by assessing the final YoDCA tool versions' content validity and developing a preliminary implementation plan. These objectives were addressed by conducting a cultural adaptation and translation process and conducting in-depth interviews with experts to test the adapted tool, which is described in Chapter 7. They are discussed below.

8.1.3.1 Key Adaptation of the YoDCA Booklet: Testing and Developing an Implementation Plan

Key priorities and adaptations were informed by the perspectives of experts and original authors in this thesis. To implement the YoDCA, the content and layout were changed accordingly. Contextualised content on nutrition and diet was added to address established kidney disease, and more resources were added that related to the target population, including entire graphics (which contained pictograms and ethnically representative photos), enhanced phrasing of text, an updated list of references and the part played by spiritual leaders in late-stage renal disease. The key strategies designed by Kreuter et al. (2003) are in line with the cultural adaptation conducted to complete the thesis, which focussed on healthcare programme development by increasing cultural competence. Kreuter et al. (2003 described five categories of strategies: (1) peripheral; (2) evidential; (3) sociocultural; (4) linguistic and (5) constituent involved. A colourful illustration of the kidneys' five main functions is provided in Chapter 7 of Version 5 of the YoDCA to enable material in the peripheral category to be more receptive and acceptable. The facts and evidence were updated on the health topic, particularly in the Muslim context: renal services unavailable in the Saudi Arabian context were removed, and additional resources useful for patients and their families were replaced by Arabic resources in the evidential category.

Under the sociocultural category, alcohol- and sex-related words were removed from the YoDCA tool, as the majority ethnic group in Saudi Arabia comprises Arab Muslims, who are concerned about discussing such sensitive topics. The experts made it clear that these topics are a potential concern. Other sociocultural examples included adding the phrase 'people with CKD and their families' throughout the document to broaden the concept of family involvement in DM in the Muslim context and adding new text explaining the importance and role of spiritual needs and leaders in coping with CKD and caring for patients who need EoL care. To accelerate YoDCA adaptation, another method was to translate the tool to a target language. In this case, the penultimate adapted Version 5 of the YoDCA was translated into the Arabic language. In this way, the linguistic category's content can be made more accessible and understood. I conducted forward translation, and professionally certified linguists conducted backward translation of adapted Version 5. I conducted a forward translation to produce Arabic version 6B. Chapter 7, Section (7.1.3), analyses these translated YoDCA tool versions' efficiency compared with culturally adapted penultimate English Version 5.

The constituent-involved category was designed to enhance understanding and allowed for 'participating in the development' of the tool. Therefore, I interviewed three previous experts about content validity. They focussed on the tool's linguistic and cultural appropriateness, as well as its utility and implementation – a crucial step that made implementation more likely to succeed when HCPs evaluated the tool and participated in the YoDCA content revision. All the interviewees stated that it was very informative and well-designed. They also noted that the adapted tool was appropriate for Muslim patients, and they were interested about how additional information was added that related to Muslim culture. Some concerns surfaced about the tool's length, and it was suggested that it should be condensed to improve usability. They found the Arabic translation difficult to understand and offered alternative words to improve it. Furthermore, they suggested a list of recommendations for future improvements, which is discussed in Chapter 7, Section (7.2).

Another key aspect of this study was developing a draft implementation plan for using YoDCA in clinical settings based on the experts' feedback, which is described in Chapter 7, Section (7.4). Some recent initiatives in the Saudi Arabian context aimed to develop and implement an Arabic decision aid tool in clinical practises for patients with metastatic colorectal cancer (mCRC) and open-angle glaucoma (Alsagheir *et al.*, 2020; Alsagheir *et al.*, 2021; Alwazae *et al.*, 2023). For example, Alsagheir *et al.* (2020 and 2021) compared Arabic DA use with usual

care for mCRC patients against usual care alone in a randomised controlled trial. In these studies, oncology physicians used Arabic DA among mCRC patients to assess patients' understanding of prognosis, treatment options, anxiety, decision certainty and satisfaction with Arabic DA. However, the barriers to implementation of DA tools in the Saudi healthcare context have not been researched in any existing studies, but according to Alsagheir *et al.* (2021), most physicians who responded to the survey were comfortable with the use of DA and were likely to use it again in the future (if available). Thus, the literature indicated that fewer potential barriers now hinder introduction of DA in clinical setups (O'Brien *et al.*, 2014). It was suggested that a deeper investigation be conducted to analyse the process of integrating Das into general clinical care. To date, use of renal disease SDM intervention in Saudi Arabia has been limited. My study builds on previous research by providing a baseline for improving renal management and professionalism in Saudi Arabia, as well as developing a draft of an implementation plan to think about ways of integrating DA into clinical settings.

However, in my study, no consensus was found among experts about how to introduce DA to hospital management, nor when and with whom they could be used, possibly due to the small sample size and participants' varying ethical and professional backgrounds. Therefore, more research is needed to examine renal HCPs, as well as patients and their families' perspectives on the implementation plan. According to the experts, the most important issue is how Muslim culture may influence using the tool in clinical settings. As a result, both religious authorities and public health policy need to be considered at a national level before implementing any education intervention for patients. According to Cabassa and Baumann (2013), an implementation science study should be combined with a cultural adaptation model. A key element of implementation science is the analysis of the internal and external environments in which the intervention would be used to help facilitate integration of evidence-based interventions into practice.

Assessing the inner context includes examining organisational elements – e.g., the leadership structure, which includes the organisation's size, services offered, workflow and the company's social environment (Mendel *et al.*, 2008). However, external contextual determinants include prevailing laws, political climate, available resources in the community, cultural and communal attitudes and beliefs about health, and what treatment methods they

expect (Mendel *et al.*, 2008). My study's results indicated that external contextual factors shaped some participants 'attitudes and views about a DA tool's implementation and availability in Saudi Arabian healthcare settings, including conservative management for renal patients. A study and evaluation of the larger organisational and health system cultures are vital to understanding where the YoDCA fits and how to sustain it.

8.1.3.2 Proposed Cultural Adaptation and Translation Process Learning and Challenges

For evidence-based practices to be effective, they must be adapted to diverse cultural contexts carefully, which requires time and effort. To do this, local politics, religious background, economic factors, internal ethnic groups' traditions and family practices, and the country must be analysed carefully (Kumpfer *et al.*, 2008). One issue faced in the present study was including representative stakeholders or experts. Movsisyan *et al.* (2019) recommended involving stakeholders in cultural adaptation processes on an ongoing basis. Integrating input from experts and original authors informs cultural adaptation. Challenges such as estimated cost, predetermined project timeline and representative stakeholders were encountered during the cultural adaptation process. Experts from specific backgrounds and varying ethnicities, as well as those who have experience in renal patient care, comprised the stakeholders. Despite all the experts being Muslims, they came from myriad cultural and linguistic backgrounds. The challenge of guaranteeing a consensual procedure for decisions regarding cultural adaptation was considered as part of general adaptation. However, the project team – comprising academic advisers, researchers and founding YoDCA members – made the final decisions.

Another issue was to find a balance between feedback from the experts, who represent the Muslim context, and the original authors who developed the tool while regarding aspects that need adaptation. As explained in Chapter 6, the experts identified many aspects to adapt from the original tool. Some were related to cultural adaptation while others were related to clinical adaptation. During the interviews, the experts emphasised the importance of adding such information for Arab and Muslim patients to help increase their health awareness. As they described it, Arab patients had a low level of health literacy compared with other cultures, particularly Western cultures. However, the original authors disagreed with all these clinical adaptations, which could affect the balance of information provided and, thus, affect

the tool's efficacy. As Kumpfer *et al.* (2008) stated, the notion that fidelity involves cultural adaptation without affecting programme elements or general structure governs the adaptation of international instruments to various populations.

The issue of how to strike a balance between mainstream intervention fidelity and core intervention components and community relevance has been debated (Castro, Barrera and Martinez, 2004; Bernal and Adames, 2017). Materials can be adapted in a culturally effective way by adding culturally appropriate stories, exercises, examples, pictures and videos. As Kumpfer *et al.* (2002) found, omitting, combining or changing a lesson's topic decreased the intervention's efficacy compared with the original. Cultural adaptations in my study were conservative, aligning with previous literature. One of Kumpfer *et al.* 's (2008) key recommendations was to keep initial adaptations of an adopted programme to a minimum. As a result, only adaptations related to the culture were made in the adapted version. Moreover, clinical adaptation lay beyond the scope of this thesis. Incorporating worldviews and cultural factors into this education intervention would strengthen its adaptation and allow for further testing, refining and trialling in renal Muslim communities.

Furthermore, stakeholder engagement requires time and resources (Oliver, Kothari and Mays, 2019), which are essential. The adaptation and translation processes were timeconsuming: It took approximately one year, including experts' engagement, to develop six versions and sub-versions of the culturally adapted and translated penultimate version, then test them. I used an existing tool rather than develop my own and translated it into Arabic (forward translation) to reduce costs and time. When culturally adapting an intervention, time and cost must be considered. This does not justify excluding other potential participants and translators from the study, nor is it equitable. For these reasons, future adaptation projects should seek funding and provide sufficient resources and time to establish relationships and collaboration mechanisms before commencing work.

In my study, the cultural adaptation process included translating the tool into Arabic, a challenging process due to tension between two somewhat conflicting requirements that researchers must maintain: keeping notions as true to their meaning as possible while maintaining quality and compatibility with the English original. In the new Saudi Arabian setting, researchers desired relevant and efficient instruments. I investigated concepts'

relevance and significance rigorously while considering structural and cultural variations between the UK and Saudi Arabia. Translation of the penultimate Version 5 and creation of the translated Version 6B involved overcoming all these difficulties and striking the correct balance between fidelity to the English origin and closeness of it. However, based on the expert feedback on the translated tool, some translated items were difficult to understand and needed to be translated using simple Arabic language. Thus, more research is needed using cognitive interviewing and debriefing with Arabic patients. This is the first written decision aid tool on CKD management, and its future plans will be available in Saudi Arabia to Saudi patients and their family caregivers. Relatively little research has been conducted on the adaptation and translation of renal Muslim patients' decision aids into their cultural contexts. My study found that despite limited resources, cultural adaptation and translation of a decision aid could be accomplished systematically. Other workgroups may build on and replicate this experience, which will contribute to the body of already-existing tools for decision-making without incurring much expense.

8.2 Strengths and Limitations

This section discusses the study's strengths and limitations.

8.2.1 Strengths

A major strength of this study was its use of multiple research methods (systematic review, qualitative studies and collaborative engagement to adapt and translate YoDCA). There was used to examine the education needs and experiences of patients and/or their family caregivers regarding current ACP and SDM practices in dialysis units and aimed to adapt and translate the YoDCA tool culturally for Saudi ESRD patients. The combination of these different methodologies enabled the development of a culturally adapted and translated YoDCA decision aid tool for Saudi renal patients, as well as the development of recommendations for future refinement and a clinical implementation plan. The study also contributes to new knowledge in the field of study by providing evidence about patients and family caregivers' experiences of living with CKD. It also provides insight on ACP discussions and decision-making processes in Saudi Arabia in the renal care field, as these issues have been examined rarely in the literature in the Muslim and Saudi Arabian contexts. By

considering patients and their families' perspectives, Saudi Arabian healthcare settings' renal care practices should improve.

In terms of modified systematic reviews, this is the first study that examined EoL communication issues, including ACP and DM, from the perspective of Muslims with ESRD and their families. Moreover, this study also can serve as a springboard for Saudi patients, their families and HCPs, as it may lead to a relevant education programme for them. This tool is the first decision aid tool developed for renal patients and their families in Saudi Arabia for CKD management, including RRT and non-dialysis options, e.g., conservative management and palliative and EoL care. Moreover, a further strength was the comprehensive description of how the YoDCA tool was adapted and translated culturally based on Chanel *et al.'s* adaptation steps alongside WHO guidelines.

8.2.2 Limitations

The study's main limitation was that it was conducted during the COVID pandemic. As a result of pandemic restrictions, the planned research project was changed, which affected data collection. This was explained in detail in Chapter 4, Section (4.4.6), and in the COVID-19 Impact Form (see supporting document). Studies on cultural adaptation and translation generally are complicated and demand a sizable research team with a broad range of pertinent specialities. Due to the nature of this thesis, I conducted most of the study's key aspects and followed all guidelines and supervisors' feedback. This study comprised two phases, each with its own limitations that should be considered.

Phase 1 comprised interviews with ESRD patients and/or family caregivers, but the study contains numerous limitations concerning the methods employed. The study was conducted in the Northern region of Saudi Arabia at only one hospital. Thus, these findings might not be generalisable to other Saudi Arabian populations or settings. Future studies in different geographical areas of Saudi Arabia would help add findings elucidated through this data set. Furthermore, due to the qualitative study design, generalizability was not expected. Considering the practical challenges of recruiting ESRD patients and/or family caregivers, a small sample was recruited (five participants), but a modified systematic review was conducted in the Muslim context as part of the complementary work that supported the

interviews. Also, interviewing middle-aged participants does not represent the myriad views of elderly patients with complex needs who need EoL care, which limits the ability to generalise this study's findings. Gender bias in qualitative research is well known. In one qualitative health research study, 74% of the sample's participants were females (Polit and Beck, 2013). However, men's tendency to express fewer emotions could be the cause of this paucity of male representation in qualitative research (Smith, Braunack-Mayer and Wittert, 2006).

Only five studies were included in the modified systematic review, reflecting a very limited evidence base in this field, which is a significant limitation. The literature cannot fully grasp interesting cultural issues because extant studies are so few, and study designs are limited. In this context, evidence-based research is required—not only quantitative, but also qualitative—which is lacking. Furthermore, a terminology problem has been identified in this review, presenting challenges in the search process and study selection. However, this terminology problem has been identified in other research in this field (O'Halloran et al., 2018; Zwakman et al., 2018; Abdullah et al., 2020; Martina et al., 2021). Papaioannou et al. (2010) found that searching for literature in fields such as palliative and EoL care is difficult because daily practice is heterogeneous, and concepts and keywords are not clearly defined. Therefore, to ensure a comprehensive search and for different practical applications to be identified in the clinical setting in different countries, the researcher used myriad search terms, e.g., 'end-of-life decision', 'end-of-life discussions' and 'end-of-life care' to refer to the ACP process and discussion. In this review, terms such as 'ACP preference' and 'EoL decisions/discussion' are the same, but in the general field, the relationship between the two is not always identical because the application of these services may differ from one country to another.

Phase 2 involved interviews with experts in renal care. Due to COVID challenges, a small sample was recruited (nine experts), only four of whom had clinical roles in Saudi Arabian dialysis care. Although a broad sample of ethnicities, genders and areas of expertise enabled diverse perspectives, no consensus was reached among key elements of the cultural adaptation and implementation plan. Neither social workers nor health educators were included in the sample, which was another limitation. Furthermore, those in a clinical role did

not have experience with any education decision aids for renal patients, likely because none were available in Saudi Arabia. A review of the adaptation process and tool evidence was conducted to ensure that they were consistent with Saudi standards and protocols. Unlike other Gulf, Arabic and Muslim countries, Saudi culture is unique, so my study's findings might not apply to other Arab and Muslim cultures.

The interviews did not include any ESRD patients and/or family caregivers from Saudi Arabia who may have voiced different views on the adaptation of YoDCA. Due to these limitations, the effect on the initial perception regarding the YoDCA at both stages of adapting and testing content validity could not be examined completely. Moreover, including a small sample size for testing the culturally adapted and translated YoDCA tool's content validity made it difficult to draw conclusions from their feedback from both Versions 5 and 6B, as well as implement the YoDCA in clinical settings. Therefore, further research with a larger sample size is needed on the acceptability of YoDCA testing, delivery methods and implementation strategies, including patients and family caregivers' perspectives. Furthermore, despite the use of an inadequate but necessary rigorous method, the comparability, accuracy, and validity of a translation cannot be guaranteed. Both quantitative and qualitative approaches, including cognitive interviews, are essential to evaluate the translated tools further (McKenna and Doward, 2005; Beck *et al.*, 2017). In my study, the culturally adapted and translated tool's validity was assessed using semi-structured interviews with three experts, but more research is needed.

8.3 Research Implications and Recommendations

8.3.1 Research Implications

Based on the findings from interviews with ESRD patients and their family caregivers, as well as a review of results from different Muslim cultural backgrounds, differences were found between views on ACP, EoL discussions and the DM process. To reach a consensus, more research is recommended in this field on patients and their families' understanding of ACP, their illnesses, their EoL wishes and how family relationships affect DM. As a result of this study, HCPs will be able to gain a better understanding of patients' attitudes towards ACP and, therefore, develop a more effective strategy to promote ACP in different cultural contexts. Research also is needed to determine what kind of care model is necessary to support people in their decision-making, particularly Muslims from diverse cultural backgrounds. When discussing EoL and ACP care with Muslims, the more acceptable model could be a family decision-making approach.

Furthermore, due to a lack of research on ACP in the Muslim renal context, future qualitative research should investigate Muslim patients and their families' perspectives on EoL, ACP and the DM process to consider individual preferences and experiences. Also, qualitative research focussing on HCPs' involvement in ACP and experiences with ACP discussions is needed urgently. Moreover, high-quality research on ACP's advantages is warranted in a broader sense, which would include examining ESRD patients' perspectives by studying ACP acceptability and viability, along with the method to implement among the masses to initiate ACP. Owing to the scant literature in Muslim countries on factors influencing decision-making on EoL care in dialysis patients, the present study recommends that more studies be conducted.

Future studies also should focus on culturally appropriate ACP intervention development and evaluation to improve care and the DM process, including research into culturally adapted decision aid tools that incorporate patients and their families' values, these aids' efficacy in facilitating care with patients and their families' wishes, and communication intervention. Although this suggestion was achieved by culturally adapting and translating YoDCA's decision aid tool to ESRD patients and their families in the Saudi Arabian context is still needed.

Feasibility and acceptability testing, enhancing culturally acceptable education interventions and conducting an efficacy trial comprise the Cultural Adaptation Process Model stages (Barrera Jr *et al.*, 2013; WHO, 2017). Although three experts assessed the content validity of the culturally adapted and translated YoDCA tool in my study, future studies should consider a larger sample size that includes a variety of users – e.g., renal patients, family caregivers and HCPs – to confirm the reported results. The next step would be to conduct trials to seek an improved ACP discussion and decision-making outcome for renal patients. Cultural adaptation studies frequently do not address this open-ended question, particularly in the context of the kingdom's large Muslim population. Its final integration into standard clinical practice will be what defines its success level. To overcome these difficulties, additional research must be conducted.

This study evaluated the cultural and translated YoDCA tool for renal patients and their families in the Saudi Arabian context for the printed version's content validity. To investigate other DA tool delivery methods, additional research is needed, as this study's results have indicated, and should include online and audio/video formats. Likewise, more research should be conducted to investigate these various approaches' relative merits. This further research is needed based on the present study's findings, focussing on developing and evaluating different versions of the YoDCA tool, as the current adapted version only provides services for a specific group of renal patients in Saudi Arabian healthcare settings. These versions need to be developed for different groups, including those with low literacy, patients at various stages of CKD and those without CKD.

Finally, this study drafted an implementation plan to use YoDCA in clinical settings. No consensus was reached among experts about this plan, as they had different opinions on how to introduce it into hospital management and when and with whom it could be used. Based on these findings, further research is required to investigate how the adapted and translated tool can be implemented and delivered within healthcare settings. Moreover, barriers that may pose challenges during implementation and evaluation of the tool within the healthcare setting need to be examined through research.

8.3.2 Implications for Clinical Practice

This study carries several implications for patients and their family caregivers, HCPs, and nephrology practices, one of which is that the YoDCA tool need to be implemented in renal units in Saudi Arabia to improve ACP and SDM. Chenel *et al.* (2018) suggests that field testing occurs prior to clinical deployment of DAs. This evaluates the DA's performance, as it is integrated into practice or health care professionals' workflows. This could be done by piloting a testing tool to ensure its acceptability and feasibility in routine renal care in Saudi Arabian clinical settings. WHO (2006) recommends pilot-testing as a first step towards a national scale-up, rather than as an independent event. Another implication is that the study's findings and literature clearly indicate that no structured pre-dialysis education programme
exists in Saudi Arabian healthcare settings. In the Saudi Arabia, no guidelines or instructions are available related to pre-dialysis education, nor the time needed to prepare ESRD patients before starting dialysis (Alhameedi, 2016). Therefore, Saudi Arabia needs to improve pre-ESRD nephrology care, which can be accomplished by developing several multidisciplinary approaches, including the following:

- High-risk patients should be identified to diagnose early CKD, and regular screenings should be conducted.
- Communication should be enhanced among HCPs, and precise guidelines for referring patients with CKD to nephrology care should be established.
- The advantages of referring patients with CKD to nephrology during the disease's initial stage should be made clear to healthcare professionals, including cardiologists, family doctors, internists and diabetologists.
- Social workers and HCPs should discuss prognoses and ACP to raise awareness among ESRD patients and their families regarding their illnesses to help them understand their current condition and make informed decisions by developing and delivering culturally appropriate education programmes.

