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# **Baby boomer women, Type 2 diabetes and sexual health discussions in primary care: An interpretative phenomenological analysis**

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## **Abstract**

The current cohort of older adults with the UK is primarily comprised of the baby boomers, people born between the mid-1940s and the mid-1960s. This cohort came of age at a time when attitudes towards sexuality were changing. Type 2 diabetes (T2D), one of the most prevalent chronic diseases in older adults, is known to impact on sexual health and well-being (SHW). Research shows that SHW is important throughout the lifespan but that it is an area often omitted in consultations between older adults and primary care healthcare professionals (HCP). A lack of discussions in primary care may lead to poor quality of life and health outcomes. A scoping review of the literature revealed a paucity of research exploring the SHW communication of baby boomer women living with T2D. Therefore, the thesis aim was to undertake an in-depth exploration of baby boomer women's (living with T2D) experiences of SHW discussions in primary care.

Ten in-depth qualitative interviews with women aged between 50 and 83 years living with T2D were undertaken. Interviews were conducted between August 2016 and March 2017. Data were analysed using an interpretative phenomenological analysis (IPA) approach.

Three superordinate themes were developed: patient-HCP relationship, sense of control over SHW and healthcare, and situating SHW within women's lives. Several barriers and facilitators to SHW discussions in primary care were identified. The gender and profession (GP or practice nurse) of the HCP were important to women, as was having HCPs that listened. Within consultations, the women's sense of control influenced their approach to discussing SHW. Upbringing and social norms also influenced the SHW issues that women addressed within consultations.

Through detailed exploration of the thesis findings and knowledge exchange activities, contributions to knowledge and implications for the primary health care of baby boomer women living with T2D were identified.



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## Abbreviations

For ease of reference, I have provided a list of the abbreviations used within this thesis. Abbreviations are also written in full the first time that they appear in each chapter.

BAME	black, Asian and minority ethnic
DoH	Department of Health
ELSA	English Longitudinal Study on Ageing
FSD	Female Sexual Dysfunction
FSFI	Female Sexual Function Index
GP	General Practitioner
HCP	Healthcare Professional
HIV	Human Immunodeficiency Disease
HRT	Hormone Replacement Therapy
ICD	International Classification of Diseases
IPA	Interpretative Phenomenological Analysis
NATSAL	National Survey of Sexual Attitudes and Lifestyles
NHS	National Health Service
PLISSIT	Permission, Limited Information, Specific Suggestions and Intensive Therapy
QOF	Quality and Outcomes Framework
SHW	Sexual health and well-being
STI	Sexually Transmitted Infections
T1D	Type 1 diabetes
T2D	Type 2 diabetes
WHO	World Health Organisation





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## **Thesis structure**

This thesis begins with a Preface, in which I briefly introduce myself to the reader. Within the Preface, I discuss my decision to embark upon research in the area of older adults and sexual health and well-being (SHW) and emphasise the centrality of reflexivity to this thesis.

Chapter One provides contextual background for the thesis through the exploration of relevant issues around the topic of older women, SHW and Type 2 diabetes (T2D). This chapter is intentionally extensive because while there is literature on older women and SHW, older women with T2D, SHW and T2D, few articles include a combination of older women T2D and their experiences of SHW. The research that does include a combination of these aspects is included in Chapter Two.

Chapter Two contains a scoping review of the literature. It provides a description of the methods used to select, review and critique the ten studies and one literature review included in the scoping review. The research aim and questions that developed as a result of the review are stated at the end of the chapter.

Chapter Three provides a description of IPA and a justification for adopting this methodological approach for the thesis. I rationalise my decision to adopt an IPA approach through an exploration of the qualitative research paradigm, phenomenology, and engaging with literature pertaining to the strengths and limitations of IPA. Reasons for the rejection of other research methodologies are also discussed within this chapter.

Chapter Four presents the description and justification of the methods used to collect and analyse the data. I describe the study sample, recruitment, interview setting, and data collection. Within this chapter, ethical considerations are also provided.

The Preface to the Findings chapter provides women's understandings of key terms used within the Findings chapter which it precedes. These are provided to clarify what is intended by the terms 'intimate partner and intimate relationships', 'sexual activity'



and 'sexual health and well-being' when they are used in relation to participants' account in Chapter Five.

Chapter Five focusses on the findings developed through the analysis of the data. The superordinate themes that were developed are included within this chapter, these are: patient-healthcare professional relationship, sense of control over sexual health and well-being and healthcare; and situating SHW within women's lives

Chapter Six discusses the thesis findings in light of existing research and theories, and states the theoretical and methodological contributions to knowledge that this thesis makes. To conclude this chapter, a synopsis of the barriers and facilitators to SHW discussions is provided.

Chapter Seven reflects on the implications of the thesis findings for primary care practice and research. Several knowledge exchange activities were organised to disseminate the research and obtain feedback from relevant stakeholders, primarily older adults and HCPs. I discuss how these activities contribute to the implications for primary care practice.

Chapter Eight regards the thesis strengths and limitations. I consider the thesis quality and reflect on each stage of thesis development, including power imbalances within interview settings and discussion around my interpretation of the data. At the end of this chapter, the thesis is concluded with a critical reflection on my theoretical position.

## **PREFACE**

My decision to undertake a PhD in the area of older adults and sexual health was born of my belief that all humans have a right to consensual, pleasurable and safe sex regardless of gender, disability and age. The thesis that you are about to read has the participants' thoughts, beliefs and experiences at its core, however my epistemological position is that we make sense of what we see through our own experiences. Therefore, within this thesis, the women's lived experiences are being shown to you through the lens of my own experiences. For this reason, I briefly introduce myself below.

I qualified as an adult nurse in 2008 and then moved to Spain where I volunteered in a non-governmental organisation, testing people for sexually transmitted infections (STIs). Later, I worked as a safe sex health advisor to teenagers within schools. During this period, I saw that recognition of the sexual activity of individuals from different cultures and genders was acknowledged but that ageism was rife. I feel that this experience taught me a lot about sexual activity throughout the life span even though training that I undertook and the majority of the health promotion material available was focussed on STI prevention in younger adults. Omission of material focussed on holistic sexual health and well-being (SHW) and older adults shaped my desire to undertake a thesis in this area.

The decision to investigate the topic of older women living with Type 2 diabetes (T2D) came later, primarily due to a gap in the literature (which I discuss in Chapters One and Two) but also due to my personal characteristics and beliefs. In the reflexivity section in Chapter Eight – Strengths, limitations and reflexivity, I consider how my identity (female, black British, 32 years of age, feminist, nurse, mother) influenced the recruitment, data collection and data analysis phases of thesis development. My belief and experience, aligning with an interpretative phenomenological approach, is that reflexivity has been present throughout the thesis development and writing process. Both the current Preface and the latter reflexivity section have been included to

elucidate the research design process, the interpretations of participant accounts and, to enhance the quality of the thesis overall.

# **CHAPTER ONE – BACKGROUND**

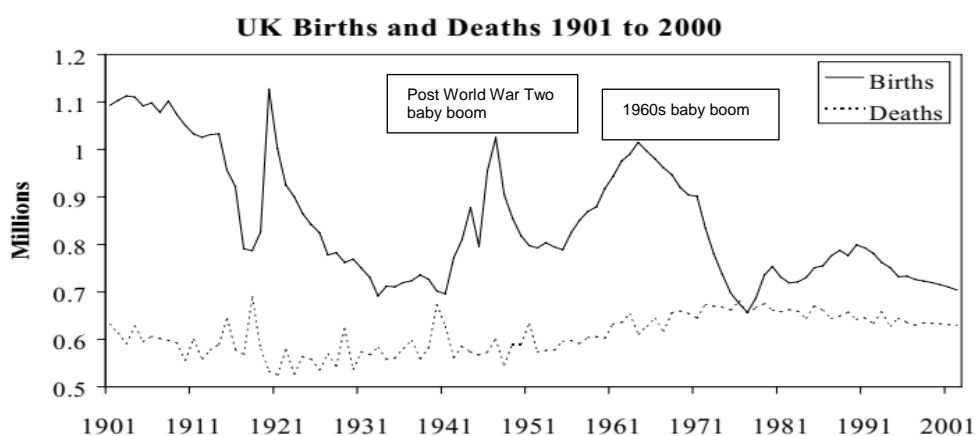
## **Introduction**

This chapter explores the social context in which ageing, and sexual health and well-being (SHW) are situated. I discuss why this thesis is necessary and why now. Key terms that are used throughout this thesis are provided. These terms include older adults, baby boomers, SHW and Type 2 diabetes (T2D). As well as defining these key terms, I discuss existing literature in these areas and begin to highlight knowledge gaps in regards to the SHW and SHW care of older women living with T2D. Throughout the following text, I draw attention to the way in which the adoption of an interpretative phenomenological analysis (IPA) approach within this thesis will enable me to bridge the knowledge gaps identified. Within this first chapter, a summary of the extant literature in the area is drawn together, providing important context and rationale for the thesis, before moving to the scoping review of the literature in the next chapter.

## **1.1 Older adults and the baby boomer generation**

Currently within the United Kingdom (UK), there are more than 12.2 million people over the age of 65 (Office for National Statistics 2018). However, no universally accepted definition of 'older' exists due to life expectancy differences between countries. Many studies based in high income countries define 65 years of age as 'older' due to this being the age most commonly associated with retirement and the start of a new life stage (Age UK 2018; WHO 2014). Within SHW research, the term 'older' tends to refer to those over 50 (Department of Health 2001b; Gott & Hinchliff 2003b) or even 40 (Dyer & das Nair 2013). However, the term 'older' is potentially problematic. Its use begs the question, older than who? This concern is alluded to by Gilleard & Higgs (2000) who avoid the term 'old age', preferring instead to write about 'ageing'. Yet, it is easy to criticise the term 'older' but difficult to find an alternative. One option is to refer to individual's birth cohort. Research referring to 'older' adults often includes the baby boomer generation. There are various definitions of the baby boomer generation but it generally refers to the surge in birth rates that occurred in Western countries after the Second World War (Bristow 2015; House of Commons Library Research 2010).

**Figure 1 - UK births and deaths 1901 to 2000**



House of Commons Library Research (1999)

Figure 1 illustrates the increased birth rates that occurred during the mid-1940s and mid-1960s in the UK. There has been debate around the fact that there were two baby booms in the UK (evident in the two spikes in Figure 1) and literature pertaining to the baby boomers varies in the definition of age ranges. In some research, baby boomers are considered those born between 1945-1955 (Woodsprings 2016) and in other research baby boomers refers to those born between 1946-1964 (Schofield & Beard 2005). Other research invokes more fluid boundaries defining baby boomers as those aged 55 years and older (Duncan et al. 2010). Within this thesis, I intended to recruit adults born between 1946 and 1964, which is why the inclusion criteria focussed on women aged between 50 and 75 years (see Chapter Four – Methods). The main reason that I chose to target a slightly wider cohort than some other studies is that I believe that barriers between generations are fluid (Mannheim 1970). I accept that while people born around the same period may have commonalities in their social experiences, great variation also exists in their lives in regards to personal or cultural experiences. A focus on the diversity of lived experience is a key tenet of the thesis and through the IPA approach, the intention is to create understanding of how experiences are understood for individuals. However, I loosely adhere to the concept of a generation throughout this thesis both in its natural and social sense. In its natural sense, a generation is usually considered to be approximately 30 years, to

encapsulate the period of time when children are prepared to replace their parents (Bristow 2015). In its social sense, a generation is defined as "...all of the people born and living at about the same time, regarded collectively" (English Oxford Living Dictionary 2018, online). My reasons for focussing on the baby boomer generation are explored below.

The baby boomers are the fastest growing cohort in Western society (Steptoe et al. 2012) and within the UK, are said to constitute a population of between 8.3 to 16.7 million people, depending on how the dates of the baby boomer generation are defined (Howker & Malik 2010; Williamson 2013; Young & Tinker 2017). In addition to the increased birth rates, discussed above, the growth of this cohort is also due to increased longevity related to improved medical and social conditions (Age UK 2018). Health and social research into the baby boomer generation is required to ensure that this population is provided with care that is specific to its needs. Recognition of this need is reflected in the recent increase in cohort specific research and literature (Hudson & Gonyea 2012; Phillipson et al. 2008; Pruchno 2012; Williamson 2013). One way of gaining knowledge about the baby boomers care needs is through providing them with opportunities to express their perspectives on the issues that they consider important. Learning about the issues that baby boomers consider important has potential to challenge the ongoing reliance on the biomedical model of health in research and practice.

The biomedical model of health draws upon biochemical explanations of ill health as the basis for treatment and disease (Ayers & de Visser 2017; Estes & Binney 1989; Yuill, Crinson & Duncan 2010). Biomedical indicators, such as level of disability reflect one facet of ill health, however subjective aspects, such as independence, relationships and well-being are now being recognised as impacting on people's lives (Bowling 2006). The biomedical model has had significant achievements in the management of many illnesses but it has a tendency to exclude psychological, social, environmental and temporal factors. Many health psychologists and sociologists, as well as academics from other fields, argue that the biomedical model's omission of the factors listed above limits our understandings of health (Ayers & de Visser 2017; Brocki & Wearden 2006; DeLamater & Koepsel 2015; Yuill, Crinson & Duncan 2010) .

The biomedical model of health has long been challenged for its construction of ageing as a medical problem, with a focus on decline and 'dysfunction' (DeLamater et al. 2017; DeLamater & Koepsel 2015; Estes & Binney 1989). In health care practice, there is an ongoing reliance on narratives around physical decline in older age. However, a growing body of research based on the first person accounts of older adults provides important insight into the factors that they consider to influence their quality of life (Pruchno 2012; Rowntree 2014). Phenomenological methodologies, such as IPA, can challenge biomedical constructions of ageing and assumptions of physical decline. It does this through the exploration of individual perspectives and the identification of aspects that have not previously been considered important to older adults (Smith, Flowers & Larkin 2009). This research can ensure that we focus on the lived experiences of older adults rather than relying on biomedical constructions of ageing and assumptions of physical decline (Bowling 2007). The SHW of older adults is one area that is benefiting from the increasing challenge to the biomedical model.

There has been a gradual increase in research exploring the SHW of older adults over the past two decades (Gott & Hinchliff 2003c; Hinchliff 2016; Hinchliff & Barrett 2018; Taylor & Gosney 2011; Træen et al. 2017a; Waite et al. 2017). The recent interest into the SHW of older adults is demonstration of two points. First, it reflects a shift in research from a focus on a biomedical model of health, to one that recognises the influence of cultural, social and personal aspects within the lives of older adults. Second, it reflects a recognition that SHW is important to many older adults (Bowling 2006; DeLamater 2012; Gott 2005; Gott & Hinchliff 2003b; Hinchliff & Gott 2004b; Lee et al. 2015). However, various definitions and understandings of SHW exist and exploration of these diverse understandings play a key role in the theoretical contribution to knowledge that this thesis makes in Chapter Six – Discussion.

## **1.2 Sexual health and sexual well-being**

Sexual health is defined by the World Health Organisation (WHO) as:

*...physical, emotional, mental and social well-being in relation to sexuality;...not merely the absence of disease, dysfunction or infirmity...  
(WHO 2006, p. 5)*

While this definition of sexual health is holistic, key policies and research in the area tend to focus on Human Immunodeficiency Virus (HIV) and sexually transmitted infection (STI) prevention, infertility, sexual 'dysfunction' and pregnancy prevention in younger adults (Department of Health 2013; WHO 2011). Sexual health interventions and surveillance are crucial facets of healthcare planning and provision. They are undoubtedly important for reducing the rates of death and disease in populations (Carneiro & Howard 2011). Yet, a focus on disease and 'dysfunction' potentially overshadows the importance of the emotional, relational and social aspects of sexual health and the impact that these aspects can have within people's lives (DeLamater 2012; Tiefer 2001, 2007; Wellings & Johnson 2013). However, recent evidence suggests a growing acceptance of more inclusive definitions of sexual health within research communities (Graham et al. 2017; Lee et al. 2015; Rosen & Bachmann 2008). In turn, the amount of academic literature which discusses holistic sexual health, sexual health in its broadest understanding, is gradually growing (Adams 2004; Jones 2018; McDaid et al. 2019; Wellings & Johnson 2013).

Given the broad and subjective nature of holistic sexual health, it is complex to define. Nevertheless, through an exploration of the academic literature that discusses holistic sexual health, I posit that an individual's understanding of holistic sexual health may include considerations around their self-image, social relationships, sexual pleasure, sexual practices, sensuality, emotions, spirituality, as well as, political factors (Adams 2004; Hirst 2013; Jones 2018; Wellings & Johnson 2013). This list is not exhaustive and the aspects of importance will vary between individuals.

In addition to research communities increasingly focussing on holistic sexual health, there is also evidence that wider society is moving towards the acceptance of holistic sexual health and sexual diversity rather than considering any diversion from what is considered 'normal' to be a perversion or 'dysfunction' (Hawkes 1996). Nevertheless, sexual activity in older adults, is still often perceived by society as a perversion due to asexual stereotypes, social taboos and because historically, sexual activity has been firmly linked with reproduction and not pleasure or well-being (Gott 2005; Hirst 2013; Tiefer 1995).



Just as well-being has long been associated with quality of life (Diener 1994; Diener et al.; Diener, Oishi & Lucas 2009), sexual well-being is now recognised as positively correlated with physical and mental health, and quality of life in older adults (Laumann et al. 2006; Rosen & Bachmann 2008). As the quote below exemplifies the term, 'sexual well-being' adds a layer of subjective understanding to the term 'sexual health' by focussing on the individual's perception. Laumann et al. (2006) define sexual well-being as "...the perceived quality of an individual's sexuality, sexual life, and sexual relationships" (p.146). This aligns with an IPA approach and for this reason, I use the term 'well-being' in addition to 'sexual health' throughout this thesis.

### **1.3 Sexual health and well-being, and older adults**

In recent years, the SHW of older adults has become recognised as an understudied but pertinent research topic. In addition to awareness that SHW is important across the life span, this acknowledgement is also due to evidence that many older adults still participate in, or want to participate in, sexual activity (DeLamater 2012; Gott 2005; Gott & Hinchliff 2003b; Hinchliff & Gott 2004b; Lee et al. 2015). Reflecting the increasing recognition of older adults' SHW in the UK, the latest version of The National Survey of Sexual Attitudes and Lifestyles (NATSAL-3) increased the upper age limit for participants from 44 to 74 and the English Longitudinal Study of Ageing (ELSA) included a sexual health questionnaire for the first time (Lee et al. 2015; Mercer et al. 2014).

The inclusion of older adults and SHW in both the NATSAL-3 and the ELSA suggests that the SHW of older adults is becoming more widely researched and accepted within the UK. The findings from the NATSAL-3 and the ELSA confirm that while the frequency of sexual activities may decline with age, many older adults remain sexually active. The studies also note that considerable changes have occurred over the last 60 years in terms of sexual practices, attitudes towards sex and the number of sexual partners. These changes suggest that the current generation of older adults, the baby boomers, may have distinct expectations of their sex lives than previous ones. The amount of research carried out focussing specifically on the SHW expectations, needs and experiences of the baby boomer generation remains limited. Nevertheless, the body of research is growing as the people within this large cohort age and with the

acknowledgement of older adults' interest in sexual activity (Hinchliff & Gott 2011; Hudson & Gonyea 2012; Marshall 2011; Rowntree 2014).

Alongside an increasing numbers of studies focussed on the SHW of older adults, the diversity of the participants represented has also been steadily increasing. The representation of non-heterosexual older adults in research, shows recognition of the differences in the lived experience between different groups (Averett, Yoon & Jenkins 2012; DeLamater & Koepsel 2015; Westwood & Lowe 2018). What this increase in literature and gradual embracement of more diverse participants in studies also reflects is that, in addition to the biological factors, the wider historical, social and cultural context require consideration for understanding SHW (DeLamater 2012; Moore & Reynolds 2016). This wider context and the meaning that it has for women will be explored within this IPA thesis.

Currently, the social, historical and cultural context is often omitted in research that considers the SHW of older adults, with the majority of academic publications still reflecting a biomedical conceptualisation of ageing and sexuality (Stanworth & Jones 2008; Trompeter et al. 2012). Specifically in the UK, within the government report titled, "A Framework for Sexual Health Improvement in England" (Department of Health 2013), respect for SHW throughout the life span is named but only in regards to HIV, sexually transmitted infections (STI) and erectile 'dysfunction'. The elements included in this key government report highlight the ongoing medicalisation of SHW. Arguably, the inclusion of older adults in the reports and publication above, demonstrates a positive step towards the recognition of their SHW needs but the omission of aspects, such as, intimate relationships, opportunities to express sexuality, and the role of social factors indicate that the SHW needs of older adults, in the wider sense, remain unexplored (Hinchliff 2016). The paucity of knowledge pertaining to the SHW needs of the baby boomer generation (Hinchliff & Gott 2011) is one of the knowledge gaps that this thesis bridges.

Linking wider factors, such as social and emotional factors, with SHW is essential to creating an in-depth understanding of older adults' lived experiences. We know that the changing social environment in which baby boomers grew up implies that they may have different SHW needs to that of previous generations (Arber, Davidsen & Ginn

2003; Gilleard & Higgs 2000) but this topic has remained relatively unexplored. In Chapter Six – Discussion, through connecting the thesis findings with existing literature on the baby boomers' social environment, I shed light on the SHW needs of baby boomer women living with T2D. However, in order to provide the reader with context, in the current chapter I briefly discuss social changes that may have influenced the intimate relationships of older adults in the Western society.

Recent changes to Western society that may have impacted on the intimate relationships of older adults include a decrease in widowhood, an increase in the number of divorces in older adults and an increase in Living Together Apart relationships (Arber, Davidsen & Ginn 2003; Borrell & Karlsson 2003; Gott 2006; Office for National Statistics 2015; Watters & Boyd 2009). The decline in widowhood, which is linked to improved mortality rates amongst older men, means that there has been an increase in the proportion of married older couples within the UK (Office for National Statistics 2015). Additionally, the increase in divorces within the UK means that many older adults are forming new relationships which more frequently involve non-traditional set ups, such as Living Together Apart (Duncan et al. 2010, 2011). These changes reflect that the current generation of older adults, the baby boomers, may consider their intimate relationships and SHW differently to that of previous generations.

The baby boomers came of age at a time when social attitudes towards SHW were changing with drugs, pop culture, the contraceptive pill, gay rights and the liberation of women's bodies, both in terms of, clothing and a loosening of governmental legislation in the UK (Bristow 2015; Woodsprings 2016). However, some argue that the effect of the "...swinging 60's was partial and localised...with a traditional framework largely retained in what people thought about sex and relationships." (Cook 2014, p.127). This suggests that while the culture may have become more accepting of ideas around sexual activity, there was significant diversity in individual experiences. Nevertheless, people of that era are now in their 50's, 60's and 70's and knowledge of how they perceive their bodies and sex has likely been influenced by their earlier social experiences. Indeed, it has been suggested that they have more relaxed attitudes towards sex than previous generations because of these key influences (Bristow 2015; Phillipson et al. 2008).

Despite this period of social change, the presence of other factors have encouraged perceptions of older adults as not sexually active remain within society (Gott 2005; Hinchliff & Gott 2008; Minichiello & Coulson 2005). Societal stereotypes of asexuality are perpetuated through the media consistently making associations between youth and sex, and the avocation of sex for procreation by religious and social institutions (Minichiello et al. 2005). This asexual stereotype can make older adults feel that they should not be having sex, and should certainly not discuss sex (Ginsberg et al. 2005). However, in recent years, this perception of asexuality in older adults is being replaced by the myth of the 'sexy oldie' (Gott 2005). The myth of the sexy oldie is based on the notion "...that 'being sexual' is fundamental to mental and physical well-being at any age, but particularly as a means to stave off old age" (Gott 2005, p. 24). This myth promotes the notion that in order for older adults to be healthy and 'normal' that they must remain sexually active (Fileborn et al. 2015b). As well as placing unnecessary pressure on older adults, this myth is also detrimental to wider society through promoting narrow stereotypes of the SHW of older adults. These narrow stereotypes influence how the SHW of older adults is perceived by society (DeLamater 2012; Fileborn et al. 2015b; Kontula & Haavio-Mannila 2009).

Both stereotypes of asexuality and the myth of the sexy oldie potentially damage understandings of SHW in older adults through oversimplifying its complex nature. They do not reflect the heterogeneity of the lived SHW of older adults, and neglect to include the aspects that older adults themselves report as important to their SHW, such as intimate touch and affection (Fileborn et al. 2015b; Gott 2005; Marshall 2011). Qualitative SHW research which reflects older adults' experiences is essential to advancing our understanding and ensuring that care provided is tailored to the SHW needs that older adults report rather than based on social stereotypes. The SHW of older adults, and older women in particular, remains an area in which stereotypes continue to exist (Gonyea 1998; Hinchliff & Gott 2008; Nusbaum et al. 2004; Sarkadi & Rosenqvist 2001; Sobocki et al. 2012).

## **1.4 Sexual health and well-being, and older women**

Distinct exploration of women's SHW on its own terms is essential for recognising differences in the SHW experiences of men and women, and to counterbalance the predominantly medicalised and androcentric focus in literature (Hinchliff 2014; Lindau & Gavrilova 2010; Mahieu et al. 2011). Through the idiographic approach of IPA and the sole inclusion of women's perspectives of their SHW, rather than focussing on intimate partners or biomedical perspectives, an in-depth exploration of women's SHW can be undertaken.

SHW difficulties that may impact on women's well-being are "...often overlooked by both women themselves and those around them." (Public Health England 2018b, p. 4). This omission may lead to a lack of support for women. However, which forms of SHW support that women may benefit from remain unknown. The quote above, taken from a report published last year by Public Health England, summarised research intended to gain understandings of women's experiences of their reproductive health and healthcare. While the inclusion of both qualitative and quantitative data provides necessary insight into women's SHW, women aged over 55 years only represent approximately 8% of their sample. The lack of older women in their sample reflects the tendency in research to focus SHW on younger populations. This focus on youth in SHW research is conflated by social fixations on youth, particularly for women.

As the Western ideal of female attractiveness is frequently based on youth and physical attributes, as women age they may internalize the perception held by society that they are less sexually desirable or that their sexuality is of less importance (Gott 2005; Hillman 2000; Hinchliff & Gott 2004b; McHugh & Interligi 2015). This can sometimes lead to feelings of undesirability and a lack of self-worth which in turn may cause a reduction in sexual desire and feelings that they should not be participating in, or even discussing, sexual activity (Gott 2005). As well as social perceptions of ageing influencing women's SHW, life events, such as menopause have been shown to influence their experiences and perceptions of SHW (Hinchliff, Gott, & Ingleton 2010; Nappi & Nijland 2008; Ussher et al. 2015; Winterich 2003).

Discussion around menopause, when women stop having menstrual periods, is important within this thesis as all participants included in this thesis were perimenopausal or post-menopausal. Baby boomer women are currently between the ages of 50 and 75 years of age and the average age for women in the UK to experience menopause is 51 (National Health Service 2014; WHO 1996). This means that many baby boomer women are experiencing perimenopause or post-menopause (National Health Service 2014; WHO 1996). From her final menstrual period, a woman is considered to be in the postmenopausal period. However, the term perimenopause covers the time shortly before the menopause and the first 12 months after the last menstrual period (NICE 2015a; WHO 1996). I discuss menopause as it relates to the thesis findings in Chapters Five and Six. The majority of research on menopause and sex has focussed on the physical effects of menopause rather than the individual, social and psychological changes that may impact on SHW during the peri and postmenopausal periods (Gilleard & Higgs 2000; Hinchliff, Gott, & Ingleton 2010; Winterich 2003).

Vaginal dryness, painful sex and a reduction in sexual desire during the peri and postmenopausal periods have been attributed to hormonal changes (DeLamater & Sill 2005; Dennerstein et al. 2003; Murtagh & Hepworth 2005; Whitehouse 2009). Indirect symptoms of menopause have also been reported as influencing women's sexual desire, such as tiredness or night sweats (DeLamater & Sill 2005; Dennerstein et al. 2003). However, more recent research findings are challenging reports of a decline in SHW around menopause, arguing that menopause can positively influence SHW with improved orgasms, and increased enjoyment from sexual activity due to liberation from menstrual periods and the possibility of becoming pregnant (Dillaway 2012; Hinchliff, Gott, & Ingleton 2010; Hinchliff & Gott 2008; Minichiello et al. 2005). Therefore, caution must be taken not to conflate the peri and postmenopausal period with a decline in women's SHW. The positive effects that menopause and ageing may have on female SHW are still seldom considered in research, even though more than 50 years have passed since Masters and Johnson demonstrated that ageing can have positive effects on female sexual desire (Masters & Johnson 1966). However, recent research pertaining to older women's attitudes towards sex is conflicting as the evidence below demonstrates.

It has been suggested that, compared to men, women give less importance to sex and are less interested in sex (Plummer, Seal & Minichiello 1996). Nonetheless, a growing body of qualitative evidence argues that some older women are interested in sex and authors warn against homogeneous definitions of sexual interest and its importance in later life (Fileborn et al. 2015b; Kontula & Haavio-Mannila 2009). Discrepancies in findings between the Plummer, Seal, & Minichiello study (1996) and the more recent studies may highlight cultural changes that have occurred since its publication. Using interest in sex as the only measure of sexual interest neglects to recognise the importance of factors, such as, relationship satisfaction and importance of sex to life. Factors which the latter studies include and that are crucial to gaining subjective understandings of SHW, particularly in older women (Fileborn et al. 2015b; Kontula & Haavio-Mannila 2009; Laumann et al. 2006; Lee et al. 2015). Furthermore, qualitative research has found sexual pleasure to be important to many older women (Averett, Yoon & Jenkins 2012; Gott & Hinchliff 2003c; Hinchliff, Gott & Wylie 2009). In addition to showing that some older women are interested in sex and that sexual pleasure is important, existing research highlights that relationship factors can influence older women's SHW experiences (DeLamater & Koepsel 2015; Hinchliff & Gott 2004a; Watson et al. 2016).

Intimate relationship factors play a central role in sexual activity and satisfaction. Conflicting partnerships, sexual problems of partners and widowhood have been associated with a reduction and cessation in sexual activity in older women (Arber, Davidsen & Ginn 2003; Gott & Hinchliff 2003c; Hartmann et al. 2004; Woloski-Wruble et al. 2010). The aforementioned decrease in widowhood within the UK may mean that there are currently more heterosexual older women who are sexually active than previously but whether the SHW needs of this cohort are being met is debatable. In addition to the possibility of social perceptions, menopause and intimate relationship factors affecting the SHW of older women, chronic health issues which increase in prevalence with age, may also influence SHW (Gott & Hinchliff 2003c; Muhamad et al. 2016; Public Health England 2018a; Trief et al. 2001). The question of who could meet the SHW needs of older women living with a chronic disease is central to this thesis.

Primary care healthcare professionals (HCPs) are often considered the first point of contact for non-urgent and chronic health concerns (Nolte & McKee 2008; WHO 2011).

Chronic health conditions, conditions which require ongoing management over a period of years, can impact on SHW (Pangman & Seguire 2000; Verschuren et al. 2010). Research in the area of SHW and chronic diseases is growing alongside the increasing prevalence of chronic diseases and the realisation that SHW is important for many older adults living with chronic diseases (Kralik et al. 2001; Pontiroli et al. 2013; Verschuren et al. 2010). However, the SHW concerns of older adults often go unaddressed in primary care (Gott et al. 2004b; Taylor & Gosney 2011). Research into why this lack of SHW discussion occurs has reported that HCPs assumptions of asexuality in their older patients, HCPs discomfort around discussing SHW, particularly with older women, and the under-recognition of patient need are all contributing factors (Gott 2005; Gott et al. 2004a; Hinchliff, Gott & Galena 2004; Politi et al. 2009).

## **1.5 Sexual health and well-being discussions between patients and healthcare professionals**

The relationship between patients and their HCPs is recognised as one of the most essential elements of healthcare, and has been cited as exerting influence over patient health and satisfaction with healthcare (Northouse & Northouse 2007). Good verbal communication between HCPs and their patients is an essential factor for maintaining a good relationship (Taylor & Gosney 2011). Verbal communication is particularly important in regards to SHW as many sexual concerns that older women may experience, such as low desire or pain during sex, may not be visually obvious in consultations (Hughes & Lewinson 2014). Openly discussing concerns, both sexual and other, is essential for highlighting potentially disparate perceptions between HCPs and their patients, a point that has been reported in the literature (Biggerstaff & Thompson 2008; Collins 2014). This means that patients may have different needs and concerns to those that HCPs assume them to have.

There is clear evidence that SHW is one of the topics that is often omitted in consultations between older women and their HCPs (Bauer, Haesler & Fetherstonhaugh 2015). Key reasons for this omission have been given as HCPs not wanting to embarrass their patients, not knowing where to direct their patients if issues do come to light or assuming SHW to be irrelevant to older adults (Fileborn et al. 2017b;



Gott et al. 2004b). Indeed, there is research reporting that SHW issues are often unexplored in practice with HCPs expecting patients to bring up SHW issues and patients expecting HCPs to (Hinchliff 2009). I argue that there are social and biomedical factors that contribute to the lack of SHW discussions in primary care.

Earlier in this chapter, I discussed two prevalent social stereotypes of older adults' sexuality, asexuality and the sexy oldie. While HCPs are expected to work independently of their personal beliefs, they have been exposed to these stereotypes in their lives outside of work. Therefore, their personal beliefs about the sexuality of their older patients may contribute to shaping the topics covered, and omitted, in consultations. A burgeoning body of literature suggests that personal belief is one of the reasons that HCPs may find SHW discussions with their older patients challenging (Taylor & Gosney 2011). Other social barriers to SHW discussions, identified in research with primary care HCPs, include a lack of training on SHW issues, discomfort around discussing sex and not wanting to embarrass the patient (Garrett 2014; Gott et al. 2004b; Hinchliff, Gott & Galena 2004; Hinchliff & Gott 2011; Kingsberg et al. 2019; Mellor et al. 2013; Stead et al. 2003).

There is also evidence to suggest that the gender of the patient may present a social barrier to SHW discussions in primary care settings. The majority of existing research in this area focuses on older adults in general but in the gender specific research, differences have been found and there is clear evidence that SHW is one of the topics frequently omitted in consultations with older women (Bauer, Haesler & Fetherstonhaugh 2015; Fileborn et al. 2017a). Studies of HCPs' perceived barriers to SHW discussions have identified considering SHW irrelevant to older women, feelings of awkwardness around a gender disparity and a lack of awareness for treatment options to be salient factors (Hinchliff, Galena & Gott 2004; Kingsberg et al. 2019). These barriers suggest that HCPs may struggle to discuss and treat SHW issues that older women may have. This means that older women may have sexual needs and concerns that are going unaddressed in practice. More in-depth qualitative research from women's perspectives would provide HCPs with understandings of what older women consider to be SHW issues, their previous experiences with HCPs and their expectations of care, hence the value of this thesis. Qualitative research from women's

perspectives also serves to challenge biomedical understandings of SHW, a point which I discuss throughout the thesis.

This 'medical gaze' may play a role in limiting the scope of SHW discussions within consultations. The 'medical gaze' is a term, coined by Foucault, to refer to the dehumanising practice of considering patients' bodies and identities as being separate from one another (DeLamater 2012; Foucault 1963; Gott et al. 2004a; Lindau et al. 2007; Minichiello et al. 2005; Person 1980; Tiefer 2007, 2001). This separation, which may be present in medical encounters, can be detrimental to the overall well-being of individuals as it prevents a holistic view of an individual. Within consultations, the psychological and emotional needs of patients require consideration in addition to the biological (Woodsprings 2016). This ensures that the wider aspects of SHW, discussed throughout this thesis, are considered and provides counterbalance to the biomedical model of health and healthcare. However, frequently in practice there is a focus on discussing the biological aspects of health rather than the psychological and emotional (Marshall 2010; May et al. 2006; Yuill, Crinson & Duncan 2010). In omitting discussion of these wider aspects of health, a comprehensive view of patients' needs and concerns are obscured.

In parallel with encouraging wider conceptions of SHW, we also need to look at distinct needs that specific populations may have. The majority of existing research in the area of SHW and older adults, focuses on older adults in general but research focussing on specific chronic illnesses is growing (Stead et al. 2003; Whitehouse 2009). I begin to explore these differences in the sections below and then discuss them in more detail in Chapter Two – Scoping review of the literature and Chapter Six – Discussion.

## **1.6 Diabetes, and sexual health and well-being**

Research in the area of SHW and chronic diseases has been growing as chronic diseases become more prevalent (Gott 2005; Hinchliff & Gott 2004b; Public Health England 2018a; Schram et al. 2009; Verschuren et al. 2010). Diabetes is one of the most common chronic diseases in older women within the UK and it is known to potentially impact on SHW (Diabetes UK 2010). The number of people living with diabetes in the UK is steadily growing. From 1996 to 2010, the number of people

diagnosed with Type 1 (T1D) or T2D in the UK increased from 1.4 million to 2.6 million (Diabetes UK 2010). Recent data show that there are currently approximately 3.8 million people living with diabetes (T1D and T2D) in the UK which is 9% of the UK adult population (Public Health England 2016). Globally, this challenge is also reflected with the number of people living with diabetes having doubled since 1980 due to the ageing population and obesity epidemic (NCD Risk Factor Collaboration 2016).

Diabetes refers to a group of disorders that are characterised by high levels of glucose in the blood caused by a lack of insulin due to an auto-immune response (T1D) or gradual insulin resistance (T2D) (Department of Health 2001a). T2D accounts for around 90% of diabetes cases and tends to occur in adults over the age of 40 (Diabetes UK 2014). People living with diabetes are prone to macro and micro-vascular complications, the latter of which can lead to eye problems, kidney damage and lower limb nerve damage (Department of Health 2001a). Neuropathy can also lead to erectile 'dysfunction' in men and vaginal dryness, pain during or after sex, and anorgasmia in women (Copeland et al. 2012; Esposito et al. 2010; Lindau et al. 2007). Despite knowledge that these sexual changes can occur, sexual problems are reportedly one of the most under recognised complications in diabetes care (Verschuren et al. 2010).

