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Exploring the barriers and facilitators towards implementation of shared decision-making in primary healthcare centres in Saudi Arabia

by

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Declaration

I, Nouf Alsulamy, hereby confirm that the work presented in this thesis is entirely my own. This thesis is submitted in the **Publication Format Thesis**, which allows the thesis to include academic publications in addition to traditional thesis sections. Three published papers are included in Chapters 2, 3 and 6 of my PhD thesis.

Student Contribution to the Papers

The PhD student developed the study protocol/methods, collected and analysed the data, and drafted the final manuscripts. Supervisors (Dr Andrew Lee and Dr Praveen Thokala) reviewed and contributed to the protocols and manuscripts.

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Abbreviations

BCW: The Behaviour Change Wheel

CASP: Critical Appraisal Skills Programme

COM-B: (capability, opportunity, motivation, and behaviour) model

CINAHL: Cumulative Index to Nursing and Allied Health Literature

EHR: Electronic Health Records

EThOS: Electronic Thesis Online Service

EMR: Eastern Mediterranean Region

MMAT: Mixed Methods Appraisal Tool

MOH: Ministry of Health

PCPs: Primary Care Physicians

PHCCs: Primary Health Care Centres

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

PsychINFO: Psychological Information Database

SDM: Shared Decision-Making

WHO: World Health Organization

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Abstract

Background: Shared decision making (SDM) is considered as a key component of patient-centred care and has been incorporated into national policy in several countries. The value of SDM has been supported by the research in improving the knowledge of patients about their treatments, improve patients' confidence and coping skills, reducing the number of major surgeries and emergency admissions, and improving patients' health outcomes and satisfaction with the clinical encounter. Despite the benefits of SDM and the policies that support its implementation, SDM is not yet embedded in clinical practice especially in non-Western countries and it confronts many barriers that hinder its implementation. There is a clear need to identify factors that facilitate and hinder the implementation of SDM in Saudi Arabia in order to inform strategies for its effective implementation.

Purpose: The overall aim of this PhD research is to develop an understanding of factors influencing SDM implementation in primary healthcare centres (PHCCs) in Saudi Arabia.

Methods: Four studies have been performed in this PhD project. An umbrella review to obtain an overview of barriers and facilitators to implement SDM (Study 1). A systematic review to identify factors that influence the adaption of SDM in the Eastern Mediterranean Region (EMR) (Study 2). A qualitative study to investigate and explore the factors obstructing and facilitating the implementation of SDM in Saudi Arabia from the perspectives of patients with diabetes (Study 3). A qualitative study to investigate and explore the factors obstructing and facilitating the implementation of SDM from the perspectives of healthcare professionals (Study 4).

Results: The findings of the umbrella review made it clear that there is a need to address the gap in the SDM literature by conducting a systematic review focused on non-Western countries to investigate and better understand the challenges and enablers of implementing SDM in these countries. The systematic review findings indicated that additional exploratory qualitative work on barriers and facilitators to SDM implementation would provide much-needed novel and detailed information. The factors revealed in the qualitative studies in Saudi Arabia are comparable to those reported in Western countries and in the EMR, such as the role of patients and their families, a lack of time and resources, and physician attitudes and behaviours. However, there were some additional important factors specific to Saudi

Arabia relating to the healthcare organisations and the health system. All the four studies demonstrated the importance of effective physician-patient communication in the success of SDM.

Conclusions: The major findings in this thesis contribute significantly to the literature on SDM, particularly in terms of factors that influence the implementation of SDM in non-western communities. Although they indicate some key similarities with existing literature, they also reveal that influential factors differ across countries and should be studied in different health systems and countries. SDM implementation necessitates structural, as well as cultural and attitudinal, changes among physicians and patients. Future researchers will be able to develop culture sensitive interventions as a result of these findings.

Dissemination

Publications of Thesis Chapters

Chapter 2

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Chapter 3

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Chapter 6

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Alsulamy N, Lee A, Thokala P. Shared decision-making in Primary Healthcare Centres in Saudi Arabia: The Perspectives of Patients with Diabetes. Sheffield Institute for International Development Postgraduate Research Conference. 2021

Chapter 1 General Introduction

1.1 Introduction

This chapter introduces shared decision making (SDM) and explains various medical decision-making models, as well as providing an overview of Saudi Arabia's cultural background and health-care system. The aim and objectives are then presented, along with the novelty and contribution to original knowledge.

1.2 Models for Medical Decision-making

Over the years, the practice of medicine has undergone extraordinary shifts in the relationship between patients and physicians (1). The role of the patient in decision-making has also changed as a result of the prevailing models of health care (2). These distinct models, which will be discussed in this section, vary in the degree of patient involvement in treatment decision-making. The first model is paternalism, where the physician dominates the process of decision-making and makes the final decision. Second is the informed model, where the patient dominates the process and makes the decision. Third, shared model where both the physician and patient share the process and make the decision.

1.2.1 The Paternalistic Model

In the paternalistic model, physicians dominate the process of decision-making as they assess the patient condition and select treatment based on the probabilities of its effectiveness (3). Paternalism is defined as "the intentional overriding of a person's known preferences or actions by another person, where the person who overrides justifies the action by the goal of benefiting or avoiding harm to the person whose will is overridden" (4). The process of decision-making in the paternalistic model is managed and controlled by the physician, patient's values or preferences for participation in this model are ignored, and there is no contribution or input from the patients (3,5). From an ethical perspective, this model does not consider the patient's ethical and legal rights to choose the treatment (6), and does not respect their values and preferences.

1.2.2 The Informed Model

In contrast to the paternalistic model, the patient is the dominator in the informed decision model where the physician provides the patient with information about harms and benefits for each treatment options and then, the patient decides alone which treatment to undertake (3). The informed model provides the patient with full autonomy and respects the patient's rights in receiving information and making decisions. However, the informed model has been critiqued for several reasons. First, the physician in the informed model may not provide the patient with sufficient information that supports the patient’s decision (7). Patients are different in their knowledge and experiences; as a result, the amount of needed information varies between them, and not considering these differences may affect the decision. The second critical aspect is how this information is interpreted by the patient (8). They may over or underestimate their illnesses depending on how they understand or interpret the information that they receive from their physician. Therefore, the way of communication between physicians and patients may influence the decisions made (9).

1.2.3 The Shared Model

The paternalistic and informed models indicate that there is an asymmetrical relationship between patients and physicians when decisions are being made (10). As a result of this recognition, SDM was adopted as an approach that fits between those two models where the patient and physician share the process of decision-making to a varying degree (11). SDM and its advantages are described in detail in the next sections.

1.3 Shared Decision Making

1.3.1 What is Shared Decision Making?

Many definitions and terms have been used in the literature to describe SDM which include ‘patient engagement’, ‘patient involvement’, ‘patient participation’, 'shared decision', ‘patient-centeredness’ and ‘informed choice’. In addition, a number of models have been identified that conceptualize SDM; however, there was no shared or universal definition, as demonstrated in a systematic review conducted by Makoul and Clayman to review the definitions and models of SDM (11), and as emphasised in another recent systematic review (12). It was suggested that what an SDM process comprises may vary depending on the healthcare settings, thus having multiple models and selecting the one that best suits one's needs may be beneficial (12); and pursuing a single, unified model may be both impractical and counterproductive (12).

The important elements of SDM in the most leading conceptual definitions included clarifying problem, creating choice awareness, introducing options, discussing benefits and risks, evaluating patient's preferences, discussing the patient ability, providing recommendations from physicians, checking patient's understanding, making-decision, and arranging follow-up (11,12). For instance, Elwyn and Coulter defined SDM as an approach where physician and patient work jointly utilizing the best available evidence to make decisions that considers patient's preferences (13). Likewise, Coulter and Collins defined SDM as a collaborative process that includes the patient and their physician when they clarify treatment, and share information about the best evidence of all the available options to make agreed clinical decision, which considers patient preferences (14). This assumes that the physician and patient should agree in the decision being made: however, others have argued that disagreeing or agreeing is also acceptable within SDM (11).

Charles and colleagues identified some key characteristics for SDM (15). The first characteristic is that there are at least two participants, physician and patient, involved in the process of decision-making. Second, both parties take steps to reach an agreement about the treatment decision. Third, the prerequisite for SDM is information sharing. Finally, both participants agree on the decision that is made.

SDM arises in situations where there is more than one medically acceptable option and where no specific solution is best for everyone (16). Considering patients' preferences toward the risks and benefits are important in such decisions (14). The SDM thus helps patients to choose the most appropriate treatment that suits their preferences. According to Lee and Emanuel, SDM is a preference-sensitive approach where the involved parties make mutual decisions by focusing on the best treatment for the patients (17).

SDM emphasises providing the patient with sufficient information about the available treatment and outcomes, including harms and benefits to support the patient to understand their condition and to make an informed decision. One of the most common reasons of dissatisfied patients with health services is that they are not being provided with information related to their condition and available treatment options (18). Research shows that patients' wishes to have information are more than what physicians think (19,20), and patients often are unaware of the available options (21). Therefore, SDM has highlighted the importance of providing patients with sufficient information.

1.3.2 Implementation of Shared Decision Making

SDM implementation is a long pathway involving many steps. As previously stated, there is no agreement in the field on what the SDM process entails, and it may differ depending on the healthcare settings (11,12). It is important for healthcare professionals who want to practice SDM to understand that there is no consensus in the field, only that some components appear to be more important to SDM than others (12).

SDM involves at least two experts in the consultation: the healthcare professional who is an expert on the knowledge of the diagnosis, treatment options, and potential side effects of each treatment; and the patient who is an expert on their personal attitude to risk, values, preferences and the appropriateness of the chosen treatment with their lifestyle (14). For SDM to occurs, both the clinician and patient must be willing to accept the responsibility for exchanging information and sharing the decision. The information related to the diagnosis and different treatment options must be provided by the physician, and the patient must inform the physician about their preferences (22). This process could be dyadic, but it could also involve many different individuals (e.g., families, health educators, nursing). Although the majority of research on SDM has centred on physicians, it is applicable to others, including nursing and allied health (23). SDM entails more than simply directing patients to a decision aid. It also necessitates physicians assessing what patient needs in order to make a decision and providing them with appropriate decision support (14). The physicians should adopt a consulting style that is curious, supportive, and non-judgmental, as well as one that communicates evidence about pros and cons in an unbiased manner (14).

SDM therefore requires physicians to have good communication skills in order to involve patients in the decision-making process and encourage them to express their views and preferences, as well as patients to play an active role in the process. This highlights the importance of building a good relationship between the patient and physician that leads to effective interaction and sharing between them. In this thesis, we focus specifically on the interaction between physicians and patients when making a decision as an essential element in SDM.

1.4 Benefits of Shared Decision-Making

SDM supports rights of the patient to be provided with information related to the available treatments, and empowers them to have an active role in the process of decision-making related to their own health. Implementing SDM has been shown to improve patients' confidence and coping skills, reduce the number of major surgeries, improve decision quality and decision-making processes, and increase patients' awareness of the benefits and risks associated with various treatment options (13,24–26). Moreover, SDM increases the appropriateness of service use and decreases emergency admissions (27,38). SDM may reduce overdiagnosis and overtreatment of conditions, lowering overall healthcare costs (29).

SDM also improves patient satisfaction. Patients are more satisfied when they are informed about the available treatment options and have a say in selecting the option that best meets their needs (30). Researchers reported that SDM has been associated with patient satisfaction. For instance, Scheibler and colleagues in their systematic review found that SDM was linked to improving patient satisfaction (31). Likewise, a national study conducted in the USA including more than 1000 participants with major depression found that SDM improved patient satisfaction (32). Similarly, strategies that support SDM and use to involve the patient or their family in decision-making are found to improve satisfaction with care (33).

SDM increases patients adherence to their treatment, feedback from health care professionals suggests that patients who are involved in the decision about their care are likely to have more treatment adherence (34). For example, dieticians in Canada found that patients are more likely to follow the chosen treatment or plan if they share and agree on the decision with their physicians (35). Likewise, a randomised trial conducted on patients with asthma found that SDM is associated with greater treatment adherence and better health outcomes such as improved quality of life and control of the symptoms over a two-year period (36).

1.5 Limitations of Shared Decision-Making

Despite the push toward SDM, it is important to note that SDM has limitations as well. SDM is based on the quality of the relationship between physicians and patients that allows the exchange between them throughout the process of decision-making (37). Nevertheless, this relationship may not always exist which may affect the communication between the patient and physician and the quality of the decision (9). Some patients are hesitant or uncomfortable discussing their health concerns with physicians with whom they have no prior relationship. Other patients may come from cultural backgrounds where individuals are not expected to make autonomous decisions, making it difficult for them to engage with their physicians.

SDM necessitates the disclosure of information about risk and uncertainty, which can be detrimental to patients (38). Even though a number of studies revealed no difference in reported side effects between patients who were given pertinent information and those who were not (39,40), it is still a source of concern. In addition, SDM requires mental capacity of the patient and cannot be used with certain patients who suffer from a particular mental disease (41). In this regard, SDM may not be suitable for every patient. However, attention has been paid to implement SDM even in complex settings, which involve people who are mentally ill (42–44).

SDM requires more time from physicians to engage with patients in SDM, which can increase the consultation time. However, the effect of SDM on consultation length remains unclear, as some studies have found increases in consultation time to engage in SDM, while others have suggested that SDM could be practised within the usual consultation time (45-47). Medical malpractice is another issue that concerns the hospitals and providers. Patients who choose not to have procedures or screening through SDM but later develop a more serious condition may be more likely to sue (48). Although the impact of SDM on malpractice lawsuits is unclear, it remains a source of concern.

1.6 Background of Saudi Arabia

1.6.1 Cultural Background

Saudi Arabia is the largest country in the Middle East that is bordered by Jordan, Iraq, Kuwait, Qatar, United Arab Emirates, Oman, Yemen and Bahrain. Saudi Arabia has a population estimated to be around 35 million in 2020 (49). The proportion of people aged below 15 years in Saudi Arabia is (24.4%) while people aged 15-64 is (72.4%) (49). The percentage of people who are aged 65 and above is (3.2%) (49). Most of the population (83.33%) of Saudi Arabia live in urban areas, which means that there are several sizable cities (50). Riyadh is the capital and largest city, with a population of approximately 9 million; Jeddah is the second largest, with a population of approximately 5 million (49). The literacy rate among the population that is aged 15 years and older in Saudi Arabia is 96.53% in males and 91.37% in females. While the literacy rate among the population that is aged 65 years and older in Saudi Arabia is 64.96% in males and 36.6% in females, the literacy rate among the population that is aged 15-24 years is about (99%) on both females and males (51). The current (94.4%) literacy rate was achieved by increasing enrolment in schools and universities with the aim of achieving (100%) literacy in the near future (52). In 2018, the government has invested US$51 billion in the education sector as part of its new vision, Vision 2030, to eradicate illiteracy by 2024 (52).

Arabic is the native language, and Islam is the religion for almost all Saudi people. Saudi Arabia is home to Mecca and Madinah, the two holiest cities in Islam. As a result, the country receives a large number of Muslims visitors from around the world every year for performing Haj and Umrah that are Islamic practices, which must be conducted at least once. Saudi people have been influenced by the culture of these visitors and become open to many other different cultures. However, Saudi culture remains family oriented, and Islam and Arab tradition are the factors that shape this culture and influence Saudi' beliefs, attitudes, and the way of their communication. As a consequence, these cultural factors may influence the process of SDM in Saudi Arabia.

The health care services in Saudi Arabia have been influenced by two factors: a large number of expats and the high percentage of young people (53,54). These factors and the expected increase in the population from 33.5 million in mid 2018 to 39.5 million in mid 2030 may influence and increase the demand for health care services in Saudi Arabia (53), which may influence the time and degree to which physicians involve patients in the process of decision making, or encourage their active role.

1.6.2 Health Care System in Saudi Arabia

The national health care model is followed in Saudi Arabia in which health services are primarily provided by the government, and patients enjoy these services and treatment free of charge (55). The services in the Saudi health sector are provided by three organisations, with the largest being the Ministry of Health (MOH). The MOH is the primary healthcare provider in Saudi Arabia and operates 58.3% of the total hospitals and all primary healthcare centres (PHCCs) (56). It regulates all activities and services related to health care in the country (56). It also provides many types of free care for the Saudi population including curative, preventive, and rehabilitative (54). Second are the Quasi-Government healthcare facilities which operate 9.4% of the total hospitals (56). The hospitals and health centres under this type are operated by the MOH and often cater for employees of the government organisations like National Guard, Ministry of Defence and Aviation, Ministry of Interior, Royal Commission (56). Third are the private sector facilities that operate 32.3% of the total hospitals. See Figure 1.1, which illustrates the healthcare system in Saudi Arabia.

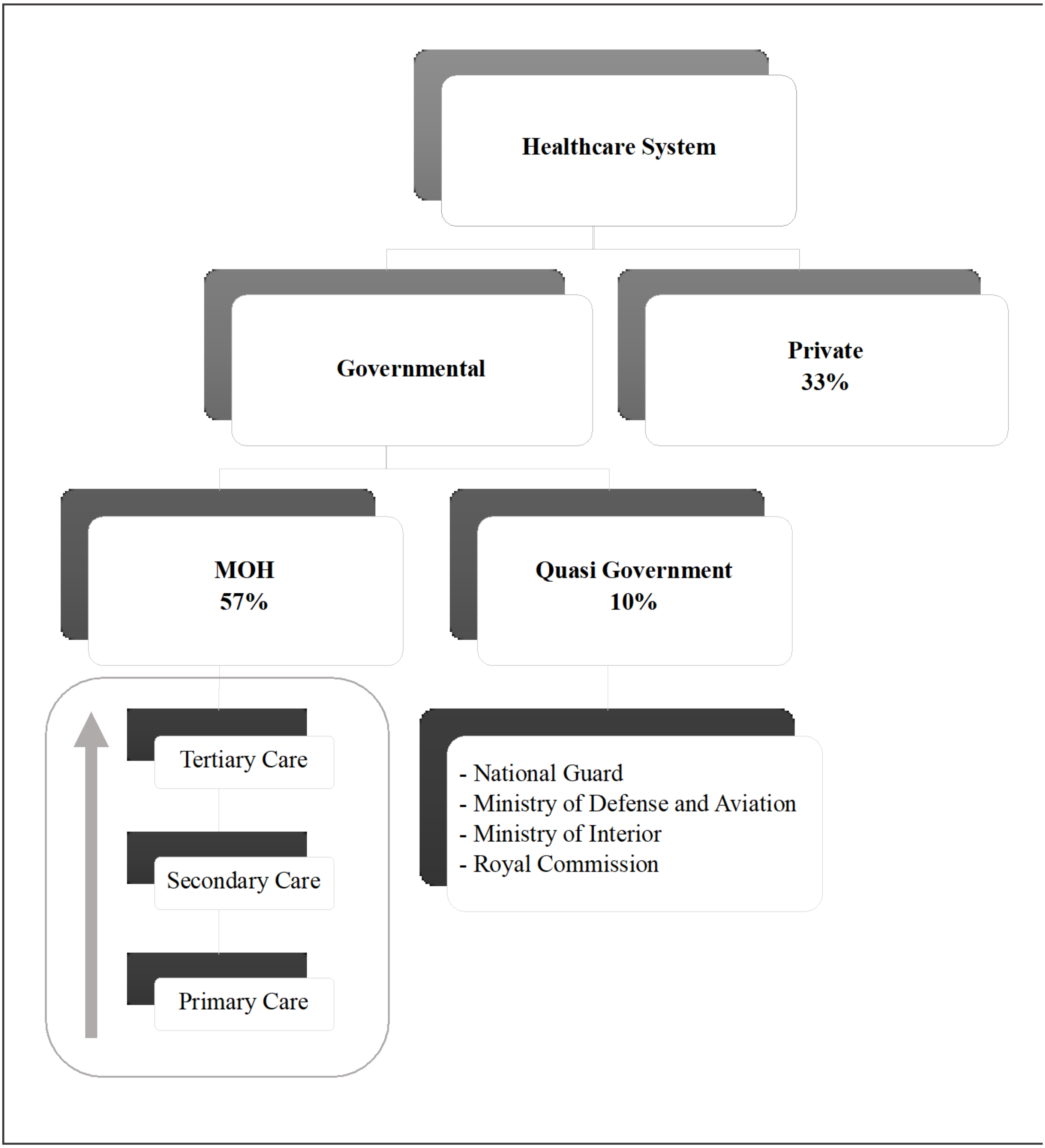

Figure 1.1: Healthcare system in Saudi Arabia

As there are three different providers in the Saudi health sector, it has been difficult to apply consistent regulations for working practice across the Saudi health sector (2). Patients and their rights have been prioritized by the MOH; however, it is unclear what regulations guide the communication between the physician and patient, and the role of the patient in decision-making in these institutions (2). Moreover, the lack of standardized clinical guidelines and poor communication between physicians and patients are reported as challenges in the Saudi health system (53). This is may influence patient involvement, and the process of decision-making.

Saudi Arabia's referral system is theoretically similar to the National Health Service in the United Kingdom. Patients in the Saudi health system first present their symptoms to general practitioners at PHCCs. Referrals to general hospitals are made when general practitioners suspect complications. Patients are assessed by family physicians assigned to hospital-based primary care clinics, who then either refer them to a specialist if their condition needs it or return them to the PHCCs. If a patient's condition is stabilized by a hospital specialist, they are returned to their PHCC for follow-up. However, tertiary care is sought if a patient's condition necessitates a more specialized treatment.

1.6.3 Primary Health Care Centres in Saudi Arabia

The Saudi government is currently prioritizing healthcare services, with a focus on PHCCs. Saudi health sector is rapidly reforming in accordance with the country's national transformation plan. The MOH primary goals are to improve healthcare access, quality, and efficiency, as well as to focus on health promotion and disease prevention (55). Saudi Arabia has already begun to shift its focus to primary care reform and restructuring in order to achieve these aims (55). Saudi Arabia has been focused on incorporating preventive and primary curative health services into PHCCs, which provide a wide range of services such as essential medications, infectious disease control through immunization, basic dental treatment, child and maternal health, chronic disease management and follow-up, and health education (57).

PHCCs are comparable to general practices in the United Kingdom. Each PHCC serves a specific population within its catchment area by providing health care services (58). According to 2020 data, there are a total of 2,257 PHCCs across the country (49). Riyadh city has the most PHCCs with 438, followed by Jazan, Hail, Asser, Eastern, Qaseem, Medinah, and Taif, which each have an average of 155 PHCCs (49) and Jeddah, despite being second largest city, only has 96 PHCCs. PHCCs mainly cover general medicine, family medicine, and obstetrics and gynaecology (57). Psychiatrists and nutritionists, on the other hand, are extremely rare in PHCCs and do not exist in some areas (57). In terms of numbers of health professionals in PHCCs, there are 14,394 physicians, 18,397 nurses, and 14,059 allied health personnel (49). In Jeddah, the 96 PHCCs contain a total of 1347 physicians, 1296 nurses, and 1331 allied health personnel (49).

1.6.4 SDM Status in Saudi Arabia

According to the MOH (53), the Saudi health system presently is centred on resource and staff rather than being patient centred. In addition, it is institution-centric instead of population-centric. However, Saudi Arabia is undergoing fundamental structural changes in all sectors of the country, including healthcare sector, as part of the Vision 2030 national transformation plan. One of the proposed goals of the transformation in the health sector is to improve health care to deliver care that is equitable, effective, safe, and patient-centred. Involving Saudi patients in their treatment plans has been emphasised in their bill of rights (59). In addition, the MOH has developed a program, “the New Models of Care”, to design, pilot, and implement patient-centric approach. The program has been designed based on a number of principles including empowering people and their families to have more control over their health, providing information to people as part of their treatment, and supporting them to be well-informed (53).

1.7 Rationale for Research

SDM is considered as a key component of patient-centred care and has been incorporated into national policy in many countries (60–62). For instance, SDM has been included in national clinical standards in Australia, e.g., for hospital accreditation and medical education (62). In addition, SDM laws have been enacted in five states in the United States, e.g., linking SDM with the formation of Accountable Care Organisation (63). This indicates that the level of awareness in SDM has been rising, and SDM is valued by policymakers, health care users, and health care professionals. The value of SDM has also been supported by the research in improving the knowledge of patients about their treatments and improving their health outcomes and satisfaction with the clinical encounters (27,64,65). Involving patients in the process of decision-making not only has a positive impact in the short term like improved satisfaction and decreased decisional conflict, but also, in the long term such as improved quality of life (66).

Despite the benefits of SDM and the policies that support its implementation, SDM is not yet embedded in clinical practice, especially in non-Western countries and it confronts many barriers that hinder its implementation (68). Many physicians find SDM difficult to implement, and most healthcare systems do not consider it the standard of care. This raises questions about the appropriateness of SDM in these cultures, the reasons behind the delay in practising SDM in these countries, and factors that impede or facilitate its implementation. SDM is not the norm in many contexts and it is seen as a Western medicine construct that is in fashion at the present time, so there are questions as to whether it is directly translatable from a Western context to another (for example, Middle East, African, or Asian) context. Some have claimed that the concept of ‘patient-centred care” and ‘active participation’ are less applicable in these settings as they are more relevant to the Western philosophy of individual autonomy (67,68). However, a previous systematic review, which assessed the feasibility and appropriateness of the strategy of patient-cantered care and patient participation in health decisions in non-Western countries, found that the patient participation research is evolving in these countries (69). In addition, patients and physicians in non-western countries, especially in Saudi Arabia, show positive attitudes and preferences toward SDM (62,70–73).

Saudi Health sector is moving towards a patient centred care approach including SDM, and involving Saudi patients in their treatment plans has been emphasised in their bill of rights (59). Therefore, we need to understand more about SDM in Saudi Arabia. Patients in Saudi Arabia are dissatisfied and frustrated with their care, as they believe they are not given adequate information and are possibly not involved in decision-making (74). There are challenges in the current care model of Saudi Arabia that may influence SDM such as poor coordination of care, especially between MOH and non-governmental organisation, as well as poor communication between providers and between physicians and patients. In addition, the healthcare system currently lacks robust, consistent, and integrated digital information systems (53).

There may be other barriers to SDM at the level of individuals, culture, environment, and organisations that need to be identified and addressed in order to implement SDM. Only a few studies have been published in Saudi Arabia to assess physicians' and patients' preferences toward SDM (70,71,73), and none have investigated issues related to SDM implementation. If the desired goal is to promote and facilitate the integration of SDM into Saudi healthcare system, there is a clear need to identify factors that facilitate and hinder SDM implementation in Saudi Arabia in order to inform strategies for its effective implementation.

1.8 Overall aim and Objectives

1.8.1 Overall aim

The overall aim of this study is to develop an understanding of factors influencing SDM implementation in PHCCs in Saudi Arabia.

1.8.2 Research Objectives

First, I was interested in obtaining an overview of barriers and facilitators to SDM in the literature. Therefore, I decided to undertake a review to be familiar with the most common factors that hinder the implementation of SDM and strategies that have been recommended to facilitate its implementation. From the review, it was found that the literature paid limited attention to implement SDM in non-Western countries, particularly those in the World Health Organization's (WHO) Eastern Mediterranean Region (EMR) (75).

As the culture, social context, and health sector leadership and governance in these countries are different to those in Western countries, and there is a possibility to transfer some lessons between some countries in the EMR, I found it is necessary to understand the perspectives of such countries toward SDM. Therefore, I decided to conduct another review that focused on the factors influences the implementation of SDM in the EMR.

The findings from the second review indicated that additional exploratory qualitative work on barriers and facilitators to SDM implementation would provide much-needed novel and detailed information. The majority of the included studies in the review used a quantitative approach which may restricts respondents from providing more information and limits their responses. Therefore, I decided to conduct two qualitative studies to explore the perspectives of healthcare stakeholders on SDM and its implementation in Saudi Arabia.

The objectives of each of the four studies are briefly outlined below

- **Study 1 objective:** understand the barriers and facilitators to the implementation of SDM

- **Study 2 objective:** identify and understand factors influencing the implementation of SDM in the EMR countries
- **Study 3 objective:** explore the perspectives of patients on SDM and its implementation in PHCCs in Saudi Arabia
- **Study 4 objective:** explore the perspectives of healthcare professionals on SDM and its implementation in PHCCs in Saudi Arabia.

1.9 Research Plan

Having delineated the aims and objectives, I will provide a brief research plan explaining steps to achieve the study aim and objectives. I have conducted four main studies in this thesis to identify the gaps in knowledge. I began by systematically reviewing the literature, , umbrella review to obtain an overview of barriers and facilitators to implement SDM; another systematic review to identify factors that influence the implementation of SDM in the EMR countries. After that, I performed two qualitative studies based on interviewing healthcare stakeholders to investigate and explore the factors obstructing and facilitating the implementation of SDM.

In the next chapters, I will discuss the findings of the umbrella review (Chapter 2), the findings of systematic review (Chapter 3), the methodological strategies selected for the qualitative studies (Chapter 4), the findings of qualitative studies (chapters 5, 6). Finally, I will discuss the thesis's strengths and limitations, the interpretation and implications of the findings, as well as recommendations for future research (Chapter 7)

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Chapter 2 (Study 1): What Influences the Implementation of Shared Decision Making: Un Umbrella Review

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Student Contribution to the Paper

The PhD student developed the study protocol/methods, collected and analysed the data, and drafted the final manuscript. Tourkiah Alessa is the second reviewer who screened the titles and abstracts, and then full-text articles for exclusion or possible inclusion. She also verified the accuracy of the data extraction and quality assessment of all the included studies. Supervisors (Dr Andrew Lee and Dr Praveen Thokala) reviewed and contributed to the protocol and manuscript.

Chapter Overview

This chapter addresses the first objective of the thesis which is understanding the barriers and facilitators to the implementation of SDM.

Abstract

Objective: To provide a cogent summation of the evidence base of the key barriers and facilitators to implementing shared decision-making (SDM).

Methods: An umbrella review of existing reviews on SDM was adopted. Databases were searched from 1997 to December 2018. Studies were included if they performed a review of barriers and facilitators to SDM.

Results: 7 eligible reviews were identified. The five themes identified were: patient factors, professional factors, environmental factors, relationship factors, and factors related to information provision. Lack of time was the main factor hindering the implementation of SDM. Encouragement and motivation of providers to use SDM was a significant enabler of SDM implementation.

Conclusions: The provision of time and resources are insufficient if not accompanied by efforts to support and motivate providers to use SDM.

Practice implications: Healthcare providers need to be educated on the importance of building a relationship with their patients. To enhance this relationship, physicians may need to improve their interaction skills. They need to be curious and explore their patients' preferences, listen to them and respect their opinions, explain options and outcomes, and encourage them to participate in the decision-making.

Keywords: Shared decision making, umbrella review, patient-centred care, barriers/facilitators, implementation

2.1 Introduction

In recent decades, Shared Decision-making (SDM) in healthcare has been increasingly advocated as an ideal form of clinical practice (1). Involving patients in the process of decision-making has a positive impact including decreased decisional conflict, increased patient knowledge, and improved health outcomes such as improved patient satisfaction and quality of life (1,2). SDM is defined as a collaborative process between patients and their physicians where they clarify treatment or self-management support, and share information about options and preferred outcomes, to form an agreed clinical decision on the best course of action (3). The need for SDM arises in situations where there is more than one medically acceptable option and where no specific option is clearly best for everyone (4). Consideration of patients' preferences of the risks and benefits are important in such decisions (3), and SDM helps patients to choose the most appropriate treatment that suits their preferences. Patients and clinicians in both Western and non-Western countries have expressed positive attitudes and preferences towards SDM (5–7).

However, despite the apparent benefits of SDM and the policies that support its implementation, SDM is not embedded in routine clinical practice. There are many barriers such as overworked physicians, poor patient-physician communication, and the lack of tools and resources. Alternatively, a number of factors have been identified which may facilitate SDM such as the provision of allocated time for SDM and encouragement of physicians to conduct SDM. A fuller understanding of these barriers and facilitators could help enable and optimise the implementation of SDM.

Research in this topic has grown over the years, and there are a number of systematic reviews published on SDM. A wide range of studies from around the world on this topic, spanning a myriad of different clinical settings, reported a multitude of different facilitators and barriers. This diversity makes it difficult to characterise and make sense of the literature. It also presents a challenge to health professionals and managers seeking to implement SDM into their services. Consequently, there is a need for a cogent summation of the evidence base that identifies and articulates the key barriers and facilitators to implementing SDM.

One possible solution is the adoption of the umbrella review approach. This involves a synthesis of existing reviews that enables researchers to collect evidence from multiple healthcare settings without the need to conduct a systematic review in each setting. In essence, it is a review of existing reviews to provide an overview of the available evidence for a particular topic and allows for comparisons between the published reviews (8). Moreover, it enables compilation of the evidence-base related to a specific question in a shorter timeframe (9). We have adopted this umbrella review approach to provide an overview of factors that may either facilitate or inhibit the implementation of SDM.

2.2 Methods

2.2.1 Search Strategy

MEDLINE via Ovid, PsycINFO via Ovid, CINAHL, Scopus, and Cochrane Library databases were searched for relevant articles published between 1997 to December 2018. The search also included other sources such as reference lists of included reviews, articles citing the included reviews, as well as a Google Scholar web search. The search strategy was based on the search strategy used by Legare and colleagues for their systematic review (10) of the barriers and facilitators to implementing SDM. The searches were restricted to articles in English and by publication type (i.e., meta-analyses and systematic reviews). The search terms used were "decision aids", "decision making", “patient involvement", "patient participation", "shared decision", and "informed decision". Other search terms included “MEDLINE.tw.”, “systematic review.tw.”, and “meta-analysis.pt.” that were added in order to identify reviews in MEDLINE. See Appendix 1 for more details of the search strategy.

2.2.2 Inclusion Criteria

Articles were included if they were published in English, reported barriers/facilitators to implement SDM as primary or secondary objectives, and were a systematic review, scoping review, literature review, or meta-analysis. All patient population groups, health conditions, and healthcare settings were included.

2.2.3 Study Selection

Electronic search results were exported to a reference management software (Mendeley) and duplicated records were identified and excluded. Two reviewers (NA and TA) independently screened titles and abstracts, and then full-text articles, for inclusion or exclusion. Where there were any uncertainties about the relevance of an article, the decision to include was discussed with researchers (PT) and (AL) and agreed by consensus. The study selection process is summarised in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram (Figure 2.1).

2.2.4 Data Extraction and Quality Assessment

One reviewer (NA) extracted data and assessed the quality of the included reviews. The other reviewer (TA) verified the accuracy of data extraction and quality assessment of all the included reviews. Any discrepancies were discussed until consensus was reached.

A data extraction sheet was developed for this study by the reviewers (NA, AL, PT) and used to extract variables that were relevant to the scope of the current review. Extracted variables included the type of review, range of years reviewed, the total number of studies included in the review, country of origin, aims or objectives of the review, participants, settings, as well as barriers and facilitators identified. As the aim was to provide a broad overview, all barriers and facilitators in each review were extracted except for those that were infrequently reported (i.e., those reported by only a few studies).

The quality of the included reviews was assessed using the Critical Appraisal Skills Programme (CASP) (11) quality assessment tool for appraising systematic reviews, which uses 10 criteria across three broad domains: validity, reliability, and applicability of the review.

2.2.5 Data Synthesis

The characteristics of the included reviews were tabulated to describe the main features of each review (see Table 2.1). Barriers and facilitators were thematically analysed. Each review article was read carefully to identify and extract the reported barriers and facilitators. The extracted barriers and facilitators were then compiled, and common themes were identified and reviewed. An initial classification of themes was performed after reading all the included reviews. The barriers and facilitators were then grouped into broad themes and then categorised into minor and major themes (see Table 2.1 and Appendix 1 Table A.3). Any uncertainties regarding the thematic categorisations were resolved through discussion and consensus by the reviewers. From the descriptive summary of the reviews tabulated, the number of studies mentioning each barrier/facilitator was determined to identify commonly recurring barriers/facilitators (see Appendix 1 Table A.1).

2.3 Results

2.2.6 Study Selection

The literature search initially yielded 505 articles. The total number of articles after removing duplicates was 414. Of these, 388 references were excluded after screening by title and abstract. Of the remaining 26 full text articles retrieved, seven eligible reviews (five systematic reviews and two scoping reviews) were identified. The main reasons for exclusion were: barriers were limited to a specific treatment or decision (such as cardiopulmonary resuscitation decision), or were not about the shared approach, or were focused on the effectiveness of specific interventions used to facilitate SDM.

2.2.7 Quality Assessment

Six of the included reviews did not search grey literature or restricted their search strategies to the English language (11–16), so there is a possibility that some relevant studies may not have been included in these reviews. All of the reviews assessed the quality of studies included within each review with the exception of one scoping review (17). A quality appraisal of all the included reviews is detailed in Appendix 1 Table A.2.

2.2.8 Overview of the Included Reviews

Table 2.1 presents a general overview of five systematic reviews and two scoping reviews that identified SDM studies published up to 2017. More than half of the reviews were published in the last five years, indicating that the level of awareness and interest in SDM is increasing. Three of the reviews described facilitators and four examined both barriers and facilitators.