Moreover, my study found that awareness of CKD exists at a low level and emphasised the use of tools to spread knowledge and develop awareness campaigns along with communitybased interventions, such as programmes related to health education. Pre-dialysis education must start immediately after a patient stabilises in circumstances when the patient is referred late to a nephrologist. Furthermore, even if a treatment plan has been decided, education must not stop. To ensure this, regular follow-ups could be conducted to determine whether the patient is satisfied with the modality, whether they wish to switch to another modality or whether the selected modality has any initial issues (Isnard Bagnis *et al.*, 2015).

My study found that ESRD patients and their family caregivers need some type of decision support related to CKD management. Patients, HCPs and policymakers should consider this for the Muslim renal patient population. My study highlighted this need and demonstrated how patients and family caregivers lacked knowledge about certain available treatment options and often were denied time to think about and discuss future care plans. Furthermore, some patients and family caregivers in the study either did not receive standard written pre-dialysis information or did not engage with it fully.

Shared decision-making (SDM) in Saudi Arabia, which includes the use of DA tools, is still not standard clinical practice for renal treatment. To augment communication and SDM, more initiatives are needed to encourage SDM among HCPs and to enhance DA tools' usability for patients and their caregivers. Muslim patients, particularly renal patients, cannot overestimate how crucial family caregivers are to their care. Involving families in patient care is an essential concept, and it may be necessary to emphasise this in guidelines worldwide, particularly when it comes to decision-making processes. Multiple stakeholders should be involved in SDM, including HCPs, patients and their families. Furthermore, HCPs must be sensitive to Muslim cultures and should be aware of fundamental Islamic concepts when planning communication strategies. For example, patients and their families must be provided with spaces where they can practise religious rituals.

Finally, no consensus exists among Muslim participants in terms of preferences in the ACP discussion and DM process, i.e., every individual has different preferences and requirements to suit their needs. The assigned ACP should address the wide range of patient beliefs, what they like/dislike in terms of their value and part in planning, and whether they choose to play an active role in planning themselves or assign it to family members or healthcare professionals. They also should be flexible on when to begin any plan. Thus, based on our findings, we recommend individualised care and planned decision-making because individuals have their own preferences and wishes.

8.3.3 Implications for Policy

A significant policy implication of my study is incorporating the use of DM tools such as YoDCA into Saudi health policy and clinical guidelines. Once the YoDCA piloting is has been completed and its effectiveness confirmed, the tool needs to be made nationally available. This is a significant route to implementation by including in things such as clinical guidelines. Then, collaborating with policymakers, religious authorities, working with clinical organizations and public health policy representatives is one way to get in tool included in guidelines, or policy framework for enabling SDM in Saudi renal care. A wider framework might be necessary to

improve SDM in renal care, for example, YoDCA could be used as part of Saudi renal care. As this is more likely to get implemented into practice.

Another study's implications in terms of improving health policy changes include how to incorporate non dialysis care, e.g., conservative management and palliative and EoL care pathways for renal patients and their families in the Saudi Arabian context. This needs to be examined at a more systematic level, and to achieve this, an emphasis on cultural perspectives could enhance palliative care practices, highlighting the need to work as a team with patients and their families and communities to ensure culturally relevant care, guarantee the highest level of palliative care in general and enhance QoL. It also may be important to realign messaging about palliative care and become more adaptable and imaginative in overall approach when developing or expanding palliative care models, which are necessary to address various Muslim cultural groups. For example, palliative care approaches could be modified to accommodate various groups' needs, people's choices and their decisions about EoL and palliative care.

Furthermore, such services could be included in national guidelines, which would ensure that all patients receive quality care. For patients who do not need RRT, HCPs should have clear guidelines for conservative management, palliative care and EoL care. Education and training should be provided to all members of the multidisciplinary team caring for ESRD patients to ensure that they are aware of these guidelines. To ensure that current guidelines are meeting patient needs, an audit of patient outcomes should be conducted as well. According to international guidelines, the minimum requirement for nephrologists is, as a treatment modality, that conservative management must be acknowledged, as well as ACP, and difficult conversations that fall under SDM should be encouraged, as well as figuring out the phases of life that are of utmost importance to patients and their families. They must accept these as core CKD competencies. Nephrologists also must broaden their knowledge and skills so that they can offer conservative management and other services through standard clinical practices.

8.4 Reflection on Research Process

I was aware of the difficulties before launching my PhD. For me, reflection was fundamental to the research process. My reflections led me to examine how my self-perceptions affected

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the research process and my data, and how I observed various power dynamics during interviews. It was beneficial to me as a researcher and as a person to have a common comprehension of and empathy for the challenges of the PhD process.

As an inexperienced researcher, conducting qualitative research, including interviews with patients and experts from HCPs, and numerous other research activities amounted to an ambitious undertaking. As an academic nursing staff member, conducting this study in a researcher role was difficult, mainly because it focussed on patients and their families in healthcare facilities. Initially, like other PhD students, I worried about reaching participants, conducting access negotiations and achieving the desired sample size. Due to COVID restrictions, I missed the opportunity to recruit participants by myself and meet them face-to-face. I did not explain my study and establish a relationship with participants, but the corresearcher and head nurse of the dialysis unit helped with the recruitment process. However, selection bias was introduced, as they identified prospective participants, and I had a very small sample size.

Although I was keen on conducting qualitative research for the first time in my study, I sometimes felt overwhelmed by the huge amount of data collected. I was very anxious and afraid that I had not collected enough data to analyse because I only interviewed four patients and/or family caregivers. Furthermore, during the interviews, the participants provided very concise answers, so I asked many questions to get more complete answers from them. These influenced my thinking about the data I collected during this phase of my research – a very small data set for a PhD project. I remember spending one week just thinking about the data set's size, and I was afraid to even examine it. I then motivated myself to read each interview several times before coding it.

Despite this, while working on data analysis and coding, I was surprised at how much data was generated from this small number of interviews, which ultimately resulted in the development of six overarching themes. Moreover, when writing up this phase, I frequently was challenged by the task of translating the participants' words (from Arabic interviews) into English and making them as understandable as possible. Furthermore, it was difficult to conduct research in the renal field within a Muslim context, particularly in palliative care. Such practices are rare in Islamic countries, and evidence-based resources and ways to find them

are limited. Moreover, handling so many study activities during Phase 2 – e.g., recruiting expert participants, conducting online interviews, analysing data and working on cultural adaptation and translation processes and their documentation for about a year – was very challenging. If time had allowed it, I would have recruited more experts in renal care, particularly Saudi experts with a clinical background.

I have found it extremely worthwhile to reflect on my own experiences collecting data during the COVID pandemic throughout my study. COVID significantly impacted my research project, leading me to change my intended plan to one that could be implemented during times of crisis. It was a very stressful time for me because the approved plan had to be changed in a very short time frame. Some modifications were conducted simultaneously as data collection began. Thus, during that time, I intended to think about modifications, conduct searches, read and write about these modifications, and submit them to seek approval from the ethics committee before I resumed data collection. Dealing with all these steps during such a short time frame was very stressful and challenging, and I sometimes lost confidence in my research project's direction. Despite all these challenges I faced during my study, the most important thing that I needed to remember was how I and my supervisory team dealt with these challenges. In the end, I not only contributed to my personal development as a researcher, but also inspired new research opportunities and ideas through reflection and awareness of one's own role in the research process.

8.5 Conclusion

8.5.1 Original Contribution to Knowledge

This study's findings add new knowledge to the field of study by providing qualitative evidence on the education needs of ESRD patients and their family caregivers, as well as their experiences in EoL communication issues, e.g., the ACP discussion and SDM processes. This insight into patients' experiences indicated that SDM practices in Islam need to be improved, particularly in Saudi Arabia. Furthermore, it is the first study in Saudi Arabia to develop an education intervention, i.e., the YoDCA tool, that is adapted and translated culturally for ESRD patients and their families in the Saudi Arabian context. The study found that the YoDCA tool can be adapted for use in Saudi Arabia, even with limited resources, as doing so would not lead to radically different content that would compromise the tool's relevance. Our cultural adaptation and translation process offers insights for use with future cultural adaptations of other chronic conditions' education programmes in Saudi Arabia.

8.5.2 Study Conclusion

This study examined ESRD patients and/or their family caregivers' education needs and experiences in a dialysis unit at Tabuk, Saudi Arabia regarding current advance care planning (ACP) and shared decision making (SDM) practices. Furthermore, the YoDCA tool was translated and adapted to be relevant to Saudi ESRD patients and their families. The study comprised two phases that used a pragmatic qualitative research design with multiple research methods employed. In Phase 1, a better understanding of current ACP and SDM practices was established, and patients' education needs in the Saudi Arabian context were identified through four in-depth phone interviews with ESRD patients and/or their family caregivers. Furthermore, a modified systematic review was conducted in the Muslim context to complement the interviews' findings. In Phase 2, interviews were conducted with renal care experts who treat patients, eliciting a wide range of experiences, as well as their views and perceptions about aspects that help adapt the YoDCA tool to the Muslim context. This phase comprised eight individual semi-structured interviews. As a final point of Phase 2, the cultural adaptation process comprised three stages, which are explained below.

This study found that most Saudi renal patients were diagnosed with CKD suddenly when visiting emergency departments for unrelated symptoms, requiring urgent dialysis. As a result of these emergency diagnoses, patients and their family caregivers were deprived of the opportunity to choose their dialysis treatment, and insufficient information was provided about the treatment they received. These patients and their family caregivers also complained that their HCPs did not provide them with adequate communication and information about their diagnoses and treatment.

Another major finding was that most study participants had little to no knowledge about the causes of their CKD and its management before starting dialysis, indicating that these participants did not receive pre-nephrology care, including pre-dialysis education. Even though this is an international issue, it was manifested differently within the Saudi Arabian clinical context due to differences in healthcare service delivery and cultural factors. The study

also found that Saudi renal patients and their family caregivers had different experiences in the decision-making process. Despite these differences, they preferred an approach that included their families in the decision-making process. Moreover, participants explained the factors that influenced their decisions to commence their first dialysis sessions, with most reporting that physicians' influence was the most significant factor in making a dialysis decision. The decision to start dialysis also was thought to be influenced by late diagnoses, the need for urgent dialysis and cultural considerations.

Another significant finding from this study is that participants had varying experiences communicating future care plans with their HCPs. Several felt they did not receive any opportunities to discuss their disease prognoses or future care plans with their HCPs, which was attributed to cultural and religious factors that hindered Muslim renal patients and their families from becoming knowledgeable about their medical conditions, discussing their prognoses and undertaking ACP. The data highlighted that the ACP concept in the Muslim context is often relevant to EoL care. To take a broader approach to ACP, this thesis supports encouraging consideration and discussion of ACP for people with life-threatening conditions, e.g., CKD, in the early stages of its development.

The ACP is not adequately discussed or documented, and family input in decision-making is crucial. In the absence of research engaging Muslims with ESRD and their families in EoL care communication concerns, e.g., the ACP discussion and DM method, a literature gap exists. Like the rest of the world, most patients in Islamic countries undergoing EoL care lack information concerning their medical conditions, thereby preventing them from making decisions concerning their health. Findings suggested that renal patients in a Muslim context differed in their attitudes towards ACP and EoL care values. Furthermore, their willingness to discuss these issues, including death and EoL care preferences, also varied.

Moreover, experiences and perspectives on who makes ACP and EoL decisions were diverse in terms of the degree of involvement and responsibility making these decisions, largely due to the religious and cultural setting, as well as the communication barrier between physicians and patients. Furthermore, limited resources that lead to strained facilities and high demand for physicians make it difficult to have patient engagement in ACP discussions and EoL care decision-making. However, in the Muslim context, these considerations often have been acknowledged. Western societies also may have comparable perspectives. As a result, improving communication and information sharing is crucial in influencing patients' decisionmaking to provide the best EoL care possible. In the context of improving current practices, participants expressed a desire for more information about all treatment options and potential benefits, harms and side effects. Moreover, they expressed a need for Information related to their disease progression, as well as a plan for future care. Some patients and their families would receive nonmedical information, e.g., treatment's impact on daily life activities, e.g., religious and social activities. They also would receive information through different communication channels. Consequently, these findings illustrated above were incorporated in the sense that they reinforced the point that such an education intervention is needed to meet their needs.

In summary, both findings from participants' interviews and the modified systematic review indicated that religion and culture influence current ACP discussion and DM process practices in the Muslim context, and that Muslim renal patients have a variety of experiences with ACP, EoL care, and SDM. However, no consensus was reached among Muslim renal patients concerning their experiences and practices with these issues; thus, questions remain, so more research is needed in this area. Individuals have their own unique preferences and wishes, so our findings suggest that we need individualised care and plan decisions. Moreover, our findings were incorporated in a sense that they reinforced the point that such a tool was needed as an education intervention, e.g., a decision aid tool to improve information received and make an informed decision to facilitate communication about future care plans and improve shared decision-making practices within the Muslim context. This can be accomplished by developing and delivering culturally appropriate education programmes. Thus, the YoDCA decision aid tool was chosen to be culturally adapted and translated for Saudi ESRD patients and their family caregivers, as explained in the next sections.

The English-based YoDCA tool was translated and culturally adapted before its implementation in Muslim contexts. Using a three-stage adaptation procedure, this was accomplished. Stage 1 achieved preliminary adaptation of the tool content based on experts' views. Overall, the experts felt that the tool was very informative and would educate patients and facilitate decision making. According to some experts, the tool was not socioculturally

appropriate for Muslim contexts, as it contained offensive words that needed to be removed and referred to conservative management treatment, which is controversial and rarely considered for renal patients in Muslim contexts due to cultural and religious norms. The interviews with experts clearly indicated that culture and religion have influenced and shaped their professional practices, particularly in relation to communication and DM within healthcare settings. Thus, the adaptation at this stage was made on two levels, including clinical and cultural content adaptations.

On Stage 2, the original author reviewed the preliminary adaptation draft in an effort to seek their approval of the adaptation. This stage involved an iterative process developing many versions in which the English version of YoDCA was redrafted and revised until a penultimate version was ready for subsequent translation and testing steps. In this adaptation, the main focus was on cultural content adaptation, content consistency with Saudi standards and protocols, and adaptation of the original illustration to make it appropriate for the Saudi Arabian context. In Stage 3, the penultimate adapted English version was translated into Arabic using the forward-backward translation technique described in Chapter 7, Section (7.1.3).

The study's overall findings after testing the culturally adapted and translated tool versions indicated that the adapted and translated version of the YoDCA tool was an informative, well-designed, culturally relevant, and usable tool for improving shared decision-making practices within Muslim healthcare facilities, particularly in Saudi Arabia. Also, the experts suggested that future improvements would be developed for different groups of patients at different stages of CKD, and a variety of communication channels would be used. Furthermore, even though the tool seems relevant, more work is needed to improve the translated items' understandability and clarity. Moreover, a draft implementation plan was developed based on expert views. Notably, conflicts arose in the data, and the respondents had differing opinions about how the tool should be introduced to hospital management, and when and how it should be applied. Governmental, health and religious organisation authorities' requirements may be necessary before the tool can be implemented. Thus, more work needs to be conducted, which includes piloting and revising the implantation plan, as well as

assessing the healthcare system further before implementing such education interventions in Saudi Arabia.

8.6 Chapter Summary

This chapter discussed this study's major findings and their significance, along with their strengths and limitations. This study contributes to a more in-depth examination of current dialysis practices regarding communication issues, e.g., ACP discussions and the SDM process, from ESRD patients and their caregivers' perspectives. This study's findings also indicated the need for national education intervention for ESRD patients and their families in Saudi Arabia. Thus, the evidence based YoDCA intervention was chosen and culturally adapted. The cultural adaptation and linguistic translation of the YoDCA tool using Chenel *et al.*'s (2018) steps alongside WHO guidelines were conducted and documented successfully. A discussion of the study's implications and future research directions also was included in this chapter, as well as personal reflections on the research process and conclusions drawn from the findings

Appendices

Appendix 1: Scoping Review Search Strategy

CINHAL (The Cumulative Index to Nursing and Allied Health Literature) (Plus with Full Text

(EBSCO)

Search ID	Search Terms	Search options	Action
S15	S9 OR S11 OR S13	Search modes- Boolean/Phrase Limiters – Published Date: 20000101- 20191231	View Results (141) View Details Edit
S14	S9 OR S11 OR S13	Search modes- Boolean/Phrase	View Results (143) View Details Edit
S13	S7 AND S12	Search modes- Boolean/Phrase	View Results (51) View Details Edit
S12	(decision making or decision-making or decision making process) OR (patient decision making or patient decision aids) OR (shared decision making or patient involvement or patient participation or patient choice) OR (withdrawal of life sustaining treatment decision or treatment withdrawal or "withdrawal of treatment")	Search modes- Boolean/Phrase	View Results (141,219) View Details Edit
S11	S7 AND S10	Search modes- Boolean/Phrase	View Results (83) View Details Edit
S10	(communication or interaction or conversation) OR (communication skills or experiences or conversation) OR (communication with patients or end of life care communication)	Search modes- Boolean/Phrase	View Results (530,933) View Details Edit
S9	S7 AND S8	Search modes- Boolean/Phrase	View Results (75) View Details Edit
S8	(plan* or planning) OR (advance care planning or acp or advance directive or advance- care planning or ACP) OR ("end of life planning" or advanced care plan or living will)	Search modes- Boolean/Phrase	View Results (312,906) View Details Edit
S7	S1 AND S4 AND S5 AND S6	Search modes- Boolean/Phrase	View Results (292) View Details Edit
\$6	(education or learning or teaching or training) OR ("educational interventions" OR "learning interventions" OR educational program or teaching program OR training program) OR (educational sessions or teaching sessions or training sessions or learning sessions or educational project OR workshops or educational initiatives) OR (patient education or patient information or nursing education or healthcare professional education)	Search modes- Boolean/Phrase	View Results (806,773) View Details Edit
S5	(healthcare professionals or healthcare workers or healthcare providers or physician or nurse or doctor) OR (nurse practitioner or practice nurse or general practitioner OR primary care) OR (staff nurses or registered nurses OR graduate nurse OR qualified nurse) OR (family or caregiver or surrogate OR patients or patient care or clients)	Search modes- Boolean/Phrase	View Results (2,337,744) View Details Edit

S4	S2 OR S3	Search modes- Boolean/Phrase	View Results (75,462) View Details Edit
S3	(renal care OR nephrology care OR renal replacement therapy OR RRT) OR (dialysis or haemodialysis or haemodialysis or dialysis treatment or long term dialysis or pre-dialysis OR pre dialysis) OR Peritoneal dialysis OR (conservative treatment" or "conservative management" or non-surgical OR "non- dialysis management") OR ("dialysis withdrawal" OR "withholding dialysis" OR "cessation of dialysis")	Search modes- Boolean/Phrase	View Results (23,641) View Details Edit
S2	(renal disease OR renal failure OR kidney disease OR kidney failure) OR (chronic renal failure OR chronic kidney failure OR chronic renal disease OR chronic kidney disease OR CKD) OR (end stage renal disease or end stage renal failure or esrd or end stage kidney disease OR ESKD OR CKD stage 5)	Search modes- Boolean/Phrase	View Results (59,169) View Details Edit
S1	("palliative care" or "end of life care") OR (supportive care OR terminal care OR terminally ill OR care of dying Or actively dying) OR (continuing care OR holistic care OR total care OR comprehensive care OR comfort care or pain and symptoms management OR quality-of-life care OR chronic illness care)	Search modes- Boolean/Phrase	View Results (88,077) View Details Edit

Appendix 2: Descriptive summary of included studies.