Currently, people living with T2D in the UK are invited to attend an annual review. The review consists of a thorough check-up performed by a General Practitioner (GP) or practice nurse (NICE 2015c). Most GP surgeries offer more frequent appointments, however. Under National Institute for Health and Care Excellence (NICE) guidelines, during these appointments patients receive advice regarding their diet and exercise patterns. HCPs also screen for and manage potential complications of diabetes that patients may be experiencing (NICE 2015c). After the annual review, HCPs may refer their patients to other members of the multidisciplinary team such as the diabetes specialist nurse, dietician or podiatrist. These referrals may be for general support, additional checks or specific education. The annual review, along with additional appointments, suggests that HCPs potentially have frequent contact with patients providing opportunities for SHW discussion between older women with T2D and their HCPs.

While people living with T2D diabetes may have more frequent appointments and so more frequent opportunities to discuss SHW, evidence suggests that some patients may not want to receive SHW information during consultations. Rutte et al. (2015) found that some patients living with T2D felt that they were already presented with a wealth of information on diabetic complications. Some participants felt that additional information about potential sexual ‘dysfunction’ led to anxiety or an inability to assimilate the information. However, the focus here may be on the HCP *asking* their patients about SHW, giving the patient the option to decline to discuss SHW if they wish. In Chapter Seven, I expand on this point using feedback provided by HCPs during the knowledge exchange activities to explore HCP experiences of asking their older female patients living with T2D about SHW. The gender disparities reported in research on SHW discussions between HCPs and their older patients (above), are also reflected in the SHW T2D literature.

While a document published by Diabetes UK (Diabetes UK 2014) discussed SHW, it focused on male erectile ‘dysfunction’ with little reference to female SHW which, considering the equal potential for neuropathy, highlights how SHW issues in women often go unexplored (Wild et al. 2004). Older women remain a group with a high prevalence of T2D (NCD Risk Factor Collaboration 2016) and yet the disparity in the quantity of SHW research between older men and women remains. More research into the SHW of groups with a high diabetic prevalence, such as, older women, is required to address this imbalance (Lemone 1996; Rockliffe-Fidler & Kiemle 2003; Rutte et al. 2015). The decision to focus this thesis on women’s experiences, specifically older women’s experiences was in response to the paucity of existing research in the area. However, my recognition of the paucity of research and compulsion to redress the disparity was likely influenced by being a feminist along with other aspects of my identity (see Preface and Chapter Eight – Strengths, Limitations and Reflexivity).

The disparities between the considerations given to SHW of men living with T2D compared to that of women is also reflected in care provision. The Quality Outcomes Framework (QOF) are a list of indicators used to measure the quality of patient care (Calvert et al. 2009; NHS Digital 2018). Since 2004, the scheme has offered financial

incentives to all GP surgeries in the UK for achieving a series of outcomes measured by indicators. Through addressing the indicators, surgeries accumulate points which translate into financial reward for the practice (NHS Digital 2018). There are 18 indicators for T2D, two of which pertain to asking male patients about erectile 'dysfunction' (NHS Digital 2018). There is no mention of female SHW despite research which indicates that T2D may also impact on female SHW, which I discuss in the next section. It could be argued that erectile 'dysfunction' is a marker for cardiovascular complications, which is the reason why it has been included. However, HCPs involved in indicator development have argued that its inclusion is closely linked to male erectile 'dysfunction' as a quality of life issue (NICE 2012). This indicates a perception that SHW is more important to quality of life for women than for men. The omission of female SHW from the QOF, and HCPs use of the QOF as a measure of high quality consultations for their patients, may provide one explanation for why discussion of the SHW of women living with T2D may be omitted within consultations. Nevertheless, recognition of the SHW needs of women living with T2D is growing.

In April 2016, Diabetes UK added the opportunity to discuss sexual problems to their list of 15 Healthcare Essentials and identify both men and women as having a higher risk of sexual 'dysfunction' (Diabetes UK 2016). This perhaps signifies the increasing attention to the SHW of women with diabetes in UK practice. This recent inclusion of discussions of sexual problems is encouraging but whether HCPs incorporate this into their practice and whether a focus on sexual 'dysfunction' in women is wholly positive is uncertain. In diabetes research, there has been a shift towards studying women's sexual 'dysfunctions'. This shift has drawn well-needed attention to SHW of older women living with diabetes but, as I discuss below, frequently neglects to consider aspects of SHW that the women consider important.

## **1.7 A focus on female sexual 'dysfunction' and diabetes**

As this thesis is concerned with perceptions and lived experiences of older women, the terms 'function' and 'dysfunction' are used with scare quotes. I recognise that these terms are established biomedical nomenclature but by placing them in scare quotes, I highlight that a biomedical focus is incongruous with an IPA approach. This is because it imposes a pre-existing categorisation onto the women rather than permitting the

women to define their SHW on their own terms, using their own words. Using scare quotes also acts as a reminder that for many decades academics have highlighted the importance of context to SHW and challenged defining sexual changes that women may experience as ‘dysfunctions’ (Drew 2003; Graham, Boynton & Gould 2017; Moynihan 2003; Tiefer 1988, 2001, 2007).

Despite careful consideration around use of the term sexual ‘dysfunction’, I consider it important to explore the sexual ‘dysfunction’ literature in the area of older women living with T2D within the current chapter. There are two reasons for this. First, the majority of existing literature in this area uses these terms and focuses on the incidence, frequency and prevalence of sexual ‘dysfunction’ in women living with T2D (Esposito et al. 2010; Fatemi & Taghavi 2009; Ogbera et al. 2009; Pontiroli et al. 2013). Even though this thesis adopts a more holistic approach to SHW, knowledge of the current research focus in the area of T2D provides the reader with context. The second reason for providing a comprehensive exploration of existing literature in the area is that it highlights knowledge gaps in the area of the SHW of older women with T2D. However, given the breadth and dominance of the literature pertaining to female sexual ‘dysfunction’ (FSD), it has potential to overshadow the small body of literature which does not focus on measuring sexual ‘dysfunctions’ and is more closely aligned with this thesis. For this reason, I exclude literature focussed solely on FSD from Chapter Two – Scoping review of the literature (the scoping review includes studies that discuss wider aspects of SHW, which is more aligned with the ethos of the thesis. I provide a detailed explanation of my inclusion and exclusion criteria in the next chapter). For these reasons, I explore research focussed on FSD in women living with T2D within this section.

According to the latest version of the International Classification of Diseases (ICD-11)(WHO 2018), sexual ‘dysfunctions’ are defined as:

*...syndromes that comprise the various ways in which adult people may have difficulty experiencing personally satisfying, non-coercive sexual activities. Sexual response is a complex interaction of psychological, interpersonal, social, cultural and physiological processes and one or more of these factors may affect any stage of the sexual response. In order to be considered a sexual dysfunction, the dysfunction must: 1) occur frequently, although it may be*

*absent on some occasions; 2) have been present for at least several months; and 3) be associated with clinically significant distress.*

In comparison with the above definition, the previous version of the ICD (WHO 2016) made no mention of the complex interactions involved in the sexual responses suggesting increasing WHO recognition of the wider factors influencing SHW and a much needed move away from primarily biomedical understandings of what constitutes a sexual 'dysfunction'. The definition highlights how complex it may be to measure or diagnose sexual 'dysfunctions' due to the various interacting processes and the different meaning that these aspects may have within people's lives. Despite this recent development to the ICD, the majority of existing research in the area of the SHW of older women living with T2D has used the Female Sexual Function Index (FSFI) to measure sexual 'function' (Ammar et al. 2016; Bakk et al. 2017; Bal et al. 2015; Bjerggaard et al. 2015).

The FSFI is an instrument designed by Rosen et al. (2000) that assesses sexual function for women with six domains: desire, arousal, lubrication, orgasm, satisfaction and dyspareunia (pain during or after sexual intercourse). Using this index, high rates of FSD have been found in women living with T2D (Giraldi & Kristensen 2010; Pontiroli et al. 2013). Research focussed on sexual 'dysfunction' frequently finds that women living with T2D may experience difficulty in reaching orgasm, dyspareunia, reduced lubrication and lower sexual satisfaction than women without T2D (Bakk et al. 2017; Bargiota et al. 2011; Meeking et al. 2013; Nowosielski et al. 2010; Pontiroli et al. 2013).

Currently explanations for the high rates of sexual 'dysfunction' in women living with diabetes focus on hyperglycaemia (high blood sugar) and vascular damage:

- 1) Hyperglycaemia is associated with an increased incidence of vaginosis and thrush which may lead to painful sexual intercourse (de Leon et al. 2002; Lemone 1996; Nowosielski et al. 2010)
- 2) Hyperglycaemia causes a reduction in the hydration of all mucous membranes, which may lead to poor vaginal lubrication and painful sexual intercourse (Pontiroli et al. 2013)

- 3) Vascular damage may mean that there is poor vascular flow and neuropathy, causing a reduction in clitoral engorgement and again, less lubrication. This may cause, not only painful sexual intercourse, but also less enjoyment of sexual intercourse (Ammar et al. 2016; Pontiroli et al. 2013)

However, wider effects of hyperglycaemia on sexual 'function', such as tiredness and weight gain, are frequently omitted from this research, again highlighting the focus on the biological effects of diabetes on SHW. Studies that include tiredness and weight gain as factors influencing SHW are discussed in the scoping review in the next chapter (Rockliffe-Fidler & Kiemle 2003; Sarkadi & Rosenqvist 2003). While there is a focus on the biological impact of diabetes on women's sexual 'function', some research also discusses the psycho-social impact, for example, irritability and difficulty in adapting to a diabetic status (Enzlin et al. 2009; Meeking et al. 2013; Nowosielski et al. 2010). Women living with T2D have also been found to experience higher rates of depression (Pontiroli et al. 2013). Depression has long been linked to higher rates of FSD, with effects being reported as a reduction in sexual desire, difficulty in achieving an orgasm and difficulty in becoming sexually aroused (Meeking et al. 2013; Mezones-Holguin et al. 2008; Newman & Bertelson 1986). Women living with T2D are also generally thought to be at a significantly higher risk of experiencing painful sex than women without (Baldassarre et al. 2015; Enzlin et al. 1998).

However, measuring sexual health using the FSFI has various limitations. The FSFI excludes women who have not been sexually active in the last four weeks, which is problematic for assessing the sexual health of older adults as they may be less sexually active than younger populations (Bjerggaard et al. 2015). This may lead to their exclusion from current sexual health research and presents a serious limitation for the use of this index in older populations. In fact, research using the FSFI tends to exclude older women, which may contribute to an underestimation of sexual problems in this population. It has been suggested the FSFI is an effective tool for measuring 'function', but it may not be the most appropriate tool for measuring holistic SHW (Forbes, Baillie & Schniering 2014). Nor does it account for women's own perceptions of their sexual well-being or partnership dynamics which have been shown to be key to SHW (DeLamater & Koepsel 2015; Hinchliff et al. 2012; Hurd Clarke 2006; Watson et al. 2016).



Below, the authors of the FSFI discuss the limitations of the terms 'function' and 'dysfunction', and the FSFI:

*...the current emphasis on female sexual dysfunction has diverted attention from the study of sexual happiness or satisfaction in non-dysfunctional women, and the potential contribution of sexual and relationship satisfaction to physical and emotional well-being.*

*(Rosen & Bachmann 2008, p. 296)*

The above quote highlights the recent shift from a focus on sexual 'function' to sexual well-being, and the consequences of doing so means that research focussing sexual well-being rather than sexual 'dysfunctions' is gradually increasing. There is a growing recognition that narratives around sexual 'dysfunction' and the tools used to measure it, do little to inform our understanding of SHW within the context of women's lives. This points to the importance of this IPA thesis which will provide much needed insight into how older women living with T2D make sense of their own SHW. The majority of articles which focus on FSD do acknowledge the multifactorial nature of female sexuality but their findings focus on the biological aspects of female sexuality and sexual response cycle (Bargiota et al. 2011; Meeking et al. 2013). Inconsistencies exist in regards to measuring the prevalence of FSD in women with diabetes and considering its possible causes, although most of the literature agrees that organic, psychological and social factors are implicated (Bargiota et al. 2011).

A key review of the literature on the topic of FSD and women with diabetes (Bargiota et al. 2011) includes a useful table with distinctions between T1 and T2D. However, on closer inspection, several of the papers included in the review exclude post-menopausal women or women over the age of 60 (Erol et al. 2002; Olarinoye & Olarinoye 2007) making the transferability of their findings to older women questionable. In diabetes and SHW research, the priority seems to be given to younger women reflected in that the majority of studies focus on women of reproductive age (Bal et al. 2015; Laumann et al. 2006; Nowosielski et al. 2010; Şahin & Şahin 2015) despite a higher prevalence of diabetes in older women (Diabetes UK 2014). The findings from comparative studies between older and younger women show that the

occurrence of FSD is correlated with age (Bağ et al. 2017) suggesting that older women may have worse SHW outcomes than younger women. Specific research pertaining to older women with diabetes is necessary given that older women may experience SHW differently to their younger counterparts due to co-existing effects of diabetes, ageing and cohort effects (Hinchliff & Gott 2008; Kralik et al. 2001; Mezones-Holguin et al. 2008; Sarkadi & Rosenqvist 2003). They may also have different healthcare requirements than their younger counterparts, which is an issue addressed in this thesis (see Chapter Five – Findings and Six – Discussion).

Women living with T2D are also generally thought to be at higher risk of sexual ‘dysfunction’ than women living with T1D (Rockliffe-Fidler & Kiemle 2003; Schreiner-Engel et al. 1987). In contrast to findings reporting that women with T2D may have worse SHW outcomes than those living with T1D, are findings showing no differences (Doruk et al. 2005). However, many studies aggregate T1 and T2D and this is problematic because “...diabetes is not a single phenomenon. T1D and T2D are two different conditions with regard to pathophysiology, age of presentation, and treatment.” (Giraldi & Kristensen 2010, p.207). Given this information, along with an exploration of the sexual ‘dysfunction’ literature, I decided to focus upon older women living with T2D.

As stated above, evidence suggests that women with T2D tend to have worse sexual ‘function’ than women with T1D (Erol et al. 2002; Esposito et al. 2010; Rockliffe-Fidler & Kiemle 2003). One reason for this may be that it is often diagnosed later than T1D (due to it being less symptomatic and that it tends to have a more gradual onset) allowing complications that might affect SHW to develop before interventions are made. Age may also be a factor as women with T2D are more often older (Celik et al. 2015). Not all the evidence suggests that there are significant differences between the SHW of women with differing diabetic sub-types (Wallner, Sarma & Kim 2010) but due to the high prevalence of T2D in older women and the reportedly worse SHW outcomes for this population, this is another reason that only women with T2D are the focus of this thesis.

Through exploring the background surrounding the topic of sexual health discussions between older women and their primary care HCPs, knowledge gaps around holistic

SHW care in primary care and the SHW discussion experiences of baby boomer women living with T2D have been highlighted.

### **Summary of the Background Chapter**

The historical and social context for the thesis has been presented in this chapter and key issues in relation to older women living with T2D have been highlighted. The key issues highlighted were the androcentric and youth focus in existing SHW research, that SHW communication barriers exist between HCPs and their older female patients, and the biomedical focus of current T2D and SHW academic literature. I have defined several key terms that are used throughout the thesis and provided a rationale for focussing this thesis on the SHW of older women living with T2D. This rationale is reinforced in the next chapter.

Exploring the existing research, patient information, practice guidelines and current knowledge led to identification of knowledge gaps that shaped the inclusion criteria for the scoping review of the literature. Through the exploration of the background literature, I became aware that the predominance of research in the area of older women living with T2D takes a biomedical focus and uses the term sexual 'function'. I therefore realised that it was important to omit such literature from the scoping review in the next chapter in order to facilitate the identification of specific knowledge gaps in the area.

# CHAPTER TWO – SCOPING REVIEW OF THE LITERATURE

## Introduction

This chapter builds on the previous chapter by using scoping review methods to explore evidence around the sexual health and well-being (SHW) of older women living with Type 2 diabetes (T2D) and communication with their primary healthcare professionals (HCPs). Within this chapter, I provide a rationale for adopting a scoping review method, and describe the search strategy and the data management process. The scoping review findings are presented in a narrative form in the chapter. After the presentation of the findings, I provide a critique of the studies included in the scoping review. The critique of the studies formed an important step in the thesis development. In addition to shaping the research aims and questions, the critique formed the basis for decisions around which methodology and methods should be adopted to achieve the research aim and answer the research questions. The research aim and research questions are presented at the end of this chapter.

## 2.1 Scoping reviews

Scoping review methods are considered ideal tools for identifying and analysing the scope of a body of literature (Arksey & O'Malley 2005; Grant & Booth 2009; Munn et al. 2018). Scoping reviews are a relatively novel approach to evidence synthesis, and as yet do not have a universal definition (Grant & Booth 2009; Peters et al. 2015). However, scoping reviews have several defining characteristics, namely, they need to have an inclusion criteria, a transparent search strategy and a way of standardising data extraction (Munn et al. 2018). These aspects were adhered to in the scoping review presented in this chapter. A scoping review of the literature was chosen for two reasons. First, it allowed me to examine the existing evidence on SHW with more than a biomedical approach. Second, it permitted the identification of knowledge gaps (Arksey & O'Malley 2005; Munn et al. 2018). The aims of scoping reviews are often broad, particularly on a topic of which little is known, such as SHW of older women living with T2D (Munn et al. 2018; Peters et al. 2015). Therefore, the aim of this scoping review was to explore the literature pertaining to the holistic SHW of older women living with T2D and communication with HCPs.

Before conducting the scoping review, I considered undertaking a systematic review due to their popularity in the health sciences (Grant & Booth 2009; Munn et al. 2018). Systematic reviews are used for searching, appraising and synthesising research evidence, frequently complying with the guidelines provided by Cochrane or the Joanna Briggs Institute (Grant & Booth 2009; Munn et al. 2018). Their aim is often to synthesise search results to inform practice and/or policy but as this was not the aim of the current review, I chose not to undertake a systematic review (Munn et al. 2018). Additionally, the exploration of the background literature revealed a limited amount of publications on the SHW of older women living with T2D, therefore a systematic review may not have identified sufficient evidence to synthesise and make practical recommendations. Other reasons that I chose not to undertake a systematic review include that heterogeneous subject areas are not amenable to systematic reviews of the evidence (Munn et al. 2018; Peters et al. 2015). Due to the lack of literature on the subject area, the complexity of the topic and the broad aim of the review, a scoping review was best suited. Analysis of the scoping review findings, and the subsequent critique, led to the development of the thesis aim and research questions (presented at the end of this chapter).

## **2.2 Inclusion criteria and search strategy**

To qualify for inclusion, articles had to be qualitative, quantitative or literature reviews published in English in any country. The studies had to include women over the age of 50 years living with T2D. Articles published within a 20-year period were included. While it has been argued that only articles published within 5-10 years should be included when reviewing literature, time restrictions are determined by the amount of available information which in this case, was limited (Cronin et al. 2008).

As the aim of the scoping review was to explore holistic SHW, articles that focussed only on the incidence, frequency or prevalence of sexual 'dysfunctions' or only used the Female Sexual Function Index (FSFI) to determine SHW were omitted from the scoping review. These articles are included in Chapter One – Background as they provide context to the topic area. As discussed in the previous chapter, literature into the SHW of older women living with T2D, is predominantly biomedical and focusses

on sexual 'dysfunction'. Therefore, I wanted to review the scope of the existing literature pertaining to women's SHW once sexual 'dysfunction' was removed from the equation. I explore how I endeavoured to achieve this criterion in more detail below (see Section 2.3 Data management and extraction).

Five major science and social science electronic databases were searched between February and March 2015. They were chosen for their extensive coverage of international Health Sciences literature:

- MEDLINE via PubMed
- the Cumulative Index to Nursing and Allied Health Literature (CINAHL)
- PsycINFO
- Applied Social Science Index and Abstracts (ASSIA)
- Web of Science

The databases were searched using the search terms included in Table 1, below. The exploration of the background literature in Chapter One, showed that the majority of existing literature in the topic area used the terms "older", "women", "diabetes" and "sexual\*". Therefore, these key terms were used to search for their potential to yield results. Alternative terms observed in the background literature were also used to increase the number of articles found and to ensure that no relevant articles were omitted.

**Table 1 - Scoping review search terms**

Key search terms (these were grouped together with the Boolean operators “AND” and “OR”	Alternative terms also searched (truncation included)
<b>Older</b>	Elderly, middle-aged, aging, age*, menopaus*, postmenopaus*
<b>Women</b>	Female
<b>Diabetes</b>	Type 2 diabetes, diabet*
<b>Sexual*</b>	Sexual health, sexual well-being, intimacy

The alternative search terms along with truncation (denoted with an \* in Table 1) allowed for the various constructions of the chosen terms to appear in results. Diabetic subtype (Type 2 diabetes) was originally included as an alternative search term, as shown in Table 1. However, it was subsequently excluded as many studies either included both sub-types or did not stipulate which they were studying in the title. Searches which included the terms “healthcare professionals”, “general practitioners” and “practice nurses” were attempted but subsequently excluded, as they did not produce any results when combined with the other search terms.

As recommended by Aveyard (2014), supplementary search strategies were used in conjunction with the electronic databases. In light of this, I searched Google Scholar to increase the number of results (Boeker, Vach & Motschall 2013). While it ensured the inclusion of pertinent literature, due to its low precision, significant manual sifting through the results was required to identify relevant studies. I also used backward chaining (referring to the reference lists of relevant articles) and forward chaining (referring to the articles that cited relevant articles) to ensure extensive coverage of the literature. 401 articles were retrieved using these search methods. After duplicates were excluded, 253 articles remained.

### **2.3 Data management and extraction**

All titles and some abstracts of the 253 results were screened for their relevance to the topic area. In some cases, it was necessary to read the abstract of the articles

even if the title suggested that the article might not be relevant to the thesis topic, as on occasion the article title did not reflect its content. For example, some articles used the term sexual 'function' or 'dysfunction' in the title, suggesting a biomedical focus, but then wider issues were discussed in the abstract and text (Copeland et al. 2012). Another example is that one article in particular did not have the word "diabetes" in the title but all participants were older women living with T2D (Sarkadi & Rosenqvist 2001). The converse was also applicable in that some articles used the term "sexuality" in the title but reading the article in full revealed that sexuality was exclusively measured using the FSFI which as discussed, was an exclusion criterion for the scoping review. After excluding the 236 articles that were not focussed on diabetes, did not include women over the age of 50, measured sexual 'function' and were not published in English, 17 articles remained. See Appendix A – Flow diagram of the literature inclusion process for details of how many articles were excluded at each stage and the reason why.

The remaining 17 articles were obtained from the University Library, or requested from the British Library, and read in full. Reading these 17 articles in full was a necessary step because some studies used only the FSFI to determine SHW but did not state it in the title and/or abstract (Wallner, Sarma & Kim 2010). An additional rationale for reading some articles in full is that the participants' age range was not included in some titles and/or abstracts (Fatemi & Taghavi 2009). However, it is important to reiterate that some of the articles included in this scoping review, do use the FSFI but it is used in conjunction with forms of data collection. These other forms of data collection included the Sexual Quality of Life questionnaire (Celik et al. 2015), additional questions to assess women's perceptions of their sexual lives (Copeland et al. 2012) and qualitative interviews (Rockliffe-Fidler & Kiemle 2003). Additionally, some of the articles included in this scoping review include individuals living with Type 1 diabetes (T1D) or younger than 50. However, as far as possible, I have extracted and reviewed data and discussion material pertaining to older women living with T2D. The original scoping review was carried out in February 2015 and eight articles (seven studies and one literature review) were identified that fit the inclusion criteria.

As I had two periods of maternity leave between 2015 and 2018, I performed a second scoping review in March 2018 to ensure that no relevant literature, published since the



original review, had been omitted. Through following the same search and data management steps outlined above, I identified three additional studies that had been published between 2015 and 2018 and fit the inclusion criteria (Bijlsma-Rutte et al. 2017; Bjerggaard et al. 2015; Rutte et al. 2016). The findings from these three studies have been incorporated into the scoping review presented below. Finally, these eleven articles (ten studies and one literature review) were saved in the reference manager, Mendeley, and analysed.

## **2.4 Included studies and data analysis**

For a brief description of study aims, country where the study was conducted, sample size and characteristics, data collection and analysis and key findings of the ten studies and one literature review, see Appendix B – Synopses of the scoping review articles.

The literature review article by Whitehouse (2009) included studies which focussed on older women with diabetes (Malacara et al. 1997) or SHW and older women (Addis et al. 2006; Nusbaum et al. 2004) or sexual ‘dysfunction’ in younger women with diabetes (Erol et al. 2002; Rutherford & Collier 2005). On assessment only two of the studies in their literature review included all three key concepts of SHW, older women and diabetes (Sarkadi & Rosenqvist 2001, 2003)<sup>1</sup>. Nevertheless, this literature review article was important to include as it reflected existing knowledge of the SHW of older women living with diabetes. The literature review performed by Whitehouse (2009) highlighted gaps in the evidence base through illuminating the absence of information pertaining to the SHW of older women with T2D. The absence of studies that focus directly on older women living with T2D in their literature review is due to a dearth of literature in the area, and confirms the need for research in this area.

The ten remaining studies included in this scoping review consisted of five quantitative studies (Bijlsma-Rutte et al. 2017; Bjerggaard et al. 2015; Celik et al. 2015; Copeland et al. 2012; Lindau et al. 2010), four mixed-methods studies (Erten et al. 2014; Rockliffe-Fidler & Kiemle 2003; Rutte et al. 2016; Sarkadi & Rosenqvist 2003) and one qualitative study (Sarkadi & Rosenqvist 2001). The studies were conducted in Sweden

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<sup>1</sup> Both of these studies by Sarkadi & Rosenqvist are included in the scoping review below

(Sarkadi & Rosenqvist 2003, 2001), Turkey (Celik et al. 2015; Erten et al. 2014), the Netherlands (Bijlsma-Rutte et al. 2017; Bjerggaard et al. 2015; Rutte et al. 2016), the USA (Copeland et al. 2012; Lindau et al. 2010) and the UK (Rockliffe-Fidler & Kiemle 2003). In addition to the FSFI, quantitative data around SHW were collected using checklists, questionnaires and scales. These included the Brief Sexual Symptoms Checklist for women (BSSC-W), Sexual Quality of Life Questionnaire for women (SQLQ), the Sexual Functioning Questionnaire (SFQ), the Arizona Sexual Experiences Scale (ASEX) and sexuality scales designed for the individual study (Bijlsma-Rutte et al. 2017; Bjerggaard et al. 2015; Celik et al. 2015; Erten et al. 2014; Rockliffe-Fidler & Kiemle 2003). Quantitative data were also collected from a national survey and a question that was added on to the FSFI about the participants' perceptions of their physical health and sexual 'function' (Copeland et al. 2012; Lindau et al. 2010). Qualitative data were collected using individual interviews and focus groups, and data were analysed using content analysis (Erten et al. 2014; Rutte et al. 2016; Sarkadi & Rosenqvist 2001), Malterud analysis (Sarkadi & Rosenqvist 2003) and IPA (Rockliffe-Fidler & Kiemle 2003). Sample sizes within the qualitative data collection ranged from 8-33 women. Sample sizes within the quantitative data ranged from 38-486 women. The range of disciplines that the literature in this scoping review comes from (nursing, medicine, public health and psychology) is testament to the transversal relevance of this topic to health research.

After the scoping review findings presented below, I provide a critique of the literature included in the scoping review. Critical appraisal is not required of scoping reviews (Grant & Booth 2009). However, I considered a critique of the studies included in this scoping review to be important for identifying knowledge gaps and justifying methodological decisions taken in later chapters. A synopsis of the ten included studies can be found in Appendix B. Data were extracted from the ten studies. The relevant findings that were identified were then separated into three main themes of: 1. Factors affecting the sexual health and well-being of older women with Type 2 diabetes; 2. Sexual health and well-being comparisons between older women with diabetes and other samples; and 3. Sexual health and well-being communication between healthcare professionals and older women with diabetes.

## **2.5 Scoping review findings**

### **2.5.1 Factors affecting the sexual health and well-being of older women with T2D: Theme 1**

Evidence presented in Chapter One – Background suggests the T2D can have an impact on many aspects of older women’s SHW, but which specific aspects remained unclear. Within this first theme, I explore the factors affecting the SHW of older women living with T2D. Some of these factors overlap with those identified in Chapter One – Background, such as menopause, lubrication and orgasm. However, through the exploration of studies that did not have a solely biomedical focus, novel factors were identified. These included emotional, psychological, intimate relationship factors and the interplay between these factors.

Copeland et al. (2012) found that diabetes, or its medications, tended to have a greater impact on lubrication and orgasm compared to sexual desire and subjective arousal in older women. These results imply that the biological effects of diabetes may have a greater impact on SHW than psychosocial factors. However, as their study was primarily focussed on determining sexual ‘function’ from a biomedical perspective, they propose that wider aspects, which were not included in their study such as attitudes and expectations about sex, may have played a role in the SHW of participants.

Other studies also concluded that women with diabetes experienced reduced lubrication and orgasm (Bijlsma-Rutte et al. 2017; Rockliffe-Fidler & Kiemle 2003). However, through the inclusion of qualitative data, Rockliffe-Fidler & Kiemle (2003) found that reduced enjoyment, feeling unable to “*let go*” (the meaning of which was not explored in the article) and tiredness were also contributing factors to the women’s SHW suggesting that biological responses are not fully responsible for sexual pleasure and satisfaction. In fact, women have been found to have worse SHW outcomes after a diagnosis of diabetes (Celik et al. 2015). While a worsening of SHW after a diagnosis may be due to the effects of diabetes, equally, it may be due to women associating diabetes with ill health. This association may result in women experiencing less sexual desire. However, there are a myriad of other factors known to influence women’s

sexual desire, such as tiredness, poor relationships and low self-esteem. This makes it difficult to determine the biological effects of diabetes on a woman's sexual desire. The complexities of sexual desire and associations that people may make between diabetes and ill health are often hard to quantify thus, qualitative methods are better suited to their identification.

Qualitative research has shown that for many women with diabetes, emotional, psychological and interpersonal factors are important to SHW (Erten et al. 2014; Rockliffe-Fidler & Kiemle 2003; Sarkadi & Rosenqvist 2001). Older women with diabetes have reported experiencing emotions such as guilt, shame and embarrassment due to the perception that diabetes is a self-inflicted disease caused by poor eating habits or being overweight (Sarkadi & Rosenqvist 2003). These views, which have been found to influence women's perceptions of their bodies and self-confidence, were in contrast to quantitative findings by Rockliffe-Fidler & Kiemle (2003) that poor body satisfaction and obesity were not correlated with sexual problems. Rockliffe-Fidler & Kiemle's (2003) qualitative findings did, however, find that participants' weight gain affected how they perceived themselves sexually. The identification of self-perception issues that were not detected through quantitative data collection in the Rockliffe-Fidler & Kiemle (2003) study highlights the importance of exploratory research to identify areas that may not immediately appear to be relevant to SHW but that people consider important.

Equally, areas that may be assumed problematic for women, such as a high FSFI score, may be unproblematic for these women. Through asking their participants questions to determine sexual distress in addition to using the FSFI, the study by Bjerggaard et al. (2015) found low levels of sexual distress (28%) in women considered to have a sexual 'dysfunction'. This provides evidence that not all sexual changes that may be considered sexual 'dysfunctions' are problematic within the context of women's lives. It also suggests the benefit of further investigation into which concerns women do find distressing and why that may be so.

In the area of SHW and diabetes, the link between psychological factors and SHW is more firmly established but it is unknown whether this relationship is diabetes specific or not (Bjerggaard et al. 2015; Rockliffe-Fidler & Kiemle 2003). The Rockliffe-Fidler &

Kiemle (2003) study concluded that depression and anxiety were factors for poor SHW but they accounted for a small percentage of total variance. This led the author to conclude that depression and anxiety are only one area that requires consideration in regards to the SHW of older women with diabetes. Nevertheless, anxiety surrounding diabetes related infections (e.g. thrush, cystitis) was identified in interviews as affecting the women's decisions to partake in sexual activity due to fear of pain, embarrassment and their sexual partner's response to them having diabetes (Rockliffe-Fidler & Kiemle 2003). This anxiety related to SHW, likely impacts on intimate relationships and sexual quality of life for these women.

The decision to disclose diabetic status to intimate partners and engaging in sexual activity to please a partner, were some of the relationship factors identified by the studies in this scoping review. In particular, Erten et al. (2014) found that feelings of duty toward intimate partners encouraged women to continue having sexual intercourse even if they felt pain or did not want to. While it is important to recognise that the latter study was set in Turkey, where social norms are tightly bound to culture, religion and duty to partner, participating in sexual activity to please one's partner has also been found in UK based studies (Rockliffe-Fidler & Kiemle 2003). This demonstrates the importance of sexual activity to intimate heterosexual relationships across various cultural contexts. Furthermore, this importance was confirmed in the frequency that women discussed factors related to intimate partners, such as, the lack of an intimate partner, sexual 'dysfunction' of an intimate partner, general health of an intimate partner or inability to talk to an intimate partner (Bijlsma-Rutte et al. 2017; Rockliffe-Fidler & Kiemle 2003; Sarkadi & Rosenqvist 2003)<sup>2</sup>. While intimate relationships have been identified as important to the SHW of older women living with T2D, personal factors, such as menopause, have also been recognised as linked to the SHW of older women.

In the literature, the interplay between menopause and SHW is frequently discussed but what menopause means within the lives of women remains poorly understood (Copeland et al. 2012; Sarkadi & Rosenqvist 2003). As discussed in Chapter One,

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<sup>2</sup> As far as I could discern, none of the participants of the studies included in this scoping review were in intimate relationships with women. I explore this point in the critique of the scoping review at the end of this chapter.

there is evidence that both diabetes and menopause can have physical, psychological and psycho-social effects on the SHW of older women. Researchers have highlighted the difficulty in determining the cause of sexual problems (Celik et al. 2015). Given that T2D diagnosis and menopause may occur around a similar time within women's lives, there may be ambiguity concerning the source of SHW issues that may be experienced. This may lead some women, and even HCPs, to have difficulty in knowing whether SHW changes are attributable to the menopause or diabetes.

The complexity of the relationship between menopause and diabetes is reflected in the literature. The study by Copeland et al. (2012) includes menopausal status as a quantitative variable but whether it is associated with SHW and diabetes is not discussed. Rockliffe-Fidler & Kiemle (2003) recognise that menopause may affect SHW but they only separate their participants into 'over 50 years old' and 'under 50 years old', which means that they are not able to accurately associate menopausal status with SHW as participants may have been pre, peri- or post-menopausal. Nevertheless, participants in the 'over 50 year old' group were found to have significantly less sexual desire and worse SHW outcomes than the younger group. These results suggest that age may be a more significant factor in the SHW changes of women with diabetes than menopause but it is unlikely that age is the only important factor for SHW issues.

Determining the cause of SHW issues can be problematic when considering the multitude of factors that contribute to them and the interplay between them. While the aim of the qualitative study by Sarkadi & Rosenqvist (2001) was to determine the effects of diabetes on 'womanhood and intimacy', there is little discussion of the *effect* of diabetes on the SHW of their participants. A later study by the same authors (Sarkadi & Rosenqvist 2003) had the more general aim of exploring the relationship, if any, between diabetes and intimacy. The second Sarkadi & Rosenqvist study did not attempt to disentangle the causes of alterations to SHW, perhaps having been informed by the findings from the first, that determining the effect of T2D is difficult to achieve and that participants were more concerned with the impact of sexual disturbances rather than the cause (Sarkadi & Rosenqvist 2003). Women's ideas around why they think SHW changes have occurred are important to the exploratory aim of this thesis. The emphasis is on what *they* consider important to their SHW rather

than determining the cause of their SHW changes. However, the findings from the literature comparing the SHW outcomes of women living with T2D to other samples reveals that potential differences exist which require consideration.

## **2.5.2 Sexual health and well-being comparisons between older women with diabetes and other samples: Theme 2**

### **2.5.2.1 Older women without diabetes**

Evidence from biomedical studies suggests that older women with diabetes report lower sexual satisfaction and experience more lubrication and orgasm changes compared to their non-diabetic peers (Ali et al. 2008; Doruk et al. 2005; Fatemi & Taghavi 2009). This suggests that while many older women with diabetes may be interested in sex, their enjoyment of it may be limited (Copeland et al. 2012; Lindau et al. 2010). However, the literature review by Whitehouse (2009) found that women with T2D had similar SHW outcomes to women without diabetes meaning that factors other than diabetes, which affect older women in general, may also be influential on women's experiences of SHW. For example, intimate relationship factors that are not related to diabetes, could affect interest in sex.

Some of the older women with diabetes included in this scoping review were found to be more frequently single and have partners with SHW concerns than women without diabetes (Copeland et al. 2012). Relationship factors may not explain all the differences between the women. For example, the study by Lindau et al. (2010) found that older women with diabetes were less likely to masturbate than women without even though they had similar levels of interest in sex. Without further investigation and perhaps a qualitative component, it is unclear why this difference occurred. Copeland et al. (2012) attributed the worse SHW outcomes of women living with T2D to complications of the disease or treatments. However, this analysis does not account for the emotional or psychosocial implications of having diabetes and would benefit from further exploration.

### **2.5.2.2 Diabetic sub-type (Type 1 diabetes or Type 2 diabetes)**

In Chapter One – Background, I introduced the argument that T1D and T2D required exploration as separate conditions. Here, I develop this argument through a revision

of the literature pertaining to SHW differences between women with T1D and T2D. Most of articles discussed in this scoping review focus on only T2D (Bijlsma-Rutte et al. 2017; Bjerggaard et al. 2015; Rutte et al. 2016; Sarkadi & Rosenqvist 2001, 2003) or do not differentiate between diabetic sub-type (Copeland et al. 2012; Erten et al. 2014; Lindau et al. 2010). However, the two articles that do compare the SHW of women by diabetic subtype (Celik et al. 2015; Rockliffe-Fidler & Kiemle 2003), found that women with T2D reported lower sexual quality of life scores and lower overall sexual 'function' scores than women living with T1D. They also found significantly less sexual desire and enjoyment than women living with T1D. However, it is noteworthy that in both these studies, the group of women living with T2D was older than those in the T1D group. Therefore, age and possibly menopausal status may have contributed to differences between the two groups, as well as relationship factors. This again highlights the need for specific research that focuses on the individual experiences of older women with T2D rather than younger and heterogeneous samples.