There was significant variation in the number of studies included in each review. This tended to depend on the scope of the review. For instance, the three reviews that were broad (i.e., not limited to a specific healthcare setting or condition) (10,15,17) included a greater number of studies than reviews that were limited to specific health settings or conditions. Likewise, the reviews that were conducted recently included more studies than the older reviews, reflecting the increasing amount of relevant literature over time. The studies included in the reviews were carried out in 19 countries, most of which were high-income countries in North America and Europe. Very few studies were from low- and middle-income country settings.

There was considerable diversity in terms of study settings as well as intended objectives of the included reviews. This ranged from one review focused on identifying strategies to encourage SDM within paediatric oncology (13), to another focused on understanding factors that hindered or promoted effective SDM for people with dementia and other types of cognitive impairment within extended care settings or their own home (12). Two reviews concentrated on SDM within a mental health setting (14,16). Three reviews were general and did not comprise of any specific healthcare settings. Of these, two of them primarily focused on exploring barriers and facilitators to implementing SDM as perceived by patients (15) and health professionals (10), whilst the other focused on understanding the organizational and system-level characteristics that affected the implementation of SDM (17). Most of the target study participants in the reviews were healthcare practitioners and service users. Three reviews considered parents and carers of patients.

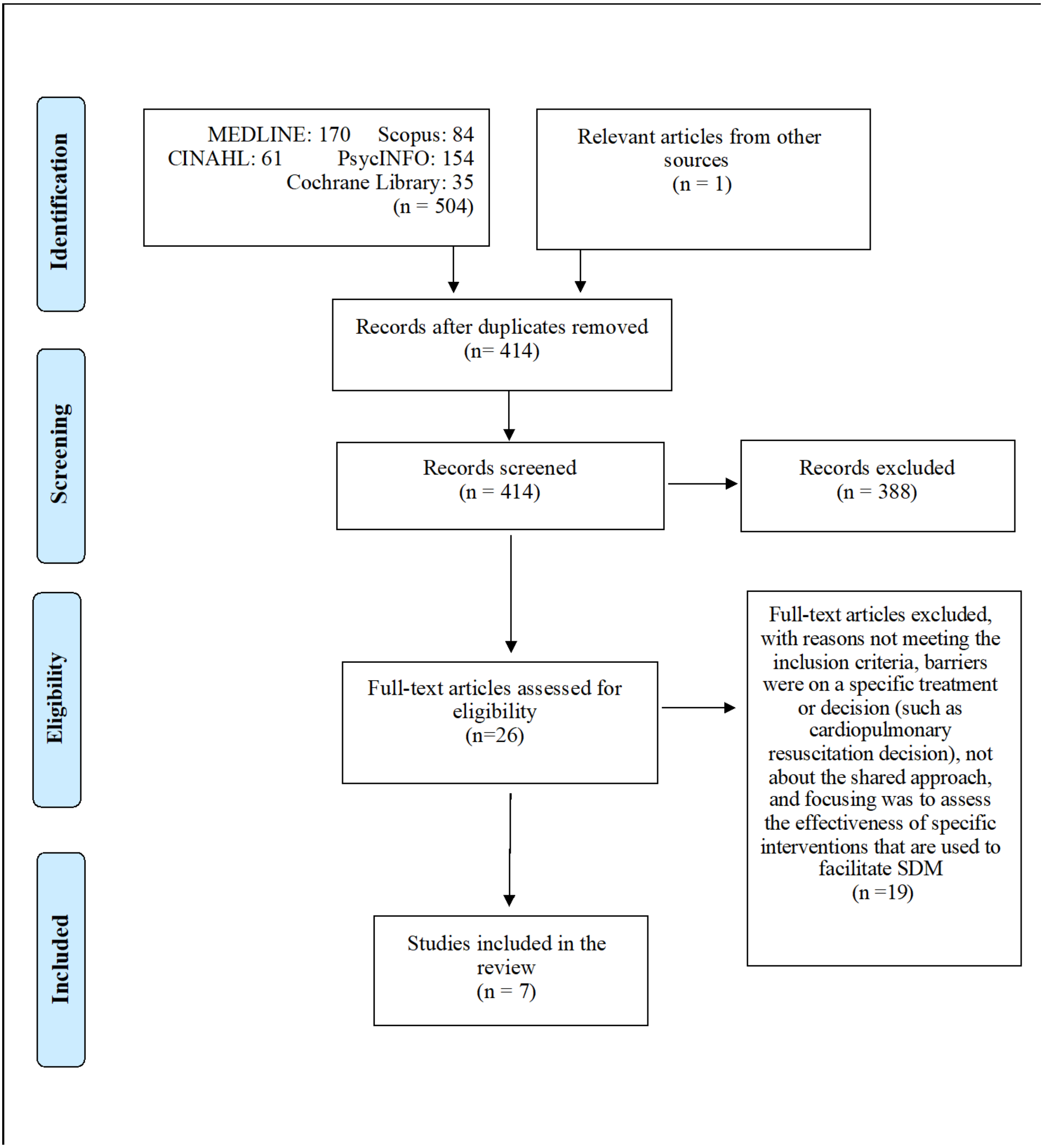

Figure 2. 1: PRISMA flow diagram

Review	Type of Review	Years covered	Number of studies in the review	Country	Setting	Aim/ Objective	Participants
Legare et al. (10)	Systematic review	1990 to December 2006	38	UK, USA, Canada, Netherlands, France, Mexico, Australia, Norway, Germany, China.	General	Review of factors perceived by health professionals as barriers and facilitators to implementing SDM in clinical practice.	Health professional
Daly et al. (12)	Systematic review	1996 to October 2016	19	UK, USA, France, Australia, Norway, Holland, Sweden	Extended care setting or home	Objective to understand the factors that hinder and promote the effectiveness of SDM for people with dementia and their relatives.	People with dementia or cognitive disorder
Robertson et al. (13)	Systematic review	1990–2017	17	US, Netherlands, Denmark, Canada	Paediatric oncology clinical trials	Highlight recommended strategies to facilitate SDM in paediatric oncology clinical trials.	Parents, young people, healthcare professionals
Gondek et al. (14)	Systematic review	Until 6 November 2015	23	UK, USA, Canada, Hong Kong, Australia, Sweden, Belgium	Mental health services	Review the influencing factors for patient centred care reported by providers, service users/carers in mental health services for children or young people.	Professionals, service users and carers in mental health services
Joseph-Williams et al. (15)	Systematic review	Until 15 August 2012	45	UK, USA, Canada, Netherlands, Australia, Norway, Germany, and China, Sweden, Iran, Belgium, Indonesia, Japan, South Korea, Finland	General	Review of barriers and facilitators to SDM reported by patients.	Patients
Cheng et al. (16)	Scoping review	1806 to September 2016	22	UK, USA, Canada, Netherlands, Australia	Mental health	Scoping review of approaches used to promote SDM in child and youth mental health.	Child, adolescent, or their carers
Scholl et al. (17)	Scoping review	1997 to October 2016	48	USA, UK, Australia, Finland, Canada	General	Scoping review of organizational and system-level characteristics which influence the implementation of SDM, as well as strategies to overcome barriers.	Implementation projects

Table 2. 1: Characteristics of included reviews

2.2.9 Barriers and Facilitators to SDM

The five themes identified were: patient factors, professional factors, environmental factors, relationship factors, and factors related to information provision. The factors under each theme were classed as barriers or facilitators based on the description provided in the included reviews. Table 2.2 presents a summary of barriers and facilitators identified under each theme; these are described in more detail below.

Patient Factors

This theme comprised of patient perceptions, preferences and fears, and patient capacity (i.e., patient related factors that can be barriers or facilitators to SDM). The most common barrier was the patient's belief that the "doctor knows best" and that the patient lacked knowledge, as was reported in 29 studies in one review (15). Other common barriers were the nature of the health condition (e.g., infectious disease, severity of symptoms, drug addiction) as reported in 28 studies in two reviews (10,15), the patient's belief that only the clinician could make decisions (15), individual characteristics of the patient (10), and the patient's fear of the consequences of being described as difficult or troublesome that may result in poorer quality care or less attention (15). The most frequently identified facilitators were related to the patient's perception of the acceptability of asking questions (10), their acknowledgement that the medical encounter involves two experts (doctor and patient) (10), and their acceptance of responsibility for participating in decision-making (10).

Professional Factors

This theme encompassed professionals' perceptions, characteristics, and behaviours. The key barriers included: clinicians not adequately listening to or respecting the patients' concerns or opinions (as reported in 24 studies in two reviews) (14,15), clinicians not asking the patient about their preferred role in decision-making (reported in 19 studies in two reviews) (10,15), clinicians with poor interpersonal skills (15), and clinicians believing that patients prefer not to be involved in decision-making and did not need it. (15). The main facilitators identified in three separate reviews included: clinicians who listened to service users/carers and respected their opinions (13–15), clinicians who discussed the preferences of patients/families with regards to their involvement in decision-making (10,13,15), and clinicians who used simple terminology (13,15).

Environmental Factors

Organizational characteristics and characteristics of the healthcare system were two other common themes that emerged from the analysis. The most common barriers were time constraints (as stated in 34 studies in two different reviews) (10,15), the lack of resources (10,12,14), and clinicians being too busy to involve patients in the SDM process (10). Efforts to encourage and motivate providers to use SDM (as reported in 31 studies in two different reviews) (10,17) and provide adequate time for SDM were important facilitators for the implementation of SDM (10,13,17).

Relationship Factors

Many factors related to the clinician-patient relationship were identified under this theme. They included poor clinician-patient relationships (12,14), or patients who are not known by the clinician (15). Of these, the most common factor was the patients' trust in their clinicians which reflects the quality of the relationship between the clinicians and patients (10). The quality of this relationship was clearly identified as a key enabler in four other reviews (12–15).

Factors related to Information Provision

The lack of information sharing, particularly with regards to the patients' condition, treatment options and outcomes, was the most frequently identified barrier to SDM (14,15). Conversely, the provision of sufficient information about the patients' condition, options and outcomes (13–15) was a key facilitator.

Table 2. 2: Barriers and facilitators to SDM (10,12-17)

Environmental Factors	**Organizational factors** • Time (bar and fac) • Too many clinicians involved in care (bar) • Inadequate environmental conditions (bar) • Lack of resources (bar) • Support for the use of decision aids (bar and fac) • Motivation of healthcare professionals to implement SDM (bar and fac) • Multiple consultations for SDM (bar and fac) • Electronic health record prompt for SDM (fac) • Performance measurement and feedback on SDM (fac) • Engagement of non-physician personnel (e.g., nurse, social workers) (bar and fac)	**Healthcare system factors** • Policies and regulations (bar and fac) • Embedded SDM communication skills into medical education (fac) • Using a payment model to incentivize providers to involve patients in SDM (fac)
Professional Factors	**Professional behaviour** • Discussing patients' preferences (bar and fac) • Listening and respecting patients' concerns or opinions (bar and fac) • Checking information comprehension regularly (fac) • Giving explicit permission to participate in SDM (bar and fac) • Not giving explicit choices to patients (bar) • Explaining treatment options and outcomes (bar and fac) • Using simple terminology (bar and fac) • Using decision support tools (fac) • Sharing responsibility with patient (fac)	**Professional characteristics** • Interpersonal skills (bar and fac) • Lack of familiarity with SDM (bar) • Authoritarian style in decision-making (bar) • Shared style in decision-making (fac) • Social attitudes (bar) **Professional perception** • View that patients prefer not to be involved and do not need it (bar) • Recognising abilities and rights of patients to be involved in a decision-making (bar and fac)

		• Expectations about SDM on patient outcomes and healthcare process (fac) • Agreement of aspect of SDM (bar and fac)
Patient/Family Factors	**Patients' perceptions** • Belief that "doctor knows best" (bar) • Not capable of understanding medical information (bar) • Acceptability of asking questions (bar and fac) • Clinicians are against the involvement of patients (bar) • Acknowledgement that the medical encounter involves two experts (fac) • Recognizing equipoise and uncertainty (fac) • Accepting the responsibility to participate (bar and fac) • Lack of expectation for SDM in consultations (bar)	**Patient capacity** • Health condition (bar and fac) • Patient characteristics (bar and fac) • Lack of self-efficacy (bar) • Parental involvement (fac) **Preferences and fears** • Preferences to be involved (bar and fac) • Fear the consequences of being described as difficult (bar) • Fear of knowing and accepting a diagnosis (bar)
Relationship Factors	• Quality of the relationship (bar and fac) • Trust in clinician (bar and fac) • Patient is known/not known by the clinician (fac and bar) • Difference in personal characteristics of the patients and clinicians (e.g., sex, language) (bar)	
Factors related to information provision	• Provision of sufficient information on options and outcomes (bar and fac) • Provision of information in multiple modalities (fac) • Repetition of information at multiple time-points (fac) • Provision of translated materials or interpreters (fac) • Provision of psychoeducational information (fac)	

When a factor was reported as a facilitator or barrier to SDM, this is indicated: Fac = Facilitator; Bar = Barrier

2.4 Discussion and Conclusion

2.4.1 Discussion

Our umbrella review highlighted different factors that influence the implementation of SDM, providing decision-makers in health-care with an overview of the field, and information for the implementation of SDM. The majority of included reviews were published in the last five years, which confirms the growth and interest in the field of SDM. However, there is considerable heterogeneity of the evidence base that makes translation of SDM into practice challenging.

It is apparent from the reviews that time constraints was the main factor hindering the implementation of SDM. Physicians are often under considerable time pressure during the consultation as they have to complete recommended tasks and clinical documentation, which reduces the time for conversation with their patients (18). The lack of time may also result in the lack of listening to patients and lack of sharing of sufficient information between physicians and patients. The provision of ample time in consultations could make a significant difference as longer consultations are more likely to involve elements of SDM (19,20).

However, there is a debate about the additional time required to engage in SDM with some studies suggesting that SDM could be carried out within the usual time allocated for a consultation (21), and other studies reporting that not all applications of SDM increase the time requirements for the consultation (22,23). In this review, it was found that encouragement and motivation of providers to use SDM was also a significant enabler of SDM implementation. It should be noted that the provision of resources, such as time, information, or SDM tools alone, is insufficient if not accompanied by efforts to support and motivate providers to use SDM (24,25).

Another key barrier was the patient's belief that the “doctor knows best”. This perception is reinforced through the lack of information sharing by the clinician involved. Consequently, the patients feel that they lack knowledge and confidence, which disempowers them from participating. Unsurprisingly, they are more likely to leave the decision to their clinicians. This finding mirrors an Italian study that found that most people wanted to be involved in decision making, but their lack of knowledge was a barrier to their participation (26).

The process of SDM starts with the interaction between physicians and patients. Good communication enhances the experience of collaboration and should lead to the engagement of physicians in behaviours that are specifically oriented to SDM (27). However, we also identified factors that influence the quality of communication between physicians and patients, such as a lack of listening and respect for the patient's concerns or opinions, and the lack of sufficient information provision. Patients who experienced these behaviours might be less inclined to engage in the decision-making process.

Patients value building a respectful and trustful relationship with their clinicians, and the open exchange of information (28,29). It requires clinicians to listen to their patients and to elicit their preferences and fears. It enables patients to ask their clinicians for information they need without hesitation. In addition, such a relationship enables clinicians to encourage their patients to participate in the decision making. Consequently, patients may feel better supported by their clinicians and permitted to take an active role in the decision making.

Decision aids also facilitate the implementation of SDM. They reduce decisional conflict, and improve patient knowledge and patient-clinician communication (30–32). The measures that facilitate the use of decision aids include allowing flexibility on the use of decision aids, having decision aids/tools available in workspaces and exam rooms, and providing decision aids on electronic health records and patient portals. In addition, our review found that some professional and practitioner behaviours, such as the use of decision supportive tools with patients (e.g., for action planning or goal setting, as discussion prompts, and written decisions) also promote and support SDM.

SDM might not be appropriate in all circumstances. The clinical situation or health condition of the patient may affect their capacity and willingness to be involved in the decision making. Patients with more acute, severe or life-threatening conditions may be less inclined to participate in SDM. In these instances, SDM may be less appropriate or desired. However, it should be noted that even in these situations, some patients may want to be involved in decisions despite their health conditions, but their clinicians may not be aware or supportive of their desire for SDM. Indeed, some studies have found that patients value SDM even in the case of severe illness (33,34), which raises the question as to whether the acuity and severity of the health condition is a genuine patient barrier or a clinician-perceived phenomenon. Similarly, the patients' capacity to be involved may be assumed by clinicians, particularly for those with mental disorders. Yet our review found studies where people with mental disorders did desire and could be engaged in SDM in this setting. The professional biases of clinicians may need to be tempered and their assumptions challenged regarding patient capacity (and readiness) to participate, as they may be incorrect. Recent evidence shows that physician perceptions change based on a recognized learning curve to SDM implementation (35). In addition, Hargraves and colleagues highlight a model of SDM that directly refutes the notion that SDM is only applicable to highly specific clinical scenarios (36).

Most of the studies included in the reviews were conducted in Western countries, which reflect the trends in those healthcare systems that is increasingly driven by the patient-centred care approach. However, this is not yet the case in non-Western countries. Consequently, the findings may not be transferable to non-Western cultures, and especially in developing countries where values, social contexts, and healthcare systems are different. The SDM concept has propagated internationally as globalization brings Western views and ideas about choice, disclosure, and autonomy to patients in non-Western countries. However, SDM may not be fully available in many of those settings (37,38). Further research is needed to understand differences in the extent to which SDM can be applied in these countries, as well as the barriers, and the strategies needed to address them. In particular, health communication behaviours associated with health delivery have been widely reported to be a barrier or enabler to the implementation of SDM. These interpersonal communication challenges seem important both across health systems and within systems. The power dynamic in the physician-patient relationship can also be a source of problems during communication between them as involving patients in decision-making necessitates a balance of power and responsibility between physicians and patients (39). Patients from non-Western cultures are unaccustomed to exercising autonomy in medical decision-making and rely on their physicians and families (40-44).

2.4.2 Limitations

The findings in this study are subject to some limitations. Firstly, some of the included reviews have some limitations in their search strategies (e.g., not searching grey literature or not including non-English publications) resulting in the possibility of missing some of the relevant studies. A potential limitation to the umbrella review approach could be overlapping studies that appear in more than one review (45). However, when the studies included in each review were reviewed, there was only one instance where one study appeared in two reviews (15,17). Another limitation to the umbrella review approach is that it can only report what researchers have investigated and published. For example, some factors may have a strong influence, but if they were not adequately investigated in the included studies, they may be reported as less important factors or they may not even be included in the review (46). We acknowledge that the identification of barriers and facilitators based solely from the synthesis of reviews found in our umbrella review might lead to bias (e.g., some of the findings may seem out of place when uninformed by other non-reviews in the field). In order to mitigate this issue, other key literature not identified in this umbrella review were actively referenced. Lastly, the inclusion criteria were restricted to reviews that reported barriers/facilitators to implementing SDM as the primary or secondary objectives of the reviews. Thus, there is a possibility that some of the excluded reviews may have useful information relevant for the implementation of SDM (47–49). Finally, whilst our review focussed on barriers and facilitators to implementation, we acknowledge that there are many other considerations such as incentive structures and poor protocol fidelity.

2.4.3 Conclusions

The lack of time is perceived as the main factor that hinders the implementation of SDM. Strategies such as the engagement of non- physician personnel (e.g., nurse, social workers) throughout the process of decision making, and provision of multiple consultations for SDM, may overcome this barrier. However, the provision of time and resources is insufficient if not accompanied by efforts to support and motivate providers to use SDM. Healthcare providers need to be motivated, provided with regular training to use SDM and educated on the importance of building a trusting relationship with their patients.

The quality of the clinician-patient relationship is crucial, and the willingness to share information is a key part of this. To enhance this relationship and obtain the most out of the consultation, physicians need good interaction skills. They need to be curious and explore their patients' preferences, listen to patients and respect their opinions, explain treatment options and outcomes, and encourage them to ask and participate in the decision-making process. Patients have to acknowledge they have role as well and need to engage with their physicians in information sharing.

2.4.4 Implications for Future Research

Implementation issues are likely to be dissimilar between Western and non-Western countries, so there remains a need for further research on SDM to be conducted in non-Western settings. The generalisability of findings worldwide as well as its translation into practice is uncertain. Most of the studies focused at the clinician-service user/carer level which highlights a paucity of research at the systems-level. Consequently, further research is also needed to understand factors that influence organizational managers and policymakers that may facilitate the implementation of SDM.

Ethical Approval

Ethical approval was not required

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Declaration of Competing Interest

The authors have no conflicts of interest.

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Chapter 3 (Study 2): Views of Stakeholders on Factors Influencing Shared Decision-Making in The Eastern Mediterranean Region: A Systematic Review

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Student Contribution to the Paper

The PhD student developed the study protocol/methods, collected and analysed the data, and drafted the final manuscript. Tourkiah Alessa is the second reviewer who screened the titles and abstracts, and then full-text articles for exclusion or possible inclusion. She also verified the accuracy of the data extraction and quality assessment of all the included studies. Supervisors (Dr Andrew Lee and Dr Praveen Thokala) reviewed and contributed to the protocol and manuscript.

Chapter Overview

In the previous chapter, we provided an international exploration of factors influencing SDM implementation. This chapter addresses the second objective of the thesis, which is identifying and understanding factors influencing the implementation of SDM in the EMR countries.

Abstract

Background: Shared decision-making is advocated as a key component of patient-centred care and associated with many benefits that improve patient outcomes. However, shared decision-making is not yet embedded in clinical practice and confronts many barriers that hinder its implementation, especially in countries of the World Health Organization (WHO) Eastern Mediterranean Region. **Aims:** We conducted a systematic review to identify and understand factors influencing shared decision-making in the Region. Methods: We searched PsycINFO, CINAHL, PubMed, Medline, Scopus and Saudi Digital Library for articles published between January 1997 and February 2019. Studies conducted in the Region that reported barriers, facilitators, experiences, expectations and attitudes to shared decision-making were included. The Mixed Methods Appraisal Tool (MMAT) was used to assess the methodological quality of the studies in this review. **Results:** Of the 1813 initial articles retrieved, 19 eligible articles were identified. The main factors that emerged were grouped under three broad themes: participant factors (patients/families and physicians); consultation factors (relationship between participants, engaging patients, evaluating preferences, introducing options, providing information, and decision making); and healthcare system factors (organizational characteristics, time constraints, continuity of care, and healthcare resources). **Conclusions:** There is growing interest in shared decision-making in several countries in the Region. However, there are many existing barriers that hinder the implementation of shared decision-making, which need to be addressed before shared decision-making can be fully adopted in these countries.

Keywords: shared decision-making, Eastern Mediterranean Region, barriers, facilitators, implementation.

3.1 Introduction

Shared decision-making (SDM) is an approach in which physicians and patients work jointly, utilizing the best available evidence, to make decisions that considers the patients' preferences (1). SDM is considered to be a key component of patient-centred care and corroborated in high-level policy in developed countries (2,3). Patients and clinicians in Western and non-Western countries show positive attitudes and preferences toward SDM (4–6). According to The Health Foundation (7), there is robust evidence of benefits from implementing SDM that include greater treatment adherence, better patient confidence and coping skills, and reductions in the demand for major surgical interventions.

There is also a large and growing body of literature on the factors that influence SDM and its implementation, and many reviews have been conducted that provide comprehensive evidence on this topic (8–11). However, most of the reviews in the literature are from high-income settings, predominantly in Western countries. Little is known about SDM in the World Health Organization (WHO) Eastern Mediterranean Region and it is not clear which factors may hinder or facilitate the implementation of it in these countries. Similarly, in many of the high-income Western countries, the concept of patient-centred care or SDM is being integrated into health systems, but this is not yet the case in the Region and other developing countries.

The Region comprises 21 countries as defined by WHO (12). Despite some cultural similarities (Islamic culture) and commonalities in historical background, there is also a high degree of diversity when it comes to developmental profiles and socioeconomic conditions that invariably affects the maturity of health systems and population health status in the different countries in the Region (13). Notably, the Region includes high- middle-, lower- and lower–middle-income countries (14). Moreover, the culture, social context, and health sector leadership and governance in these countries are different to those in Western countries. If the desired aim is to promote and facilitate the integration of SDM into existing healthcare systems in the Region, there is a need to investigate and better understand the perception of SDM and challenges of implementing SDM in these countries. Therefore, we carried out a systematic review of the literature that sought to identify and understand the factors influencing SDM in the Region.

3.2 Methods

3.2.1 Search Strategy

The following databases were searched for relevant articles published between 1997 and February 2019: PsycINFO, CINAHL, PubMed, Medline, Scopus, Saudi Digital Library, Open Grey, EThOS, Social Care Online. The search included other sources such as reference lists of included studies and articles citing the included studies. The searches were not restricted by language and relevant articles were translated into English. The search terms were built with help from one of the information specialists. We searched for articles on SDM or related concepts such as “patient engagement”, “patient-centred care”, “patient activation”, “decision support” and “decision aids”. Full details of the search strategies in (Medline, PsycINFO, CINAHL, Scopus and PubMed) can be found in Appendix 2. Other electronic databases were searched using keywords from the search strategies.

3.2.2 Inclusion Criteria

The eligible studies were all qualitative, quantitative, or mixed-method studies that mentioned SDM or associated terms. Participants included were patients, families, healthcare and medical professionals, facility managers, and policy-makers. The intervention was SDM or its tools, such as decision aids, as they are tools often used in the SDM process. Studies were included if they reported perceptions, barriers, facilitators, experiences, expectations or attitudes to SDM. All healthcare settings in countries in the WHO Eastern Mediterranean Region were included.

3.2.3 Study Selection

Electronic search results were exported to reference management software (Mendeley) and duplicated records were identified and excluded. Two reviewers (NA and TA) screened the titles and abstracts, and then full-text articles for exclusion or possible inclusion. Uncertainty over inclusion of articles was resolved through discussion with researchers PT and AL, and agreed by consensus.

3.2.4 Data Extraction and Quality Assessment

One reviewer (NA) extracted data and assessed the quality of the included studies. The other reviewer (TA) verified the accuracy of the data extraction and quality assessment of all the included studies. Data were abstracted using a data extraction sheet developed specifically for this review. The variables extracted were: country of origin, healthcare setting, methodology and design of study, data collection tools, participants and sample size, aim of study, influencing factors, and type of results (Table 3.1). The Mixed Methods Appraisal Tool (MMAT) version 2018 (15) was used to assess the methodological quality of the studies (see Appendix 2). MMAT is a validated tool for appraising primary qualitative, quantitative and mixed-methods studies for systematic reviews. Although MMAT did not propose a scoring system, we categorized reviews as “good” when 6 or 7 of the criteria were achieved, “moderate” when 3–5 of the criteria were achieved, or “poor” when 0–2 of the criteria were achieved.

3.2.5 Data Synthesis

Narrative synthesis was used to synthesize the findings from multiple studies in the review, using words and text to summarize and explain the key findings (16). This approach was chosen due to the heterogeneity of study designs, study populations, types of factors, and study contexts. Study characteristics were extracted to describe the main features of each study (Table 3.1). The data extracted were compiled and key themes were subsequently identified and categorized.

3.2.6 Ethical approval

Ethical approval was not required.

3.3 Results

3.3.1 Study Selection

The study selection process is summarized in the PRISMA flow diagram (Figure 3.1). The searches yielded 1813 references. After removing duplicates, there were 1201 unique articles, and 1172 were then excluded after screening by title and abstract. Of the remaining 29 full-text articles retrieved, 19 eligible articles were identified. The main reasons for exclusion included: studies did not mention SDM; focus on the purpose of the written informed consent; patients’ views were on a specific decision, such as decision-making for antenatal screening, and not about the shared approach; or focus on how emergency physicians decide and assess the process of using clinical decision-making.

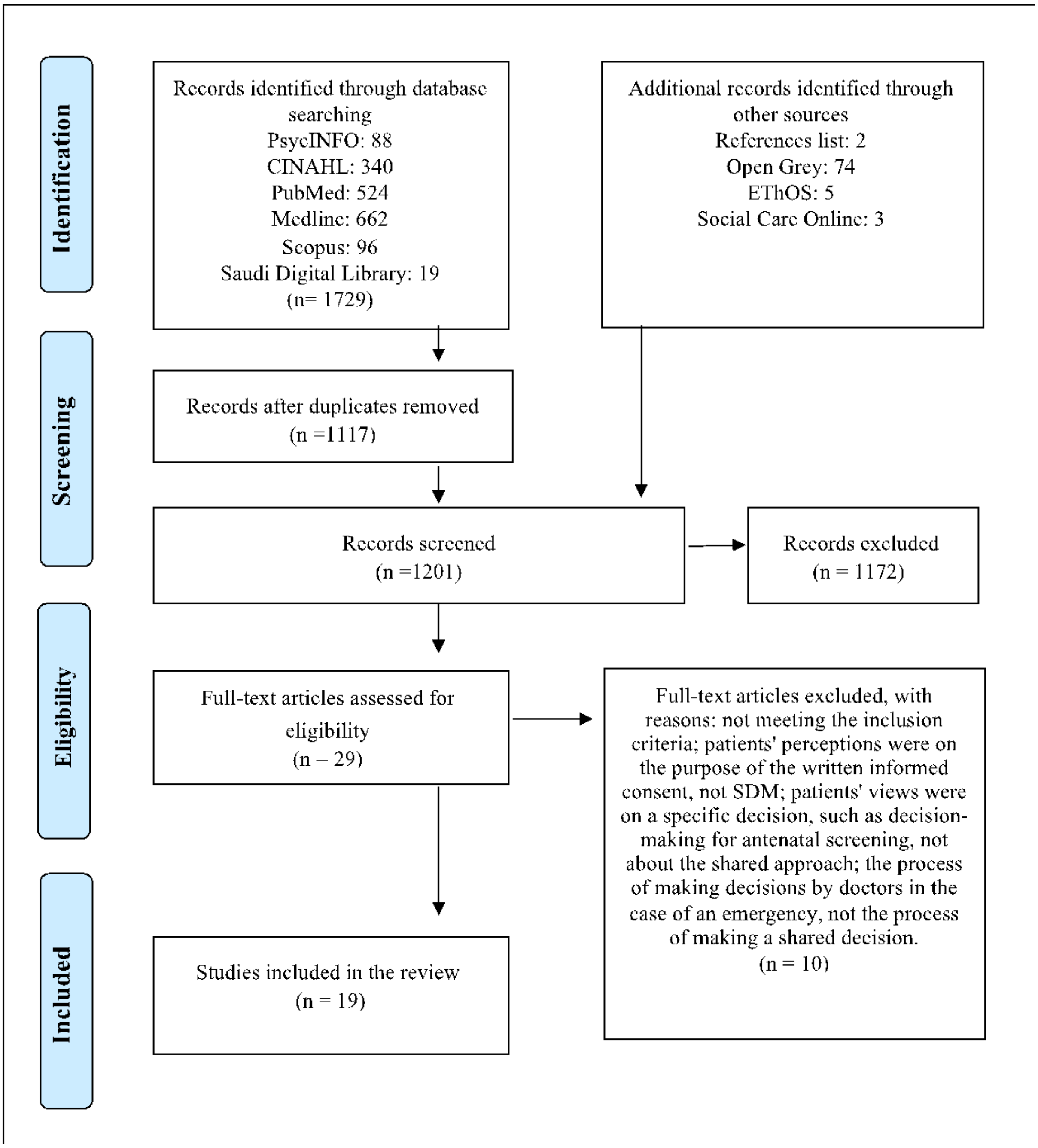

Figure 3. 1: PRISMA flow diagram

3.3.2 Study Characteristics

An overview of the 19 included studies is presented in Table 3.1. They were from Islamic Republic of Iran, Saudi Arabia, Jordan, Oman, Morocco, Egypt and Pakistan. All were in English except for one in French (17).

Study participants included clinical staff (doctors and nurses), and patients and their family members. The study settings covered public, private and teaching hospitals, of which half were teaching hospitals. Seven studies were from oncology units while the remaining studies were from other clinical settings: rehabilitation, neurology, dentistry, rheumatology, orthopaedics, anaesthesia, urology, gynaecology, emergency medicine, general internal medicine, and general surgery.

In terms of type of results, two studies assessed the role of family in the treatment decision-making process (18,19). Seven studies reported patients' perspectives, participation, preferences, beliefs and knowledge (4,5, 17,20–23). Five studies reported physicians' perceptions, attitudes and experiences (24–28). Four studies explored experiences, perceptions and preferences of both patients and clinical staff (29–33).

In terms of the aims of the studies, two sought to determine physicians' and patients' perspectives on barriers to and facilitators of the use of patient decision aids (27, 29). Two other studies assessed the role of family members in treatment decision-making and factors that influenced that decision (18,19). The other studies reported on factors influencing physicians' and patients' preferences with regards to SDM. Only one study explored the process of decision-making by physicians and their patients during consultations (33).

Fifteen studies used a quantitative approach (mainly involving questionnaires). A qualitative approach was used in two studies (26,29) and in one thesis (33). A mixed- methods approach was used in another thesis (30).

First author (year)	**Language**	**Country**	**Healthcare setting**	**Methodology/ design**	**Data collection tool**	**Participants/ sample size**	**Aim**	**Type of result**
H. Rashidian (2015)	English	Iran	University hospital	Quantitative	Questionnaire	Physicians/150	Understand physician attitude to the barriers of patient decision aids	Physicians' attitudes
A. Alhaqwi (2015)	English	Saudi Arabia	Family practice centre/ public	Quantitative/ cross-sectional study	Questionnaire	Patients/236	Explore preferences of Saudi patients to be involved in medical decision-making and the factors influencing their preferences	Patients' preferences
R. Obeidat (2015)	English	Jordan	Cancer specialty centre, public and teaching hospital	Quantitative/ cross-sectional	Semi-structured interviews	Patients/156	Assess the preferences of women with breast cancer regarding their participation in decision making	Patients' preferences
R. Obeidat (2016)	English	Jordan	Cancer centre, public and teaching hospital, private clinics	Quantitative/ comparative research design	Questionnaire	Physicians/86	Assess the attitude of physicians toward information disclosure, comfort and use of different approaches in decision-making, and patient involvement in treatment decision making.	Physicians' attitudes
M. Al-Tannir (2017)	English	Saudi Arabia	Rehabilitation, neurology/public	Quantitative/ cross-sectional	Questionnaire	16 patients/ 22 family members/ 64 nurses/ 36 physicians	Assess patients' experiences of engagement and nurses and physicians' perceptions of patients' engagement, and compare this perception with patients' experience	Patients' experiences, physicians' and nurses' perceptions
A. Al-Bahri (2019)	English	Oman	Oncology/teaching hospital	Quantitative/ cross-sectional study	Questionnaire	Patients and their family members/ 79	Assess the role of family members in the treatment decision-making process among adult Omani women with breast cancer and the influencing factors on treatment decision making	Reported role of the family
S. Kumar (2010)	English	Pakistan	Oncology/university hospital	Quantitative	Questionnaire	Patients/230	Assess the influence of patients' beliefs and knowledge about cancer on their decisions regarding its management	Patients' perceptions, beliefs and knowledge
M. Alizadeh (2013)	English	Iran	University of Medical Sciences	Qualitative/ descriptive phenomenology	Focus group discussion	Clinicians/6	Explore the experiences of clinicians on patient values and patient centred decision making	Physicians' experiences

First author (year)	Language	Country	Healthcare setting	Methodology/ design	Data collection tool	Participants/ sample size	Aim	Type of result
F. Asghari (2008)	English	Iran	General internal medicine, general surgery/teaching hospital	Quantitative/ mixed method design	Questionnaire	Patients/299	Assess patients' preferences for participating in decision-making and receiving clinical information	Patients' preferences
A. Al-Bahri (2018)	English	Oman	Oncology/teaching hospital	Quantitative/ cross-sectional study	Questionnaire	Patients and their family members/185	Assess the role of family members in the treatment decision-making process among adult Omani and the influencing factors on treatment decision making	Reported role of the family
H. Rashidian (2013)	English	Iran	Rheumatology and orthopaedic/private and public	qualitative	In-depth interviews	14 physicians/8 patients	Explore the viewpoints of physicians and patients on the barriers, facilitators, and the benefits of using decision aids	Viewpoints of physicians and patients
E. Mohammed (2018)	English	Egypt	University Hospital	quantitative/ cross-sectional study	Questionnaire	Patients/514	Assess patients' awareness of their rights, the predictors of their knowledge score, and patients' perspective on the degree of the providers' adherence to these right	Assessment for awareness
A. Alzahrani (2016)	English	Saudi Arabia	Medical centre	Qualitative/ cross-sectional ethnographic	Observation/inter views	3 dentists/32 patients	Explore the process of decision-making associated with patients who underwent dental implants.	Evaluation and observation
W. Alkhatrawi (2013)	English	Saudi Arabia	Private and public hospitals	Mixed methods/ exploratory study	Questionnaire/ in-depth focus groups	Questionnaire (296 patients/93 physiotherapists), 10 focus groups	Explore the perceptions and preferences of patients with low back pain and physiotherapists for patient involvement in decision-making and information provision.	Perceptions and preferences of patients and doctors
R. Obeidat (2018)	English	Jordan	Cancer centre, public and teaching hospital, private clinics	Quantitative	Survey	Physicians/86	Physicians' perception about barriers and facilitators to shared decision-making	Physicians' perception
M.Ebrahimi (2014)	English	Iran	Anaesthesia, urology,	Quantitative	Questionnaire	Physicians 81	Evaluate physicians' perception about shared decision-making by validating and	Physicians' perception

First author (year)	Language	Country	Healthcare setting	Methodology/ design	Data collection tool	Participants/ sample size	Aim	Type of result
			gynaecology, emergency/teaching hospitals				translating SDM questionnaire	
H. Mostafaie (2014)	English	Iran	University of Medical Sciences	Quantitative	Questionnaire	Patients/200	Assess the relationship between patient age, location and their preference toward SDM	Patients' perspectives
A. Boukir (2015)	French	Morocco	National institute of oncology	Quantitative	Questionnaire	Patients/272	Assess patients' participation in treatment choice	Patients' participation
H. Saleh (2014)	English	Saudi Arabia	Public hospital	Quantitative/ cross-sectional study	Questionnaire	Patients/408 Physicians/68	Assess the perspective of patients' and physicians' perspective toward SDM and compare their preference in SDM.	Patients' and physicians' perspectives

Table 3. 1:Characteristics of included studies

3.3.3 Quality Assessment

All of the included studies performed well in MMAT except for two that performed moderately (31,32). The qualitative and mixed-methods studies met all of their criteria. However, the majority most of the quantitative studies were limited by use of convenience or purposive sampling techniques or small sample size (See Appendix 2 Table A.1).