Appendix 2A: Summary of Randomized Controlled Trials Educational Interventions Studies in Renal Context

Author (Year)/ Country/ aim	Study Design, Sample Size and Settings	Intervention Nature and	Outcomes	Results	Comment
Perry et al. (2005) USA Aim: exploring the effect of peer mentoring on decision making and planning for EoL Journal: American Journal of Kidney Diseases	Study design: RCTs. Participants: 203 long term Haemodialysis patients. Setting: 21 dialysis centres across Michigan. Baseline survey and follow-up survey 2 to 4 months later.	 Group 1: individual face-to-face peer mentoring, and supportive phone calls (n=63) Group 2: Printed information on AD (n=59), "Advance directives: a guide for patients and family" Group 3: control (n=81), routine care providers in dialysis unit. Patients' characteristic not clear which stage and if patients on transplant waiting list. In addition, patients not yet have completed an AD. Intervention type: Peers were trained through an advance directive (AD) workshop and completed their own Ads. Eight contacts with patients over a two- to four-month period: three face to-face and five by phone. Discussion of chronic illness experiences, values, spirituality, fears, AD issues, and document. Peers showed their AD knowledge through pretesting and post testing and role- nlaving. 	 Completion of advanced directives (AD) Comfort with discussing AD. 	 Significantly, the group of peer mentors addressed Ads more confidently after the intervention and 35 percent finished an AD compared to others. There is a large race-interaction with the state of intervention. For example, following the peer mentor intervention, African Americans were most likely to complete an AD; peer feedback among white participants did not appear to have influence on completing AD. In reaction to peer mentoring, psychosocial outcomes such as health and anxiety were positive effects for African Americans. Conclusion: Common practise believes that written materials are successful in informing patients about healthcare and decision making. However, in some cultural groups peer mentoring may be more successful because it shares oral traditions rather than written ones, a person-to-person approach cantered on relationships. 	Include ESRD patients only as research participants.
Kirchhoff et al. (2012) USA Aim: To compere EoL treatment patient	Study design: RCTs, Post-test only control group design Participants: 313 participants their surrogates	Group 1: 153 participants in control group (64 with ESRD, 90 with CHF) expose to usual care. Group 2: 160 participants in intervention (70 with ESRD and 90 with CHF) with their family exposed to PC-ACP intervention.	 Patients' preferences compared to the care received at EoL determined by surrogate interviews or medical charts 	 Significantly, among ESRD patients, more- experimental patients (37.7%) opted to withdraw from dialysis than controls (17%) however; this was not addressed in the interview. 43.5 % of the intervention group had outcomes that suited their initial interests in CPR. About one-third (33/110) of patients 	Patients with ESRD risk or serious complication or death in the next 2 years, and

expectations with care provided at EoL. Journal: The American Geriatrics Society	Patient-surrogate recruited as pairs (not mentioned if family member). Settings: Two canters in Wisconsin (clinics and dialysis units).	Intervention type: 1-to-1.5-hour PC-ACP interview, delivered by a trained ACP facilitator to assess the patient and surrogate understanding of illness; provide information about treatment options, benefits, and burden; assist in documentation of treatment preferences; help prepare surrogates to make decisions that honour the patient's preferences; ending with the documentation of patient preferences for care using the Statement of Treatment Preferences (STP) form.	-	Patient preferences regarding whether to continue treatment in the case of low chance of survival or to attempt resuscitation.	changed their minds about their CPR preferences. Conclusion: In general, patients and their surrogates were prepared to meet with a professional facilitator to discuss preferences. Many patients received the treatment they preferred at the end of their lives, or adjusted their choices to be compatible with the care they might receive. More research needed for factors influencing the care decisions of EoL patients and tests the booster effect for the initial discussion, and a larger sample of decision-makers from surrogates is expected.	serious comorbidity Although Study not specific to ESRD patients, results were illustrated separately.
Song et al. (2009) USA Aim: determine the feasibility and acceptability of the SPIRIT with ESRD in African Americans their surrogate decision makers; assess preliminary effects of SPIRIT on surrogate patients and to determine the EoL decision- making of patient deaths and surrogates to test the understanding of SPIRIT advantages and drawbacks by surrogates.	 Study design: RCTs pre and post-test use surveys and semi- structured interviews. Participants: African Americans with ESRD and their chosen surrogate decision makers (N = 58 dyads) Pt. on dialysis at least 3 months prior enrolment. Setting: 6 outpatients dialysis centre in western Pennsylvania Measures obtained at three times baseline (T1), 1 week (T2) and 3months (T3). 	 Group 1: expose to Sharing Patients' Illness Representations to Increase Trust (SPIRIT) intervention. 1-hour duration single session interview which designed to enhance communication regarding end-of-life care for ESRD & their surrogates. Intervention provided by trained nurse. Group 2: exposed to usual care which is written information on advance directives and the patient's right to have an advance directive to every patient on the first day of dialysis treatment. Patients were encouraged patients to complete an advance directive and addressed their individual questions about life- sustaining treatment options. Usual care provided by social worker. 	-	Patient-surrogate congruence in goals of care Decisional Conflict Decision-Making Confidence Psychosocial- spiritual well-being Quality of patient- clinical communication about EoL care Feasibility and acceptability of survey and interview via telephone.	 Patient-surrogate congruence in goals of care was not significantly improve from baseline. The decision-making confidence of the Surrogates and the psychosocial-spiritual well-being of both patients and surrogates improved over time, but there were no variations on these indicators between the groups. Over time, decisional disagreement in the patient has not changed. No group's difference. The quality of communication scores for the intervention patients is significantly higher than for the T2 and T3 control group. Similarly, quality of communication ratings of intervention surrogates was substantially higher than the control group at T2 and T3. 	Include ESRD patients and their surrogates as research participants. Patients on different types of dialysis

Song et al. (2010) USAStudy design: RCTs (Pilot study).Gropp11 (n=11) exposed to 1-hour PC-ACP interview, delivered by a trained ACP facilitatorPatient's level of difficulty in making choices,-Include ESRD ommunication quality than control group.Aim: To determine the feasibility and acceptability and patient cantered alaning (PC-ACP) among African surrogate surrogateGroup 2: (n=8) exposed to usual care which is writh en information on advance directives provided by a nurse or social worker who encouraged patients to complete an AD and addressed their questions about life-sustaining treatment optionsPatient's level of difficulty in making choices,-Include ESRD indicated at the post-test that they would comprunce in folInclude ESRD about 2 (n=8) exposed to usual care which is written information on advance directives provided by a nurse or social worker who encouraged patients to complete an AD and addressed their questions about life-sustaining treatment optionsPatient same comprunce in fol. conserve to nurse all iffe-sustaining intervention groupInclude ESRD showed greater improvement in congruence, and higher perceived communication quality than control groupInclude ESRD intervention of group.Journal: Applied Nursing Research.Setting: diaysis centre-Freatomet Song and acceptability and acceptab	Journal: Research in nursing and health					 Most of the feedback about the intervention was positive. Conclusion: SPIRIT has been effective and well received for promoting interaction between African American dialysis patients and their chosen surrogates. A subsequent session can 	
Song et al. (2010) USAStudy design: RCTs (Pilot study).Gropu1: (n=11) exposed to 1-hour PC-ACP interview, delivered by a trained ACP facilitatorPatient's level of difficulty in making choices, 						help patients and their surrogates to draw up concrete plans to communicate patients 'wishes with others (e.g., other family members, spiritual counsellors and health care providers).	
improve patients and their surrogates	Song et al. (2010)SUSA(Aim: ToFdetermineAthe feasibility andAacceptability oftpatient canteredaadvance carerplanning (PC-ACP)among AfricanFAmericans andstheirasurrogateddecision makers.SJournal: Applied(Study design: RCTs (Pilot study). Participants: 19 African Americans with stage 5 CKD with their surrogates. On dialysis at least three months Patient and surrogates recruited as pairs. Setting: dialysis centre Measures obtained at three times baseline (T1), 1 week (T2)	 Gropu1: (n=11) exposed to 1-hour PC-ACP interview, delivered by a trained ACP facilitator. Group 2: (n=8) exposed to usual care which is written information on advance directives provided by a nurse or social worker who encouraged patients to complete an AD and addressed their questions about life-sustaining treatment options. Intervention type: PC-ACP interview Addressing: 1) representational assessment of participants' beliefs about their illness; 2) exploration of misunderstandings about CKD and life-sustaining treatment, including dialysis; 3) creation of conditions for conceptual change; 4) introduction of replacement information; and 5) summarization of the discussion. 	-	Patient's level of difficulty in making choices, Patient–surrogate congruence in EoL care preferences, Surrogate's level of comfort in decision making Psychospiritual well-being of patient and surrogate. Feasibility and acceptability via (tracking refusal reasons and complete entire study).	 In EoL treatment preferences, PC-ACP dyads showed greater improvement in congruence, and higher perceived communication quality than control group. 80 % of patients in the intervention group indicated at the post-test that they would choose to pursue all life-sustaining interventions in a situation of low survival risk. 90% of patients in the intervention group indicated at the post-test that they would choose to undergo cardiopulmonary resuscitation even if the likelihood of surviving the attempt is small other than control group. In decisional conflict, all groups before and after did not change. Both groups surrogate high confidence in DM, but the difference before and after the intervention is not significant. The will-being of patients and surrogates improves but no significant difference before and after intervention. 	Include ESRD patients and their surrogates as research participants. Patient stage 5 CKD on haemodialysis and peritoneal

			improve intervention in terms of culturally appropriate treatment for patients in African America.	
Song et al. (2015)Study designUSAParticipants: dyads of pre- dialysis patient their surroga Patients on co- for at least 6 charlson Cor 	a: RCTsGroup 1: (n=109) exposed to ACP psychoeducational intervention (SPIRIT) + usual care.valentusual care.valentGroup 2: (n=101) exposed to Usual care which is Written information for advance directives dialysisdialysiswas provided to every patient on the first day of dialysis, addressed questions about life- sustaining treatments.of 5 and on in the sIntervention type: SPIRIT intervention used to help patients clarify EOL preferences and prepare the surrogate for making excisions on the patient's behalf, and a follow-up session at home two weeks later, with completion of a "goals of care" document to indicate patient preferences and Ads. Facilitator adherence to protocol monitored. A trained nurse facilitator at the centreotained nent 2 weeks, ths after h.atrained nest sion at ks later.	 Preparedness outcomes dyad congruence using goal of care include 2 seniors. Patient decisional conflict Surrogate decision-making confidence Bereavement outcomes at 2 weeks, 3, 6, months after patient death were measured: symptoms of anxiety, depression, and posttraumatic distress. 	 Dyad congruence and surrogate decision-making confidence were higher in the intervention group, but the decision-making conflict between the patients was not significant. Conflict in decision of patients in SPIRIT group decreased over time and major overtime impact of intervention. Surrogates in intervention group showed less anxiety, depression and posttraumatic symptoms than other group. Conclusion: SPIRIT intervention has a positive impact on patient development and the preparation of EoL DM by their surrogates, as well as surrogate bereavement outcomes. Further research required the impact of SPIRIT being applied in clinical practise and ethnic group. 	Include ESRD patients and their surrogates as research participants. Patient DM included both patients on haemodialysis and peritoneal dialysis.
Courtright <i>et al.</i> Study design (2017) USA	a: RCTs Group 1: N= 127 expose to randomize standard choice set Group 2: N= 129 exposed to expand choice set.	 Completed and returned advance directive. 	 Though providing more options for Ads was not significantly associated with increased completion rates and the proportion of patients who wanted to complete an AD 	Include only patients as research participants.

Aim: effect of increasing the number of options for completing the Advance Directive among patients with serious illnesses. Evaluated the effect of extended choice sets on whether nationts said they	Participants: (N= 316) ESRD receiving haemodialysis Setting: 15 outpatients' dialysis centre in Philadelphia.	Intervention type: Intervention offered different forms of Ads. The standard choice set form included a dichotomous choice of "yes" or "no." The living will section of these 3 advance directives assessed treatment preferences in each of 4 ("brief"), 6 ("expanded"), or 8 ("comprehensive") clinical scenarios. All versions offered additional space for patients to clarify or expand on their preferences. The brief advance directive was used for the standard choice set group. The clinical scenarios described a spectrum of neurologic cognitive, and physical dizabilities	 Satisfaction with Decision score measured immediately following patients' decision using a standard or expanded choice set, Change in quality of life at 3 months. 	 and took one home among the groups is significantly increased. There was no difference in satisfaction between groups (P = 0.65) or improvement in quality of life (P = 0.63). A higher average quality of life was independently related to the completion of the advance directive (P = 0.006). Conclusion: While an expanded range of options can initially allow patients to complete advance guidelines without limiting their choice, actual completion can require additional steps to overcome downstream barriers. 	
complete an advance directive and, on the happiness, and quality of life of their decisions. Journal: Medical Decision Making					

Appendix 2B: Summary of Pre and Post-Test/Post-Test Educational Interventions Studies in Renal Context

Author (Year)/ Country/ aim	Study Design, Sample Size and Settings	Intervention Nature and	Outcomes	Results	Comment
Hing et al. (2016) Malaysia Aim: To determine the clinical effect of education on the determination of ACP decisions among ESRD patients about routine haemodialysis and to assess patient awareness/knowledge and attitude towards issues related to ACP and EoL. Journal: Indian Journal of Palliative care	Study design: cross- sectional study pre- and post-test. Participants: 56 ESRD on long term regular haemodialysis. Settings: University Malaya Medical centre and University Malaya Specialist centre.	Intervention type: Two real life ACP experience stories from the Canadian Hospice Palliative Care Association (CHPCA) online website used as educational brochure. During the dialysis session, patient pre-test questioner related to CPR and intubation was conducted then education brochure was given to read at home and post survey conducted at following dialysis session.	 ACP decisions, knowledge, and attitude of patients toward ACP and EoL issues. Use Lyon's ACP survey and Moss cardiopulmonary resuscitation (CPR) Attitude Survey Form. 	 Opinion regarding ACP value and planning such as CPR decisions outside dialysis, increased after exposure to the educational brochure, but this was not statistically significant. 75% of participants had never heard of ACP before, and only 3.6% had previously drafted an advanced written guideline. Conclusion: The ACP Educational Brochure scientifically influences the attitudes and actions of patients about EoL treatment; however, this is statistically not significant. More research needed for the creation of an ACP survey form specifically for the ESRD population and the inclusion of discussions on dialysis withdrawal. 	Include only patients as research participants. Muslim considered 69.6% of study population. It does not effect of the frequency of EoL dissuasion among participants.
Oarde (2017) USA Aim: To raise awareness about palliative care services among patients in an effort to improve their quality of care through education. Electronic Dissertation University of Arizona	Study design: A quantitative pre- and post-survey. Quality improvement project Participants: six participants (5 patients and 1 family member) ESRD and receiving HD Settings: outpatient haemodialysis clinic and DaVita Desert Dialysis in Sun City,	Intervention type: Professional educational intervention. Participants viewing of a three-minute voice over presentation about palliative care include palliative care use and purpose, benefits to patient, services provided by palliative care, how palliative care affects symptom management, who pays for it, and how to obtain palliative care services. list of available palliative care services in the Sun City area were given to the participants after the post- survey.	 Palliative care awareness, knowledge of availability Readiness for palliative care services. Explore if ESRD patients are knowledgeable about palliative care and if providing education might change their behaviour. 	 Results from the pre-survey showed that four participants did not know what palliative care was and one was not interested in using palliative care services and was aware of palliative care availability in their living area. Pot-survey 100% of the patient had better awareness and knowledge of palliative care. Five participants are interested in using palliative care, meaning they expect to use it now and five in the future, and 6 (100%) have a greater 	Include patients and one family member as research participants. Small sample size and geriatric population was studied in a research participant was from 71-80 years of age.

					understanding of what palliative care can do for them. Conclusion : Intervention shows that all participants had increased awareness, accessibility of information and preparation for palliative care services. Future of research to further generalize the effects and advantages of palliative care education and services for the < 60- year-old age group.	
Kapell Brown, Kryworuchko and Martin (2018) Canada Aim: To develop, test and evaluate a new CPR video decision aid (VDA) in a clinical setting for patients with ESRD and their families. Journal: BMC nephrology	 Study design: A prospective quasi- experimental design included pre/post-test. Survey and interview Participants: 260 patients stage 5/ ESRD on HD and their families 8 physicians to determine patient. Settings: outpatients and inpatients dialysis centre 	Intervention type: CPR-VDA is a seven-minute video. The video presents information about CPR and the alternative option (comfort care) as well as information about the patient experience and important health outcomes. CPR decision worksheet, which included a values clarification exercise, tailored the generic patient decision aid format to the CPR decision, and was completed with the study nurse questionnaire. Physicians discuss with patient and their families about CPR decision to assess whether they want or not in event of cardiac arrest. The study nurse asked patients their CPR preference after viewing the CPR- VDA and completing the values clarification worksheet.	-	Measures of knowledge and confidence in decision-making, Post-test only measure of uncertainty about the decision (decisional conflict). Relevance of CPR decision for the patient pre-and post-intervention. Self-confidence and self- efficacy physician caring for the patient discussed CPR with the patient and/or family member. Feasibility and acceptability vis survey, physician CPR discussion via quality of communication about CPR)	 Participants have expanded awareness about CPR following intervention. Decisional self-efficacy slightly improved from 84% pre- intervention to 86% post- intervention. Decisional conflict overall was lower and 36% of patients using SURE clinical test found that there was no definitive conflict. Before the intervention, most patients 43 out of 49 had a physician order to have CPR and very few 7 out of 49 had an order not to have CPR. Immediately after viewing the CPR- VDA and Completing the Worksheet on meaning clarity, less 28 out of 49 chose CPR, 13 chose not to have CPR and 8 were unsure. Acceptability and feasibility: After intervention CPR-VDA was important to them and finished it feasible and appropriate among patients, families and HCPs. In terms of relevance, amount of information, clear information, help 	Include patients, families, and HCPs as research participants

					in plan and recommended for other people as well as satisfaction with discussion. Conclusion: The CPR-VDA positively influenced decision making increasing patient and family awareness of CPR, consistency of principles, decision- making self-efficacy of patients, congruence between the instructions of reported physicians and the preference of patients, quality of contact about CPR, thus eliminating definitive tension between patients, families, and physicians.	
Amro et al. (2016) USA Aim: Improve patient autonomy and informed decision taking as calculated by the completion rate of the MOLST type, define patient expectations for life-sustaining treatment options and explain the status of the code. Journal: American Journal of Kidney Diseases	Study design: pre-and post-intervention code status. Quality improvement project. Participants: 201 patients with ESRD receiving Haemodialysis And 9 Nephrologists caring dialysis patients. Setting: 2 outpatient dialysis facilities and Dialysis Clinic, Boston and St Elizabeth's Medical Centre, Boston,	Intervention type: Patients identified with a "no" response to the surprise question were invited to participate in nephrologist-facilitated advance care planning, including completion of MOLST form. HCPs training included the conduct of mock interviews with patients and families addressing goals of care and EoL care issues. A separate training session on the elements of the MOLST form and its use was conducted. Patient and their families invited to dedicated face-to-face encounter lasted 15-60 minutes. Patients and their HCPs complete the MOLST form and each one has copy. Moreover, patients' code status assessed pre-and post-intervention.	-	Change in Medical Orders for Life- Sustaining Treatment (MOLST) completion rate. Identification of preferences for limits on life-sustaining treatment.	 Nephrologists answered "no" to the surprise query for patients with haemodialysis in 50 of 201 (25%). Of these, 82% of patients were in full-code status, and 18% were in do – not-resuscitate (DNR). After the experience, 42% of patients favoured DNR status and 58% retained full-code status. The completion rate of MOLST increased from 10% to 90%. For patients whose nephrologists replied "no" to the surprise question, one-year survival was 58% compared to 92% for those with a "yes" response (P < 0.001). 12-month follow-up 39 patients has died. Conclusion: The intervention resulted in significant changes in reported perceptions of patients with CPR and life-sustaining therapy limitations that show the value of dialysis ACP patients 	Include patients and HCPs as research participants. The HCPs only facilitate participate in the project, but the face-to-face ACP encounter outcomes focused on patients.

				and are likely to reflect a better understanding of treatment options for EoL. Further studies are needed to assess the feasibility of applying such a programme on a wider scale, in various populations and patient settings.	
Bristowe et al. (2014) UK Aim: Describes the development, piloting, and early evaluation of the Renal Specific Advanced Communication Training (REACT) programme for improving ACP discussions for all ESKD patients. Journal: Palliative Medicine	 Study design: Pre and post intervention (pilot study) Participants: 16 participants (9 renal nurses/health-care assistants and 7 renal consultants). Settings: 2 large renal units in London Teaching hospital. 	Intervention type: The Renal specific Advanced Communication Training program one full-day session and two half-day follow-up sessions.	 Communication skills and confidence Acceptability of program 	 The unique Advanced Communication Training programme developed by Renal was appropriate and feasible. Non-significant increase in confidence in communicating about EoL issues and continued at 3 months. Confidence gains slightly, providing information on efficacy treatment and discussion of death and dying between pre-training and at 3 months but not statistically significant. Qualitative feedback on the RACT program with recommendations for full trial. Conclusion: EoL treatment needs to be improved for patients with ESRD, so that they can make informed decisions about future care. The challenges include giving priority to training between service providers in communications. 	Include only HCPs as research participants
Cohen et al. (2016) Boston, USA Aim: Assessed the effectiveness of an intervention to improve	Study design: Prospective, single-group, longitudinal survey study includes open-ended Q. mixed methods. Per and	Intervention type: The Harvard Nephrology Fellows' Communication Workshop. Full-day annual workshops using didactics, discussion, and practice with simulated patients. Content focused on delivering bad	 Communication skills changes in self-reported patient communication skills, attitudes, and behaviours 	 Response rates were 100% (pre- and post-surveys) and 68% (follow- up). Participants registered improvement in all domains, with a mean overall increase of 1.1 	Include only HCPs as research participants

the quality of education designed to improve communication between fellows and patients with advanced kidney diseases. Journal: American Journal of Kidney Diseases	post workshop& after 3- month follow up Participants : (N=26) first- year nephrology fellows Settings : 2 Harvard- affiliated training programs. Measures obtained at 3 time; pre-workshop T1; post-workshop T2 and 3 months following up T3.	news, acknowledging emotion, discussing care goals in dialysis decision making when prognosis is uncertain and addressing dialysis therapy withdrawal and end of life.		 (summed average scores: pre- course, 2.8; post-course, 3.9 [1-5 scale; 5 = "highly well prepared"]; P < 0.001), with 3 months progress maintained. Participants reported meaningful changes that put specific skills they learned into practise, such as "Ask- Tell-Ask" and use open-ended questions. Conclusion: the intervention can enhance Fellows' self-reported skills and practices. 	
Schell et al. (2013) USA, North Carolina Aim: Describes NephroTalk's design, material, and assessment, a communication skills workshop built to assist nephrology fellows with difficult dialogues regarding beginning and forgoing dialysis. Journal: Clinical Journal of the American Society of Nephrology	Study design: pre-and post-workshop surveys Participants: (n=22) nephrology fellows Setting: Duke University and the University of Pittsburgh	Intervention type: NephroTalk designed as a half-day 4 h workshop. Include didactics and practice sessions with standardized patients. It is focused on delivering bad news and helping patients define care goals, including end-of-life preferences.	 Baseline assessment of communication teaching. Received in the past; process measures, including learner satisfaction; and outcome measures of perceived preparedness 	 Prior palliative care training reported by less than one-third (6 out of 22). 8 out of 22 participants received structured training for initiating or withdrawing from dialysis discussions. 100% of participants felt that communication skills were important to being a great nephrologist. The level of preparedness for all skills was significantly increased, including giving bad news, showing empathy and debating initiation and removal of dialysis. All participants reported they would recommend this training too their fellows. Conclusion: NephroTalk training is successful in increasing the ability of nephrology fellows to have complex 	Include only HCPs as research participants. Generalizability was limited by the small sample size. The lack of control group also limited its validity.