Through qualitative data collection, Rockliffe-Fidler & Kiemle (2003) found that women living with T2D attributed changes, such as reduced desire and increased tiredness to their T2D. These issues were distinct to the SHW issues reported by women living with T1D. The issues highlighted by the women living with T2D were more closely linked to the psychological aspects of SHW suggesting a need to focus on these issues rather than sexual 'function'.

### **2.5.2.3 Older men with diabetes**

This part of the review contains the four studies which included a comparison of SHW and diabetes by gender (Bijlsma-Rutte et al. 2017; Bjerggaard et al. 2015; Lindau et al. 2010; Rutte et al. 2016). As discussed in Chapter One – Background, more studies address the SHW of older men than older women living with diabetes. Evidence does exist suggesting that older women may consider sex to be of less importance to them than men (Laumann et al. 2006; Lee et al. 2015; Lindau et al. 2007). However, rather than leading to the conclusion that older women are not interested in sex or that SHW discussions are not necessary, it suggests the benefit of research into wider factors affecting SHW and a rejection of limited understandings of what is important to women's SHW.



Three of the studies that included a comparison by gender reported that women with diabetes were less likely to be sexually active and less likely to be sexually dissatisfied than men (Bijlsma-Rutte et al. 2017; Lindau et al. 2010; Rutte et al. 2016). Therefore, women may be engaging in less sexual activity but less concerned about it than men, which would support the findings above of sexual disinterest. This may also suggest that some women living with diabetes may not need to discuss SHW with their HCPs. However, one study found that women living with diabetes had significantly higher rates of sexual distress than men, with 35 % of women reporting sexual distress compared to 28% of men (Bjerggaard et al. 2015). The women in the latter study had completed the FSFI and been diagnosed as having a sexual 'dysfunction' which may provide one explanation of the differences in the findings around sexual satisfaction and distress between these studies. This discrepancy in the research findings but, also in the language used to describe women's experiences of SHW (distress satisfaction, concerns) highlights the need for research that uses the women's own words. This type of research would provide a clearer picture of women's SHW needs, experiences and understandings of SHW.

Within some of the studies which focus on SHW difference between genders, there is discussion around SHW communication (Bijlsma-Rutte et al. 2017; Lindau et al. 2010; Rutte et al. 2016). They found that women with diabetes were less likely to bring up the subject of sex and physicians were less likely to approach the subject with their female patients than with their male patients. It aligns with research presented in Chapter One – Background, reporting that female SHW appears to receive less attention than male SHW in diabetes care, which again highlights the need for increased recognition of the SHW of older women with diabetes in healthcare practice.

### **2.5.3 Sexual health and well-being communication between older women with diabetes and their HCPs: Theme 3**

The literature reports that there are high rates of sexual dissatisfaction in older women living with T2D and that a large number of these women report a need for help from their HCPs (Bijlsma-Rutte et al. 2017). Women who had received care for SHW issues from cardiologists, sexologists and GPs, reported dissatisfaction with the care provided due to a lack of psychological support and a focus on treatment for sexual

'dysfunctions' (Rutte et al. 2016). These findings, in addition to those on the range of factors influencing SHW presented in the Theme 1, suggest that sometimes women may prefer psychological support rather than medical solutions to manage their SHW changes. However, these findings are contrasted in participants expressing that the discussion of SHW issues is only helpful if HCPs can provide solutions (Rutte et al. 2016). This highlights the complexities of providing satisfactory SHW care for patients with a diversity of needs.

The latter study by Bijlsma-Rutte et al. (2017) in particular, highlights that screening for sexual 'dysfunctions' is insufficient as not every women experiencing a sexual 'dysfunction' was sexually dissatisfied. Their results suggest that some women may want to discuss their SHW when they are sexually dissatisfied but not all 'dysfunctions' necessarily require discussion with HCPs. This reiterates the concept of holistic SHW that I use within this thesis and challenges the biomedical focus on sexual 'function' in the literature. It also highlights the knowledge gap around which SHW needs women require professional help for. In that only 47.2% of sexually dissatisfied women living with T2D reported a need for help, it begs the question, if they are sexually dissatisfied, why do they not consider themselves to need professional help? The factors discussed above linked to intimate relationships e.g. lack of availability of intimate partners or intimate partners' health, may provide one explanation but there is very little exploration of this topic in the research literature.

Another possible reason for a high rate of women reporting sexual dissatisfaction but a low need for professional help lies in results from the same study by Bijlsma-Rutte et al. (2017) and another study from the same authors (Rutte et al. 2016). They reported that the longer the period of dissatisfaction, the lower the need for help. This suggests an adjustment period where women may become accustomed to their new situation. The qualitative data in the latter study by Rutte et al. (2016) discusses the range of SHW experiences that people living with T2D with sexual problems can encounter. They draw attention to what may be a cause for concern for one individual may be perceived as unproblematic for another. This again highlights the complexity of measuring SHW using quantitative tools, even if they are measuring sexual satisfaction rather than sexual 'function'.

Older women with diabetes have reported lack of time, lack of privacy and fear of embarrassment as barriers to SHW discussions in consultations (Erten et al. 2014; Lindau et al. 2010; Rutte et al. 2016; Sarkadi & Rosenqvist 2001, 2003). These barriers can lead to a lack of SHW knowledge in patients, shown in that many participants did not know that diabetes, or its medications, could have an effect on their SHW (Rutte et al. 2016; Sarkadi & Rosenqvist 2001). It is cause for concern that women lack information about the potential impact of T2D on their SHW, and even more so, in that men appear to be better informed about this link (Rutte et al. 2016). Not knowing that their SHW changes could be linked to T2D led to the female participants attributing SHW changes to intimate relationships and other factors discussed in Theme 1 of this scoping review. Another notable finding, which should help our understanding of SHW communication between patients and HCPs, lies in who initiates the SHW discussions. The participants expressed that if HCPs brought up SHW, it could lower the threshold for discussion in demonstrating that the HCP is open to discussions around sexuality (Rutte et al. 2016). This highlights the important role that HCPs could play in SHW discussions but more knowledge around this topic is required.

A study limitation highlighted in the Bijlsma-Rutte et al.'s (2017) study of patients with T2D sheds light on the fact that HCPs may be more comfortable discussing SHW with their male patients with T2D than with their female patients with T2D. When recruiting participants for this study, practice nurses were trained to recruit patients living with T2D at random, but the final study sample was predominantly male. Practice nurses expressed that it was easier for them to approach their male patients than their female ones. Other studies also highlighted recruiters/selection bias as a potential limitation to the study samples (Rockliffe-Fidler & Kiemle 2003). This highlights that HCPs may struggle to discuss SHW with their female patients living with T2D and so these patients' SHW needs may be overlooked in practice. It also provides evidence that selection biases may exist in study samples meaning that the SHW needs, concerns and experiences of older women living with T2D may be frequently underestimated. In order to ensure that evidence exists which does not omit women's SHW needs, research that focuses solely on the SHW experiences of women's can go some way to counterbalancing the male focus in diabetes and SHW research.

The final theme of this scoping review focussed on SHW discussions between older women and their HCPs. This theme confirmed findings from Chapter One and the preceding themes, that older women with T2D do experience SHW issues. It also built on these findings by reporting that women may not always discuss their SHW needs. This discrepancy between women experiencing SHW issues and the lack of discussion of their SHW issues forms another key knowledge gaps bridged in this thesis.

## **2.6 Critique of the scoping review studies**

The scoping review findings build upon the general exploration of the literature around older adults, sexual health and diabetes presented in Chapter One – Background. Even after the exclusion of studies which only measured sexual SHW, using the FSFI, the majority of the literature published in this area was based on quantitative data (Bijlsma-Rutte et al. 2017; Bjerggaard et al. 2015; Celik et al. 2015; Copeland et al. 2012; Erten et al. 2014; Lindau et al. 2010; Rockliffe-Fidler & Kiemle 2003; Rutte et al. 2016). The extensive use of quantitative scales and questionnaires in existing research into the SHW of older women living with T2D provides information on the sexual 'function' and sexual symptoms of older women living with T2D. However, capturing the lived experience of SHW, and its discussion with HCPs, has not been thoroughly explored and would be challenging to do using quantitative data collection techniques. Therefore, a qualitative study exploring the SHW of older women living with T2D has potential to redress this methodological imbalance.

Authors of the quantitative and mixed-methods studies make valid points based on their quantitative data but without qualitative data to add depth, much of the complexity is lost. For example, in Bijlsma-Rutte et al.'s (2017) study, they found that within their sample of women living with T2D, 47.2% of sexually dissatisfied women wanted to talk to their GPs about their sexual problems. While this is an interesting finding, if they had included qualitative data, they may have been able to identify why these women did not want to discuss their sexual dissatisfaction with their GPs. Similarly in the Bjerggaard et al.'s (2015) study of sexual concerns, they found high level sexual dissatisfaction in women living with T2D but reasons as to why this might be so are not suggested. In-depth qualitative research, which focusses on the barriers to SHW

discussions, has the potential to address this knowledge gap of why older women living with T2D may experience sexual dissatisfaction but may not want to discuss SHW this with their HCPs.

The mixed-method studies in this scoping review that included qualitative components did so to great effect (Erten et al. 2014; Rockliffe-Fidler & Kiemle 2003). The qualitative component of these studies allowed for an exploration of the SHW issues that women interviewed considered important. This is advantageous for obtaining knowledge of what aspects of SHW women consider important. However, within the mixed-method studies, qualitative data analysis was conducted with the aim of enriching and contextualising their quantitative data analysis rather than providing in-depth understandings of women's SHW experiences (Rockliffe-Fidler & Kiemle 2003).

One mixed-method study used an IPA approach to analyse their qualitative data (Rockliffe-Fidler & Kiemle 2003). However, IPA is used to strengthen their quantitative findings rather than explore what the women consider important to their SHW. Their quantitative findings focus on the women's sexual 'function' (they use the SFQ). The authors themselves state that their aim was not to "exhaust themes" (Rockliffe-Fidler & Kiemle 2003 p. 146) which suggests a less rigorous analysis of the data than that which IPA promotes. It also suggests that their study used IPA in a different way to how it is applied within the current thesis, which I explore in the next chapter. However, the validity of the qualitative findings by Rockliffe-Fidler & Kiemle (2003) is increased through interrater reliability.

It has been argued that using more than one analyst during the qualitative data analysis process improves the reliability of the results; this is called interrater reliability (Pope, Zieblan & Mays 2000). In addition to the Rockliffe-Fidler & Kiemle (2003) stating that they used interrater reliability to increase the validity of their findings, using multiple researchers to check the coding of the data is also discussed by other studies included in this scoping review (Erten et al. 2014; Rutte et al. 2016; Sarkadi & Rosenqvist 2003, 2001). The authors of these latter studies do not discuss interrater reliability but their approach to data analysis, using more than one researcher during the data analysis process, increases the validity of their qualitative results.

In the studies that used qualitative methods (Sarkadi & Rosenqvist 2001) or mixed-methods (Erten et al. 2014; Rockliffe-Fidler & Kiemle 2003; Rutte et al. 2016; Sarkadi & Rosenqvist 2003), the heterogeneity of their samples and the fact that they often do not separate their findings by gender, age or diabetic sub-type makes it difficult to distinguish the data that refers specifically to older women with T2D. It is also unknown whether older women face unique, gendered barriers. SHW differences found between men and women with the scoping review studies highlight the value of studying women's SHW separately to that of men (Bijlsma-Rutte et al. 2017; Lindau et al. 2010; Rutte et al. 2016). Analysing the data from these studies provided the opportunity to compare the SHW experiences and needs of women and men living with T2D. As discussed above, differences were found between the SHW needs and discussions of male and female participants, with women less likely to broach the topic of SHW with their HCPs. Therefore, studies exploring what older women living with T2D consider to be the barriers and facilitators to the discussion of SHW in primary care settings have the potential to make important contributions to knowledge and practice.

The age range of the study samples provides another area for critique of existing research. The first concern in regards to the age of the participants in the scoping review study samples is that only two of the included studies focussed on the age range that is the focus of this review, referring to the age of their participants as "middle-aged" and "older" in the title (Copeland et al. 2012; Lindau et al. 2010). The women participants in these studies were aged between 40-85 years. In the other studies, discerning which data specifically pertained to older women was challenging. Knowledge of which data pertained to older or younger women is important as the scoping review findings highlighted that older women may experience SHW differently to younger women. Reasons for this difference may be linked to experiencing the menopause and changes in intimate relationship (see the scoping review findings above). A clearer understanding of the SHW of older women and what they consider important to their SHW could be achieved by focussing more closely on this sample in future research.

The second concern regarding the age range of participants is that some of the data within this review were collected nearly 20 years ago (Sarkadi & Rosenqvist 2003,

2001). Both the lack of focus on older women and the time that has passed since some of the studies were conducted makes it possible that a significant amount of the data in these studies was not collected from women of the baby boomer generation. As explored in Chapter One, the baby boomer generation experienced social changes which may have influenced their approach to their SHW. Little is known about baby boomer generation approaches to SHW and its discussion with HCPs. The combination of potentially differing experiences of older and younger women and the unique experiences of the baby boomer cohort, suggests that research that explores the SHW experiences of baby boomer women is timely.

Another area of critique lies in the inclusion criteria for some of the studies. Some of the studies had the inclusion criterion that women had a sexual life with a single partner (Erten et al. 2014) or were married (Celik et al. 2015). Inclusion criteria that exclude women who do not have a sexual partner, who have more than one sexual partner or who are unmarried restricts what is known about women's SHW. Also restrictive to the pursuit of knowledge are studies that only interviewed or, permitted entry to the next stage of data collection, women who scored highly on the FSFI or the ASEX questionnaire (thereby labelling them as having a sexual 'dysfunction') (Bjerggaard et al. 2015; Erten et al. 2014). The study by Erten et al. (2014) used the ASEX to measure the sexual experience of their participants. The ASEX was designed to measure sexual experiences, defined as drive, arousal, vaginal lubrication, orgasm and satisfaction from orgasm (McGahuey et al. 2000). It has been used within several studies and has tested high for internal consistency (Erten et al. 2014; McGahuey et al. 2000). Internal consistency is the extent to which the items on a scale accurately measure the construct, in this case sexual experience (Barchard 2010). However, I argue that sexual experiences are subjective and complex to quantify which makes it difficult to design a quantitative tool that is internally consistent and valid for the measurement of sexual health.

Credibility is the qualitative equivalent of internal validity (Korstjens & Moser 2018). Some of the studies identified in the scoping review that analysed qualitative data ensured the credibility of their analysis through investigator triangulation (Erten et al. 2014; Rockliffe-Fidler & Kiemle 2003). Investigator triangulation is the process of using two or more investigators to make decisions around analysis (Korstjens & Moser

2018). Methodological triangulation is a different type of triangulation, referring to using various methods to investigate a research problem (Johnson, Onwuegbuzie & Turner 2007). It is argued that the use of mixed methods to collect the data makes the findings more reliable as they come from multiple sources (Johnson, Onwuegbuzie & Turner 2007). Therefore, this increased the credibility of the qualitative evidence from the mixed-method studies identified in this scoping review (Erten et al. 2014; Rockcliffe-Fidler & Kiemle 2003; Rutte et al. 2016; Sarkadi & Rosenqvist 2003).

The mixed-methods study by Erten et al. (2014) followed up their quantitative data collection, using the ASEX, with an interview on the women's treatment for sexual problems and reasons for taking treatment or not. The exclusion of women with ASEX low scores i.e. not considered to have a sexual 'dysfunction', means that the experiences of these women were not explored. Exploration of the qualitative data of women not considered to have a sexual 'dysfunction' would have enriched their study findings providing information on what a greater range of women considered important to their SHW. The inclusion criteria of the Copeland et al. (2012) study was more considered as they chose to record the level of sexual satisfaction and sexual desire of all participants, regardless of sexual activity. They defined sexual activity as any activity that was arousing to the individual, including masturbation. The study of sexual concerns by Bjerggaard et al. (2015) has an equally broad definition of sexual activity. However, other studies exclude masturbation from their definition (Lindau et al. 2010). These disparate definitions of sexual activity by researchers makes the study findings hard to compare, and reflect ongoing challenges in the field of SHW research.

Different perspectives of SHW, such as those from women who are ethnic and sexual minorities, have potential to contribute to what is known about women's SHW needs and experiences. However, these potentially varying perspectives were not reflected within the scoping review studies. None of the studies included data on their participants' sexual orientation. If women who have sex with women were included, this data was not collected. One study specifically considers the lack of asking participants about their sexual orientation as a limitation (Bjerggaard et al. 2015). Neglecting to collect data on women who have sex with women means that important information is missing from our knowledge in this area. Similarly only two of the studies include data on their participants' ethnic background (Copeland et al. 2012; Lindau et



al. 2010). These studies, respectively, aimed to recruit a target race/ethnicity composition and a nationally representative sample and women living with T2D. This demonstrates that in order to produce research reflective of the population of women living with T2D, women from ethnic minorities should be included. Women from both ethnic and sexual minority backgrounds should be included in research in this area. Women from sexual and ethnic minorities first, may experience their SHW differently and second, deserve to have their voices represented in the literature. Research that includes a range of perspectives is crucial to expanding our knowledge of the potentially diverse range of SHW care needs.

Through the exploration of the background literature, performing a scoping review and a critique of the literature, I have identified several gaps in current knowledge in the area of the SHW of older women living with T2D. These gaps focus on the lack of SHW research in the area of baby boomer women living with T2D, the lack of in depth qualitative research which uses women's voices to understand their SHW and a lack of diversity in those voices. Furthermore, the existing literature does not consider why women may or may not discuss their SHW with their HCPs. The research aim and questions below were developed to bridge these gaps.

## **2.7 Research aim and research questions**

### **2.7.1 Research aim**

The aim of this thesis is to undertake an in-depth exploration of baby boomer women's (aged 50-75 years living with T2D) experiences of SHW discussions in primary care.

### **2.7.2 Research questions**

Primary research question

- What do baby boomer women (aged 50-75 years with T2D) consider the barriers and facilitators to SHW communication in primary care consultations?

Secondary research questions

- What do baby boomer women consider important to their SHW?
- Which factors influence the decision to discuss (or not to discuss) SHW within primary care consultations?
- What role does the HCP play in SHW communication?
- What are the implications of these findings for healthcare practice?

The research aim was designed to provide a broad statement to guide the thesis. The research questions that followed were constructed to allow focus on specific areas of study that the thesis would address. In line with an IPA approach, I wanted to ensure that the women's voices were at the fore so open and exploratory research questions were formulated to encourage an understanding of the women's experiences (Smith, Larkin & Flowers 2009). Designing the research aim and questions was a significant step in the thesis development as it guided methodological and methodical choices that are explored in the two following chapters.

# CHAPTER THREE - METHODOLOGY

## Introduction

Exploration of the extant literature in the previous two chapters identified knowledge gaps which led to the development of the research aims and questions. In this chapter, I justify why an Interpretative Phenomenological Analysis (IPA) approach was chosen to address the research aims and questions. This is accomplished through a discussion of the qualitative paradigm, phenomenology and IPA, as well as consideration of research methodologies that were not chosen. Detailed knowledge of the methodological underpinnings of IPA were key to ensuring coherence throughout, in regards to the thesis design, the analysis of the data and the conclusions reached.

### 3.1 The qualitative paradigm

Paradigms are based on the epistemological and ontological view shared by a scientific community (Holloway 1997; Kuhn 1970). Differing attitudes held by researchers and their communities towards epistemology, the study of knowledge and ontology, assumptions about the world and the nature of being, influence the decision of which methodological paradigm to adopt for a study (Bryman 2016; Crotty 1998). Evidence of my recognition of different epistemological positions is provided in the Preface where I state my epistemological position and how it influenced my decision to develop the thesis using an IPA approach. Within qualitative research, epistemology provides answers to the question “How, and what, can we know?” (Willig 2008a, p. 1), so how best to acquire knowledge and if a valid and reliable claim to that knowledge can be made. Conversely, quantitative research takes a deductive approach, tends to focus on numerical values and is used for determining the generalisability of phenomena (Denzin & Lincoln 2005; Yardley 2000). Quantitative findings are important for assessing treatment outcomes, clinical governance and survival rates, relevant to the biomedical model of healthcare. However, quantitative research is often considered objective. I consider the concept of objectivity to be problematic because I argue that the perspective of the researcher constitutes a position which inherently influences the research process, be it which variables to measure, participants to include or conclusions that are drawn.

Research based in the qualitative paradigm takes an inductive, 'bottom-up' approach to knowledge generation and posits that what can be known is dependent on context; this then leads to reflection on the ontological position being adopted. The ontological stance of a researcher determines whether they believe that the event of interest exists separately from underlying structures or if it depends on interpretation (Campbell & Wasco 2000; Rodriguez & Smith 2018; Stanley & Wise 1993; Willig 2013). Qualitative research tends to adopt the latter approach considering 'reality' to be context-specific and dependent on interpretation (Creswell 2003; Holloway 1997; Ormston et al. 2013; Silverman 2010). While ontological stances are complex, with positions situated along a continuum rather than being categorically defined as objective or subjective, (Shinebourne 2011a), the researchers view of the nature of 'reality' tends to determine whether their research is qualitative or quantitative in nature.

The qualitative and quantitative paradigms are based within the two dominant methodological traditions that exist in health and social research which are naturalism and constructivism (Creswell 2003; Moses & Knutsen 2007). Naturalism is an epistemological position most commonly associated with the belief in an objective reality, a singular truth and quantification of an event before it can be deemed reliable and valid knowledge (Creswell 2003; Pope & Mays 1995). In contrast to naturalism, constructivism is based upon the epistemological premise that the way that people view the world is dependent on a combination of social and contextual factors and that subjective meanings attributed to experiences are changeable (Crotty 1998; Flick, von Kardorff & Steinke 2004; Moses & Knutsen 2007). Applied to health and social sciences it translates as the belief that the construction of 'reality' and 'truth' is based on the perspective of the observer. As Moses & Knutsen (2007) explain:

*Individual characteristics (such as age, gender, race) or social characteristics (such as era, culture and language) can facilitate or obscure a given perception of the world.*  
(p.10)

When applied to practice, qualitative methodologies, which are based in this paradigm, explore understandings of health from the individual's perspective. They offer the researcher the opportunity to interpret the 'reality' from the perspective of the individual and to accept a plurality of understandings (Biggerstaff & Thompson 2008). Thus,

qualitative methodologies are appropriate for gaining a deep understanding in complex areas of research as they allow for the emergence of previously unknown factors that influence the phenomena of interest. They allow the data to inform on phenomena rather than imposing pre-existing theories (Flick, von Kardoff & Steinke 2004).

Recently there has been debate around how data are constructed and use of the terms 'emerging themes' and 'findings' during qualitative data analysis. While qualitative researchers agree that data informs on topics of interest, how the data are generated and analysed is debated (Fugard & Potts 2016; Malterud et al. 2016). Specifically, there is an argument within qualitative research communities that research findings are co-constructed between the researcher and participants, and that there is no one 'reality' waiting to be found (Clarke & Braun 2013). Therefore, the assertion is that the terms 'emerging' and 'findings' do not accurately represent the methodological process of data generation within qualitative research (Clarke & Braun 2013). See Chapter Four – Methods for discussion on the use of the terms 'emerging' and 'findings' within this thesis.

### **3.1.1 Justification for qualitative paradigm**

A qualitative approach was appropriate for this thesis for various reasons. First, the decision to adopt a qualitative approach, and later IPA, was determined by the fact that my position is aligned with inductivity and a belief that the researcher's identity and perspective shape the conclusions drawn. The ontological premise of this thesis assumes that the reality of each participant is based on experience of historical, social and contemporary events which influence their perception of sexual health and well-being (SHW) and communication of it with their healthcare professionals (HCP) (Creswell 2003).

Second, the complexity of SHW and the previously unknown factors involved in the decisions around its communication in a primary care settings meant that a qualitative approach ensured that I would be able to make a contribution to knowledge. The significance that SHW discussions hold for each participant is more important to this thesis than forming hypotheses or seeking causality, which follow a positivist tradition. The inductive nature of qualitative research allows aspects that participants consider

relevant to be explored in greater depth (Foucault & Hurley 1990; Tiefer 1995; Yardley 2000). Rather than using scales designed to measure, predefined variables, a qualitative approach goes some way to ensuring that the elements that participants consider pertinent are not overlooked. In this way, I am able to present in this thesis, a comprehensive understanding of the phenomena under investigation in Chapter Five – Findings and Chapter Six – Discussion.

Further supporting the notion of enabling participants to determine what they consider relevant to their SHW, Tiefer (1995, 2001) urges sex researchers to invest more time in the exploration of women's perspectives. She argues that we should not use measurement tools which impose pre-existing, inadequate paradigms and encourage assumptions which are based on sexual 'function'. She instead argues for research into meanings of SHW in the contexts of women's lives. In situating this thesis within the qualitative paradigm, I am therefore able to explore some of the complexities of the women's experiences of SHW discussions.

Within the qualitative paradigm, there are many approaches to research. In the field of health some of the most commonly used are approaches are discourse analysis, grounded theory and phenomenology (Doody & Bailey 2016; Starks & Trinidad 2007). While all these approaches have advantages, the decision of which to use depends partially on the research aims, research questions, and sometimes, gender of the population of interest as is the case with feminist approaches to qualitative research (this is also briefly discussed below). In this thesis, a phenomenological approach is used, for reasons which are explained in the next section. First, however, I will briefly explain why I decided not to use other commonly used qualitative methodologies.

Grounded theory evolved from sociology with the goal of developing explanatory theories of social processes (Sokolowski 2000; Starks & Trinidad 2007; Willig 2008a). The adoption of a grounded theory approach would generate a theory to explain under what circumstances HCPs and older women with T2D discuss SHW needs. A grounded theory study would have provided a mid-level theoretical account whereas I wanted to provide detailed explorations of individual experiences (Eatough & Smith 2008). While a grounded theory study would have contributed to existing knowledge

in a distinct manner, theory development was not the objective for this study and so I discarded the possibility of this approach.

Discourse analysis was another approach which I considered but chose not to adopt. Discourse analysis evolved from linguistic study and focuses on the role of language in the construction of meaning (Starks & Trinidad 2007). Strongly based in social constructionism, it focuses on how people make use of linguistic and cultural resources in specific contexts (Smith, Flowers & Larkin 2009; Willig 2008b). This approach would provide an opportunity to learn about how participants were *constructing* their accounts of experiences rather than how they were making sense of their experiences (Smith, 2011; Starks & Trinidad, 2007). I wanted to get close to the women's experiences of SHW communication but I felt that a methodology that focussed primarily on language and social structures may obscure some of the subtleties of the women's experiences. I felt that there would be a danger of attributing too much importance to the performative act of communication in primary care rather than women's experiences and perspectives of SHW, T2D *and* communication. However, similarities between discourse analysis and IPA have been noted in the literature, specifically around their shared concern about the implication of context (Smith 2011; Smith, Flowers & Larkin 2009). Differences lie however, in that discourse analysis has a more obvious focus on the structural factors implicated in the phenomena of interest. Discourse analysis will be explored in more detail later in this chapter, when its contribution to the development of IPA is discussed.

In addition to the commonly used qualitative approaches described above, I also considered adopting a feminist approach<sup>3</sup> within the thesis. I initially considered this approach as I am a feminist (see Preface) and this thesis is focussed on women's experiences. This thesis is not feminist phenomenology, but it is influenced by feminism because of my position as a feminist. I now provide a brief rationale for my decision not to adopt a feminist approach. Feminist approaches are designed to seek social justice, enhance women's influence within society, and explore our ways of understanding the world (Gergen 2011; Hesse-Biber & Leavy 2007; Stanley & Wise

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<sup>3</sup> Contemporary feminist scholarship includes both qualitative and quantitative methodologies (see Campbell & Wasco, 2000), however, in the context of the current research, consideration of the adoption of a feminist approach focussed on qualitative feminist approaches.

1993). A plurality of meanings have been applied to the term 'feminism'. It is generally agreed between scholars and theorists that 'feminisms' is more appropriate nomenclature to encapsulate the wide range of methodologies and epistemological stances that exist (Campbell & Wasco 2000). However, three main feminist epistemologies have emerged as dominant (Brooks & Hesse-Biber 2007).

The three dominant feminist epistemologies frequently discussed in the literature are: empiricism (an objective world exists and we need to explain that world in a way that does not reflect gender biases), post modernism (that there is no one truth in any form) and standpoint (no objective world exists and a person's 'reality' is constructed based on their class, race, gender and sexual orientation) (Brooks & Hesse-Biber 2007; Campbell & Wasco 2000; Stanley & Wise 1993). Feminist standpoint epistemology, the feminist methodology most closely aligned with the thesis methodology, encourages an understanding of the world through women's eyes and the application of knowledge to generate social activism and change (Brooks 2007). There is undoubtedly overlap between the phenomenological endeavour of this thesis and feminist standpoint theory, particularly using women's lived experiences to generate knowledge and learn more about the world. However, concerns over the differing aims of feminist standpoint and phenomenological approaches led to the rejection of a feminist methodology. Feminist standpoint research has the aim of using experiences to critically examine society as a whole and report the struggle for women's liberation. This differs from phenomenology, and IPA in particular, which endeavours to use these experiences to idiographic ends, to understand the meaning of a particular event or situation for the individual (Brooks 2007; Hill Collins 2000; Smith, Flowers & Larkin 2009).

An additional reason for the rejection of this approach is around the concept of a united feminist standpoint. Feminist scholars argue that women hold multiple standpoints across a diversity of lives (Brooks 2007; Brooks & Hesse-Biber 2007; Hill Collins 2000). As well as being women, the thesis participants were also older, living with a chronic illness, from various social classes, sexual orientations and ethnic backgrounds. Within this thesis, the intersections of these aspects of women's lives were important and indeed, form the basis for the theoretical contribution to knowledge that this thesis makes (see Chapters Five – Findings and Chapter Six – Discussion). In adopting a



feminist standpoint approach for this thesis, I had concerns that the other aspects of the participants' worlds may be overshadowed by focussing on gender. Therefore, while the thesis developed partly due to the recognition of gender inequalities, I did not want to prioritise gender inequalities over other inequalities that the women may have experienced linked to their age, chronic illness or any other aspects of their lives. However, rather than denoting that the thesis findings cannot make a contribution to the body of feminist literature, I suggest that the thesis findings make contributions to several bodies of research, one of which is feminist research. These contributions are discussed in Chapter Six – Discussion.

Due to the disparate aims of feminist and phenomenological approaches and an objection to prioritising gender, I decided not to adopt a feminist approach. However, despite making a conscious decision not to adopt a feminist approach, it is pertinent to recognise that one of the greatest similarities between phenomenological and feminist approaches is that they both transform reflexivity from a problem to a resource (Brooks & Hesse-Biber 2007; Moran 2000; Smith, Flowers & Larkin 2009).

Phenomenological and feminist approaches have also previously been combined (Dukas 2014; Evans et al. 2014; Fisher 2010; Zeiler & Kall 2014). Supporters of feminist phenomenology argue that it holds potential to obtain significant understandings of women's lives that cannot be grasped by the other qualitative approaches discussed above (de Beauvoir 1949; Evans et al. 2014). Conversely, others argue that, despite affinity of theoretical concern for giving 'voice' to participants, that feminist theory is potentially incompatible with phenomenology due to inattention to women's voices in the development of phenomenology and the differing aims of phenomenological and feminist research which are discussed above (Evans et al. 2014; Fisher 2010, 1999). I reflect on my position as a feminist and how this influenced the thesis development, and my interpretation of women's accounts, in Chapter Eight – Strengths, limitations and reflexivity.

## 3.2 Phenomenological approaches

Phenomenology originated as a philosophical approach to the study of lived experience and the way in which these experiences are perceived and given meaning by an individual (Moran 2000; Sokolowski 2000; Willig 2013). Key philosophers who influenced the development of phenomenology, and particularly those that influenced the development of IPA, are discussed later in this chapter. The aim of phenomenological research is "...to capture as closely as possible the way in which the phenomenon is experienced within the context in which the experience takes place" (Giorgi & Giorgi 2003, p. 27). Accordingly through a reliance on the participants' accounts of their experiences, phenomenology permits in depth and personal understandings (Willig 2008a). Phenomenological research refers to the nature of social reality, making no claims about the cause of the participant's experience nor whether it is a reflection of 'reality' but rather it studies lived experience, exposes established assumptions and enables the researcher to obtain a profound understanding of a phenomenon (Giorgi 1994; Norlyk & Harder 2010; Sarkadi & Rosenqvist 2001; Starks & Trinidad 2007).

Phenomenology has now been adapted for use as a methodology in health and social research, and is frequently employed in nursing research (Balls 2008; Crotty 1996; Lopez & Willis 2004; Norlyk & Harder 2010). However, in the past phenomenological nursing research has faced criticism for a lack of critical thinking and a misunderstanding of key concepts resulting in research that was inconsistent with the original principles of phenomenology (Crotty 1996; Paley 1997). Research published more recently has urged nursing researchers to pay greater attention to philosophical underpinnings and not only discuss key concepts but ensure that these are implemented within their research (Norlyk & Harder 2010). A key article by Norlyk & Harder (2010) highlighted some of the methodological difficulties that nursing researchers face when using phenomenological approaches. Specifically, they refer to nursing research as focussing on the descriptive experience of participants without taking into account the specific context to which the participant has attached meaning. An additional concern that they highlight refers to the lack of adherence to a specific phenomenological approach in nursing research. Therefore, they suggest that nursing

researchers should be more definitive about which phenomenological approach they are using in order to ensure methodological clarity (Lopez & Willis 2004).

All phenomenological research focuses on what experiences mean to a participant but differences exist in regards to whether the approach is descriptive or interpretative (Willig 2013). Descriptive phenomenology, most commonly associated with Giorgi's phenomenology (Giorgi 1994), is concerned with gaining insight into phenomena based entirely on the participant's accounts of their experiences. Interpretative phenomenology focuses on the role of interpretation of a small set of accounts while taking the social and theoretical context into account (Eatough & Smith 2008). The interpretative role of the researcher is also granted more credence than in descriptive phenomenology. I discuss this in more detail later in this chapter.

Due to the aims and usage of phenomenological research, discussed above, phenomenology was deemed a befitting approach for placing the women's experiences of SHW communication at the heart of this thesis. However, an interpretative phenomenological approach was chosen over a descriptive phenomenological approach. As shown in Chapter One – Background, the social context of SHW, baby boomer women and T2D is relevant when considering their SHW discussions. A descriptive focus based entirely on the participants' accounts would not enable me to consider the wider social context in which SHW discussions were taking place. In consequence of the emphasis on interpretation and the consideration of the wider social context, IPA was chosen over descriptive phenomenological methodologies.

### **3.3 Interpretative phenomenological analysis**

#### **3.3.1 Origins**

IPA, an interpretative phenomenology, was developed in the mid-1990's within the discipline of psychology (Smith, Jarman & Osborn 1999; Smith 1996). It emerged as a compromise between the social cognition and discourse analysis paradigms (Brocki & Wearden 2006; Smith, Jarman & Osborn 1999; Smith 1996). Social cognition is an approach that has an epistemological and ontological focus on mentalism and the

quantification of participant's cognitive activity (Smith, Flowers & Larkin 2009). Discourse analysis challenged this approach by claiming that often the participants' verbal reports do not reflect their underlying cognitions but rather the context that the participants find themselves in (Potter & Wetherell 1987). This balance between the cognitive processes that participants experience and the recognition of context as central to sense-making is one of the theoretical foundations of IPA, along with symbolic interaction and Husserl's phenomenology (Eatough & Smith 2008; Shinebourne 2011a; Smith 1996).

Symbolic interactionism is the way that people act towards situations based on the meaning that they ascribe to them, but also the effects that social interactions and context have on their interpretation (Denzin 2004; Smith 1996). According to Benzies & Allen (2001), there are three basic assumptions attached to symbolic interactionism. These being that first, people interpret the world based on the meaning that things have for them. Second, these meanings are created through interactions with other people, and third that these meaning are constantly evolving. When these three assumptions are applied to SHW discussions in primary care consultations, it would suggest that women and HCPs decisions to discuss SHW are, at least partially, based on the meanings that they attribute to SHW, ageing, women, living with T2D and the primary care consultation.

The symbolic interactionism aspects of IPA asserts that people understand their experiences in the wider, social context and are not passive perceivers of an objective reality (Brocki & Wearden 2006; Smith 1995; Willig 2008b). Symbolic interactionism has been included as part of the theoretical foundation of the current thesis because of its importance to IPA and the thesis focus on communication in the primary care context. IPA researchers should be aware that access to their participants' experiences is only partially feasible as the researcher's own social and interpersonal context also influences the research process and conclusions that are drawn (Brocki & Wearden 2006; Lavie & Willig 2005). The following sections discuss the key phenomenological philosophers whose work influenced the thesis development, and the major theoretical underpinnings of IPA; phenomenology, hermeneutics and idiography.

### **3.3.2 Interpretative phenomenological analysis and phenomenology**

Husserl, one of the major phenomenological philosophers, considered how to set aside the preconceptions of the observer and allow the experience of the observed to come to light (Smith, Flowers & Larkin 2009). His phenomenology focussed on 'epoché' or 'bracketing' our assumptions about the world, removing oneself from preconceptions and focussing instead on a description of the phenomenon (Balls 2008; Smith, Flowers & Larkin 2009; Sturgess 2018). Husserl's vision of phenomenology was fundamental in the development of IPA (Smith, Flowers & Larkin 2009). However, in contrast with Husserl's descriptive approach to phenomenology which requires the bracketing of our fore conceptions, an IPA approach questions our ability to bracket. It argues that we are unable to bracket our antecedent understandings and beliefs and that these inevitably influence the interpretation of our participants' accounts (Lopez & Willis 2004; Rodriguez & Smith 2018). Furthermore, an IPA approach considers the researchers' thoughts, feelings and experiences to be legitimate and necessary components for making sense of participants experiences rather than as a source of bias (Smith, Flowers and Larkin 2009). Because of the key role of the researchers interpretation, IPA studies require researchers to evaluate their own experiences and the role of these experiences in shaping their interpretation of the participants' accounts (Eatough & Smith 2008). Heidegger, a former student of Husserl, developed a less descriptive, more interpretative phenomenology, which was committed to the concept of hermeneutics (Tuffour 2017).