3.3.4 Barriers and Facilitators

The main themes were grouped under three broad themes: participant factors (factors related to patients or their families and physicians); consultation factors (factors related to the relationship between participants, patient engagement, evaluation of preferences, introduction of options, information provision, and decision-making); and healthcare system factors (factors related to organizational characteristics, time constraints, continuity of care, and healthcare resources). Table 3.2 summarizes the identified barriers and facilitators under each theme.

Patients' age was reported to have an influence on SDM: 4 studies observed that older patients preferred a more passive role than younger patients (4,18–20). Patients' sex was mentioned as a factor in 6 studies. Four of the included studies reported that male patients were more engaged than their female counterparts (12,13,16, 20), while 1 study confirmed the positive attitudes of women toward the shared approach (25). Another study reported the difficulty of engaging women because of their behaviour in comparing themselves with others and asking for the same treatment (15).

The patients' level of education was the most influential factor frequently reported in 10 studies as a barrier to or facilitator of patient participation in SDM (4,17–20,23,27,29,30,32). Patients with higher levels of education were reported to have greater preference for SDM and willingness to participate. Conversely, patients with lower levels of education were said to trust their physicians for making decisions, and believed that their physicians knew best. The provision of sufficient information to patients was also reported in four different studies to be a facilitator for SDM (17, 23, 26, 33).

The review also found that the family plays an important role in the decision-making process in the Eastern Mediterranean Region. Some of the included studies reported that family members engaged more than patients in SDM (18,19,31). The family members' feeling of responsibility was cited as a reason for this.

There were several healthcare system factors. Notably, time constraints and type of hospital were the most cited factors that influenced the adoption of SDM (25,29,30, 32). Three studies found contrasting trends in the adoption of SDM by hospital type (20,27,28). One study found that the shared approach was more likely to be used in a university hospital with a small caseload, while another study observed that it occurred in a private hospital. Another study reported that SDM was more likely to be used in speciality centres than in public, private or teaching hospital settings. However, it should be noted that these studies were all from Jordan.

Table 3. 2: Barriers and facilitators to SDM in Eastern Mediterranean Region (12–28, 30)

1. Participants factors		
1.1 Physicians' factors		
1.1.1 Physicians characteristics	1.1.2 Knowledge and experiences	1.1.3 Physicians' perceptions
• Age (bar & fac) • Gender (bar & fac) • Position (bar & fac) • Language (bar)	• Years of experience (bar & fac) • Differences in using SDM as usual approach (bar & fac) • Comfort level with shared approach (bar & fac)	• Patient engagement is not important (bar) • There is no room for SDM in our culture (bar) • Patients are unlikely to weigh different treatment options (bar) • Patient involvement decrease trust in physicians (bar) • Expectations in health care outcomes (bar & fac)
1.2 Patients' factors		
1.2.1 Knowledge and experiences	1.2.2 Patients' perceptions	1.2.3 Patients' preferences
• Clinical knowledge (bar & fac) • Level of education (bar & fac) • Lack of knowledge about their right for sufficient information (bar) • Unfamiliar with their rights in decision-making (bar) • Unfamiliar with the principles of decision-making (bar) • Financially depend on their family (bar)	• Consider a consent as a form of participation (bar) • Perceptions about physicians' abilities in diagnosis (bar & fac) • Perceptions about physicians' caring about patients' budget (bar & fac) • Providers are uncooperative or not willing to listen to patients (bar) • Patients do not see themselves as decision-makers (bar)	• Preferences for participation (bar & fac) • Preferences for taking responsibility (bar & fac) • Preferences for obtaining information (bar & fac) 1.2.4 Patients' characteristics • Sex (bar & fac) • Age (bar & fac) • Unmarried female (bar) • Unemployed (bar) • Health condition (bar & fac)
1.3 Family' factors		
1.3.1 Degree of involvement	1.3.2 Families' attitudes	
• Accompany patients at the consultation (fac & bar) • Over-riding the process of decision-making (bar)	• Families' fears of patients' reaction to diagnosis (bar) • Families' beliefs in their responsibility for the treatment decision (bar) • Delays in informing their patients about the diagnosis (bar) • Families usually come together to discuss the decision and finalize it (bar)	

Table 3.2 Barriers and facilitators to SDM in Eastern Mediterranean Region - continued

2. Consultation factors		
2.1 Relationship between participants	2.3 Evaluating preferences	2.5 Introducing options
• No effort to interact or build relationship with the patients (bar) • Respectful behaviour from physicians (bar & fac) • Emotional support from physicians (bar & fac) • Providing physical comfort for patients (fac) • Providing an opportunity to discuss Patients' problem (bar & fac) • Passive role in communicating with providers during the visits (bar) • Providers and their roles are known by their patients (fac) • Cultural influences on the way of greeting and interaction (bar) • Trust in providers (bar & fac)	• Considering patients' preferences (bar & fac)	• Introducing options (bar & fac) • Physicians lead patients to use specific treatment (bar) • Patients ask for a certain treatment (bar)
2.2 Engaging patients	2.4 Decision making	2.6 Providing information
• Degree to which physicians involve patients (bar & fac) • Patients' satisfaction with the degree of being involved (bar & fac) • Provider make patients feel they are partners (fac) • Consider patients' conditions (fac) • Initiating a discussion with patients about participating in decision-making (fac) • Physicians clarify the necessity of making a medical decision (fac)	• Physicians select the final decision alone (bar) • Decision-making takes place in the presence or absence of the patient (bar) • Consider patients' rights to choose a treatment (fac) • Disagreement on treatment proceeding (bar) • Patients seek a second medical opinion abroad (bar) • Patients share the decision with more than 1 family member (bar) • Agreement between family members on the decision (bar) • Patients' emotional readiness for decision-making (fac) • Patients want their doctor to make the decision (bar) • Patient want their family to make the decision (bar)	• Providing sufficient information for the treatment (bar & fac) • Help patients to understand all useful information (fac)

Table 3.2 Barriers and facilitators to SDM in Eastern Mediterranean Region - continued

3. Healthcare system factors	
3.1 Time constraints	3.3 Organizational characteristics
• Consultation time (bar & fac) • Use expert teams or trained nurses to overcome the problem of time shortage (fac) • Providing decision tool at the time of patients' admission to allow adequate time to decide (fac)	• Type of hospital (bar & fac) • Specialists per capita (bar) • Workloads (bar)
3.2 Continuity of care	3.4 Health care resources
• Not recognizing the patients (bar) • Providers address and refer to patient directly (fac) • Staffing changes (bar)	• Lack of an evaluation system for patients' and physicians' rights in decision-making (bar) • Lack of training in the field of SDM (bar) • Creating incentives (fac) • Provide appropriate role model among medical instructors (fac) • Acculturate people through public media to the use of decision tools (fac) • Increase physicians' skills and awareness in assessing patients' expectations of the treatment (fac) • Increase patients' knowledge to demand their rights (fac) • Consider cultural influences when developing awareness tools (fac) • Design decision tools that suit any level of education (fac) • Improving physicians' interactive skills (fac) • Presenting existing information in educational CD formats instead of handbooks (fac) • Developing the consent forms to include all sufficient information (fac)

bar = barrier; fac = facilitator

3.4 Discussion

This review identified several influential factors for SDM in the Eastern Mediterranean Region that include physician, patient and family member perspectives. These factors span the individual participant's role in decision-making, current SDM practices during clinical consultations, and SDM at the system level. However, the studies were from only seven countries. This indicates that SDM is not widely practised in countries in the Region as most developing countries have not integrated the concept of person-centred care into their health systems (34).

Unsurprisingly, patient and physician characteristics, such as their prior knowledge, experience and perceptions of SDM, and preferences towards it, are influential in determining whether it is practised. However, the practice of SDM is also affected by the attitudes of family members and the degree of their involvement in the decisions. These factors affect the interactions between the physicians and patients, as well as the consultation process including patient engagement, information provision and option sharing, elicitation and evaluation of patient preferences, and eventual decision-making. System-level factors also play a part such as time pressures, availability of healthcare resources to support SDM, and the degree of continuity of care provided. Figure 3.3 represents the relationship between these factors.

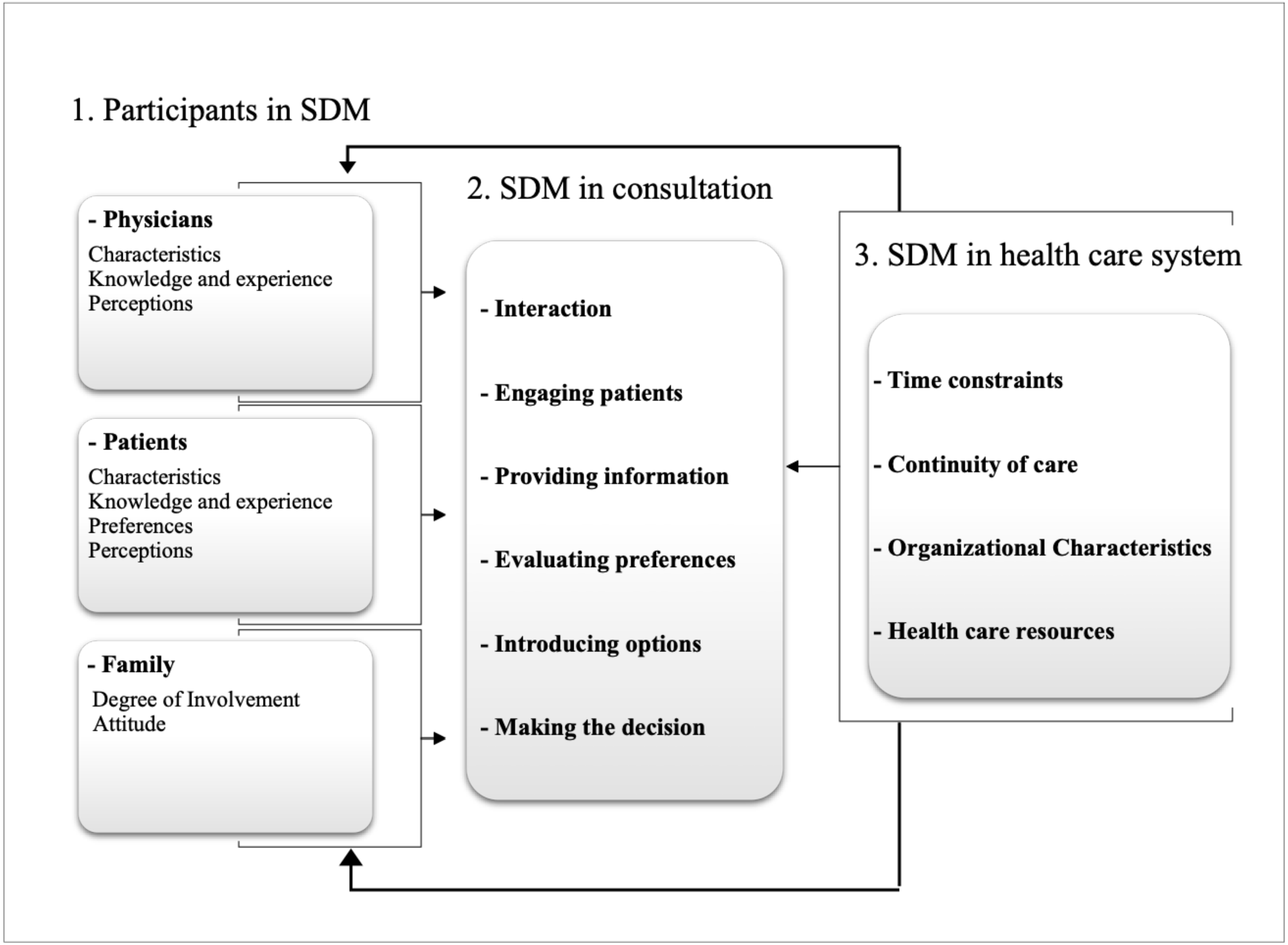

Figure 3.2: Relationship between the main themes

The most frequently cited factor was patients' level of education. Similar findings were previously reported in other studies from western countries (35,36). The lack of education and knowledge exacerbates the power imbalance between physicians and patients. In Iran, for example, the patient-physician relationship is likely to be paternalistic, with physicians rarely providing patients with enough information to make decisions or allow them to participate in an informed manner. They believe that patients will be unable to comprehend such information (5). A power differential between physicians and patients may be the result of a gap in education and knowledge between them.

Patients' age was also a determinant in the Region, with a notable preference for a passive role with increasing age. Although this mirrors a study from Japan (47), this age factor is not consistent worldwide. For example, one American study found that older people wanted to share their medical decisions or make their own (37). In the Region, older patients may lack clinical knowledge and have lower levels of education overall, which may explain the tendency towards adopting passive roles in decision-making (4,18–20).

This review found patient gender preferences for SDM. Al-Bahri and colleagues stated that family structures are more likely to be hierarchical in Middle Eastern culture (18). Traditionally, male family members such as husbands, fathers, and eldest sons have more authority in decision-making and therefore often dominate the decision-making process (38). This may explain the positive attitudes that male participants have towards decision-making. However, our review found that this trend was not universal and further exploration of the role of gender in decision-making is warranted, particularly as gender norms in the Region continue to evolve.

The quality of the physician–patient relationship is clearly vital and the behaviour of physicians is a key facilitator of patient trust (39). Linked to this is the adequacy of information provision as an enabler for SDM (40). Patient trust was boosted when physicians provided patients with a significant amount of information about their condition, test results, and adverse effects of different treatment options (39). However, patients' preferences for the amount of information provided differs among patients, and physicians need to tailor what information is exchanged with their patients. Key considerations include: the amount of prior knowledge that the patient has; how much information is considered to be sufficient; and who should decide if this information is enough for decision-making (41). An assessment of the level of patient understanding of the information provided is needed, as there are variations in patients' health literacy.

Family involvement can facilitate patient participation in SDM and enhance this process. Family involvement can increase the probability for patients to experience positive emotions, and decrease the likelihood of them experiencing stress and uncertainty when making decisions about their condition (42). There are commonalities in the culture in the Region, which has a collective nature and is family-centred. The families feel a moral responsibility for their members who are patients, and believe that they should be involved in the decision-making process (43,44). That said, this is not unique to the Region and has been reported in other cultures where family involvement in the decision-making process enhances patients engagement and autonomy (45). However, family involvement can also be a barrier to patient participation when the family dominates the decision-making process. Family involvement may disrupt communication between patients and physicians, and may delay treatment decisions where there are conflicting views (46). This raises the question of how best to include family members in the decision-making process.

A key limitation of this review is the diversity of the countries included in the Region, ranging from high- income countries like Saudi Arabia to more resource-constrained settings such as Pakistan. There are significant resources, socioeconomic and health system differences, as well as variations in demographic profiles. Moreover, the studies included did not cover all countries in the Region, and there were not many studies on SDM in the Region. Consequently, the aggregated findings in this review may not be truly representative or readily generalized to all countries in the Region. This highlights a need for further country-specific research into local SDM practices and determinants.

The implementation of SDM in any setting is subject to a complex landscape of interacting barriers. These need to be identified and addressed to ensure effective implementation, and can be enhanced through utilizing known facilitators. Much of the focus previously has been on physician factors, but as this review shows, there is a need to address patient factors, family involvement, as well as wider health system issues. The development of simple patient decision aids that could be understood by patients with low literacy levels could be efficacious. Encouraging clinicians to provide patients with more tailored information is also key, but this will require resourcing such as the provision of more consultation time. We need more research that considers cultural norms and the organizational and health system perspective, as well as SDM research in other countries in the Region where little has been done so far. Future research into these aspects is warranted.

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Chapter 4: Methodology

4.1 Introduction

This chapter discusses and justifies the research philosophy and methodological strategies chosen for the next two studies.

4.2 Philosophical Underpinnings this Thesis

In determining the paradigm for this study, careful consideration was given to a number of critical factors. The first thing worth noting is that this is an exploratory study, as the aim is to gain a better understanding of the perceived barriers and facilitators of SDM by various stakeholders, as well as how they are constructed, and how this relates to the attitudes and behaviour of the participants when making decisions. It is also essential to consider and integrate the perspectives of diverse groups who are directly involved in SDM in order to discuss the subject of concern holistically. Further to that, since decision-making primarily requires communication between different groups, the social element of meaning-making is often thoroughly examined.

Based on the critical considerations and the aim of this research, the constructivist paradigm was chosen. Constructivism or social constructivism philosophy, where most often qualitative research is located, presumes that there are various realities or interpretations of a single event (1). It assumes that there is no single or observable reality; it is socially constructed (1). Individuals form subjective meanings of their experiences, which are often discussed in social and historical contexts. They are created by interactions with others as well as historical and cultural norms that operate in people's lives (2). Constructivist research seeks to understand the phenomena from the experiences and perspectives of individuals who are directly involved with the phenomenon being studied (3). In constructivist paradigm, researcher must be at the centre of the research process in order to comprehend the social world. Researchers often pay attention to the particular contexts in which people live and work in order to comprehend the participants' historical and cultural settings (2). The researcher's involvement and personal, cultural, and historical experiences are also recognised as crucial in comprehending the topics under investigation (4). The intention of the researcher is to make sense of or interpret the worldviews of others. Instead of beginning with a theory as in post-positivism, inquirers create or establish a theory or pattern of meaning inductively (2).

4.3 Justifications for Using Qualitative Methodology

As the aims of the qualitative studies were to explore the perspectives of health care stakeholders around barriers and facilitators to SDM implementation, and to ask questions such as what are the barriers to implement SDM and how SDM can be implemented successfully in Saudi Arabia, it was decided to use qualitative methods of research. In addition, the findings of the systematic review (Study 2) showed that the majority of the included studies used a quantitative approach, primarily a questionnaire, which restricts respondents from including more information and limits their answers. This highlights the need for qualitative studies to understand the respondents' true feelings and attitudes. Using qualitative methods would be useful with health care stakeholders as this allows for an understanding of the main issues that hinder/facilitate SDM implementation.

4.4 Qualitative Research Methods

Inductive reasoning is of interest in qualitative research. It is primarily a process of theory building or explanations of a phenomenon (5). The initial step in this approach is to collect data, which is then analysed to develop concepts, hypotheses, or theories (1). The inductive approach does not border the themes that may emerge from the data, and it frequently results in generating new knowledge. Findings derived inductively from data can take many forms, including themes, categories, concepts, hypotheses, and theories. Qualitative study is often undertaken by researchers because of a lack of theory or failure of existing theories to adequately explain a phenomenon (1). In qualitative research, researchers construct a theory based on data gathered from various sources such as interviews, observations, and documents. This data is grouped and ordered into themes as researchers work from the particular to the general.

In contrast to quantitative research, qualitative research allows the investigator answer 'how' and 'why' questions, provides a rich and deep understanding of the area being studied, and does not restrict participants to a specific set of answers. It has been suggested that for answering some research questions, an in-depth understanding of the area being studied is required, as merely looking at the surface does not provide a full picture (6).

Basic qualitative inquiry, also known as interpretive, fundamental, or generic qualitative inquiry, was chosen for studies three and four because it is consistent with the constructivism philosophy and the aims of these studies (1,7). The growing interest in qualitative health research has resulted in an increase in a variety of qualitative methodologies, resulting in increased difficulty in identifying an appropriate approach. According to Creswell, traditional qualitative research methodologies include phenomenology, ethnography, grounded theory, narrative, and case study (2). These types of qualitative research share some characteristics with basic qualitative research, which lead to their classification as "qualitative." They do, however, have a slightly different focus, which results in differences in how the research question is framed, sampling methods, data collection and analysis, and write-up (1).

Adherence to one of these methodologies may put researchers under pressure if their research does not fit into one (8). When an ill-fitting methodology is placed to research, it is unlikely to produce any theoretical or methodological contributions while ignoring any possible benefits of a basic qualitative approach (7,8). In the basic qualitative study, there is no need to adhere to any of the established qualitative research methodologies, such as phenomenology, grounded theory, or ethnography (9). Studies adopting a basic qualitative approach may be designed to incorporate some elements of these traditional methodologies, resulting in the development of a new approach, or they can disregard this and adopt no methodological framework (10).

In a basic qualitative study, a qualitative researcher would be concerned with how individuals perceive their experiences, construct their worlds, and assign meaning to their experiences. The overarching goal is to comprehend how people create meaning and experiences (1). Although this understanding underpins all qualitative research, certain types of qualitative studies have additional dimensions that make them unsuitable for the aims of studies three and four. The qualitative case study, for example, seeks to conduct an in-depth analysis of a bounded system. The purpose of phenomenology is to explain the essence of a phenomenon. Ethnography seeks to understand not only how people communicate with one another, but also how they interact with the culture of the society they live in. Narrative research investigates people's stories, interpreting them in various ways in order to comprehend the meaning of their experiences. Grounded theory research aims to both explain and construct a substantive theory about the phenomenon under study. Critical qualitative research focuses on social criticism in order to raise awareness and motivate people to effect change (1).

4.5 Data Collection Methods in Qualitative Research

Various data collection methods are used in qualitative research. In contrast, interviews are the most commonly used method in health care research (11,12). Many authors consider interviews to be the gold standard for eliciting in-depth exchanges between the researcher and qualitative research participants (13–15). The purpose of the interviews is to explore participants' experiences, beliefs, and views on specific matters. This method is also useful for identifying sensitive issues that participants may not want to discuss in a group setting (15). Interviews are consistent with constructivist paradigm as the interaction between the researcher and the participants is critical for producing meaningful data. Therefore, interviews were employed as the primary data collection method.

Semi-structured interviews are a common type of interviews in healthcare (1). Several open-ended key questions are posed to participants, which help in determining the area to be discovered while also allowing interviewer to deviate from the structured set of questions in order to pursue a more detailed idea or response (11). This format allows participants to comment and expand on topics that are important to them, while also allowing the interviewer to react to the situation at hand and respond to new ideas on the topic. These new ideas could be used to guide further interviews in order to obtain a variety of perspectives (1,18). As a result, this type of interview produces richer and more detailed data (15).

The interview approach used in studies three and four included combining structure with flexibility by taking into account a list of questions that needed to be elaborated and picking up on ideas raised by participants. As this approach is aligned with the semi-structured interviews, it was selected. This type of interview enables the researcher to focus on the questions as most of the busy participants have limited spare time to give an interview.

4.6 Development of Topic Guide

The topic guide developed was based on the key themes arising from umbrella review (Study 1) and systematic review (Study 2). Interviews consisted of open-ended questions seek to elicit the participants' perspectives on SDM as well as the barriers and facilitators to its implementation. Prompts were used to elicit information about patients, physicians, and the environment (see appendix 3). Participants were given the opportunity at the end of the interview to contribute any additional relevant information that was not addressed during the interview.

Interview questions were developed in English and translated into Arabic, as the interviews were conducted in Arabic. The back-translation method was used to check the reliability of the translation. This involves re-translation of the translated instrument back into the first language and then the comparison of the first version with the one that is back-translated. (19). This method plays a role in ensuring that there are no variations between the first version and the targeted version (20).

The first translation was carried out by the main researcher who translated the interview questions from English into Arabic language, and this was followed by another translation from Arabic to English by a Saudi colleague in medical school who is fluent in both languages. The Arabic version of the questions was pilot-tested on two participants to ensure that they understood the language and concepts, and they were excluded from the analysis.

4.7 Sampling in Qualitative Research

In qualitative research, a large number of participants are not needed to gain rich data. Participants are continuously recruited until data saturation is reached where no new information, understandings, or insights are forthcoming (1). It is critical to use a sample size that is sufficient for answering the research questions while also allowing for maximum diversity across the target population (21). Since a qualitative approach can necessitate adjusting sample size as required during the study phase, data collection could continue until saturation is reached and no new categories arise (21).

In qualitative research, non-probability sampling is the most appropriate sampling strategy. Purposive and snowball sampling are the most common forms of non-probability sampling. Purposive sampling allows discovery and deep understanding from a sample that can provide rich information (1). It aims to recruit participants who are most likely to provide rich information for in-depth study (22). In purposive sampling, the researcher determines the questions that need to be answered based on the topic of interest and sets out to find potential participants who can provide the information based on their experiences and knowledge and provide a range of views (23,24). Snowball sampling is a type of purposive sampling in which well-informed participants are recruited, and then recommend other people of interest to be recruited. These methods are useful if participants are typically difficult to locate or are inaccessible via other sampling strategies (1,2,25). Purposive and snowball sampling are not free from bias, in contrast to probability sampling. However, they can provide robust and reliable data as the goal in qualitative research is more for the depth of analysis than representativeness (26).

Snowball sampling was used in study four, while purposeful sampling was used in studies three and four. They are more efficient when used properly than probability sampling in practical field environments (23). For instance, participants, who are selected randomly, may not be as experienced and knowledgeable as an expert participant (27). The current research aims to interview different individuals who can provide rich information to help understand issues around the implementation of SDM in Saudi Arabia. Patients were recruited based on their condition, gender, level of education, age and settings while healthcare professionals were recruited based on their experiences, gender, age, settings and positions in the healthcare sector.

4.8 Data analysis in Qualitative Research

In qualitative research, there are numerous approaches to data analysis, one of which is thematic analysis. Thematic analysis is defined as the process where themes or patterns are identified within qualitative data (28). The goal of thematic analysis is to determine themes or patterns in the data that are significant or interesting. Thematic analysis was informed by the approach of Braun and Clarke, which provides a six-stage guide, a very useful framework for conducting the analysis (see Table 4.1). Researchers may move forward and back between these stages, perhaps many times, specifically if they deal with a large quantity of complex data (28).

Analytical Steps	Activities
1. Becoming familiar with the data	Reading, re-reading the transcripts, making notes, and jotting down early impressions
2. Generating initial codes	Coding interesting features of the data, collecting data relevant to each code
3. Searching for themes	Collecting and combining codes to form initial themes, gathering data relevant to each initial theme
4. Reviewing themes	Reviewing, modifying, and develop the initial themes that were identified in Step 3, examining how the themes relate to the coded extracts and the entire data set
5. Defining and naming themes	Continuing analysis to revise themes and the overall story that the analysis tells, creating definitions and names for each theme
6. Producing the report	Writing-up of a scholarly report of the analysis

Table 4. 1:Braun and Clarke a six-stages framework for conducting a thematic analysis (29)

Braun and Clarke recommend that thematic analysis should be the first qualitative method to be learned as it provides essential skills that will be of use for conducting different forms of qualitative analysis (29). Thematic analysis is not bound by any particular theoretical or epistemological position and as such, it can be used alongside or in place of any theoretical framework (29). Therefore, thematic analysis found to be useful to analyse the data in studies three and four.

In addition to thematic analysis, the COM-B (capability, opportunity, motivation, and behaviour) model was chosen for data analysis. This entails performing initial inductive thematic analysis and then mapping the developed themes into COM-B. This analysis process was used in conjunction with qualitative research in many of the studies (30–34), demonstrating its applicability.

4.9 Choice of Theoretical Framework

The aims of studies three and four were to investigate healthcare stakeholder perspectives on factors influencing SDM implementation. After completing the inductive thematic analysis of the data, my supervisors and I agreed that the themes needed to be organised. We then confirmed the need for a theoretical framework to help structure the findings, explore more thoroughly the characteristics of the themes formed, and better understand the connection not only between the themes and their features but also between the themes as a whole. COM-B was chosen as a theoretical framework due to its compatibility with the study aim as SDM implementation requires behavioural changes. It also fitted well with the developed themes as the themes in studies three and four addressed factors related to individuals capabilities, opportunities around them either social or environmental, and factors that motivate participants to engage in SDM process. In addition, COM-B demonstrated its applicability in identifying barriers and facilitators to SDM implementation in a variety of studies (35–37).

The COM-B model is a simple framework for understanding behaviour in which three essential conditions for behaviour are conceptualized: capability (physical and psychological), opportunity (physical and social), and motivation (automatic and reflective) (38). COM-B is the cornerstone of the Behaviour Change Wheel (BCW), a toolkit for behaviour change intervention design (38), which is the starting point for the implementation of an intervention as illustrated in Figure 4.1. COM-B components can be linked to the BCW and Behaviour Change Technique Taxonomy, which promote the selection of intervention techniques that are likely to be suitable and successful in overcoming barriers and facilitators for each component in COM-B.

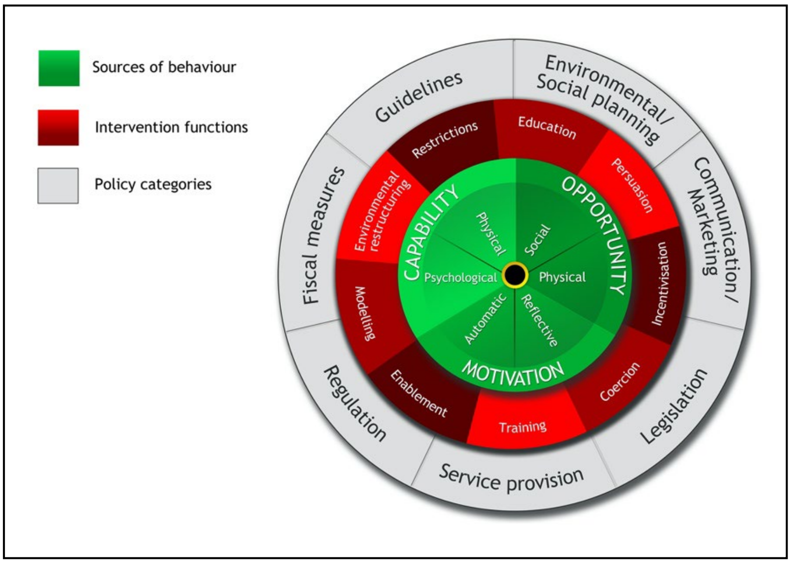

Figure 4. 1: The Behaviour Change Wheel. Reproduced from Michie (38)

Michie illustrated how capability, opportunity, and motivation interact in a ‘behaviour system,' resulting in behaviour that affects these components as shown in Figure 4.2. Capability can be defined as “individual’s psychological and physical capacity to engage in the activity concerned”. It entails possessing the necessary skills and knowledge. Motivation is “all those brain processes that energize and direct behaviour, not just goals and conscious decision-making. It includes habitual processes, emotional responding, as well as analytical decision-making”. Opportunity is “all the factors that lie outside the individual that make the behaviour possible or prompt it”. Figure 4.2 depicts the potential influence of system components as represented by single-headed and double-headed arrows. For example, opportunity and capability can both influence motivation; engaging in a behaviour can alter capability, motivation, and opportunity (38).

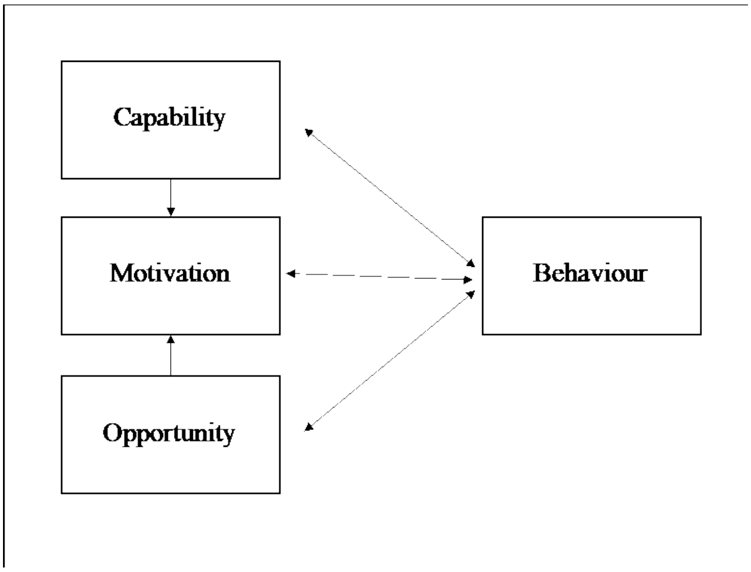

Figure 4. 2: COM-B Behaviour Change Model. Adapted from Michie (38)

4.10 Mapping Themes into COM-B

The themes and subthemes in studies three and four were derived from the data using an inductive approach. A deductive approach was deemed undesirable at this stage as it would impose a pre-determined framework on the data and classify it within that framework, resulting in the loss of significant meaning and insight in the process of fitting the data into the framework. Deductive analysis was considered at a later stage, and COM-B was used to categorize the developed themes and help in understanding the relationship between themes.

The developed themes in studies three and four were placed under different components of COM-B. Some of themes take the form of limitations in physical or mental abilities of individuals who are involved in the process of SDM. For instance, patients may want to participate more actively in decision-making, but their level of education or lack of knowledge may prevent them from doing so. Things in the physical or social environment can also inhibit behavioural change. These are referred to as opportunities. For example, physicians may want to practice SDM but lack resources such as time and treatment options. Finally, their automatic or internal responses can either inhibit or promote behaviour. These materials are classified as motivations. For example, physicians or patients may want to engage in the SDM process but avoid doing so due to different preferences or perceived benefits of SDM.

4.11 The Role of the Researcher in Qualitative Research (Reflection)

In line with constructivism paradigm, it is crucial to acknowledge the values, beliefs, and experiences of the researcher in order to comprehend how they influenced the research. Thus, a discussion of the researcher's reflexivity position is important, as it is intimately tied to the credibility and quality of the study.

While I had my own opinions about the importance of SDM at the beginning of the research, I tried to remain neutral, as much as possible, throughout the interviews, and I avoided expressing an opinion in order to obtain truly honest responses. I made every effort to ask probing questions in order to gain a better understanding of the participants' responses. Keeping track of my thoughts allowed me to be more transparent about my feelings. Following each interview, notes were taken and kept, serving as a reflexive tool containing my own feelings and thoughts during the interviews.

Additionally, my Saudi background was considered to have an influence on the study. Working with a researcher who has a similar cultural background to the participants gives the impression that they share a common understanding, which may lead them to share more details about their experience than they would with a non-Saudi researcher. Being Saudi gave me the opportunity to reflect on and investigate specific aspects of the participants' perspectives that I considered to be essential components of Saudi culture, such as the influence of family and some societal norms. However, being from the same culture may limit the researcher's ability to analyse participant experiences from a fresh perspective, free of preconceived assumptions. To overcome this and to ensure a higher level of reflexivity, I engaged with my supervisors on a regular basis to discuss data analysis, which raised questions that helped reveal hidden meanings that I had overlooked.

Lastly, the quality of the studies may have been influenced by my experience and skills as a researcher. Despite the fact that I was an inexperienced qualitative researcher, I made every effort to read more and attend many training courses in qualitative methodology and methods.

4.12 Validity and Reliability in Qualitative Research

To ensure trustworthiness and rigor, several criteria were used in this study (39). Rigor was assessed in terms of credibility, transferability, dependability, and confirmability in the report.

4.12.1 Credibility

Credibility assesses whether the data is represented in a way that reflects the opinions of the participants and whether the results are accurate. Methods by which to accomplish this include peer debriefing, paying attention to the contradictory cases, verbatim quotations, involving multiple researchers in the analysis process, iterative questioning, reflexivity, and examining of previous studies findings to see how closely the project's findings align with those previous studies (40,41). Triangulation also is an effective technique for promoting credibility that is built on the principle of bringing together different perspectives for mutual data validation in order to verify that all facets of a phenomenon have been examined (42).