Gross (2015) USAStudy design: Plan, Study, Do, Act (PDSA) project.Intervention type: A process for the successful implementation of the POLST program. Educated patient and their families' about POLST program. Educating the dialysis staff about the benefits of the POLST program along with training the appropriate stakeholdersMake a dialysis patient more suitable for a POLST conversationEducating the dialysis workers about the benefits of the POLST system was completed along with HCPs as required to implement the POLST programme successfully.Include patient families, a their families' about POLST program. Educating the dialysis staff about the benefits of the POLST program along with training the appropriate stakeholdersMake a dialysis patient more suitable for a POLST conversationEducating the dialysis workers about the benefits of the POLST programme successfully.Include patient families, a the's required to implement the POLST programme successfully.Life-Sustaining Treatments (POLST)Patting: Dialysis centreDialysis centreUse educational sessions and handouts 14 hours of training, sixMake a dialysis patient more suitable for a POLST conversationEducating the dialysis workers about the benefits of the POLST programme successfullyInclude patient about the benefits of the POLST programme successfully.Use educational sessions and handouts 14 hours of training, sixInclude patients suitable for a POLST mightEducating the dialysis workers onversationDialysis staffUse educational sessions and handouts 14 hours of training, six-Development of con					discussions about DM dialysis and EoL care.	
Doctoral dissertation online hours, and Eight class hours, about how to have a POLST Bemidji dialysis centre are still being introduced. provided feedback the POLST State University was provided with a booklet of information that included practice material for the conversations along with handouts that could be used to help guide conversations. introduced. the POLST education Educational handouts purchased from the Respecting Choices Model were provided to. Dialysis patients and their families. The handouts were provided to patients during and after their dialysis treatments. The handouts program and its benefits. Patients received the handout without organized face-to- face or group education. Dialysis staff offered information regarding discussions between staff and patients that revealed patients were knowledgeable about POLST. Her Sepecting Choices Intervent	Gross (2015) USA Aim: to plan, develop and implement of Provider Orders for Life-Sustaining Treatments (POLST) Doctoral dissertation study North Dakota State University	Study design: Plan, Study, Do, Act (PDSA) project. Participants: ESRD Patient and dialysis staff Setting: Dialysis centre	 Intervention type: A process for the successful implementation of the POLST program. Educated patient and their families' about POLST program. Educating the dialysis staff about the benefits of the POLST program along with training the appropriate stakeholders Use educational sessions and handouts 14 hours of training, six online hours, and Eight class hours, about how to have a POLST conversation. Each trained facilitator was provided with a booklet of information that included practice material for the conversations along with handouts that could be used to help guide conversations. Educational handouts purchased from the Respecting Choices Model were provided to. Dialysis patients and their families. The handouts were provided to patients during and after their dialysis treatments. The handouts included information about the POLST program and its benefits. Patients received the handout without organized face-toface or group education. Dialysis staff offered information regarding discussions between staff and patients that revealed patients were knowledgeable about POLST. 	Make a dialysis patient more suitable for a POLST conversation. The screening tool was used as a guide for staff members consider certain measures that might.	 Educating the dialysis workers about the benefits of the POLST system was completed along with educating the stakeholders required to implement the POLST programme successfully. Development of a POLST-process flow chart to fit the Bemidji dialysis unit was successfully completed. Conclusion: POLST discussions at the Bemidji dialysis centre are still being introduced. 	Include patient, families, and HCPs as research participants. Did not use an objective design. Dialysis staff and patients provided verbal feedback about the POLST program for educational sessions

Corbett (2017) USA Aim: To enhancing nephrology providers' knowledge of the Renal Physician Association guidelines on Shared Decision Making in the Appropriate Initiation of and Withdrawal from Dialysis to increase advance care planning and palliative care referral to improve the quality of life of renal patients. Doctoral Study University of Missouri- Kansas City	Study design: The project was an evidence- based quality improvement initiative, Participants: 13 nephrology providers and nurses received the educational intervention. Work at nephrology practices. Settings: medical centres' nephrology practices in the Midwest	Intervention type: Evidence Based Practice Intervention (EBQI) project intervention involved educating nephrology providers and nurses of the guidelines supporting shared decision-making, ACP, and appropriate palliative care referral. Through literature review and presentation, the SI imparted the importance of the project to the participants. Interventional sessions started with introductions, verbal consent, and a discussion of the EBQI project including pre-intervention data. A review of the RPA guidelines and discussion and ACP tools were introduced as a resource. Participants were provided handouts regarding ACP as well as a copy of the guidelines. Additionally, a pocket card was provided as a resource tool.	 Number of palliative care referrals for patients with CKD Stage 4 and 5 over a four-month span of time. Post-intervention, compared to the number of referrals over a sixmonth span of time pre-intervention. Number of ACPs completed during the same timeframe. 	 Palliative care referrals and 22 ACP from a baseline of zero / unknown over four months. Palliative care provides relief of the symptoms associated with renal disease and other chronic conditions, ensuring relaxation and improved QoL for patients. Post-intervention ACP completions in the outpatient setting totalled 19 (21 including those referred to as palliative care), conducted mainly through the NPs of the practices. Conclusion: palliative care provides relief for the effects of kidney disease and other chronic conditions, providing comfort and improved QoL for patients, reducing the burden on families, nursing staff and the health care system. 	Include only HCPs as research participants. Nurses caring for patients in the chronic dialysis setting were excluded, focusing instead on advanced CKD in the outpatient setting.
García-Llana <i>et al.</i> (2017) Spain Aim: To CoBiT design, content and pilot testing, a communication skills workshop built to assist ACKD Unit workers in difficult discussions about beginning and selecting dialysis choices or a conservative renal pathway.	Study design: pre- and post-test, (pilot study) Participants: 36 HCPs Setting: Advanced Chronic Kidney Disease (ACKD) unit, Spain	Intervention type: Program one-day intensive course, divided into two sessions during one intensive training day. 8-h workshop based on role- playing methodology	 Self confidence in communication and bioethical issues regarding the shared decision-making process for treatment options Self-reported questionnaires and satisfaction-related measures and teamwork difficulties 	 CoBiT's Communication and Bioethical Learning program strengthens the self-confidence of ACKD Unit healthcare professionals in their ability to perform a particular communication function. Significantly improve after the workshop Conclusion: Future studies are needed to examine the effectiveness of this program in a larger population and to review outcomes based on formal correlates of patient care or real clinical observations	Include only HCPs as research participants. Lack of randomization and control group limited the validity and reliability of the study findings.

Simpson (2017) Study design: quality improvement project, quantitative pertest, post-test approach Intervention type: e-learning module. Educational presentation was presented in a didactic style with multiple checkpoint choice questions throughout the presentation. The presentation also included reference to information relating to the Shared End-Stage Renal Patients – Decision Making (SHERPA-DM) tool. - Staff knowledge and awareness, comprehension, and importance of 33%, 67% and 78% of participants to clinical practice respectively. Include only HCPs as outstanding", resulted in awareness, comprehension, and importance of 33%, 67% and 78% of participants to clinical practice respectively. Include only HCPs as outstanding", resulted in awareness, comprehension, and importance of 33%, 67% and 78% of participants agreed on the post-surve related to the SHERPA-DM tool and 22 percent agreed strongly that learning about the SHERPA-DM tool and 22 percent agreed strongly that learning about the SHERPA-DM tool and 22 percent agreed strongly that learning about the internal validity. - A needs assessment was conducted - The cause and effect could not be clearly established which limited the internal validity. Dissertation Doctoral study Walden university - A needs assessment was conducted - The knowledge and awareness of clinicians about patient involvement increased from an average post-test score of 6.22 (78%). - Their understanding of patient involvement increased and 44%	Journal: Psychology, health & medicine					
agreed strongly that thinking about patient engagement would benefit their clinical practice. - 78% of participants agreed that the presentation would be helpful to other physicians in learning about patient participation. - Conclusion: The e-learning platform will bring positive social change as the staff of the renal program and the students learn about their clinical practice and adopt patient engagement principles.	Simpson (2017) Canada Aim: Increase patient knowledge and awareness among clinicians working with CKD Patients. Dissertation Doctoral study Walden university	 Study design: quality improvement project, quantitative pertest, post-test approach Participants: 9 clinicians work with CKD patients. Setting: community Hospital in Ontario 	Intervention type: e- learning module. Educational presentation was presented in a didactic style with multiple checkpoint choice questions throughout the presentation. The presentation also included reference to information relating to the Shared End-Stage Renal Patients – Decision Making (SHERPA-DM) tool. - A needs assessment was conducted	- Staff knowledge and awareness about patient engagement in decision making	 Pre-survey ratings of perceptions of participants as "very strong and outstanding" resulted in awareness, comprehension, and importance of 33%, 67% and 78% of participants to clinical practice respectively. 33% of the participants agreed on the post-survey related to the SHERPA-DM tool and 22 percent agreed strongly that learning about the SHERPA-DM tool strengthened their patient engagement knowledge and awareness. The knowledge and awareness of clinicians about patient participation increased from an average pertest score of 5.22 (65%) to an average post-test score of 6.22 (78%). Their understanding of patient involvement increased by 78 %. 44% of participants agreed and 44% agreed strongly that thinking about patient engagement would benefit their clinical practice. 78% of participants agreed that the presentation would be helpful to other physicians in learning about patient participation. 	Include only HCPs as research participants. The cause and effect could not be clearly established which limited the internal validity. Generalizability was limited by small sample size.

Appendix 2C: Summary of Qualitative Educational Interventions Studies in Renal Context

Author (Year)/ Country/ aim	Sample Size	Study Design	Results	Comment
Song, Metzger and Ward (2017) USA Aim: Explore the experiences of dialysis patients 'bereaved surrogates on the mechanism and effect of ACP intervention and compare the perceived impacts of African American- White intervention. Journal: Palliative medicine	24 bereaved surrogates. Both patients and surrogates had been participants in a larger efficacy study and had received an advance care planning intervention, SPIRIT (Sharing Patient's Illness Representations to Increase Trust).	Qualitative interviews	 Results: Two themes related to the process of SPIRIT were as follows: (1) SPIRIT offered a timely opportunity to reflect on and discuss issues which were avoided and (2) SPIRIT helped patients and surrogates to share their feelings. Four themes of the SPIRIT's impact were as follows: (1) SPIRIT was an eye-opening experience, acquiring knowledge and understanding of the patient's illness and end-of-life care, (2) SPIRIT helped strengthen relationships between patients and surrogates, (3) SPIRIT helped surrogates feel prepared during the time leading up to end-of-life decision-making, (4) SPIRIT helped surrogates have peace of mind during and after actual end-of-life decision-making. Conclusion: Themes linked to the influence of SPIRIT on feeling prepared for end-of-life decision-making and the actual experience of decision-making emerged more frequently in African Americans than in Whites. The results of surrogates in SPIRIT and in a control, group should be contrasted with future studies. Yet our study helps explain how SPIRIT has produced positive results for surrogates and racial differences in SPIRIT's effect. 	Exhibited internal validity and reliability. The study findings were generalizable

	Criteria													_	Includ ed / exclud ed
Include d studies / year	 Was true randomiz ation used for assignme nt of participa nts to treatmen t groups? 	2- Was allocat ion to groups concea led?	3- Were treatme nt groups similar at the baseline ?	4- Were particip ants blind to treatm ent assign ment?	5- Were those deliveri ng treatm ent blind to treatm ent assign ment?	6- Were outcome s assessors blind to treatmen t assignme nt?	7- Were treatme nt groups treated identicall y other than the intervent ion of interest?	8- Was follow up compl ete and if not, were differe nces betwe en groups in terms of their follow up adequ ately descri bed and analys ed?	9- Were participa nts analysed in the groups to which they were randomiz ed?	10- Were outcome s measure d in the same way for treatme nt groups?	11- Were outco mes measur ed in a reliabl e way?	12- Was appropri ate statistic al analysis used?	13- Was the trial design appropri ate for the topic and any deviatio ns from the standard RCT design account ed for in the conduct and analysis ?	Tot	reason
Kirchho ff <i>et al.</i> (2012) USA	Yes, participants were randomly assigned into two groups. Stratified according to setting and disease.	Yes, Used sealed- enveloped method	Yes, both group compara ble	Yes. Used sealed- enveloped method	Yes, interviewers were blinded to group to determined treatment patient receive.	Yes, two blinded reviewer s reviewed the data	No,	Not applicable	Yes, 23 participa nts not complete study and 2 die before complete interventi on	Yes	Yes	Yes	Yes	11/ 13	The study met the inclusi on criteria given that it was

Appendix 3: Joanna Briggs Institute Critical Appraisal Checklist of Included Studies. Appendix 3A: Joanna Briggs Institute Critical Appraisal Checklist or Included Studies Randomized Controlled Trials

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															primar y researc h study. Based on the apprais al, the article was of high quality
Perry <i>et al.</i> (2005) USA	Yes, participants were randomly assigned into three groups.	No, there is no evidence of concealmen t in the study	Yes, both group compara ble	Yes	Yes, social worker conducts interviews for all patients regardless to randomize study assignment	Yes	No, in one unit participa nt was assigned to two group only because the peer mentor was ill.	Νο	Yes, 34 not complete the study because change in clinical status, 25 hospital admissio n/ death, 6 kidney transplan t and 3 transfer to different dialysis centre.	Yes, other study related intervent ion was not planned	Yes	Yes	No	9/1 3	It was include d becaus e it met the inclusi on criteria . The study howev er had biases that might have impact ed on the outco mes
Song et al. (2009) USA	Yes, participants were randomly assigned into two groups. Stratified according to type of dialysis.	Yes, used permuted block randomizati on	Yes, both group compara ble	Yes, use sequential, opaque, and numbered enveloped	Yes, third party was involved in assessing the participant	Yes, data collector s were blinded to group assignme nt	No	No	Yes, 11% attrition drop and death. (1 surrogate at T2, 2 patients and 2	Yes	Yes	Yes	Yes	11/ 13	It was include d becaus e it was a primar y researc h

									surrogate s at T3)						article and it scored highly followi ng critical apprais al
Song <i>et</i> <i>al.</i> (2010) USA	Yes, participants were randomly assigned into two groups. Stratified according to type of dialysis.	Yes, used permuted block randomizati on	Yes, both group compara ble	Yes,	Yes	Yes	Νο	Νο	Yes	Yes	Yes	Yes	Yes	11/ 13	It met the inclusi on criteria , was a primar y researc h article and it had high validity and reliabili ty
Song et al. (2015) USA	Yes, participants were randomly assigned into two groups. Stratified according to type of dialysis, dialysis centre and race (African American and white).	Yes, used permuted block	Yes, both group compara ble	Yes, use sequential, opaque, and numbered enveloped	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	13/ 13	It met the inclusi on criteria and scored highly in the critical apprais al.
Courtri ght et	Yes, participants	Yes, used electronic	Yes, both group	Yes	Yes, the researcher was blinded	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	13/ 13	It met the inclusi

al.	were randomly	number	compara	to group					on
(2017)	assigned.	generation.	ble	assignment					criteria
USA									and
									scored
									highly
									in the
									critical
									apprais
									al.

Adopted from: Tufanaru C. et al. (2020).

	Criteria											Included / excluded reason
Included studies / year	1- Is it clear in the study what is the 'cause' and what is the 'effect' (i.e. there is no confusio n about which variable comes first)?	2- Were the participants included in any comparison s similar?	3- Were the participants included in any comparisons receiving similar treatment/care , other than the exposure or intervention of interest?	4- Was there a contro I group?	5-	Were there multiple measurements of the outcome both pre and post the intervention/exposure ?	6- Was follow up complete and if not, were differences between groups in terms of their follow up adequatel y described and analysed?	7- Were the outcomes of participants included in any comparison s measured in the same way?	8- Were outco measu d in a reliabl way?	9- Was appropriat re estatistical analysis e used?	Tota	
Hing <i>et al.</i> (2016) Malaysia	Yes	Yes	Yes	Yes	Yes		Not applicable	Not applicable	Yes	Yes	7/9	Though it scored highly in the critical appraisal checklist.
Oarde (2017) USA	Yes	Yes	No	No, not separated group, use the same group	Yes		Not applicable	Not applicable	Yes	Yes	5/9	It met the inclusion criteria.
Kapell Brown, Kryworuchk o and Martin (2018) Canada	Yes	Yes	No	No, not separated group, use the same group	Yes		Not applicable	Not applicable	Yes	Yes	5/9	It met the inclusion criteria.

Appendix 3B. Joanna Briggs Institute Critical Appraisal Checklist for Included Studies (Pre and Post-Test Studies) Quasi-Experimental Studies

Amro <i>et al.</i> (2016) USA	Yes	Yes	Yes	Νο	Yes	Yes, 12- month follow-up.	Yes	Yes	Yes	8/9	Scored highly following critical appraisal, met the inclusion criteria, and exhibited internal validity and reliability
Bristowe <i>et</i> <i>al.</i> (2014) UK	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	8/9	It met the inclusion criteria. Scored highly following appraisal.
Cohen <i>et al.</i> (2016) Boston, USA	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	8/9	It met the inclusion criteria. Scored highly following appraisal.
Schell <i>et al.</i> (2013) USA	Yes	No	Yes	No	Yes	Yes	Yes	Yes	Yes	7/9	It met the inclusion criteria.
Gross (2015) USA	Yes	Yes	Yes	Νο	Yes	No	Yes	Νο	Νο	5/9	The evaluation method used was ineffectua l in measuring the success of education. The study did not use an

											objective design such as survey or pre- and post-test.
Corbett (2017) USA	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	8/9	It met the inclusion criteria, and was a high- quality study
García-Llana <i>et al.</i> (2017) Spain	Yes	No	Yes	No	Yes	Not applicable	Yes	Yes	Yes	7/9	Met the inclusion criteria
Simpson (2017) Canada	No	Yes	Yes	No	Yes	Not applicable	Yes	Yes	Yes	6/9	Met the inclusion criteria
Schell <i>et al.</i> (2018) USA	Yes	No	Yes	No	Yes	Yes	Yes	Yes	Yes	7/9	It met the inclusion criteria.

Adopted from: Tufanaru C. et al. (2020).