### **3.3.3 Interpretative phenomenological analysis and hermeneutics**

Hermeneutics is the theory of interpretation, and refers to the realisation that interpretation of what we see is connected to previous experience, knowledge and social context (Clarke 2009; Eatough & Smith 2008; Pringle et al. 2011; Willig 2008b). Compared with descriptive phenomenology, IPA identifies more strongly with hermeneutic traditions laid down by Heidegger, Merleau-Ponty, Sartre and Ricouer (Tuffour 2017). Heidegger and Sartre's phenomenology are centred around existentialism while Merleau-Ponty's work focuses on embodiment (Smith, Flowers & Larkin, 2009; Tuffour 2017). The work of different philosophers becomes more or less influential for the development of research depending on the aims and research questions posed by the research, as well as the ontological perspective of the

researcher. In the development of this research, the works of Heidegger and Ricoeur have been particularly influential.

Heidegger aimed to understand existence and believed that this understanding was developed through the analysis of being (Davidsen 2013; Heidegger 1962; Smith, Flowers & Larkin 2009). He argued that for people, being is always being-in-the-world or 'dasein'. Dasein is a concept concerned with how the world appears to us and how it is made meaningful through discourse and interactions with others (Davidsen 2013; Sturgess 2018, 2016). The concept of dasein underpins this thesis as how women discuss their SHW in primary care settings, and also within interviews, is influenced by intersubjective understandings and relationships with others in the world e.g. with their intimate partners, General Practitioners (GP), practice nurses or interviewer. Understandings of the women's 'lifeworld' will generate knowledge about discussions in primary care and, as I will demonstrate in Chapter Six, they are inextricably linked.

The lifeworld is a term, introduced by the philosopher Husserl and used by Heidegger, to show that individuals' lives are influenced by the context in which they live, their previous experiences and their taken-for-granted assumptions (Ashworth 2008; Heidegger 1962; Tuffour 2017). As a researcher entering into the participants' lifeworlds, it is important to encourage participants to describe their feelings, interactions, relations to others and previous experiences in order to get as close to the experiences of the 'other' as possible (Larkin, Watts & Clifton 2006; Lopez & Willis 2004; Smith, Flowers & Larkin 2009; Tuffour 2017). The focus on the lifeworld, and the meaning of 'being' in an intersubjective context and situation, is where Heidegger turned his attention (Tuffour 2017). Thus, hermeneutics is not just the study of the subjective understandings of individuals but also "...explores what the individual's narratives imply about what he or she experiences every day." (Lopez & Willis 2004, p.729). This focus on, not only the description, but also the implication of meaning of the experience within the lives of individuals means that the researcher interprets the participants' words or worlds. This again connects with the co-construction of knowledge between the researcher and participants, discussed earlier.

Heidegger argued that our understandings of things are based in our own experiences and we cannot objectively judge or explain what we are seeing (Davidsen 2013). Thus,

finding meaning in what we are seeing, always involves a degree of interpretation (Smith, Flowers & Larkin 2009). In practical terms, it means that I consider my analysis of the women's accounts to be based upon my position in the world; a position from which I can never separate myself from in order to analyse women's accounts. As Smith, Flowers & Larkin (2009) summarize, the researcher:

*“...brings their fore-conceptions (prior experiences, assumptions, preconceptions) to the encounter and cannot help but to look at any new stimulus in the light of their own prior experience...”*  
(p.25)

These fore-conceptions, which shape how the researcher interprets the participant accounts, are unavoidable but also advantageous. They allow the researcher access to perspectives of the experience that the participant may not be aware of, meaning that they form legitimate components for sense-making becoming a part of the research findings (Lopez & Willis 2004; Smith 1996; Willig 2008b). This researcher's interpretation of the participant's lifeworld is part of what is known as the 'double hermeneutic' (Pringle et al. 2011; Smith, Flowers & Larkin 2009). The double hermeneutic element of IPA transforms research from the description of an experience to a context specific understanding of a phenomenon (Clarke 2009; Lopez & Willis 2004).

This is the balance between understanding participant experiences as they were lived and additionally, interpreting and understanding the context in which the experience took place. However, it should be noted that IPA views the participant's experience to hold priority over the researcher's preconceptions (Shinebourne 2011b). These preconceptions may only become known once the analysis is underway, highlighting the need for ongoing reflexivity in IPA research. While I am not claiming that the data analysis presented in Chapter Five – Findings is an objective representation of women's accounts, the Discussion of the Findings in Chapter Six, is where I shift from “...immersion in the world of the participants” to viewing their accounts “...through a lens of cultural and socio-historical meaning.” (Tuffour 2017 p. 3).

Ricoeur sheds light on the differences in these perspectives (Ricoeur 1970; Tuffour 2017). Building on Heidegger's dedication to hermeneutics, he devised two forms:

hermeneutics of empathy and hermeneutics of suspicion (Ricoeur 1970). The former lays the groundwork for more descriptive approaches, whereas the latter attempts to explore accounts from a more distant perspective (Davidsen 2013; Shinebourne 2011b). The hermeneutics of suspicion have previously been linked to psychoanalysis and Marxist theory (Ricoeur 1970) but as they apply within IPA they encourage a questioning, critical, interpretative approach to understanding participant accounts, providing a perspective that the participants may not be able to see themselves (Davidsen 2013; Eatough & Smith 2017; Smith, Flowers & Larkin 2009).

However, my interpretation of the participant's account does not discount the participant's perspective and, in accordance with the phenomenological tradition, the objective remains to gain an emic perspective of the participant's experience (or as close as is possible). IPA accepts that conclusions drawn from the data are co-constructed and seen through a contextual lens. Because of the co-construction of meaning between the participants and researchers, IPA requires an iterative interpretative process, with the researcher moving constantly between the part and the whole and reflecting on their fore-conceptions rather than attempting to understand the phenomenon as an independent event. This cyclical process of moving between the data and context is called the 'hermeneutic circle' (Crotty 1998). While IPA's approach to hermeneutics has adopted elements of Heidegger's and Ricoeur's phenomenology, the idiographic commitment differentiates it (Pringle et al. 2011).

### **3.3.4 Interpretative phenomenological analysis and idiography**

The idiographic focus of IPA, on the individual rather than the universal, is in contrast to nomothetic approaches which are concerned with making group or population level claims in order to form theories of human behaviour (Smith, Flowers & Larkin 2009). IPA is idiographic on two levels. First, in the detail and depth of analysis. The depth of analysis provides unique insight into participants' experiences that other methodologies may not offer. The second level in which IPA is idiographic is through its commitment to understanding the meaning of a particular event or situation for the participant (Smith, Flowers & Larkin 2009). These two levels however are interlinked. Through the in-depth and thorough analysis of individual accounts the universal can emerge allowing researchers to "...connect the individual unique life with a common humanity" (Eatough & Smith 2008). This highlights the contribution that detailed



inspection of the individual can make towards understanding shared aspects of a phenomenon. Thus, exploring the subjective perspectives of individuals allows for a better understanding of phenomena of interest in general. The idiographic nature of IPA, the requirement of a detailed examination of particular instances, influenced upon sample choice and data analysis (Shinebourne, 2011). The sample choice and data analysis process are discussed in the next chapter, Methods.

### **3.3.5 Criticisms of interpretative phenomenological analysis**

In order to make a balanced decision about whether to develop an IPA study, I engaged with the current criticisms of IPA in the literature. In recent years, a debate has ensued between phenomenologists. Within this section, some of the criticisms directed at IPA are addressed.

The lack of a prescriptive method in IPA has been posited by Giorgi (2010, 2011) as a demonstration of poor scientific practice. However, I argue that the lack of prescriptive method does not denote poor scientific practice if it is well articulated within the research report. This means that critical others are able to follow the steps taken by the researcher and replicate the study if they wish to, that is not to say that they will obtain the same results, due to a whole host of factors, discussed previously in this chapter. Furthermore, I argue that the lack of prescriptive methods has two advantages (Brocki & Wearden 2006; Smith, Flowers & Larkin 2009; Tuffour 2017). First, it enables the design of research that suits the research aims rather than imposing pre-established rules on what can be discussed within interviews and during data analysis. Second, it permits accessibility to the methodology for a range of researchers not just those that are experts in phenomenology.

This brings me to the second main criticism that IPA has recently faced, which is that IPA research does not address phenomenological questions (van Manen 2017). Armed with the knowledge of the current criticisms, I ensured that this thesis was developed bearing in mind genuine phenomenological understandings and insights. I did this through engaging not only with the seminal IPA text (Smith, Flowers & Larking 2009) but also wider phenomenological literature which ensures that my findings are rooted in the wider discipline of phenomenology (Giorgi & Giorgi 2003; Heidegger

1962; Lopez & Willis 2004; Moran 2000; Reiners 2012; Ricoeur & Kearney 1996; Sturgess 2016)

Another criticism directed at IPA is that it does not take sufficient account of the role of language and that it "...relies upon the representational validity of language" (Willig 2008b p. 66). Arguably, not being able to express oneself in an articulate fashion means that the description of experiences does not reflect the lived reality for that person as it relies on the participant's ability to describe their experiences and the researcher's ability to communicate the nuances of the participants' experiences. This means that language may, in some cases, prohibit access to, and description and interpretation of, participant's experiences. This criticism is particularly pertinent within the current topic of SHW discussions where the phenomena of interest can be difficult for some women to discuss. I explore the role of language, and silence, and their implications for the thesis findings in Chapter Six – Discussion.

While IPA can generate detailed and rich descriptions of participants' perceptions of their experiences in different contexts, another criticism of IPA is its lack of ability to explain *why* phenomena take place (Tuffour 2017; Willig 2008b). However, I argue that through a focus on rich descriptions from the participants' perspective, in depth analysis and the researcher's interpretation compelling suggestions for why a phenomenon occurs can be posed. Again, this will be seen in Chapter Six where I connect the women's accounts of SHW discussions to existing literature and my own interpretations to suggest reasons why SHW discussions may or may not take place in primary care settings.

### **3.3.6 Justification for interpretative phenomenological analysis**

Having explored the history of IPA along with some of its criticisms, the rationale for choosing IPA for this thesis is now presented. IPA was chosen for several reasons, some of which are related to the criticisms presented in the previous section. First, as with the decision to adopt a qualitative methodology, my epistemological and ontological position were deciding factors. My belief is that knowledge does not exist without interpretation by the observer and that SHW is a holistic, context-dependent concept, which aligns with the underpinnings of IPA. This is twinned with the belief

that my own experiences during and prior to embarking upon this thesis have shaped my interpretation of the data (Biggerstaff & Thompson 2008).

Second, the exploratory nature of the aim and research questions are aligned with the exploratory, in-depth nature of an IPA approach, which facilitates insight into and comprehension of the lived experiences of the participants (Flick, von Kardoff & Steinke 2004; Willig 2008b). While it could be argued that all qualitative methodologies seek to comprehend the experiences of participants, the idiographic focus of IPA in particular allows for the investigation of convergence and divergence within a small number of accounts and the interpretation of meaning by the researcher (Eatough & Smith 2008; Smith, Flowers & Larkin 2009; Smith 1995; Tuffour 2017; Willig 2008b). As discussed in Chapter One – Background, the majority of existing research on the sexual health of older women with T2D focuses on sexual ‘dysfunction’ (Ammar et al. 2016; Bağ et al. 2017; Bal et al. 2015; Bjerggaard et al. 2015). However, in order to explore if and how these SHW changes impact upon baby boomer women’s lives, a manner of investigation which prioritises the first person experience is advantageous.

As previously discussed, there is existing research on women’s sexual health, older women’s sexual health and the sexual health of women living with T2D. However, there is very little research which considers how these aspects may overlap. Determining where these aspects intersect within women’s lives is complex and accordingly benefit from close analysis of the lifeworld. This close analysis of aspects of importance to individuals will enable an understanding of what participants consider to be the barriers and facilitators to SHW conversations in primary care settings. Given IPAs focus on understanding experiences in given contexts, it is useful for generating insights into the SHW meanings that older women living with T2D attribute to the specific context of primary care (Smith, Flowers & Larkin 2009). This leads to the third justification for using an IPA approach for the thesis

IPA is increasingly being used in health-related research, where there is an intrinsic focus on patient care, as researchers realise that IPA is a useful tool for challenging assumptions, the ‘othering’ people, and the biomedicalisation of health behaviours and sex (Balls 2008; Clarke 2009; Gaveras et al. 2014; Smith 1996; Smith 2011; Tiefer 2007). While IPA has been used in the field of SHW, and specifically in the field of

female SHW (Duncan et al. 2001; Free, Ogden & Lee 2005; Holt & Slade 2003; Lavie & Willig 2005; Sanders & Carter 2015), it has not yet been applied to the domain of older women and SHW nor used to explore SHW discussions. An IPA approach allowed me to observe and understand the personal meaning that older women with T2D assign to SHW discussions in primary care consultations and thus, generate original contributions to existing knowledge (Smith, Flowers & Larkin 2009).

### **Summary of the Methodology Chapter**

This chapter has not only provided an overview of the qualitative paradigm, phenomenology and IPA, but also, a justification for the decision to use these approaches to fulfil the thesis aim, and answer the research questions. Additionally, explanations for why other methodologies were rejected have been included demonstrating the conscientious manner in which the thesis has been developed. The inclusion of a theoretical backdrop, and discussion of some of the main criticisms of IPA, have helped to demonstrate the careful construction of this thesis. In the next chapter, I describe and justify my methods of recruitment, data collection and data analysis, and demonstrate their suitability for this IPA thesis.

# CHAPTER FOUR - METHODS

## Introduction

The previous three chapters have discussed the need for research which takes an in-depth look at the lived experiences of baby boomer women living with Type 2 diabetes (T2D) regarding their sexual health and well-being (SHW) communication. To address the research aim and questions, I carefully considered the most appropriate methods to use. In this chapter I present an attentive description of the research process and how this thesis developed, describing participant recruitment, sampling, data collection and analysis. The level of detail to which I describe my process is a key aspect of ensuring the quality of this thesis, which I discuss in more detail in Chapter Eight – Strengths, limitations and reflexivity. During this stage of the research, I paid close attention to the ethics of conducting health research on the sensitive subject of SHW and how to incorporate these into the design and execution of this thesis.

### 4.1 Ethical considerations

The University of Sheffield Research ethics policy states that maintaining the “...dignity, rights, safety and well-being of human participants” is the priority of any research undertaken (University of Sheffield 2012, p. 6). SHW is a sensitive subject, so in order to prevent harm to the participants and ensure that ethical principles were upheld, several measures were taken (Hopf 2004; Silverman 2010). These were seeking ethics approval from the School of Nursing and Midwifery, ensuring that the participants were fully informed about the study before consenting to participate and maintaining the confidentiality and anonymity of the participants.

#### 4.1.1 Ethics approval

I submitted my ethics application to the School of Nursing and Midwifery, University of Sheffield Ethics Committee in July 2016. I received approval on 22 August 2016 (see Appendix C). In January 2017, recruitment slowed so I applied for an amendment to my original ethics application requesting permission to recruit from additional settings (a local Afro-Caribbean Organisation and additional South Yorkshire Diabetes UK groups). This permission was granted (see Appendix D – Letter of approval for minor amendment to ethics submission).

#### **4.1.2 Participant information and consent**

Prior to interviews, the participants received an information sheet, either via email or hard-copy (see Appendix E – Participant Information Sheet), explaining the aim of the study, interview topic, risks, benefits, that participation was voluntary, how data would be collected, who would have access to the recordings and an offer to see their transcript and/or publications resulting from the research. The information sheet ensured that participants were fully informed about the study and their role.

Providing a detailed information sheet in lay language that was easy to understand ensured that participants were able to make reasoned decision, fully informed as to what they were consenting to (Holloway 1997). In addition to providing this information, the researcher's judgement was also used to determine whether participants had the capacity to consent (Department of Health 2009). Capacity to consent was also implied in that the women interested in participating contacted the researcher.

At the beginning of the interviews, I asked the women to read through the Information Sheet (Appendix E) and sign and date the Informed Consent Form (Appendix F) if they were still happy to participate. Two consent forms (see Appendix F) were given at the beginning of the interview, which both I and the participant signed. Participants were made aware that even if they signed, they could stop the interview at any time and withdraw their consent up to one month after the interview. One month was considered the time that transcription would have been completed and analysis would have begun and so I considered it an appropriate amount of time to give participants to withdraw before their interview would contribute to findings. One copy of the Informed Consent Form was kept by the participant and the other by myself. Verbal consent was also audio-recorded before the interview commenced as further confirmation of voluntary participation (Smith et al. 2009). With their consent, I then switched on the audio recorder and asked for their verbal confirmation that we could start the interview.

At the end of each interview, I thanked the participant and ensured that they had the Information sheet (see Appendix E – Participant information sheet) and told that they could contact me at any time. I also gave them a sheet with details of where they could

access sexual health support, in case they wanted to discuss matters that arose in greater detail (see Appendix G – Sexual Health Support sheet).

### **4.1.3 Confidentiality and anonymity**

I completed the 'Protecting Research Data' course at the University of Sheffield to ensure that I was clear on how to manage the data in a way that protected the confidentiality and anonymity of participants. The confidentiality of the participants was respected throughout and only the researcher and her supervisory team had access to the recordings and transcripts. All identifying information was kept in a secure, private locker that only the researcher had access to. Consent forms, which were read and signed before the interview began, had the names and signature of participants but did not contain the participant's pseudonym (Holloway 1997). One copy was given to the participant and one was kept by the researcher. Once the interview had been recorded, it was transferred to a password protected file on the researcher's computer and a hard drive.

Close attention was paid, especially during transcription, to details which may have threatened the anonymity of participants. To anonymise the transcript, I transcribed recordings, using pseudonyms, and vague geographical terms to ensure that the participants could not be identified. Once I had transcribed the interview, I deleted it from the voice recorder. Having detailed the key ethical considerations for this thesis and the ways in which the participants were protected, I now move onto describing the how the inclusion and exclusion criteria for the sample was developed.

## **4.2 Developing the inclusion and exclusion criteria**

Defining the inclusion and exclusion criteria of the sample was an important part of ensuring that this thesis addressed the research aim and questions. In part due to the lack of previous research that focussed solely on the perspectives of older women with T2D, as discussed in previous chapters, I aimed to recruit this population. The decision to focus on such a specific sample (baby boomers, women living with T2D) was driven by the desire to fill knowledge gaps around the SHW of older women with T2D as well as the recommendation of homogeneous samples for interpretative phenomenological analysis (IPA) studies (Smith, Flowers & Larkin 2009).

The boundaries of homogenous sampling, choosing participants who have similar characteristics, vary depending on the topic under investigation. Within the current thesis, the common features of living with T2D within the UK, being older and being a woman denoted a considerable degree of homogeneity in itself. Therefore, I considered that the homogeneous nature of the sample would permit a detailed examination of convergences and divergences between the participants' accounts.

As stated, I aimed to recruit a sample that was homogenous in regards to their birth cohort, gender and diagnosis of T2D. However, diversity was sought regarding other aspects of the women's lives. The homogeneity principle of IPA is discussed frequently in the literature and considered imperative to an IPA approach (Shaw et al. 2014; Smith 2011a; Wagstaff et al. 2014). However, the way in which this principle is adhered to varies greatly between high-quality IPA studies in the area of SHW (Flowers et al. 1997; Jarman, Walsh & De Lacey 2005; Sanders & Carter 2015). Some studies in the area necessitate that the individuals in their samples all have the same sexual orientation and class background but do not require that they have a similar age range (Flowers et al. 1997). Whereas others consider that they achieve heterogeneity of their samples based on their participants' gender and health condition but do not require that their sample are of a similar sexual orientation nor cultural background (Jarman, Walsh & De Lacey 2005; Sanders & Carter 2015). Therefore, it appears that definitions of heterogeneity, and how it is applied within studies, are at the discretion of the researcher. Part of the researcher's decision is likely determined by the aim of the research. For the current thesis, as the aim was to explore baby boomer women's (aged 50-75 years living with T2D) experiences of SHW discussions in primary care, I considered it appropriate not to exclude certain groups of baby boomer women living with T2D.

An additional motive for choosing a relatively wide inclusion criteria i.e. not focussing on one ethnic group or women who identify as one sexual orientation, was the lack of previous research in this area. As this is the first IPA study to look at SHW discussions between baby boomer women and their HCPs, the wider inclusion criteria was designed to capture a range of women's voices and identify similarities and differences within and between participant accounts. It was important to include women from a diverse range of backgrounds because we do not know where the similarities and



differences lie. The exploration of the women's diverse experiences was achieved through the detailed examination and analysis of the women's accounts of their lived experiences.

I endeavoured to include women who were not sexually active. Many studies on SHW and older women exclude women who are either not married and/or not sexually active, and definitions of sexual activity differ between studies (Bjerggaard et al. 2015; Celik et al. 2015; Copeland et al. 2012; Lindau et al. 2010). As this thesis endeavoured to explore SHW from a holistic perspective, having an intimate partner or being sexually active were not considered appropriate as inclusion criteria.

As discussed in the Section 4.1 Ethical considerations, the participants' ability to consent was determined through both my judgement and that women who were interested in participating contacted me for more information. These measures have both been reported as appropriate for demonstrating consent in health research (Department of Health 2009). Concerns around the capacity to consent, as well as practicality, contributed to the decision not to recruit women who were unable to read, understand and speak fluent English.

### **4.3 Inclusion and exclusion criteria**

The inclusion criteria stipulated that participants had to be:

- women between the age of 50 and 75
- diagnosed with T2D
- able to read, understand and speak fluent English
- able to consent to take part in research

### **4.4 Sampling and recruitment**

Purposive sampling, whereby participants are selected according to a specific criteria, was used to ensure that participants "...granted access to a particular perspective" (Smith, Flowers & Larkin 2009, p. 49); in this case the perspective was participants' experiences of SHW discussions in primary care. The definition of purposive sampling used within this thesis is one whereby participants are selected according to the

inclusion criteria stipulate above, designed to fulfil the research aim and questions (Willig 2008a). As stipulated in the research aim at the end of Chapter Two, I decided to focus this thesis on women with T2D aged between 50 and 75 as this includes the baby boomer generation. I focussed on the recruitment of baby boomers because this generation are reported to have experienced specific social changes that differentiates them from the generations that went before them or came after them (Arber, Davidsen & Ginn 2003; Bristow 2015).

After ethical approval was granted, I began recruiting participants. Recruitment took place between August 2016 and March 2017 (see Appendix C – Letter of approval from University ethics). First, I recruited participants through contacts made when attending meetings and events with Diabetes UK, Sheffield over the period of a year. While attending these meetings, I shared details about my research and once ethical approval had been granted, approached them again to discuss whether they would like to participate in the study and/or give them the recruitment leaflet (Appendix H – Recruitment Leaflet). The wording of the recruitment leaflet was carefully considered with my supervisory team and the decision was made to use the phrase “intimate relationships” as there was concern that framing the study a “sex” study may have discouraged some participants. Studies in the area of sexuality, in addition to engagement work that my supervisors were undertaking in Sheffield on the topic, suggested that the term “intimate relationship” may have been more acceptable to older adults than the term “sexual health” (Politi et al. 2009). Furthermore, alluding to “sexual health” in the recruitment material may have led women who did not consider themselves sexually active to assume themselves ineligible for participation.

Nevertheless, it was important to ensure that women understood the research aim. Accordingly, in order to balance, not discouraging women from participating with ethical issues around consent, I chose to use the terms “intimate relationships, well-being and health” in the recruitment leaflet. I then included the terms “sexual health, well-being and intimacy” in the information sheet which they saw subsequently. At the point of reading the information sheet, the women then had the option of not taking part before confirming participation. Thus, ensuring that women were able to consider whether they wanted to consent to take part in the research. The women’s decisions of whether to participate and which aspects of SHW to discuss were likely shaped by

words and phrases that I used in the Information Sheet and recruitment leaflet (see Appendix E – Participant Information Sheet and Appendix H – Recruitment Leaflet). This led me to think that if I used the word “sexuality” instead of the phrase “sexual health and well-being”, the women’s accounts and the subsequent study findings may have been different, a point which I reflect on in Chapter Six – Discussion.

Once a woman showed interest in participating and agreed that I could contact her, I wrote down her contact details and she was given or emailed the Information Sheet, depending on her preference (see Appendix E – Participant Information Sheet). I then contacted women, either through email or phone depending on their preference, and we organised a date, time and place to meet that was convenient for her. I recruited three participants through attending local Diabetes UK meetings. The Recruitment leaflet and Information sheet were also included in the monthly Diabetic UK newsletter, which covers South Yorkshire, in order to generate awareness and facilitate recruitment. However, no women contacted me and asked to participate as a result of having seen that information. A further four participants were recruited through word of mouth, people contacting me because they had “heard” about my study from their friends. A woman of European decent also showed interest in the study and then decided not to participate. She gave the reason as “personal”. Her decision not to participate was linked to the thesis findings around intimate relationships and is discussed in Chapter Eight – Strengths, limitations and reflexivity.

When recruitment slowed in January 2017, I applied for an amendment to my original ethics application requesting permission to recruit from a local Afro-Caribbean Organisation and additional South Yorkshire Diabetes UK groups. This permission was granted (see Appendix D). Through these means a further three women were recruited through the local Afro-Caribbean organisation but none from the other South Yorkshire Diabetes UK groups.

While the ethnic diversity of the sample was important from the outset, recruiting through Diabetes UK, no women from non-White British backgrounds had agreed to participate in the research. Importance was attributed to the inclusion of Black, Asian and Minority Ethnic (BAME) women for three reasons. These were the high rates of T2D in people of South Asian and Afro-Caribbean descent (Diabetes UK 2010; Shah

et al. 2015; Tillin et al. 2013), that studies have shown that these populations are often overlooked in the recruitment phases of health research (Wendler et al. 2005) and for personal reasons which I discuss in Chapter Eight – Strengths, limitations and reflexivity. Two South Asian women showed interest in the study and then declined to participate at a later date. Therefore, the minor amendments to my ethics application provided an opportunity to include settings where I would be able to recruit BAME women, promoting ethnic diversity within my research. While the intention was not to present a representative sample, amending my ethics applications provided an opportunity to search for a more ethnically diverse sample. The inclusion of this population also means that the thesis findings could be more widely applicable in practice and speaks to the transferability of the findings, as HCPs may be more likely to encounter these patients in their practice. I discuss this in more detail in the quality section of Chapter Eight – Strengths, limitations and reflexivity.

In addition to ethnic diversity, sexual orientation diversity was also sought. The historical omission of the voices of women in same-sex relationships in SHW research (Fredriksen-Goldsen & Muraco 2010; Westwood & Lowe 2018) in addition to research to show that lesbians and bisexual women may have a higher risk of T2D (Corliss et al. 2018) further increased my determination to recruit women in same-sex relationships. One woman in a same-sex relationship was recruited through professional networks. I also contacted the Sheffield 50+ LGBT group in an attempt to recruit more women in same-sex relationships but was unable to recruit any more participants via this route.

One 85 year old Black British woman living with T2D volunteered to participate. While she is not a part of the baby boomer generation, during her interview she had many shared experiences with other participants and I wanted to include the lived experience of as many BAME women as possible. For these reasons, as well as the lack of a clear definition of when the baby boomer generation began and ended (discussed in Chapter One), I decided to include this particular participant. Within the following chapters, where necessary, I draw attention to the older age of this participant and reflect on how differences between her experiences and those of the other participants may in part be influenced by her age. I believe that her reflection on

her middle and later years made an invaluable contribution to the thesis findings presented in the next chapter.

#### **4.5 Sample size and participant demographics**

The final sample consisted of ten women aged between 50 and 85 years with T2D. While this may be considered a small sample compared to other qualitative research studies, as discussed in the previous chapter, small sample sizes are recommended in IPA due to the level of detail required for data analysis and the time constraints that this imposes (Eatough & Smith 2017; Silverman 2010; Smith, Flowers & Larkin 2009). The chosen sample size permitted immersion in the women's lifeworlds, both during data collection and analysis. This immersion enhanced the richness of the data gained and the final levels of analysis achieved. Additional justification for the sample size can be found in the existence of several successful IPA PhD theses (Lannan 2015; McNeilly 2012; Osborn 2002) and research projects undertaken by IPA experts (Smith & Rhodes 2015; Wagstaff et al. 2018) which have sample sizes of ten individual participants or less. Demographic characteristics of the ten women included in the thesis are presented on the next page (Table 2 – Participant demographics).

**Table 2 - Participant demographics**

Participant No. and pseudonym	Age	Ethnic origin	Education level	Employment status	Social class	Religion	Practising	Children	Relationship status	Gender of partner	Duration of T2D	Length of time in UK, if not from birth
P1: Ann	73	White British	College diploma	Retired	Middle	Spiritualist	Yes	No	Married	Male	17 years	
P2: Bev	68	White British	O levels	Retired	Working	C of E	Didn't say	Yes	Separated	Male	1 month	
P3: Cath	50	White British	College diploma	Part-time employed	Didn't say	None	No	Yes	In a relationship	Male	8 years	
P4: Debra	69	White British	Degree	Retired	Didn't say	C of E	Yes	Yes	Married	Male	5 years	
P5: Ellie	58	White British	Degree	Full-time employed	Middle	C of E	No	Yes	In a relationship	Male	7 years	
P6: Fiona	54	White British	Degree	Full-time employed	Lower-middle	C of E	No	No	Single	n/a	7 years	
P7: Grace	63	White British	Masters	Self-employed	Middle	None	No	Yes (step)	Married	Female	5 years	
P8: Hazel	69	Black British	Diploma	Retired	Working	Methodist	Yes	Yes	Divorced	Male	9 years	From 10 years old
P9: Isobel	83	Black British	Year 12/13	Retired	Working	C of E	Yes	Yes	Widowed	Male	10 years	From 24 years old
P10: Joanna	66	Black British	NVQ Level 2	Retired	Lower middle	C of E	Yes	Yes	Married, living apart	Male	3 years	From 15 years old

## 4.6 Data Collection

### 4.6.1 Setting

It is important to discuss the context in which IPA interviews take place as an understanding of the interview setting provides context for the findings. Therefore, the following section details the research settings in which interviews took place and how decisions were made around where to conduct interviews.

Most of the interviews were conducted in a natural setting, in the women's homes. This aligns with the aims of IPA, and this thesis, which were to understand how participants make sense of their personal and social worlds and the meaning of these experiences (Eatough & Smith 2008). Therefore, conducting interviews in natural environments provided a comfortable and safe space for women to explore their SHW needs and experiences.

Within Appendix K: Individual lifeworld and interview reflections, I have described how I felt in the interview setting and how the participants may have felt. Through describing the interview setting in the level of detail provided below, and in Appendix K, is a demonstration of how important the role of context is in IPA studies.

Participants were offered a choice of their homes or an office at the University of Sheffield for interviews to take place. Of the ten participants, seven opted to be interviewed in their homes, one at an office at the University of Sheffield and two asked to be interviewed at their place of work. Giving the women a choice of where they wanted to be interviewed meant that the interview took place in a setting that they considered convenient and felt comfortable talking about issues of a personal nature. Giving the women a choice of where they wanted to be interviewed also reduced the power imbalance that the women may have experienced during our interview. I expand on the discussion around power imbalances between participants and myself in Chapter 8: Section 3 – Reflexivity. I ensured that the setting allowed for privacy by discussing the interview setting with women prior to our interview. Privacy was particularly important for maintaining confidentiality because of the sensitive nature of the topic of SHW.

The interviews that took place in the women's homes had the advantage of flexibility in that some interviews took place on weekends as this was when the women were available. Interviewing in their homes may also have helped the women feel at ease and able to disclose information of a personal nature. However, on one occasion, interviewing in a participant's home may have impinged upon her openness as her daughter came into the room during the interview unexpectedly. After this interruption, the participant appeared to be more guarded. This is discussed in Chapter Eight – Strengths, limitations and reflexivity.

For the interview that took place at an office at the University of Sheffield, I chose a small room, changed the seating plan and offered refreshments to help the participant to feel as relaxed as possible. I was concerned that the interviews that took place in the participants' offices would not provide the required level of privacy and that the women would not feel able to disclose personal details about themselves in their work settings. I discussed my concerns about privacy with the women prior to the interviews and they assured me that they would reserve a space where they felt confident that we would not be overheard. My concerns about the women feeling unable to disclose their personal feelings were unfounded. However, because the interviews took place in their working hours and the Information Sheet (Appendix E) and Recruitment Leaflet (Appendix H) stipulated that interviews would take between 30 minutes and one hour, both women stopped the interviews at 30 minutes, as they needed to return to work. Nevertheless, given the prior knowledge that we only had 30 minutes perhaps meant that the interviews were more intensive than the others, which all lasted between one and two hours. Both women were offered the opportunity to continue our interviews at a later date in a setting of their choosing but declined.

#### **4.6.2 Demographic data collection**

At the beginning of the interviews, participants were asked their date of birth, education level, employment status, social class, postcode, ethnic origin, religion and whether practising, children, relationship status and gender of partner, duration of T2D and length of time in the UK, if not from birth. The form used to collect these data is included in Appendix I – Demographic Questionnaire and the data collected is presented above in Table 2 – Participant demographics. Postcode has been omitted and the number of



children removed from Table 2 to protect the anonymity of the participants. These demographic data were deemed important for identifying potential relationships between the demographic details and their perspectives of SHW discussions at the later analysis and discussion stage. The process of collecting these data provided an opportunity for me to get to know the women a little and set a relaxed tone for the interview. Setting the tone was important for developing rapport and establishing a relationship of trust between myself and participants prior to moving on to the semi-structured section of the interview (Miller & Glassner 2004).

### **4.6.3 Semi-structured data collection**

Methods of data collection that were considered and rejected include observations and focus groups. Observational methods were rejected because it may have involved observing a consultation and would have presented complex ethical issues. The presence of a researcher may have made patients feel unable to express themselves as openly or influenced the HCPs decision of when to discuss SHW in consultations. Additionally, the amount of data produced would have been impractical to analyse for a research project of this time and financial scale. Focus groups were also considered due to having been used in previous sexuality research with older women with diabetes (Sarkadi & Rosenqvist 2003). The women in the Sarkadi & Rosenqvist (2003) study found relief in being able to discuss their sexuality with other women, providing one advantage of conducting focus group interviews. However, focus groups also have potential for making participants feel unable to express themselves openly due to fear of being judged by others in the group or the emergence of complex group dynamics (Willig 2013). Considering that this thesis required the potential discussion of intimate aspects of lived experience, in a sample of women who may not be accustomed to discussing SHW, I decided against using focus groups as a data collection method. An additional reason for rejection of focus groups was that while focus group studies in the field of IPA do exist, when analysing, it may have become difficult to maintain focus on the idiographic and personal meaning of the women's lived experiences (Smith 2004; Willig 2013).

Unstructured interviews are most commonly used in IPA to facilitate free expression of the participants' thoughts, feelings, perspectives and understandings of phenomena; they enable the researcher to get closer to the participant's perspectives (Lavie &

Willig 2005; Silverman 2004; Smith, Flowers & Larkin 2009). However, I used a semi-structured interview schedule to create a flexible agenda while allowing me to prepare the phrasing of sensitive issues. I also used the interview schedule (see Appendix J) to prompt when required and check that I had not omitted any areas of interest (Eatough & Smith 2008). The schedule was developed through a review of the literature in the area, the thesis aim, the thesis research questions and discussions with my supervisors who have extensive experience of interviewing participants in sensitive topics. Recommendations around the collection of data in IPA studies were also useful when designing the interview schedule. These included the preparation of prompts to encourage the participant to discuss aspects of importance to her, open-ended questions and phrasing to ensure that the data collected was suited to phenomenological analysis (Smith, Flowers & Larkin 2009). The schedule was designed to encourage the participant to express what she considered important to SHW communication whilst providing me, as a novice researcher, with guidance within the interview situation.

When designing the semi-structured interview schedule, I considered the wording carefully. The phrase “sexual health and well-being” was chosen over the term “sexuality” for two main reasons. First, as stated in Chapter One, definitions of sexuality are complex. Due to the various definitions of sexuality, the participants may have assumed that the focus of the interview was their sexual orientation, as the term “sexuality” is commonly used in this way in society. Second, as this thesis is focussed on the consultation context, I was concerned that the participants may struggle to perceive the link between their sexuality and their primary care consultations. The term “sexual health” has more health care connotations and in combination with the term “well-being” ensured that wider aspects influencing the women’s sexual health were included in interviews. The format and the wording of the interview schedule (see Appendix J) ensured that typical experiences of primary care communication were captured in accounts as well as, wider experiences of SHW, conversations and ideas around primary care. Exploring these experiences within interviews and analysing these wider experiences afterwards permitted entry into the participants’ lifeworlds.

The interview itself was executed with sensitivity and I took care to appear non-judgemental, both verbally and through my body language. The participants were able

to ask questions at any point (before, during and after the interview). I was prepared to encourage women to seek help if any issues arose during the interview but no issues arose. If participants did become upset at any point during the interview, I would have switched off the recording and comforted the participant. No participants became upset during interviewing. Every participant was given a Sexual Health Support sheet (Appendix G) with information about counselling services that they could access after the interview, in case they wanted to discuss matters that arose in greater detail.

After each interview, I wrote in my reflexive diary on how I felt the interview had gone and if I had had any new insights during the interview process. In addition to this, and aligned with the idiographic aim of IPA, I developed an Individual lifeworld and interview reflection for each participant. Bearing in mind the importance of both these aspects to IPA and in the interest of providing context to the participant accounts and my interpretations, these reflections are included in Appendix K – Individual lifeworld and interview reflections. These reflections serve several important roles. First, they allowed me to maintain the idiographic focus on the lived experience of each individual woman. Second, they acted as a reminder that all that is seen and heard in an interview goes through a process of interpretation by the researcher and third, they encouraged me to reflect on the thoughts and feelings that I had during the interview. Furthermore, they provide context for the reader, elaborating upon my interpretations of women’s accounts and promoting ‘thick’ description of the data collection and analysis process. Below, I have described the data analysis process, step-by-step, beginning with the first interview.

## 4.7 Data analysis

### Step 1: Immersion in the original data

After the first interview, I listened to the audio-recording in full twice, once whilst transcribing the interview and once checking my transcript for accuracy. I transcribed each interview as soon as possible after it had been done as I did not want to forget

#### **Transcript notation**

- |     |   |
|-----|---|
| ... | pause   |
| ()  | explanatory material added by myself e.g. laughter, sighing |

any details, such as the participant's tone and pauses and feelings that I had during the interview. These aspects are an essential part of analysing the data using an IPA approach. I transcribed all interviews verbatim and used transcript notation as described by Smith, Flowers, & Larkin (2009), see below.