The first step to enhance credibility was that two independent assessors checked the research for appropriateness and feasibility at the end of the first year (transfer year). Triangulation of data sources relies on variation in time, space, and individual to capitalize on the variety of data that may lead to a full understanding of the phenomenon under investigation. This was accomplished by recruiting various healthcare stakeholders (physicians, patients, and managers) from several PHCCs to form a rich picture of their perspectives towards SDM. The involvement of the supervisory team in this process also contributed to the credibility of the findings, as the researcher's thoughts were validated by those who were not involved in the main analysis process. The supervisory team addressed and reviewed the researcher's work on a regular basis. In addition, previous research were examined to frame the findings (Chapters 5, 6), background and experience of researcher were discussed (see Reflection), and verbatim quotes and contradictory cases are highlighted and presented (Chapters 5, 6). Lastly, the qualitative research was submitted to peer-reviewed journals. This allowed questions to be asked of the researcher, as well as any possible issues in the study to be identified and corrected or defended.

4.12.2 Transferability

The author of a qualitative study should be transparent about participants and include as much information as possible about them to help the reader determine the transferability of the results to a similar setting. The author should also provide a thorough explanation of the study's context (41).

Thick description, which began with a detailed description of the Saudi context (Chapter 1), was used to achieve transferability criteria in this study. Demographic information about the participants was provided, as well as background information about the PHCCs from which they were recruited (Chapters 1,5, 6, and 7). Additionally, the study sample included a diverse group of stakeholders whose perspectives on SDM are critical. This level of diversity and detail helps in determining whether it is transferable to other groups.

4.12.3 Dependability

Dependability assesses whether the research process is logical, traceable, and well-documented, with an emphasis on the methods used and the conclusions reached by the researchers. Debriefing, peer review, audit trails, triangulation, and reflexivity are examples of dependability evaluation tools (41).

In addition to the techniques used under credibility, which also ensure dependability, an audit trail was an effective strategy for increasing dependability in qualitative studies. This is accomplished by maintaining transparency throughout all research studies and providing detailed information on participant selection, data analysis, and so on.

4.12.4 Confirmability

The confirmability of the findings refers to how accurate they are likely to be. This can be determined by the author's reflexivity and transparency regarding their own views and background, which may have influenced the results (41).

In addition to the audit trails mentioned, the researcher's background and view on the topic were discussed (see Reflection) so that the reader could see how the researcher's background could have influenced the findings described. Constant feedback from my supervisors throughout the research process improved confirmability as well.

4.13 Chapter Summary

Qualitative methodology is the most appropriate approach as it aligns with the philosophical perspective and the research aim. Thematic analysis and semi-structured interview were chosen as the most appropriate method to complement the research methods. Credibility, transferability, dependability, and confirmability all addressed the trustworthiness and rigour of the qualitative studies.

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Chapter 5 (Study 3): Shared Decision-Making in Primary Healthcare Centres in Saudi Arabia: The Perspectives of Patients with Diabetes

Student Contribution to the Paper

The PhD student developed the study protocol/methods, collected and analysed the data, and drafted the final manuscript. Supervisors (Dr Andrew Lee and Dr Praveen Thokala) reviewed and contributed to the protocol and manuscript.

Chapter Overview

In the chapter prior to the methodology chapter, we provided regional exploration of factors influencing the implementation of SDM in the EMR countries. This chapter addresses the third objective of the thesis, which is exploring the perspectives of patients on SDM and its implementation in PHCCs in Saudi Arabia.

Abstract

Objective: To identify and understand the factors that influence shared decision-making (SDM) from the perspectives of patients with diabetes in Saudi Arabia.

Methods: We conducted qualitative semi-structured interviews with a purposive sample of patients with diabetes attending primary health care centres (PHCCs). Interviews were recorded, transcribed, translated and thematically analysed. Themes were mapped using the COM-B model.

Results: 14 patients with diabetes were interviewed. Nine key themes and ten sub-themes emerged: patients knowledge and understanding, patient socio-demographic characteristics, environmental context and resources, family and community, physicians behaviours and attitudes, preferences for SDM, perceived value and benefits of SDM, patient self-efficacy and confidence, and patients' trust and confidence in PHCCs.

Conclusions: Patients have good awareness about SDM and its benefits, and expressed a preference for it, although SDM is not fully practised at PHCCs. The quality of physicians' communication with patients was a key factor that hinders or facilitates patient involvement in decision-making, as it impacts information sharing between them.

Practice implications: Physician training on SDM and improved communication skills are needed. Physicians should be aware of the importance of providing sufficient information to their patients in order to enable SDM.

Keywords: patient-physician communication, diabetes, shared decision-making, implementation, barriers/facilitators

5.1 Introduction

Diabetes is one of the conditions with the greatest disease burden in Saudi Arabia, affecting one-fourth of the adult population and is further expected to more than double by 2030 (1). These numbers are alarming, and the burden of diabetes is likely to overwhelm the Saudi health system in the future, especially given that adults constitute 72.4 % of the entire population (2). The most worrying factor is the increase in the prevalence of diabetes in recent years, which has risen almost tenfold in Saudi Arabia over the last 30 years (1).

Previous findings from Saudi Arabia revealed that there is a low-level of knowledge regarding the disease among patients with diabetes and the general population. A study found that 15% of patients with diabetes had insufficient knowledge of the disease, while 72% had moderate knowledge (3). It is important for patients with diabetes to better understand the medications and lifestyle modifications that can help them control their situation and delay the onset of diabetes complications (1).

Diabetes is managed using insulin, oral anti-diabetic medications, or a combination of both (4). Weight management and the use of alternative and complementary medications are other methods of managing diabetes in Saudi Arabia (5). Alternative medicine is popular among Saudis, owing to the fact that it is recommended in Islam. A study discovered that when Saudi patients take herbs to treat chronic disease, they are less likely to seek medical treatment as prescribed (6).

Various management options have been devised to improve the care of patients with diabetes. However, physicians may find it difficult to select the best option for the patient as this relies on the patient’s preferences and their situation (7). Even in cases where reliable evidence shows that a particular treatment option is more efficacious than another, there is a possibility that this option does not suit the patient and another inferior option may be better for them (7). The reason behind this may be the effect of that option on other outcomes that are important to the patient such as costs and risks, or its effect on patients' ability to carry out other activities (7).

SDM is a patient-centred approach that can help enhance the quality of care for patients with chronic diseases such as diabetes (8). SDM is a process that involves the exchange of information between providers and patients, where patients share their views and lifestyle preferences and providers share the benefits and risks of potential treatments. The aim of this strategy is to enable decisions based on the best available evidence in relation to each patient's preferences and needs (9,10), which improves medication adherence and outcomes (11–13). It increases the patients’ knowledge about various stages of their condition and the best way to manage the situation and risks related to each treatment. This helps them to be more actively involved in the processes of decision-making (14).

Despite the benefits of SDM and the policies that support its implementation (15–18), SDM is not yet embedded in clinical practice, and there are many barriers that hinder its implementation. This is especially true in non-Western countries where cultural aspects and social contexts are different from those in Western countries. This raises the question as to what are the determinants that impede or facilitate its implementation. This study was conducted to try and identify those determinants that influence the implementation of SDM in PHCCs in Saudi Arabia from the perspectives of patients with diabetes.

5.2 Methods

5.2.1 Study Design

We conducted an exploratory qualitative study involving semi-structured interviews with a purposive sample of patients with diabetes.

5.2.2 Study Setting

The study was conducted in the city of Jeddah, Saudi Arabia. PHCCs were invited to help recruit participants for this study. Health services in Saudi Arabia are provided by governmental, non-governmental, and private organisations, the largest of which is the Saudi Ministry of Health (MOH). It is in charge of public health services and offers curative, preventive, and rehabilitative care. Primary care services are provided by MOH, free at the point of access. Depending on the community it serves, each PHCC has three to four physicians and usually runs twice-weekly clinics that see patients with chronic diseases.

5.2.3 Participant Eligibility, Sampling and Recruitment

Using purposive sampling, patients from PHCCs who are aged 18 and above, with diabetes (type I and II) and able to give consent to participate in the study were invited. Purposive sampling is a useful approach to achieve maximum diversity over key characteristics that were deemed most useful in this study, such as age, gender, and level of education, and was thus used in this research process to identify potential informants. Ethics approval for this study was granted by the Directorate of Health Affairs, Jeddah Institutional Review Board (see Appendix 13).

Initially, patients were approached by the lead researcher in the waiting areas at PHCCs and invited to take part in the study. Information sheets were provided to patients and signed consent was obtained if they agree to participate (See Appendix 3 and 5). For participants who are not able to read, the information was provided verbally. Participation was not remunerated. We asked for a quiet room in PHCC to see potential participants and made it clear to all patients that their participation was voluntary and their agreement to participate or not would not influence the health care they would receive.

However, due to coronavirus restrictions (March 2020), we could not continue the in-person recruitment and interviews in PHCCs. Instead, patients were recruited through social media, such as Twitter based on their bio page from accounts of diabetes associations or hashtags for diabetes such as (#diabetes_now). We also asked some diabetes associations to post the invitation on their Twitter accounts. Updated ethical approval for this change was sought and obtained from the same institutional review board. The information sheet and consent form were sent via email or WhatsApp to those who agreed to participate, where they were signed, scanned, and returned to the researcher.

After obtaining participants' consent, face-to-face interviews were conducted with those who were recruited in PHCCs, and telephone interviews were conducted for those who were recruited through Twitter.

5.2.4 Procedures

Face-to-face (n= 8) and telephone (n = 6) in-depth semi-structured individual interviews were conducted. The interviews were in Arabic, the native language for Saudis, to ensure that there were no language restrictions. The topic guide for interviews was developed based on a previous literature review (19,20) (See Appendix 7) and piloted on two participants (excluded from analysis). This included open-ended questions aiming to elicit the participants' perspective on SDM and identify barriers and facilitators. The interviews lasted between 20-30 mins, were audio-recorded with participants' permission and transcribed afterwards. Field notes were taken during each interview to record emerging ideas that need more explanation or discussion with participants, and after each interview to reflect the interview process and the interviewer's overall impression. No further patients were recruited after 14 interviews as no new themes or findings were emerging, suggesting data saturation was reached.

5.2.5 Analysis

Transcripts were uploaded into NVivo software to be analysed thematically using an inductive approach (21). Following the completion of the transcription, all the interviews were translated from Arabic into English so that the other researchers could verify and confirm the validity of the data. To ensure that meaning was not lost in translation, the interviews were undertaken by the lead researcher who speaks both Arabic and English and shares a similar culture with the participants; Arabic transcripts were translated into English by a Saudi professional translator; and the lead researcher checked the accuracy of the translation of the transcripts to ensure that there was no change in meaning. The lead researcher then coded all the English transcripts after reading them.

Ideas that were linked to each other were grouped into codes and then discussed with the researchers (supervisors AL, PT). Codes were collated and combined to form initial themes and sub-themes, and all researchers verified that the themes reflected the complete collection of data. Where there were any differences in interpretation, the researchers discussed these until consensus. The key themes and sub-themes were organised by continued discussion among the researchers. In order to help to make the data more understandable, the three researchers confirmed the need for a theoretical framework to explore more thoroughly the characteristics of the themes formed, and to better understand the connection not only between the themes and their features but also between the themes as a whole. More information on the selection of theoretical framework was provided in Chapter 4.

5.3 Results

5.3.1 Participants' Characteristics

The key characteristics of the 14 patients with different type of diabetes interviewed are summarised in Table 5.1. The study design did not attempt to look for differences between type I and type II patients. However, when analysed retrospectively, the differences between them had no effect on the results. It is important to note that this result is based on the small sample size used in this study. Therefore, participants were not differentiated in the Table 5.1 based on their type of diabetes.

Patient ID	Age	Gender	Level of education
1	- 40	Female	Secondary
2	- 40	Female	Undergraduate
3	- 40	Female	Undergraduate
4	- 40	Male	Elementary
5	+40	Female	None
6	- 40	Male	Undergraduate
7	+40	Female	Undergraduate
8	+40	Male	Secondary
9	- 40	Female	Undergraduate
10	- 40	Male	Undergraduate
11	- 40	Male	Undergraduate
12	- 40	Male	Undergraduate
13	- 40	Female	Undergraduate
14	- 40	Male	Undergraduate

Table 5. 1: Participants' demographic characteristics

5.3.2 Factors influence the implementation of SDM in Saudi Arabia

The thematic analysis of the data resulted in the development of key nine themes and ten sub-themes. These spanned all three areas of the COM-B model as presented in Tables 5.2-5.4.

COM-B	Themes	Sub-themes	Representative quotes
Capability	Patients knowledge and understanding	Awareness of the concept of shared decision-making	“The doctor should take from the patient information about his lifestyle, his routine and on that basis they both should discuss things and make the treatment plan.” (Patient 9) (Female, 21years, undergraduate). “I chose the right option for me (the insulin pump). I discussed with the doctor the advantages and disadvantages of using the pump and what to do if facing any of the disadvantages.” (Patient 2) (Female, under 40, undergraduate).
		Awareness and knowledge regarding care and treatment options	“Initially, no, they didn’t give me any options…I searched about diabetes and tried to find what was happening with me. As a result, my visits to the PHCC increased slightly. They got bored of me until they started to give me treatment options…They like to impose their opinion at the beginning until they discover that you’re knowledgeable then they start giving you options and share things with you.” (Patient 14) (Male, under 40, undergraduate).
	Patients Socio-demographic Characteristics		"Some patients really care about their health so they cooperate. Other patients however, are indifferent, and this is due to many reasons, such as the patient’s interest, his level of education plays a major role, the environment where he lives also plays a role. This means that a young patient in his twenties is not like an old one in his sixties. An elderly patient would not care much…The younger patients are also different, so the one who is educated and have broad knowledge is not like the one who does’t care.” (Patient 12) (Male, under 40, undergraduate). “Perhaps, some elderly illiterate patients don’t like this way of shared treatment. On the other hand, if the patient is educated and aware, SDM will be good for him.” (Patient 7) (Female, above 40, undergraduate).

Table 5. 2: Illustrative quotes for the themes and sub-themes under capability

COM-B	Themes	Sub-themes	Representative quotes
Opportunity	Environmental context and resources	Administration and time pressures	“The large number of the patients makes it hard for doctors to engage patients and explain to them…because doctors are under so much pressure, they can’t implement SDM, and I don’t blame them…The number of doctors should be increased. The patients ’numbers are huge compared to the doctors ’numbers. The doctors have many duties. If the doctor has a reasonable number of patients, he will manage to give them enough time for

			discussion.” (Patient 8) (Male, 76 years, secondary).
		Availability of the treatment options	“But at the beginning, I used to go to my local PHCC. Then, I was referred to the diabetes centre. There (in the centre) they told me about the insulin pump but I got it after two years of follow-up appointments at the centre.” (Patient 2) (Female, under 40, undergraduate). “Moreover, most of the treatment options aren’t available. The treatment options should be made available.” (Patient 8) (Male, above 40, secondary).
		Clinic atmosphere	Sometimes the clinic door is open. You know, elderly people just open the door and walk in saying see me and let me finish. Another patient walks in to make an appointment and another one wants the medication. They all interrupt you. So even if you planned to say something you discover later on that you only asked two out of the ten questions you wanted to ask…Sometimes there are trainee doctors with the doctor who make you feel that there is someone standing in the middle. The presence of the trainee doctor is a hindrance to me as a patient because I want to feel comfortable talking to the doctor. (Patient 14) (Male, under 40, undergraduate).
		Continuity of care	“Also, the problem we have at the PHCC is that I don’t follow up with one doctor. I go to my appointment to find out that I am seeing Dr X, in the next appointment I see another doctor because the previous doctor is on a training leave. I mean I follow up with a doctor who has background information about me and has prescribed me the medication then comes the other doctor who asks you why you are using this mediation and changes what the first doctor prescribed. One doctor would say, why aren’t you using (insulin) injections and another one would say no, you shouldn’t be using insulin injections. Each doctor has his own point of view. I know that they are doctors and each one of them has his own diagnosis and his point of view but the patient feels that he is an experiment field, which affects him. Initially, I suffered because of the doctors but eventually I learnt how to control my blood sugar level because of the number of times I visited them and tried to learn how the treatment should be.” (Patient 14) (Male, under 40, undergraduate)
	Family and community	Family involvement	As soon as they know that you have another diabetic family member in the house, they expect you to take the information from that patient; they urge you to keep going back to that patient and benefit from his knowledge. Ok, maybe this diabetic patient doesn’t know much or he has the wrong information!! This is the most annoying thing. (Patient 3) (Female, under 40, undergraduate). “I prefer to make my own decisions. However, sometimes, I do share my family some decisions to make because my father is very hot-tempered. I get scared that he might lose his temper if I do something he doesn’t know about. He may go to the doctor (and find out) and say, you have shocked me, why didn’t you tell me? Why didn’t

			you discuss your decision with me?” (Patient 3) (Female, under 40, undergraduate).
		Influence of social media	“I did some research about diabetes by myself, I read about it and checked some hashtags on Twitter and joined diabetic groups. I learnt more from that than from the doctor.” (Patient 3) (Female, under 40, undergraduate). “I found myself closer to other patients than to the doctors. They would give you the information you need politely and with manners. They give you the correct information and cooperate with you a lot whereas doctor’s time is limited. He just barely takes from you the main points.” (Patient 6) (Male, under 40, undergraduate).
	Physicians behaviours and attitudes	Communication style	“I tried once or twice to discuss things with him, but he kept telling me that this can be used and that cannot be used and just follow what I say, and that is it. There is no chance for discussion, he doesn’t give me the chance to discuss things with him. It is like I am the doctor and you’re the patient, so you should listen to me. He looks at me as if to say I know better than you do, so do what I am telling you.” (Patient 13) (Female, under 40, undergraduate). “Some doctors have good manners and accept the patient’s point of view. Those doctors prefer to share the patient in the decision-making of the treatment plan...For me, it was the doctor who motivated me to show what I am capable of and the information I have. He allows me to share with him everything...This is reason why I have a good relationship with him. Even when I walk into his clinic, he always stands up and shakes my hands.” (Patient 10) (Male, under 40, undergraduate). “My sharing in making the decision is hindered by the doctor who is bored and exhausted and who rushes you. When I see such a doctor, I say to myself this doctor barely stands himself let alone listening to me...Some doctors are not in the mood to even listen to you. I was once talking to a doctor and she interrupted me saying, I don’t want you to tell me your life story...There are others who don’t pay you any attention.” (Patient 7) (Female, above 40, undergraduate).
		Information and recommendations	The second one didn’t tell me about the available (treatment) options…This was the case with the previous doctors in the PHCC, not in the diabetes centre. For example, no one told me about the carbs calculation. I came to know about it from other patients with diabetes like me on Twitter. All of the previous doctors kept giving me only one option, which is the fixed insulin dosage, and stressed the importance of adhering to it. No one told me that there is an option other than the fixed dosage. They didn’t tell me that my insulin needs could be different from day to day…The majority don’t give out such information. If you go on Twitter and check the hashtag (#diabetes_now), you will find so many people asking about the basics that our doctors should have told us. (Patient 2) (Female, under 40, undergraduate)

			"The doctor was thorough. Initially he prescribed me tablets to take, then he prescribed me insulin injections. Then he prescribed another type of insulin injections but I refused to take them because they increased my weight. I did not take them at all...The doctor then prescribed the tablets again. He suggested going through gastrectomy and I agreed. He referred me to the gastrectomy clinic. He told me that if I undergo gastrectomy the problem of diabetes will disappear." (Patient 4) (Male, under 40, elementary).

Table 5. 3: Illustrative quotes for the themes and sub-themes under opportunity

COM-B	Themes	Representative quotes
Motivation	Preferences for SDM	"I would prefer to choose because I am the one who knows very well whether this option is suitable for me or not." (Patient 13) (Female, under 40, undergraduate). "I prefer to hear from the doctor and discuss things with him. However, the final decision is the doctor's because he knows better than me." (Patient 7) (Female, under 40, undergraduate) "I would prefer to share the choice with the doctor. When he explains to me the risks and benefits (of each option) and knows my routine and sleeping hours, we will be able to choose together something better." (Patient 12) (Male, under 40, undergraduate)
	Perceived value and benefits of SDM	"I mean, I am with the principal of sharing but it should (take place) from the beginning. If a person is included in the decision-making, it would improve his health situation because he is not forced but taking the medication by choice." (Patient 14) (Male, under 40, undergraduate)
	Patient self-efficacy and confidence	"I usually give the doctor my blood sugar readings, and the latest results of my cumulative (average) blood sugar. On that basis, he prescribes the treatment type and the dosage…However, he doesn't explain anything about the treatment type. So, I started searching about the medicines and taught myself. I depend on myself for everything else…I increase and decrease the dosage based on my blood sugar measures. I also consider my routine patterns, e.g., if I do exercise strenuously on a certain day, I decrease the dosage. But if I don't exercise, I increase it." (Patient 13) (Female, under 40, undergraduate).
	Patients trust and confidence in PHCCs	"To be honest with you, in the PHCC, there are general practitioners and family doctors and they don't have the resources. I feel I know more about diabetes than them so how can I take from their time to discuss things with them? There are things they don't know, especially the older doctors. They don't read up about what is new…The doctors at the PHCCs are not qualified or specialised enough to discuss the treatment plans because they are not familiar enough with insulin and its working (active) hours…I feel I will be wasting my time if I discuss things with them." (Patient 6) (Male, under 40, undergraduate).

Table 5. 4: Illustrative quotes for the themes under motivation

Capability

Factors that influence the capability of patients' involvement in the decision-making process were categorized into knowledge and understanding, and patients' socio-demographic characteristics (See Table 5.2) and described in detail below.

Knowledge and Understanding

Awareness of the concept of shared decision-making

The majority of patients in this study were aware of SDM as a concept. When asked to clarify what they knew about patient participation in decision-making or if they have been involved in decision-making, they outlined examples such as offering options, expressing opinions, discussing side effects, sharing information and decisions. These suggest an understanding of some of the elements of SDM, which may influence their preferences towards it and empowers them to have an active role in their decisions making.

Even though the majority of patients in this study knew of SDM, they were unaware of their rights, specifically the patient's bill of rights in Saudi Arabia, which includes aspects of SDM. Participants outlined that increasing patients' awareness about their rights in SDM may drive them to demand it when they interact with their physicians. Furthermore, they suggested some strategies to raise their awareness including the use of social media platforms, posters, TV, brochures, lectures and symposiums. Physicians may also contribute to increasing patients' awareness by informing them about their rights or practising SDM with them.

Awareness and knowledge regarding care and treatment options

Patient knowledge around treatment options may facilitate their involvement in the decision-making process, by bringing their views about the options to discuss them with their physicians during the consultation. Patients in this study who are aware of different treatment options confirmed their active role in discussing these options with their physicians. In contrast, patients who have a lack of knowledge trusted their physicians and agreed with the treatment options that were recommended to them. Patients' knowledge also influenced the attitude of their physicians towards involving them in the decision-making process. For example, one patient described how his physician's attitude towards him changed when they discovered he was knowledgeable.

Health education is important to enhance patients' knowledge about care and treatment options, which may increase their confidence in engaging in discussions around treatment options and sharing in making decisions. Participants in this study highlighted the importance of educating patients. However, patients have to be careful when they seek the information as "information overload" may increase their confusion and distraction, which may hinder their participation in decision-making, and leaving the choice to their physicians.

Patients Socio-Demographic Characteristics

Participants in this study highlighted some characteristics that may influence patients' care for themselves and their preferences towards decision-making such as their age, socioeconomic status and level of education.

A few patients thought that elderly patients may prefer not to be involved in the decision-making process. When we asked to elaborate why this was the case, one less educated patient stated that she prefers to leave the decision for them because they "know better". However, this is not always the case, as another educated elderly participant stated that he preferred to have that choice as long as his physicians explained to him the risks and benefits of each option. This is because he felt he knew himself better and would be able to choose what suits him. These suggest that the patient's level of education may influence their involvement in the decision-making process, regardless of their age.

Opportunity

The opportunity domain comprised social and physical environmental factors that encourage or discourage SDM. See table 5.3.

Environmental Context and Resources

Administration and time pressures

Staff shortages, increased patient demand, and time constraints were perceived as factors influencing SDM by the majority of patients interviewed. During the interviews, patients spoke of how their physicians see them in a hurry, prescribing medicine without discussion, in order to finish the consultation quickly. However, several patients are understanding of this situation as they see that physicians are exhausted with a large number of patients.

To overcome these issues, patients suggested some solutions such as increasing the consultation time or managing patients' appointments better. Other suggestions included increasing the number of doctors to cope with the increased number of patients, empowering technology to facilitate patient-physician communication, providing multiple consultations for SDM and engaging other professionals such as psychologists or social workers. The role of health educators may be helpful in reducing the pressure on physicians and raising patients' awareness. However, participants reported that they do not benefit from health educators because their appointments with them are far apart from their appointments with doctors.

Availability of the treatment options

Lack of treatment options was highlighted by the majority of participants as a barrier to SDM. Treatment options are more limited at PHCCs, and there is a greater range of options at public hospitals or diabetes centres but patients need to be referred to access them. Moreover, there is a waiting list for patients who need these options. Increasing the provision of treatment options in PHCCs may be one solution as suggested by several participants.

Clinic atmosphere

The atmosphere of the clinic was seen as an influencing factor in SDM, as this is the environment in which decision-making occurs. Patients highlighted that the clinic atmosphere is not conducive to facilitate this process and makes them feel uncomfortable. The presence of their family, or a trainee doctor, hinders patients from talking freely to their doctor as there is a lack of privacy. Also, patients explained how they are often interrupted, by the number of times that the clinic's door is opened by nurses and other patients.

Continuity of care

Another important issue that emerged is that patients meet different physicians during their follow-up. Participants highlighted the value of sustained patient-physician relationships to facilitate SDM. Indeed, several patients mentioned that they do not attend an appointment if their physicians are on holiday as they wanted to see a specific doctor. This would help maintain information and management continuity that may be affected if they are followed up by different physicians.

One patient, who saw a different doctor on each visit, reported experiencing confusion as his prescriptions changed each time he met a new doctor. As a result, he was unsatisfied with the management that he received, and even felt that he was an experiment field for physicians. However, he also added how he benefited later from meeting different physicians as this brought new perspectives about different management options, which enabled him to learn how to manage his condition.

Family and Community

Family involvement

The majority of participants interviewed preferred not to involve their family in their decision-making and view it as not important. This is despite the fact some physicians urged them to get information about diabetes from a diabetic family member if they had one.

Although physicians appreciate the involvement of the family in providing their patients with information, patients prefer not to share with them, either because they do not want to be confused from hearing more than one opinion, or their families' lack of knowledge about diabetes. However, some of the patients mentioned that they do share information with their family sometimes because they need their support or that they may be more knowledgeable and well educated. Another reason is that some patients are not allowed to decide without the approval from their family.

Influence of social media

The analysis of the interviews showed that several patients seek information from other patients with diabetes on social media. Participants emphasised that they benefited from social media more than from their doctors. Reasons for this include the ability to interact freely with others without time restrictions and ease of access to information about diabetes and its treatments options. Participants spoke about how they felt comfortable interacting with other patients with diabetes on social media, as they feel that they are welcomed. They even trust information that they obtain from social media as they spend enough time discussing it with others, unlike the short time with doctors, which limits information sharing between them.

Physicians Behaviours and Attitudes

Communication style

Participants highlighted some types of communication that felt paternalistic including dominating decision-making encounters, imposition of an opinion, blaming patients and use of threatening messages. Another type of communication issue that patients encountered in consultations was the physicians' partnership style. This is exemplified by physicians who encouraged patients to be involved in their decision-making, listened to them, discussed with them and respected their points of view. Physicians that did not dominate the consultation and used a partnership approach, facilitated SDM and developed a more trusting relationship with their patients.

Participants also highlighted how some physicians' attitudes influenced their communication with them, such as negative verbal or non-verbal behaviours. An example was given of how these negative behaviours reduced the patient's desire to participate actively in discussing their problems and concerns with their physician. In contrast, there are some facilitative attitudes and behaviours suggested by patients, such as the use of open-ended questions during the consultation, that enable patients participation, sharing the responsibility with them, welcoming and paying full attention to them.

Information and recommendation

The other major factor that emerged was a lack of information sharing which is one of the essential elements of SDM. A few patients gave examples of how medication was prescribed paternalistically without clarification of other available options or a discussion about the possible side effects of the chosen medication. The lack of information led patients to seek external information and support from others (e.g., internet, social media, peers, etc.) to satisfy their needs for it. This may confuse them as they may get improper or contradictory information. From one patient, we also understand that the provision of options and information was different by setting, as she received more information from the Diabetes centre than the PHCC.

Furthermore, patients are rarely given options other than the recommended one. Alternative treatment options were presented to them only if they were experiencing problems with the treatment prescribed by their physicians.

Motivation

This domain explores factors that influence patients' motivation in sharing decision making. Four themes will be explained in relation to motivation (See table 5.4):

Preferences for SDM

Participants in this study expressed a desire for sharing information with their physicians. However, they may have different preferences as to how the final decision is made. For example, some of the educated participants who felt confident of their ability to make their decisions favoured autonomous decision-making, where patients make the decision. This is in contrast with other participants who gave the final decision-making power to their physicians, believing that they know the best. This may be despite the fact that they appreciated discussion and information sharing with their physician. Others preferred collaborative approach where the physician and patient made the decision together, an approach between active and passive roles in decision-making.

Perceived Value and Benefits of SDM

The majority of patients outlined the benefit of SDM in increasing patients' awareness about their disease, building a trusting patient-physician relationship, improving patient satisfaction, treatment adherence and health status. Some participants highlighted the significance of increasing physicians' awareness about the importance of SDM because if they are convinced by it, they will practice it.

Patient Self-Efficacy and Confidence

Participants with a greater level of self-efficacy and confidence in their knowledge tended to involve themselves more by expressing their needs and problems, asking for or suggesting other treatment options, or refusing the treatment that does not suit them. They are more likely to ask for information, make decisions, and seek another opinion if they found that their physicians did not share information with them around treatment options.

Patients Trust and Confidence in Primary Care Physicians (PCPs)

The majority of patients outlined that they do not feel confident discussing information or sharing treatment options with PCPs. Some of them even admitted that they only attended their PHCC to get their medicines. This is because they perceived that PCPs are inexperienced, have outdated information and lack knowledge about diabetes and its treatments. Furthermore, some of the participants experienced negative situations such as wrong diagnosis or the doctor needing to consult another doctor in front of them about things that they thought the doctor should know.

5.4 Discussion and Conclusion

5.4.1 Discussion

This study represents the first qualitative understanding of the views of patients with diabetes in Saudi Arabia regarding SDM. The role of communication between the patient and physician has been highlighted in previous studies as an important factor that influences the involvement of patients in decision-making (20,23,24). Patients in the present study also viewed physicians' communication with patients as a leading factor that hinders or facilitates their involvement in decision-making. A few examples of the power dynamic in the physician-patient relationship were described, which can be a source of problem during the consultation. Power disparities in clinical encounters are a key barrier to SDM (25). In Saudi Arabia there is a high-power imbalance, and physicians have the upper hand in decision-making. A power differential between physicians and patients may reflect the physicians' sense of superiority to patients in the context of the consultation, or it may be the result of a gap in education and knowledge between them as the findings demonstrated that patients' level of education and knowledge influence their ability to involve in the SDM process. Physicians who dominate decision-making encounters and use negative verbal or nonverbal behaviour hinder the development of a collaborative relationship with their patients, and their patients may be less likely to communicate or participate in decision-making. This finding echoes other studies that show patients are uncomfortable discussing with physicians who perceive themselves as superior during their interactions with their patients (26,27).

The communication between physicians and patients has an impact on information sharing between them, which is a critical element of the SDM. Physicians who adopt a paternalistic style of communication tend to prescribe the medication without a presentation of other available treatments or a discussion on the recommended treatment. The lack of information maybe a way that they impose their opinions through the lack of transparency in providing options or not disclosing information about other treatment options or sequencing in presenting them. This suggests SDM tends not to be practised in Saudi Arabia. The lack or ambiguity of information may affect the ability of patients to manage their condition and could result in a lack of treatment adherence (28,29). To engage patients productively, the information provided should be unbiased and adequate. This is critical for empowering patients to understand their treatment options and choose their preferred option (30). The present study also identified the importance of providing sufficient information by physicians as patients can access information about diabetes from the internet and peers on social media, which will have variable quality of information. This would not only have an impact on the patient-physician relationship, but would also lead to patients seeking non-evidence-based treatment, unneeded testing, or expensive treatments (31).

Patients in Saudi Arabia can visit their PHCCs either with an appointment or walk-in. They can also book an appointment with PHCCs outside of their neighbourhoods. This can lead to a concentration of patients in a short space of time that puts added pressure on the doctor. The majority of patients in this study reported that they felt rushed by their physicians to finish the consultation. Increasing patient demand along with staff shortages may influence the ability of physicians to provide sufficient information or explanation on the available treatments. This not only affects information sharing between them but also the patients' confidence in the recommended treatment. Staff shortage also had an impact on the continuity of care. This issue is problematic especially in Saudi

Arabia where there tends to be a lack of communication between physicians and a dual medical records system, paper-based medical records and electronic medical records, that may affect the accuracy and sufficiency of patients records (32). This may also affect decision-making as patients have to repeat the same information to new physicians. It also hinders the opportunity for developing rapport between physicians and patients. Follow-up with the same physician facilitates the development of a better, long-term relationship between patients and physicians, which enables the development of robust health interactions over time (33,34). It also helps physicians to have a better understanding of the progression of their patient's disease as they have the opportunity to review the decision that was made previously and discuss other treatment options that were not made. However, this is not easily achieved with the increased demand of patients and shortage of physicians.

That said, there are also potential benefits to having different physicians, as it can bring new perspectives about the different treatment options and recommendations. This is consistent with a study by Frongillo and colleagues, which confirmed that patients, who have access to more discussions about different options related to their health condition, are more involved in decision-making (35).

It has been previously reported that the involvement of family in the decision-making process can enhance the patients’ engagement and autonomy, and reduce the stress of decisions on managing their condition (36,37). Surprisingly, this study found that patients prefer not to involve their family in their decision-making and they consider it not important. A possible explanation for this is that the majority of patients in this study had a good level of education and knowledge that enabled them to be independent in their decisions and increased their self-confidence. However, further investigations are needed to enhance our understanding of the perceptions and preferences of patients for the involvement of their families in decision-making.

The patients’ trust in their physicians is essential for effective clinical encounters (37). Previous studies have found a link between patients’ trust and other interpersonal aspects of the physician-patient relationship in the consultation. This involves the significance of good communication for patients (38), a sense of collaboration between physicians and patients (39), and the perception of the patient being given ample time during the appointment (40). Nevertheless, our findings showed that patients' perception of PCPs' expertise and knowledge of different treatment options was a stronger factor in patients' trust. This reflects a change in culture, as patients are more conscious about the available treatment options. This is not surprising, as patients today are more exposed to the internet and social media than before and can more easily exchange information around different treatment options, and increase their knowledge about their conditions.

5.4.2 Limitations

This study is subject to some limitations, including recruiting only patients with diabetes, which limits the generalisability of its findings to other patient groups. Another limitation is that phone interviews lack visual cues and nonverbal data, potentially hindering rapport, probing, and response interpretation. There is also a possibility of selection bias as we were unable to complete the interviews in PHCCs and had to recruit the other participants from Twitter, which may restrict those with limited technological knowledge from participating.

5.4.3 Conclusions

This study aimed to explore the perceptions of patients on SDM and its implementation. We found that patients are aware of the concept of SDM and its benefits, which boosts their preferences towards it. However, SDM is not fully practised at PHCCs in Saudi Arabia. The patients' view is that the quality of physicians' communication with patients is a key contributory factor that hinders or facilitates their involvement in decision-making. The findings also highlighted several ways in which physicians could demonstrate effective communication and building a trustful relationship with their patients, to facilitate SDM.

5.4.4 Practical implications

The barriers and facilitators that were identified in this study should be considered for developing interventions to implement SDM. Physicians training on SDM and improved communication skills are needed for better physician-patient communication. Physicians should consider the importance of providing sufficient information to their patients that may protect them from seeking information from other less reliable sources that may adversely influence patient adherence and management of their condition. Patient interventions are also needed to improve health literacy, raise awareness of their rights, and prepare them to be active participants in their care decisions.

Further research is warranted to understand patients' perceptions and preferences for family involvement in decision-making. Factors influencing organizational managers and physicians that may facilitate SDM implementation should also be investigated.

Ethics Approval

Ethical approval was obtained from the Directorate of Health Affairs, Jeddah Institutional Review Board (IRB registration number with KACST, KSA: H-02-J-002, 26/11/2019, research number: 01136).

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Conflict of Interest

The researchers have no conflicts of interest.

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Chapter 6 (Study 4): Healthcare professionals' views on Factors Influencing Shared Decision-Making in Primary Health Care Centres in Saudi Arabia

Student Contribution to the Paper

The PhD student developed the study protocol/methods, collected and analysed the data, and drafted the final manuscript. Supervisors (Dr Andrew Lee and Dr Praveen Thokala) reviewed and contributed to the protocol and manuscript.