Appendix 3C. Joanna Briggs Institute Critical Appraisal Checklist for Included Studies (Qualitative Studies)

	Criteria											Included / excluded reason
Include d studies / year	1- Is there congruity between the stated philosophical perspective and the research methodolog y?	2- Is there congruity between the research methodolog y and the research question or objectives?	3- Is there congruity between the research methodolo gy and the methods used to collect data?	4- Is there congruity between the research methodolog y and the representati on and analysis of data?	5- Is there congruity between the research methodolog y and the interpretati on of results?	6- Is there a statement locating the researcher culturally or theoretically ?	7- Is the influence of the researche r on the research, and vice- versa, addressed ?	8- Are participant s, and their voices, adequately represente d?	9- Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriat e body?	10- Do the conclusions drawn in the research report flow from the analysis, or interpretatio n, of the data?	Tota I	
Song, Metzge r and Ward (2017) USA	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	9/10	Met the inclusion criteria. Considere d to be high quality document

Adopted from: Lockwood C. et al. (2020).

Appendix 4: Details of the Educational Interventions in Scoping Review

Study	Purpose/focus	Intervention description	Mode of delivery	Tools used
Study Perry <i>et al.</i> (2005) USA	Purpose/focus End of life decision and end of life planning particularly Advance directives (Ads)	Intervention descriptionPeer to peer mentor intervention: Patients were contacted by the trained mentors in 5 telephone calls and 3 face-to-face meetings, to discuss the value of completing an AD and to assist with the process (such as discussing any concerns or worry the patient may have).Patients were provided with an article, which was discussed with peer mentor. Content involved: 1. Introduce peer mentor program and provide a handout to be discussed at next meeting.2. Peer asked about the value of the article and spoke personally about how chronic illness affected their life.3. A discussion about what has made life worth living since illness, shifting focus and goals outside of kidney failure.4. Addressed what gave the patient and the peer strength during hard times, touching on spiritual orientation and discussing spiritual fears.5. The peer shared their AD and EOL considerations and initial barriers to doing AD. A blank AD was offered to patients.6. The patient and peer discussed the value of contributing to others, ways the peer and patient contributed to others in life, and how an AD was a contribution to others.7. No structured contact and patient chose topic to foster independence.	Mode of delivery Delivered by trained patient as peer mentors. Video (25 min five wishes videotape on Ads development) and Mentor facilitated. Mode: Peer mentors	Survey for psychological measures include depression, well-beings, death acceptance, anxiety, and suicidal thinking. Hopkins Symptoms Checklists; Diener Scale.
		8. To share the peer's written observations of the patient's strengths, and the peer offered to be available to patient after study Participants also watched a video highlighting the need for support at Fol.		
Hing <i>et al.</i> (2016)	ACP decision	Two real life ACP experience stories from the Canadian Hospice Palliative Care Association (CHPCA) online website were used as educational brochure.	Delivered by the researcher.	Lyon's ACP Survey Form Patient Version in combination with Moss cardiopulmonary resuscitation
Malaysia		 Patients provided with the pertest survey form and were encouraged to answer on the spot; during dialysis session is four h/ in home in addition to demographic data. After survey completion the educational brochure introduced, and pt. has 2 days to read the brochure. Post-tests complete at the next dialysis session. 	Mode: Online education Brochure	(CPR) Attitude Survey Form.
Oarde (2017) USA	Palliative care knowledge/ quality of care	Educational intervention was the viewing of a three-minute voice over presentation about palliative care on an electronic laptop connected to Wi-Fi.	Delivered by the researcher.	Questionnaire was adopted was from the study of Hirai et al. (2011) which measured palliative
		 Survey and education presentation were played to the patient or taken on their own depending on their preference. Palliative care education included use and purpose, benefits to patient, services provided by palliative care, how palliative care affects symptom management, who pays for it, and how to obtain palliative care services. The Survey and educational intervention were administered individually due to patient placement in the clinic (chairs alongside HD machine), and to provide and protect everyone's privacy. A list of available palliative care services in the Sun City area were given to the participants after the post survey. 	Mode: Three-minute voice over presentation about palliative care.	care awareness, knowledge of availability, and readiness for palliative care services in cancer patients
--	---	--	--	--
Kapell Brown, Kryworuchko and Martin (2018) Canada	SDM of CPR Confidence and knowledge in DM	 CPR-VDA is a seven-minute video, view on a portable screen. The video presents information about CPR and the alternative option (comfort care) as well as information about the patient experience and important health outcomes. CPR decision worksheet, which included a values clarification exercise, tailored the generic patient decision aid format to the CPR decision, and was completed with the study nurse questionnaire. The study nurse asked patients their CPR preference after viewing the CPR-VDA and completing the values clarification worksheet. Patient and families (pre- and post-test). Physician's post-test survey (completed after engaging in each discussion about CPR: Decisional Conflict Scale). Medical record of participating patient, at enrolment (consent) and 1 week from date of enrolment, Chart Abstraction Tool (co-morbid illnesses, the presence of 'Goals of Care' orders, 'DNR' orders, 'Resuscitation Care-plan' orders and any order related to CPR) 	Delivered by researcher nurse. Mode : seven-minute video adapted from pervious study (plane language script)	Interview and survey Decisional self-efficacy Decisional conflict Decisional conflict was also measured for patients using the clinical SURE test on the values clarification worksheet. Physician discussed the CPR decision with the patient and/or family member with variable quality of patient involvement as assessed using OPTION
Amro <i>et al.</i> (2016) USA	ACP and End of life care	 Dedicated face-to-face encounter focusing on ACP conducted by a nephrology fellow. Information about the MOLST form was provided during the patient encounter. The teach-back technique was used to clarify what physicians and patients understood at the end of each encounter. This was achieved by asking patients to explain in their own words what had been discussed. Following completion of the MOLST form by the patient and his or her physician, the original document was given to the patient and a copy was placed in the dialysis facility's medical record, along with a written documentation of the discussion. Brief discussion was carried out with the patient's physician at that facility to communicate any wishes in the patient's code status following the dedicated clinical encounter. 	Delivered by research as well as nephrologist. Mode: Dedicated face- to-face encounter interview.	MOLST form completion

Bristowe <i>et</i> <i>al.</i> (2014) UK	Communication skills and Confidence	 Two stages: 1) Development of REACT program through multi-professional focus group to identify training needs for renal staff regarding ACP discussion and patient survey regarding improve communication concern, treatment plan and decision. Development the program using PREPARED model (guidance to preparing and managing discussion) include different sessions. 2) piloting the REACT program 	Mode: Training (REACT) program one full-day session and two half-day follow-up sessions.	Confidence questionnaire adapted from oncology
Cohen <i>et al.</i> (2016) Boston, USA	Communication skills	 Full-day annual workshops using didactics, discussion, and practice with simulated patients. Content focused on delivering bad news, acknowledging emotion, discussing care goals in dialysis decision making when prognosis is uncertain and addressing dialysis therapy withdrawal and end of life. The Harvard Nephrology Fellows' Communication Workshop. Learning involved large-group sessions (all fellows) for course introduction, didactics, and observed interview with an invited patient, and course conclusion. Small-group sessions (6-7 fellows) focused on skills practice with simulated patients in a supportive safe environment, enabling individual practice and feedback.19 3 dietetic sessions with the skills and communication framework for patients and the case discussed (skills to discussing bad news, Exploring Patient's Goals and Making a Recommendation About Dialysis and Discussing Dialysis Withdrawal and End of Life). 	Mode: Training workshops	Survey
Schell <i>et al.</i> (2013) USA, North Carolina	Communication skills	 NephroTalk: a half-day 4 h workshop the goal of the workshop was to increase fellows' preparedness in having difficult conversations surrounding end-of-life kidney care. Include two communication scenarios: Delivering Bad news participants introduce to two communication skills: giving information using an Ask-Tell-Ask model and responding to emotion using the NURSE acronym to give information and responding to a patient's emotion then practice this session on simulated patient. Defining goal of care: encouraged to use open-ended "big picture" questions to better understand the patient is functioning before the clinical decline and to assess what the patient or family hoped for in the future after that nephrologist could offer a treatment recommendation based on the patient's goals and preferences. Fellows were then introduced to a third communication skill for addressing unrealistic goals using "wish" statements. 	Mode: Training workshops	survey

García-Llana <i>et al.</i> (2017) Spain	Communication skills	 Training sessions begin with a brief theoretical framework on the 'how-to' perform and every didactic unit finishes with a role-play, presenting an opportunity for participants to practice with a focus on observation and feedback. Project steps: Development the program; interdisciplinary focus group to identify training needs for renal staff. Creation of measurement 10 items regarding SDM process; communication skills and bioethical procedures. Creation of program aim to improve the communication skills of renal health professionals to support people at ACKD units in making informed choices about their future care. Piloting program 	Mode : Training program (workshop) include 8 sessions (print the program)	Self confidence in communication Self-reported questionnaires and satisfaction-related measures and teamwork difficulties
Simpson (2017)	Improvement Patient engagement in	Quality improvement project. Needs assessment was conducted using Lewin's force field analysis (LFFA) to facilitate in developing the e-learning module.	Mode: e-learning module	Survey adapted from the program or
Canada	DM	 The educational presentation was developed and adapted from previous CKD/nephrology educational materials, articles and journals from literature search, and support from experts within the CKD/nephrology program within the community hospital. The educational presentation was presented in a didactic style with multiple check point choice questions throughout the presentation. The presentation also included reference to information relating to the SHERPA-DM tool. The educational presentation was a 30 presentation, with a five-minute questionnaire pre survey prior to the beginning of the presentation and a five-minute questionnaire post survey at the end of the presentation. 		Hospital's previous educational evaluation surveys and based on resource(s) that taught how to develop survey questions (Taylor- Powell & Renner, 2009).
Corbett (2017)	Palliative care knowledge and	Evidence based Quality initiatives; The EBQI project intervention involved educating nephrology providers and nurses of the guidelines supporting shared decision-	Mode: Printed materials	Survey The demographic survey from the nephrology providers
USA	number of ACPs completed.	making, ACP, and appropriate palliative care referral. This EBQI project supported the research recommendations in educating nephrology providers on the RPA (2010) guidelines with the result of improved renal patient QOL. Participants were provided handouts regarding ACP as well as a copy of the guidelines. Additionally, a pocket card was provided as a resource tool. The dependent variable was the increased number of ACPs and palliative care referrals over four months from baseline data.		practice years, awareness of the guidelines, and use of the guidelines.
Kirchhoff et	Pt. preferences at	The PC-ACP is an interview with the patient and a surrogate conducted by a trained	Delivered by clinical	Demographic data, functional
al. (2012)	EoL care	facilitator and lasting 1-to1.5 hours. It designed to assess patient and surrogate	staff who trained by	status (activities of daily living
		understanding of and experiences with the illness, provide information about	researcher (content-	(ADLs) and instrumental activities
USA		disease-specific treatment options and their benefits and burden, assist in	techniques- delivery od	of daily living (IADLs)), and

		documentation of patient treatment preferences, and assist the surrogate in understanding the patient's preferences and prepare surrogates to make decisions that honour those preferences.	intervention). They receive reading materials, classes with return demonstration	presence of advance directives (Ads). Statement of Treatment
		The interview is organized by five stages:	and videotaping and evaluation feedback.	Preferences (STP).
		 Assessment of the patient's understanding of his or her current medical condition, prognosis, and potential future medical events Exploring misconceptions about future medical decision-making Reviewing the rationale for future medical decisions. Helping the patient understand potential complications and possible future treatment decisions using the STP (the facilitator may introduce replacement information to correct misconceptions) Facilitator summarization of the conclusions reached the need for future discussions as situations and preferences change, and the value of the discussion for the patient and surrogate. 	Mode: Interview	For patients who died, surrogates were interviewed by telephone, and medical records from the site of death were obtained to determine whether the patient was decisional at the end of life, whether the patient's preferences had changed, and what care was received in the days before death.
		Treatment was compared with tow situation which expressed in STP, low chance of survival and cardiopulmonary arrest.		
		Usual care: Included standard AD counselling, assessment of an AD on admission to the organisation and questions regarding whether patients would like more information.		
Song et al.	To enhance	The SPIRIT intervention: This was a 1-hour, single session, interview with	Delivered by trained	Patient-surrogate congruence in
(2009)	communication	a patient-surrogate dvad, delivered by a trained nurse interventionist who	nurse interventionist	goals of care by Goals of Care
()	regarding	had completed 3.5 days of training. The intervention consisted of 5	for 3.5 days include	document (two scenarios).
USA	end-of-life care	elements:	role playing and skill	presented according to patients'
	between African	1. Representational assessment: The dyads describe illness	demonstration.	medical condition.
	American ESRD	representations along the dimensions of identity, timeline,		
	patients and their	consequences, controllability, and spiritual and emotional	Mode: 1 to 1 single	Decisional Conflict Scale
	chosen surrogate	representations. The purpose of this is for both parties to	interview	
	decision makers.	understanding of the patient's illness experience and the surrogate's		Colf Dercention and Delationship
		experience with loved one's illness.		Tool (S-PRT) to measure
		2. Identifying and exploring gaps and concerns: The nurse identifies		nsychosocial-spiritual well-being
		and explores gaps and concerns the dyad may have about illness,		psychosocial-spiritual weil-beilig.
		treatments and decision making. Dyad to exchange values and		Dialusia Comentana Index
		concerns about LST at EOL.		Dialysis Symptom Index
		3. Creating conditions for conceptual change: dyad shares views and		
		ideas about death and EOL care. Nurse assists patient identify his/her		

		 threshold for unacceptable outcomes of LST to develop understanding of dyad's values of treatment outcomes and concerns. 4. Introducing replacement information: Nurse presents EOL scenarios and encourages patient to clarify goals and express concerns. Nurse examines willingness to take responsibility to act on them and appreciate their role. 5. Summary. Each intervention was audio recorded for quality monitoring. The outcome measures and additional measures were collected 1 week after baseline (T2) and 3 months after baseline (T3). Usual care: written information on advance directives and the patient's right to have an advance directive to every patient on the first day of dialysis treatment. 		SF12v2 health Survey to assess patient's health-related quality of life. Medical record review to collect information about the last hospitalization, withdrawal of dialysis or other life-sustaining treatment,
Song <i>et al.</i> (2010) USA	To help patients and their surrogates better understand the likelihood of illness progression and the benefits and burdens associated with life-sustaining treatment and to clarify their values on life sustaining treatment under situations where	 PC-ACP was an in-depth interview with the patient-surrogate dyad, delivered by a trained nurse interventionist. The intervention took place over approximately 1 hour (from 48 to 65 minutes) in a face-to-face session. During that session, the interventionist addressed the five elements of the representational approach: (a) representational assessment of participants' beliefs about their illness condition along the five dimensions of illness representation (b) exploration of gaps or misunderstandings regarding CKD and its progression and life-sustaining treatment, including dialysis I Creation of conditions for conceptual change (d) introduction of the discussion. Usual care: Written information on advance directives was provided to every patient by a nurse	Delivered by trained nurse interventionist had 20 years' experience in medical- surgical nurse and had complete 2.5 days of PC-ACP training. Mode : 1 to 1 single interview	Charlson comorbidity index Dialysis Symptom Index Patient–Surrogate congruence in treatment preferences was measured using the statement of treatment preferences. Decisional conflict scale decision-making confidence scale Self-Perception and Relationship Tool
	the risks and burden of the treatment are high.	or social worker who encouraged patients to complete an advance directive and addressed their questions about life-sustaining treatment options. Completed advance directives were placed in the medical record. Questions about medical conditions and end-of-life treatment options were referred to patients' physicians.		Accessibility and feasibility
Song <i>et al.</i> (2015) USA	To assist patients to clarify their end-of-life preferences, help surrogates increase their understanding of	Intervention + usual care The SPIRIT intervention included 2 sessions, and all sessions included both patient and surrogate. During the first session in a private room at the dialysis centre, the interventionist assessed cognitive, emotional, and spiritual/religious aspects of the dyad's representations of the patient's illness, prognosis, and EoL care. The interventionist aimed to help the surrogate prepare for being a decision maker and for the emotional burden of end-of-life decision making by actively involving the	Delivered by trained nurse interventionist had 2 years' clinical experience and had complete 3.5 days of communication skills	Preparedness outcomes: Dyad congruence using goal of care documents. Patients decisional conflict using Decisional Conflict Scale

	the patient's wishes, and prepare surrogates for the role and responsibilities of being a surrogate.	surrogate in the discussion. A goals-of-care document was completed at the end of the session to indicate the patient's preferences. Second session delivered 2 weeks later at the patient's the goals-of-care document and resuscitation preferences were reviewed. If the surrogate was someone out of the order of the hierarchical compensatory model (e.g., a sibling was chosen when the patient had a spouse), the interventionist explored potential family conflicts and encouraged the dyad to talk with other family members and complete a health care power of attorney. The interventionist then summarized the patient's end-of-life	training and knowledge in ESRD and EoL care. Mode: 1 to 1 single interview	Surrogate decision-making confidence using Decision Making Confidence scale. Bereavement outcomes: anxiety, depression symptoms and posttraumatic distress symptoms scales.
		preferences, listed the surrogate's name and relationship to the patient's child of inc indicated whether the patient desired a DNR order or assistance in completing an advance directive. The interventionist communicated this information to dialysis staff (the social worker and nurse manager or the medical director), and the document was placed in the medical record.		
		Usual care Written information for advance directives was provided to every patient on the first day of dialysis, and a social worker encouraged patients to complete an advance directive and addressed questions about life-sustaining treatments. A nephrologist, physician assistant, or nurse practitioner reviewed resuscitation statements with the patient to determine whether the patient wanted a do-not-resuscitate (DNR) order in the centre.		
Gross (2015) USA	To plan, develop and implement of Provider Orders for Life-Sustaining Treatments (POLST)	First, all dialysis staff and patients would need to be given education about the POLST program. Two educational sessions for all dialysis staff, and all dialysis patients were given written material provided by the Respecting Choices Organization. Second, dialysis staff trained facilitators needed to be trained using the Respecting Choices Model. That included six hours of online training and eight hours of classroom training. Third, develop a POLST screening tool to help guide dialysis staff members with identifying which dialysis patients met the necessary criteria for a POLST conversation. Dialysis staff were educated about how to use the tool in order to help them identify patients for the POLST conversations.	Printed materials and teaching sessions + different tanning sessions include classroom and online education.	
Courtright <i>et</i> <i>al.</i> (2016) USA	To determine whether offering multiple alternatives for the decision to complete an advance directive	Standard choice set form included a dichotomous choice of "yes" or "no." The expanded form was identical to the standard except that it offered 4 potential responses: "no" and 3 "yes" options for different advance directive versions. The living will section of these 3 advance directives assessed treatment preferences in each of 4 ("brief"), 6 ("expanded"), or 8 ("comprehensive") clinical scenarios. All versions offered additional space for patients to clarify or expand on their preferences. The brief advance directive was used for the standard choice set	Mode: Delivered by 5 trained research coordinators. Printed materials,	ACDs different forms McGill Quality-of-Life Questionnaire (MQOL)

	and evaluated the influence of expanded choice sets on whether patients said they wanted to complete an advance directive and on their decision satisfaction and quality of life.	group. The clinical scenarios described a spectrum of neurologic, cognitive, and physical disabilities along with loss of decision-making capacity		The 12-item Short-Form Health Survey (SF-12) single-item scale to measure overall quality of life.
Schell <i>et al.</i> (2018) USA, Pennsylvania	Communication skills	 NephroTalk: expanded curriculum comprises brief didactics, faculty demonstrations, and small group skills practice addressing four key communication tasks: Giving bad news using the SPIKES framework (Setting, Perceptions, Invitation, Knowledge, Empathy, Summary and Strategy). Within the bad news task, fellows are explicitly taught skills for how to respond to emotion including the NURSE acronym (Name, Understand, Respect, Support, Explore), use of silence; and wish statements. Negotiating goals of care using VitalTalk REMAP (Reframe, expect emotion, Map values, align with values, and Propose Plan) framework. Managing conflict using a three-step approach. Addressing transitions at end of life with emphasis on support of the decision, assuring comfort and non-abandonment and addressing timing. The cases developed for skills practice focus on two scenarios commonly experienced in nephrology practice: 1) conservative care for an elderly patient with advanced comorbidities facing treatment decisions for advanced kidney disease and 2) a surrogate decision maker for a critically ill patient with oliguric acute kidney injury. 	Mode: Training workshops	Survey and communication skills checklist

Appendix 5: Study Ethical Approvals Appendix 5A: Ethical Approval the University of Sheffield



Downloaded: 26/06/2020 Approved: 26/06/2020

Nuha Alatawi Registration number: 180277777 School of Nursing and Midwifery Programme: NURR31 Nursing and Midwifery

Dear Nuha

PROJECT TITLE: The feasibility and acceptability of a culturally adapted decision aid tool for patients with ESRD, their family caregivers and health care providers in Saudi Arabia: mixed methods study APPLICATION: Reference Number 035156

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 26/06/2020 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 035156 (form submission date: 18/06/2020); (expected project end date: 30/05/2021).
- Participant information sheet 1079870 version 2 (18/06/2020).
- Participant consent form 1079871 version 2 (18/06/2020).