During transcription, close attention was paid to eliminate details that may have threatened the anonymity of participants. To anonymise the transcript, I transcribed recordings, using pseudonyms, and used vague geographical terms to ensure that participants could not be identified. An anonymisation log was kept to ensure that real names and pseudonyms were stored in separate data files. Prior to analysis I decided that I would not use qualitative data analysis software, as I wanted the sensory immediacy of a hard copy of the data and a pen, and this way of working is encouraged in IPA and other phenomenological studies (van Manen 2017).

After I had transcribed the first interview, I then printed off the transcript with one column to the right, for noting down exploratory comments and another, to the left, for emergent<sup>4</sup> themes in later steps (see Appendix L – Transcript extract). I then read the transcript, noting down first impressions and feelings in the exploratory comments column (column to the right). This was to encourage a more complete analysis and allow me to develop a deeper understanding of the participant's account. Repeated reading allowed me to identify feelings that I had during the interview and rapport that built up during the interview, which was important for reflecting on my role as a researcher and how this shaped the data collected and subsequent interpretation, a

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<sup>4</sup> Within qualitative research literature, terminology of themes 'emerging' and data being 'found' have been problematised for their suggestion that themes pre-exist rather than being generated through the researchers interpretation of the data (Clarke & Braun 2013). However, within the thesis, I use the terms 'emerge' and 'findings' because of my understanding of the terms and their use in the IPA textbook. My usage of the terms relies on an understanding that I consider data to be co-constructed between the participant and the researcher. However, the way in which themes are identified and developed is emergent in that certain aspects become recognised as important, both during interviews and data analysis. I am not using the words 'emerge' and 'found' in terms of a pre-existing phenomenon that is waiting for me to identify it but rather themes as they 'emerged' in my thinking during data analysis. Reasons for why I may have found those particular themes and realisation that others may 'find' other themes are discussed in the Reflexivity section. The second reason for using these terms is that 'emergent themes' is the phrase used within the IPA textbook to describe the identification of patterns within the data (Smith, Flowers & Larkin 2009). Suggestions for alternatives include, themes were 'developed', 'generated' and 'identified', and I also use these terms in places that I feel it highlights particular features in the data analysis process, but for practicality and ease of recognition within current IPA literature, the terms 'emerge' and 'findings' are frequently used within the thesis.

point which I return to in Chapter Eight – Strengths, limitations and reflexivity. This step allowed me identify aspects of the interview that I had not previously realised during the interview for example repetition of certain words or phrases. Within this first step, I had frequent meeting with my supervisors who also supported data analysis both verbally during supervision meetings as well as in written form on transcripts.

### Step 2: Exploratory coding

I then performed a line-by-line analysis and began to identify specific ways the participant discussed issues and meaning of their words in the exploratory comments column on the right hand margin of transcripts (Appendix L - Transcript extract). At this stage, I aimed to write notes that described aspects of importance to the participant, as well potential meanings, but avoided superficiality. In order to avoid superficial comments and stay focussed on the meanings for the participant, Smith, Larkin & Flowers (2009) suggest three different types of commenting; descriptive (direct comments on the participant's account), linguistic (comments on the participant's use of language) and conceptual/interpretative (comments that involve the researcher considering the participant's account on a more conceptual level). I put a D, L or C next to the comments depending on which type of comment they were. Some comments were noted down without a letter or with a question mark as it was more important to get my initial thoughts down even if I did not know what type of comment it was. This is called free association and is encouraged during initial noting. While trying to ensure that I was looking at each account as an individual, during later interviews when I was in the early stage of analysis, I noted down in the margins if something in the participant account reminded me of something another participant had said in order to aid the later stages of analysis. This was a creative endeavour that meant that, in addition to the aforementioned comments (descriptive, linguistic and conceptual) the exploratory comments column included small sketches, comments with question marks if I was not sure what was going on but felt it important to document and perhaps return to it later (see page 14 and 15, respectively, of Appendix L – Transcript extract). As with the first step, my doctoral supervisors assisted through commenting on my analysis within the transcript and during supervisory meetings. See the comments in red in Appendix L – Transcript extract, for examples of how analysis was supported by supervisors within the initial stages. This

checking of my interpretations of the women's accounts enhances the credibility of the research findings, which I discuss in Chapter Eight.

### Step 3: Development of emergent themes

Whereas the previous two steps involved in depth interaction with the interview transcript, this step had a greater focus on the relationship between the exploratory codes. I used the column to the left of the transcript, to develop emergent themes (see the left hand column in Appendix L – Transcript extract). In this step, I found that a focus on my exploratory notes rather than the interview transcript made the task easier (in terms of not becoming overloaded with the transcript data). However, having the transcript data in between the two columns allowed me to check that my interpretations were grounded in the data. The emergent themes were a synthesis of my exploratory codes, either chosen because they were recurrent and/or meaningful. I then created a table in a word document where I had the name of the emergent theme, the page number and the extract and left a column to later insert Subordinate themes developed in the next stage (see Appendix M – Table of emergent and subordinate themes). Once I had filled in the emergent themes, with a transcript extract and the page number, I printed and cut out all of the emergent themes (Appendix N – Visual grouping of emergent themes). This visual method made it easier for me to search for connections across emergent themes.

### Step 4: Searching for connections across emergent themes.

The aim of this stage was to group themes that were frequently reoccurring, meaningful or similar. With the printed out pieces of paper, I placed them on a large table and organised them into groups. Once I grouped the pieces of paper with the emergent themes, I then began to think about how they could be grouped together into more concrete, subordinate themes. I then used the column on the far left of the document in Appendix M – Table of emergent and subordinate themes. At the bottom of this document, I put the title of every subordinate theme and grouped them into overarching superordinate themes, meaning that each participant account had its own superordinate themes (see the bottom of Appendix M – Table of emergent and subordinate themes). Going through these steps in a systematic way was useful for providing a structure for the data analysis process. It also served as a prelude to writing

up and also facilitated an appreciation of the data consistency within, and later between, accounts.

#### Step 5: Writing up the next interview

Once I had completed steps one to four for the first interview, I repeated the process for the next interview. It was helpful that I analysed one interview at a time meaning that I became immersed in the participant's lifeworld and that I was concentrating on the aspects of importance to the participant rather than focussing on how their account related to other cases. Finally, I came to accept that themes inevitably changed in light of data that had been previously been collected and that the double hermeneutic is a key component of IPA research. As stated in the previous chapter, my interpretation was an important part of the analysis, as long as I ensured that my pre-conceptions, in this case, from previous interviews, did not influence the interview process, obscure other findings from emerging and were clearly disclosed as they are within the thesis, they would not constitute any kind of thesis limitation.

#### Step 6: Looking for patterns across accounts

This step involved looking at how themes were related across and between accounts. After the first four interviews, I found that I was beginning to form preliminary ideas about possible patterns across cases. I did not want these preliminary ideas to alter the questions that I was asking participants but equally, I felt it necessary to record these potential findings. After discussion with my supervisors and reflection on how best to proceed, it was decided that I would create an Excel table with the name of each participant and name of subordinate themes and then insert participant quotes to support the subordinate theme. See Appendix O – Master data table extract which provides an example of how the table was organised for the superordinate theme 'Relevance attributed to SHW in different contexts', which later became 'Situating SHW within women's lives'). The table was useful for two reasons. First, it allowed me to map the subordinate themes in a clear manner, also facilitating transparency and coherence which are important to the quality of the research. Second, I was able to see which quotes were good examples of each subordinate theme, for potential inclusion in Chapter Five - Findings. While realising that the significance of what the

women said was more important than the number of times it was said, the table also allowed me to identify recurrent themes early on in the study. When I had analysed the accounts of several participants, it also served to highlight contrasting examples (in purple in Appendix O) which elucidated nuances between, and sometimes within, accounts. After the development of this table, I then went back to carrying out and analysing interviews, adding to it as more interviews were undertaken (see Appendix O – Master data table extract). Themes were renamed, merged and developed as more interviews and analysis was undertaken.

#### Step 7: Developing superordinate themes and writing-up

Once I had undertaken all ten interviews, there was still a considerable amount of merging and separation in terms of what I was considering and naming a theme. In order to gain some clarification, I printed off and cut out the individual emergent themes from each interview and tried to group them into superordinate themes. Superordinate themes are defined as "...a construct which is usually applies to each participant within a corpus but which can be manifest in different ways within the cases" (Smith, Flowers, & Larkin 2009, p.166). Working with this definition in mind, I organised subordinate themes into superordinate themes. Through the process of organising subordinate themes into superordinate themes, similarities between themes then became clearer and I was able to divide them into the three rough superordinate themes. I realised that the titles of superordinate themes would likely change but titling them was an important step towards their organisation.

At this point, after a discussion with my supervisors, I began writing up some of the super and subordinate themes. Subordinate themes allowed for nuances, convergences and divergences within accounts to emerge. Writing themes up was helpful because it allowed me to see which subordinate themes could be grouped together, for example, I had "Being listened to" and "Having health conversations" as separate subordinate themes. It was only once I began attempting to write them up as two separate subordinate themes that I realised that there was too much overlap to consider them separate themes. Conversely, I had "Rapport" as a subordinate theme in the data table and then once I began writing up realised that it was not a subordinate theme in itself but required discussion in more than one subordinate theme as it was woven throughout several subordinate themes.

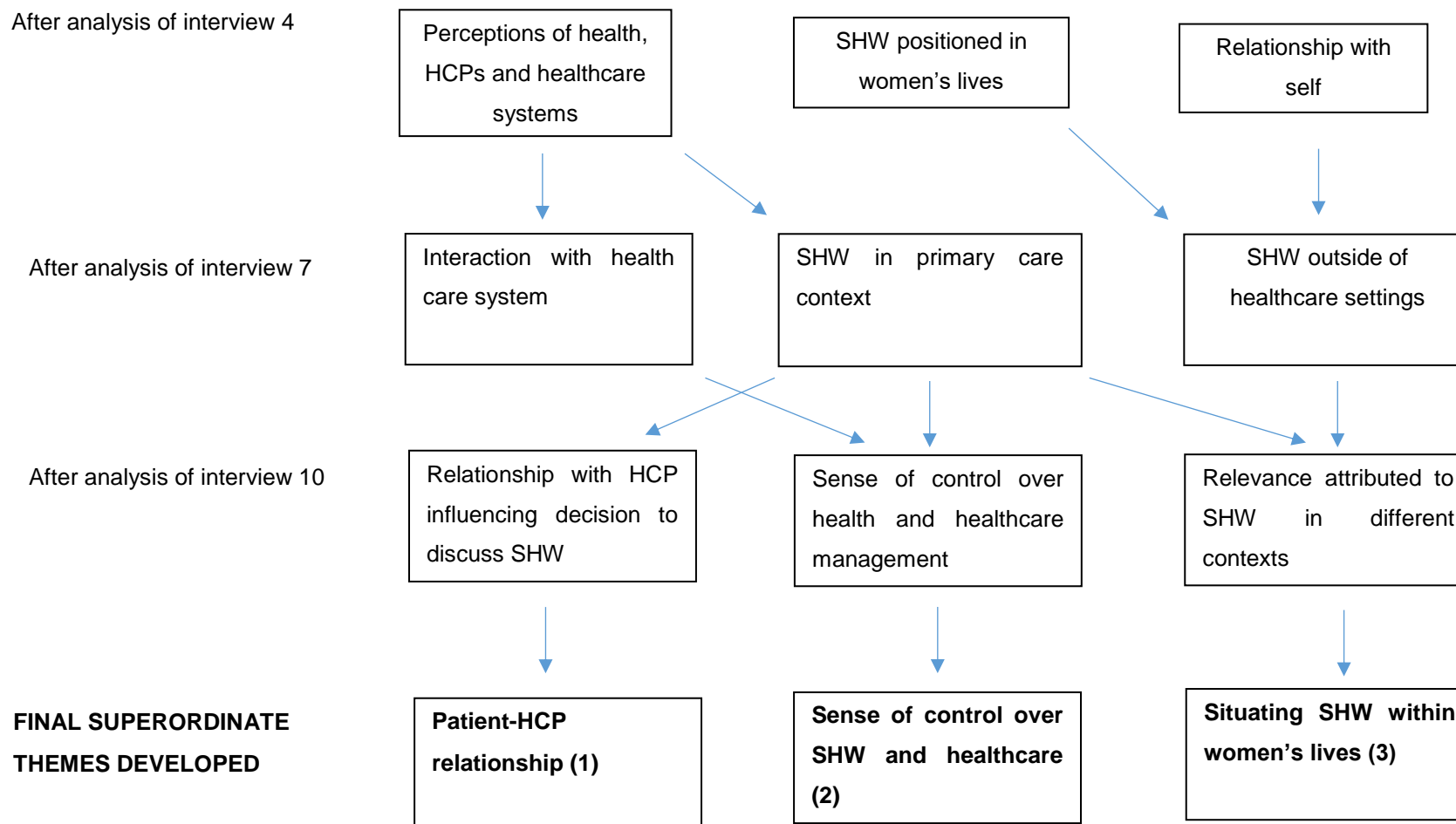


No subordinate themes were discarded as such but rather enveloped by other broader subordinate themes. One example of this was the subordinate theme “Understandings of SHW through family”. As the reader will see from Appendix O – Master data table and from the findings chapter, many of the quotes included in this initial theme are included in the subordinate theme “Sexual health and well-being, and social relationships”. These findings around the influence of familial relationships on SHW discussions are then explored in relation to the existing literature in Chapter Six. I felt that not discarding themes was essential to ensuring the inclusion of aspects of importance to the women rather than applying my own notions of which aspects were important to focus on. However, in line with an IPA approach, I acknowledge that my presence in the design of the research, within the interview itself and during data analysis will have influenced the conclusions reached within this thesis (Larkin, Eatough & Osborn 2011; Smith, Flowers & Larkin 2009).

Once the Findings chapter, consisting of the superordinate and subordinate themes, began to take shape, I started to write the Discussion chapter. I include writing the Discussion chapter in the data analysis process because throughout writing the Discussion chapter, I was still undertaking data analysis, examining the participants’ accounts and altering the super and subordinate themes. This reflects the iterative nature of qualitative research and IPA in particular. Superordinate theme development was a complex process, which required frequent re-reading of participant accounts, revising earlier stages of analysis and partaking in discussions with my supervisors. Finally, three superordinate and eight subordinate themes were identified.

Figure 2 below illustrates the development of the superordinate themes presented in the next chapter.

**Figure 2 - Superordinate theme development**



The findings presented in the next chapter are organised in this way and reflect the co-construction of knowledge between the participants and myself. This means that feasible alternative sub and superordinate themes could have been developed and that the preceding findings are one representation of the participant experiences, based on my own subjective interpretation (Smith, Flowers & Larkin 2009).

## **Summary of the Methods Chapter**

This chapter has presented the reader with a comprehensive account of the recruitment, the participants included in this thesis (and reasons why), where interviews took place, and how the data were analysed. This clear explanation of the research process with the inclusion of examples of data analysis, promotes the transparency of the research process and ensures that the reader is able to understand the following findings armed with knowledge of how the data was obtained and analysed. However, before embarking upon the thesis findings, in the next part of this thesis, Preface to the Findings, I clarify what is meant by the terms 'intimate partner', 'sexual activity' and 'sexual health and well-being' when they are used in the latter parts of this thesis. This is important for reflecting the subjective nature of these concepts for the thesis participants.

## **PREFACE TO THE FINDINGS CHAPTER**

The following Preface to the Findings highlights the different ways in which participants talked about their sexual health and well-being (SHW), and the key factors that played a part. In order to provide context, understandings of key terms used throughout the following Findings chapter are presented here. The key terms are ‘intimate partner and intimate relationships’, ‘sexual activity’ and ‘sexual health and well-being’. These terms are considered key as their meanings are pivotal within this thesis. Moreover, they are concepts which people frequently interpret subjectively, meaning that participant understandings may have differed from my own, and from the definitions provided earlier in the thesis. Understandings have been developed through a close look at the women’s accounts and how the women used the terms, directly or indirectly. Understanding how the participants used and defined these terms was essential for clarity, for both data analysis and ensuring that the reader understands what is being referred to in subsequent chapters.

### **Understandings of intimate partner and intimate relationships**

Whilst the women described having a “*husband*”, “*wife*” or “*partner*”, I made the decision to use the term ‘intimate partner’ and ‘intimate relationship’ as the women were in a range of relationship arrangements, such as, being married, in long term relationships, living apart, widowed and single. Not all women with an exclusive partner were sexually active. Consequently, I considered the terms ‘intimate partners’ and ‘intimate relationships’ appropriate to encompass all relationship types for participants that had, or discussed, partners.

### **Understandings of sexual activity**

A comprehensive understanding of what ‘sexual activity’ meant for the women was challenging, as they tended to describe sex broadly. The women used the term ‘sex’ in a different way to when they discussed other aspects of intimacy such as, hand holding. This aligns with societal understandings of the word, with ‘sex’ usually referring to penetrative or genital sexual intercourse. This understanding was used during analysis and therefore informs the findings presented in Chapter Five. When participants referred to sexual activity, it was most commonly called “*sex*” (Bev, Ellie,

Fiona, Grace, Isobel, Joanna) but also called “*sexual relations*” (Ann), “*sexual relationship*” (Bev) and “*sex life*” (Cath, Grace).

Some women described themselves as not currently sexually active (Fiona, Hazel, Joanna, Isobel). Some participants also struggled to find the vocabulary to express their lack of sexual activity instead tailing off at the end of sentences, waiting for me to suggest phrases which they then agreed or disagreed with. For example:

*Ann: ...the actual physical erm (pause) was a problem so we stopped having (long pause)*

*Interviewer: So at the moment you're not sexually active?*

*Ann: No*

*(Ann, 73 years)*

## **Understandings of sexual health and well-being**

I identified that the women understood SHW to comprise both emotional and physical aspects. The emotional aspects included the quality of intimate relationships as well as feelings about other ongoing situations in their lives. Physical aspects of SHW focussed on vaginal lubrication and the absence of sexually transmitted infections (STI). SHW was broadly defined by participants, though sexual activity was often closely linked to emotions. For some women, this related to periods in their lives where sexual activity had been a source of discord (Bev, Joanna) and for most, its relevance was based within the context of their intimate relationships. I discuss this in more detail in the subordinate theme ‘Adapting to SHW circumstances’. Several women also expressed that affection (Ann, Bev, Cath, Isobel) and good communication (Ann, Bev, Debra) were key components of a healthy intimate relationship for them.

In regards to physical aspects of SHW, many women expressed that sexual activity was just one aspect of their SHW (Ann, Bev, Debra, Ellie, Joanna). The importance attributed to sexual activity was connected to upbringing (Ellie), partner’s sexual needs (Ann, Bev, Cath, Ellie, Isobel), current health issues (own or their partner’s) (Ann, Cath, Debra) and relationship status (Ellie, Isobel, Joanna). Isobel, the oldest participants, felt that her age and that she was a widow meant that she considered SHW irrelevant now but interestingly, felt that if she did have any SHW issues that she would be better able to address them now than previously. However, it is noteworthy that not having a

partner, as was the case of Fiona, did not automatically mean that SHW was considered irrelevant. In fact, Fiona expressed clearly that good SHW, which she considered to be maintaining a high level of sexual desire and vaginal lubrication, was important to her.

Other women also considered vaginal lubrication important to their SHW, with participants linking a lack of lubrication with painful penetrative sex and an increased susceptibility to thrush and vaginosis. However, there was also an acceptance of the reduction of lubrication with it frequently considered age-related. The women also linked other changes to SHW, such as reduced sexual activity, to older age suggesting changing understandings of SHW changes with age. Indeed, understandings of good SHW varied between older and younger participants.

Younger participants tended to first discuss STIs and menopause, while older participants began with aspects pertaining to intimate relationships. All three participants in their 50s (Cath, Ellie and Fiona) first brought up STIs and menopause when asked about SHW in interviews. While STIs and menopause also came up in the interviews with older participants, the immediacy with which they did, compared with the younger participants, was notable perhaps because they had experienced menopause more recently or were experiencing peri-menopause at the time of the interview. When asked about aspects important to their SHW, the older participants (Bev, Debra, Isobel, Joanna) began their answers talking about intimate relationships, particularly highlighting that having the right partner and physical closeness were considered meaningful.

Intimate partners, sexual activity and SHW do not have universally agreed definitions. While I included existing definitions and my own interpretation of SHW in Chapter One – Background, I felt it was important to expound the women's understandings of these terms, which have informed the way in which they are used in the forthcoming chapters. All three terms used frequently over the course of the upcoming chapters. Reflecting an IPA perspective, it was important to explore the women's subjective understandings of the key terms and their meaning within their lifeworlds before exploring the superordinate themes of 'Patient-HCP relationship', 'Sense of control over SHW and healthcare', and 'Situating SHW within women's lives' in the next chapter.

# CHAPTER FIVE – FINDINGS

## Introduction

The analysis of the data from which the underlying barriers and facilitators to sexual health and well-being (SHW) communication in primary care were developed is presented in this chapter. To justify the statements made, verbatim interview extracts are included throughout. These verbatim extracts were selected for their capacity to represent the experience of the women (each is followed by the participant pseudonym and age). In certain instances, findings are separated by consultation type (appointment for Type 2 Diabetes (T2D) only or other health issues) or healthcare professional (HCP) type (General Practitioner (GP) or practice nurse) where it adds depth or highlights a particular feature of the analysis. Additionally, pauses and explanatory material have been added in certain places in order to elucidate the nuances of the interview experience.

The findings have been organised into three superordinate themes, which bring together a series of recurrent and related topics identified during analysis. The first superordinate theme presented is 'Patient-HCP relationship', followed by 'Sense of control over SHW and healthcare', and lastly 'Situating SHW within women's lives'. Within each superordinate theme are subordinate themes, which provide a description and detailed analysis of convergences and divergences within participant accounts.

### **5.1 Patient-healthcare professional relationship (Superordinate theme 1)**

The analysis showed that the relationship that the participants shared with their HCP influenced their decision of whether to discuss SHW and how comfortable they were doing so. Most participants considered themselves to have a good relationship with their current HCPs although several identified encounters which they believed could have been improved. Unsatisfactory experiences recounted were also valuable as they provided further understanding of what constituted good rapport with HCPs. Within the relationship between participants and their HCPs, particular aspects influenced whether and how SHW discussions took place in practice. These aspects

are presented as the subordinate themes 'Being listened to and having health conversations'; 'Continuity of patient-HCP relationship' and; 'HCP characteristics'.

### **5.1.1 Being listened to and having health conversations (Super theme 1: Sub theme 1)**

Participants' willingness to discuss SHW was influenced by their previous consultation experiences with their HCPs. Participants who did not like their HCPs were unlikely to discuss SHW with them. In particular, how HCPs had listened to participants in the past, often about health issues unrelated to SHW, was a deciding factor for whether to bring up SHW, as the following extract demonstrates:

*I think you can get a good idea of whether they're going to listen and whether they're going to take you seriously by just a couple of consultations about just ordinary, everyday things (pause) unless I know what their attitude is, I don't think I would want to talk about sexual health  
(Debra, 69 years)*

In this way, the feeling that HCPs were listening appeared to be more significant than knowledge of available treatment or a referral. The importance of being listened to was reinforced when participants described experiences of not having been listened to in previous consultations and how this affected the rapport with the HCP:

*...it was rubbish but he was just not listening at all and he was just a horrible person  
(Debra, age 69)*

Not having been listened to also led to the sense that their knowledge of their own bodies was being challenged by their HCPs. The participants expressed that their experiential knowledge of their bodies was extensive:

*Nobody knows my body better than I do. I know what makes me ill  
(Ann, age 73)*

As this last extract illustrates, participants held this experiential knowledge of their own bodies in high esteem. Ann's use of the word "nobody" implies that she believes her knowledge and experience of her own body are superior to that of her HCP. In this way, when HCPs did not listen to her or she felt her knowledge of her own body was



being undermined, it would “*get on [her] nerves*” and had an adverse effect on rapport with the HCP. This is also discussed in the next superordinate theme ‘Sense of control over SHW and healthcare’.

In addition to being listened to, a two-way dialogue between participants and HCPs was found to be valuable to the participant-HCP relationship. Many participants recounted experiences of discussing their healthcare with their HCPs. These experiences usually involved the participant agreeing or disagreeing with the advice provided by the HCP. However, while this two-way dialogue was an essential component of consultations for participants, they expressed a desire for HCPs to “*ask more questions*” suggesting that if more questions were asked, they would be more willing to discuss SHW issues that they did not feel able to bring up themselves. Wanting HCPs to explore within consultations was a common finding, and HCPs that did this were popular. The participants indicated that these health conversations or “*tossing ideas around*” with HCPs ensured a good relationship with their HCP. The phrase “*tossing ideas around*” demonstrates that not only the exchange of information was important but also that it occurred in a casual manner suggesting that women may prefer for SHW discussions to be introduced to consultations in a relaxed way:

*...so when you're having your blood taken for instance, our health practitioners sit there and they have a conversation with you at that point. How have things been going? How's it been...*  
(Grace, age 63)

The value of such health conversations was also exemplified through situations where the participants had been denied the opportunity to discuss health issues within consultations:

*I was a bit miffed [annoyed, irritated or upset] because...you would have thought that there would have been an opportunity to look at addressing it [T2D] through diet and exercise which wasn't a conversation that was had...I would have liked to talk about it*  
(Grace, age 63)

Crucially, in regards to SHW, some participants suggested that their HCPs would not discuss SHW without being prompted by their patients, implying that women may perceive HCPs to be reluctant to discussing SHW. Indeed, a perception of HCP

reluctance to engage in SHW discussions was present in several accounts, with some participants suggesting that HCPs would expect patients to bring up SHW concerns rather than ask themselves. This balancing of responsibility over SHW discussions is explored in more detail in the subordinate theme 'Balancing pragmatism and embarrassment':

*I don't think they would actually bring it [SHW] up to you unless you went and say something. I don't think they would unless the illness that you go for is something to do with down there.*  
(Isobel, age 83)

A lack of previous conversations about SHW was clear in that only a few participants had engaged in conversations with their HCPs about T2D and possible SHW changes. Three participants could recall their HCP having informed them of a link between T2D and lower sexual desire or frequent episodes of thrush:

*...the thrush...and vaginosis and that's all related to being diabetic.*  
(Hazel, age 69)

The remaining seven participants had not been asked about their SHW by HCPs, demonstrating the infrequency with which conversations about SHW take place in practice with baby boomer women with T2D. This lack of discussion about SHW changes meant that most participants were unaware of a possible link between T2D and SHW changes demonstrated in the following extract:

*I wouldn't see that any sexual problems were related to my diabetes...You're making a connection between two things which are two poles apart...*  
(Ellie, age 58)

The lack of previous discussion about SHW did not always indicate that participants considered it irrelevant to health demonstrated through claims that SHW should have been explored in previous consultations:

*It's [SHW] not a subject that ever crops up (long pause) and it should have been really thinking about it.*  
(Isobel, age 83)

The above extract indicates that although SHW had not been discussed in previous consultations, the act of discussing SHW in the interview setting brought the issues to

the forefront of Isobel's consciousness and she realised that it was a topic that she considered relevant to discuss within consultations. Her reflection on the topic was additionally highlighted by her long pause. This was particularly interesting as Isobel expressed that she had never discussed SHW with anyone, HCP or otherwise, suggesting that when given the opportunity to reflect on and explore their SHW in consultations, women may become aware of SHW needs that could be addressed.

Exploration by the HCP was frequently cited as key to ensuring that any SHW issues were identified in consultations. The participants conveyed that experiences where HCPs had asked questions, it made them feel that the HCP was comfortable discussing SHW. This suggests that HCPs may need to be more proactive in bringing up SHW in consultations in order to demonstrate to patients that they are comfortable discussing SHW. A lack of exploration by HCPs could lead to SHW issues being overlooked:

*I would like for the doctor to ask me questions...he only deals with what I'm presenting. There's other things that maybe I'm not presenting and he could be asking and trying to get more information...*  
(Hazel, age 69)

Hazel wanting her GP to ask her questions was particularly interesting as she stated very clearly that she would not want to discuss her frequent episodes of thrush with the GP in question as he was male. This preference for discussing SHW with certain HCPs will be discussed in more detail in the subordinate theme 'HCP characteristics'.

### **5.1.2 Continuity of patient-healthcare professional relationship (Super theme 1: Sub theme 2)**

Many participants repeatedly and frequently saw HCPs for T2D management. The analysis showed that because of the number of interactions that many participants had had with their HCPs, they felt that they knew how their HCPs would react to discussing SHW, whether the topic had been broached previously or not. As all participants were living with T2D, the HCPs they saw most frequently tended to be the practice nurse, who they visited every three to six months depending on how the practice organised T2D care, and the needs of the individual. All the practice nurses mentioned by participants were female (I explore how HCP sex was linked to

participant's willingness to discuss SHW in the next subordinate theme, 'HCP characteristics'). GPs were usually seen for health issues unrelated to T2D or when participants were referred by the practice nurse for complications related to T2D. The analysis revealed that relationships built over time with practice nurses and GPs influenced the women's level of comfort in discussing SHW:

*I have quite a good relationship with the couple of GPs that I see... also a nurse practitioner... so yeah, I'd be comfortable [discussing SHW]  
(Cath, age 50)*

The participants believed that seeing the same practice nurse for their T2D contributed to their sense of continuity in their primary care. Bev had been diagnosed with T2D just over a month before the interview whereas the remaining participants had been living with T2D for periods ranging from three to 17 years. Bev did not state that she felt she could talk to her practice nurse as other participants did. This suggests a potential link between length of relationship with practice nurses and comfort in discussing SHW, a point which I return to in Chapter Seven – Implications for primary care practice and research. Alternatively, it could also mean that given the short amount of time since Bev had been diagnosed with T2D, that she had not had time to reflect on her SHW in the context of T2D or that her HCP had not had the opportunity to broach the topic of SHW in consultations. Most of the participants expressed that they could discuss SHW with their practice nurses, even if, as discussed in the previous subordinate theme, they did not know of a connection between T2D and SHW changes:

*Now I've got a diabetic nurse, these are things that if I want to ask, I'll ask her.  
(Joanna, age 66)*

It was clear from the analysis that the participants preferred to discuss general health issues with HCPs they had known for a significant amount of time, usually years. The participants felt that seeing the same HCP repeatedly meant that HCPs knew the patient's medical, and sometimes social, history and they considered this advantageous in terms of their general health. The participants who had long term-relationships with their HCPs described informal relationships and "chatting" with them. The participants decided how comfortable they would feel discussing SHW with their

HCPs, and the attitude the HCP would have towards it, based on previous informal discussions, with some participants indicating that that feeling that the HCP knew them made them feel more comfortable discussing SHW:

*...there is one or two new GPs that I haven't seen so I don't know about them but certainly all the ones that have been there a very long time I think would have the same sort of attitude and...I wouldn't have any problems [discussing SHW] or anything like that...and practice nurses, this time I went it was another one again, a new one and (pause) I think I would have reservations about talking to somebody new about things.  
(Debra, age 69)*

The extract above also demonstrates that encountering various HCPs within consultations may not be problematic for SHW discussions but encountering new HCPs may be. However, a long-term relationship with HCPs was not always advantageous as some participants expressed discomfort with discussing SHW with HCPs that they had known for a long time, complicating the link between continuity of HCP and SHW discussions. I discuss some of the reasons for this in the next chapter:

*Interviewer: Do you feel like because he [her male GP] knows you that well, that the sexual discussions are more uncomfortable?  
Joanna: I think so.  
(Joanna, age 66)*

These two contrasting perspectives demonstrate complexity when discussing the role of continuity in SHW discussions. For some participants having a long term relationship with HCPs facilitated SHW conversations but for others made SHW discussions more difficult, HCP gender may also be implicated, a point which I explore below. Length of relationship has links to the later subordinate theme of 'SHW and social relationships', where participants described feeling more comfortable discussing SHW with a "stranger". In this way, developing an informal relationship with an HCP over time may inhibit some women to discussing SHW. It is also necessary to recognise that length of relationship was considered irrelevant to some participants. For these participants, aspects that they considered unrelated to temporality were frequently discussed, such as the aforementioned, good rapport and being listened to, but also HCP gender.

### 5.1.3 Healthcare professional characteristics (Super theme 1: Sub theme 3)

The analysis revealed the participants' preference for discussing SHW with HCPs who had certain characteristics. In general, the women showed a preference for discussing SHW issues with female HCPs. There was diversity within the sample with some participants feeling more strongly about only seeing female HCPs than others:

*I suppose it's the way I've been brought up really...it's not nice to discuss things like that with a man and it doesn't matter that he's a male doctor, he's trained in all of these things, I still don't feel comfortable talking about my thrush with him.*  
(Hazel, age 69)

The extract illustrates that on the one hand, HCPs were perceived as professionals and in possession of a similar level of knowledge whether male or female, and yet on the other hand, participants were conscious of the HCPs sex and this influenced their willingness to discuss SHW. This awareness of the HCP's sex led to some participants avoiding discussing SHW with male HCPs and was often attributed to their own upbringing and previous social norms. In addition to upbringing and previous social norms, age was also found to have some bearing in reluctance to discuss SHW with male HCPs, with the women suggesting that as they got older, they preferred to speak to female HCPs:

*Like maybe now I would say "Can I talk to a female doctor?"*  
(Ann, age 73)

Age also influenced SHW discussions in the form of perceived ageism. Ageism was given by the women as a rationale for why SHW may not have been previously broached by HCPs. This assumption, that the HCP actively decides not to broach the topic of SHW in consultation, shows two things. First, a perception of ageism and second, that women reflect on the perceived attitude of their HCPs:

*... well, probably they just look at me and think "No, she's not having (pause) [sex]"*  
(Isobel, age 83)

It was evident from the analysis that assumptions about HCPs feelings about discussing SHW shaped the participants willingness to discuss SHW. Some discomfort was linked to the perceived awkwardness of the HCP around discussions. This particularly applied to male HCPs. Participants assumed that their male HCPs would be uncomfortable discussing SHW and did not want to cause this feeling. This was particularly salient in the accounts of participants who had known their HCPs for a considerable amount of time, confirming the complexity of continuity of patient-HCP relationship discussed in the previous subordinate theme:

*I don't think he would have wanted to [discuss SHW], you know what I mean?  
I don't want him to feel uncomfortable  
(Joanna, age 66)*

It is worth reporting however, that not all participants found the sex of their HCP to be relevant to whether SHW discussions took place, with mentions of perceived HCP knowledge and good rapport occurring more frequently in the accounts of these participants:

*It is the nature of the person that makes the difference to me...It doesn't make any difference what their gender is...I almost see GPs and health professionals as gender neutral in as much as they've got a skill and a knowledge that they can sort me out so I don't think about it like that  
(Grace, age 63)*

Grace's lack of consideration to HCP sex when having SHW discussions in the primary care context was interesting as she felt that outside that context, women communicated more openly about SHW with each other. This suggests a perceived difference between those SHW conversations that took place outside of the primary care consultations and those that took place within:

*Our female friends don't have the same conversations with their male partners as myself and my [female] partner would do, same-sex partner...I get a feeling that there's more of a stigma for men talking about sexual health in a way that there isn't for women. I may be wrong (pause) it's my perception but I think that that makes a difference in terms of having a same sex partner that those sorts of conversation are more normal  
(Grace, age 63)*

The perception that men primarily experience “*stigma*” around talking about SHW, showed a perception of gender appropriate behaviours, with women more easily able to discuss SHW outside of the primary care context. A second point of interest here is that Grace refers to perhaps having different communication habits within her intimate relationship to those of heterosexual women and men in same-sex relationships. I return to potential communication differences between same-sex and heterosexual women within their intimate relationship in the subordinate theme ‘Sexual health and well-being, and social relationships’. In addition to the perception of gender difference around communication outside of the primary care context, the participants also perceived gender differences in SHW communication within healthcare settings. This was illustrated through more than one participant referring to their male intimate partner as being reluctant to seek help for erectile ‘dysfunction’:

*I'd definitely consider it [seeking help for partner's erectile 'dysfunction'], yeah, definitely, but you know what men are like they're a bit stubborn sometimes especially when it comes to anything like that.*  
(Cath, age 50)

The participants’ perceptions of men outside of the primary care context influenced the women’s approaches to discussing SHW, with some women viewing HCPs as men first and HCPs second. An example of this is demonstrated in the first extract of this theme where Hazel states that the professional knowledge of her HCP is secondary in regards to his sex.

As discussed earlier, all participants regularly saw a practice nurse for T2D care. The participants frequently recounted exploratory conversations with practice nurses. This was juxtaposed with the lack of conversation with their GPs, who were perceived as being more focussed on diagnosing and prescribing. The influence that this distinction in perception of the role of the GP and the practice nurse may have on SHW will be explored in more detail in Chapter Six – Discussion:

*As soon as I go in, we say hello, I sit down, "What's the problem?", he turns to the computer and looking at the computer and I'm just sat there watching him looking at the computer and then he'll print out a prescription or whatever...*  
(Hazel, age 69)



One participant of Black Caribbean origin expressed that race concordance with her HCPs was important for her primary care health needs but how this applied to SHW specifically remains unknown as it was not discussed further within the interview. None of the other Black Caribbean participants stated that race concordance with HCPs was important to their health needs.

### **Summary of Superordinate theme 1**

The preceding findings have revealed prominent features of the relationship between the women and their HCPs, and its relevance to SHW discussions. Many women living with T2D form long-term relationships with their HCPs due to recurrent appointments. While this was found to be advantageous in some aspects, it sometimes appears to complicate women's feelings around discussing SHW, particularly with male HCPs. The sex of the HCP was also found to influence comfort around SHW discussions.

The analysis revealed that health discussions about aspects unrelated to SHW were important for the women in that they helped to shape how they felt about potential SHW discussions in primary care. Simultaneously, there was a preference for HCPs to explore more within consultations demonstrating a balance between the women's and the HCP's responsibility for broaching the topic of SHW. This links with the next superordinate theme, 'Sense of control over SHW and healthcare'.