Chapter Overview

In the previous chapter, we explored the perspectives of patients on SDM and its implementation in PHCCs in Saudi Arabia. This chapter addresses the fourth objective of the thesis, which is exploring the perspectives of healthcare professionals on SDM and its implementation in PHCCs in Saudi Arabia.

Abstract

Objective: To describe the perspectives of healthcare professionals regarding the implementation of Shared decision-making (SDM) in primary healthcare centres (PHCCs) in Saudi Arabia. **Methods:** Qualitative semi-structured interviews were conducted with a purposive and snowball sample of healthcare professionals in PHCCs. Interviews were recorded, transcribed, translated and thematically analysed. Themes were mapped to the COM-B model. **Results:** 16 healthcare professionals were interviewed. The data analysis identified six themes and 14 sub-themes. Physicians are unlikely to practice SDM in the context of time pressures, shortage of physicians, lack of treatment options, and decision-making aids. The findings also underscored the importance of building a trustworthy physician-patient relationship through the use of effective conversation techniques. **Conclusions:** There are multiple barriers to SDM in primary care. Unless these barriers are addressed, it is unlikely that physicians will effectively or fully engage in SDM with patients. **Practice implications:** Additional involvement in the process of SDM by psychologists and health educators may be beneficial. Continued medical education and training on SDM skills are also needed.

Keywords: Patient-physician communication, primary care, shared decision making, barriers/facilitators, and implementation.

6.1 Introduction

Patient-centred care has become a core principle for many healthcare systems around the world, and the focus is now on how to make it a practical reality (1). Promoting SDM, which is considered the crux of patient-centred care (2,3), is a key strategy in this initiative (4). SDM is a process that requires reciprocal sharing of information, where providers share the benefits and risks of possible treatment and patients share their values and lifestyle preferences. The aim of this approach is to make decisions that are based on the best evidence available in relation to the preferences and needs of each individual patient (5,6). Research shows benefits of implementing SDM, including increased adherence to treatment, appropriate use of services, reduced number of major surgery and emergency admissions, and improved patient confidence, satisfaction, and coping skills (7–10). Health policy researchers suggest that SDM may minimise over-diagnosis and over-treatment of conditions, resulting in a decrease in overall healthcare costs (11). As a result of the growing body of evidence supporting SDM, an increasing number of countries are integrating SDM into their health care policies and reform programs (12–14).

Primary care settings have provided much of the ground breaking evidence and research on SDM (15–20). They provide a fertile foundation for creative decision-making due to the large number of services used in primary care settings, the wide range of health problems faced, and the wide variety of medical decisions taken on a regular basis (21–23). In addition, most of the management of chronic diseases takes place mainly in primary health care settings. Relationships between physicians and patients may last for years in primary care settings, providing a basis for trust, understanding and appreciation, which can be extremely beneficial to SDM (23,24).

Although interest in SDM is increasing, and there is a growing demand for its adoption in primary care (12), it is still not widely used by health professionals in their daily practice (25,26). The purpose of this study is to describe the perspectives of healthcare professionals regarding the implementation of SDM in PHCCs in Saudi Arabia. In particular, we explore the perspectives of physicians, PHCCs managers, medical directors and training directors. Understanding their perspectives helps to better anticipate implementation challenges and identify enablers that facilitate the adoption of SDM.

6.2 Methods

6.2.1 Study Design

Qualitative semi-structured interviews with a purposive and snowball sample were used to explore healthcare professionals' perspectives on SDM in Saudi Arabia.

6.2.2 Study Setting

The study was conducted in in the city of Jeddah, Saudi Arabia. The services in the Saudi health sector are provided by governmental, non-governmental, and private organisations, the largest of which is the Saudi Ministry of Health (MOH). It provides free medicine and care and operates a number of hospitals, diabetes centres and all PHCCs. Each PHCC has a different number of physicians based on the community it serves. Some of the PHCCs have a clinic specifically for patients with chronic diseases while others see these patients within the family medicine clinic.

6.2.3 Participant Eligibility, Sampling and Recruitment

Purposive sampling was used to ensure maximum diversity. Purposive sampling is a useful approach for achieving maximum diversity over key characteristics that were considered most useful in this study, such as expertise, experience, gender, and positions, and was thus used in this research process to identify potential informants. The manager of each of the PHCCs was contacted to explain the study, seek their approval and obtain information on health staffing at the PHCC. The researcher then approached health professionals individually. Each clinic was visited to establish rapport with those interested in participating. Potential participants were provided with information sheets and offered a choice of face-to-face or telephone interviews. Those who chose a telephone interview were contacted later to arrange interview times. Due to coronavirus restrictions (March/2020), we were unable to complete all face-to-face interviews and some participants had to be interviewed by phone. Snowball sampling was used to recruit the remaining participants. Those recruited were asked to suggest other potential participants for this research.

6.2.4 Procedures

Semi-structured individual interviews were conducted face-to-face (n= 4) and by telephone (n = 12). To ensure that there were no language barriers, the interviews were conducted in Arabic, which is the native language of Saudis. Based on a previous literature review (27,28) of this topic, the interview schedule was developed (See Appendix 9, 11), and piloted on two participants (who were excluded from analysis). Open-ended questions were used to elicit the participants' perspectives on SDM, as well as the barriers and facilitators to implementing it. Prompts were used to elicit factors related to patients and their families, physicians, and the environment. The interviews lasted 20-50 minutes and were audio-recorded with the consent of the participants, which were then transcribed. During each interview, field notes were taken to document emerging concepts that required more clarification or discussion with participants, as well as after each interview to reflect on the interview process and interviewer's overall impression. Interviews were ceased at 16 interviews when there were no new themes emerging, and data saturation was reached.

6.2.5 Analysis

After the transcription was completed, all of the interviews were translated from Arabic to English so that the other two researchers could confirm and validate the data. To minimise the risk of loss of meaning, the following steps were taken: the interviews were conducted and subsequently analysed initially by the lead researcher who was fluent in Arabic and English who also had a similar cultural background to the participants. A Saudi translator was then used to translate the Arabic transcripts into English. The lead researcher double-checked the translation's accuracy; English transcripts were then read and coded by (NA). Ideas that were linked to each other were grouped into codes and discussed with the researchers (AL, PT).

Transcripts were imported into NVivo software and thematically analysed using an inductive approach. Codes were compiled and combined to form initial themes and sub-themes. Both of the researchers double-checked that the themes represented the entire set of data. The key themes and sub-themes were refined through continuing discussions among the researchers. In order to organize the themes, the COM-B model was used as the theoretical framework to help structure the findings. More information on the theoretical framework selection was provided in Chapter 4.

6.3 Results

Twenty-five participants were invited and 16 agreed to take part in the interview (See Tables 6.1 and 6.2). The data analysis identified six emergent themes and 14 sub-themes. These spanned all three areas of the COM-B model and are illustrated with representative quotations. (See Table 6.3-6.5).

Physicians	Specialty	Years of Experience in Family Medicine	Age (years)	Gender	Position
1	Family Medicine	-8	+40	Female	Specialist
2	Family Medicine	+8	+40	Female	Consultant/Training Supervisor
3	Family Medicine	+8	+40	Female	Consultant
4	Family Medicine	-8	- 40	Female	Consultant/Training Supervisor
5	Family Medicine	+8	+40	Male	Consultant
6	Family Medicine	-8	- 40	Male	Specialist
7	Family Medicine	-8	- 40	Female	Specialist
8	Family Medicine	-8	- 40	Male	Specialist

Table 6. 1: Physicians' demographic characteristics

Manager	Specialty	Years of Administration Experience	Age (years)	Gender	Position
1	Family Medicine	-8	+40	Female	Consultant /Medical Director
2	Family Medicine	-8	- 40	Female	Resident/Medical Director
3	Family Medicine	+8	+40	Female	Consultant / Manager
4	Family Medicine	-8	- 40	Female	Consultant /Medical Director
5	Hospital administration	+8	- 40	Male	Manager
6	Family Medicine	-8	- 40	Male	Specialist/Manger
7	Family Medicine	+8	+40	Male	Consultant /Medical and Training Director
8	Laboratory specialist	-8	+40	Male	Manager

Table 6. 2: Managers' demographic characteristics

COM-B	**Themes**	**Sub-themes**	**Representative quotes**
Capability	Patient related factors	Knowledge and understanding	“Some patients tell you that this medicine is better than that one so why don’t you give it to me instead of this one? Why is this particular medicine not offered by the ministry? “(Physician 4) (female, under 40) “Sharing the decision with the patient is possible when the patient in front of you understands to a certain extent what is going on. So, it depends on each individual case.” (Physician 5) (male, above 40) “The issue of understanding and comprehending the sharing of the decision-making by the individuals in society. I mean, how aware are the public? Is the public we have really aware enough to completely understand that the responsibility of health is shared between the doctor, the patient and the system and not on one only. I would imagine this problem should be discussed freely and the public should be educated.” (Manager 7) (male, above 40)
		Health condition	“It is the patient’s right to know the options and make the choice but this is linked to the patient’s ability to make a choice. He may not be able to choose due to a disability or something then the doctor would be the one who makes the choice.” (Manager 8) (male, above 40) “Sometimes, it’s hard to decide in such a case because sometimes it is not only diabetes but diabetes and hypertension. Other times, it is diabetes, hypertension, and a heart disease. Since each case is different, we should balance the risks through management. If there are options, then for sure we would offer him these options." (Physician 5) (male, above 40)
		Characteristics	“The educated patients prefer to make the decisions by themselves. However, the uneducated patients or those whose level of education is low usually say, you are our doctor so you know better the suitable treatment for our cases. Sometimes, the elderly people show some preferences by saying prescribe me X medication, I don’t want Y medication. So, some of the elderly are amongst those who like to choose, but not all of them would like to choose, of course.” (Physician 7) (female, under 40).
	Health professional related factors	Education and experiences	“Training and holding lectures made a big difference…Even the general practitioners at PHCCs have an initial awareness of sharing the decision-making. It is not practiced when there is no training, no one tells them about the options and nor do they see anyone practicing these ways.” (Physician 3) (female, above 40) “It depends on the major of speciality because not all of them (teach and practice) these skills. We (have been taught) these skills in family medicine.” (Physician 4) (female, under 40) “The general practitioner, or the specialist or the consultant who has just graduated is different (from the one with) experience.” (Manager 4) (female, under 40).

		Knowledge on how to practice SDM	“First of all, I should fully explain to him his case and make sure he understands the nature of his condition and how it could be treated. Then, I show him the treatment options and see which one would be suitable for him…I also explain to him the side effects of each option, and the one I recommend and see as suitable. I mean I offer him all the options and explain them, then I say my point of view, but he is the one who chooses (the treatment) at the end.” (Physician 7) (female, under 40). “He could explain to the patient the available options. He could say, this is the 1st option and according to how you feel with it, we will do this and that. Then, after 3 months if the patient doesn’t get on well, we will move onto the 2nd option. Or we could give the patient a medicine to control his cumulative sugar level and follow him up to see the side effects. If it’s suitable for him and he is convinced, we keep using the same medicine.” (Manager 6) (male, under 40).

Table 6. 3: Illustrative quotes for the themes and sub-themes for capability

COM-B	Themes	Sub-themes	Representative quotes
Opportunity	Environmental context and resources	Treatment options and decision aids	“We have samples of the different types of insulin which we use to explain to them. We use a board on which there are the medications to explain the differences between them and that this is better than this. We do this if we had time.” (Physician 2) (female, above) “We don’t have any resource aids for diabetic patients.” (Manager 4) (female, under 40). “We need more options to be available so I could share them with the patients. If I don’t have options, what would I share with the patient then?” (Manager 2) (female, under 40). "Usually, if it is not available at the PHCC, the option is still offered to the patient on the basis that he can get it at the hospital. However, if it wasn’t offered to the patient, it could be because the doctor doesn’t know about it. It is possible that he doesn’t know about it or its availability.” (Manager 4) (female, under 40).
		Characteristics of healthcare setting	“This doesn’t happen in the chronic disease clinic. Look, not all PHCCs have a chronic diseases clinic. I mean some centres include the chronic disease clinic in the family medicine clinic, so they become under pressure. But in our centre, we have a clinic only for the chronic diseases such as diabetes, hypertension. And we see the other cases in the family medicine clinics. This actually helps the patient to take his full due right in our centre.” (Physician 7) (female, under 40). “To be honest with you we can't do that now, or at least not in this centre. I have been to other PHCCs during my training and they do have the opportunity and time. They have a few number of patients and those patients are somehow of upper class…Also, the environment of the centre we are in is miserable which has an effect on the patient

			and on his respect of the services we offer. It also affects us, to be honest.” (Physician 8) (male, under 40).
		Characteristics of healthcare system	“ The ministry of health complicates things. They created a system for booking appointments, then they said you should see everyone who comes; don’t reject anybody! When they created the system for booking appointments, people started to come with appointments. However, some people came without appointments and were rejected, so they complained. The ministry then decided that no one should be rejected. You have made a system for booking appointments and you accept everyone! This actually was the cause of the pressure” (Physician 5) (male, under 40) “Firstly, in order to share the treatment plan with the patient, he should not be from outside my catchment area. I want to be patient oriented and not disease oriented. I shouldn’t get a patient I don’t know, just to prescribe them medication.” (Manager 3) (female, under 40)
		Continuity of care	"The most important thing to me is that there should be a plan of care and a follow up plan which are written in the doctor's notes. That is what matters to me, so that the patient is taken care of. First and foremost, the patient wants medical services. However, if the doctor is available then that is a good thing because (he is) following the patient and knows his situation. There is no guarantee, though, that the doctor will be available and that is why these two things are the most important things so that the second doctor follows them and continues with the patient...The problem is that no one is keeping a record. No one believes that keeping a record of the treatment plan is very important. They think the whole thing is just about writing and that is it. They don't know that this is very important for the patient.” (Physician 3) (female, above 40)
		Environmental stressors	“I mean the doctor himself may not like to communicate (with others) or has work place issues, i.e., facing problems at work such as they have lengthened the clinic times, he has a heavy work load, or they have increased the number of patients.” (Physician 1) (female, under 40). “Other patients, like the diabetic patients, need that extra time, and you would also be quick with them but you tell them to book another appointment to come again to further discuss things and answer your questions if you have any.” (Physician 5) (male, above 40) “The doctor may have the skills but doesn’t have the time to apply them, so it is difficult to apply them properly.” (Manager 6) (male, under 40). “The doctors are assigned in the PHCCs are according to the number of the patients. Each doctor should see 40 patients, and according the number of patients in the PHCC, we identify the number of the doctors needed. Sometimes, we might have an additional doctor to allow for doctor’s leaves. This means that time is never an obstacle and the number of doctors is good, i.e., there isn’t any pressure.?” (Manager 1) (female, above 40).

	Patient-physician communication	Involvement of family /other parties	"I prefer to make the decisions with the family but sometimes the patient doesn't like someone to come with him... However, some of patients come alone and wouldn't bring anyone with them even if you ask them to. Especially in the case of chronic diseases, there are a lot of things within the illness itself that the patient requires family help and support, such as changing the life style of the entire family in order for it to succeed. It is much better when it is a family's way of life. However, sometimes their presence is a hindrance for example, some of them answer instead of the patient or imposes his opinion or says negative things to the patient making him feel that he made the wrong decision." (Physician 2) (female, above 40). "Some of the patients need more time but not necessarily from the doctor's time, may be from the health educator, the social worker, the psychologist or the nutritionist." (Manager 1) (female, above 40).
		Patients' attitudes	"Also, we mustn't forget that some patients nag and complain that he is busy and that he came first etc...These people really stress you because they make nurse constantly come in and out and other people are also coming in and out." (Physician 1) (female, under 40). "It is also possible that the patient has an aggressive attitude." (Physician 2) (female, above 40). "The patient is the one who should talk. He should tell me that he cannot take the insulin injections and should clarify his point of view about the treatment." (Physician 5) (male, above 40)
		Physicians' behaviours and attitudes	"Some doctors ask closed-ended questions. I usually like to ask open-ended questions such as, how things are going with you? Any problems? This way, you open the door for the patient to talk freely. This way makes you also talk and then you can close up the discussion." (Physician 5) (male, above 40) "We try to stick to the guidelines which don't always give us options. For example, we put the diabetic patients straightaway on Metformin and the diabetes regulator. If he doesn't comply to the treatment, we may explain other treatment options in more details." (Physician 8) (male, under 40). "Some doctors can't control their feelings and show them in the way they are dealing with the patient." (Manager 2) "This would be by enhancing our communication with the patients especially the eye contact. Also, we should use a simple understandable Arabic language and avoid the medical terms." (Manager 6) (male, under 40).
		Trust	"The most important point in sharing the patient is trusting the doctor. If the trust is established between them, then the patient's compliance to the treatment will be better." (Physician 6) (male, under 40). "I give my attention to the patients with chronic diseases because you cannot gain their trust by merely giving the medicine and sending them home." (Manager 3) (female, above 40). "We should make people trust PHCCs and their physicians." (Manager 5) (male, under 40)

Table 6. 4: Illustrative quotes for the themes and sub-themes for opportunity

COM-B	Themes	Representative quotes
Motivation	Patient-physician preferences toward SDM	“I mean, in our culture, when the doctor asks the patient, what do you think, what do you see is appropriate for you, the patient sees it as a weakness in the doctor. Or he might say, you should be telling me or would reply, you are the doctor. They don’t see it as options. They see it as you should make the decisions for me because you know better…others are contrary to that. They want to make the decision by themselves or have a role in making it.” (Physician 2) (female, above 40). "I have seen many of my colleagues and those I train mostly trying to share the treatment plan with the patient." (Manager 7) (male, above 40)
	Physicians’ perceived value and benefits of SDM	“When the patient gets better, the number of his visits gets less…We will not reach this outcome unless the patient is involved. I mean SDM has a big effect on the patient’s response to the treatment and the extent to which he follows the treatment… Belief of the doctors (in these practices). If the doctors don’t believe in them, they would not practice them” (Physician 1) (female, under 40).

Table 6. 5: Illustrative quotes for the themes and sub-themes for motivation

Capability

Patients Related Factors

Knowledge and understanding

SDM could be influenced by the patients' level of knowledge about their disease and the treatment options. The healthcare professionals reported that patients who are knowledgeable are more likely to be engaged. They know more about the different treatments offered for their condition. They may even bring new options to their physicians, and engage in a discussion around these options.

The patients' level of understanding also influences SDM. Some patients find it easy to understand their physicians and find their language is clear while others need more clarification and ask many questions. The healthcare professionals reported that they cannot get some patients to fully understand the options especially in a single sitting with limited time as they need more clarification. Raising patients' understanding about their rights and role in SDM is also highlighted as an important factor that facilitates the patients' involvement in the decision-making.

Health condition

Another determinant frequently cited was the patient's health condition. Some patients may not be able to engage in the decision-making process due to a disability or comorbidity. Sometimes the patient's case is complicated; they might be taking multiple medications for several co-morbidities such as hypertension, diabetes, heart diseases, etc. This may limit the range of options that can be shared, or influence the patient's understanding of their condition and treatment plans. The patient may also be under the care of more than one physician, which may also limit SDM.

Characteristics

The healthcare professionals also described how the applicability of SDM may be contingent on the patients' characteristics, such as their age, level of education, or socioeconomic backgrounds. Most healthcare professionals reported that the patients' age and level education were key determinants. The elderly or patients with low-levels of education may not have sufficient understanding to engage in a discussion around decision-making. However, elderly patients who were more highly educated and aware, were more likely to seek their physician's engagement to discuss different treatment options. Patients' socioeconomic level was also suggested as a factor that makes a difference. Patients from lower socioeconomic backgrounds were reported to have health, education, and economic issues that deterred SDM. For example, they may not be able to afford a treatment option other than what is provided by the MOH, or may not have transport to get their medicines regularly, which can restrict their options and preferences.

Health Professional Related Factors

Knowledge on how to practice SDM

Many of the healthcare professionals interviewed were aware of and understood the concept of SDM. They spoke about the need to recognise the patient's knowledge, provide patients with sufficient information, clarify options, consider their preferences and provide recommendations and follow-up consultations. However, it was apparent that some healthcare professionals did not understand the concept of SDM or lacked knowledge of how to put it into practice. For example, they spoke about convincing patients to choose the recommended treatment, or sequencing options to them that prioritise the physician’s preferences first. Others even thought that SDM is achieved when patients accept and adhere to the treatment plan conceived by the doctor.

Education and experiences

Whether the physician practised SDM may be contingent on whether they have received professional education about it. Their level of expertise also determines what options they may be able to share with patients. Specialists/medical consultants may have a greater understanding of the diseases themselves and are more knowledgeable about the treatment options than the general practitioners. Their level of experience also makes a difference. Many healthcare professionals reported that they were skilled at engaging their patients in the decision-making process. However, it was recognized that a lack of training on communication skills can influence SDM. The healthcare professionals noted the importance of training and continuous medical education on SDM, and the importance of having a role model or consultation simulation for doctors to enable the practice of SDM. The doctor also ideally needed to be up to date with the new treatment options before they could discuss them with patients.

Opportunity

Environmental Context and Resources

Treatment options and decision aids

A lack of treatment options was reported as a barrier to SDM by many healthcare professionals. Under the MOH in Saudi Arabia, the choices are limited at both PHCCs and the hospitals. The medicines available determine what options physicians can offer the patient. Some physicians do explain to their patients the range of available options at PHCCs, or elsewhere such as hospitals, Diabetes Centres or private pharmacies. Their patients would therefore be aware of the choices available, some of which would be dependent on their ability to afford them.

The healthcare professionals also noted a lack of decision aids. Consequently, they would have to resort to verbal explanations to patients, or occasionally using a sample of the medicines, or where available referring patients to a health educator. The healthcare professionals felt that having a range of different treatment options and decision tools could enable treatment plans to be shared with their patients.

Environmental stressors

The healthcare professionals outlined how work stress influences their ability to engage properly in SDM with their patients, as they have many responsibilities besides the clinic. For example, they may be responsible for training, technical management, or quality control. These responsibilities meant their limited time and efforts have to be split. Many reported feeling frustrated and fed up due to the time pressures, shortage of physicians, and the sheer number of patients to be seen. These limit SDM, as they would not be able to explain everything to the patient and lack enough time to listen to them. Instead, they would often prescribe treatment without considering the values and preferences of patients. To overcome this, many healthcare professionals highlighted the importance of increasing the number of physicians and providing more consultations for SDM. There should be also enough time for each patient, as patients with a chronic disease require more time. However, some managers in this sample thought that the time allocated and the number of physicians was appropriate to practice SDM, as physicians are assigned in the PHCCs by the number of patients.

Continuity of care

Another important issue that was identified was the fact that patients meet different physicians during their follow-up. Physicians in PHCCs do not manage the same group of patients as the appointments are linked to the clinic and not to a specific physician. The healthcare professionals interviewed prefer to have allocated physicians for every patient to build relationships. However, this is not always possible as the physician could be absent or on leave. It is not enough for a different physician to just hear from the patient. Sometimes the patients are fed up with having to repeat their story to different physicians each time. As a result, they may not provide more details that could include important information for the physician. Consequently, a complete patient record that included the plan of care and a follow-up plan is deemed vital by the healthcare professionals so that the patient isappropriately cared for.

Characteristics of healthcare setting

The environment in which decision-making occurs was seen as important to many of the participants. It should be well-equipped and clean, as well as private and without interruptions that may make the patient nervous and refrain from expressing their views openly. Healthcare professionals reported that PHCCs are different in terms of the number of patients seen, work pressures, and whether there was a chronic diseases clinic or health educator clinic. PHCCs that have a dedicated clinic for chronic diseases were reportedly much better than those that saw patients with chronic diseases in the family medicine clinic. This was because the chronic diseases clinics were not under as much pressure as the number of patients in these clinics are limited and patients almost always saw the same physician. However, some managers interviewed disagreed with having a specific clinic for chronic diseases on the basis it may undermine the resident physician. This was because the policy was that patients with chronic diseases were to be seen by only specialists and consultants. Another common complaint was the frequent interruptions during consultations when other staff or patients may interrupt the physician such as when requesting appointments. This would disrupt communication between the physician and the patient being seen at that point in time.

Characteristics of healthcare system

The characteristics of the current health system also influenced the workflow for physicians. This created work pressures on the physicians, who felt rushed and therefore deterred SDM as they were disinclined to deliberate decisions with their patients.

The current situation was that patients can visit any PHCC they want even if it is not connected to their catchment area or even when they do not have an appointment. These all affect patients' continuity of care, increases the number of patients and workload, that in turn shortens the consultation time for other patients and cause the physicians to feel exasperated.

Other issues that increase the PHCCs workload were problems with the management of patient referrals to hospitals. For example, one respondent described that when a patient is referred from the PHCC to the hospital and there is then a need to refer the patient on to another specialist, the patient is sent back to the PHCC for this referral. In addition, the healthcare professionals pointed that there is a dual system in place, i.e., paper-based medical records and electronic medical records. The paper record is for patient records while the electronic record is used to register prescriptions and for ordering tests and results. Furthermore, each hospital and clinic had its own system.

To address these barriers, the healthcare professionals reported that the system should allow a limited number of patients and consultation appointments. The e-system should be unified. If there is one system that covers everything related to the patient such as the patients' file, their medicines, medical information, it would have saved the doctor more time. Also, filling the field "plan of care" in patient medical records should be mandatory and form the requirements of excellence. In addition, the PHCCs should not accept patients from outside their catchment area. Applying the appointment system correctly where physicians do not see patients without an appointment is also important; physicians would organise themselves depend on how many patients will be visiting them, and the patient would prepare themselves and the questions to ask.

Patient-Physician Communication

Involvement of family and other parties

Many of the healthcare professionals discussed the importance of involving other professionals such as psychologists, nutritionists, and health educators who could help further explain treatment options, know their patients' views, or help investigate the matter further with them before a decision is made. The health educators tended to have fewer patients and therefore more time than the doctor to engage in this discussion.

Most of the participants acknowledged the significant role of family members in supporting patient engagement. The family could help the patient to comply with treatment, especially if the patient had difficulties. However, sometimes their presence can be a hindrance when they imposed their opinion, said negative things to the patient that made him regret their decisions, or opposed the decision.

Patients attitudes

Healthcare professionals discussed some patients' attitudes that influence the communication between patients and physicians. There were patients who insisted on their opinions and were difficult to deal with. They sometimes prevented their physicians from sharing different treatment options, as they wanted a specific treatment. Some patients were initially seen in private clinics using their health insurance but once their health insurance had expired, they attended the PHCCs for prescription renewals but did not discuss treatment options with the primary care physicians (PCPs). In addition, not all patients wanted to be referred to the Diabetes Centres or hospitals where they would be offered more options, as it was easier for them to attend the PHCCs. Others were demanding, nagging, or talkative. Some patients were aggressive, or would interrupt another patient's consultation. The healthcare professionals felt patients should take more of the initiative by asking questions and talking about their concerns and views, to open the discussion and facilitate decision-making. Also, the patients' keenness about their health, feeling of responsibility, and respect for clinic appointment times would help facilitate SDM.

Physicians behaviours and attitudes

Participants in this sample discussed some physicians' attitudes when introducing options to their patients. Sometimes, in the interest of the patient, physicians were enthusiastic about a particular idea and saw it as the right one. Therefore, without realising it, they would push the patient towards a particular decision. At other times, physicians may impose their opinions and try to convince the patient of it or try to stick to the guidelines, which involves a sequence of treatment options.

The lack of communication, listening and explanation of treatment options, as well as use of medical terminology, were all obstacles to SDM. Some physicians were in a hurry and sought to finish consultations quickly. Others were authoritarian, and liked to control the whole process. Some believed that as they are physicians, they understood things better than patients.

Enablers to build trusting relationships between the physician and the patient included greetings and welcoming the patient to make them feel comfortable, attentive listening, understanding the situation of the patient, respecting their opinions and privacy, being honest and clear with them. The use of open-ended questions and conveyance of information in simple understandable language was also necessary for effective discussion.

Trust

A trusting patient-physician relationship was seen as a prerequisite for SDM. In order to build a trusting relationship, physicians needed to pay attention to their patients, listen to them, and give them the opportunity to talk. The entire treatment plan may collapse if they did not trust each other, and there would not be any compliance or commitment. Participants reported that there was a lack of trust in PCPs and patients usually trusted the hospital physicians more. There is therefore a need to improve societal awareness and respect of the expertise of PCPs.

Motivation

Patient-physician preferences toward SDM

Most physicians preferred to share the decision with their patients if the context and patients allowed them the opportunity to do so. However, patients have different preferences to decision-making. Some patients preferred to share the decision with their physicians while others preferred to leave the choice to them to make, but only after providing patients with enough explanation. Patients nowadays do not accept the passive role, as many have a good level of education. With elderly patients, their family members do not accept a passive role either. However, it worth noting that some patients do not like the physician discussing treatment choices with them; they see it as a weakness in the physician. They may believe that it is the physician who dictates the treatment and the patient follows it. Patient education or awareness-raising may help patients to understand their role in decision-making and share the responsibility with their physicians.

Physicians perceived value and benefits of SDM

The physicians’ belief in SDM and its benefits also plays a crucial role. Healthcare professionals who believed in SDM and were motivated to practice it were able to state many benefits such as increasing patient satisfaction and confidence, enhancing their knowledge about treatment options and empowering them, improving treatment adherence and health status, reducing patient visits, and developing patients-physicians trust.

6.4 Discussion and Conclusion

6.4.1 Discussion

This study represents the first qualitative understanding of the views of healthcare professionals in Saudi Arabia regarding SDM. Patients' willingness to participate is determined by their knowledge and understanding, health conditions, and characteristics, whereas physicians' ability to practice SDM is determined by their knowledge, education, and experience. Factors that motivate physicians and patients towards SDM were grouped under two themes: patient-physician preferences for SDM, and physicians' perceived value and benefits of SDM. The environmental context and resources as well as physician-patient communication were common themes that enable or prevent SDM.

Unlike other studies, the physicians interviewed have shown a sufficient understanding of SDM (30,31). This could be attributed to the fact that SDM was part of the training of physicians during the board certification in family medicine. However, not all medical programs emphasise the skills required for SDM and ensure that they are practiced. Increased investment in education and training for physicians could overcome knowledge and skill barriers (32).

Physicians are unlikely to practice SDM in the context of time pressures, or where there is a shortage of physicians, lack of treatment options, or decision-making aids (28). In the absence of adequate consultation time, most physicians cannot give the patient the opportunity to discuss or clarify treatment options. This also leads to a more directive approach to decision-making rather than a shared approach. Although time barriers in SDM are a common concern for physicians with respect to SDM (28), some researchers have refuted the need to increase session time, and emphasised that PCPs can improve their ability to respond to their patients' needs and concerns without having to extend their visits (33–35). To address the time issue, strategies include providing patients with multiple SDM consultations and having enough physicians for a clinical setting (28).

Other allied health professionals such as psychologists and health educators could play a role in facilitating SDM, especially in situations where the physicians may lack the time to explore options with patients. For instance, a health educator would have more time to provide patient counselling than a family physician who sees a large number of patients with diverse diseases. Many studies in the Western countries have shown that healthcare professionals other than physicians, such as psychologists, social workers, allied health professionals and nurses play an important role in ensuring that patient decision aids are successfully implemented by recognising eligible patients, communicating with patients about the patient decision aid, and providing decision coaching (36–39). Participants of this study also suggested that psychologists and health educators could help further explain treatment options or help investigate the matter further with patients before a decision is made.

Another important factor in facilitating SDM implementation is the need for patients to be followed up by the same physician to ensure continuity of care. Because SDM is an ongoing interactive process between physicians and patients, continuity of care is critical. The lack of continuity of care may make it difficult for patients to discuss issues related to previous consultation decisions. It also prevents physicians and patients from developing rapport, which could lead to more informed decision-making (36). Continuity of care is challenging in Saudi Arabia due to the high patient load, physician shortages, time constraints, and disorganized referral procedures. Better physician-physician exchange of information through better patient electronic health record systems can be a means of ensuring continuity of care (40).

Establishing a good physician-patient relationship requires good communication (41,42). It is especially essential in SDM where uncertainty on treatments and outcomes cannot always be fully excluded from the decision-making process (43). Our findings underscored the importance of building a trusting physician-patient relationship with effective conversation techniques (44). When trust is established, physicians can better understand the concerns of their patients and define their needs and preferences (41). Patient trust and compliance with treatment will also be more likely (45,46).

6.4.2 Limitations

The study only includes family physicians and managers in PHCCs which limits the findings to this setting. Selection bias is likely to have been another limitation, for example, recruiting family physicians who know about SDM or are interested in it, which may influence their answers and the way that they should present themselves. The majority of the managers, with the exception of two, are family physicians. As a result, their perspectives may be similar to those of other physicians, limiting different views.

6.4.3 Conclusions

SDM may be the desired optimal situation for patient consultations, especially those that involve a significant degree of uncertainty or plurality of treatment options. However, SDM is not easily practiced due to the presence of multiple barriers that exist in clinical settings currently in Saudi Arabia. Unless these barriers are addressed, SDM will continue to be minimally practiced or practiced ineffectively. Increased investment in SDM training as part of medical education will be also needed. Finally, whilst many of these determinants are linked to physicians and the clinical setting, the patient is a key actor too and there is a need to develop their capacity to actively engage in decision-making.

6.4.5 Practical implications

Given the growing interest in SDM and its tools, it is important to consider the perspectives of stakeholders on the challenges and opportunities of SDM. Further exploration of the role of patient activation especially in certain population groups such as the elderly, the illiterate/poorer groups is needed. Continued medical education and training on SDM skills are warranted. More investigation on the role of managers and other allied health professionals in facilitating SDM in clinical settings is also needed.

Ethics approval

Ethical approval was obtained from the directorate of health affairs-Jeddah-Institutional review board (IRB registration number with KACST, KSA: H-02-J-002, 26/11/2019, research number: 01136. (See Appendix 13)

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Conflict of interest

The researchers have no conflicts of interest.

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Chapter 7: General discussion

7.1 Introduction

This chapter begins by summarising the four studies of this thesis, outlining aims and key findings of each study and discussing the thesis's strengths and limitations. Reflection on the main findings and interpretation, as well as recommendations for future research, are emphasized.

7.2 Aim and Key Findings

The overarching aim of this thesis is to explore factors influencing SDM implementation in PHCCs in Saudi Arabia. Four studies were used to achieve this aim: an umbrella review in study one, a systematic review in study two, and a qualitative design in studies three and four.

Chapter one introduced SDM and explained various medical decision-making models, as well as providing an overview of Saudi Arabia's cultural background and health-care system. The aim and objectives are then presented, along with the novelty and contribution to original knowledge. The umbrella review was described in Chapter two, followed by a systematic review in Chapter three. Chapter four reviewed and justified the research philosophy and methodological strategies used. Finding of the interviews with patients was described in Chapter five and with healthcare professionals in Chapter six. A summary of this doctoral research is provided in Figure 7.1.

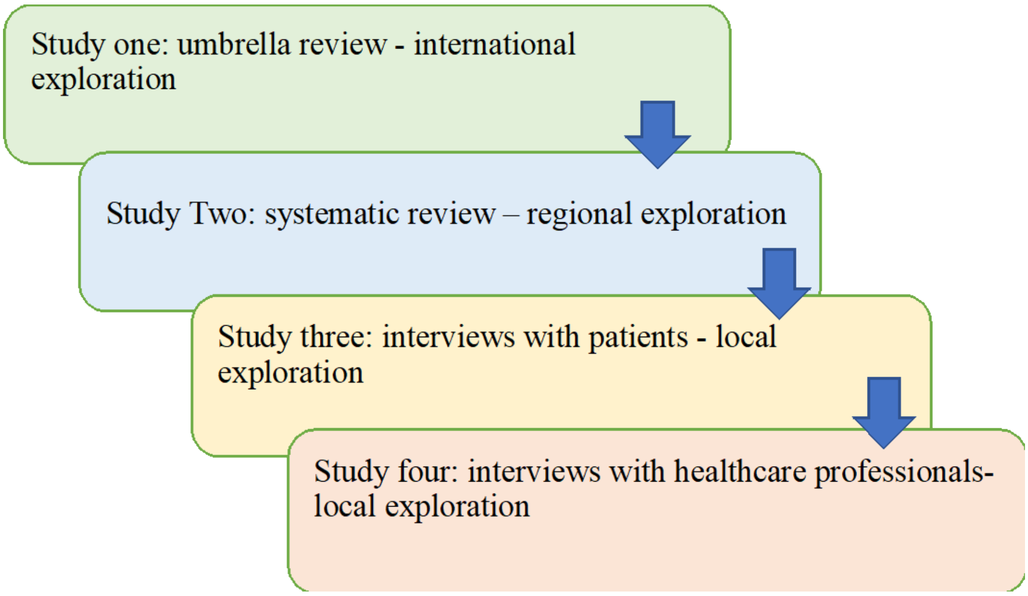

Figure 7. 1: Summary of the research studies

7.2.1 Study One: Umbrella Review

Umbrella approach enables researchers to collect evidence from multiple health care settings without doing a systematic review in each setting. Performing an umbrella review enables researchers to address a wide scope of matters regarding a topic of interest. Thus, the umbrella approach was used in study one, as the aim was to obtain an overview of factors that may either facilitate or inhibit the implementation of SDM.