If during the course of the project you need to deviate significantly from the above-approved documentation please inform me since written approval will be required.

Your responsibilities in delivering this research project are set out at the end of this letter.

Yours sincerely

Kate Chadwick Ethics Administrator Health Sciences School

Please note the following responsibilities of the researcher in delivering the research project:

- The project must abide by the University's Research Ethics Policy:
- https://www.sheffield.ac.uk/rs/ethicsandintegrity/ethicspolicy/approval-procedure
- The project must abide by the University's Good Research & Innovation Practices Policy:
- https://www.sheffield.ac.uk/polopoly_fs/1.671066!/file/GRIPPolicy.pdf
- The researcher must inform their supervisor (in the case of a student) or Ethics Administrator (in the case of a member
 of staff) of any significant changes to the project or the approved documentation.
- The researcher must comply with the requirements of the law and relevant guidelines relating to security and confidentiality of personal data.
- The researcher is responsible for effectively managing the data collected both during and after the end of the project in line with best practice, and any relevant legislative, regulatory or contractual requirements.

Appendix 5B: Ethical Approval Hospital in Saudi Arabia

ARMED FORCES HOSPITALS ADMINISTRATION NORTHWESTERN REGION, KSA



إدارة مستشفيات القوات المسلحة بالمنطقة الشماقية الغربية المملكة العربية السعونية

ACADEMIC AFFAIRS

RESEARCH ETHICS COMMITTEE APPROVAL FORM

NAME OF PRINCIPAL INVESTIGATOR: NUHA AYAD ALATAWI

ETHICS ID NUMBER: KSAFH-REC-2020-352

TITLE: The feasibility and acceptability of a culturally adapted decision aid tool for patients with ESRD, their family caregivers and health care providers in Saudi Arabia: mixed methods study

CO- INVESTIGATORS: Ahmed Serageldeen, Clare Gardiner

The above-noted proposal has been submitted for expedited ethics review and found to be ethically acceptable. The proposal includes:

1. The Ethics Approval Form 2. Research Protocol 3. Data sheet collection.

Please note that this approval is subject to the following conditions:

- Consent for participant agreement to be enrolled in the trial and access to personal information in chart review is required. Participation in the questionnaire is considered as approval of the participant.
- 2. A Progress Report must be submitted by the year end, containing the following information:
 - The number of subjects recruited;
 - ii.) A description of any protocol modification;
 - iii.) Any unanticipated problems involving risks to subject or to others, withdrawal of subjects from the research, or complaints about the research.
 - iv.) A summary of any recent literature, findings, or other relevant information, especially information about risks associated with the research.
 - v.) The expected date of termination of this project.
- 3. A final report must be submitted to the research office at the completion of the project.
- 4. The research project must be published under the name of our hospital with the name of the investigators and also need to mention had approval from the Research & Research Ethics Committee.

Please note that you have been named as the principal collaborator on this study because students are not permitted to serve as principal investigators. Please accept the Board's best wishes for success in your research.



Form No. 109.2/1389

KACST Reg. No: HO-07-TU-002 Date: 16/12/1434 Date: 02 November 2014 Stock No.: X

Page 1 of 1

Appendix 6: Phase 1 : Participants Invitation Letter, Information Sheets, Consent Form Appendix 6A: Arabic Participants Invitation Letter

المرحلة الأولى من البحث

قابلية تنفيذ ومقبولية أداة مساعدة على اتخاذ القرار متكيفة ثقافياً للمرضى المصابين بأمراض الكلى ومقدمي الرعاية الأسرية ومقدمي الرعاية الصحية في المملكة العربية السعودية: دراسة مختلطة الأساليب.

خطاب الدعوة للمشاركة في الدراسة للمرضى وعائلاتهم (النسخة العربية)

المرحلة الأولى من البحث

مرحبا اسمي نهى العطوي. لدي خلفية في تخصص التمريض وحاليا انا طالبه في جامعة شفيلد في المملكة المتحدة لدراسة درجة الدكتوراه. هذه الرسالة هي دعوة للمشاركة في دراستي.

الهدف من هذه الدراسة هو تطوير أداة "المساعدة على اتخاذ القرار" لمرضى الكلى وأسرهم. أداة "المساعدة على اتخاذ القرار" هي شيء سيساعدك أنت وعائلتك في اتخاذ قرارات مهمة حول رعايتك ، وحول رعايتك المستقبلية. لمساعدتنا في تطوير هذه الأداة ، أود أن ادعوكم للمشاركة في هذه الدراسة و تشمل الموافقة على المشاركة في مقابلة معى (الباحث). مشاركتك طوعية تماما.

أود أن اتواصل واتحدث معكم عبر الهاتف بشأن الدراسة وأعطيكم المزيد من التفاصيل حول ما ستشمله.

إذا كنت مهتمًا بمكالمتي لمناقشة مشاركتك ، فيرجى:

- · لتواصل معي على رقم الهاتف : ٥٥٣٥١١٧٠٠ او ٥٥٩١٦٤٠٠٠
 - او بالبريد الالكتروني معامد naalatawi1@sheffield.ac.uk
- أو ابلاغ مقدم الرعاية الصحية الذي أعطاك هذه الرسالة ليعرف أنك على استعداد لمقابلتي.

شكرا لك على وقتك اليوم

الباحثة: نهى العطوي

قسم التمريض والقبالة

جامعه شفيلد

مبني: باربير هاوس

۳ ا طريق كلاركهاوس

شفیلد S10 2LA

الهاتف: ٥٥٣٥١١٧٠٠ او ٥٩١٦٤٠٠٠

البريد الإلكتروني: naalatawi1@sheffield.ac.uk

Appendix 6B: Phase 1: Arabic Participant Information Sheet

ورقة مشاركة المعلومات للمرضى وعائلاتهم للمرحلة الاولى (النسخة العربية)

عنوان الدراسة: قابلية تنفيذ ومقبولية أداة مساعدة على اتخاذ القرار متكيفة ثقافياً للمرضى المصابين بأمراض الكلى ومقدمي الرعاية الأسرية ومقدمى الرعاية الصحية فى المملكة العربية السعودية: دراسة مختلطة الأساليب.

أود أن أدعوكم للمشاركة في دراسة بحثية حول تطوير أداة جديدة للمساعدة على اتخاذ القرار للمرضى الذين يعانون من أمراض الكلى وأسرهم ومقدمي الرعاية الصحي. قبل أن تقرر ما إذا كنت تريد المشاركة أم لا ، أود منك أن تفهم سبب إجراء البحث وما ستشمله لك. يرجى تخصيص بعض الوقت لقراءة المعلومات التالية بعناية ومناقشتها مع الآخرين إذا كنت ترغب في ذلك. إذا كان لديك أي أسئلة حول هذه الدراسة ، فلا تتردد في الاتصال بأحد أعضاء فريق البحث باستخدام تفاصيل الاتصال في نهاية ورقة المعلومات هذه. شكرا لقراءتك هذا.

ما هو الهدف من المشروع؟

الهدف من هذه الدراسة هو تطوير أداة "المساعدة على اتخاذ القرار" لمرضى الكلى وأسرهم. أداة "المساعدة على اتخاذ القرار" هي شيء سيساعدك أنت وعائلتك في اتخاذ قرارات مهمة حول رعايتك ، وحول رعايتك المستقبلية. لمساعدتنا في تطوير هذه الأداة ، أود أن أستكشف التجارب التي مررت بها أنت وعائلتك حول قرارات الرعاية والعلاج ووضع الخطط ، وأي أفكار يمكنك مشاركتها حول ما هو أكثر أهمية بالنسبة لك في مرضك.

لماذا تم اختياري؟

تمت دعوتك للمشاركة في هذه الدراسة لأنك من الأشخاص الذين يعانون من أمراض الكلى و / أو أنك أحد أفراد الأسرة لشخص يعاني من أمراض الكلى. سيتم استخدام إجاباتك لتطوير فهم أفضل لكيفية مواجهتك انت وعائلتك لمشاكل صنع القرار والتواصل. سنستخدم هذه المعلومات لمساعدتنا على تطوير أداة مساعدة على اتخاذ القرار يمكن استخدامها من قبل الأشخاص المصابين بأمراض الكلى وأسرهم ، لاتخاذ قرارات بشأن رعايتهم. سيتم دعوة عشره من الاشخاص للمشاركة في مقابلة.

هل يجب أن أشارك؟

مشاركتك طوعية تماماً والقرار يعود لك لاتخاذ القرار. إذا قررت المشاركة ، فسيتم إعطاؤك نسخة من ورقة المعلومات للاحتفاظ بها وسأشرح الهدف من هذه الدراسة وأراجع ورقة المعلومات هذه معك عبر الهاتف. إذا كنت توافق على المشاركة ، فسيُطلب منك التوقيع على نموذج موافقة سيجمعه مقدمو الرعاية الصحية / رئيس وحدة غسيل الكلى منك. إذا قررت المشاركة ، فلا يزال لك مطلق الحرية في الانسحاب في أي وقت ، دون إبداء أسباب. مشاركتك اليوم لن تؤثر على الرعاية التي تتلقاها أنت وعائلتك.

ماذا سیحدث لی إذا شارکت؟

تشمل الموافقة على المشاركة في مقابلة مع الباحث. ستتم المقابلة عبر الهاتف (أو عبر الإنترنت في الحالات التي يكون فيها ذلك متاحًا) ووقت المقابلة على الأرجح عندما يكون المشاركون في المنزل أو قادرين على التحدث على هواتفهم المحمولة. تستغرق هذه المقابلة ستون دقيقة تقريبًا وسوف يتم تسجيلها. لست مضطرًا للإجابة على الأسئلة التي لا تريدها ويمكنك التوقف في أي وقت.

خلال المقابلة ، سأسألك عن تجربتك المرضية وما الذي تتذكره بشأن أي قرارات علاجية اتخذتها. أنا مهتم أيضًا بتذكرك للمناقشات حول هذه الأمور مع الأشخاص الذين يهتمون بك ، وما إذاكان لديك أي معلومات قدمت لك لمساعدتك. سوف تفيد نتائج المقابلات بوجود أداة تسمى "المساعدة على اتخاذ القرار" لمساعدة المرضى ومقدمي الرعاية الصحية على اتخاذ قرارات في مجال رعاية الكلى. سوف أسجل المقابلة باستخدام جهاز تسجيل. الغرض من التسجيل هو السماح لي بالتقاط جميع المعلومات التي تمت مناقشتها خلال المقابلات ، وهو أمر مهم بالنسبة لى لتحليلها في وقت لاحق.

قبل هذه المقابلة ، سأتصل بك قبل 24 ساعة للتأكد من أنك سعيد بوقت المقابلة وما زلت ترغب في أن تكون جزءًا من الدراسة. إذا كنت ترغب في المشاركة ، يرجى الاتصال برقم الاتصال أدناه. سيتم تحديد موعد ووقت المقابلة لتناسبك.

ما هي المساوئ والمخاطر المحتملة للمشاركة؟

على الرغم من أنه من غير المحتمل حدوث أي مخاطر ، أثناء المقابلة ، قد تطرح أسئلة حول مواضيع حساسة أو قد تزعجك. يمكنك رفض الإجابة على أي أسئلة تشعر بعدم الارتياح منها. إذا أصبحت منزعجًا أو حزينًا أو متعبًا أثناء المقابلات ، فيمكن إيقاف المقابلة. سأقدم تفاصيل الاتصال الخاصة بشخص ما يمكن للمشاركين التحدث إليه ، في حال وجدوا المشاركة في البحث مزعجه او مقلقه. سوف أتحقق أيضًا من سلامة المشاركين بعد مشاركتهم في الدراسة وتقديم محادثة غير رسمية معهم. إذا لم تعد ترغب في مواصلة المقابلة ولكنك تريد البقاء جزءًا من الدراسة ، يمكن ترتيب وقت بديل مناسبًا لك لمواصلة المقابلة. إذا كنت لا ترغب في الاستمرار ، لك مطلق الحرية في الانسحاب من الدراسة في أي وقت.

ما هى الفوائد المحتملة من المشاركة؟

لا توجد فوائد متوقعة للأشخاص المشاركين في المشروع، ولكن المعلومات المستسقاة من هذه الدراسة قد تعكس تجربتك في صياغة أداة مساعدة اتخاذ القرار التي قد تلبي احتياجاتك وقد تساعدك كمريض وأسرتهم على فهم أنواع المعلومات التي تحتاجها لتخطيط رعايتك المستقبلية أثناء رحلة المرض.

هل سيتم الحفاظ على سرية المشاركة في هذا المشروع؟

جميع المعلومات التي أجمعها منك أثناء البحث سوف تبقى في سرية للغاية ولن تكون متاحة إلا لأعضاء فريق البحث. سوف يتم إخفاء هوية جميع المعلومات الشخصية. سيتم حذف جميع التسجيلات في نهاية الدراسة بينما سيتم تخزين النصوص بشكل آمن. سيتم نقل جميع البيانات التي تم جمعها إلى محرك الجامعة عن طريق الشبكة الخاصة الافتراضية عند العمل عن بُعد. سيتم فحص جميع بيانات البحث التي تم جمعها في شكل ورق نسخها وتخزينها في مجلد على محرك الأقراص. X الآمن في الجامعة باستخدام كلمة مرور آمنة

سيتم الاحتفاظ بنسخ مجهولة الهوية لمدة 10 سنوات ، بما يتماشى مع توصيات جامعة شفيلد. الحفاظ على بياناتك .سيتم الاسترجاع من:

www.sheffield.ac.uk/library/rdm/preserving

لن يكون بالإمكان التعرف عليك في أي تقارير أو منشورات ما لم تكن قد أعطيت موافقتك الصريحة على ذلك. سيتم استخدام البيانات التي أجمعها فقط لأغراض هذا البحث. إذا استخدمت البيانات في الدراسات المستقبلية، سيتم طلب المزيد من الموافقة على لجنة أخلاقيات البحث.

ما هو الأساس القانوني لمعالجة بياناتي الشخصية؟

وفقًا لتشريع حماية البيانات ، نحن مطالبون بإبلاغك بأن الأساس القانوني الذي نطبقه لمعالجة بياناتك الشخصية هو أن "المعالجة ضرورية لأداء مهمة يتم تنفيذها للمصلحة العامة" (المادة 6 (1) هـ). يمكن العثور على مزيد من المعلومات في إشعار الخصوصية للجامعة من خلال الرابط التالى:

www.sheffield.ac.uk/govern/data-protection/privacy/general

سوف أقوم بجمع بيانات "فئة خاصة" تتضمن معلومات تتعلق بصحتك ، حيث ستناقش مشاكلك الصحية. أحتاج أيضًا إلى إعلامك بأننا نطبق الشرط التالي في القانون: أن استخدام بياناتك "ضروري لأغراض البحث العلمي أو التاريخي (التخزين)".

ماذا سيحدث لنتائج هذا المشروع البحثي؟

يمكن استخدام الاقتباسات المباشرة من المقابلة في التقرير والمنشورات ؛ ومع ذلك ، سوف تكون الاقتباسات مجهولة المصدر لضمان أنه لا يمكن تحديد هويتك. سيتم نشر نتائج هذه الدراسة في المجلات الطبية أو تقديمها في المؤتمر.

سيتم إرسال ملخص النتائج إلى قسم أبحاث مستشفى الملك سلمان للقوات المسلحة. لن يتم تحديد هويتك في أي تقارير منشوره دون طلب موافقتك الكاملة.

نظرًا لطبيعة هذا البحث ، من المحتمل جدًا أن يجد الباحثون الآخرون أن البيانات التي تم جمعها مفيدة في الإجابة على أسئلة البحث المستقبلية. في هذه الحالة ، سيتم طلب مزيد من موافقة لجنة الأخلاقيات البحثية لمشاركة بياناتك بهذه الطريقة.

من الذي يقوم بتنظيم وتمويل البحث؟

ستنفذ هذا المشروع نهى العطوي ، طالبة دكتوراه في قسم التمريض والقبالة في جامعة شفيلد.

من هو مراقب البيانات؟

ستعمل جامعة شفيلد ومستشفى الملك سلمان للقوات المسلحة كمراقب بيانات لهذه الدراسة. وهذا يعني أن الجامعة والمستشفى مسؤولان عن رعاية معلوماتك واستخدامها بشكل صحيح.

من قام بالمراجعة الأخلاقية للمشروع؟

تمت الموافقة على هذا المشروع أخلاقيا من خلال إجراء مراجعة الأخلاقيات بجامعة شفيلد ، كما يديره قسم "قسم التمريض والقبالة"، في المملكة المتحدة، وقد تمت الموافقة على هذا المشروع أخلاقيا عبر إجراء مراجعة أخلاقيات البحث من مستشفى الملك سلمان للقوات المسلحة.

ماذا لو حدث خطأ ما ورغبت في الشكوى من البحث؟

إذا كان لديك قلق بشأن أي جانب من جوانب هذه الدراسة ، فيجب أن تطلب التحدث معي – نهى العطوي – الباحثة ، وسأبذل قصارى جهدي للإجابة على أسئلتك. تفاصيل الاتصال الخاصة بي في نهاية ورقة المعلومات هذه. إذا كنت غير راضٍ وترغب في تقديم شكوى رسمية ، فيمكنك الاتصال بشخص من خارج الدراسة وهو الدكتور توني رايان الذي سيقوم بعد ذلك بتصعيد الشكوى من خلال القنوات المناسبة ، تفاصيل الاتصال الخاصة به في نهاية هذه الورقة.

إذا كنت تشعر أن الجامعة لم تتعامل بشكل صحيح مع بياناتك الشخصية ، فيمكنك تقديم شكوى إلى مكتب مفوض المعلومات من خلال الرابط التالى:

https://ico.org.uk/make-a-complaint/

اتصل للحصول على مزيد من المعلومات يرجى سؤال فريق البحث: الباحثة: نهى العطوي قسم التمريض والقبالة جامعه شفيلد جامعه شفيلد مايي: باريير هاوس ۳ اطريق كلاركهاوس ۳ اطريق كلاركهاوس ۱ الهاتف: ٥٩١٦٤٠٠٠ او ٥٥٩٦٦٤٠٠٠ البريد الإلكتروني: naalatawi1@sheffield.ac.uk

الباحث الرئيسي: د. كلير جاردنر

قسم التمريض والقبالة

جامعه شفيلد

مبني: باربير هاوس ١٣ طريق كلاركهاوس شفيلدS10 2LA الهاتف: ٠٠٤٤١٤٤٢٢٢٢٠٣٨ البريد الإلكتروني: c.gardiner@sheffield.ac.uk

للتواصل مع شخص من خارج المشروع: مدير البحث: د. توني رايان قسم التمريض والقبالة جامعه شفيلد مبني: بارير هاوس ٣ اطريق كلاركهاوس شفيلد210 S10 البريد الإلكتروني: t.ryan@sheffield.ac.uk

شكرا لك على التفكير في المشاركة في البحث. إذا كنت ترغب في المشاركة فسوف تحصل على نسخة من ورقة المعلومات ويرجى ملء نموذج الموافقة ثم إعادته إلى الباحث ، والحصول علي نموذج موافقة موقع للاحتفاظ به.