### **5.2 Sense of control over SHW and healthcare (Superordinate theme 2)**

Building on the previous superordinate theme, the participants' sense of control over their SHW and healthcare will now be explored. A recurrent feature in the women's accounts was that they perceived themselves to have differing levels of control over their SHW. This differing level of control influenced whether or not they would bring up SHW with their HCPs. Also influencing their SHW discussions was feeling in control within primary care consultations. However, this sense of control was considered more favourably in regards to general health discussions, whereas when it came to SHW they expressed a preference for HCPs to raise the topic during consultations. Two subordinate themes were relevant to sense of control over SHW and healthcare: 1., 'adapting to SHW circumstances' and, 2., 'balancing pragmatism and embarrassment'.

### 5.2.1 Adapting to sexual health and well-being circumstances (Super theme 2: Sub theme 1)

The participants attributed different levels of importance to their SHW. However, most spoke of their current sexual situation as having been different in the past, and potentially changing in the future, suggesting fluidity of SHW in their lives, a point which I explore in the next chapter. It was within the context of their lives that the women decided how, or whether, to embrace these changes. The importance that SHW held appeared to influence their acceptance of these changes. Some participants expressed a lack of conscious consideration given to SHW in the past but the act of discussing it within the interview caused women to reflect, sometimes for the first time. This suggests that the participants' understandings of SHW were still changing. I discuss this, and how it is linked to SHW discussions, in more detail in the next chapter:

*I've never thought about it [SHW], thinking about it now (pause)*  
(Isobel, age 83)

Nevertheless, this lack of previous consideration did not reflect a lack of importance within the participants' lives with their accounts reflecting aspects of SHW that they considered important, even if they had not previously thought about them. It is also noteworthy that there was recognition of the ebb and flow of SHW circumstances throughout life, so even if SHW had not previously been considered or was not currently a central feature in their lives, it could be at a later date. Joanna made numerous references to potentially becoming more sexually active in the future:

*It'd be nice to have someone to cuddle up to and things like that but its early days yet...*  
(Joanna, age 66)

For all the participants in intimate relationships, both with women or men, the value attributed to sexual activity was defined within the context of their intimate relationship, as the extract below indicates:

*It [sexual activity] isn't important except how it might affect our relationship but my partner is older and his libido isn't fantastic so maybe we fit together.*  
(Ellie, age 58)

The participants brought up sexual desire disparities within intimate relationships and discussed how this could present a problem. However, for all participants in intimate relationships their current level of sexual desire was described as unproblematic, and none had discussed it with their HCP. It was clear that there were occasions when their level of sexual desire within their intimate relationships was higher than their partners, or when they were not sexually active or when other life events took priority. In these instances, they satisfied their sexual desire by masturbating or dealt with the situation by deprioritising their SHW needs. One participant labelled it “switching off” implying that she had considered herself to have some control over her sexual desire. However, there was discrepancy in perception of control over sexual desire as some participants described it as an element that they had little control over, as illustrated by Bev’s description below:

*In that few years in my early 20's. It [sexual desire] came and it went and it passed and...I don't know where it went but it disappeared and I've never got it back.*

*(Bev, age 68)*

This perception of not being in control of their own sexual desire potentially presented a barrier to seeking help in that women may believe that sexual changes are inevitable and that nothing can be done about them. However, the findings demonstrated that while many participants could recall times in their lives when their sexual desire had been higher or lower, often they were unconcerned which presents a more likely explanation for why professional help was not sought or required:

*Interviewer: So you mentioned your libido [mentioned previously in the interview that she had low sexual desire]. Is that something you would discuss with the GP or (pause)?*

*Ellie: Not as a problem. It is what it is.*

*(Ellie, age 58)*

Even when the women had not experienced any SHW changes, they expressed an awareness, or even expectation, that SHW could decline with ageing:

*...whether it's [her vulva] functioning because at my age, you just never know (pause) I've been quite lucky.*

*(Fiona, age 54)*

Fiona's use of the word "*lucky*" reflects an expectation for a decline in SHW with ageing even though her personal experience has not been so. The participants Ellie and Isobel also used the term "*lucky*" to describe their SHW experiences of ageing even though they had experienced emotional changes and vaginal dryness, respectively. Attributing SHW changes to luck reflects a perception of a lack of control over SHW with ageing. Three of the 10 participants considered themselves fortunate, and expected more severe SHW changes with ageing, this implies that there is an expectation for serious SHW decline among older women even if it has not been their personal experience.

The participants often perceived a reduction in sexual activity as an inevitable and common occurrence with ageing (but not linked with T2D). As in the case of sexual desire, the participants did not consider this reduction distressing so long as their level of sexual desire and activity was appropriate within the context of their intimate relationships and lives. Thus, help from HCPs was not sought for a reduction in sexual desire or sexual activity. Accepting the reduction in sexual activity in this way meant that this change was perhaps easier to accept on a personal level, as demonstrated in Grace's use of the word "*normal*" in the extract below:

*...as I've, as we've got older (pause) our sex life isn't as active as it was when we were younger but just normal, you know what I mean don't feel I'm hard changed.*  
(Grace, age 63)

However, the participants were clear about sexual health issues that they considered "*not right*" and for which they sought help. These will be discussed in the subordinate theme 'SHW as 'medical' in consultations'. Most participants without intimate partners expressed that they desired the emotional aspects of SHW:

*...if I did have a husband, it's just cuddle. All I need is cuddles. Lots of cuddles, no down there at all.*  
(Isobel, age 83)

While the extract above shows that for some participants without intimate partners, sexual activity was not desired as much as the non-sexual physical contact, other participants without intimate partners expressed that they would like to engage in

sexual activity with an intimate partner. In lieu of sexual activity with an intimate partner, these participants talked about masturbation as a way of fulfilling their sexual desire:

*Well, I do masturbate but most people do or I think most people do, I don't know...and that's how I deal with it.  
(Fiona, age 54)*

Fiona's use of the phrase "deal with it" shows that she responded to her sexual desire independently. That phrase, and indeed other accounts where masturbation is discussed, does not allude to sexual pleasure but rather management of sexual feelings. Indeed, many participants took an independent, pragmatic approach in regards to, not only their sexual needs, but also wider health needs. This is discussed in more detail in the following subordinate theme.

### **5.2.2 Balancing pragmatism and embarrassment (Super theme 2: Sub theme 2)**

While it was clear that the participants were pragmatic in their approach towards their health, there was diversity with regard to the expression of this pragmatic approach. The common feature was that most had ways of managing their health and well-being away from the primary care context. Many participants wanted to deal with SHW problems independently and to avoid medication:

*I like going for regular check-ups because I do respect that doctors are the only people that can diagnose you. I like to get a diagnosis if I think there's something not right but then I like to try and deal with it myself.  
(Bev, age 68)*

In part, this pragmatic approach to health needs stemmed from a preference to dealing with health issues independently but also from participants' perceptions that the health service was struggling and so were reluctant to 'waste' the time of HCPs. This was made apparent through the participants discussing the problems the health service was experiencing:

*...people need to be a bit more pragmatic about when they feel they actually need to actually see a doctor...because the system can't afford what it is  
(Grace, age 63)*

Further influencing the participants' perceptions of a struggling health service was that it was problematic to obtain an appointment. This sometimes led women to wait until a problem was considered sufficiently grave before requesting an appointment. Management of health outside of a primary care context was also undertaken with many participants considering themselves "*pragmatic*", "*practical*" or "*stubborn*" when it came to managing their health. This preference for self-management of health problems, in addition to a sense that health changes were inevitable and normal seen in the previous subordinate theme, were linked with not seeking help from HCPs:

*I just accept it [frequent urinating during the night]. You know, you know, one of those things...  
(Cath, age 50)*

All participants discussed behaviours they engaged in to manage their T2D outside of clinical settings. This was usually in the form of diet and weight control and for some, monitoring their blood sugars. Sometimes the women undertook these behaviours to prevent their T2D disrupting daily life. In the case of Cath, she described not drinking late at night to avoid the frequent need to urinate during the night which she attributed to T2D. While Hazel, attributed her episodes of thrush and vaginosis to times when she had consumed more sugar and so tried to reduce the frequency of these episodes by monitoring her sugar intake. These ways in which women self-managed their T2D provided further evidence of their independent approach to health. This independent approach to health was also evident with frequent occurrences of the phrase "*I just get on with it*" or similar. This approach, not only to health, but to life meant that women tolerated some SHW changes that were problematic, such as vaginal dryness, rather than seeking help. I return to this point in the next chapter.

Participants' pragmatic approach was also reflected in the language used to describe their bodies and their active management of their health care. Descriptions of interactions with primary care services and HCPs were functional with check-ups being referred to as "*MOTs*". This perception of their bodies as car-like, mechanical, demonstrates different discourses around bodies within consultations, which was in contrast the language used outside of health context which focussed more on how women felt. It also suggests that bodies were perceived as an entity which required

maintenance. The participants believed that this maintenance, their healthcare, was their responsibility:

*... it's for me then to go and see them if there's anything concerning me. And that puts it squarely back into me for them to do something about it.*  
(Hazel, age 69)

This extract demonstrates that while participants believed it their responsibility to initiate health discussions, they believed that it was the HCP's responsibility to resolve the problem that was presented. However, analysis revealed complexities around how this division of responsibility was applied to SHW discussions and where the responsibility lay for bringing up these conversations. Some participants expressed that the HCP needed to bring up SHW as many patients, particularly older adults, would not:

*... if they don't ask for that [about SHW] I'd say there are a lot of people my age who wouldn't automatically think "Oh, I'll have a conversation now about my sexual health and well-being"*  
(Grace, age 63)

Not seeking help for some health issues had unfavourable impacts on SHW for participants. The next extract makes it clear that women sometimes tolerate SHW issues:

*...for me it [sex] was pain and agony and I bear with it*  
(Isobel, age 83)

Use of the words "suffer", "pain" and "agony" in accounts made it clear that there were SHW problems, which women attributed to menopause, that were not dealt with. Reasons that the participants gave for these issues not having been treated included not wanting to take medication, not having brought it up in consultations or HCPs not having asked about SHW. Isobel in particular expressed that sexual activity was very painful due to vaginal dryness. Yet, it was not discussed in consultations even though she and her HCP had engaged in a discussion about vaginal bleeding at the same time that she was experiencing vaginal dryness:

*He didn't ask "Are you having dryness?" and things like that, all he said I must watch it [the vaginal bleeding] and if it gets worse, I must come back to him  
(Isobel, age 83)*

The above quote illustrates that a lack of direct enquiry on the part of the GP, led to a lack of discussion around Isobel's vaginal dryness and suggests that when HCPs do not ask direct questions about specific SHW issues, patients may be reluctant to bring them up, preferring instead to tolerate the SHW problems. This relates to a differentiation between SHW concerns that the participants were content to discuss with HCPs, those that they considered connected to their 'medical' SHW, and those that were more difficult. Distinctions between these issues will be discussed in more detail in the subordinate theme, 'SHW as 'medical' in consultations'.

Not all SHW issues were tolerated however, with the participants' pragmatism facilitating SHW discussions in some cases. The participants based their decision of whether to bring up SHW issues on the perceived severity of the issue and treatment options that their HCP could provide:

*Yeah, I'd go see the GP. Like with the bleeding after intercourse, I went straight to the GP...I'm fairly pragmatic when it comes to talking...I do get embarrassed but I cover it up so underneath I might be a bit embarrassed but I'm very pragmatic  
(Ellie, age 58)*

The "*pragmatic*" approach of Ellie and her concern for the potential severity of the vaginal bleeding after sexual intercourse allowed her to overcome her embarrassment and raise the issue with her GP. Seeking help for issues related to smear tests, fertility and STIs were more difficult for some women than for others but they felt it essential to maintaining good general health and so overcame any feelings of embarrassment in order to preserve their health. Analysis showed that the most frequent SHW problems that the participants had sought professional help for were cysts, vaginal bleeding and thrush but, as the following two extracts demonstrate, issues around vaginal dryness, sexual desire and intimate relationship were avoided in most cases:

*From the sort of infection point of view, that [discussing SHW] would be not a problem at all, I mean if I got thrush or something that wouldn't be a problem. Sort of, sexual health around...loss of libido or that sort of thing, disparity in*



*sexual appetite between me and my partner or whatever (long pause) I'd probably read a book (laughs)  
(Debra, age 69)*

The way in which SHW was discussed by the participants often showed embarrassment. Avoidance of discussing certain aspects of SHW due to embarrassment is a point which is evident in the account of Isobel, who experienced vaginal dryness during menopause, which made sexual activity with her husband painful but did not seek help for this issue due to embarrassment:

*Even my doctor, it's [painful penis-vaginal sexual intercourse] just intimate that I feel I don't think I could really go to somebody and (pause) Probably now I would but at the time [previously in her life], no, I don't think I would be able to  
(Isobel, age 83)*

However, it is noteworthy that Isobel differentiated between her previous reluctance to discuss SHW with HCPs and that she would feel more comfortable seeking help if the same situation arose in the present day demonstrating that women's ability to seek help for SHW issues may change over time. She attributed her recent ability to discuss SHW to both her older age and life context (her husband had passed away). The relationship between age, life context and SHW discussions is explored in the following chapter. However, for most participants, the previously discussed discomfort around discussing SHW issues remained. The participants were willing to discuss certain aspects of SHW when they felt it essential to preserving their general health but some struggled to use the words "sex", "vagina" or "vulva", instead choosing to use phrases such as "down there" (Ann) or even preferring to gesture (Ann, Hazel) to the general area of their vulva without using words at all. This demonstrates how difficult it may be to bring these issues to their HCPs, presenting another potential barrier to seeking help, another point which will be discussed in the next two chapters of this thesis.

## **Summary of Superordinate theme 2**

A pragmatic approach to health was both a facilitator and a barrier to SHW conversations. On the one hand, the pragmatic approach presented a barrier in that, the women considered themselves able to manage their concerns independently and, perceived a paucity of health service resources and so would not seek help. On the

other hand, a pragmatic approach was a facilitator for help seeking as when the SHW issue was severe enough, pragmatism enabled the women to overcome feelings of embarrassment so that they could broach SHW with their HCPs.

Many women had experienced SHW changes and most had become used to these. The women adapted to sexual changes if they were viewed as unproblematic within the context of their intimate relationships and lives. However, other sexual changes were considered problematic yet were tolerated for a range of reasons, which I begin to discuss in the final superordinate theme below, and which are further developed in the next chapter (Chapter Six – Discussion).

### **5.3 Situating sexual health and well-being within women's lives (Superordinate theme 3)**

This theme builds on the previous ones by situating SHW in the context of the participants' lives. From the analysis, it was evident that decisions around discussing SHW in primary care settings were often influenced by SHW conversations had, both inside and outside of primary care contexts. The participants' health issues, theirs and those of their intimate partners, also impacted upon the place that SHW currently held in their lives. It was evident that how participants experienced and discussed SHW was influenced by the way in which significant others within their lives engaged (or did not engage) with SHW discussions. The subordinate themes presented here capture these interconnecting factors, and are: 'SHW as 'medical' in consultations', 'SHW and health issues' and 'SHW and social relationships'.

#### **5.3.1 Sexual health and well-being as 'medical' in consultations (Super theme 3: Sub theme 1)**

As explored in the earlier theme 'Patient – healthcare professional relationship', while living with T2D and attending frequent appointments with the same HCP potentially facilitated SHW conversations for some participants, consultations for T2D tended to focus on 'medical' issues such as weight, diet, neuropathy and blood sugars. This meant that the women often did not feel that there had been an opportunity for SHW discussions to take place. One participant, Grace, suggested the use of a "*framework*" for HCPs to ask SHW questions to ensure that SHW changes that women wanted to

address within consultations were not neglected – a point which I return to in Chapter Seven – Implications for primary care practice and research.

It was evident that participants had experienced SHW changes that they had discussed with HCPs and others that they had not. This illustrated a dividing line between SHW issues that participants did and did not feel comfortable bringing up within consultations. This adds to the findings, stipulated in the previous paragraph, around a need for exploration on the part of the HCP. There were issues that the participants had sought or would seek professional help for; those considered ‘medical’ e.g. fertility, vaginal infections and those that were considered to be connected to sexual activity e.g. sexual desire, vaginal dryness. ‘Medical’ SHW issues which had previously been addressed in consultations included smear tests, fertility, STIs and polyps. The participants’ approaches to seeking help for ‘medical’ SHW issues was linked to their previous experiences. For example, in the next extract, Ellie, using clear, impersonal language, describes her experiences of medical examinations, whilst being pregnant and giving birth. These medical examinations changed the way in which she perceived the role of healthcare professionals. She highlights those experiences as having given her a more pragmatic approach to seeking professional help for reproductive issues. Other women also used impersonal and medical language when describing their experiences of trying to conceive and pregnancy. This may have links with the historical medicalisation of women’s bodies, which I discuss in Chapter Six - Discussion:

*...once you've had children you've had your feet up in the stirrups and the man with the light, you know (laughs) After that, yeah...get the baby out (laughs) I know that's a long time ago but you know, you become far more...pragmatic.  
(Ellie, age 58)*

Key in the decision making process for whether to seek professional help was the severity of the issue in question. When participants considered the issue severe, the reluctance shown towards bringing up SHW problems with their HCPs was set aside:

*If I had a [sexual] problem and it was big enough, I'd want it sorting.  
(Cath, age 50)*

Another circumstance in which women sought professional help was when they wanted to determine the cause of the SHW issue. Determining the cause ensured that the SHW issue was not a sign of a more serious health issue. From the analysis, it was evident that previous SHW discussions had mainly occurred, or would occur, when pertaining to possible treatment to resolve SHW issues. For example, women might not seek help for SHW issues that they consider severe and have an impact on their lives because they assume that either no treatment exists or no treatment that they want to take exists. As the next extract shows, this also links back to women's experiential knowledge of their own bodies described in the earlier subordinate theme 'Being listened to and having health conversations' and, again, highlights the balance between the women's experiential knowledge of their own bodies and that of the HCP:

*Good sexual health is about knowing your body, knowing when there's any sort of changes and that you can be aware of and that you can get treatment for.  
(Hazel, age 69)*

Once professional help had been sought, if treatment was offered by HCPs, decisions around whether to accept the treatment were influenced by how they felt about the treatment, how concerned they were about the cause of the SHW change and how it impacted their lives:

*She put me back on the pill [for vaginal bleeding at menopause], and I thought to myself, I can't be doing with this at my age, messing about with pill taking so I said that I'm stopping it.  
(Joanna, age 66)*

In this case, Joanna decided not to accept the treatment offered. Other participants also recounted experiences where they had rejected treatment suggestions given by their HCPs, such as synthetic hormones, statins and diabetes medications. The HCPs were just one source of health information. This shows the role of health information in enabling patients to make decisions about their health and also reiterates the sense of control, explored in the previous superordinate theme:

*I mentioned it [night sweats] to my doctor and they recommended taking something to counteract it but if it's anything to do with HRT, this is where I feel I'm in control of my health, I don't take it. I refuse to take it.  
(Hazel, age 69)*

As discussed in the Preface to the Findings, most participants considered STIs relevant to their SHW. Participants often wanted to convey that they had either been tested for, or did not perceive themselves to be at risk of STIs even if they were currently sexually active suggesting that this had not recently been a part of discussions with HCPs:

*I had obviously tests that I didn't have any sexually transmitted diseases you know (pause) before I had me coil fitted.  
(Cath, age 50)*

Some participants did comment on the relevance of SHW to their more general health and well-being but this perspective did not occur frequently suggesting women may separate the two or may not see them as connected, particularly when it comes to primary care.

### **5.3.2 Sexual health and well-being, and health issues (Super theme 3: Sub theme 2)**

As previously indicated, women described health issues, both their own and their intimate partners, that impacted on their lives. T2D and menopause came up frequently in accounts as expected; however, the participants infrequently linked T2D with their SHW. Two participants brought up knowledge of a link between T2D and thrush, Hazel who experienced frequent episodes of thrush and vaginosis and Joanna, who had been told by HCPs that people living with T2D were “prone” to thrush. Of all the participants, only Hazel, explicitly expressed that she perceived T2D to have had a direct impact on her SHW, in the form of frequent episodes of thrush and vaginosis. She found that her episodes of thrush occurred at times when her blood sugar readings were high and referred to trying to control her blood sugar in order to avoid these frequent episodes of thrush. This connects with the previous superordinate theme of ‘sense of control over SHW and healthcare’ and reiterates that the SHW of older women without intimate partners is also important. The impact that the frequent episodes of thrush and vaginosis had on Hazel’s life (through itching and odour) meant that she frequently brought them up with her HCPs. Other participants that had experienced episodes of thrush, attributed the episodes to ageing or just something

that happens rather than attributing it to T2D demonstrating a lack of previous discussion in primary care settings regarding T2D and the potential impact on SHW.

The participants expressed a desire for the emotional aspects of T2D to receive more attention in practice:

*The emotional side of diabetes I don't think is probably explored enough with people. What it feels like to be diagnosed and what that really means and what really are the options...You don't really feel you get sort of that sort of information.*

*(Grace, age 63)*

While Grace did not describe how these emotional aspects of the T2D diagnosis could impact on her SHW, she had experienced episodes of depression which had affected her intimate relationships. This demonstrates how a lack of exploration of the emotional aspects of T2D could influence the SHW, and general well-being, of individuals (I explore the importance of the interactions between T2D, other health issues and women's lives in later chapters). The next extract shows how Joanna's partner's T2D had impacted on their intimate relationship as they were unable to have penis-vagina sexual intercourse, demonstrating the more visible (though no more important) effects of T2D on men and how this can impact on intimate relationships:

*He's been a diabetic for over 30 years or so. He's been longer than me. Well, it's affected him sexually. It make him (pause) so we didn't have (pause) we weren't doing anything for 20 odd years (pause) he was impotent.*

*(Joanna, age 66)*

The findings also showed connections between T2D, its medications and intimate relationship quality through more than one participant alluding to a link between T2D medication and mood swings:

*He [her husband] says I've got worse with the diabetes...mood swings. Normally, I'm quite placid. Easy-going but now I explode a lot more and shout at him for things...Are the pills I take [for T2D] because I'm not on insulin or anything; Can they affect mood?*

*(Ann, age 73)*

However, this was not something that Ann had asked her current HCPs about. She had a previously good relationship with HCPs in which she felt she could have asked

about mood changes, which she attributed to her T2D medication. The comparison of her previously good patient-HCP, where she would have felt able to seek help, with her current patient-HCP relationship where she did not feel able to seek help suggests that lack of rapport may be a barrier to discussions around mood changes. Other participants had also experienced mood changes but more commonly attributed these changes to menopause.

When the participants described their experiences of menopause, most referred to both emotional and physical changes. This included irritability (Cath), depression (Cath, Grace), night sweats (Hazel), heavy vaginal bleeding (Isobel, Joanna) and vaginal dryness (Isobel). Some participants perceived these changes to have had an impact on their intimate relationships and health:

*I had such heavy bleeding, really such heavy bleeding and stuff and... that put me off any sex.  
(Joanna, age 66)*

Several participants were currently taking, or had taken, synthetic hormones, either hormone replacement therapy (HRT) or the contraceptive pill, which they perceived to have alleviated some of their health issues that they attributed to menopause:

*...it was the hot sweats and night sweats and irritability and just I found it hard to put a smile on my face really I was quite down about things so I've been a lot better since I've been on the tablets.  
(Cath, age 50)*

All three Black British participants expressed a dislike of taking synthetic hormones, and had actively decided not to take them. One had tried them and decided that she did not like them and two rejected them specifically due to a perceived link between HRT and cancer. This concern of the relationship between HRT and cancer was not seen in the White British participants suggesting a cultural difference within the sample. This and other cultural differences will be explored, in the next subordinate theme and in more detail in Chapter Six – Discussion.

Those who did not have symptoms connected with menopause expressed that they “*didn't have the hot sweats*” showing awareness of what could happen at menopause.

Other symptoms of which women were aware could occur during menopause included mood changes and lower sexual desire. As discussed in the above theme 'Adapting to SHW circumstances', those that had not had symptoms considered themselves fortunate to have avoided them, as they perceived them to be common among other women:

*It [menopause] is strange because a lot of people have a lot of symptoms. Some people get angry, some friends say they get angry, annoyed, it affects them in different ways. I never went through anything like that.  
(Isobel, age 83)*

In addition to living with T2D and going through, or having gone through, the menopause, the participants described living with various other health issues, such as, osteoarthritis, hernias and cancer. Several participants discussed how these health issues, and their medications, influenced the position that SHW held in their lives, with some considering sexual activity to be “*on the back burner*” because it had become physically painful or difficult to engage in. The use of this phrase implies that sexual activity was not currently a priority, because of their health issues, but that it could become one again in the future:

*...only when I started on this medication [for cancer] I got very tired very quickly so I probably wasn't really awake enough (laughs) but yeah, I think because of, the problems we've had we've probably not as sexual as we would have been  
(Debra, age 69)*

In this last extract, Debra expressed that the frequency of which she and her partner engaged in sexual activity was not only connected with her health (the side-effects of her cancer medication) but also the health of her partner, shown in her use of the word “we” and also references to her partner’s health within her account. Other participants described health issues that their partners had experienced (e.g dementia, heart conditions, T2D, depression) and how this impacted their SHW. Indeed, the analysis showed that the relational context was key to the frequency and quality of sexual activity – an aspect which I explore in the next chapter.

It was clear that in addition to the aforementioned issues, financial and familial situations influenced the priority given to sexual activity and intimate relationships



within the participants' lives. Indeed, these issues were shown to be relevant to the SHW of some participants due to their psychological impact on sexual desire and for other the time pressures which were exerted:

*I find it quite challenging with my parents because they live in [a city one hours drive away] which means I travel up there (pause) but that's my general well-being, I think my sexual health seems OK.  
(Grace, age 63)*

In this last extract, however, Grace separates her general well-being from her sexual health and yet she included her familial situation in the same sentence as her discussion of her SHW showing her perception of a connection between SHW and social relationships.

### **5.3.3 Sexual health and well-being, and social relationships (Super theme 3: Sub theme 3)**

Social relationships and more specifically how SHW was discussed outside of a primary care context was found to influence SHW discussions which took place within primary care. A common feature in participants' accounts was that HCPs were just one source of SHW information available. The participants frequently referred to friends, partners and family as a source of SHW discussion, information and support. Comparison of symptoms and sharing of information with female friends influenced the women's perceptions around what was regarded to be "normal" sexual changes and whether it was necessary to seek professional help. Moreover, discussions with friends would often occur before seeking professional help for sexual issues:

*...we've got plenty of friends that we could have that sort of conversation with or that they might have with us if there was something wrong or whatever so, yes, there are plenty of people that we talk to about everything.  
(Grace, age 63)*

This extract is also noteworthy in that it highlights that Grace, the participant in a same-sex relationship, discussed talking about SHW with friends *with* her partner, shown in her use of the word "we". She was the only participant to do so providing further evidence that women may be more comfortable discussing SHW with other women, including a preference for female HCPs. Grace highlighted that communication about

SHW took place in her relationship. She attributed this ease of communication to being in a relationship with a woman implying a perception of differing SHW communication habits in female same-sex relationships compared to heterosexual and male same-sex relationships. The reference to “*plenty of friends*” in Grace’s extract above suggests an abundance of friends with which she could discuss SHW, in comparison with the other women who described discussing SHW with “*a friend*”. This may highlight an additional difference between the SHW communication habits of heterosexual and lesbian women, with lesbian women having a larger social network to discuss SHW issues.

Contrasting with the preference that most participants showed towards discussing SHW with female friends, a few participants expressed a reluctance towards discussing sexual problems with anyone including female friends due to feeling that it was a private topic:

*...to tell somebody else from outside [about her vaginal dryness], I couldn't (pause) I probably wouldn't. Not even a friend.  
(Isobel, age 83)*

Despite some participants expressing an unwillingness to discuss sexual activity and sexual problems with anybody, reflected in many accounts of these same participants who expressed reluctance, were experiences of discussing menopause with female friends. On occasion, discussions with female friends influenced perceptions of synthetic hormones and contributed to decisions around their usage:

*She had to wear a patch... you've heard about the patch? Somebody told her that they said that it can give you cancer, I don't know if you heard that.  
(Isobel, age 83)*

Some participants did not discuss sexual activity, sexual problems or menopause with friends at all. The participants that did not discuss sex with friends described other sources of SHW information reflecting that women can access a range of resources when in need of SHW support:

*... if it were a [sexual health] problem I'd probably read a book (laughs)  
(Debra, age 69)*

For the participants in intimate relationships, their SHW intersected with that of their partners but was often not discussed within their relationships. They attributed this lack of discussion to embarrassment stating that they found it easier to discuss sexual activity with a “*stranger*” than with their partner:

*I think I'm more embarrassed to discuss it [sexual activity] with my partner than I am with a stranger (motions towards me) (laughs)  
(Ellie, age 58)*

However, while there was evidence suggesting that the women may have been more comfortable talking about issues such as sexual activity with HCPs than intimate partners, as described earlier in this chapter, the participants also described feelings of embarrassment when discussing issues such as vaginal dryness with HCPs providing seemingly contradictory accounts. In addition to this reluctance around discussing SHW with intimate partners in private, some participants were also reluctant to discuss SHW with intimate partners present in clinical settings. The presence of partners, and indeed other family members, in consultations was found to present an additional barrier to discussing SHW with HCPs.

The participants also recalled previous experiences of being present whilst their intimate partners sought help for SHW issues as being “*off-putting*”. This intimates that the act of seeking professional help or treatments such as Viagra may impact on women’s sexual desire as it may be perceived as spoiling the naturalness of sexual activity:

*We've been to the clinic and he's had all sort of stuff, Viagra and all things but it just put me off. I just find it distasteful. It just sort of turned me off... it wasn't like in a loving situation.  
(Joanna, age 66)*

There was also evidence to the contrary, with participants expressing frustration that their intimate partner did not want to seek help for their inability to maintain an erection, demonstrating that the SHW help-seeking habits of intimate partners influenced the type of SHW issue that women discussed in consultations. In this way, if an intimate partner is unwilling to discuss SHW with HCPs, this may present a barrier to the individual accessing SHW care.

Many of the participants in intimate relationships, including those that did not discuss sex with their partners, believed that they knew how content their partner was with their level of sexual activity, indicating a non-verbal element to SHW communication in intimate relationships:

*I think he's quite aware of the situation [erectile 'dysfunction'] but on the other hand not overly desperate to do anything about it.  
(Cath, age 50)*

While most participants did not discuss SHW with their intimate partners, nor with intimate partners present in clinical settings, the participant's perception of their intimate partner's contentment with their level of sexual activity was a priority:

*I would get upset if I think I've upset Steve... About the fact that we don't have sexual relations  
(Ann, age 73)*

*It [discussing sex] isn't important except how it might affect our relationship  
(Ellie, age 58)*

*I just grin and bear it [pain during sexual activity]  
(Isobel, age 83)*

In the last extract, Isobel uses the phrase “*grin and bear it*” to describe times when she engaged in painful penetrative sexual intercourse with her intimate partner without disclosing to him that it was painful for her. She repeats the same phrase later in her account in regards to other situations in her life that were unpleasant and that she remained silent. She reported that she tolerated painful penetrative sexual intercourse as she did not feel she could discuss it with her intimate partner. Furthermore, use of the word “*grin*” in addition to “*bear*” suggests that in addition to not feeling able to discuss SHW with her intimate partner, she attempted to conceal the pain from him. This suggests that sometimes women wanted to be perceived as enjoying sexual activity by their intimate partners, even if it was not the case, reiterating the key role of prioritising the feelings of intimate partners. Other accounts supported this and I develop this idea in more detail in Chapter Six – Discussion.

It is also notable that it was Isobel, the oldest participant, who described tolerating painful sexual intercourse with her intimate partner, whereas none of the other

participants did. This may suggest age related differences in regards to how women communicate with their intimate partners regarding sexual activity. However, younger participants also described not discussing sexual activity, albeit to avoid putting pressure on their intimate partners rather than to avoid pain.

Some participants in heterosexual relationships expressed that they enjoyed sexual activity but that they did not initiate it because their intimate partner experienced less sexual desire than they did or they did not want to cause emotional distress to their intimate partners:

*I suppose I (pause) don't initiate because I don't want to put pressure on him because his libido has declined and he has commented on that so (pause) yeah (pause) so maybe sometimes I don't simply because, you know, I don't want to put any pressure on him  
(Ellie, age 58)*

The way in which Ellie talked about her intimate partner and their sexual relationship was it was as if she did not want to complain, as if she felt uncomfortable verbalising anything that could be construed as discontentment. This was demonstrated through her hesitancy, unfinished sentences, which was in contrast to the articulate and clear way that she spoke throughout the rest of her account. This hesitancy around SHW within her relationship was in contrast to the pragmatic way in which she discussed other topics, such as her T2D, family and relationship with her HCPs. See Appendix K – Individual lifeworld and interview reflection for more details on this participant and earlier subordinate theme ‘Balancing pragmatism and embarrassment’ for information on the pragmatic approach of participants more generally. Within interviews, other participants in intimate relationships also demonstrated reluctance discussing issues that could be construed as critical of their intimate partners, again highlighting the participants’ focus on the feelings of their intimate partners and its contribution to the SHW of the individual.

The participants frequently considered social activities, such as dancing, attending the Dementia café (for one participant whose intimate partner was living with dementia) and going on holiday as contributing to their intimate relationships. Most participants who discussed these activities at length and in detail were not currently sexually active. This suggests that social activities may constitute an essential component of intimate

relationships, particularly in couples that are not sexually active. The significance of these social activities was demonstrated through one participant even considering suicide when she was told by HCPs that she could not dance:

*...we'll just drive off the end of...together kind of thing and now and again he'll look at me and especially when they said I mustn't dance and I said, "It's not time for [place with a cliff] is it? I feel it is".*  
(Ann, age 73)

Ann was instructed that she could not dance because she had been told not to weight bear due to a health issue common in people living with T2D. While discussion of the health issues could have been included in the previous subordinate theme 'SHW and health issues', the development of the health issue impacted on her intimate and social relationships, hence its inclusion in the current subordinate theme. However, what this example serves to demonstrate is the holistic and interlinked nature of the SHW, health, well-being and social relationships in women's lives. The interwoven nature of social, health and SHW aspects of life forms one of the key features of Chapter Six – Discussion. SHW was not only influenced by the participants' focus on their intimate partner's needs but also those of family and friends:

*...you get urges...it's just other things in my life take over.*  
(Joanna, age 66)

The above quote exemplifies how sexual needs were deprioritised in light of competing aspects of the participants' lives. In addition to intimate partners sexual needs, discussed above, examples of the competing aspects that women referred to included, health issues (both their own and their partners) caring for parents, caring for children and work responsibilities. This also has links with the superordinate theme, 'Sense of control over SHW and healthcare', as women controlled their sexual "urges" in order to focus on other aspects of their lives. In this way, women did not need to discuss SHW with HCPs if first, they were managing their SHW needs independently and second, their SHW needs were not currently a priority in their lives.

In addition to relationships with family, friends and intimate partners influencing feelings around SHW discussions, discussions with family members, particularly mothers, affected current attitudes towards SHW discussions. Many participants

described a reluctance towards discussing SHW and attributed this to previous social expectations of their gender from their upbringing. When describing said reluctance to discuss SHW, the language women used was often ambiguous:

*Because ladies just didn't talk about [sex]... we were brought up not to talk about that sort of thing. Like "down there" you just didn't.  
(Ann, age 73)*

The word “*ladies*” suggests that gender expectations that were ingrained from childhood, proscribed that women should not discuss sex. This appeared to influence whether they discussed SHW with their HCPs, particularly male HCPs, as discussed in the earlier theme ‘HCP characteristics’. Providing further understanding of the impact that upbringing had on willingness to discuss SHW, below we see how for Fiona, who had an upbringing where sex was openly discussed, attributes her ease at having SHW discussions with HCPs to familial discussions around sex:

*I must admit my parents did bring me up to be open. They were a very happy and open couple so... So that [discussing SHW with HCPs] wouldn't be a problem.  
(Fiona, age 54)*

Fiona reiterated her belief that childhood experiences influence feelings around SHW discussions using a family member’s attitude, to exemplify the contrast between her own and the family members. This is demonstration of a perceived link between past experiences of SHW discussions and current perspectives towards SHW:

*My [family member], she had a lot of problems... she hadn't started her periods even at 16. My gran had a big influence on her and used to tell her some really nasty [sexual] old wives tales so it frightened her to death... it's affected her. She is a lot more inhibited than any of us.  
(Fiona, age 54)*

The participant accounts also reflected that there were feelings of guilt around SHW and in particular around sexual pleasure, a point which is explored in Chapter Six – Discussion:

*I did have a sex toy at one point but I got rid of it (pause) I just felt like guilt  
(Joanna, age 66)*

The accounts of the other Black British participants also reflect feelings of guilt around engaging in and discussing sexual activity. All three Black British participants were practising religion in contrast to the majority of the White British participants who were not practising (see Chapter Four – Table 2 – Participant demographics). Practising of religion highlights a cultural difference between Black and White British women within this thesis. It also demonstrates a link between practising religion and the feelings of guilt that Black British participants experienced around discussing SHW. This suggests that practising religion may be linked with a social expectation for not discussing SHW.

Nevertheless, a perception of changing social expectations for women over time was also present in several accounts. The participants described how previously engaging in sexual activity felt like an obligation within their intimate relationships but now felt that there was less pressure to fulfil this obligation due to changes both within themselves as they age, and socially:

*I think I've always thought it's [sexual activity] just something that you have to do but times have changed  
(Bev, age 68)*

*I love how these young people are, my children and everybody have a partner and everything is a partnership and everything, I love that but it wasn't like that  
(Isobel, age 83)*

As the last extract demonstrates, the participants also discussed perceived social differences between generations. Three participants discussed SHW discussions that they had had with their sons and daughters, some of these conversations were uncomfortable for participants, particularly for Joanna, as her children rebuked her for wanting an intimate partner:

*She [her daughter] said "You're too old and decrepit. Nobody will fancy you, what do you want a man for?"  
(Joanna, age 66)*

When put in the context of the interview setting, it was clear that this comment was part of a humorous exchange between Joanna and her daughter. However, being aware of a perception of older women as undesirable by younger generations may



have implications for how able they feel about broaching the topic of SHW with others, particularly the HCPs who are from a younger generation.