Summary of key findings

The umbrella review highlighted various factors that influence SDM implementation, providing health-care decision-makers with an overview of the field, and information for SDM implementation. More than half of the included reviews were published in the last five years, indicating that there is a growing level of awareness and interest in SDM. There was a diverse variety of study settings as well as the intended objectives of the included reviews. There were reviews included from 19 countries, the majority of which were high-income countries in North America and Europe with very few studies from low- and middle-income countries. Key barriers included time constraints, patient’s belief that the "doctor knows the best", poor health condition, lack of listening to the patient, and lack of sharing of sufficient information between physicians and patients. Providing sufficient information, motivating healthcare professionals to use SDM, listening to the patient, and building a respectful and trustful physician-patient relationship are essential for successful implementation. The findings from this review assisted in developing the interview guide for research studies three and four.

The findings of this review may not be transferable to non-Western cultures, and particularly in developing countries where values, social contexts, and healthcare systems are different from those in Western cultures.

7.2.2 Study Two: Systematic Review of SDM studies in EMR

After mapping and understanding the barriers and facilitators to SDM through the umbrella review in study one, it was found that the literature paid limited attention to implement SDM in the WHO Eastern Mediterranean Region. Most of the reviews included in the umbrella review are from western countries. Little is known about SDM in the EMR and it is not clear what factors may hinder or facilitate the implementation of it in this Region. Therefore, the systematic review was used in study two to investigate and understand the factors influencing SDM in the EMR.

Summary of key findings

The results of the review have shown that there is growing interest in SDM in several countries in the EMR. Several influential factors for SDM were identified, including physician, patient, and family member perspectives. Factors influencing SDM implementation span participant's role in decision-making, current SDM practices during clinical consultations, and SDM at the system level. Patient and physician characteristics, such as prior knowledge, experience, and perceptions of SDM, as well as preferences for it, all have an impact on whether it is practiced. The attitudes of family members and their level of involvement in decision-making also influence SDM practice. These factors influence physician-patient interactions as well as the consultation process. System-level factors also play a part such as time pressures, availability of healthcare resources to support SDM, and the degree of continuity of care provided.

The findings in this review found that there are not many studies on SDM in the Region and there is a need for more research that considers the organizational and health system perspective. Results from the review showed that only a few qualitative studies on SDM in the Region have been conducted. The findings of this review also helped in developing the interview guide for qualitative studies.

7.2.3 Study Three: Interviews with Patients in Saudi Arabia

The findings of the systematic review (study 2) demonstrated that the majority of the included studies used a quantitative approach which may restricts respondents from providing more information and limits their responses. This highlights the need for qualitative research to gain a deep understanding of the participants' perspectives.

Aim

Identifying and understanding factors influencing SDM implementation in PHCCs in Saudi Arabia from the perspectives of patients with diabetes.

Summary of key findings

Factors that influence patients' capability to involve in the decision-making process included patients' characteristics and knowledge, and understanding of the concept of SDM and treatment options. Patients' awareness of SDM and their rights should be raised. Health education is also essential to improve patients' knowledge of care and treatment options. Factors that influence patients' motivation in SDM are self-efficacy and confidence, trust in physicians, preferences, and expectations for SDM outcomes.

Factors that encourage or discourage SDM included provision of treatment options, clinic atmosphere, continuity of care, family and community involvement, and physician attitudes and SDM behaviours. SDM is also influenced by staff shortages, increasing patient demand, and time constraints. To address these issues, there is a need to increase consultation time or better manage patients' appointments, increase the number of physicians, empower technology to facilitate patient-physician communication, provide multiple consultations for SDM, and involve other health professionals such as psychologists, social workers, and health educators.

Findings of this study found that patients are aware of the concept of SDM and its benefits, but SDM tends not to be practised in PHCCs in Saudi Arabia. Patients viewed physicians' communication with patients as a leading factor that hinders or facilitates their involvement in decision-making.

7.2.4 Study Four: Interviews with Healthcare Professionals in Saudi Arabia

Aim

Exploring the perspectives of healthcare professionals regarding the implementation of SDMs in PHCCs in Saudi Arabia.

Summary of key findings

Patients' willingness to participate is determined by their knowledge and understanding, health conditions, and characteristics, whereas physicians' ability to practice SDM is determined by their knowledge on SDM and experiences. SDM can be influenced by a lack of training on communication skills. There is a need to develop patients' capacity to participate more actively in decision-making. SDM training and continuing medical education for healthcare professionals are also needed to promote their ability to practice SDM. The preferences of patients and physicians influence their motivation in SDM. Physicians' motivation is also influenced by their expectations for SDM outcome.

Factors that encourage or discourage SDM implementation included characteristics of healthcare settings and systems, continuity of care, provision of treatment options and decision aids, and environmental stressors such as time, staff shortages, and workload. Involvement of family and other parties like psychologists and health educators, patients' and physicians' attitude, trust and respect in physician-patient relationships, also encourage or discourage SDM implementation. Unless these barriers are addressed, it is unlikely that physicians will effectively, or fully, engage in SDM with patients.

7.3 Reflection on the Main Findings

The findings of the umbrella review made it clear that there is a need to address the gap in the SDM literature by conducting a systematic review focused on non-Western countries to investigate and better understand the challenges and enablers of implementing SDM in these countries. The systematic review findings indicated that additional exploratory qualitative work on barriers and facilitators to SDM implementation would provide much-needed novel and detailed information. The factors revealed in the qualitative studies in Saudi Arabia are comparable to those reported in Western countries and in the EMR, such as the role of patients and their families, a lack of time and resources, and physician attitudes and behaviours. The findings from Saudi Arabia, on the other hand, revealed additional important factors related to the healthcare organisations and the health system. Table 7.1 summarizes the main comparisons with all studies as well as the main findings pertaining to Saudi Arabia. The findings were also mapped into COM-B as illustrated in Figure 7.2.

7.3.1 Similarities Between the Four Studies

The four studies demonstrated the importance of effective physician-patient communication in SDM success. Physicians and patients have an impact on this communication, as does the healthcare system, which has an impact on both patients and physicians. A fundamental shift in how physicians interact with patients, from domineering decision-making encounters to a more collaborative approach, is required, as is a shift in how patients interact with physicians, from a passive role to an active role and sharing responsibility. This frequently entails changing physician attitudes and behaviours, as well as patients' attitudes. Patients' trust in physicians is also required for effective interaction. Family involvement should be assessed because it can either support or hinder communication between physicians and patients, as well as the decision-making process.

The four studies also emphasised that physicians' willingness to communicate and practice SDM is influenced by their education and training in communication skills and SDM, as are their expectations of SDM outcomes, highlighting the importance of investing in their education and training.

The patient's role was highlighted in the four studies in terms of patient's health condition, age, level of education, and self-efficacy and confidence, all of which should be evaluated because they may affect the patient's capacity and willingness to participate in decision-making. Although the patient's age is a determinant in the EMR, with an increasing preference for a passive role, findings from Saudi interviews revealed that the patient's level of education influences their involvement in the decision-making process regardless of age. Patients' preferences for participation, obtaining information, and making the final decision differ, necessitating an assessment of their preferences.

Time constraints, workload, and following up with multiple physicians were all identified as major barriers to SDM implementation across the four studies. Increasing consultation time is a top priority for consideration. The use of decision aids and the involvement of non-physicians (e.g., psychologists, social workers, and health educators) can help to overcome time constraints and improve physician-patient communication

7.3.2 Specific Findings Within the Qualitative Studies

The findings of qualitative studies emphasised the importance of patients' knowledge of care and treatment options. They also revealed a lack of awareness among patients regarding their rights in SDM. However, as the systematic review reported, this is not limited to Saudi Arabia and extends throughout the EMR. Raising patient awareness of their right to SDM is essential in encouraging them to demand it. Other issues identified during the two qualitative studies included staff shortages and increasing patient demand, as well as the system and organisation issues in areas such as clinic atmosphere, admission, appointments system, referral system, patient records system, and healthcare setting type (e.g., private or public hospitals, Diabetes Centres, PHCCs). The impact of clinic atmosphere was also highlighted in a few studies within the umbrella review, and the type of healthcare setting was emphasised in the systematic review. Healthcare organisations and system must be efficient, well equipped to support SDM, and not have a negative impact on the interaction between healthcare professionals and patients. Providing treatment options and increasing the number of physicians were emphasised for successful implementation. Multiple consultations for SDM are needed, and this was also emphasised in the umbrella review.

When a factor was reported as a facilitator or barrier to SDM, this is indicated: F= Facilitator; B = Barrier.

Comparisons with umbrella review, systematic review, and interviews from Saudi Arabia	**Specific findings with interviews in Saudi Arabia**
<u>Patients Factors</u> Patient health condition (B) Patient characteristics (age, level of education) (B/F) Patient' self-efficacy and confidence (B/F) Patient preferences toward SDM (B/F) Trust and confidence in physicians (B/F) Involvement of family (B/F) Patients' attitudes ☐ Asking questions and talking about concerns and views (B/F) ☐ Taking responsibility (B/F)	**<u>Patients Factors</u>** Patient knowledge regarding care and treatment options (B/F) Patients' awareness about their rights in SDM (B/F)
<u>Physicians Factors</u> Physicians' attitudes ☐ Sharing the responsibility with patients (B/F) ☐ Dominating decision-making encounters (B) Physicians SDM behaviours ☐ listening to patients (B/F) ☐ Encouraging patients to participate (F) ☐ Discussing information with patients (B/F) ☐ Respecting patients' opinion (B/F) ☐ Explaining treatment options and outcomes (B/F) Physicians' expectations about SDM outcomes (B/F) Training physicians on communication skills and SDM (B/F)	**<u>Physicians Factors</u>** Physicians' attitudes ☐ Welcoming and paying full attention to patients (F) ☐ Using open-ended questions during the consultation (F) Physicians SDM behaviours ☐ Imposing their opinion (B) ☐ Sequencing in introducing options to patients (B)
<u>Healthcare System Factors</u> Provision of decision aids (B/F) Workloads (B) Time (B/F) Meeting different physicians (B/F) Involvement of non-physicians (F)	**<u>Healthcare System Factors</u>** Staff shortages (B) Increasing the number of physicians (F) Provision of treatment options (B/F) Multiple consultations for SDM (F) Increasing patient demand (B) Clinic atmosphere (B/F) Characteristics of healthcare system (admission, appointments system, referral, and dual system) (B/F) Type of healthcare setting (private, Diabetes centre, hospital, PHCC) (B/F)

Table 7. 1: Comparisons with all studies and the main findings pertaining to Saudi Arabia

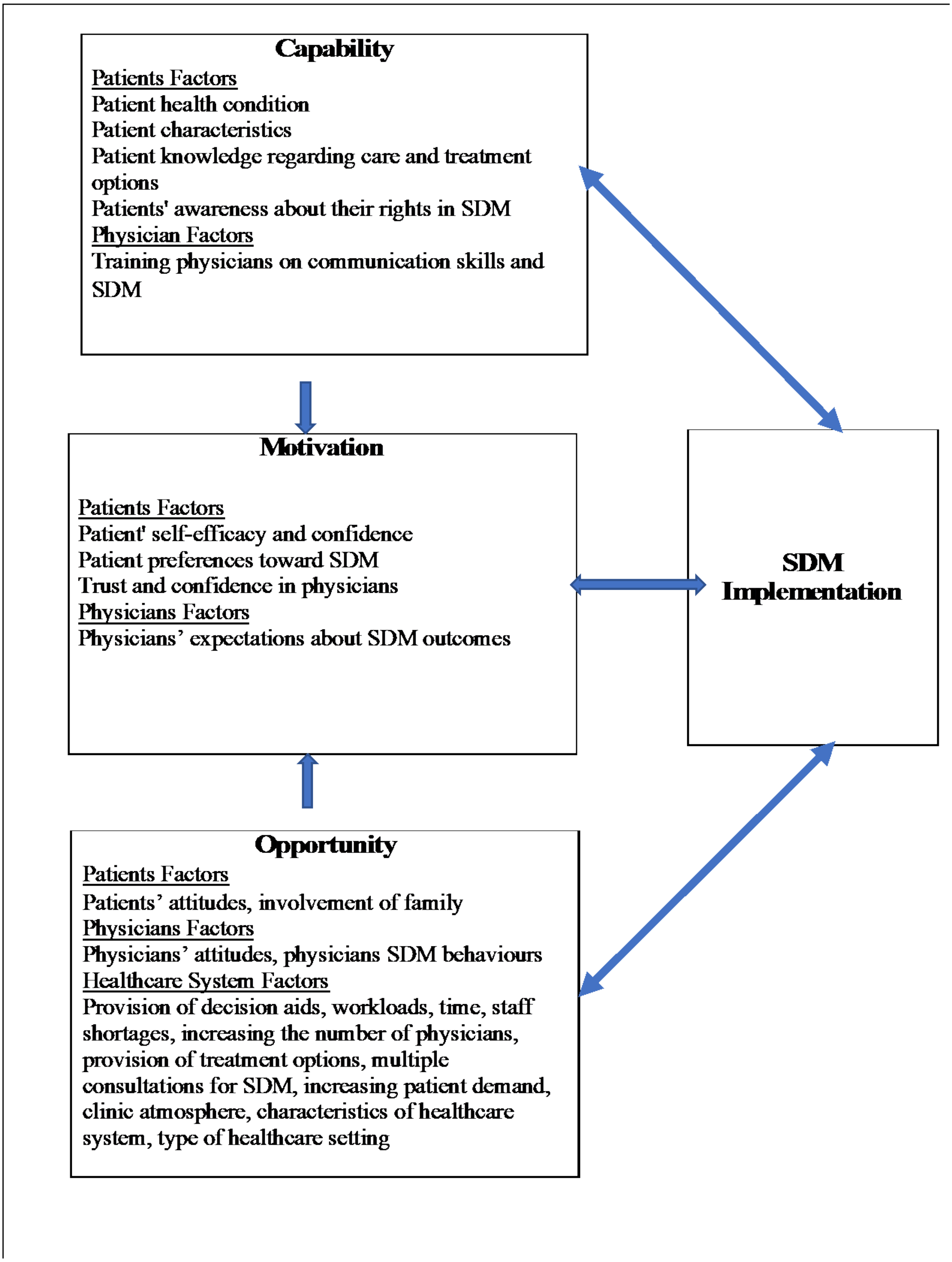

Figure 7. 2: Barriers and facilitators to SDM implementation in PHCCs in Saudi Arabia

7.3.3 Interpretation of Qualitative Findings in Relation to Cultural and Structural Perspectives

Individuals' perceptions of themselves are shaped by culture, and their environments determine who they are, what they expect, and what is expected of them (1). SDM implementation is likely to be influenced by cultural and structural factors, and should be studied in different health system and countries.

Cultural Perspectives

Saudi Arabia has an Arab-Islamic culture that is more collective and family oriented (2), with people viewing themselves as agents of their family, and health-care professionals are frequently held in high regard in this culture. Saudi Arabian traditions influence the culture of organisations within the country to some extent and the Saudi Arabian society's centralized tradition is also reflected in the health-care services (3,4).

Patients in Saudi Arabia are not used to making medical decisions on their own; rather, they rely heavily on their physicians or families. For instance, while some patients in this study preferred shared or informed decision-making, others delegated final decision-making authority to their physicians, believing that they know best. This is consistent with another study conducted in Saudi Arabia, which discovered that patients' preferences for involvement in clinical decision-making are different, with shared style being the most preferred, followed by paternalistic, and then informed style (5). Patients from Jordan and Oman, who share a cultural background with Saudis, are also unaccustomed to exercising autonomy in medical decision-making and rely on their physicians and families (2,6,7). However, this is not limited to the EMR but also in other non-Western cultures such as Tanzania, China, and Turkey (8–10).

The role of education and knowledge in influencing SDM was discovered in Saudi Arabia and in other countries in EMR, as reported in study two. A recent Saudi study found that the majority of participants had inadequate health literacy, which was linked to a lack of knowledge of health information, emphasising the importance of understanding Saudis' health literacy status and raising their health literacy awareness (11). A study from Taiwan found that education level has a direct impact on health literacy, and health literacy has a direct impact on SDM (12). Another Saudi study discovered that inadequate health literacy was linked to patients' low levels of education and low socioeconomic status (13). It is understandable that levels of education and socioeconomic status to be a determinant in PHCCs in Saudi Arabia, as patients with greater income are more likely to use private services (14).

The lack of knowledge about the disease, treatment options, and the right to information and participation in decision-making exacerbates the power imbalance between physicians and patients. The power dynamic in the physician-patient relationship was highlighted in studies three and four, which can be a source of problem during communication between them. Involving patients in decision-making necessitates a balance of power and responsibility between physicians and patients (15), especially that both parties are open to the idea of involving patients in decision-making. However, there is a high-power imbalance, and physicians have the upper hand in decision-making in Saudi Arabia. Iran, which has a Middle Eastern culture, is comparable. In Iran, the patient–physician relationship is likely to be paternalistic, and physicians rarely offer patients enough information to make decisions or allow them to participate in an informed manner. They believe that patients will be unable to comprehend such information (16). A power differential between physicians and patients may reflect the physicians' sense of superiority to patients in the context of the consultation, or it may be the result of a gap in education and knowledge between them, as the findings of this thesis demonstrated that patients' level of education and knowledge influence their ability to involve in the SDM process. In addition, there are no policies that encourage high levels of patient participation, which may encourage physicians to adopt a more paternalistic approach, limiting patients' participation and encouraging a more passive role. The findings of study three, in which patients reported being unaware of their rights in SDM, support this understanding. In addition, several Saudi Arabian studies confirmed a lack of knowledge about patients bill of rights among patients and physicians (17,18). This is true not only for Saudi Arabia, but also for EMR, as reported in study two. Increasing patient clinical knowledge and awareness of their rights in SDM could empower patients and thus balance the power between them and their physician.

Structural Perspectives

Saudi Arabia has made significant progress in the healthcare sector in recent years, in accordance with the national transformation plan, with significant improvements to both PHCCs and public hospitals. However, there are challenges that need to be addressed in the primary healthcare sector to be ready for SDM implementation.

PCPs are frequently subjected to high levels of pressure, which is especially prevalent in developing countries such as Saudi Arabia. This phenomenon is also shared by China and Pakistan, where there is no appointment system and PCPs may conduct more than 90 consultations per day, with a significant amount of time spent providing prescriptions renewal (19–21). In Saudi Arabia, the MOH has made numerous efforts to regulate patient appointments, reduce pressure on PHCCs, and improve access to health services. For instance, establishing "Mawid"[1], an application that allows patients and beneficiaries to book, cancel, or reschedule appointments at PHCCs (22). In addition, there is "Wasfaty"[2], an advanced electronic service that connects hospitals and PHCCs with community pharmacies so that patients can receive medication from the nearest community pharmacy for free. There is also e-prescription service, which enables patients to obtain their medication from private pharmacies by consulting the MOH's remote channels. Patients can contact the service centre or use "Mawid" to obtain a prescription that can be dispensed from the nearest pharmacy (23,24). However, evidence from study four revealed that some patients do not use these services and instead visit PHCCs without appointments, putting a strain on physicians and potentially preventing SDM opportunities. These practices are remaining in place because patients used to be seen on a walk-in basis at PHCCs: first come, first served. Another explanation is that MOH requires PHCCs to consider everyone who walks in, even if they do not have an appointment, and no patient is turned away. To reduce these practices and to regulate the appointment system, the MOH should raising patient awareness of the importance of appointments and investigate the reasons for not using the appointment system. A study from the UK found that one of the reasons for seeking primary medical care in emergency departments is the intricate appointment systems in the general practitioner (20).

Staff shortages and increased patient demand were identified as barriers to SDM implementation. These factors are expected to be highlighted in Saudi Arabia. The population of Saudi Arabia has been rapidly growing in recent years, with a rate of 2.4 percent in 2019 (25). However, the number of PHCCs is not growing in tandem with the population (26). In addition, many nurses and other health care professionals transfer to administration positions or other non-nursing departments within their organisations (27). This trend is also noticed among physicians in Saudi Arabia (28). Physicians have a variety of leadership positions in health authorities, exacerbating physician shortages in primary care (28). All of these factors create pressure on PCPs and limits opportunities for SDM.

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[1] The Arabic word for appointment

[2] The Arabic word for my prescription

Another structural barrier in the Saudi health system that influences SDM implementation is the flaws of the present referral system, as demonstrated in qualitative studies and emphasised in another published study (29). Private hospitals can accept patients without a referral, whereas general hospitals only accept referred cases. In addition, there is no communication channels or system in place for returning patients from general hospitals to primary health care services, affecting patient continuity of care (28). However, implementing an efficient referral system from PHCCs to the next level and back to PHCCs is a key objective in Saudi Arabia's proposed strategy to reform the health system, as part of the health sector transformation plan (30).

Continuity of care is also influenced by the absence of an electronic system that would allow access to patient information at all potential sites of care. In recent years, Saudi Arabia has made significant progress in implementing Electronic Health Records (EHRs). The use of EHRs is part of the MOH National E-Health Strategy, which was established to support the transition of the Saudi health sector from a paper-based to an electronic platform (31). However, as reported by physicians in study four, there are still shortcomings in the electronic system. EHRs are mostly used by physicians for order entry (e.g., lab orders, radiology orders, pharmacy orders), with documentation functions and communication tools being ignored. This highlights the importance of investigating the reasons for PCPs' limited use of EHRs and assessing their level of computer literacy. A recent systematic review found that barriers to PCPs' mature use of EHR included, but were not limited to, a lack of awareness of EHR functionality, physicians' inability to learn more about EHR due to their limited availability, the use of completing clinical tasks successfully using only basic EHR functions, and a lack of training (32). In addition, Singapore launched its national EHR system in 2011, but private-sector uptake has been slow (33). A study conducted across Singapore to investigate the slow adaptation discovered that 81% of general practitioners were concerned that their autonomy would be compromised and that the use of national EHR would increase monitoring and control of their practices. Concerns about ethical and legal issues were also among the other barriers (33). PCPs in the United States reported that EHR consumes the majority of their time and influences the quality of their communication and that new communication measures should be considered during medical consultations to improve patient-centred care (34). Complete EHRs are essential as they make it easier to maintain track of patient information and recall it, ensuring continuity of care but it needs to be managed effectively so it does not affect patient care. One of the MOH's commitments by the end of 2025 is that the entire population will be covered by a unified EHRs system (35).

Another limitation is that EHRs only connect to PHCCs and not to other private or quasi-governmental health institutions (36). The MOH should prioritise connecting the EHR system for PHCCs to other health agency systems. Collaboration with other healthcare facilities would result in a unified electronic record that could be accessed from any site where the patient is being treated (36), reducing unnecessary duplication of services, improving patients' continuity of care, and improving communication between physicians and patients as well among physicians.

These barriers, however, may be less severe in other healthcare settings, and SDM may have opportunities there. A recent Saudi Arabian study that assessed patients' perceptions of SDM in private, public, teaching, and military hospitals confirmed that there is a good deal of SDM in the Saudi health system (37). It is understandable that SDM is being implemented in hospitals, given that the Saudi health system's previous emphasis was on tertiary and secondary care levels. However, Saudi Arabia has already begun to shift its focus and investment toward reforming and restructuring primary care (38). Findings from the same study revealed that implementing SDM varies depending on type of clinic. For example, the paediatric and surgery clinics had the highest SDM score when compared to the other clinics. Evidence from study four also highlighted differences in healthcare settings and how they may influence SDM implementation. For example, hospitals or diabetes centres have a wide range of treatment options than PHCCs, increasing the chances of introducing different treatment options to patients in those settings. Another example is that PHCCs with chronic disease clinic perform much better than those that see patients with chronic diseases in the family medicine clinic. This is due to the fact that the chronic diseases clinic is not under as much pressure as the number of patients in these clinics is limited to appointments only and patients almost always see the same physician, ensuring continuity of care and providing the time required for SDM conversations between patients and physicians.

In comparison to other countries, there is a lack of policies put in place by the Saudi government to facilitate SDM implementation. For example, Taiwan has implemented a nationwide SDM program that includes the development of patient decision aids, the establishment of SDM platform, and the integration of SDM into clinical practice (39). In the UK, SDM has been emphasised in national guidelines (40,41) and SDM has been included in national clinical standards in Australia, e.g., for hospital accreditation and medical education

(42). In addition, SDM laws have been enacted in five states in the United States, e.g., linking SDM with the formation of Accountable Care Organisation (43). In Saudi Arabia, the MOH has passed legislation on informed consent and patient rights in participating in making decisions about care and treatment. As such, the country is moving toward patient-centred care, and the physician duties guideline emphasises communication between patients and physicians, with a focus on respecting patient autonomy and encouraging patients to ask questions (44). However, there are no formal policy or clear plans for SDM implementation.

7.3.4 Contribution to SDM and its Implementation

In comparison to existing evidence, this thesis of factors influencing SDM implementation was conducted in a distinct cultural and social context, resulting in new discoveries and insights. Previous research on the factors influencing SDM implementation has been conducted in Western settings. This is the first study investigating barriers and facilitators to SDM implementation in PHCCs in Saudi Arabia, a non-Western country.

Our findings provide comprehensive evidence on barriers and facilitators of SDM in Western and non-Western countries, particularly in EMR. They assessed patients' and physicians knowledge of SDM, as well as patient knowledge of their rights in SDM. Our findings add to the existing SDM by supporting the importance of effective physician-patient communication and emphasising the benefits of SDM as perceived by various groups of healthcare stakeholders. The significance of societal culture and the structure of the health-care system in facilitating SDM implementation is also emphasised in our findings. Additionally, findings describing the influence of cultural norms and the structure of the healthcare system will help to promote interventions that target both individuals and the system.

Regarding perspectives, this was the first SDM study in Saudi Arabia to provide a comprehensive understanding of the facilitators and barriers to SDM implementation in PHCCs from various perspectives. Different group of healthcare stakeholders have contributed to the findings. This understanding aids in the development of future strategies to promote SDM implementation in Saudi Arabia.

Lastly, there is a lack of evidence regarding SDM implementation in Saudi Arabia and other countries in EMR. Most of studies in EMR did not target SDM implementation, were quantitative in nature, or did not focus on physicians and patients’ preferences to SDM. This thesis primarily addresses this gap by investigating the perspectives of different groups of stakeholders. As a result, another benefit of this thesis is that the perspectives of patients, physicians, and managers have been revealed and comprehended, which were previously overlooked in quantitative research.

7.4 Strengths and Limitations of the Thesis

All research studies are novel and add to the body of knowledge about the factors that influence SDM implementation. The umbrella review undertaken in first study is the first published review that provides a cogent summation of the evidence base that identifies and articulates the key barriers and facilitators to implementing SDM, as well as the systematic review undertaken in study two was the first published review on factors that influence SDM implementation in EMR. Study three represents the first published study with qualitative understanding of the views of patients with diabetes in Saudi Arabia regarding SDM, while study four represents the first qualitative understanding of the views of healthcare professionals in Saudi Arabia regarding SDM. This work will serve as the foundation for future research and will contribute to the development of interventions to support SDM implementation not only in Saudi Arabia but also in some other countries in EMR.

7.4.1 Strengths of the Reviews

The literature for inclusion in the umbrella and systematic reviews was searched using a variety of databases. The rigor of the literature inclusion and exclusion decisions was increased by the involvement of two independent researchers. The development of data extraction forms by three researchers ensured the consistency of the data extracted and that no relevant data was missed. The use of well-known and appropriate assessment tools to assess the quality of the included studies in the two reviews contributed to ensuring that important aspects of study quality were thoroughly examined.

The umbrella review provides an overview of the majority of the barriers and facilitators to SDM in many different countries. Moreover, these barriers and facilitators considered all those involved in SDM including service users and their relatives, health care professionals, organisations, and health care systems. The systematic review had no language restrictions and included all types of study designs. Furthermore, it was broadened to include all factors influencing SDM preferences, as well as any perceptions of SDM, such as barriers, facilitators, experiences, expectations, and attitudes toward SDM.

7.4.2 Strengths of Qualitative Studies

The recruitment of a diverse group of key stakeholders in the qualitative studies (patients, physicians, PHCC managers, medical directors, and training directors) provided a diverse and wide range of perspectives, allowing for a comprehensive understanding of the barriers, and facilitators to improve SDM uptake. The use of the COM-B as a theoretical framework in the analysis stage is also a strength in the qualitative studies. It helped in organising the themes, structuring the findings, and making the data more understandable. Another benefit of COM-B is that it serves as the foundation for BCW; COM-B elements can be linked to the BCW and Behaviour Change Technique, promoting the collection of intervention strategies that are likely to be appropriate and effective in addressing obstacles and facilitators for each component.

7.4.3 Limitations of The Reviews

A limitation to the umbrella review is its approach, which focuses only on systematic reviews and excludes primary research articles, book chapters, and discussion papers that may provide useful information. However, the aim of the current review is to obtain an overview of the barriers and facilitators to implementing SDM, and an umbrella review is a good approach in providing an overview and collecting data from multiple health care settings without conducting a systematic review in each setting. Second, studies published in languages other than English were not included, potentially increasing the likelihood of missing relevant research. Other limitations on the umbrella review can be found in Chapter 2.

The majority of included studies in the systematic review used a quantitative approach (mainly a questionnaire), which restricts respondents from including more information and limits their answers. Other limitations on the systematic review can be found in Chapter 3.

7.4.4 Limitations of The Qualitative Studies

The first limitation of the qualitative studies is that it is limited to PHCCs; thus, the findings may not be applicable to other settings such as public or private hospitals. Although the sample included one of the major cities in Saudi Arabia, it may not be representative of the entire country, as other cities in the country were not included in the study. However, the city in question is home to a diverse community of Saudis.

Face-to-face interviews were planned for the qualitative studies. However, due to COVID-19 restrictions, we were unable to complete all face-to-face interviews, and some participants were interviewed over the phone. Phone interviews have been criticized for their difficulty in establishing the same level of rapport with participants as face-to-face interviews, as well as their lack of visual cues and nonverbal data, which may impede rapport, probing, and response interpretation. Furthermore, we were unable to continue in-person recruitment in PHCCs. Instead, patients were recruited using social media, while healthcare professionals were recruited using snowball sampling, potentially leading to selection bias. Patients with limited technological knowledge may be excluded from participating, whereas in snowball sampling participants are chosen by individuals who have already been recruited, and it is possible that all of the participants will share certain characteristics, limiting different views.

Although involving two or more researchers to independently code the transcripts is important in determining the perceived reliability of research findings, only one researcher was in charge of coding all of the transcripts. However, efforts were made to improve reliability by double-checking that the themes represented the entire set of data with both supervisors. The key themes and sub-themes were also refined as a result of ongoing discussions with the supervisors.

7.5 Recommendations for SDM Implementation in PHCCs in Saudi Arabia

SDM implementation is challenging but not impossible. Changing attitudes is an important part of it as in any change initiative. SDM implementation requires structural changes in the healthcare system, as well as cultural and attitudinal changes among physicians and patients. It necessitates a combination of interventions to assist patients, physicians, and organisations. Individual interactions are the foundation of any organisation, and they can make or break it. As a result, overlooking these in planning, policy formulation, and decision-making could be detrimental because an organisation's willingness to change is not sufficient unless its members are willing to adapt to the changes (45).

7.5.1 Patients-Related Interventions

This study discovered that patients in EMR were unaware of their rights to SDM, highlighting the importance of raising public awareness of these rights. Patients' rights should be widely publicised and compliance should be closely monitored to strengthen this aspect of public policy. One strategy could be to post on some Twitter accounts, such as the Diabetes

Association or other disease associations. It can also be displayed in the waiting room on posters or patient education screens. Physicians could also assist patients by informing them of their rights on SDM.

In Saudi Arabia and other EMR countries, the role of education and knowledge in influencing SDM was also discovered. This highlights the importance of interventions such as patient activation campaigns or other interventions aimed at improving health literacy, educating patients about SDM, and preparing them to be active participants in their care decisions. Another method for increasing patient knowledge and confidence in their decision is to create simple and understandable decision aids and incorporate them into patient encounters.

7.5.2 Health Care Professionals -Related Interventions

Education is required to ensure that healthcare professionals are ready to adapt to changes. If SDM is to be implemented, it should be integrated into medical curriculums and interprofessional training programs. Organisations also play a pivotal role in fostering a culture of continuous learning. To enable SDM practice, physicians must receive ongoing education and training in SDM and communication skills, as well as be provided with a role model or consultation simulation. There is also a need to improve PCPs' knowledge of the benefits and risks of treatments in order to aid decision-making.

7.5.3 System-Related Interventions

PHCCs are underutilized in Saudi Arabia, with many patients visiting them to request a hospital referral. Simultaneously, PHCCs may be lacking in advanced medical resources, which may drive health-seeking behaviour toward hospitals rather than potentially more appropriate primary care settings. PHCCs must be well-equipped and offer a wide range of treatment options.

Other recommendations that should be considered included first the development of a unified electronic medical record system that would allow access to patient information and follow-up treatment plans at all potential sites of care, including hospitals, PHCCs, and Diabetes Centres. Secondly, involving non-physicians in the SDM process such as psychologists, social workers, and health educators who could save physician time by further explaining treatment options to patients, learning about their preferences and assisting them in further investigating the matter before making a decision. Thirdly, incorporating SDM into Saudi

Arabia's national policy and MOH's strategic plans is recommended. Lastly, empowering technology to facilitate patient-physician communication and help them in developing deeper and more engaged relationships

7.6 Future Research

Each empirical study in this thesis has added to our understanding of barriers and facilitators to SDM practice in PHCCs. This provides opportunities for future researchers to develop interventions that target organisations, physicians, and patients and then assess the impact of these interventions in facilitating SDM implementation. Research is also needed to consider the perspectives of other allied health professionals, as well as key national stakeholders such as policymakers. Future research could shed light on how allied health professionals collaborate on various aspects of decision-making.

The empirical studies also revealed that patients have varying preferences regarding SDM; therefore, studies should focus on how patients prefer to be involved in decision-making. In study four, the majority of healthcare professionals agreed that family members play an important role in supporting patient engagement. In study three, patients, on the other hand, stated that they prefer not to involve their families in their decision-making and believe it is unimportant. More research is needed in Saudi Arabia to better understand patients perception and preferences for family involvement in decision-making.

Qualitative studies could be an effective way to further investigate why patients visit PHCCs without an appointment, as well as the reasons for PCPs limited use of EHRs. There is also a need for research to assess physician awareness of patients' rights in SDM, PCPs computer literacy and its influence on use of EHR, and the impact of financial incentives or training (e.g., SDM workshops) on SDM implementation.

7.7 Reflective Account

Throughout the journey of this PhD, I have learned a lot about SDM, PHCCs, patients' with diabetes, qualitative research, and myself. It was an educational opportunity full of new experiences. I have learned how to perform umbrella and systematic reviews, how to conduct qualitative interviews, and how to analyse qualitative data. The publication of journal articles, including the publication process and responding to the reviewers' comments, also was a new experience for me. All of these will be useful to me as a university lecturer and will be passed on to my students. As I gain a better understanding of SDM and the issues surrounding its implementation, I will be able to present more SDM lectures and seminars.

The PhD journey has made an impact on my personal development. I have experienced the power of perseverance. Even during difficult times, such as the Coronavirus pandemic, I learned how to push myself to accomplish my work as efficiently as possible. After making several decisions on my own during my PhD path, I became more confident and responsible towards myself. All of the meaningful relationships in my life grew stronger over this time as people stood by my side and encouraged me while I went through this experience. It has put me to the test both mentally and emotionally, which led me to gain the habit of working under pressure. I am more aware of my limitations, more patient, and ultimately more confident in myself than I was at the beginning of the project, which produced growth in my abilities as a person.

7.8 Conclusions

The major findings in this thesis contribute significantly to the literature on SDM, particularly in terms of factors that influence the implementation of SDM in non-western communities. In comparison to existing evidence, this thesis of factors influencing SDM implementation was conducted in a distinct cultural and social context, resulting in new discoveries and insights. Although they indicate some key similarities with exiting literature, they also reveal that influential factors differ across countries and should be studied in different health systems and countries. The four studies of this thesis demonstrated the significance of effective physician-patient communication in the success of SDM. This communication is influenced by physicians and patients, as well as the healthcare system that affects both patients and physicians.

SDM implementation is influenced by physicians' and patients' capability to engage in the SDM process, which is influenced by many factors related to each of them, such as patients' health conditions, characteristics, Knowledge, awareness about their rights in SDM, and physicians' training on SDM and communication skills. SDM implementation is also influenced by opportunities that surround physicians and patients that can help them engage in the SDM process, such as attitudes and behaviours of physicians and patients during communication, and family involvement in that communication. Other opportunities for SDM are the provision of resources and the structure of the healthcare system. All of these factors can either motivate or demotivate patients and physicians toward SDM.