Appendix 6C : Phase 1 : Participant Consent Forms

	لیت Informed ir پ دراسه مید	وزارة الدفاع وزارة الدفاع الادارة العامة للخدمات الطبية Medical Services General Directorate M.S.D Consent to Participation Research Study موافقه منفوهة بالعلم على للشاركة و	PATIENT I.D.
ł	Department / Wa	rd:	Code: Date:
	Consultant Name		Number:
+			
[No abbreviation to	be used on this form	لا يجوز إستعمال الإختصارات لتعبنة هذه الإستمارة
	I, the under signed Subject Legal (Relationship to the	guardian Relative subject)	انا الموقع أدناء للشارك في البحث ولي الأمر القريب (بيان القرابة
	I consent to partici	pate in the following research study	الرس مي مدرية ي مارية منية اليه .
ł	Researcher's Stat	ement	الباحث توضيح
Ī			ة. لقد قمت بشرح كل مما يلي تلمشارك قبل مشاركته في الدراسة العلمية :
	 I have explained Hospital pro Purpose and Description must be foll Expected be Expected Alternatives Refusal t participa hospital i Confidential 	cess for reviewing research. duration of the study. of the study and procedure that owed. nefits. I discomforts and risks. that might help participant. o participant or withdraw from tion will not compromise access to the services. lity of information.	*مياسة للمنتشقي في مراجعة الأكمات العلمية. *هدف الدراسة و مدة المشاركة تما. *وصف لإجراءات الدراسة. *المغاظر المتوقعه من الدراسة. *المغالل التي يمكن أن تساعد المشارك. * إفاد المشاركة في الدراسة أو الإنسحاب لن تؤثر على المخدمات المقدمة للمريض. *مياة للعلومات.
	and allow for subje	ct/ representative to read them and sig	الموافقة، والسماح للمشارك بقراءها والتوقيع على ذلك. 19.
İ	Signature of Rese	archer	الباحث توقيع
	Full Name:Nuha	Ayad Alatawi	إسم الباحث كاملا :

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Signature:	مكان العمل :
Date/Time:01/09/2020	الترقيع:
	التاريخ / الوقت :
Subject's Statement	المشارك توضيح
 I have read and understood the information provided in this form. 	* لقد قرأت وفهمت المعلومات الواردة في هذا النموذج ومرفقاته.
· Researcher has adequately explained to me the	"لقد قام الباحث بالشرح الوافي في عن البحث العلمي للذكور، كما ام إعلامي
research set above along with its risks, benefits and other information described in this form.	بالمضاعفات والمخاطر التي ام ذكرها.
 I had a chance to ask questions, and I have received 	لقد ام إعطاني الفرصة للإستفسار ومناقشة الأمور التي تتعلق بالبحث العلمي المذكور،»
all of the information, and I agree to participate in	ولي رغبة بالمشاركة في الدراسة.
the study.	
Subject's Signature	المشارك توقيع
Subject's Full Name:	اسم المشارك كاملاً :
Subject's Signature:	انوقيع:
Legal Guardian/Relative Full Name:	يسم الولي / القريب كامالا :
Legal Guardian/Relative Signature:	توقيع الولي / القريب :
Date/Time:	التاريخ / الوقت :
Interpreter's Statement	المترجيه توضيح
	6.245
Specifics Language Requirements (if any)	أذكر اللغة
I dealars that I have intermented the dialogue between the	
r deciare that i have interpreted the dialogue between the	ألحماه فنخرته مقالمة ببنائلهم الشاه مرب
parterpair and researcher to the cest of my ability.	اوصح التي هت بترجمه الحوار اين البحث والمسرت حسب. الاطاعة.
Interpreter's Signature	بست علي للتحد تدقيع
incepteter s Signature	المرجع توقيع
Interpreter's Full Name:	إسم المترجع كاملا :

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Interpreter's Signature:	التوقيح:
Date/Time:	التاريخ / الوقت :

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Appendix 7: Search Strategy in CINHAL via EBSCO

Search ID	Search Terms	Search options	Action
S16	S3 AND S9 AND S12 AND S15	Search modes- Boolean/Phrase	View Results (711) View Details Edit
S15	S13 OR S14	Search modes- Boolean/Phrase	View Results (167,539) View Details Edit
S14	(Saudi Arabia or United Arab Emirates or Kuwait or Bahrain or Egypt or Iraq or Qatar or Jordan or Oman or Lebanon or Syria or Iran or Yemen or Turkey or Algeria or Cyprus or Morocco or Tunisia or Palestine or Libya or Pakistan or Sudan or Djibouti or Afghanistan or Somalia or the Comoros or Brunei or Bangladesh or Indonesia) OR (Kyrgyzstan or Maldives or Malaysia or Tajikistan or Turkmenistan or Uzbekistan or Albania or Kosovo or Mayotte or Burkina Faso or Chad or Gambia or Guinea or Mali or Mauritania or Niger or Senegal or Sierra Leone or Western Sahara or Azerbaijan or Kazakhstan)	Search modes- Boolean/Phrase	View Results (156,214) View Details Edit
S13	(islam or muslim or slamic) OR (Islamic countries or Muslim counties) OR (Islamic communities or Muslim communities) OR (Persian or Arbic or Arab) OR (East-Asian communities or East-Asian countries)	Search modes- Boolean/Phrase	View Results (20.429) View Details Edit
S12	S10 OR S11	Search modes- Boolean/Phrase	View Results (1,991,400) View Details Edit
S11	qualitative* OR (grounded theory or ethnographies or phenomenology) OR interview* OR focus group* OR questionnaire* OR survey* OR narratives* OR "participant observation"	Search modes- Boolean/Phrase	View Results (1,141,792) View Details Edit
S10	experiences* OR (perception or attitude or perspective or opinion) OR (beliefs or views or feelings) OR (preferences or values) OR personal autonomy	Search modes- Boolean/Phrase	View Results (1,362,568) View Details Edit
S9	S4 OR S5 OR S6 OR S7 OR S8	Search modes- Boolean/Phrase	View Results (1,680,503) View Details Edit
58	(palliative care or end of life care or terminal care or hospice care) OR life support care OR (death or dying) OR (life sustaining treatment* or life- sustaining treatment* or lst) OR (resuscitation or cpr or cardiopulmonary resuscitation) OR mechanical ventilation OR (dialysis or hemodialysis or haemodialysis) OR conservative management or cm or non-dialytic treatment or non-dialytic management or withdrawal from dialysis or withholding dialysis or stopping dialysis	Search modes- Boolean/Phrase	View Results (470,607) View Details Edit

S7	decision* OR choice* OR (decision making or decision-making or decision making process or decision-making process or dm) OR (shared decision making or shared decision-making or sdm) OR (involvement or participation or engagement) OR decision support techniques OR (decision aid* or decision tool*) OR (patient decision aid* or pda or PtDAs) OR 'patients decision making'' OR (healthcare proxy* or health care proxy*) OR power of attorney	Search modes- Boolean/Phrase	View Results (567,868) View Details Edit
S6	communication* OR conversation* OR discussion* OR document*	Search modes- Boolean/Phrase	View Results (485,426) View Details Edit
S5	living will* OR ("end of life planning" or "end-of- life planning") OR ("end of life wishes" or "end- of-life wishes") OR "future care goals")	Search modes- Boolean/Phrase	View Results (3,698) View Details Edit
S4	plan* OR advance care OR (advance care plan* or acp) OR "Advance care planning" OR (advance healthcare plan* or advanced healthcare plan*) OR (advance health care plan* or advanced health care plan*) OR (advance health-care plan* or advanced health-care plan*) OR (advance medical plan* or advanced medical plan*) OR (patient care plan* or "patient care planing") OR (advance directive* or advanced directive*) OR (advance medical directive* or advanced medical directive*)	Search modes- Boolean/Phrase	View Results (427,881) View Details Edit
53	S1 AND S2	Search modes- Boolean/Phrase	View Results (69,768) View Details Edit
S2	patient* OR family* OR (family members or relative or carers or caregivers) OR (informal caregivers or family caregivers or informal carers or family carers)	Search modes- Boolean/Phrase	View Results (2,678,011) View Details Edit
S1	(kidney disease or renal disease or renal failure or kidney failure) OR (end stage renal disease or end stage renal failure or end-stage renal disease or end-stage renal failure or esrd) OR (chronic kidney disease or chronic renal failure or ckd) OR (established kidney disease or ekd or established renal failure or erf) OR advance chronic kidney disease or advanced chronic kidney disease or (haemodialysis or hemodialysis or peritoneal dialysis or dialysis or kidney transplant* renal replacement therapy or RRT or renal treatment)	Search modes- Boolean/Phrase	View Results (108,518) View Details Edit

	Criteria									Included / excluded reason
Included studies / year	1-Were the criteria for inclusion in the sample clearly defined?	2- Were the study subjects and the setting described in detail?	3- Was the exposure measured in a valid and reliable way?	4- Were objective, standard criteria used for measurement of the condition?	5-Were confounding factors identified?	6- Were strategies to deal with confounding factors stated?	7- Were the outcomes measured in a valid and reliable way?	8- Was appropriate statistical analysis used?	Total	
Al-Jahdali <i>et al.</i> (2009)	Unclear	Yes	Unclear	Unclear	Not applicable	Not applicable	Unclear/ questionnaire developed by researchers	Yes	2 out of 8	Low quality
Baharoon <i>et al.</i> (2010)	Unclear	Yes	Unclear	Unclear	Not applicable	Not applicable	Unclear	Yes	2 out of 8	Low quality
Saeed <i>et</i> <i>al.</i> (2020)	Unclear	Yes	No	No	No	No	Yes	Yes	3 out of 8	Low quality
Maniam, Tan and Chong (2021)	Yes	Yes	Yes	No	No	No	Yes	Yes	5 out of 8	Moderate quality
Azahar and Ibrahim (2022)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	8 out of 8	High quality

Appendix 8: Joanna Briggs Institute Critical Appraisal Checklist for Systematic Review Included Studies

Appendix 9: Shortlist of Four Chosen Decision Aid Tools

PtDA Tools Title	Organisation and country	Format and published year	Target	Treatment options	Link/reference
Advance care planning: Should I stop dialysis	Healthwise, USA	Interactive website and online PDF. Published year NA	People with kidney failure treated with dialysis, who are considering stopping of treatment	Continue kidney dialysis versus stop kidney dialysis	https://www.healthlinkbc.ca/illnesses- conditions/kidneys/advance-care-planning-should-i-stop- kidney-dialysis
The Dialysis Decision Aid Booklet: Making the Right Choices For You	Kidney Research UK, UK	Online PDF, Paper Published in 2014	People with CKD or their carers	Four dialysis options— Home HD Hospital Dialysis, Automated PD, Continuous Ambulatory PD	https://kidneyresearchuk.org/wp- content/uploads/2019/05/KR-decision-Aid-DOWNLOAD.pdf
The Five wishes	Aging with Dignity organisation, USA	Online PDF, Paper. Published date not available.	People with any serious illness.	Helping to express care preferences and options, which include Living will and Advance directive document.	http://reclaimingwisdom.com/wp- content/uploads/2020/10/Five-Wishes-Blank-Document.pdf
A Dialysis and Conservative Care Decision Aid: Living with Kidney Disease	Kidney Research Yorkshire, UK	Online PDF, Paper Published in 2020	People with advanced CKD or their carers	Dialysis versus Conservative management	https://www.kidneyresearchyorkshire.org.uk/wp- content/uploads/2022/11/Diaysis-Conservative-Care-FINAL- SEPT-2020.pdf

Appendix 10: Phase 2: Participants Information Sheets and Consent form Appendix 10A : Experts Participants Information Sheets

Participant Information Sheet

An online Expert panel individual discussion

Title of the study: the feasibility and acceptability of a culturally adapted decision aid tool for patients with ESRD, their family caregivers and health care providers in Saudi Arabia: mixed methods study

I would like to invite you to take part in a virtual expert panel discussion (one to one individual interviews) as part of a research study about developing a new decision aid tool for patients with End Stage Renal Disease (ESRD), their family and health care providers. Before you decide whether or not to participate, I would like you to understand why the research is being done and what it will involve for you. Please take time to read the following information carefully and discuss it with others if you wish. If you have any questions about this study, please feel free to contact a member of the research team using the contact details at the end of this information sheet. Thank you for reading this.

What is the project's purpose?

This aim of this study is to develop a 'decision aid' tool for patients with kidney disease and their families. Due to complexity, the time, and costs required for developing the DA tool, adapting an existing DA tool, which is Yorkshire Dialysis and Conservative Care Decision Booklet, could be a solution for other cultural settings. This tool was established in English-speaking county, so, it is must be linguistically translated and culturally adapted to Saudi Arabian context.

Therefore, to help us develop a pre-final version of this tool, I would like to conduct a virtual individual expert panel to assist in the cultural adaptation process of the DA tool. This process includes appraisal of the original DA to identify what parts needed to be translated and adapted. Then, linguistically translated and cultural adaptation in terms of DA scope & format, revise terminology and expressions for any inconsistencies and ensuring they use the clinical setting's own terminology.

Why have I been chosen?

You have been invited to take part in this study because you have experience in a clinical role or an academic/research role. In addition, you have experience either in renal care, discussion care planning, decision-making, or palliative care. A maximum of 10 experts who has agreed to take part will be invited to participate in the online individual panel discussion.

Do I have to take part?

Your participation is entirely voluntary and it is up to you to decide. If you decide to take part_you will receive your information sheet copy via email to keep and I will describe the aim of this study and go through this information sheet with you over the telephone. If you agree to take part, you be will be required to sign a consent form and have your copy to show you have agreed to take part. The consent form will be collected from you via email. If you decide to take part you are still free to withdraw at any time, without giving a reason. This would not affect your work. If you choose to withdraw after the discussion has started, information already collected from you will still be used.

What will happen to me if I take part?

Taking part will involve participating in an online individual panel discussion with a researcher. This can be conducted via video call through google meets (hangout)/Zoom or I could conduct via an online call if you would. Before conducting the panel discussion, all supported materials such as the DA tool and discussion guide will be provided to you in advance.

During the discussion, I will explore the linguistically translated and cultural adaptation process of the DA tool. This process includes an appraisal of the original DA to identify what parts needed to be translated and adapted. Also, linguistically translated and cultural adaptation in terms of DA scope & format, revise terminology and expressions for any inconsistencies and ensuring they use the clinical setting's own terminology. Also, obtain their input for field-testing. Then, the recommendations of the experts that are presented in this discussion will reflect the draft of the pre-final version of the tool for field-testing. The online discussion will last approximately 60 minutes and I will record the online discussion using an audio tape recorder. The purpose of recording is to allow me to capture all the information discussed, which is important for me to analysis later.

If you wish to take part, please reply to this email or ring the contact number below. The discussion date and time will be arranged to suit you. Once you have agree I will send you an email including a link to join the call, time and date of this discussion. Kindly read the consent form and if you agree to participate, sign the form and send back to the researcher email.

What are the possible disadvantages and risks of taking part?

There are no anticipated disadvantages or risks of taking part in this study. This individual discussion uses to reach an agreement and produce pre-final version of the decision aid tool for testing the tool in the dialysis unit in Saudi context. If you feel upset or uncomfortable, you can stop the discussion at any time.

What are the possible benefits of taking part?

There are no anticipated benefits for those people participating in the project. The information from this study may this reflect on your experience of drafting the cultural adapted decision aid tool that might meet your patients' needs. Taking a part in a project would improve your understanding the types of information that patients and their family may need to plan their future care during their disease journey. Also, improve decision making engagement process and future care planning discussion.

Will my taking part in this project be kept confidential?

All the information that I collect about you during the course of the research will be kept strictly confidential and will only be accessible to members of the research team. All information will be anonymised. All recordings will be deleted at the end of the study while transcripts will be stored securely.

All data collected will transfer to University Drive by Virtual Private Network (VPN), when working remotely. All research data collected as paper copied will be scanned and stored in a folder on the University's secure X: drive with secured password.

Anonymised transcripts will be kept for 10 years, in line with University of Sheffield recommendations (Uos, 2018. Preserving your data. Retrieved from <u>www.sheffield.ac.uk/library/rdm/preserving</u>).

You will not be able to be identified in any reports or publications unless you have given your explicit consent for this. The data I collect will be used only for the purposes of this research; if the data were to be used for future studies, further research Ethics Committee approval will be sought.

What is the legal basis for processing my personal data?

According to data protection legislation, we are required to inform you that the legal basis we are applying in order to process your personal data is that 'processing is necessary for the performance of a task carried out in the public interest' (Article 6(1) e). Further information can be found in the University Privacy Notice www.sheffield.ac.uk/govern/data-protection/privacy/general.

What will happen to the results of the research project?

Direct quotes from the online individual discussion may be used in report and publications; however, the quotes will be anonymised to ensure that you cannot be identified. The results of this study will be published in medical journals and /or presented at conferences.

A summary of the results will be sent to the King Salman Armed Forces Hospital research department and your email. You will not be identified in any publications report without seeking your full consent.

Due to the nature of this research it is very likely that other researchers may find the data collected to be useful in answering future research questions. In this case further research Ethics Committee approval will be sought for your data to be shared in this way.

Who is organising and funding the research?

This project is being carried out by Nuha Alatawi, who is a PhD student researcher at the Division of Nursing and Midwifery at the University of Sheffield.

Who is the Data Controller?

University of Sheffield and King Salman Armed Forces Hospital (KSAFH) will act as the Data Controller for this study. This means that the University and KSAFH are responsible for looking after your information and using it properly.

Who has ethically reviewed the project?

This project has been ethically approved via the University of Sheffield's Ethics Review Procedure, as administered by 'Division of Nursing and Midwifery' department' and this project has been ethically approved via King Salman Armed Forces Hospital Ethics Review Procedure.

What if something goes wrong and I wish to complain about the research?

If you have a concern about any aspect of this study, you should ask to speak to me -Nuha Alatawi- the researcher, and I will do my best to answer your questions. My contact details are at the end of this information sheet. If you remain unhappy and wish to complain formally, then you can contact the person outside of the study, Dr Tony Ryan who will then escalate the complaint through the appropriate channels, his contact details are at the end of this information sheet.

If you feel that the University has not dealt correctly with your personal data you can complain to the Information Commissioner's Office <u>https://ico.org.uk/make-a-complaint/</u>

Contact for further information

Please ask the research team:

Researcher: Nuha Alatawi

Division of Nursing and Midwifery

University of Sheffield

Barber House

3a Clarkehouse Road

Sheffield S10 2LA

Tel: 00966553511700 or 00966591640008

naalatawi1@sheffield.ac.uk

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Principal Investigator: Dr Clare Gardiner

Division of Nursing and Midwifery University of Sheffield Barber House 3a Clarkehouse Road Sheffield S10 2LA Tel: 0044 114 222 2038 c.gardiner@sheffield.ac.uk

To contact a person outside the project:

Director of Research: Dr Tony Ryan Division of Nursing and Midwifery University of Sheffield Barber House 3a Clarkehouse Road Sheffield S10 2LA <u>t.ryan@sheffield.ac.uk</u>

Thank you for considering taking part in the research. If you would like to participate will be given a copy of the information sheet and please fill out the consent form then return it to the researcher, a signed consent form to keep.

Appendix 10B: Experts Consent Form

Consent form an online Expert Panel Discussion

The feasibility and acceptability of a culturally adapted decision aid tool for patients with ESRD, their family caregivers and health care providers in Saudi Arabia: mixed methods study

Consent Form

Please tick the appropriate boxes	Yes	No		
Taking Part in the Project				
I have read and understood the project information sheet dated 06/07/2021 or the project has been fully explained to me. (If you will answer No to this question please do not proceed with this consent form until you are fully aware of what your participation in the project will mean.)				
I have been given the opportunity to ask questions about the project.				
I agree to take part in the project. I understand that taking part in the project will involve taking part in an online individual expert panel discussion and that this will be audio recorded and transcribed. Any identifiable information will be removed.				
I understand that my taking part is voluntary and that I can withdraw from the study within 3 weeks ; I do not have to give any reasons for why I no longer want to take part and there will be no adverse consequences if I choose to withdraw.				
How my information will be used during and after the project				
I understand my personal details such as name, phone number, address and email address etc. will not be revealed to people outside the project.				
I understand and agree that my words (my data) may be quoted in publications, reports, web pages, and other research outputs. I understand that I will not be named in these outputs unless I specifically request this.				
I understand and agree that other authorised researchers will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form.				
I understand and agree that other authorised researchers may use my data in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.				
I give permission for the data that I provide to be deposited in the University's ORDA data repository so it can be used for future research and learning.				
So that the information you provide can be used legally by the researchers				
I agree to assign the copyright I hold in any materials generated as part of this project to The University of Sheffield.				