### **Summary of Superordinate theme 3**

Perceptions of SHW as 'medical' within consultations influenced the types of SHW issues that had been or would be discussed with HCPs. Also influencing the place of SHW in the lives of the women was health problems, both theirs and their intimate partners. Health problems most commonly discussed were T2D and issues related to menopause. Experiencing these health issues meant that sexual activity was sometimes considered less of a priority. However, intimate partner's feelings about sexual activity could influence how important the women felt SHW was to them. Social relationships were linked with how women felt about discussing SHW with HCPs. Upbringing and discussions with friends and family were all found to influence whether women engaged in SHW discussions with HCPs, and how comfortable these experiences were.

### **Summary of the Findings Chapter**

In this chapter, I have presented the findings which resulted from an intensive and detailed analysis of the data. To summarise, most of the women had encountered SHW issues but they did not consider all of these problematic, meaning that they did not always seek professional help. SHW issues were considered problematic, or not, within the context of the intimate relationship or life more generally. For SHW issues which were considered problematic but had not been discussed with HCPs, women used other sources of information, with conversations with female peers found to be a particularly important source of SHW support.

Most women had experienced little or no discussion with HCPs about SHW and few knew of a potential link between T2D and SHW. As SHW discussions had seldom taken place in practice, women often did not attribute SHW changes to their T2D. More often changes were attributed to menopause or ageing, generally. SHW issues that had been discussed with HCPs were focussed on 'medical' issues with discussion of issues less connected with 'medical' aspects of SHW, causing feelings of embarrassment. Potential reasons for this embarrassment included the women's

current and previous feelings about SHW and where, if anywhere, they felt was an appropriate context to discuss it. While the women also found SHW discussions pertaining to 'medical' aspects of SHW embarrassing, they had discussed them due to their perceived severity and sometimes, a need to know the source of the SHW issue. Seeking professional help did not mean that treatment offered by HCPs was automatically accepted. The decision of whether to accept treatment offered by HCPs was based on how problematic the SHW issue was, the context of the women's lives and how the women felt about the treatment and the HCP.

In terms of HCP characteristics, the women predominantly preferred female HCPs for SHW discussions. When looking at length of the participant-HCP relationship, the data were divided. Age was found to be relevant in two ways. First, the women expressed some expectation of ageism within consultations and second, it was suggested that older women may prefer to see female HCPs. Practical barriers were also identified by the women.

When SHW conversations did take place rapport between the women and their HCP was essential to ensuring that the women felt comfortable. It highlighted how the women perceived their HCPs and their relationships with them to influence experiences of discussing SHW and willingness to do so in the future. Even women who had not spoken about SHW with their current HCPs had clear ideas of who they would and would not discuss SHW with. They reached these decisions through considering previous communication experiences they had had with their HCPs. The findings are discussed in relation to the broader literature in the next chapter.

# CHAPTER SIX – DISCUSSION

## Introduction

The discussion situates the thesis findings within current research about the sexual health and wellbeing (SHW) of older women with Type 2 Diabetes (T2D) and considers how, through the adoption of an interpretative phenomenological analysis (IPA) approach, the thesis findings answer the research questions and fulfill the research aim stated in Chapter Two. Through this process, the theoretical and methodological contributions to knowledge that this thesis makes are asserted. For clarity, I have divided this chapter into two sections: 1. Findings in relation to existing literature; 2. Contribution to knowledge.

Section one builds on the close and critical engagement with the women's accounts presented in the previous chapter by adding depth to my interpretation of the findings (Smith 2011; Larkin, Watts & Clifton 2006). I achieve this through incorporating existing research, theories and IPA with the thesis findings. Within this first section, the role of the double hermeneutic – that is, the researcher making sense of the participants' accounts – comes to the fore. Building on the women's accounts of the barriers and facilitators to SHW discussions, this section leans more towards my interpretation of the women's accounts. This balance, between a descriptive reading of women's accounts in the previous chapter and the more interpretive reading presented here, reiterates the tension between the phenomenological obligation to 'give voice' to participants and the interpretative obligation to make sense of participants' accounts based on context, existing literature and the researcher's personal experience (Davidsen 2013; Larkin, Watts & Clifton 2006; Ricoeur 1970; Smith, Flowers & Larkin 2009). The intense focus and role of the double hermeneutic in IPA promotes a broad and developed understanding of the barriers and facilitators to SHW communication in primary care settings. The purpose of interpretative analysis is not to discount or verify the experiences of the participants but rather to "...offer meaningful insights which exceed and subsume the explicit claims of our participants" (Smith, Flowers & Larkin 2009, p. 23). Moreover, the contributions to knowledge this thesis offers are co-constructed between the women and myself as the researcher.

Building on the discussion of the findings, in section two I present the two theoretical and methodological contributions to knowledge that this thesis makes. These pivot on the premise that, to the best of my knowledge, this is the first IPA thesis to explore the SHW discussions of baby boomer women with T2D as well as highlighting that key intersecting factors influence SHW communication between baby boomer women with T2D and their healthcare professionals (HCP). To illustrate the strength of the contributions to knowledge and distinguish the thesis from what is currently known, I draw heavily on the thesis findings from Chapter Five as well as existing literature.

The aim of the thesis was to undertake an in-depth exploration of baby boomer women's (aged 50-75 years living with T2D) experiences of SHW discussions in primary care. Within this chapter, I achieve the thesis aim and answer the research questions below<sup>5</sup>:

#### **Primary research question**

What do baby boomer women (aged 50-75 years with T2D) consider to be the barriers and facilitators to SHW communication in primary care consultations?

#### **Secondary research questions**

What do baby boomer women consider important to their SHW?

Which factors influence the decision to discuss (or not to discuss) SHW within primary care consultations?

What role does the HCP play in SHW communication?

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<sup>5</sup> The fifth, and final research question 'What are the implications for practice?' is addressed in Chapter Seven – Implications for primary care practice

## **6.1 Section One – Findings in relation to existing literature, theories and the contribution of IPA**

### **6.1.1 Women's lifeworlds**

#### **Introduction**

The central focus of this thesis is women's experiences of and perspectives about SHW discussions in primary care settings. The in-depth analysis of their accounts illustrated that the women's approaches to discussing SHW with their HCPs were embedded in their experiences outside of consultations. Insight into the women's lived experiences and wider engagement with the world provides the background for the subsequent exploration of their perspectives regarding SHW help-seeking and primary care consultations (Lopez & Willis 2004; Smith, Flowers & Larkin 2009; Tuffour 2017). The thesis findings highlight that the varying factors implicated in decision making around SHW discussions in consultations are tethered to life outside of the consultation. Therefore, understanding the difficulties that women face when discussing SHW outside of the healthcare consultation provides essential context for understanding barriers to SHW discussions *within* primary care consultations.

It was clear that outside of consultations, talking about SHW was fraught with difficulties and that many of the aspects I go on to discuss in this section were interlinked. However, in order to present a coherent account of my interpretation of the relevant aspects of SHW discussions outside of consultations, the first part of this section is divided into discrete sub-sections: historical context; socio-cultural context; and personal context.

#### **6.1.1.1 Historical context: Past experiences and upbringing**

In contrast to descriptive phenomenology, historical context is implicit in understanding the phenomenon in question when adopting an interpretative phenomenological approach (Rodriguez & Smith 2018). Therefore, I build on the historical context introduced in Chapter One and consider how the women's past experiences of discussing, or not discussing, SHW reverberated in their present lives. Taboos around female sexuality from the last century appeared to linger with social norms from previous generations influencing the women's current feelings about discussing SHW

(Foucault 1979). Conversations with the previous generation in early life, usually with their mothers, contributed to the women's feelings of embarrassment or ease around discussing SHW, in contexts both inside and outside of primary care. The women's embarrassment around their sexual feelings appeared to stem from deeply entrenched traditions and sexual taboos from childhood, which echoes findings from other studies with women of this age range (Hinchliff & Barrett 2018; Sarkadi & Rosenqvist 2003). The tension between the women's perceptions formed in their youth and their current lived realities demonstrates the influence that early experiences can exert on current circumstances as well as the importance of exploring past experiences to provide a more detailed understanding of current behaviours.

The women were born between 1933 and 1966 and therefore grew up in the conservative era of 1950s UK<sup>6</sup> where messages about sexuality, both from sex education at school and wider society, were predominantly linked to reproduction and the privileging of male sexual pleasure (Wood et al. 2007). The sex education that the baby boomers received in school was developed in response to concerns in the medical community about "venereal disease during the Second World War" (Hampshire 2005, p. 87), which explains their focus on sexually transmitted infection (STI) prevention and reproduction. Additionally, the Church had concerns about pregnancies outside of marriage as well as abortions, which also influenced the content and scope of pupils' sex education (Hampshire 2005). Thus, driven by medical and religious communities, the sex education that most baby boomers received focussed on STI prevention and pregnancy, with sexual pleasure frequently omitted (Giami & Hekma, 2014; Hampshire, 2005). Through these means, social rules about the appropriate context within which sex should take place and be discussed were reinforced. This focus on STI prevention and reproduction, and omission of pleasure, partially explains the women's current understandings about which aspects of SHW are acceptable to discuss. Evidence suggests that discussion around sexual pleasure remains largely absent from sex education in UK schools, implying that these taboos around SHW remain (Hirst 2008, 2004, 2013). Indeed, sexual pleasure was one of the aspects to which participants infrequently referred. However, rather than pointing to a

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<sup>6</sup> Of the three participants born in the Caribbean, Isobel arrived in the late 1950s/early 60s when in her mid-twenties, meaning that in her early youth, she may not have been exposed to the same messages around sexuality as other participants.

lack of sexual pleasure, this may indicate a lack of language and permission to articulate sexual pleasure (Hirst 2008).

The exclusion of sexual pleasure in the women's accounts of SHW discussions may also be reflective of widespread Christian religiosity in the era in which baby boomer women grew up. Historically, religiosity has played a key role in the repression of SHW, with female sexuality and pleasure being portrayed as threatening to the moral and social fabric of society (Weeks 2010; Hampshire 2005). While none of the women made overt reference to religion influencing their personal views on SHW, several were practising Christians. In addition to this, evidence suggests that religious influences dictate what is considered acceptable within society at large, not just on a personal level (Hinchliff & King 2018; Turner & Samson 1995; Weeks 2010). Therefore, whether baby boomer women are religious or not, the social norms born of the religiosity inherent in society mean that sexual activity may still be linked with reproduction rather than pleasure or liberal sexual expression in the minds of these women. The restrictive sex education, high religiosity and conservative messages around sex that existed in their youth could mean that women of the baby boomer generation remain inhibited by these factors when considering the discussion of their SHW needs.

Shifts in the medical community may have provided a counterbalance to the historic inhibition around the discussion of women's SHW and pleasure (Giami & Hekma 2014; Todd 1984). Messages about the link between women's sexual activity and reproduction have changed over the years, influenced by the increased availability of contraception (Higgs & Gilleard 2013; Tyrer 1999). The medical community's shift in focus from the prevention of STIs to pregnancy prevention freed many women from frequent pregnancies, and in turn produced a recognition by society that women may engage in sexual activity for pleasure. This shift may have influenced social expectations of how women should behave, a point to which I return below in the sub-section 'socio-cultural context'.

Understanding the influences that baby boomer women received regarding their SHW is complex, with influences from the Church, sex education, the medical community and home meshing together. The impact of these messages is reflective of an

accumulative 'social heritage' in which values and social norms are passed on from generation to generation (Bristow 2016; Mannheim 1970). This accumulative social heritage is transmitted via a combination of conscious teachings, such as the sex education discussed above or, as seen in the previous chapter, more informal mechanisms of generational interaction, such as conversations with mothers. However, the values and social norms of the past are not preserved within women's lives but instead assimilated, developed and given a new perspective in light of the changed social and cultural environment (Mannheim 1970).

The more liberal way in which participants lived, compared to previous generations, was arguably influenced by the social changes that baby boomers experienced after the conservatism of their youth during the 1950s, 60s and 70s, discussion of which was introduced in Chapter One (Bradway & Beard 2015; Bristow 2015; Woodsprings 2016). These increasingly liberal social values and the availability of contraception may have provided a contrast to the conservative messages received from other sources, but there was evidence of continuing taboos around sex in many women's accounts.

While some women expressed a desire for SHW discussions to be a part of their primary care consultations, previous experiences of SHW being taboo, both inside and outside of consultations, came to the fore. Avoidance of correct anatomical language for genital areas is one example of how this taboo manifested. This linguistic silence was a clear indication of existing taboos around SHW for baby boomer women. The participants were willing to discuss certain aspects of SHW in consultations when they felt it essential for preserving their general health but most struggled to use the words "sex", "vagina" or "vulva", during the interviews. They instead chose to use phrases such as "down there" or even preferred to gesture to the general area of their vulva without using words at all. Without the language to describe experiences, women's abilities to discuss SHW issues may be limited (Ashworth 2008; Davidsen 2013; Tuffour 2017). The women's sense of linguistic silence was born of their lived experiences in the social world and is therefore reflective of the challenges of understanding sexuality outside of its lifeworld context (Foucault 1979). However, as discussed above, the social world is not static and notions around acceptable behaviour, and the appropriate forum in which to discuss these behaviours, change over time and between generations.



Indeed, the participants were aware of differences in approaches to SHW between their own and other generations. Comparisons were made by the participants between previous and current norms of sexual and intimate relationship behaviour using their mothers, daughters, and sons as examples of how social norms have changed. These comparisons demonstrated recognition of a cultural shift towards women's liberation regarding sexuality, even if these perceived socio-cultural changes did not substantially influence their comfort in discussing SHW. Focussing on the socio-cultural climate in which the women lived is essential for deepening our understanding of the factors influencing SHW discussions in primary care.

#### **6.1.1.2 Socio-cultural context: Social norms and social lives**

The current findings support recent qualitative studies reporting that many factors relevant to the SHW of older women are socially constructed (Fileborn et al. 2015b; Jen 2017; Weeks 2010). The potential that social processes have to oppress or normalise sexual discussions (Foucault 1979) and the implications of this for norms around SHW discussion require consideration. Within this thesis, there are examples of how previous and current social norms exerted a strong influence over the participants' feelings towards discussing SHW. The important social changes that baby boomer women have experienced, which I discuss below, suggest that new generations of older women may have different relationships with their bodies as well as their HCPs. These social changes likely influence how SHW is experienced and how it is discussed within consultations (Estes & Binney 1989; Hinchliff & Gott 2011; Marshall 2011).

The changes in Western society that baby boomer women have lived through include the separation of sex from marriage, the ability to get a divorce, second-wave feminism and the 'sexual revolution' (Arber, Davidsen & Ginn 2003; Borrell & Karlsson 2003; Gott 2006; Watters & Boyd 2009). However, the social reality is that perceptions and judgement of baby boomer women's sexual behaviour remain relatively conservative in comparison with those relating to men and younger generations (Bristow 2015; Giami & Hekma 2014; Phillipson et al. 2008; Rowntree 2014; Thorpe et al. 2018; Woodsprings 2016). As discussed earlier in this section, the participants had embraced some of the liberal values around SHW, but there was evidence of guilt

around sexual pleasure and a reluctance to play an active role in the initiation of sexual activity with intimate partners. This reluctance reiterates that while baby boomer women may have lived through important social changes, they remain influenced by their younger years and may not have fully accepted current, more liberal social values.

Consideration around how old the participants were at the time that these social changes occurred is necessary to provide further context. Nine of the 10 women included in the thesis sample were born between 1946 and 1965 (with one born in 1933). The older women would have been in their late 20s when some of these social changes occurred. For example, the Divorce Reform Act, which made it easier for couples to divorce, passed in 1969 (Great Britain 1969), while the sexual 'revolution' is reported to have taken place roughly between 1965 and 1970 (Cook 2014). The older women may not have experienced these social changes in the same way that younger participants did. Indeed, a comparison of data analysis between older and younger participants demonstrated some differences regarding understandings of SHW, with younger participants first discussing STIs and menopause, and older participants discussing intimate relationships first (see the Preface to the Findings chapter). However, there was great variation in the participants' acceptance of liberal social values, with individual aspects of their lived experiences of familial relationships, intimate partner relationships and general health also playing key roles. The importance of the women's individual, lived experience to their SHW constitutes one of the crucial contributions to knowledge that this thesis makes and is discussed at the end of this chapter.

Evidence of the participants' embracing of the more liberal social values was shown in the myriad types of intimate relationships and living arrangements they reported. This greater diversity in the intimate relationships of older women is reflected in the literature, with reports of increasing later life divorces and remarriages as well as older women more frequently living apart from their intimate partners (Connidis 2006; Karlsson & Borell 2005; Watters & Boyd 2009). However, this openness towards non-traditional relationship arrangements was not reflected in SHW communication habits, with the participants frequently expressing embarrassment over discussions of SHW in many contexts, including consultations. In the few studies that have explored the topic, embarrassment has also been found to be a barrier to SHW discussions

between older women with T2D and their HCPs (Rutte et al., 2016; Sarkadi & Rosenqvist 2001). This means that while social changes may have increased a feeling of liberty regarding lived experiences in intimate relationships and sexual expression, SHW discussion may still invoke feelings of awkwardness, signifying a disparity between behaving a certain way and talking about it (Foucault 1979).

The disparity between experiences of SHW and talking about SHW can be understood by looking at discourses around femininity and ageing. Social scripts, which prescribe what is 'normal' to discuss in a given situation, explain that a woman's sense of her sexuality is influenced by various factors, such as social expectations, generational aspects and continuing discourses around femininity and youth (Sandberg 2013; Simon & Gagnon 1984; Sontag 1972). These social and cultural components were identified in the participants' accounts of SHW discussions, with women drawing on experiences with family, friends and HCPs to determine which aspects of SHW were appropriate to discuss, and in which contexts (Gagnon 1990; Simon & Gagnon 1984; Wiederman 2005).

One context in which most women felt able to discuss SHW was with female friends. Within female friendships, SHW discussions included experiences of menopause, intimate relationships and sexual activity. Through these conversations, women constructed definitions of what was 'normal' regarding SHW changes. These candid conversations often took place before women sought professional help and contributed to beliefs about and attitudes towards their SHW, thus influencing which issues they would bring up with HCPs. When women were making sense of their SHW, they balanced their own first-person, embodied experience with the experiences of the 'other' – that is, other women – which they obtained through conversations with female friends. The participants' beliefs around a 'normal' menopause were particularly influenced by the experiences of other women. Women's knowledge of the negative menopausal experiences of others may lead to a normalisation of difficult menopausal symptoms and perpetuate the notion that menopausal suffering and SHW changes are an inevitable part of the ageing process (Bergeron et al. 2017; Calasanti & Slevin 2006; Faccio et al. 2018; Hinchliff & Gott 2011).

A perception of the inevitability of menopausal suffering, gained through conversations with friends, can lead to women tolerating unwanted symptoms rather than seeking help. However, conversations with female friends also potentially provide emotional support for women who are experiencing SHW changes that they want to discuss. In certain instances, this may mean that women have access to the necessary emotional and social resources to cope with SHW changes and so do not require professional help. The role that informal social support networks have in meeting the emotional care needs of older women has been identified in other research (Calasanti & Slevin 2006). In particular, the role that women's groups play in supporting SHW concerns has been suggested in other research focussed on women with T2D (Sarkadi & Rosenqvist 2001, 2003). I discuss this in more detail in the next chapter – Implications for primary care practice. However, these conversations about the diverse lived experiences of the participants' friends, which provided real-world evidence of baby boomer women as having diverse menopausal experiences and being sexually active, may be at odds with dominant social discourses that position older women as asexual (MacRae 2018; Thorpe et al. 2017). The implication of this is that the asexual stereotype is not grounded in the experiences of baby boomer women themselves, but is instead a prevalent stereotype in Western societies, of which participants showed awareness.

The generalised perception of older women as asexual persists within Western cultures despite a wealth of evidence rejecting this notion (Bergeron et al. 2017; Gott 2005; Hinchliff & Gott 2008; Taylor & Gosney 2011). As discussed, awareness of this stereotype may lead women to avoid SHW conversations in order to hide their sexual agency. The stereotype of asexual older women is potentially confounded by the T2D diagnosis, with research suggesting that patients with chronic diseases may not be perceived as sexual beings within society (Verschuren et al. 2010). While the social stereotype of older women, and particularly older women with a chronic disease, may be asexual, the current findings showed that women rejected the notion of older age as a time of SHW decline. This rejection was reflected through accounts of current sexual activity, openness to new relationships and discussions around potentially becoming more sexually active in the future. This aligns with Diamond's theory of dynamic sexuality (2008), which stipulates that sexuality is fluid over the life-course rather than reflecting a unidirectional decline into old age, a finding highlighted in

several other qualitative studies (Carpenter 2010; Gott & Hinchliff 2003b; Jen 2017; Miller 2018; Simon & Gagnon 1984; Sontag 1972; Thorpe et al. 2018). While Diamond's theory (2008) does not explicitly refer to old age, it does refer to 'life span', of which old age is a part, reflecting how the fluidity applies to women throughout the life course. In the thesis findings, there was a dissonance between women experiencing their sexuality as ongoing and fluid while simultaneously assuming that others, including HCPs, would assume them to be sexually inactive.

Five of the women in this study reported that they were sexually active, either with an intimate partner or solely through masturbation. Masturbation was described as a way of satisfying sexual desire, implying pleasure, but discussions around the pleasure and enjoyment of sexual activity were notably absent from most of the women's accounts. Other studies have found sexual pleasure to be important within the lives of older adults (Foley 2015; Trompeter et al. 2012) and the WHO working definition of sexual health (see Chapter One) includes "pleasurable...sexual experiences" (WHO 2006, p. 5). However, the women's perceptions of SHW in the context of consultations did not appear to include pleasure. There are potentially a number of reasons for this lack. Further to the aforementioned taboos around women's sexual pleasure, another explanation lies in the study design. The language used in the recruitment material and data collection tools (see Appendices E, F, H and I) may have led to the omission of discussion around sexual pleasure in interviews. The way in which the study was framed, for example, using the term 'sexual health and well-being' rather than 'sexuality' may have inadvertently indicated to participants that pleasure was not within the scope of the research. Therefore, while the women may have experienced sexual pleasure, they may have considered it inappropriate to discuss in the interviews.

Furthermore, expanding on the earlier discussion, guilt also provides a possible explanation for the participants' lack of discussion around sexual pleasure and desire. When asked, those participants who felt guilt around sex were unable to explain why this was. When these feelings of guilt are taken in conjunction with the asexual older women stereotype discussed above, I posit that they are linked to the social expectation for women, and particularly older women, to be disinterested in sexual activity. More importantly to this thesis than the *cause* of guilt around sex is that these feelings of guilt are potentially detrimental to SHW discussions in primary care, leading

to unaddressed issues around sexual enjoyment in consultations. In this way, social norms around older women and sexual activity may present a barrier to discussions around sexual pleasure and desire in primary care settings. However, while women infrequently referred to sexual pleasure, many discussed sexual desire.

Women considered sexual desire to be both out of and within their control at different times in their lives. When changes in sexual desire were perceived as happening to them, participants usually attributed these changes to aspects over which they had little or no control, such as their hormones or intimate partners (that is, the availability of an intimate partner, their partner's sexual desire levels, health status and so on). However, the women also described sexual desire as being within their control, as they felt able to suppress that desire if it did not fit within the context of their life circumstances, for example, if no intimate partner was available or if they had caring responsibilities which they prioritised over their own sexual needs. Nevertheless, in both instances, women may not perceive the benefit of discussing changes in sexual desire with HCPs if they feel unable to change their, or their partner's, sexual desire, do not want to increase their level of sexual desire or feel able to manage that desire independently.

Exploration of the women's sexual desire highlights how interlinked various aspects of SHW are. As described in the paragraph above, sexual desire was influenced by biological, social and emotional factors. The findings also highlight the influence of the individual factors of their current life circumstances on their experiences of sexual desire. Examples included how recently they had been separated from their intimate partners, feelings towards their intimate partner, and health concerns. Intimate relationships and health concerns were two key aspects of women's personal lives which impacted on decisions around SHW discussions.

#### **6.1.1.3 Personal context: Intimate relationships and health issues**

When considering the SHW needs of baby boomer women, their personal lives and idiosyncratic features cannot be understated. The thesis findings demonstrate that SHW is embodied and perspectival. The historical and social aspects of the women's lives discussed above provide important context for understanding their decisions around SHW discussions. However, comprehension of the women's individual

experiences is essential for allowing the women's SHW needs and discussions to come to the fore. Intimate relationships and health issues experienced by the women strongly influenced their feelings around SHW and its discussion.

Intimate relationships have long been recognised as influencing women's sexual contentment and their adaptation to SHW changes (Gott & Hinchliff 2003; Hinchliff et al. 2017; Hurd Clarke 2006; Rowntree 2014; Verschuren et al. 2010), and the studies included in the scoping review of the literature in Chapter Two found that this was the same for populations of older women living with T2D (Erten et al. 2014; Rockliffe-Fidler & Kiemle 2003; Sarkadi & Rosenqvist 2003). A shift in focus from generic measurements of sexual health to the needs identified by those within intimate relationships would encourage a more comprehensive understanding of women's SHW. The shifting importance of sexual activity across the adult life course as understood within the context of the intimate relationship has also been found in other studies of older women and reiterates the sexual dynamism across the life span discussed above (Hinchliff et al. 2017; Hinchliff & Gott 2008; Miller 2018; Trompeter et al. 2012). Women's SHW is intertwined with that of their intimate partners, and the thesis findings concur that intimate relationships are a crucial part of how women regard their SHW. This was demonstrated by the reports of several participants that a reduction in sexual activity was unproblematic, provided that both they and their partners were accepting of the change. This suggests that when both intimate partners are accepting of a reduction in sexual activity, professional help may not be required.

The women's acceptance of changes in the frequency of sexual activity was linked to their intimate partners' general health and SHW as well as their own contentment in the relationship, findings which are supported by DeLamater & Koepsel (2015), Carpenter (2010) and Lindau et al. (2010). Other research suggests that women may compromise between expressing their sexual wishes and the desire to ensure harmonious relationships (Connidis 2006; Hinchliff, Gott & Wylie 2012; Hinchliff & Gott 2008; Wood et al. 2007). This sense of responsibility towards the maintenance of harmony within intimate relationships, in addition to social pressures exerted by society which dictate that older women are not interested in sexual activity, may compound and contribute to women's silence around their own sexual needs. This also reiterates that understandings of SHW, and feelings around discussing it, are not

fixed, but instead are closely linked to the social context of women's lives (Bryman 2016; Crotty 1998).

The findings show that many of the participants enjoyed engaging in social activities, such as dancing or going on holidays, with intimate partners. In situations when these activities became difficult or impossible, usually due to health reasons, their own or their intimate partners', this lack impacted on the relationships. Recognition of the importance of social activities within the women's lives aligns with the holistic understanding of SHW adopted within this thesis. Research exists on the importance of social networks for well-being and the marriage as a social context (see Waite et al. 2009 and Waite et al. 2015), but the importance of social activities for SHW has been largely omitted from the literature. Given the importance of these issues to the SHW of the women, I find the paucity of research discussing the importance of social activities *within* intimate relationships of older adults surprising. While these social aspects were discussed with HCPs when considered necessary, the question of whether the HCPs realised the significance of these activities to women's SHW and their well-being more generally will be discussed in Chapter Seven.

Both the literature and thesis findings are divided regarding the role of SHW discussions within intimate relationships. On the surface, a lack of verbal communication about SHW could be interpreted as a demonstration of poor intimate relationship quality. Alternatively, this lack has been interpreted in some studies as demonstrating a level of consideration for and understanding of each other's needs that transcends verbal communication between older adults (Hinchliff & Gott 2004a; Lindau et al. 2011). Within this thesis, some of the women described their frustration over the unwillingness of male intimate partners to seek professional help for an inability to maintain an erection, a finding which has been discussed in another study of older adults and sex (Hinchliff et al. 2017). However, the thesis findings also provided evidence to suggest that women may find treatment for the inability to maintain an erection a "*turn off*" as sex is perceived to be something that should be spontaneous (Joanna). This means that women may not want their intimate partners to seek help for SHW if they believe that sex should happen naturally – that is, without medication – possibly presenting a further barrier to discussions in consultations. Therefore, intimate partners' help-seeking behaviour, or lack thereof, may influence



women's SHW in diverse ways. The meaning that women attribute to an inability to maintain an erection and the impact that has on the intimate relationship is likely linked to the importance of penetrative sexual activity to the couple as well as the sexual taboos surrounding older women and sexual activity discussed above.

A reluctance to discuss sexual activity, perhaps born of the unwillingness to admit to having sexual feelings, may mean that sexual interest is under-reported in other studies on the SHW of older women (University of Michigan, 2018), particularly research using the Female Sexual Function Index (FSFI) introduced in Chapter One (Pontiroli, Cortelazzi, & Morabito 2013; Forbes, Baillie, & Schniering 2014). Surveys which report that older women have little interest in sex when compared to older men (University of Michigan 2018) may be understood differently when taken in conjunction with the current findings. Considering that many older women may not discuss SHW with their intimate partners or HCPs and may have seldom vocalised feelings about their SHW, I ask why, after a lifetime of silence, would they 'admit' to being interested in sexual activity in a survey. While the data presented in such surveys provide a necessary and concise account of the sexual health of older adults, their results have the potential to perpetuate stereotypes of the sexual disinterest of older women.

In contrast, the qualitative, interpretative nature of this thesis has revealed nuances in the restrictions on women's sexual feelings as well as an inability (and/or unwillingness) to vocalise these feelings. To clarify, while some participants described sexual activity as currently unimportant to them, my interpretation of their accounts was that sexual activity might be more important to them or more enjoyable than they were willing to express explicitly. Thus, while sexual activity may be important and enjoyable for some women, harmony in their intimate relationships, maintained through participants not requesting more or different sexual activity, may take priority. This may shed light on the findings that women reported being sexually satisfied even if my interpretation of their accounts revealed potentially unfulfilled sexual needs. Nevertheless, the ontological orientation of IPA asks 'what does it mean to be a particular person, in that context, with those needs?', suggesting that my interpretation of women's needs should not overshadow their expressed needs (Rodriguez & Smith 2018).

Interpreting the participants' expressed needs as a suppression of 'true' desires should also be carefully considered as the findings demonstrated that some of the SHW changes the women in this thesis experienced, such as low sexual desire, did not cause them distress when they "*fit*" within the context of the personal lives and intimate relationships (Ellie). The acceptance of these SHW changes means that not all SHW changes require discussion with HCPs. These findings are in line with recent arguments rejecting the medicalisation of sexual changes and challenging the classification of all female sexual changes as 'dysfunctions' (Graham et al. 2017; Marshall 2011; Taylor & Gosney 2011; Tiefer 2007, 2001). In 2017, Bijlsma-Rutte et al. (2017) made the distinction between sexual 'dysfunction' and sexual dissatisfaction in adults living with T2D and emphasised that the two are not synonymous. Furthermore, they concluded that not all sexual changes require professional help (Rutte et al. 2016). Indeed, recent literature focuses on the importance of not labelling all sexual changes as problematic but rather understanding sexual change within the context of people's lives, as I argue throughout this thesis (Barrett et al. 2018; Graham et al. 2017; Hinchliff, Gott, & Ingleton 2010).

The meaning that the women attributed to sexual activity and their sexual needs was also influenced by familial and work responsibilities. These women frequently placed the needs of others ahead of their own, both sexual and other. This prioritisation of the needs and perceptions of the other not only refers to intimate partners, family members and friends but also to the potential thoughts and reactions of HCPs when deciding whether to bring up SHW issues. I discuss this in more detail in the following sub-section, the context of the consultation.

The thesis findings provide evidence that some older heterosexual women may even tolerate painful sexual activity. I suggest individual as well as social reasons for this finding. The first reason is that each intimate relationship has its own dynamic that has developed over time and that is unique to the individuals within that relationship. The phenomenological approach used within this thesis allowed for a close analysis of aspects important to individual relationships of the women who experienced pain during sex and they described their experiences of their intimate relationships in detail. It suggested that their tolerance of painful sex was complex and linked to aspects specific to the individual relationship as well as wider issues, such as a feeling of duty

to male intimate partners. This sense of duty, to which participants alluded has also been found in other studies of older women (Barrett et al. 2018; DeLamater & Koepsel 2015; Loe 2004).

Heterosexual women's sexual scripts may deprioritise their own sexual needs while privileging the sexual and emotional needs of their male intimate partners (Bristow 2015; Dillaway 2012). The suppression of sexual desire, discussed above, in addition to the women's explanation of the tolerance of painful sex, provide evidence of their prioritisation of needs. Both these feelings of duty and the de-prioritisation of the participants' own sexual needs demonstrate that while society has undergone meaningful changes, traditional gender roles within heterosexual intimate relationships remain.

The presence of traditional gender roles and lack of communication within the heterosexual intimate relationships was in contrast to the openness that the participant in a same-sex relationship described. This is consistent with Winterich's (2003) study of the menopause. In recent years, research exploring the SHW experiences of older women in same-sex relationships has slowly increased (Averett, Yoon & Jenkins 2012; Westwood & Lowe 2018). The findings presented in the previous chapter highlighted that elements of SHW that were considered important by the women were generally consistent across the group. However, this openness regarding SHW discussions within the female same-sex relationship was a key difference between participants. She also made comparisons between SHW communication within her intimate relationship and with those of her friends in male same-sex and heterosexual relationships. This finding suggests that baby boomer women may be more comfortable discussing their SHW with other women, and tentatively suggests female patients may communicate better about SHW with female HCPs. I present arguments for and against this statement later in this section.

A preference for discussing SHW with other women may be linked to having shared experiences, such as menopause. Women's accounts of their menopausal experiences provided insight into their approach to managing their health more generally. Much evidence now shows that menopause can signify a cultural and social transition rather than an exclusively biological one (Gilleard & Higgs 2000; Gott &

Hinchliff 2003a; Hinchliff, Gott, & Ingleton 2010; Murtagh & Hepworth 2005; Ussher et al. 2015; Winterich 2003). Participant experiences also reflected this. When participants discussed their experiences of menopause, examples provided were given meaning within the context of their lives. For example, the ways in which sudden, heavy bleeding impacted on the enjoyment of a party or how mood changes had impacted on their intimate relationships. This demonstrates how the effects of menopause, such as hot flushes, night sweats and so on, are given meaning within the context of women's lives, as has been found in other studies (Faccio et al. 2018).

The meanings attributed to menopausal changes also influenced participants' decisions about taking medication for menopausal symptoms. All participants were taking medication for either T2D, menopausal symptoms or other health conditions. However, most expressed a reluctance to increase their use of medication, even in situations where avoidance meant that they had to tolerate unwanted symptoms such as night sweats. The absence of discussion of SHW changes with their HCPs did not indicate that these changes were not experienced or were not problematic. In addition to changes in sexual desire and painful penis-vaginal sexual intercourse discussed above, women reported experiencing increased episodes of thrush, vaginosis and reduced vaginal lubrication. These findings align with studies discussed in Chapter One which reported high levels of sexual 'dysfunction' (reduced desire, arousal, lubrication, orgasm, satisfaction and increased pain during sexual intercourse) in women living with T2D (Bağ et al. 2017; Meeking et al. 2013; Nowosielski et al. 2010; Pontiroli et al. 2013). However, participants commonly attributed these changes to ageing and menopause rather than T2D. This is in contrast to women in other studies on SHW and T2D who attributed some of their reduced sexual desire and vaginal dryness to T2D (Rockliffe-Fidler & Kiemle 2003; Sarkadi & Rosenqvist 2003). The UK-based study by Rockliffe-Fidler & Kiemle (2003) included women from the ages of 35 to 83 years and provided interview extracts, but it is not clear whether these quotes are from older or younger participants in the sample, making comparison difficult. However, some women in the Rockliffe-Fidler & Kiemle (2003) study attributed a reduction in sexual activity to ageing in addition to T2D. I discuss how this thesis builds on those findings in the 'Contribution to knowledge' section below.

In addition to living with T2D and going through, or having gone through, the menopause, participants described living with various other health issues, such as osteoarthritis, hernias and cancer. Several participants discussed the ways in which health issues, both their own and their intimate partners', influenced the position SHW held in their lives, with some considering sexual activity to be "*on the back burner*" as it had become physically painful or difficult to engage in (Debra). The impact that these health conditions had on the importance attributed to sexual activity coheres with evidence suggesting that women with fewer health conditions are more likely to perceive sexual activity as important (Bergeron et al. 2017; Hinchliff & Gott 2011, 2004a; Hurd Clarke 2006; Thorpe et al. 2018; University of Michigan 2018). Since people living with T2D may experience more health issues than people without T2D (Einarson et al. 2018), certain types of sexual activity may be less feasible, but also less important.

To end this sub-section I will reiterate that while there were consistencies across the participants' experiences in terms of what the women considered important to their SHW, exploration of the women's individual life circumstances was key to understanding their approach to SHW and its discussion. As described in Chapter Five, the women held their experiential knowledge of their lives and bodies in high esteem, knowledge gained through personal experiences over the course of their lives (Fjelland & Gjengedal 1994; Larkin, Eatough & Osborn 2011; Smith, Flowers & Larkin 2009). Exploration of this experiential knowledge is essential to our understandings of the aspects of importance to women's SHW and some of the reasons why. Throughout this first sub-section, I have discussed the ways in which SHW is embedded within women's lives as well as how historical, socio-cultural and personal context are important for our understandings of SHW and its discussion by baby boomer women living with T2D. The following sub-section takes a closer look at SHW discussion in the specific context of primary care consultations.

## **6.1.2 Primary care consultations and SHW discussions**

### **Introduction**

Building on the exploration of participants' lives outside of consultations, I now focus on their experiences of SHW discussions within consultations, as well as the barriers

and facilitators present within consultations. As noted earlier in this chapter, many of the experiences that participants had throughout their lives influenced their feelings and decisions about SHW discussions within consultations, which demonstrates the overlap between their engagement with the world within and outside of consultations. However, drawing similarities between SHW discussions inside and outside of consultations is complex as participants' expressions of SHW changed in given contexts, as will be discussed. In the forthcoming section, the complexities of SHW discussions in primary care and how they relate to the world outside of the consultation are elucidated.