Implementing SDM is difficult but not impossible. As with any change endeavour, changing attitudes is a critical component. SDM implementation necessitates structural, cultural and attitudinal changes. It demands a combination of interventions to help patients, physicians, and organisations. Patient activation campaigns and other interventions aimed at improving health literacy, educating patients about SDM, and preparing them to be active participants in their care decisions are examples of such interventions. SDM should be incorporated into medical curricula as well as interprofessional training programs. Organisations can also help to foster a culture of continuous learning among healthcare professionals. PHCCs must be well-equipped and offer a wide range of treatment options. There is also a need to develop a unified electronic medical record system that would allow access to patient information and follow-up treatment plans, enable technology to facilitate patient-physician communication, and integrate SDM into Saudi Arabia's national policy and MOH's strategic plans. I hope that future researchers will be able to develop these interventions.

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Appendix 1: Supplementary Data for the Umbrella Review

Search strategy

PsycINFO

1. "decision aids".tw.
2. "decision making".tw.
3. *Decision Making/
4. *Decision Support Systems/
5. 1 or 2 or 3 or 4
6. "patient involvement".tw.
7. "patient participation".tw.
8. *Patient Participation/
9. 6 or 7 or 8
10. "shared decision".tw.
11. "sharing decisions".tw.
12. "informed decision".tw.
13. "informed choice".tw.
14. meta-analysis.tw.
15. systematic review.tw.
16. 10 or 11 or 12 or 13
17. 14 or 15
18. 5 and 9
19. 9 and 16
20. 18 or 19
21. 17 and 20
22. limit 21 to (english language and yr="1997 -Current")

MEDLINE

1. "decision aids".tw.
2. "decision making".tw.
3. *Decision Making/
4. *Decision Support Systems, Clinical/
5. decision support techniques/
6. 1 or 2 or 3 or 4 or 5
7. "patient involvement".tw.
8. "patient participation".tw.
9. *Patient Participation/
10. 7 or 8 or 9
11. 6 and 10
12. MEDLINE.tw.
13. systematic review.tw.
14. meta analysis.pt.
15. 12 or 13 or 14
16. 11 and 15

17. limit 16 to (english language and yr="1997 -Current")

Cochrane Library

1. ("patient participation"):ti,ab,kw in Cochrane Reviews (Word variations have been searched)
2. ("patient involvement"):ti,ab,kw in Cochrane Reviews (Word variations have been searched)
3. MeSH descriptor: (Patient Participation) explode all trees
4. ("decision aids"):ti,ab,kw in Cochrane Reviews (Word variations have been searched)

5. ("decision making"):ti,ab,kw in Cochrane Reviews (Word variations have been searched)
6. MeSH descriptor: (Decision Making) explode all trees
7. MeSH descriptor: (Decision Support Systems, Clinical) explode all trees
8. #4 or #5 or #6 or #7
9. ("shared decision".):ti,ab,kw in Cochrane Reviews (Word variations have been searched)
10. ("informed decision"):ti,ab,kw in Cochrane Reviews (Word variations have been searched)
11. ("informed choice"):ti,ab,kw in Cochrane Reviews (Word variations have been searched)
12. #9 or #10 or #11
13. #1 or #2 or #3
14. #8 and #13
15. #14 or #13
16. (facilitators):ti,ab,kw in Cochrane Reviews (Word variations have been searched)
17. (barriers):ti,ab,kw in Cochrane Reviews (Word variations have been searched)
18. #16 or #17
19. #12 and #18
20. #13 or #8 or #12
21. #20 and #18

CINAHL

1. shared decision-making OR decision aids OR decision-making OR treatment choice OR decision-making OR sharing decision
2. patient involvement OR patient participation OR patient preference OR patient perspective
3. physician patient relationship OR physician patient communication OR attitude of health personnel OR physician perspective
4. 2 or 3
5. 1 and 4
6. 2 and 3
7. 5 or 6 or 1
8. TI decision-making
9. 7 and 8
10. 7 and 8 Published Date: 19970101-20181231; English Language; Publication Type: Meta Analysis, Meta Synthesis, Systematic Review

11. AB barriers Published Date: 19930101-20181231; English Language; Publication Type: Meta Analysis, Meta Synthesis, Systematic Review
12. 10 and 11
13. AB shared decision making
14. 10 and 13
15. 12 and 14

Scopus

(((TITLE-ABS-KEY("decision aids") OR TITLE-ABS-KEY("decision making")OR TITLE-ABS-KEY(*Decision Making)) AND DOCTYPE(re) AND PUBYEAR > 1997) AND ((TITLE("patient involvement") OR TITLE-ABS-KEY("patient participation")) AND DOCTYPE(re) AND PUBYEAR > 1997)) AND ((TITLE-ABS-KEY(barriers*) OR TITLE-ABS-KEY(facilitators*)) AND DOCTYPE(re) AND PUBYEAR > 1997)

Table A.1

Articles presenting barriers to implementing SDM

Factors	Studies identified				
	Joseph-Williams et al. (15)	Daly et al. (12)	Gondek et al. (14)	Legare et al. (10)	Total (X)
1. Patient/Families Factors					
1.1 Patients perception					
1.1.1 Doctors know the best	29				29
1.1.2 Capability of understanding medical information	5				5
1.1.3 Clinician making the decisions	17				17
1.1.4 Acceptability of asking questions	14				14
1.1.5 Clinicians against the involvement of patient	14				14
1.1.6 There are right and wrong decisions and don't want to take responsibility	13				13
1.1.7 Lack of expectation about SDM consultation	4				4
1.2 Patient preferences and fears					
1.2.1 Preferences to be involved				14	14
1.2.2 Fear the consequences of being described as difficult	15				15
1.2.3 Fear of accepting the reality of diagnosis	11				11
1.2.4 Shock of knowing the diagnosis	3				3
1.3 Patient capacity					
1.3.1 Age (older, younger)	9				9
1.3.2 Health condition	12			16	28
1.3.3 Cognitive/physical impairments	6				6
1.3.4 Not being able to express themselves	5				5
1.3.5 Lack of self-efficacy				9	9
1.3.6 Characteristics of the patient				18	18
1.3.7 Lower level of education	4				4
2. Professional Factors					
2.1 Professional perception					
2.1.1 Not possible to reach a mutual understanding of SDM by both parties				5	5
2.1.2 Complexity of the use of SDM				4	4
2.1.3 SDM is too artificial				4	4
2.1.4 SDM is not practical				3	3
2.1.5 SDM increases costs				3	3
2.1.6 Lack of expectancy on patient outcome				3	3
2.1.7 Lack of expectancy on the health care process				3	3
2.1.8 Not all elements of SDM are supported by evidence				4	4
2.1.9 Patient prefer not to involve and does not need it.	15				15
2.1.10 Patient is not permitted to a choice	11				11
2.2 Professional characteristics					
2.2.1 Poor interpersonal skills	17				17
2.2.2 Lack of familiarity about SDM				7	7

2.2.3 Paternalistic style	10				10
2.2.4 Social attitudes		3			3
2.3 Professional behaviour					
2.3.1 No explicit permission for the patient to participate	12				12
2.3.2 Not asking patients about their preferred role in decision-making.	10			9	19
2.3.3 lack of listening and respecting patient’s concerns or opinions.	20		4		24
2.3.4 Clinicians promote passivity	4				4
2.3.5 Not giving explicit choices to patient	7				7
2.3.6 Using medical terminology	14				14
2.3.7 Not explaining options or outcomes from clinicians	8				8
3. Environmental Factors					
3.1 Organizational characteristics					
3.1.1 Time constraints	10			24	34
3.1.2 Lack of resources		3	7	5	15
3.1.3 Inadequate environmental conditions e.g., noisy, lack of privacy	4				4
3.1.4 lack to motivate physicians to use SDM				5	5
3.1.5 Lack of written decision support.	3				3
3.1.6 System does not offer multiple consultations for SDM if needed	3				3
3.1.7 Lack of access to supportive services				3	3
3.1.8 Too many clinicians involved in care	10				10
3.1.9 Clinicians are too busy	15				15
3.2 Characteristics of the health care system					
3.2.1 Extensive policies and regulations			7		7
3.2.2 Clinician does not address the patient directly	3				3
5. Relationship Factors					
5.1 Poor Relationship		5	3		8
5.2 Trust in clinicians	16				16
5.3 Lack of trust in clinicians	3				3
5.4 Patients are not known by clinicians	3				3
5.5 Difference in personal characteristics between clinicians and patients (e.g., gender, language)	5				5
6. Factors related to information provision					
6.1 Lack of sharing information regarding options and outcomes	19		8		27

- X total number of studies in each factor from all of the included reviews.
- Grey background colour highlights the most recurring factor across studies

Articles presenting facilitators to implementing SDM

Factors	Studies identified							
	Legare et al. (10)	Daly et al. (12)	Robertson et al. (13)	Gondek et al (14)	Joseph-Williams et al. (15)	Cheng et al (16)	Scholl et al. (17)	Total (X)
1. Patient/Families Factors								
1.1 Patients perception								
1.1.1 Acceptability of asking questions.					17			17
1.1.2 acknowledge that the medical encounter involves two experts					15			15
1.1.3 Accepting the responsibility of participating in decision making					16			16
1.1.4 Recognizing equipoise and uncertainty					6			6
1.2 Patient preferences								
1.2.1 Preferences to be involved	6							6
1.3 Patient capacity								
1.3.1 Health condition	4							4
1.3.2 Parental involvement				6				6
1.3.3 Patient characteristics	6							6
2. Professional Factors								
2.1 Professional perception								
2.1.1 SDM has positive impact on the health care process	15							15
2.1.2 SDM has positive impact on patient outcomes	16							16
2.1.3 SDM is practical	10							10
2.1.4 SDM is consistent with one's own approach	4							4
2.1.5 SDM is easy to use	3							3
2.1.6 SDM is modifiable	3							3
2.1.7 SDM saves time	5							5
2.1.8 Recognising abilities and rights of patients to be involved in the process of SDM.		3		3				6
2.2 Professional characteristics								
2.2.1. Positive interpersonal skills					8			8
2.2.2 Shared style in decision making					14			14
2.3 Professional behaviour								
2.3.1 Discuss preferences of patients/families in their involvement in decision making	3		4		11			18
2.3.2 Check information comprehension regularly			6					6
2.3.3 Assess preference for the amount of information			3					3
2.3.4 Encourage values-based decision-making			3					3
2.3.5 Orienting information to individual preferences			3					3
2.3.6 Promote question-asking			4					4
2.3.7 Listen to patients and respect their opinions			3	9	10			22
2.3.8 Explicit ‘‘permission’’ to participate in					12			12

SDM								
2.3.9 Use action planning or goal setting						3		3
2.3.10 Use discussion prompts						4		4
2.3.11 Use written decision support					3			3
2.3.12 Sharing responsibility with Patient	4							4
2.3.13Provide anticipatory guidance (advice and support)			4					4
2.3.14 Uses simple terminology			11		6			17
2.3.15 Explaining options and outcomes					12			12
3. Environmental Factors								
3.1 Organizational characteristics								
3.1.1 Provide tools and resources		4						4
3.1.2 provide adequate time for SDM			7		7		3	17
3.1.3 Provide access to supportive services (e.g., nurses, social workers) throughout the process of decision making.			5					5
3.1.4 Encourage healthcare professionals (HCPs) in learning SDM skills							4	4
3.1.5 Support the implementation of SDM in each level of the organisation's leadership.							4	4
3.1.6 Provide continuous feedback and performance monitoring on SDM and its tools.							12	12
3.1.7 Allow flexibility of the use of decision aids and freedom in the achievement of SDM implementation goals.							3	3
3.1.8 Foster effective communication between teams about SDM implementation							3	3
3.1.9 Engage non-physician personnel(e.g., nurse, office staff)					4		4	8
3.1.10 Combine SDM with other intervention or changes (e.g., chronic disease management program)							3	3
3.1.11 Have decision aids/tools available in workspaces and exam rooms.							3	3
3.1.12 Introduce scheduling system for SDM and its tools.							3	3
3.1.13 Use electronic health record (EHR) to document and prompt the process of SDM.							4	4
3.1.14 Use EHR to identify the eligibility of the patient for decision aids.							5	5
3.1.15 Provide decision aids on EHR and patient portal.							5	5
3.1.16 Use of decision aids						10		10
3.1.17 Motivating healthcare professionals (HCPs) to use SDM	22							22
3.1.18 Provide multiple consultations for SDM			7					7
3.1.19 Nominating an internal champion to encourage HCPs							9	9
3.1.20 Encouraging HCPs to be empathic, physically present, and to acknowledge that making a decision has a stressful nature.			4					4
3.2 Characteristics of the health care system								
3.2.1 Create a legislation that fosters SDM							3	3

3.2.2 link the use of decision aids with the quality of care indicator and consider SDM as performance metric.							3	3
3.2.3 Embedded SDM communication skills as mandatory curriculum into medical school.							3	3
3.2.4 Offer continuing medical examination and education units' credits for training in SDM and watching of decision aids.							3	3
3.2.5 Use a payment model to promote providers to involve in SDM							3	3
5. Relationship Factors								
5.1 Good relationship		5	3	9	12			29
5.2 Patients are known by clinicians					5			5
5.3 Trust in clinicians					8			8
5.4 Lack of trust in clinicians					3			3
6. Factors related to information provision								
6.1 Provide information in multiple modalities			6					6
6.2 Repeat information at multiple time-points			5					5
6.3 Provide sufficient information about condition, options and outcomes			6	5	16			27
6.4 Provide translated materials or interpreters			4					4
6.5 Provide psychoeducational information						4		4

- X total number of studies in each factor from all of the included reviews
- Grey background colour highlights the most recurring factor across studies

Table A.2
Quality appraisal for included reviews

CASP Questions	Reviews						
	Legare et al. (4)	Daly et al. (2)	Robertson et al. (5).	Gondek et al. (3)	Joseph-Williams et al. (1)	Cheng et al. (6)	Scholl et al. (7)
1. “Did the review address a clearly focused question?”	Yes	Yes	Yes	Yes	Yes	Yes	Yes
2. “Did the authors look for the right type of papers?”	Yes	Yes	Yes	Yes	Yes	Yes	Yes
3.” Do you think all the important, relevant studies were included?”	Yes	No	No	No	No	No	No
4. “Did the review’s authors do enough to assess quality of the included studies?”	Yes	Yes	Yes	Yes	Yes	Yes	No
5. “If the results of the review have been combined, was it reasonable to do so?”	Yes	Yes	Yes	Yes	Yes	Yes	Yes
6. “What are the overall results of the review?”	-	-	-	-	-	-	-
7. “How precise are the results?” (confidence intervals)	N/A	N/A	N/A	N/A	N/A	N/A	N/A
8. “Can the results be applied to the local population?”	Can't tell	Can’t tell	Can't tell	Can’t' tell	Can’t tell	Can't tell	Can’t' tell
9. “Were all important outcomes considered?”	Yes	Yes	Yes	Yes	Yes	Yes	Yes
10. “Are the benefits worth the harms and costs?”	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Table A.3
Summary of barriers and facilitators

Themes	Barriers	Facilitators
1. Patient/Families Factors	**1.1 Patients perception** Doctors know the best The capability of understanding medical information Clinician making decisions Acceptability of asking questions Clinicians against the involvement of patients Lack of expectation about SDM consultation **1.2 Preferences and fears** Preferences to be involved Fear the consequences of being described as difficult Fear of accepting diagnosis and its reality **1.3 Patient capacity** **Patient characteristics** • Age (older, younger) • Patient characteristics • Lower level of education **Health condition** • Cognitive/physical impairments • Health condition **Lack of self-efficacy** • Not being able to express themselves • Lack of self-efficacy	**1.1Patients perception** Acceptability of asking questions. Recognizing equipoise and uncertainty Acknowledge that the medical encounter involves two experts Accepting the responsibility of participating in decision-making **1.2 Preferences and fears** Preferences to be involved **1.3 Patient capacity** Health condition Patient characteristics Parental involvement

Themes	Barriers	Facilitators
2. Professional Factors	**2.1 Professional perception** Patients prefer not to involve and do not need it. Patients are not permitted to a choice **Lack of agreement with aspect of SDM** • Not possible to reach a mutual understanding of SDM by both parties • Not all elements of SDM are supported by evidence • SDM increases cost • SDM is not practical • SDM is too artificial • Complexity of the use of SDM **Expectations about SDM** • Lack of expectancy on patient outcome • Lack of expectancy on health care process **2.3 Professional characteristics** Poor interpersonal skills Lack of familiarity with SDM Authoritarian Social attitudes **2.4 Professional behaviour** No explicit permission for the patient to participate Not explaining treatment options and outcomes Not asking patients about their preferred role in decision-making Lack of listening and respecting patient's concerns or opinions. Not giving explicit choices to patient. Using medical terminology	**2.1 Professional perception** Recognising abilities and rights of patients to be involved **Agreement with aspect of SDM** • SDM saves time • SDM is practical • SDM is consistent with one's own approach • SDM is modifiable • SDM is easy to use **Expectations about SDM** • SDM has positive impact on the health care process • SDM has positive impact on patient outcomes **2.3 Professional characteristics** Positive interpersonal skills Shared style in decision making **2.4 Professional behaviour** Check information comprehension regularly Listen to patients and carers and respect the patient's opinions Giving explicit ''permission'' to participate in SDM Uses simple terminology Explaining treatment options and outcomes Sharing responsibility with Patient **Discuss patients preferences** • Discuss patients/families about their preferred role in decision-making • Assess preference for the amount of information **Using decision support tools** • Use action planning or goal setting • Use discussion prompts • Use written decision support • Provide anticipatory guidance

Themes	Barriers	Facilitators
3. Environmental Factors	**3.1 Organizational characteristics** Too many clinicians involved in care Lack of resources lack to motivate health care professional to use SDM Does not offer multiple consultations for SDM Inadequate environmental conditions (e.g., noisy, lack of privacy) Lack of access to supportive services Lack of written decision support **Time** • Time constraints • Clinicians are too busy **3.2 Characteristics of the health care system** Extensive policies and regulations	**3.1 Organizational characteristics** Adequate time for SDM Performance measurement and feedback on SDM Multiple consultations for SDM **Supporting the use of decision aids** • Have decision aids available in workspaces and exam rooms • Allow flexibility of the use of decision aids and freedom in the achievement of SDM implementation goals. **Encouraging healthcare professionals to implement SDM** • Motivate health care professionals to use SDM • Nominate an internal champion to encourage healthcare professionals • Encourage healthcare professionals (HCPs)in learning SDM skills • Encouraging HCPs to be empathic, physically present, and to acknowledge that making a decision has a stressful nature. • Encourage the implementation of SDM in each level of the organisation's leadership • Foster effective communication between teams about SDM implementation **Electronic health record to prompt SDM** • Provide decision aids on EHR and patient portal. • Use EHR to identify the eligibility of the patient for decision aids. • Use EHR to document and prompt the process of SDM **Engage non-physician personnel(e.g., nurse, social workers)** • Engage non-physician personnel(e.g., nurse, office staff) • Provide access to supportive services (e.g., nurses, social workers) throughout the process of decision making.

Themes	Barriers	Facilitators
		3.2 Characteristics of the health care system Using a payment model to promote providers to involve in SDM **Policies and regulations** • Create a legislation that fosters SDM • link the use of decision aids with the quality of care indicator and consider SDM as performance metric **Embedded SDM communication skills into medical education** • Embedded SDM communication skills as mandatory curriculum into medical school • Offer continuing medical examination and education units' credits for training in SDM and watching of decision aids.
4. Relationship Factors	4.1 Poor Relationship 4.2 Trust in clinicians 4.3 Patients are not known by clinicians 4.4 Difference in personal characteristics between patients and clinicians (e.g., sex, language)	4.1 Good relationship 4.2 Patients are known by clinicians 4.3 Trust in clinicians
5. Factors related to information provision	5.1 Lack of sharing information regarding options and outcomes	5.1 Provide information in multiple modalities 5.2 Repeat information at multiple time-points 5.3 Provide sufficient information about options and outcomes 5.4 Provide translated materials or interpreters 5.5 Provide psychoeducational information

Appendix 2: Supplementary Data for the Systematic Review

PsycINFO and MEDLINE

1. (Afghanistan or Bahrain or Djibouti or Egypt or Iran or Iraq or Jordan or Kuwait or Lebanon or Libya or Morocco or Oman or Pakistan or Qatar or Saudi Arabia or Somalia or Sudan or Syria or Tunisia or United Arab Emirates or Yemen).mp.
2. "decision making".tw.
3. Decision Making/
4. Patient Participation/
5. (decis* adj choic*).mp.
6. Patient Preference/
7. patient involvement.mp.
8. informed decision*.mp.
9. preference sensitive.mp.
10. patient activation.mp.
11. (patient adj3 decision making).mp.
12. "patient participation".tw.
13. "shared decision".tw.
14. "sharing decisions".tw.
15. "informed choice".tw.
16. "Decision Support".tw.
17. "shared decision making".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
18. "decision support techniques".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
19. "patient-centered care".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
20. Patient engagement.mp.
21. Choice Behavior/
22. 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21
23. 1 and 22

24. (clinician* or doctor* or physician* or "Health care Professionals" or "Health Professionals" or patient*).mp.
25. (eastern Mediterranean or eastern mediterranean region or Arab countries).mp.
26. 1 or 25
27. 22 and 24
28. 26 and 27
29. limit 28 to yr="1997 -Current"

CINAHL

1. TI (("Decision Making" or "Patient Participation" or "Patient Preference" or "patient involvement" or "informed decision" or "preference sensitive" or "patient activation" or "shared decision" or "sharing decisions" or "Informed choice" or "Decision Support" or or "shared decision making" or "decision support techniques" or "patient centered care" or "Patient engagement" or "Choice Behavior")) OR AB (("Decision Making" or "Patient Participation" or "Patient Preference" or "patient involvement" or "informed decision" or "preference sensitive" or "patient activation" or "shared decision" or "sharing decisions" or "Informed choice" or "Decision Support" or "physician patient communication" or "shared decision making" or "decision support techniques" or "patient centered care" or "Patient engagement" or "Choice Behavior")) OR MH (("Decision Making" or "Patient Participation" or "Patient Preference" or "patient involvement" or "informed decision" or "preference sensitive" or "patient activation" or "shared decision" or "sharing decisions" or "Informed choice" or "Decision Support" or "physician patient communication" or "shared decision making" or "decision support techniques" or "patient centered care" or "Patient engagement" or "Choice Behavior")) OR SU (("Decision Making" or "Patient Participation" or "Patient Preference" or "patient involvement" or "informed decision" or "preference sensitive" or "patient activation" or "shared decision" or "sharing decisions" or "Informed choice" or "Decision Support" or "physician patient communication" or "shared decision making" or "decision support techniques" or "patient centered care" or "Patient engagement" or "Choice Behavior"))
2. Afghanistan or Bahrain or Djibouti or Egypt or Iran or Iraq or Jordan or Kuwait or Lebanon or Libya or Morocco or Oman or Pakistan or Qatar or Saudi Arabia or Somalia or Sudan or Syria or Tunisia or United Arab Emirates or Yemen

3. Eastern Mediterranean or Arab countries
4. clinician* or doctor* or physician* or "Health care Professionals" or "Health Professionals" or patient*
5. 1 and 4
6. 2 or 3
7. 5 and 6

PubMed

((((((“eastern Mediterranean”[Title/Abstract] OR “eastern Mediterranean region”[Title/Abstract] OR “Arab countries”[Title/Abstract])) OR (“eastern Mediterranean”[MeSH Subheading] OR “eastern Mediterranean region”[MeSH Subheading] OR “Arab countries”[MeSH Subheading]))) OR (((Afghanistan[Title/Abstract] OR Bahrain[Title/Abstract] OR Djibouti[Title/Abstract] OR Egypt[Title/Abstract] OR Iran[Title/Abstract] OR Iraq[Title/Abstract] OR Jordan[Title/Abstract] OR Kuwait[Title/Abstract] OR Lebanon[Title/Abstract] OR Libya[Title/Abstract] OR Morocco[Title/Abstract] OR Oman[Title/Abstract] OR Pakistan[Title/Abstract] OR Qatar[Title/Abstract] OR “Saudi Arabia”[Title/Abstract] OR Somalia*[Title/Abstract] OR Sudan[Title/Abstract] OR Syria[Title/Abstract] OR Tunisia[Title/Abstract] OR “United Arab Emirates”[Title/Abstract] OR Yemen[Title/Abstract])) OR (Afghanistan[MeSH Subheading] OR Bahrain[MeSH Subheading] OR Djibouti[MeSH Subheading] OR Egypt[MeSH Subheading] OR Iran[MeSH Subheading] OR Iraq[MeSH Subheading] OR Jordan[MeSH Subheading] OR Kuwait[MeSH Subheading] OR Lebanon[MeSH Subheading] OR Libya[MeSH Subheading] OR Morocco[MeSH Subheading] OR Oman[MeSH Subheading] OR Pakistan[MeSH Subheading] OR Qatar[MeSH Subheading] OR “Saudi Arabia”[MeSH Subheading] OR Somalia*[MeSH Subheading] OR Sudan[MeSH Subheading] OR Syria[MeSH Subheading] OR Tunisia[MeSH Subheading] OR “United Arab Emirates”[MeSH Subheading] OR Yemen[MeSH Subheading])))) AND ((((clinician* or doctor* or physician* or "Health care Professionals" or "Health Professionals" or patient*)))

AND (((“Decision Making”[Title/Abstract] OR “Patient Participation”[Title/Abstract] OR “Patient Preference”[Title/Abstract] OR “patient involvement”[Title/Abstract] OR “informed decision”[Title/Abstract] OR “preference sensitive”[Title/Abstract] OR “patient activation”[Title/Abstract] OR “shared decision”[Title/Abstract] OR “sharing decisions”[Title/Abstract] OR “Informed choice”[Title/Abstract] OR “Decision Support”[Title/Abstract] OR “shared decision making”[Title/Abstract] OR “decision support techniques”[Title/Abstract] OR “patient centered care”[Title/Abstract] OR “Patient engagement”[Title/Abstract] OR “Choice Behavior”[Title/Abstract] OR “decision aids”[Title/Abstract])) OR (“Decision Making”[MeSH Subheading] OR “Patient Participation”[MeSH Subheading] OR “Patient Preference”[MeSH Subheading] OR “patient involvement”[MeSH Subheading] OR “informed decision”[MeSH Subheading] OR “preference sensitive”[MeSH Subheading] OR “patient activation”[MeSH Subheading] OR “shared decision”[MeSH Subheading] OR “sharing decisions”[MeSH Subheading] OR “Informed choice”[MeSH Subheading] OR “Decision Support”[MeSH Subheading] OR “shared decision making”[MeSH Subheading] OR “decision support techniques”[MeSH Subheading] OR “patient centered care”[MeSH Subheading] OR “Patient engagement”[MeSH Subheading] OR “Choice Behavior”[MeSH Subheading] OR “decision aids”[MeSH Subheading]))) Sort by: Best Match

Scopus

((TITLE-ABS-KEY (decision AND making OR shared AND decision OR informed AND decision AND patient AND participation OR patient AND involvement OR patient AND preference) OR TITLE-ABS-KEY (patient AND engagement OR decision AND aids OR patient AND centered AND care OR patient AND activation OR decision AND support OR shared AND decision AND making)) AND PUBYEAR > 1996) AND (((TITLE-ABS-KEY (afghanistan OR bahrain OR djibouti OR egypt OR iran OR iraq OR jordan OR kuwait OR lebanon OR libya OR morocco OR oman OR pakistan OR qatar OR "Saudi Arabia" OR somalia* OR sudan OR syria OR tunisia OR "United Arab Emirates" OR yemen) OR TITLE-ABS-KEY ("eastern Mediterranean" OR "Arab countries")) AND PUBYEAR > 1996) AND ((TITLE-ABS-KEY (decision AND making OR shared AND decision OR informed AND decision AND patient AND participation OR patient AND involvement OR patient AND preference) OR TITLE-ABS-KEY ("Patient engagement" OR "decision aids" OR "patient centered care" OR "patient activation" OR "Decision Support" OR "shared decision making")) AND PUBYEAR > 1996))

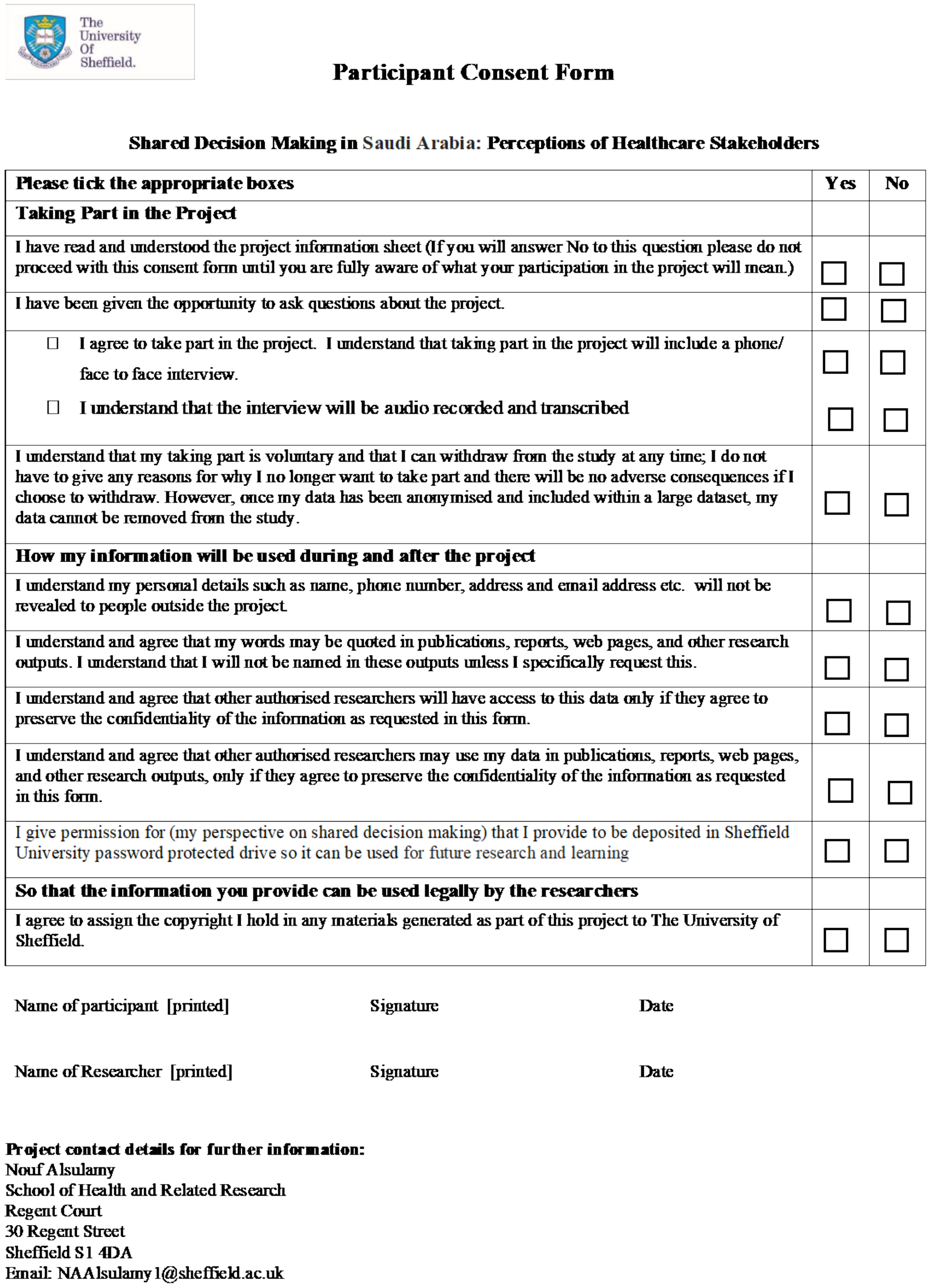
Table A.1
Quality appraisal for included studies

Category of study designs	**Methodological quality criteria**	**Studies**														
		Rashidian (2015)	Alhaqwi (2015)	Obeidat (2015)	Obeidat (2016)	Al-Tannir (2017)	Al-Bahri (2019)	Kumar (2010)	Asghari (2008)	Al-Bahri (2018)	Mohammed (2018)	Obeidat (2018)	Ebrahimi (2014)	Mostafaie (2014)	Boukir (2015)	Saleh (2014)
Screening questions (for all types)	S1. “Are there clear research questions?”	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
	S2. “Do the collected data allow to address the research questions?”	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Quantitative	“Is the sampling strategy relevant to address the research question?”	N	Y	N	N	N	Y	Y	Y	Y	Y	N	Y	Y	Y	can't tell
	“Is the sample representative of the target population?”	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N
	“Are the measurements appropriate?”	Y	Y	Y	Y	Y	N	Y	Y	N	Y	Y	Y	Y	Y	N
	“Is the risk of nonresponse bias low?”	Y	can't tell	Y	Y	can't tell	Y	Y	Y	Y	Y	Y	Y	Y	Y	can't tell
	“Is the statistical analysis appropriate to answer the research question?”	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Overall study quality		**Good**	**Good**	**Good**	**Good**	**Moderate**	**Good**	**Good**	**Good**	**Good**	**Good**	**Good**	**Good**	**Good**	**Good**	**Moderate**

Category of study designs	**Methodological quality criteria**	**Studies**			
		Alizadeh (2013)	Rashidian (2013)	Alzahrani (2016)	Alkhatrawi (2013)
Screening questions (for all types)	S1. “Are there clear research questions?”	Y	Y	Y	Y
	S2. “Do the collected data allow to address the research questions?”	Y	Y	Y	Y
Qualitative	“Is the qualitative approach appropriate to answer the research question?”	Y	Y	Y	
	“Are the qualitative data collection methods adequate to address the research question?”	Y	Y	Y	
	“Are the findings adequately derived from the data?”	Y	Y	Y	
	“Is the interpretation of results sufficiently substantiated by data?”	Y	Y	Y	
	“Is there coherence between qualitative data sources, collection, analysis and interpretation?”	Y	Y	Y	
Mixed methods	“Is there an adequate rationale for using a mixed methods design to address the research question?”				Y
	“Are the different components of the study effectively integrated to answer the research question?”				Y
	“Are the outputs of the integration of qualitative and quantitative components adequately interpreted?”				Y
	“Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?”				Y
	“Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?”				Y
	Overall study quality	**Good**	**Good**	**Good**	**Good**

Quality appraisal for included studies - continued

Appendix 3: Consent Form (English version)



The University Of Sheffield.

Participant Consent Form

Shared Decision Making in Saudi Arabia: Perceptions of Healthcare Stakeholders

Please tick the appropriate boxes	**Yes**	**No**
Taking Part in the Project		
I have read and understood the project information sheet (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 include a phone/ face to face interview. ☐ I understand that the interview will be audio recorded and transcribed	☐ ☐	☐ ☐
I understand that my taking part is voluntary and that I can withdraw from the study at any time; 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. However, once my data has been anonymised and included within a large dataset, my data cannot be removed from the study.	☐	☐
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 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 (my perspective on shared decision making) that I provide to be deposited in Sheffield University password protected drive 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:
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Appendix 4: Consent Form (Arabic version)

استمارة موافقة المشارك

مشاركة المريض في اتخاذ القرارات العلاجية في المملكة العربية السعودية تصورات أصحاب المصلحة الصحية

يرجى وضع علامة على المربعات المناسبة	نعم	لا
المشاركة في الدراسة		
لقد قرأت وفهمت ورقة معلومات الدراسة (إذا كنت تجيب ب"لا" لهذا السؤال يرجى عدم المضي قدما في نموذج الموافقة هذا حتى تكون على علم تام بما تعنيه مشاركتك في الدراسة.)	☐	☐
لقد أتيحت لي الفرصة لطرح أسئلة حول الدراسة.	☐	☐
☐ أوافق على المشاركة في الدراسة. وأفهم أن المشاركة في المشروع ستتضمن مقابلة وجها لوجه أو عن طريق الهاتف. ☐ أفهم أن المقابلة ستكون مسجلة صوتيا	☐ ☐	☐ ☐
أفهم أن مشاركتي تطوعية ويمكنني أن أنسحب من الدراسة في أي وقت ولست مضطرا لإعطاء أي أسباب لماذا لم أعد أرغب في المشاركة ولن تكون هناك عواقب إذا اخترت الانسحاب. ولكن عندما تصبح البيانات الخاصة بي مجهولة الاسم وضمنه ضمن مجموع بيانات كبيرة فلا يمكن إزالتها من الدراسة.	☐	☐
كيف سيتم استخدام المعلومات الخاصة بي أثناء الدراسة وبعدها		
أفهم أن التفاصيل الشخصية الخاصة بي مثل الاسم ورقم الهاتف والعنوان وعنوان البريد الإلكتروني الخ. لن يتم الكشف عنها للأشخاص خارج الدراسة.	☐	☐
أفهم وأوافق على أنه يمكن اقتباس كلماتي في المطبوعات والتقارير وصفحات الويب وغيرها من المخرجات البحثية. وأفهم أنه لن يتم ذكر اسمي في هذه المخرجات إلا إذا طلبت ذلك على وجه التحديد.	☐	☐
أفهم وأوافق على أن الباحثين المعتمدين الآخرين لن يحصلوا على هذه البيانات إلا إذا وافقوا على الحفاظ على سرية المعلومات على النحو المطلوب في هذا النموذج.	☐	☐
أفهم وأوافق على أن الباحثين المعتمدين الآخرين قد يستخدمون بياناتي في المنشورات والتقارير وصفحات الويب وغيرها من مخرجات البحث فقط إذا وافقوا على الحفاظ على سرية المعلومات على النحو المطلوب في هذا النموذج.	☐	☐
أعطي الإذن لوجهة نظري التي أقدمها حول (مشاركة المريض في اتخاذ القرارات العلاجية في المملكة العربية السعودية) لتودع في جامعة شفيلد بشكل آمن بحيث يمكن استخدامها للبحث والتعلم في المستقبل	☐	☐
بحيث يمكن استخدام المعلومات التي تقدمها بشكل قانوني من قبل الباحثين		
أوافق على تعيين حقوق الطبع والنشر في أي مساهمات تقدمت بها أو كجزء من هذا المشروع إلى جامعة شفيلد.	☐	☐

اسم المشارك [مطبوع]　　　　التوقيع　　　　التاريخ

اسم الباحث [مطبوع]　　　　التوقيع　　　　التاريخ

تفاصيل الاتصال بالمشروع لمزيد من المعلومات:
نوف السلمي
جامعة شفيلد
[رقم الجوال: 447853775736 +]
البريد الإلكتروني: naalsulamy1@sheffield.ac.uk

Appendix 5: Participants Information Sheet Form (English version)

Participant Information Sheet

1. Research Project Title:

Shared Decision Making in Saudi Arabia: Perceptions of Healthcare Stakeholders

2. Invitation paragraph

I would like to invite you to take part in a research study. Before you decide whether or not to participate, it is important to understand this sheet, which provides you with information about the study and what it involves. Please takes time to read it carefully and feel free to contact me with any questions you may have.