Name of participant [printed]

Signature

Date

Name of Researcher [printed]

Signature

Date

Project contact details for further information:

Researcher: Nuha Alatawi

Division of Nursing and Midwifery University of Sheffield Barber House 3a Clarkehouse Road Sheffield S10 2LA Tel: 00966553511700 or 00966591640008 naalatawi1@sheffield.ac.uk

Principal Investigator: Dr Clare Gardiner Division of Nursing and Midwifery University of Sheffield Barber House 3a Clarkehouse Road Sheffield S10 2LA Tel: 0044 114 222 2038 c.gardiner@sheffield.ac.uk

To contact a person outside the project:

Director of Research: Dr Tony Ryan

Division of Nursing and Midwifery University of Sheffield Barber House 3a Clarkehouse Road Sheffield S10 2LA t.ryan@sheffield.ac.uk

Yorkshire Dialysis and Conservative Care Decision Aid (YoDCA)

Permission For Use - Statement

We expect people to inform us when they want to use YoDCA in their research, education and health practices. Copyright © of the Yorkshire Dialysis and Conservative Care Decision Aid (YoDCA) will remain with the University of Leeds and the Leeds Teaching and Hospitals NHS Trust. There is no charge to use YoDCA but users must reference YoDCA, and the following publication, in presentations, reports and publications:

- Winterbottom A, Mooney A, Russon L, Hipkiss V, Williams R, Ziegler L, Finderup, J, Bekker HL. The Yorkshire Dialysis Decision and Conservative Care Aid Booklet (YoDCA). (2020) University of Leeds, Leeds, UK. [date accessed from https://www.kidneyresearchyorkshire.org.uk/wp-content/uploads/2020/09/Diaysis-Conservative-Care-FINAL-SEPT-2020.pdf]
- Winterbottom A, Bekker HL, Russon L, Hipkiss V, Ziegler L, Williams R, Mooney A. Dialysis versus Conservative Care Decision Aid: study protocol. Journal of Kidney Care. 2018; 3:3:179-185. <u>https://doi.org/10.12968/jokc.2018.3.3.179</u>

YoDCA cannot be amended in any way without consultation with the YoDCA Team. It is expected researchers will contact the YoDCA team when they need to translate and validate other language versions of YoDCA for use in their education, research and health practices. It is expected that they will send the YoDCA team translated versions of YoDCA, and associated publications. These resources will be included in the YoDCA repository, and be freely available to use. We will notify you of any requests to use the relevant version. Copyright © of the translated and validated versions will remain with the YoDCA team.

Permission for Use - Details

We would like to collect your name and contact details so that we can get in touch with you in the future about your use of YoDCA. We will use this information so that we can review how useful YoDCA is to the research, educational, people with kidney disease, and healthcare services. We may also contact you in future regarding your request and to see if we can use it to improve YoDCA. This information will further support our research, which we carry out in the public interest.

Contact the YoDCA team for more details:

Anna Winterbottom, Senior Research Psychologist <u>A.E.Winterbottom@leeds.ac.uk</u> Hilary Bekker, Professor of Medical Decision Making <u>H.L.Bekker@leeds.ac.uk</u> Andrew Mooney, Consultant Nephrologist <u>andrew.mooney2@nhs.net</u>

Yorkshire Dialysis and Conservative Care Decision Aid (YoDCA)

Permission For Use - Form

Thank you for your interest in YoDCA and our research. Please complete the details below. Name & Affiliation:

Nuha Ayad H Alatawi PhD researcher

Health Sciences School

Division of Nursing and Midwifery

The University of Sheffield

Name & Affiliation of Supervisors and Collaborators:

Clare Gardiner PhD

Professor of Palliative Care Co-Director Mesothelioma UK Research Centre Health Sciences School The University of Sheffield

Jane Seymour Professor

Emeritus Professor of Palliative and End of Life Care Health Sciences School The University of Sheffield

Contact Email(s):

naalatawi1@sheffield.ac.uk

c.gardiner@sheffield.ac.uk

jane.seymour@sheffield.ac.uk

Purpose of Use (tick all that apply):

Education/ Training 📃 Research 📕 Kidney Services/ Quality Improvement 🗌

.....

.....

Other (please state)

Location of Use (state town and country):

The decision aid tool or booklet will be used in Tabuk City, Kingdom of Saudi Arabia. ...

Translation Agreement Required: yes 📕 no 🗌

State translation method:

The decision aid tool or booklet will be translated into the Arabic language with a forwardbackward translation by a professional translator.

.....

.....

..... I agree to the terms and conditions of use (insert signature & date):

16/05/2022Nuha Alatawi

.....

The YoDCA team grant permission for YoDCA to be used according to these terms & conditions (YoDCA team member signature &

Contact the YoDCA team if you cannot access YoDCA directly from this link: https://www.kidneyresearchyorkshire.org.uk/wp-content/uploads/2020/09/Diaysis-Conservative-Care-FINAL-SEPT-2020.pdf

Appendix 12: Certified Back Translation Version 6C

Qalam for Certified Translation قلعم للترجمة المعتمدة

إلى من يهمه الأمر TO WHOM IT MAY CONCERN

إفسادة

AFFIDAVIT

To Whom It May Concern Greetings,

Qalam We. for Certified Translation, CR No. 1010625723, hereby certify that attached translation is correct and identical to the attached original document.

إلى من يهمه الأمر تحية طيبة ويعد

بهذا نشهد نحن مؤسسة قلم للترجمة المعتمدة، سجل رقم 1010625723, بأن الترجمة المرفقة صحيحة ومطابقة للنص الأصلى المرفق.

Best Regards,

وتفضلوا بقبول وافر التحية والتقدير

قلم للترجمة المعتمدة Qalam for Certified Translation

Albaraa Bahhari





٢٠٢٣ تقاطع ش التحلية (الأمير محمد بن عبدالعزيز) مع ش العليا، الرياض ١٢٢٢٢- ٧٩٥٥ - رقم السجل ١٠١٠٦٢٥٧٢٣ - رقم العضوية ٥٤٩٤٦٢
 2073 The intersection of Tahlia (Prince M. bin Abdulaziz) St. and Olaya St. - Riyadh 12222-7795 - CR No. 1010625723 - Membership No. 549462

 Tel.: (+966) 011-4612809

 Mobile: (+966) 0567206262
 www.qalam.info

 E-mail: info@qalam.info
 www.qalam.info

Appendix 13 : Tool Content Validity Exercise Appendix 13 A Tool Content Validity Participants Information Sheet

Participant Information Sheet 08/06/2022 version 1

An online individual interview with an expert healthcare provider

Title of the study: The feasibility and acceptability of a culturally adapted decision aid tool for patients with kidney disease their family caregivers and health care providers in Saudi Arabia: mixed methods study.

I would like to invite you to take part in an online consultation interview (one to one individual interviews) as part of a research study about developing a new decision aid tool for patients with End Stage Renal Disease (ESRD), their family and health care providers. Before you decide whether or not to participate, I would like you to understand why the research is being done and what it will involve for you. Please take time to read the following information carefully and discuss it with others if you wish. If you have any questions about this study, please feel free to contact a member of the research team using the contact details at the end of this information sheet. Thank you for reading this.

What is the project's purpose?

This aim of this study is to develop a 'decision aid' tool for patients with kidney disease and their families. Due to complexity, the time, and costs required for developing the DA tool, adapting an existing DA tool, which is Yorkshire Dialysis and Conservative Care Decision (YODCA) Booklet, could be a solution for other cultural settings. This tool was established in English-speaking County, so, it must be linguistically translated and culturally adapted to Saudi Arabia or Muslim context. Therefore, to improve the quality of the pre-final version of the culturally adapted for both translated and non-translated versions of the YODCA booklet before it is tested in clinical settings in Saudi Arabia, I would like to conduct a virtual individual expert interview to test the validity and acceptability for both Arabic and English version of the booklet. This process includes critical appraisal of the culturally adapted booklet content and making comments in terms of three main points: culturally appropriateness; linguistically appropriateness; and plan of utility in clinical settings.

Why have I been chosen?

You have been invited to take part in this study because you have experience in a clinical role or an academic/research role. In addition, you have experience either in renal care, discussion care planning, decision-making, or palliative care. A maximum of 3 experts who have been chosen to take part will be invited to participate in the online individual consultation interview.

Do I have to take part?

Your participation is entirely voluntary, and it is up to you to decide. If you decide to take part, you will receive your information sheet and consent form copy via email to keep and you will be required to sign a consent form and send it back to me via email to show you have agreed to take part. If you decide to take part, you are still free to withdraw at any time without giving a reason. This would not affect your work. If you choose to withdraw after the discussion has started, information already collected from you will still be used.

What will happen to me if I take part?

Taking part will involve participating in an online individual interview with a researcher. This can be conducted via video/tele call through google meets (hangouts). Before conducting the interview discussion, all supported materials such as the YoDCA booklet and interview guide will be provided to you in advance.

During the interview, I will explore the culturally and linguistically appropriateness of the YoDCA booklet for the Muslim context. The discussion will focus on content validity by evaluating the cultural adaptation of the YoDCA

booklet and ensuring the validity of the content of the YoDCA booklet in terms of cultural appropriateness, relevance, usefulness, and transparency. The linguistic assessment aims to provide information about translation and how the content is understood. To ensure that the YoDCA booklet is clear, understandable, and uses the clinical setting's own terminology. Moreover, consider its utility by assessing how practical it is to use the tool or booklet in the field. Then, the recommendations of the experts that are presented in this discussion will be reflected in the draft of suggestions for future changes to the pre-final version of the tool for future field-testing. The online interview will last approximately 40–60 minutes, and I will record the online discussion using an audio tape recorder. The purpose of recording is to allow me to capture all the information discussed, which is important for me to analyse later.

If you wish to take part, please reply to this email or ring the contact number below. The discussion date and time will be arranged to suit you. Once you have agreed, I will send you an email including a link to join the call, time and date of this discussion. Kindly read the consent form and if you agree to participate, sign the form and send back to the researcher email.

What are the possible disadvantages and risks of taking part?

There are no anticipated disadvantages or risks to taking part in this study. This individual discussion or interviews are used to test the validity and acceptability of the culturally adapted and translated and non-translated YoDCA tool. Moreover, to obtain expert suggestions for future changes to the tool pre-tested in the dialysis unit in Saudi context. If you feel upset or uncomfortable, you can stop the discussion at any time.

What are the possible benefits of taking part?

There are no anticipated benefits for those people participating in the project. The information from this study may reflect on your experience of suggesting improvements to the pre-final version of the culturally adapted and translated decision aid tool that might meet your patients' needs. In addition to drafting a preliminary implementation plan of the adapted tool in clinical settings. Taking a part in a project would improve your understanding of the types of information that patients and their family may need to plan their future care during their disease journey. Also, improve decision making engagement process and future care planning discussion.

Will my taking part in this project be kept confidential?

All the information that I collect about you during the course of the research will be kept strictly confidential and will only be accessible to members of the research team. All information will be anonymised. All recordings will be deleted at the end of the study while transcripts will be stored securely.

All data collected will transfer to University Drive by Virtual Private Network (VPN), when working remotely. All research data collected as paper copied will be scanned and stored in a folder on the University's secure X: drive with secured password.

Anonymised transcripts will be kept for 10 years, in line with University of Sheffield recommendations (Uos, 2018. Preserving your data. Retrieved from <u>www.sheffield.ac.uk/library/rdm/preserving</u>).

You will not be able to be identified in any reports or publications unless you have given your explicit consent for this. The data I collect will be used only for the purposes of this research; if the data were to be used for future studies, further research Ethics Committee approval will be sought.

What is the legal basis for processing my personal data?

According to data protection legislation, we are required to inform you that the legal basis we are applying in order to process your personal data is that 'processing is necessary for the performance of a task carried out in the public interest' (Article 6(1) e). Further information can be found in the University Privacy Notice www.sheffield.ac.uk/govern/data-protection/privacy/general.

What will happen to the results of the research project?

Direct quotes from the online individual interviews may be used in report and publications; however, the quotes will be anonymised to ensure that you cannot be identified. The results of this study will be published in medical

journals and /or presented at conferences. A summary of the results will be sent to the King Salman Armed Forces Hospital research department and your email. You will not be identified in any publications report without seeking your full consent. Due to the nature of this research, it is very likely that other researchers may find the data collected to be useful in answering future research questions. In this case further research Ethics Committee approval will be sought for your data to be shared in this way.

Who is organising and funding the research?

This project is being carried out by Nuha Alatawi, who is a PhD student researcher at the Division of Nursing and Midwifery at the University of Sheffield.

Who is the Data Controller?

University of Sheffield and King Salman Armed Forces Hospital (KSAFH) will act as the Data Controller for this study. This means that the University and KSAFH are responsible for looking after your information and using it properly.

Who has ethically reviewed the project?

This project has been ethically approved via the University of Sheffield's Ethics Review Procedure, as administered by 'Division of Nursing and Midwifery' department' and this project has been ethically approved via King Salman Armed Forces Hospital Ethics Review Procedure.

What if something goes wrong and I wish to complain about the research?

If you have a concern about any aspect of this study, you should ask to speak to me -Nuha Alatawi- the researcher, and I will do my best to answer your questions. My contact details are at the end of this information sheet. If you remain unhappy and wish to complain formally, then you can contact the person outside of the study, Dr Tony Ryan who will then escalate the complaint through the appropriate channels, his contact details are at the end of this information sheet.

If you feel that the University has not dealt correctly with your personal data you can complain to the Information Commissioner's Office <u>https://ico.org.uk/make-a-complaint/</u>

Contact for further information

Please ask the research team:

Researcher: Nuha Alatawi

Division of Nursing and Midwifery

University of Sheffield

Barber House

3a Clarkehouse Road

Sheffield S10 2LA

Tel: 00966553511700 or 00966591640008

naalatawi1@sheffield.ac.uk

Principal Investigator: Dr Clare Gardiner

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Division of Nursing and Midwifery University of Sheffield Barber House 3a Clarkehouse Road Sheffield S10 2LA Tel: 0044 114 222 2038 c.gardiner@sheffield.ac.uk

To contact a person outside the project:

Director of Research: Professor Tony Ryan Division of Nursing and Midwifery University of Sheffield Barber House 3a Clarkehouse Road Sheffield S10 2LA t.ryan@sheffield.ac.uk

Thank you for considering taking part in the research. If you would like to participate will be given a copy of the information sheet and please fill out the consent form then return it to the researcher, a signed consent form to keep.

Appendix 13B: Tool Content Validity Consent Form

Consent form an online individual interview with an expert healthcare provider version 1

The feasibility and acceptability of a culturally adapted decision aid tool for patients with ESRD, their family caregivers and health care providers in Saudi Arabia: mixed methods study

Consent Form

Please tick the appropriate boxes	Yes	No		
Taking Part in the Project				
I have read and understood the project information sheet dated 08/06/2022 or the project has been fully explained to me. (If you will answer No to this question, please do not proceed with this consent form until you are fully aware of what your participation in the project will mean.)				
I have been given the opportunity to ask questions about the project.				
I agree to take part in the project. I understand that taking part in the project will involve taking part in an online individual interview and that this will be audio recorded and transcribed. Any identifiable information will be removed.				
I understand that my taking part is voluntary and that I can withdraw from the study within 3 weeks ; I do not have to give any reasons for why I no longer want to take part and there will be no adverse consequences if I choose to withdraw.				
How my information will be used during and after the project				
I understand my personal details such as name, phone number, address and email address etc. will not be revealed to people outside the project.				
I understand and agree that my words (my data) may be quoted in publications, reports, web pages, and other research outputs. I understand that I will not be named in these outputs unless I specifically request this.				
I understand and agree that other authorised researchers will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form.				
I understand and agree that other authorised researchers may use my data in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.				
I give permission for the data that I provide to be deposited in the University's ORDA data repository so it can be used for future research and learning.				
So that the information you provide can be used legally by the researchers				
I agree to assign the copyright I hold in any materials generated as part of this project to The University of Sheffield.				

Name of participant [printed]

Signature

Date

Name of Researcher [printed]

Signature

Date

Project contact details for further information:

Researcher: Nuha Alatawi

Division of Nursing and Midwifery University of Sheffield Barber House 3a Clarkehouse Road Sheffield S10 2LA Tel: 00966553511700 or 00966591640008 naalatawi1@sheffield.ac.uk

Principal Investigator: Dr Clare Gardiner Division of Nursing and Midwifery University of Sheffield Barber House 3a Clarkehouse Road Sheffield S10 2LA Tel: 0044 114 222 2038 c.gardiner@sheffield.ac.uk

To contact a person outside the project:

Director of Research: Professor Tony Ryan Division of Nursing and Midwifery University of Sheffield Barber House 3a Clarkehouse Road Sheffield S10 2LA t.ryan@sheffield.ac.uk
Appendix 14: Confidentiality Agreement Non-Disclosure Form



Division of Nursing and Midwifery

Confidentiality Agreement for use with School of Nursing & Midwifery

Research Study Title: the feasibility and acceptability of a culturally adapted decision aid tool for patients with ESRD, their family caregivers and health care providers in Saudi Arabia: mixed methods study

1. I, ______ transcriptionist, agree to maintain full confidentiality of all research data received from the researcher related to this research study.

2. I will hold in strictest confidence the identity of any individual that may be revealed during the transcription of interviews or in any associated documents.

3. I will not make copies of any audio-recordings, video-recordings, or other research data, unless specifically requested to do so by the researcher.

4. I will not provide the research data to any third parties without the client's consent.

5. I will store all study-related data, including video and audio recordings and transcriptions in a safe and secure location in a restricted access folder as long as they are in my possession.

6. All data provided or created for purposes of this agreement, including any back-up records, will be returned to the researcher or permanently deleted. When I have received confirmation that the transcription work, I performed has been satisfactorily completed, any of the research data that remains with me will be returned to the researcher or destroyed, pursuant to the instructions of the researcher.

7. I understand that University of Sheffield has the right to take legal action against any breach of confidentiality that occurs in my handling of the research data.

Transcriber's name (printed)

Transcriber's signature _____

Date _____

Appendix 15: The YoDCA Cultural Adaptation and Translation Process Timeline



Appendix 16: Additional Minor Alterations for Version 1

Some additional considerations were made when developing version 1 to make it more appropriate for the targeted audience in a Muslim context. These are the following:

- This sentence was removed from the adapted version: 'More copies of this booklet are available from Kidney Research Yorkshire's website www.kidneyresearchyorkshire.org.uk/home/yodca or ask your kidney team.' Because of this electronic version, refer to the original tool and not the adapted version. Due to limited time and resources, the adapted version is available only in hardcopy.
- The following statements were added 'Remember to bring this decision aid to your next appointment with your kidney professional. Having it at hand maybe useful when discussion treatment options.'
- There are some services that are not available in Saudi Arabia's daily practices, such as patient support groups, home dialysis, continuous ambulatory peritoneal dialysis, hospice care, and community nursing. So, we should not talk about the services that are not available. All these services were removed from the text and glossary in version 1. Keeping such services in the adapted version while they are unavailable will cause users of DA tools to become confused.
- Other useful phone numbers were removed from page 23, including those for the hospital switchboard, renal pharmacists, palliative care specialists, and general practitioners, as this was not related to patients who were visiting Saudi Arabia's healthcare facilities.
- The useful information and links for people with EKD and their friends and families on page 23 were updated with resources and links that provided extra information in Arabic, as advised by the Saudi Ministry of Health.
- The reference list was updated, and new references that were used within the text were added.

Appendix 17: Meeting Agenda with the Original Authors

Agenda	Meeting of Adapted Decision Aid Tool and Copyright Process
Date and time:	Monday 13 th December 2021 at 11.00am
Location:	Via Google Meets
То:	Yorkshire Dialysis and Conservative Care Decision Aid (YoDCA)
	Study team: Anna Winterbottom, Hilary Bekker, Yvette Bell
In attendance:	Clare Gardiner and Nuha Alatawi

Welcomes and Hello's

Catching up and small talk

> Summary of Findings

The interviews focused on four themes.

- Overall attitude toward the DA tool
- Content and comprehension of information
- Sociocultural appropriateness
- Application and implementation of the DA tool

Summary of Modifications

- Cultural Adaptation
- Clinical Adaptation

Discussion about adaptation

Talk about adapted parts to reach agreement, seek approval, and answer questions.

> Next step and summary

- Copyright Process
- Tool Translation

Appendix 18: Additional Minor Alterations for Version 2

Further, other slight general modifications made in version2:

- On page 2, I removed this sentence, 'More copies of this booklet are available from Kidney Research Yorkshire's website, www.kidneyresearchyorkshire.org.uk/home/yodca,' from the newly adapted tool because it will confuse the users since the online version is the original version and is in English, which is not appropriate for Saudi Arabian culture. I wrote it as follows: For more copies of this booklet, ask your kidney team.
- On page 9, I removed this sentence: 'All kidney units follow national guidance about the care they offer [e.g., NICE NG107 4]' because it refers to a different situation (guidance/guidelines) in Saudi Arabian clinical settings.
- On page 15, I removed this sentence: 'People who decide to have dialysis choose the type that best fits their lifestyle.' See the Dialysis Decision Aid for facts about haemodialysis (HD) and peritoneal dialysis (PD) options. This sentence refers to the previous tool, which was developed for western-cultured people in the English language. Therefore, I replaced this sentence with 'People who decide to have dialysis choose the type that best fits their lifestyle. On page 25, you'll find useful information and links for people with EKD, their friends, and family'. This page includes Arabic leaflets for patients about CKD and its management.
- On page 15, I kept the term 'end of life,' but I defined it as follows: End-of-life care, as defined in the National End of Life Strategy (2008), is total care that helps all those with advanced, progressive, and incurable illnesses live as well as possible until they die. It enables the supportive and palliative care needs of both patients and families to be identified and met throughout the last phase of life and into bereavement. It includes the management of pain and other symptoms and the provision of psychological, social, spiritual, and practical support.

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