3. What is the project's purpose?

This research is part of a PhD study which aims to understand the various individually, cultural, environmental, and organisational barriers to SDM from the perspective of different health stakeholders, so as to understand the opportunities and measures required to implement SDM in Saudi Arabia.

4. Why have I been chosen?

The study aims to recruit a total of 30 participants aged 18 or above living in Saudi Arabia, including patient, physician, organization' head/manager. You are invited to take part in this study because I feel that your experience can contribute much to my understanding and knowledge of factors that hinder or facilitate the implementation of SDM.

5. Do I have to take part?

Taking part in this study is a voluntary and that you can withdraw from the study at any time; you do not have to give any reasons for why you are no longer want to take part, and there will be no adverse consequences if you choose to withdraw. However, once your data has been anonymised and included within a large dataset, your data cannot be removed from the study.

6. What will happen to me if I take part? What do I have to do?

Your decision to take part in the study will involve signing a consent form and speaking to me in a face to face/ telephone interview for about an hour or less if you prefer. I will ask you some open- end questions about SDM, and your perspective on facilitators of and barriers to its implementation in Saudi Arabia. The interview will be recorded with your permission.

7. What are the possible disadvantages and risks of taking part?

There are no obvious risks to take part in this study. However, once you want to stop the interview, you can withdraw at any point without giving a reason.

8. What are the possible benefits of taking part?

There is no direct benefit from taking part in this study; however, the information you provide will help to help highlight factors that hinder the implementation of shared decision making in Saudi Arabia, and to identify factors that facilitate its implementation.

9. Will my taking part in this project be kept confidential?

Your name will not be shared with the other participants in the study, and the information you provide will be protected and kept strictly confidential. Once collected, data will be transcribed and stored on a password-protected computer, and only the main researcher has access to the identifiable data. A numerical code will be assigned to each transcript, and all identifying information will be removed. Direct quotes, what you said in your own words, may be used in the write-up and possible publication of the study, but any information which could identify you (like your name, where you work etc.) will not be used. If you agree to share the information you provide with other researchers, your personal details will not be included unless you explicitly request this. The provided information will be kept for long term after the completion of the PhD project if it is found to be useful in answering future research questions.

10. What will happen to the results of the research project?

The results will be included in my PhD thesis, which will be submitted to the University of Sheffield for a PhD degree and may be published in academic journals.

11. Who is the Data Controller?

The University of Sheffield will act as the Data Controller for this project. This means that the University is responsible for looking after your information and using it properly.

12. Who has ethically reviewed the project?

This study is approved by Saudi Ministry of Health.

13. What if something goes wrong and I wish to complain about the research?

Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered can be addressed by contacting my supervisor Dr Andrew Lee or Dr Praveen Thokala using the contact details at the end of the information sheet. However, if you feel your complaint has not been handled to your satisfaction (e.g. by the Supervisor) that you can contact the dean of the School of Health and Related Research (ScHARR). If your complaint relates to how your personal data has been handled, you can contact Anne Cutler, The University of Sheffield Data Protection Officer.

14. Contact for further information

For further information please do not hesitate to contact me or my supervisors on the following addresses:

Nouf Alsulamy, PhD student – [University of Sheffield - Mobile Number: +447853775736 - Email: naalsulamy1@sheffield.ac.uk]
Supervisor: Dr Andrew Lee – [University of Sheffield- Tel.: (+44) (0) 114 2220872- Email: andrew.lee@sheffield.ac.uk]
Supervisor: Dr Praveen Thokala – [University of Sheffield- Tel.: (+44) (0) 1142220784- Email: p.thokala@sheffield.ac.uk]
Dean of School of Health and Related Research (ScHARR):
[Professor John E Brazier -Tel: (+44) (0)114 222 0726 Email: k.rooney@sheffield.ac.uk]
Data Protection Officer: Anne Cutler – [University of Sheffield- Tel.: (+44) (0) 1142221117- Email: A.Cutler@sheffield.ac.uk]

Thank you once again for taking the time to read this information.

Appendix 6: Participants Information Sheet Form (Arabic version)

ورقة المعلومات

1. عنوان مشروع البحث:

مشاركة المريض في اتخاذ القرارات الخطة العلاجية في المملكة العربية السعودية تصورات أصحاب المصلحة الصحية (أطباء، مرضى، مدراء)

2. فقرة الدعوة

أود أن أدعوك الى المشاركة في دراسة بحثية وقبل ان تتخذ قرارك في المشاركة او عدمها من المهم ان تفهم هذه الورقة التي توفر لك معلومات عن الدراسة وما تنطوي عليه. الرجاء اخذ الوقت الكافي لقراءتها بعناية وبإمكانك الاتصال بي عند الرغبة في الاستفسار.

3. ما هو الغرض من الدراسة؟

هذا البحث هو جزء من دراسة الدكتوراه التي تهدف الى معرفة الحواجز المعرفية والثقافية والمهنية والتنظيمية التي تواجه "مشاركة المريض في صنع الخطة العلاجية" من منظور أصحاب المصلحة الصحيين. وذلك من أجل فهم الفرص والتطوير اللازمة حول هذا التوجه في المملكة العربية السعودية

4. لماذا تم اختياري؟

تهدف الدراسة الى توظيف مجموع تقارب (٣٠) مشاركا بالغين من العمر (١٨) عاما أو أكثر، ويعيشون في المملكة العربية السعودية بما في ذلك المرضى، الأطباء، ورؤساء/مدراء المراكز الصحية. وأنت مدعو للمشاركة في هذه الدراسة لأن تجربتك وتوقعاتك يمكن ان تساهم كثيرا في فهم وجهة نظرك حول العوامل التي تعيق أو تساعد تطبيق "مشاركة المريض في صنع القرارات العلاجية".

5. هل يجب ان تشترك؟

المشاركة في هذه الدراسة هي تطوعية ويحق لك الانسحاب من الدراسة في اي وقت بدون تقديم أسبابك حول عدم رغبتك في الاستمرار، ولن يكون هناك أي عواقب إذا اخترت الانسحاب. ولكن عندما تصبح البيانات الخاصة بك مجهولة الاسم وضمن مجموع البيانات الكبيرة، فلا يمكن ازالتها من الدراسة.

6. ماذا سيحدث لي إذا شاركت؟ ماذا علي ان أفعل؟

سيتم بعد قرارك بالمشاركة في الدراسة التوقيع على استمارة الموافقة والتحدث معك في مقابلة وجها لوجه لمدة ساعة أو أقل، سأطرح عليك بعض الأسئلة المفتوحة حول "مشاركة المريض في القرارات العلاجية" ووجهة نظرك الشخصية عن التسهيلات والحواجز التي تعترض تطبيقها في المملكة العربية السعودية. وسيتم تسجيل المقابلة بإذن منك.

7. ما هي المساوئ المحتملة ومخاطر المشاركة؟

لا توجد مخاطر واضحة للمشاركة في هذه الدراسة. ومع ذلك بمجرد الرغبة في إيقاف المقابلة يحق لك الانسحاب في اي وقت دون إعطاء سبب.

8. ما هي الفوائد المحتملة من المشاركة؟

لا توجد فوائد مباشرة من المشاركة في هذه الدراسة؛ ومع ذلك فإن المعلومات التي تقدمها سوف تساعد في تسليط الضوء على العوامل التي تعيق تطبيق المشاركة في اتخاذ القرارات العلاجية في المملكة العربية السعودية وتحديد العوامل التي تساعد تطبيقها.

9. هل سيتم الحفاظ على سرية المشاركة في هذا المشروع؟

لن يتم مشاركة اسمك مع المشاركين الآخرين في الدراسة وسيتم حماية المعلومات التي تقدمها والحفاظ على سريتها التامة. وبمجرد جمع البيانات سيتم نسخها وتخزينها على جهاز كمبيوتر محمي بكلمة مرور فقط الباحث الرئيسي يمكنه الوصول الى البيانات القابلة للتعريف. سيتم تعيين رمز لكل نسخة وسيتم إزالة جميع المعلومات التعريفية. الاقتباسات المباشرة من المناقشة يمكن استخدامها في كتابة هذه الدراسة والتقرير المستقبلي لها، اي معلومات أخرى من الممكن ان يتم تحديدك من خلالها (مثل الاسم، عنوان العمل الخ) لن يتم استخدامها. إذا وافقت على ان تشارك المعلومات التي تقدمها لي مع باحثين آخرين (لن يتضمن ذلك بياناتك الشخصية) فإذا طلبت ذلك سيتم الاحتفاظ بالمعلومات المقدمة لفترة طويلة بعد الانتهاء من مشروع الدكتوراه إلا انه لن يتم تعريفك فيها في الحالة على الورقة البحثية المستقبلية.

10. ما الذي سيحدث لنتائج المشروع البحثي؟

سيتم تضمين النتائج في أطروحة الدكتوراه، التي سيتم تقديمها الى جامعة شفيلد للحصول على درجة الدكتوراه ويمكن نشرها في المجلات الأكاديمية.

11. من هو مراقب البيانات؟

ستعمل جامعة شفيلد كمراقب على البيانات لهذا المشروع. وهذا يعني ان الجامعة هي المسؤولة عن الحفاظ على المعلومات الخاصة بك واستخدامها بشكل صحيح.

12. من الذي قام بمراجعة أخلاقية المشروع؟

تمت الموافقة على هذه الدراسة من قبل وزارة الصحة السعودية.

13. ماذا لو حدث خطأ ما ورغبت في ان اقدم شكوى؟

اي شكوى حول الطريقة التي تم التعامل بها اثناء الدراسة أو اي ضرر قد تعاني منه يمكن معالجته عن طريق الاتصال بالمشرف الخاص بي الدكتور (اندرو لي) أو الدكتور (برافين توكالا) باستخدام تفاصيل الاتصال المبينة في نهاية هذه الورقة. ومع ذلك، إذا شعرت بأن شكواك لم يتم التعامل معها بشكل جيد (على مستوى الاتصال من قبل المشرف) يمكنك الاتصال بعميد كلية الصحة والأبحاث. إذا كانت شكواك تتعلق بكيفية معالجة بياناتك الشخصية يمكنك الاتصال بآن كاتلر، مسؤول حماية البيانات في جامعة شفيلد.

14. معلومات الاتصال

لمزيد من المعلومات يرجى عدم التردد في الاتصال بي أو بالمشرفين على العناوين التالية:

نوف السلمي، طالب دكتوراه - [جامعة شفيلد- رقم الجوال: 447853775736 +] البريد الالكتروني: naalsulamy1@sheffield.ac.uk]
المشرف: الدكتور اندرو لي – [جامعة شفيلد- البريد الالكتروني: andrew.lee@sheffield.ac.uk]
المشرف: الدكتور برافين توكالا – [جامعة شفيلد- البريد الالكتروني: p.thokala@sheffield.ac.uk]
عميد كلية الصحة والأبحاث: البروفيسور جون اي- [جامعة شفيلد- البريد الالكتروني: k.rooney@sheffield.ac.uk]
مسؤول حماية البيانات: آن كاتلر- [جامعة شفيلد- البريد الالكتروني: A.Cutler@sheffield.ac.uk]

شكرا لكم مره أخرى لأخذ الوقت لقراءة هذه المعلومات

Appendix 7: Interview Topic Guide for Patients (English version)

Semi-structured interview guide

Patients

Introduction

☐ Introduction about the interviewer

☐ Clarify ethical implications, confidentiality, and consent: to ensure that participants have read and signed the consent form, to emphasise the confidentiality of the data manner, and to remind them they can stop at any point without negative consequence.

☐ Background of the study

☐ Information about the interview

☐ Participants' demographic information: age, level of education, gender, and health condition.

1. **Can you tell me how to choose your treatment plan with your physician?**
   Does the physician explain to you the nature of the disease? How?
   Does the physician offer you options for your treatment? Advantages and disadvantages of each option?
2. **Have you heard about patient SDM?**
   ☐ Depending on response:
   If yes: could you please explain what it is?
   If no or give a different meaning: the interviewer will give participants an explanation of it.
3. **Would you like to have information about the available treatment options?**
4. **Would you like to discuss your treatment options with your physician before choosing a treatment?**
5. **What do you think about SDM? Why**
6. **In your opinion, what is the ideal way to make a treatment decision? to assess the decision-making model that is preferable by participants (e.g., shared, paternalism, etc)**
7. **What do you know about your rights in receiving full information about your condition or choosing treatment? If the answer is yes, from where you know?**
8. **Can you tell me some of the reasons that hinder you from participating in decision making?**
   Probe:

- Patients

  Do you think patients prefer to make decisions by themselves or leave decisions to others (physicians, family, friends)?

  Depending on the response:

  What type of patients who prefer to make their decisions by themselves?

  What type of patients who prefer to leave their decisions for others?

  How much do you prefer to involve your family in the decision making? why?
- Professional factors

  Do you get enough information related to your health condition and treatment options from your physician?

  Have you followed up with several physicians or only one? Why?

  Depending on the answer:
  - How would you describe your relationship with your physician?
  - Do you trust your physician decisions?
  - Was there a difference between physicians you have met? what is it?

  Do you think physicians prefer to make decisions by themselves or share decisions with their patients? Why?
- Environmental factors

  Resources

9. **Can you tell me what would encourage you to involve in the process of decision making?**
10. **What is your recommendation if we want to facilitate the implementation of SDM in Saudi Arabia?**
11. **Is there anything else about SDM that we have not discuss and you want to add?**

Appendix 8: Interview Topic Guide for Patients (Arabic version)

الدليل التوجيهي للمقابلة

للمرضى

مقدمة

- ☐ مقدمة عن مجري المقابلة
- ☐ توضيح الاعتبارات الأخلاقية والسرية والموافقة للتأكد من أن المشاركين قد قرأوا ووقعوا استمارة الموافقة، التأكيد على سرية المعلومات، والتذكير بأنهم يستطيعون التوقف عند اي نقطه دون الحاجة لتبرير ذلك.
- ☐ معلومات أساسية عن الدراسة
- ☐ معلومات عن المقابلة
- ☐ مقدمة عن المشارك: العمر، مستوى التعليم، الجنس، الحالة الصحية .

1 . أخبرني كيف يتم اختيار خطتك العلاجية مع طبيبك؟

- ☐ هل يشرح الطبيب لك طبيعة المرض؟ كيف؟
- ☐ هل يقدم لك خيارات العلاج كفوائد و مضار لكل خيار؟

2 . هل سمعت عن مشاركة المريض في القرارات/الخطة العلاجية؟

- ☐ اعتمادا على الإجابة:

إذا كانت الإجابة بنعم: هل يمكنك توضيح ما هي مشاركة المريض في القرارات العلاجية؟

إذا لم يكن يعرف أو أعطى معنى مختلف: مجري المقابلة سوف يعطي المشاركين تعريف لمشاركة المريض في اتخاذ القرارات العلاجية.

3 . هل ترغب في الحصول على معلومات كافية عن الخيارات العلاجية المتاحة؟

4 . هل ترغب في مناقشة الخيارات المتاحة مع طبيبك قبل اختيار العلاج؟

5 . ما هو رأيك في مشاركة المريض في القرارات العلاجية؟ لماذا؟

6 في رأيك، كيف ستكون الصورة المثالية لمشاركة المريض في الخطة العلاجية؟ ما هو نموذج اتخاذ القرارات الذي يفضله المشاركون (على سبيل المثال، النمط المشارك، النمط الأبوي، وما إلى ذلك)

7 . ماذا تعرف عن حقك في تلقي المعلومات الكاملة عن حالتك الصحية أو اختيار العلاج؟ من أين تعرف ذلك؟

8 . هل من الممكن أن تخبرني ببعض الأسباب التي تعوقك عن مشاركتك طبيبك في القرارات العلاجية؟

التحقيق:

- ☐ عوامل تتعلق بالمرضى

هل تعتقد ان المرضى يفضلون اتخاذ القرارات بأنفسهم أو تركه للغير (طبيب، اسرة، أصدقاء)؟

اعتمادا على الإجابة:

من هم المرضى الذين يفضلون اتخاذ قراراتهم بأنفسهم؟

من هم المرضى الذين يفضلون ترك قراراتهم للغير؟

إلى أي مدى تفضل أن تشارك عائلتك في قراراتك العلاجية؟ لماذا؟

- ☐ عوامل تتعلق بالمهنيين الصحيين

هل تحصل على المعلومات الكافية المتعلقة بحالتك الصحية وعلاجها من قبل الطبيب؟

هل زرت عدة أطباء ام طبيب واحد؟ لماذا؟

اعتمادا على التجربة:

كيف تصف علاقتك مع طبيبك؟

هل تثق بقرارات طبيبك؟

هل هناك اختلاف بين الأطباء الذين تمت رؤيتهم؟ ما هي؟

هل تعتقد ان الأطباء يفضلون اتخاذ القرارات بأنفسهم أو مشاركة القرارات مع مرضاهم؟ لماذا؟

☐ <u>العوامل البيئية</u>

الموارد

☐. هل من الممكن أن تخبرني ببعض الأشياء التي من الممكن ان تشجعك على المشاركة في اتخاذ القرارات العلاجية؟

☐☐. ما هي تصوراتك أو انطباعك حول اعتماد مشاركة المريض في اتخاذ القرارات العلاجية في المملكة العربية السعودية

☐☐. هل هناك اي شيء عن نهج "مشاركة المريض في اتخاذ القرارات العلاجية لم نتحدث عنه وترغب في مناقشته؟

Appendix 9: Interview Topic Guide for Physicians (English version)

Semi-structured interview guide for physicians

Introduction

- Introduction about the interviewer
- Clarify ethical implications, confidentiality, and consent: to ensure that participants have read and signed the consent form, to emphasise the confidentiality of the data manner, and to remind them they can stop at any point without negative consequence.
- Background of the study
- Information about the interview
- Participants' demographic information: age, gender, years of experience, speciality/ position.

1. **Can you tell me how can physicians share the treatment plan with their patients?**
   Do you explain the nature of the disease to your patient? How?
   Do you offer treatment options to the patient? Explain the benefits and harms of each option?
2. **Have you heard about SDM?**
   - Depending on response:
     If yes: could you please explain what SDM is?
     If no or gives a different meaning: the interviewer will give participants an explanation of SDM.
3. **Do you use any decision tools to involve patients in the decision-making process? What?**
4. **Have you taken any training or courses that are related to SDM? if the answer is yes, where? (e.g., the organization you work in, school, etc)**
5. **What do you think about SDM? Why?**
6. **In your opinion, what would an ideal SDM look like?** to assess the decision-making model that is preferable by participants (e.g., shared, paternalism, etc)
7. **Can you tell me what hinders the implementation of SDM?**
   Probe:
   - Patients/family factors
     Do patients prefer to have information about the available treatment options?
     Do patients prefer to discuss their treatment options with their physician before choosing a treatment?

From your experience, do patients prefer to make decisions by themselves or leave decisions to others (doctor, family, friends)?

Depending on response:

What type of patients who prefer to make their decisions by themselves?

What type of patients who prefer to leave their decisions for others?

To what extent patients prefer to involve their family in decision making? why?

- Professional factors

  Do you think physicians prefer to make decisions by themselves or share decisions with their patients? Why?

  How you describe your relationship with your patients?

  Do your patients trust your decisions?

- Environmental factors

  Resources

  Policies at local (organizations) and national level

8. **What would encourage you to use SDM?**
9. **What is your recommendation if we want to facilitate the implementation of SDM in Saudi Arabia?**

   Probe: requirements for SDM
10. **Is there anything that you want to add?**

Appendix 10: Interview Topic Guide for Physicians (Arabic version)

دليل المقابلة شبه المنظمة مع الأطباء

مقدمة

- ☐ مقدمة عن مجري المقابلة
- ☐ توضيح الاعتبارات الأخلاقية والسرية والموافقة. التأكد من أن المشاركين قد قرأوا ووقعوا استمارة الموافقة. التأكيد على سرية المعلومات، والتذكير بمبدأ حق المجيب في التوقف عند أي نقطة دون الحاجة لتبرير ذلك.
- ☐ معلومات أساسيه عن الدراسة
- ☐ معلومات عن المقابلة
- ☐ مقدمة عن المشارك: العمر، الجنس، سنوات الخبرة، التخصص / الوظيفة، نوع المستشفى

☐. أخبرني كيف في رأيك يمكن للطبيب مشاركة المريض في القرارات/الخطة العلاجية؟

- ☐ هل تشرح طبيعة المرض للمريض؟ كيف؟
- ☐ هل تقدم خيارات علاجية للمريض؟ تشرح فوائد ومضار كل خيار؟

☐. هل سمعت عن مشاركة المريض في الخطة العلاجية؟

اعتمادا على الإجابة:

إذا كانت الإجابة نعم:

- ☐ هل يمكنك توضيح ما هي مشاركة المريض في اتخاذ القرارات العلاجية؟

إذا لم يكن يعرف أو أعطى معنى مختلف: مجري المقابلة سوف يعطي المشاركين تعريف لمشاركة المريض في اتخاذ القرارات الطبية.

☐. هل تستخدم نموذج أو أداة تساعد على إشراك المريض في القرارات العلاجية؟ ما هي؟

☐. هل أخذت أي تدريب أو دورات مرتبطة بمشاركة المريض في اتخاذ القرارات العلاجية؟ إذا كان الجواب بنعم، أين؟ (على سبيل المثال، المنظمة التي تعمل فيها، الجامعة، الخ)

☐. ما هو رأيك في "مشاركة المريض في القرارات العلاجية"؟ لماذا؟

☐في رأيك، كيف ستكون الصورة المثالية لمشاركة المريض في الخطة العلاجية؟ وما هو نموذج اتخاذ القرارات الذي يفضله المشاركون (على سبيل المثال، النمط التشاركي، النمط الأبوي، وما إلى ذلك)

☐. هل من الممكن أن تخبرني ما هي الأسباب التي تعيق مشاركة المريض في القرارات العلاجية؟

التحقيق:

- ☐ <u>عوامل تتعلق بالمرضى</u>

هل يرغب المريض في الحصول على معلومات عن الخيارات العلاجية المتاحة؟

هل يرغب المريض في مناقشة الخيارات المتاحة مع طبيبه قبل اختيار العلاج؟

هل تعتقد ان المرضى يفضلون اتخاذ القرارات بأنفسهم أم ترك القرار للغير (طبيب، الأسرة، أصدقاء)؟

اعتمادا على الإجابة:

من هم المرضى الذين يفضلون اتخاذ قراراتهم بأنفسهم؟

من هم المرضى الذين يفضلون ترك قرارهم لطبيبهم؟

إلى أي مدى تفضل أن تشارك عائلة المريض في الخطة العلاجية؟ لماذا؟

- ☐ عوامل تتعلق بالمهنيين الصحيين

هل تعتقد أن الأطباء يفضلون اتخاذ القرارات بأنفسهم أو مشاركة القرارات مع مرضاهم؟ لماذا؟

كيف تصف علاقتك مع مرضاك؟

هل يثق مرضاك في قراراتك العلاجية؟

- ☐ <u>العوامل البيئية</u>

الموارد

السياسات على الصعيد المحلي (المنظمات) والوطني

☐. هل من الممكن أن تخبرني ببعض الأشياء التي من الممكن أن تشجعك على أن تشارك المريض في اتخاذ القرارات العلاجية؟

☐. هل هناك أي شيء حول نهج "مشاركة المريض في اتخاذ القرارات العلاجية" لم يتم مناقشته وترغب في إضافته؟

Appendix 11: Interview Topic Guide for Managers (English version)

Semi-structured interview guide for managers

Introduction

- ☐ Introduction about the interviewer
- ☐ Clarify ethical implications, confidentiality, and consent: to ensure that participants have read and signed the consent form, to emphasise the confidentiality of the data manner, and to remind them they can stop at any point without negative consequence.
- ☐ Background of the study
- ☐ Information about the interview
- ☐ Participants' demographic information: age, gender, years of experience, speciality/ position.

1. **Can you tell me how can physicians share the treatment plan with their patients?**

Do they explain the nature of the disease to the patient? How?

Do they offer treatment options to the patient? Explain the benefits and harms of each option?

2. **Have you heard about SDM?**
   - ☐ Depending on response:
     If yes: could you please explain what SDM is?
     If no or gives a different meaning: the interviewer will give participants an explanation of SDM.
3. **Do you use any decision tools to involve patients in the decision-making process? What?**
4. **Do you provide any training or courses that are related to SDM? if the answer is yes, where?**
5. **What do you think about SDM? Why?**
6. **In your opinion, what would an ideal SDM look like?** to assess the decision-making model that is preferable by participants (e.g., shared, paternalism, etc)
7. **Can you tell me what hinders the implementation of SDM?**
   Probe:
   - ☐ Patients/family factors
     From your experience, do patients prefer to make decisions by themselves or leave decisions to others (doctor, family, friends)?

Depending on response:

What type of patients who prefer to make their decisions by themselves?

What type of patients who prefer to leave their decisions for their physicians?

To what extent patients prefer to involve their family in decision making? why?

- Professional factors

  Do you think physicians prefer to make decisions by themselves or share decisions with their patients? Why?

- Environmental factors

  Resources

  Policies at local (organizations) and national level

8. **What would encourage you to implement SDM in your organization?**
9. **What is your recommendation if we want to facilitate the implementation of SDM in Saudi Arabia?**

   Probe: requirements for SDM
10. **Is there anything that you want to add?**

Appendix 12: Interview Topic Guide for Managers (Arabic version)

دليل المقابلة شبه المنظمة مع المدراء

مقدمة

- ☐ مقدمة عن مجري المقابلة
- ☐ توضيح الاعتبارات الأخلاقية والسرية والموافقة للتأكد من أن المشاركين قد قرأوا ووقعوا استمارة الموافقة، والتأكيد على سرية المعلومات، والتذكير بأنهم يستطيعون التوقف عند اي نقطة دون تقديم تبرير لذلك.
- ☐ معلومات أساسية عن الدراسة
- ☐ معلومات عن المقابلة
- ☐ مقدمة عن المشارك: العمر، الجنس، سنوات الخبرة، التخصص / الوظيفة، نوع المستشفى

☐. أخبرني كيف يمكن للطبيب مشاركة المريض في الخطة العلاجية؟

- ☐ هل يشرح طبيعة المرض للمريض؟
- ☐ هل يقدم خيارات علاجية للمريض ويشرح فوائد ومضار كل خيار؟

☐. هل سمعت عن مشاركة المريض في الخطة العلاجية؟

اعتمادا على الإجابة:

إذا كانت الإجابة نعم:

- ☐ هل يمكنك توضيح ما هي مشاركة المريض في اتخاذ القرارات العلاجية؟
- ☐ هل يتم استخدام نموذج أو أداة تساعد على إشراك المريض في القرارات العلاجية؟ ما هي؟
- ☐ إذا لم يكن يعرف أو أعطى معنى مختلف: مجري المقابلة سوف يعطي المشاركين تعريف مشاركة المريض في اتخاذ القرارات الطبية: هي عملية تعاونية تنطوي على المريض والطبيب في توضيح الحالة الصحية ومناقشة خيارات العلاج مع فوائد ومضار كل خيار (وتبادل المعلومات حول تفضيلات المريض، لاتخاذ قرار طبي مشترك يأخذ بالاعتبار تفضيلات المريض.

☐. هل تستخدمون نموذج أو أداة تساعد على إشراك المريض في القرارات العلاجية؟ ما هي؟

☐. هل يتم تقديم أي تدريب أو دورات حول تطبيق مشاركة المريض في اتخاذ القرارات الطبية؟ إذا كان الجواب نعم، أين؟

☐. ما هو رأيك في "مشاركة المريض في القرارات العلاجية"؟ لماذا؟

☐في رأيك، كيف ستكون الصورة المثالية لمشاركة المريض في الخطة العلاجية؟ ما هو نموذج اتخاذ القرارات الذي يفضله المشاركون (على سبيل المثال، النمط المشارك، النمط الأبوي، وما إلى ذلك)

☐. هل من الممكن أن تخبرني ببعض الأسباب التي تعيق الطبيب عن مشاركة المريض في القرارات العلاجية؟

التحقيق:

- ☐ <u>عوامل تتعلق بالمرضى</u>

هل تعتقد ان المرضى يفضلون اتخاذ القرارات بأنفسهم أو ترك قرارهم للغير (طبيب، اسرة، أصدقاء)؟

اعتمادا على الإجابة:

من هم المرضى الذين يفضلون اتخاذ قرارهم بأنفسهم؟

من هم المرضى الذين يفضلون ترك قرارهم للغير؟

- عوامل تتعلق بالمهنيين الصحيين

  هل تعتقد ان الأطباء يفضلون اتخاذ القرارات بأنفسهم أو مشاركة القرارات مع مرضاهم لماذا؟

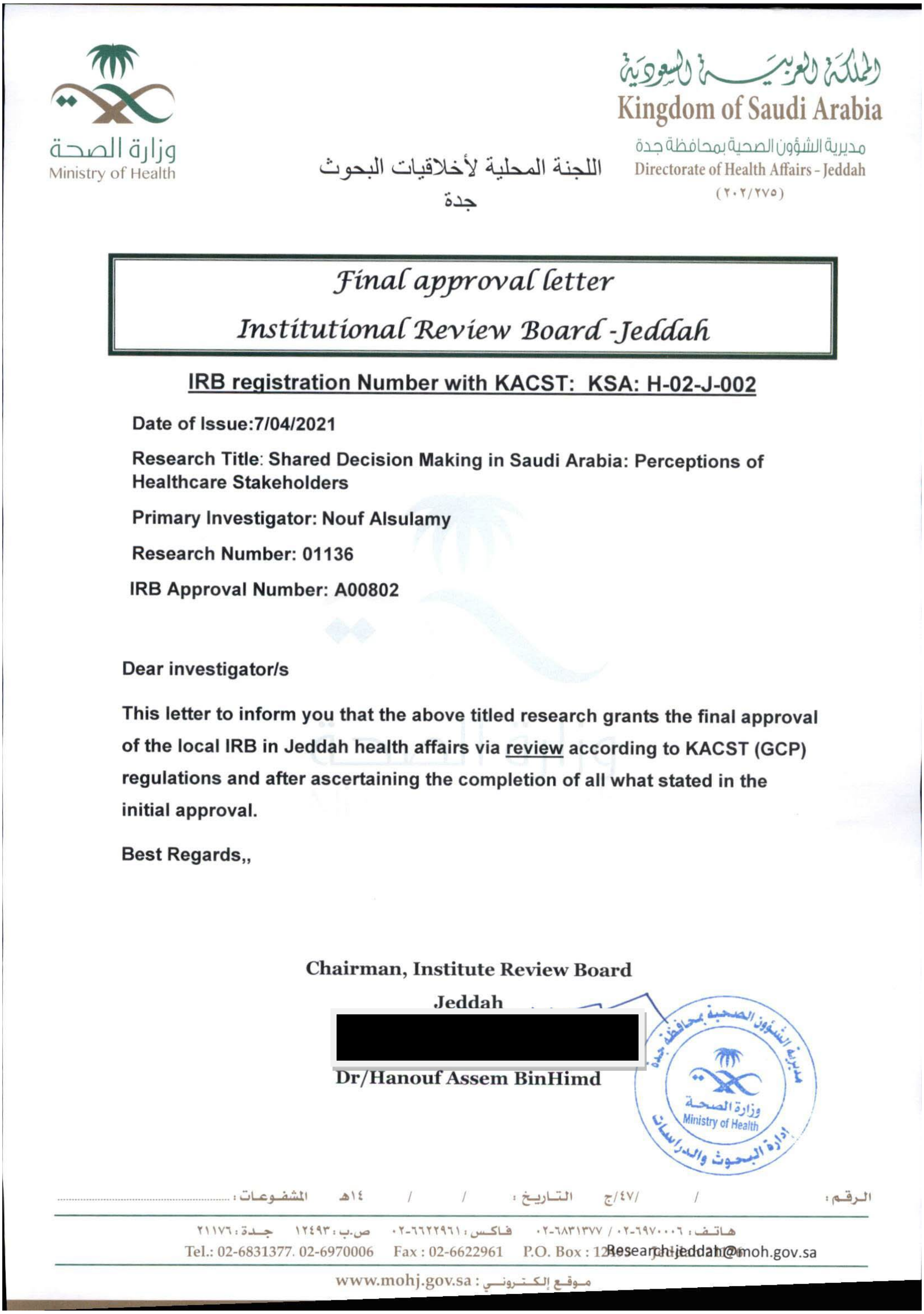
- العوامل البيئية

  الموارد

  السياسات على الصعيد المحلي (المنظمات) والوطني

- **هل من الممكن أن تخبرني ببعض الأشياء التي تشجع على مشاركة المريض في اتخاذ القرارات العلاجية؟**
- **هل هناك اي شيء حول نهج "مشاركة المريض في اتخاذ القرارات العلاجية" لم تتم مناقشته وترغب في إضافته؟**

Appendix 13: MOH Ethical Approval



وزارة الصحة
Ministry of Health

المملكة العربية السعودية
Kingdom of Saudi Arabia
مديرية الشؤون الصحية بمحافظة جدة
Directorate of Health Affairs - Jeddah
(٢٠٢/٢٧٥)

اللجنة المحلية لأخلاقيات البحوث
جدة

Final approval letter
Institutional Review Board -Jeddah

IRB registration Number with KACST: KSA: H-02-J-002

Date of Issue:7/04/2021

Research Title: Shared Decision Making in Saudi Arabia: Perceptions of Healthcare Stakeholders

Primary Investigator: Nouf Alsulamy

Research Number: 01136

IRB Approval Number: A00802

Dear investigator/s

This letter to inform you that the above titled research grants the final approval of the local IRB in Jeddah health affairs via review according to KACST (GCP) regulations and after ascertaining the completion of all what stated in the initial approval.

Best Regards,,

Chairman, Institute Review Board
Jeddah

[redacted]

Dr/Hanouf Assem BinHimd

إدارة البحوث والدراسات

الرقم : / /٤٧/ج التاريخ : / / ١٤هـ المشفوعات : ....

Appendix 14: Contribution Statements

Contribution Statements

Paper	Title	Publication status
Paper 1	What Influences the Implementation of Shared Decision Making: An Umbrella Review	Published
Paper 2	Views of stakeholders on factors influencing shared decision-making in the Eastern Mediterranean Region: a systematic review	Published
Paper 3	Shared decision-making in primary healthcare centres in Saudi Arabia: the perspectives of patients with diabetes	Under review
Paper 4	Healthcare professionals' views on factors influencing shared decision-making in Primary Health Care Centres in Saudi Arabia	Under review

Student contribution to the papers

Student contribution to the papers The PhD student developed the studies protocol/methods, collected and analysed the data and drafted the final manuscripts. Supervisors (Dr Andrew Lee and Dr Praveen Thokala) reviewed and contributed to the protocol and manuscripts.

Student/author's name	**Signature**
Nouf Alsulamy.	[redacted]

Co-author's name
Andrew Lee, Praveen Thokala, and Tourkiah Alessa.

Co-author's statement

I hereby declare that I am aware of the mentioned above works of which I am Co-author will form part of PhD dissertation by PhD student Nouf Alsulamy who made the major contribution to the work mentioned above.

Supervisor confirmation

I have sighted email or other correspondence from all Co-authors confirming their certifying authorship.

Name	**Signature**	**Date**
Andrew Lee	[redacted]	7/7/21