#### **6.1.2.1 Meanings of SHW in consultations**

Few participants could recall their HCPs broaching the topic of SHW within consultations. This absence is meaningful. As Smith, Larkin & Watt (2009, p. 19) summarise "...things that are absent are as important as those that are present in defining who we are and how we see the world." The absence is meaningful as it potentially impacts on women's health knowledge and their perceptions of their HCPs, both features that were implied by the thesis data. First, many older women living with T2D may lack knowledge of a link between SHW issues and T2D, and second, they may assume that their HCPs do not want to discuss SHW. Assuming that HCPs do not want to discuss SHW potentially prevents any related issues from coming to light, perpetuating the silence surrounding the SHW of older women in wider society, discussed earlier in this chapter. This is the first example of the overlapping nature of the women's lifeworlds with consultations and demonstrates that participants were unable to separate the influence of their experiences outside of the consultations from their assumptions and expectations of the consultations and HCPs. In addition to assuming that HCPs did not want to discuss SHW with their older female patients, participants' unwillingness to broach the topic of SHW may compound the lack of SHW discussion.

The social expectations for women, and particularly older women, to espouse conservative sexual attitudes may impact on women's willingness to bring up SHW issues with their HCPs. The thesis findings supported this (Chivers & Brotto 2017; Hurd Clarke 2006; Wood et al. 2007). Women may internalise these social expectations, in addition to the lack of HCP inquiry, and interpret them as confirmation

of ageism and a perception that HCPs see the sexual expression of older women as inappropriate. Specifically, older women may be reluctant to discuss issues related to sexual activity if they are concerned that being sexually active in later life is not expected in social nor consultation contexts (Gewirtz-Meydan et al. 2018; Hinchliff & Gott 2011).

Participants were acutely aware of age and gender biases within society regarding their sexuality (Connidis 2006; Sontag 1972). Women had experienced ridicule or rejection of their sexuality outside of consultations, with family members telling them that they were “*too old*” to express sexual desire or to want to pursue new intimate relationships (Joanna). These experiences potentially present barriers to SHW discussion in consultations as women may perceive that the verbalisation of their interest in sexual activity will meet with the same derision they had encountered outside of consultations. However, participants’ experiences of broaching certain aspects of SHW demonstrates that, depending on the type of issues which required addressing, they were able to overcome this reluctance.

The participants reported that they broached issues such as cysts, thrush and vaginal bleeding in consultations, as they considered such issues essential to the preservation of general health. While women still experienced the embarrassment, discussed earlier in this chapter, they overcame these feelings in order to discuss these issues with their HCPs. The consultation was a ‘medical space’ for the women, where they were able to discuss SHW issues perceived as being linked to their general health and therefore acceptable topics of conversation. In this way, women considered the consultations to be a specific space in which norms were distinct from those that exist in the every day, outside of consultations. In the seminal text “A history of Sexuality: Volume 1” (1979b), Foucault acknowledges the meaning that medical and therapeutic spaces can hold, describing consultations with psychotherapists as the “safest and most discrete of spaces” (p. 6). In terms of the current thesis, this recognition that different spaces hold different meanings may suggest that the consultation presents an opportunity for older women with T2D to discuss sexual issues that they may not feel able to discuss in other contexts. Nevertheless, for many of the women in this thesis, the aforementioned reluctance to discuss SHW remained.

The women in this thesis used language as a mechanism to overcome their reluctance to bring up their SHW concerns. Medical language and 'functional' descriptions allowed women to talk about their bodies in a way that disconnected those bodies from the interpersonal context. Talking about their bodies in this disconnected way facilitated the discussion of 'functional' issues but may have obscured discussion of aspects of SHW which are more challenging to describe using 'functional' language, such as changes in sexual desire. Even though the participants' lived experiences of their SHW was much more than just whether their bodies were 'functional', for example whether they had thrush or an STI or not, the medical language they used within the context of consultations reduced their SHW discussions to pertain only to these types of specific and physical issues.

The women's accounts reflected a tension between their perception of the body as a physical object in consultations and their perception of the body within the context of their lives outside of consultations. In Chapter Three, I introduced *dasein*, a concept concerned with how the world is made meaningful through discourse and interaction with others (Davidsen 2013; Sturgess 2016, 2018). Returning to *dasein* can shed light on the women's differing perceptions of their SHW in different contexts in two ways. First, the women perceived the consultation as a distinct space where it was acceptable and expected to discuss certain 'functional' aspects of SHW, such as thrush and vaginal bleeding. The adoption of a discourse that reflected the medical nature of the primary care encounter shows women's awareness of the different meanings that spaces hold, with SHW outside of the consultation being considered holistic, social and relationship-centered, and SHW within consultations being concerned with STIs and sexual 'function'. Aligning with *dasein*, this suggests that the ways in which we experience ourselves are influenced by the space in which we find ourselves; there is much evidence to show that this may be particularly applicable within medical spaces (Atkinson 1995; Bury 1982; Foucault 1963; May 2007; May et al. 2006).

Conversely, the concept of *daesin* also encompasses the inability to extract ourselves from the world and demonstrates that the barriers between spaces is permeable (Eatough & Smith 2008). Therefore, women's lifeworlds are present within consultations. From this perspective, there is an acknowledgement that the women's



SHW concerns may be the same both inside and outside of consultations, but that they may choose to omit certain aspects of their SHW concerns within medical contexts with their HCPs (Smith, Flowers & Larkin 2009; Todres et al. 2007). As discussed in the lifeworld section of this chapter, participants were immersed in their social worlds; each woman brought her own perceptions and experiences into the consultation. When considering the women's lifeworlds in this way, the consultation is an extension of their lives, with historical, social, cultural and personal elements inhibiting or facilitating conversations about SHW in consultations as well as considerations around the medical space and the intersubjective context. In addition to these more abstract elements, I also propose that women did not discuss their intimate relationships and sexual activity for a myriad of more practical reasons, such as a focus on 'medical' aspects of care, time constraints and the presence of others during the appointments.

Women attended some appointments with intimate partners or other family members. While this was not identified as a theme due to not being discussed as a barrier by the women nor reoccurring sufficiently in accounts, the presence of a family member could prevent the possibility of a SHW conversation between patients and HCP. HCPs may have concerns about confidentiality or patients may feel uncomfortable discussing SHW with family members present, as found in other studies in the area of communication between patients and providers (Ahmed et al. 2016; Gott et al. 2004a). This demonstrates how the meaning of the consultation space, and the opportunities to discuss SHW, may change through the presence of others.

The women expressed difficulties obtaining an appointment due to issues with their healthcare providers' systems and a lack of time within consultations. The women also expressed concerns about consuming National Health Service (NHS) resources, which could present a barrier to SHW conversations, particularly if, as has been found in other studies, women categorise their SHW needs as non-essential (Sarkadi & Rosenqvist 2001; Taylor & Gosney 2011). On the one hand, this reinforces the argument that baby boomer women prioritise the needs of others over their own and perceive their need to address their SHW issues as less important than the time of the HCP or other patients. However, this could also suggest that women consider the short consultation time and the difficulty of obtaining appointments to be factors that are

controlled by their HCP. Indeed, there was evidence that participants' sense of control within consultations influenced SHW discussions.

#### **6.1.2.2 Sense of control in consultations**

The participants perceived themselves as being in control of their healthcare, shown through their confidence in bringing up most aspects of their health in consultations. There is evidence to suggest that people living with chronic diseases are more apt to challenge their HCPs' decisions and are more willing to take an active role in their care (MacRae, 2018; Horton, 2007; Steinbrook, 2006). This sense of control is also evidenced through a recent societal shift from patients (May et al. 2006), particularly older female patients (MacRae 2016), from being passive recipients of treatments to active 'negotiators' of their healthcare. Participants reflected on this shift and were proactive regarding most aspects of their care, potentially suggesting that the overlapping experiences of being a baby boomer woman and living with T2D created a shared approach of independence towards health management. There was also evidence that as a result of attending regular appointments for their T2D, the participants were well informed about their condition, which in turn gave them the confidence to discuss particular aspects of their T2D with their HCPs.

Frequent appointments and a sense of expertise in their own bodies are two of a host of factors which led the baby boomer women to challenge the historically established power imbalance between older female patients and their HCPs (Calasanti & Slevin 2006; Foucault 1963; Turner & Samson 1995). The women's confidence was evident in their ability to reject HCPs' advice and suggested drug therapies when they felt that the knowledge of their own lives and bodies overrode that of medical convention. Existing literature focuses on older adults' loss of ability to make decisions about their bodies and treatments (Calasanti & Slevin 2006). However, the current findings challenge existing notions of older adults' passivity and loss of ability to negotiate. Indeed, the findings may reflect shifts in generational characteristics and approaches to help seeking, with the baby boomer cohort characterised by their pragmatism and strong sense of control over their lives (Gilleard & Higgs 2000; Rowntree 2014). The wide range of resources that women accessed provides further evidence of a pragmatic and independent approach to help seeking.

The participants used books, the internet, discussions with friends, and alternative medicine to manage health concerns outside of consultations, demonstrating that consultations provided just one source of health support and information. The confidence shown in consultations as well as the use of alternative sources of health support indicates that baby boomer women may have a greater sense of control within consultations compared to previous generations, a finding which was highlighted in a recent study of older women's interactions with their physicians (MacRae 2016). However, while the women may have felt able to bring up and debate most aspects of their health, such as medication use and lifestyle changes, it was notable that this pragmatic approach often did not extend to discussions around sexual desire or pain during sexual activity. Nevertheless, alternative sources of support meant that older women may have a greater sense of control over their health, in addition to which, other aspects may also be important. These include increased access to medical information, changes in female social standing and the changing health service discourse of shared decision. These aspects may have increased participants' confidence in rejecting, or at least resisting and debating, the medicalisation of their concerns (Evans & Robertson 2009; MacRae 2016).

While the sense of control described above is advantageous for most areas of health, I have identified three ways in which it can have potentially detrimental effects on SHW discussions. I argue that the pragmatic approach which characterises the baby boomer generation (Trudel et al. 2010; Watters & Boyd 2009), typically construed as a positive characteristic, can hinder help seeking for SHW issues through building tolerance and a sense of responsibility. The thesis findings showed that participants demonstrated resilience in the face of life changes, meaning that they adapted to and accepted SHW changes, even if they caused them physical pain or upset. The women's resilience, often construed as a positive, may present a barrier to SHW discussions through engendering the tolerance of unfavourable SHW changes, such as recurrent episodes of thrush and vaginal dryness.

The second way in which a sense of control was potentially detrimental to SHW discussions was through women's sense of responsibility over some aspects of their SHW. Through a combination of their age, T2D and other health conditions, women felt that they were more attuned to both changes and the reasons for those changes,

for example linking increased episodes of thrush to having consumed too much sugar, or feeling lethargic to having consumed carbohydrates. This sense that dietary control directly influenced their blood sugar, and subsequently their SHW, meant that women perceived these aspects as their responsibility and therefore unnecessary to bring up with HCPs. The tension between women being confident in both seeking help and making decisions for health concerns unrelated to SHW against the difficulty they faced in bringing up SHW concerns demonstrates how HCPs may erroneously perceive this cohort to have sufficient sense of agency to raise any SHW issues they would like to discuss. Consequently, I argue that the topic of SHW acquires a unique, separate categorisation from that of other health issues in consultations with HCPs, a point that I return to in Chapter Seven.

As discussed earlier in this chapter, women's views about their need and ability to discuss SHW issues were closely linked to the world outside of consultations; that is, the potential internalisation of disempowering experiences such as social taboos around their sexuality, being censored or laughed at by family members. Acknowledging the tension between the sense of control over their medical treatment and health, argued above, and disempowerment around their sexuality illuminates the paradoxical nature of SHW discussions for baby boomer women living with T2D. Other studies found the power balance shift was influenced by cultural norms around femininity and social taboos regarding sexual activity as an inappropriate topic to discuss in healthcare (Sarkadi & Rosenqvist 2001; Winterich 2003). In addition to the women's experiences outside of consultations, their lack of power specifically regarding SHW discussions can be influenced by previous experiences of primary care consultations, a point to which I return to later on in this chapter.

### **6.1.2.3 Perceptions of GPs and practice nurses**

The intersubjective aspects of the consultation were important to the women. This is the second way in which *dasein* can aid our understanding of the tension between understandings of SHW outside and inside consultations is through its focus on intersubjective meanings (Larkin, Eatough & Osborn 2011; Moran 2000; Sturgess 2018). Understanding that people interact in different ways with different people is important for understanding women's decisions around which aspects of SHW to discuss with their HCPs. Therefore, I argue that women's decisions around which

aspects of their SHW they wished to discuss altered depending on the HCP they were faced with.

Until now, I have discussed primary care consultations without differentiating between GPs and practice nurses. However, the findings demonstrated that some participants perceived consultations with GPs differently to those with practice nurses. While other studies have shown that older women either discuss SHW with their GP (Hinchliff et al. 2017; Gott & Hinchliff 2003) or do not have a preference for discussing SHW with GPs or practice nurses (Farrell & Belza 2012), the present findings show that participants were more comfortable discussing SHW with practice nurses. This links with a combination of factors, some of which may be specific to older women living with T2D, such as the frequency of contact between practice nurses and women for T2D care, women's preference for discussing SHW with female HCPs and differences in the perception of the role of GPs and practice nurses.

The frequent contact that women had with their practice nurses facilitated SHW discussions. The findings from other studies have shown that increased contact with HCPs facilitates SHW discussions as patients use their past consultation experiences to determine how open an HCP would be to such discussions (Bergeron et al. 2017; Rutte et al. 2016). People living with T2D in the UK tend to see their practice nurses rather than their GP for routine T2D management (Diabetes UK 2010; NICE 2015b). The frequent nature of T2D appointments in the UK provides opportunities to discuss SHW, but thesis findings show that these opportunities often go unfulfilled in practice, with many participants expressing a lack of previous SHW conversations.

In addition to the participants using previous consultation experiences to judge how HCPs would potentially respond to SHW conversations, frequent contact with the same HCPs also built rapport. Other studies have also highlighted that feeling comfortable with HCPs is a facilitator for SHW discussions (Lindau et al. 2011). However, the thesis findings add nuance to previous studies reporting the importance of length of relationship to high quality care, particularly in diabetes care (Naithani et al. 2005) by showing that rapport can also be built within the space of a single consultation. Interestingly, a long-standing relationship with HCPs may present a barrier to conversations, with some women assuming that their HCP would not want

to talk about SHW. This means that while length of relationship may be advantageous with regards to discussing some aspects of health, distinctions may exist for other aspects of health, reinforcing the argument that SHW discussions require unique consideration. In addition to length of relationship with the HCP, other key factors for consideration include a history of being listened to, having the opportunity to discuss aspects of importance within individual women's lives and the gender of HCP.

Evidence that older women prefer to discuss SHW with female HCPs is divided, with some studies reporting that HCP gender is not important (Rutte et al. 2016) and others reporting that female HCPs are preferred (Politi et al. 2009; Gott & Hinchliff 2003; Sarkadi & Rosenqvist, 2001). Given that the majority of practice nurses in the UK are female (Nursing and Midwifery Council 2016) this translates as there being, potentially, increased opportunities for discussing SHW with practice nurses. Most participants showed a preference for discussing SHW issues with female HCPs, though this was not always due to participant's own discomfort; rather, the assumption that SHW discussions would embarrass male HCPs was a deterrent.

Some participants were unable to separate HCPs' identities of being male and also a professional. However, for some baby boomer women, the professional identity of the HCP may be more prominent, meaning that their gendered identity is set aside, enabling them to discuss SHW issues. Evidence suggests that this may be due to upbringing, with women attributing their reluctance to discuss SHW with male HCPs to familial conversations in their youth. When the relationship between men and women is viewed through a social lens, it becomes clear why some older women may perceive barriers to discussing SHW with male HCPs. This is firstly due to the previously discussed historical and social norms discouraging women from discussing SHW with men and secondly due to a desire to not embarrass their male HCPs. This potential desire to maintain harmony with male HCPs along with a reluctance to cause discomfort echoes the women's prioritisation of their male intimate partners' feelings, seen outside of consultations. It also highlights their potential preference not to be overt about their sexual agency, in the presence of men in particular, both outside and inside of consultations.

The women highlighted consultations with their male GPs as being more focussed on determining the aetiology of SHW concerns, while consultations with female GPs and practice nurses in particular were perceived as being focussed on managing and discussing existing health conditions. Thesis findings around the women's consciousness of HCP gender and differences around the type of consultation expected from male and female HCPs may then suggest that female GPs and practice nurses may potentially be in an advantageous position for addressing the SHW needs of baby boomer women living with T2D. I explore the role of different HCPs for SHW discussions in Chapter Seven. However, both consultations with practice nurses and GPs were primarily perceived as 'medical' in nature by the women, which perhaps reflects the focus of care for people living with T2D discussed earlier.

#### **6.1.2.4 Focus on 'medical' aspects of care in consultations**

The lived experience of participants reflected a lack of SHW discussions with HCPs. Most women did not know of a link between sexual changes and their T2D or its medications. This aligns with other studies of women living with T2D who report high rates of never having been asked about SHW by their HCPs, and being unaware of an association between sexual problems and T2D (Rutte et al. 2016; Sarkadi & Rosenqvist 2001). As identified in Chapter One, older women living with T2D are more likely to experience SHW changes, such as difficulty reaching orgasm, low sexual desire and reduced lubrication (Bağ et al. 2017; Meeking et al. 2013; Nowosielski et al. 2010). Therefore, the thesis findings highlight a disconnect between this existing evidence and the women's lack of awareness of their SHW changes potentially being linked to their T2D (Baldassarre et al. 2015; Enzlin et al. 2009, 1998; Esposito et al. 2010; Girdali & Kristensen 2010; Nowosielski et al. 2010; Ogbera et al. 2009; Rockliffe-Fidler & Kiemle 2003).

One reason that the evidence around T2D and sexual changes may not be conveyed to patients lies in assumptions that HCPs may hold about the SHW needs of their older female patients (Haesler et al. 2016). Some of these assumptions include that patients prefer to have SHW discussions with HCPs of certain characteristics, that patients do not perceive SHW to be a legitimate topic within medical consultations and that HCPs fear they may offend their patients (Gott et al. 2004a; Haboubi & Lincoln 2003; Haesler et al. 2016; Hinchliff, Gott & Galena 2004). The thesis findings align somewhat with

HCPs' assumptions in these articles. However, the findings challenge some of the other assumptions that HCPs may hold about the SHW needs of their older female patients living with T2D. The participants expressed that they wanted their HCPs to explore SHW, providing evidence against the notions that patients do not perceive the legitimacy of SHW discussions and that they would be offended. The findings do this by showing that women wanted HCPs to bring up SHW. Furthermore, in the presence of evidence that the participants had experienced sexual changes and may not know of a link with T2D, the legitimacy of SHW discussion is arguably increased.

Lack of knowledge of sexual changes being potentially linked to T2D highlights how SHW discussions are frequently not brought up by women or HCPs in consultations. This lack of discussion around SHW was contrasted with the abundance of discussion around the management of other T2D symptoms in consultations. 'Medical' aspects of care occupied a potentially disproportionate amount of time in consultations. This may have overshadowed well-being if it led to consultations being perceived as 'medical' in nature, and primarily for the management of physiological concerns:

*Medical approaches such as the measurement of blood pressure and heart beat are one way to get close to our bodies, but such approaches keep us from understanding our lived body.*  
(Ichikawa 1991, p. 3)

While this quote is dated, it still resonates with contemporary patient experiences given the participants' reports of their consultations focussing on the measurement of blood pressure and other physiological aspects of care. It illustrates how little has changed over the past 20 years regarding the focus of consultations. What Ichikawa argues here, translated and quoted by Ozawa-de Silva (2002, p. 24), is that the focus on bodily functions can present a barrier to realising the holistic nature of the lived experience; only one facet of the lived experience is seen. As supported by the quote above, the effects of biomedicalisation within primary care contexts was seen in the current study through a tight focus on the biological management of T2D, such as blood sugar and dietary control. I recognise that these aspects of care are important and reflect the aim of medicine to treat and manage diseases. However, such an approach means that the impact of T2D within women's lives may be overlooked (May et al. 2006). Therefore, while women perceived their SHW and T2D holistically outside



of consultations, the focus on bodily functions in previous consultations may have led women to consider SHW and T2D as separate, unrelated aspects of their health, thus presenting a barrier to SHW discussions.

Further compounding the participants' medicalised perception of the body within primary care consultations was the women's experiences of the healthcare system when they were younger. Participants discussed experiences of attempting to conceive pregnancy with medical assistance, attending medical appointments while pregnant and giving birth. Their descriptions align with the long history and large body of literature pertaining to the medicalisation of the female body as well as women's reproductive and sexual health (Foucault 1979; Johanson et al. 2002; Joyce & Mamo 2006; Turner & Samson 1995). Therefore, the combination of being women and living with T2D means that these women's consultations may be more focussed on 'medical' aspects of care. In addition to the medicalisation of women's bodies and of those living with a chronic disease, there is also an awareness of the increasing construction of medicalisation of ageing. However, there also a body of literature challenging this construction, demonstrating that an understanding the experience of ageing requires examination of the biopsychosocial processes rather than relying solely on biology (Gott 2005; Hinchliff & Gott 2011; Katz & Marshall 2003; Marshall & Katz 2006).

A consideration of the biomedicalisation of women's bodies, chronic diseases and ageing in conjunction illustrates how, within consultations, medical aspects may receive more attention than holistic aspects. Therefore, the argument about frequent appointments creating increased opportunities for participants to negotiate their care should be carefully considered. While research has shown that patients with chronic diseases may discuss SHW more frequently (Bergeron et al. 2017), the discussion of the thesis findings has shown that this may only apply to certain 'medical' aspects of SHW, such as vaginal bleeding and cysts, with wider aspects of SHW neglected in practice. The biomedicalised nature of the consultations with older women living with T2D implies that, despite the high frequency of appointments providing additional opportunity for SHW discussion, the focus of consultations remains on 'medical' issues.

The types of SHW issues that women sought help for provided evidence that they perceived consultations as being for 'medical' rather than holistic issues. Women

equated primary care consultations with 'medical' solutions and only sought help for SHW issues for which they felt medication or treatment existed, such as cream for a vaginal cyst. Therefore, in one sense, women were complicit in the 'medical' focus of consultations, shown through their use of language and perception that consultations were only for 'medical' solutions. As suggested by Rutte et al. (2016), the perception that HCPs cannot offer a suitable solution discouraged women with T2D from discussing SHW with their HCPs. The belief that the primary purpose of consultations was the provision of medication shows the continued impact of the biomedical model on lay understandings of healthcare (Estes & Binney 1989; Marshall 2010).

However, in another sense women rejected the 'medical' focus of consultations and of their bodies, demonstrated by the way in which the women prioritised their experiential knowledge of their bodies over that of the HCP. The women actively negotiated their SHW inside and outside of consultations. Outside of consultations, the women considered their SHW broadly, as seen in the previous chapter, but within consultations, women only brought up issues they felt had a 'medical' solution. This sense of the consultation as a 'medical' space along with the rejection of the medicalisation of their bodies potentially deterred women from discussing wider aspects of their SHW with their HCPs.

Belief that the primary purpose of consultations was the provision of medication may have been a barrier to women bringing up SHW in their consultations. Studies have shown that since the availability of sildenafil, more men have sought help for erectile 'dysfunction'. However, little research exists exploring women's attitudes towards taking medication for sexual concerns (Barrett et al. 2018; Loe 2004). The participants endeavoured to avoid medication use as far as possible, and most had experiences of rejecting medication that had been suggested by HCPs. Most had attempted, or were currently attempting, to alter their lifestyle to manage their T2D rather than taking – or increasing – medicine, as they felt they were already taking enough medication. The perception of HCPs as encouraging medication use along with the desire to manage their SHW concerns without medical intervention may have meant that the participants preferred to manage their own health concerns independently.

The rejection of the biomedicalisation of their general health also impacted on women's approach to managing menopausal symptoms. The independent management of health concerns provides an alternative discourse to the medical movement around menopause which promotes synthetic hormones as necessary to maintain or restore sexuality and health as well as to offset the 'defeminizing risks' of physical decline associated with this period of time (Graham et al. 2017; Hinchliff, Gott, & Ingleton 2010; Marshall & Katz 2006). However, the thesis participants who used hormone replacement therapy (HRT) did so to alleviate heavy vaginal bleeding, mood changes and night sweats rather than to assert their femininity, to remain youthful or to improve their sexual 'functioning'. I argue that women's use of HRT challenges current feminist concerns about women being encouraged by pharmaceutical companies to use HRT to resist ageing, as those participants who did use HRT did so to improve their quality of life (Joyce & Mamo 2006; Marshall & Katz 2006; Tiefer 2001). This again links to women's sense of control in health care settings and their confidence to access help from primary care when necessary.

Discussion of suitable solutions to problems linked to menopausal changes highlighted differences between White British and Black British participants within the thesis. All three Black British participants rejected synthetic hormones due to a perceived link with cancer. Debate around a link between HRT and cancer has been observed for decades (Kumle 2008; Marshall & Katz 2006; Million Women Study Collaborators 2003) and there is no current evidence to suggest that postmenopausal Black women are at a higher risk of cancer than other populations. However, evidence of a link between HRT and increased incidences of cancer is complex, so it is easy to see why some women may choose to tolerate menopausal symptoms rather than take HRT and, from their perspective, increase their risk of cancer. This finding serves to illustrate lay knowledge about HRT and the women's lack of access to information about not only the risks and benefits of taking HRT, but also alternative treatment options. National Institute for Health and Care Excellence (NICE) guidelines on menopause (NICE 2015a) highlight the importance of giving information to menopausal women. However, the extent to which this happens in practice remains unknown. An additional barrier to discussions about menopause is that women may choose not to accept professional opinion encouraging HRT use, preferring instead to rely on knowledge acquired from previous generations of women or female friends.

Prioritising the knowledge acquired outside of consultations, such as in social settings, may also constitute a barrier to being open to discussing and/or accepting an HCP recommendation of HRT.

Nevertheless, refusal to consider synthetic hormones as a possible option for resolving problems related to menopause such as heavy vaginal bleeding and vaginal dryness may be an additional reason why women may not seek professional help. If women attribute the symptoms experienced to menopause, and they do not want to take synthetic hormones, perhaps they do not consider it worth discussing these issues with an HCP if they assume that the only treatment they will be offered is synthetic hormones (such as topical oestrogen). They may instead decide to tolerate the SHW symptoms. Indeed, analysis showed that women perceived menopause care to consist solely of synthetic hormones. The Black British participants in particular did not consider it worthwhile to discuss SHW issues if they assumed that the only treatment they would be offered was hormonal. The women in this thesis asserted themselves as their own experts and held their beliefs of HRT and cancer as valid regardless of whether there was empirical evidence to support them, demonstrating the influence of dominant social beliefs on SHW help-seeking behaviour.

## **Section One summary**

The discussion of the thesis findings has bridged the knowledge gap between the need for discussion of certain aspects of SHW and the recognition of specific barriers that exist for SHW discussions between older women with T2D and their HCPs. Previous research has identified that the SHW issues experienced by baby boomer women with T2D often do not get discussed in practice (Bijlsma-Rutte et al. 2017; Calasanti & Slevin 2006; Celik et al. 2015; Diabetes UK 2016; Rutte et al. 2016). What the current thesis has contributed is some of the reasons *why* SHW issues do not get discussed. This draws attention to the gap between the recognition in the literature that older women with T2D may have SHW needs that require discussion and the evidence provided in this thesis that these conversations are not taking place in practice.

Through the detailed discussion of existing literature, theories and IPA, the first part of this section explored the barriers and facilitators to SHW discussion in primary care as

being embedded in the women's lifeworld. The exploration of the women's lifeworlds indicated that upbringing and social taboos around older women's sexuality as well as the context of women's personal lives influence primary care conversations around SHW. I have shown that in order to grasp a comprehensive understanding of the barriers and facilitators to SHW discussions in consultations, it is necessary to locate women in their historical, social, cultural and personal environments.

The second part of the section presented compelling arguments for the interwoven relationship between SHW discussions, the women's lifeworlds and the primary care context. Through the in-depth exploration of the women's experiences both inside and outside of consultations, I have shown that the women are at once divorced from their social context when in the primary care consultations, which focus on bodily function, whilst also being bound to the same social norms, either experienced or perceived outside of consultations. Having discussed the findings in relation to existing literature, the next section will consider the contributions to knowledge that this thesis makes.

## **6.2 Section Two – Contribution to knowledge**

This thesis makes two key, interconnected, contributions to knowledge. The first contribution is theoretical and the second methodological. This section describes each in turn.

### **6.2.1 Theoretical contribution to knowledge: Key intersecting factors influence SHW communication between baby boomer women with T2D and HCPs in the primary care context**

The theoretical contributions to knowledge that this thesis makes are centred in the areas of intersection between gender, age, generation (previous and current) and T2D. By identifying these areas of intersection and explaining their relevance to understanding SHW communication, I argue that this thesis draws attention to the importance of recognising diversity in the lived experience of baby boomer women living with T2D. Additionally, I focus on the multifaceted nature of decisions around SHW discussions in primary care. For clarity, the areas of intersection are presented separately; however, they are interlinked.

The first area that I explore is the intersection of age and gender. It has been argued that issues around ageing have largely been overlooked in feminist scholarship, with race and class receiving more attention (Calasanti & Slevin 2006; King 2006):

*Feminist gerontology has rightly criticized the feminist community for its lack of attention to age, and age studies for their neglect of gender.*  
(Marshall & Katz 2006, p. 75)

Through an exploration of the SHW of baby boomer women, this thesis has contributed to filling this gap, adding to the scant existing research on age and gender (Gott & Hinchliff 2003b; Hinchliff et al. 2017, 2010; Sontag 1972; Thorpe et al. 2018). Some of this literature portrays older women as passive victims within a patriarchal society (Connidis 2006; Hurd Clarke 2011). The thesis findings challenge this portrayal of older women. I argue that older women's sense of control over SHW discussions is not static, but rather is strongly influenced by contextual and interpersonal factors such as in primary care consultations, with intimate partners, and with female friends. In this thesis, the sense of control that women experienced in the primary care consultations came to the fore. Therefore, regarding age and gender, this thesis adds to the body of literature in two ways: firstly by giving these areas much needed attention, and secondly by confirming that understandings, experiences and discussions of SHW are context-dependent.

The second area of intersection I address is age, gender and T2D. As discussed above, the "intersections of inequalities" (Calasanti & Slevin 2006, p. 3) related to age and gender have been somewhat explored in the literature (Thorpe, Fileborn, & Hurd Clarke 2018; Hinchliff et al. 2017; Hinchliff, Gott, & Ingleton 2010; Gott & Hinchliff 2003a; Sontag 1972). However, this thesis is the first study providing a comprehensive discussion of how living with T2D, a chronic disease, intersects with age and gender. Although there are four qualitative studies of the SHW of women with T2D in a Western context (Rockliffe-Fidler & Kiemle 2003; Rutte et al. 2016; Sarkadi & Rosenqvist 2003, 2001), none explore the intersection of age and gender with T2D. Research included in Chapter One showed that women living with T2D may have increased episodes of thrush, vaginosis and mood changes (Bağ et al. 2017; Meeking, Fosbury, & Cummings 2013; Pontiroli, Cortelazzi, & Morabito 2013; Bargiota et al. 2011; Nowosielski et al.

2010). These SHW changes may also be compounded by SHW changes experienced during peri-menopause and the postmenopausal period. This thesis has illuminated that socially constructed barriers formed during women's younger years may prevent current primary care discussions taking place around these sexual changes. Therefore, the current research has highlighted that despite the potentially increased propensity for experiencing SHW changes, many complex, overlapping reasons exist for why baby boomer women living with T2D may not seek professional help.

As shown in the previous section, many of the thesis findings, such as a preference for female HCPs and feelings of guilt and embarrassment around SHW discussions, concur with findings from other studies (Rockliffe-Fidler & Kiemle 2003; Rutte et al. 2016; Sarkadi & Rosenqvist 2003, 2001). However, no other studies have illuminated that women's lives outside of consultation influence their SHW discussions within consultations. One example of this important link is the way in which upbringing influenced the women's willingness to discuss SHW with male HCPs. This exploration of the participants' perspectives of SHW has enabled a deeper and broader understanding of the barriers and facilitators to SHW discussions in primary care than previously.

The third area of intersection is age and generation. This thesis has reiterated the importance of conducting cohort specific research. It has done this through focussing on the baby boomer cohort rather than older adults more generally. Baby boomers are now recognised as an empowered, autonomous cohort, indicating changing understandings of what it means to be an older adult in today's society (Gilleard & Higgs 2000; Phillipson et al. 2008; Pruchno 2012). Given this changing understanding, it is important to note that research undertaken using the term "older adults" 20 years ago refers to a different population; a population who were brought up in a different social era where SHW was perhaps discussed even less openly than nowadays. Thus, this thesis provides timely research on the perceptions of sexuality in today's generation of older women. Furthermore, frequently revisiting their perceptions and understandings will prevent us from making assumptions about their SHW needs. This, again, makes the current thesis auspicious.

As discussed in Chapter One, sexual stereotypes are frequently projected onto older women by society, such as the sexy oldie, that is, the notion that remaining sexually active is imperative to well-being, or that they all older women are asexual (Bauer, Haesler & Fetherstonhaugh 2015; Fileborn et al. 2015b; Gott 2005, 2006; Loe 2004; Moore & Reynolds 2016). Through the production of evidence, this thesis challenges assumptions, sexual stereotypes and contradictory notions around sexuality and age. While rejecting generalisations, the thesis concurs with existing literature that baby boomers share perceptions about and approaches to life (Ellwood & Shekar 2008; Pruchno 2012; Woodsprings 2016). These two positions, the rejection of generalisations and the belief of shared approaches, are not conflicting but rather promote the need for ongoing qualitative research. Such research has the capacity to build on the current findings and continue to explore the convergences and divergences of social groups and generations.

Throughout this thesis, I have argued that contextual and personal factors are crucial for understanding SHW discussions in primary care settings. Therefore, the final theoretical contribution sets aside the areas of intersection and turns to the diversity of lived experience. Below, Cronin & King (2010) highlight how a focus on the areas of intersection can oversimplify our view of inequalities:

*Although not denying the existence of such inequalities, such a perspective fails to address the meshing together of these or any other inequalities within everyday life and wider social and political structures. Unwittingly, such additive approaches may reinscribe inequalities by obscuring difference.*  
(Cronin & King 2010, p. 879)

This quote illustrates that layers of inequality interact. The areas of intersection presented above only display one facet of understanding. Within this thesis, I have focused on areas of inequality and how they interact to present barriers to SHW discussions within primary care. However, a key strength of this thesis lies in the recognition of diversity within women's lives. The diversity of lived experience, sexuality, race and relationship statuses of the women included in this thesis challenges homogeneous representations of baby boomer women and their SHW. The body of literature on women's SHW has recently started to present findings on the diversity of baby boomer women's understandings of their SHW (Garrett 2014;



Hinchliff 2014; Hinchliff & King 2018; Thorpe, Fileborn & Hurd Clarke 2018; Westwood & Lowe 2018). This thesis adds to the body of knowledge by demonstrating that significant diversity exists even within a small group of women of a similar age with a shared illness. The IPA methodology permitted the exploration of the lived experiences of the sample.

### **6.2.2 Methodological contribution to knowledge: Insight into the place of SHW in the lives of baby boomer women with T2D**

This thesis has made a meaningful methodological contribution to knowledge in two ways. The first methodological contribution focusses on the novel use of IPA. To my knowledge, this is the first occasion on which IPA has been used to explore the lived experience of SHW discussions. Women's experiences of sex and intimacy at various points in their lives, including during periods of ill health, are being increasingly explored using IPA, which is advantageous for facilitating understandings of deeply personal experiences (Loaring et al. 2015; Woolhouse et al. 2012). This reflects the growing recognition of IPA as an appropriate methodology for giving 'voice' to women in an area as complex and sensitive as SHW, which remains poorly understood. However, until now, no study has used IPA to explore SHW communication in women living with T2D. Within the current thesis through focussing on the context of primary care as well as the context of the women's lives, I have shown how IPA can be used to explore the ways in which SHW is discussed and the meaning attributed to these discussions.

Through the use of a phenomenological approach, I have been able to identify a wide range of factors influencing baby boomer women's decisions to discuss their SHW in primary care contexts. Specifically by adopting an IPA approach, I did not have to bracket my assumptions and prior engagement with the subject area (Larkin, Watt & Clifton 2006; Shinebourne 2011). Not bracketing my assumptions meant that I could use my prior experiences and revision of the literature to interpret the women's experiences (whilst being careful to question my preconceptions using reflexivity throughout (Finlay 2009, 2002; Korstjens & Moser 2018; Shaw 2010)). Therefore, IPA has enabled me to produce alternative readings of the women's accounts.

The second methodological contribution focusses on the specific mechanisms of an IPA approach in developing the compelling theoretical contribution to knowledge presented above. Three key characteristics of IPA led to the generation of new knowledge presented in this thesis. First, the level of detailed analysis permitted by the small sample size. Second, the focus on the individual's lifeworld experiences, and third, the recognition of the researcher's interpretation in making sense of participants' accounts (Lopez & Willis 2004).

The specificity and size of this thesis sample means that the findings provided insight into the areas of age, gender, generation and T2D. These factors intersect to present specific barriers and facilitators to SHW discussions in primary care. As discussed in Chapter Two, the few existing qualitative studies of SHW in older adults with diabetes often did not sub-group their samples by age, diabetic sub-type or gender for analysis (Bijlsma-Rutte et al. 2017; Rockliffe-Fidler & Kiemle 2003). Analysis conducted in this way makes it difficult to distinguish between the findings that are transferable to baby boomer women with T2D and those that are not. The sample size is another advantage of the methodological choice for this thesis. The level of analytic depth achieved in this thesis would not have been possible with a larger sample size. Therefore, the number of women included in the current thesis facilitated the detailed exploration of diversity between the participants' accounts, which constitutes an essential part of the theoretical contribution to knowledge stated above.

Similarities and differences between the contexts of women's lives came to the fore through the in-depth exploration of the consultation context and the women's lifeworlds. This demonstrates the interconnected nature of women's SHW and their approaches to discussing this outside and inside the consultation. The thesis elucidates the contrast between SHW as holistic, being broadly understood outside of consultations and as pertaining to 'medical' issues within consultations. The thesis findings highlight a mismatch between these two understandings of their SHW for the women who are actively negotiating the different contexts. Through paying close attention to the language used within women's accounts, I was able to identify the women's sense of expertise in their own bodies, both within and outside of consultations.

This thesis has found that within consultations, SHW is a unique facet of health for baby boomer women, where the confidence and pragmatism that they show in regards to most areas of health is frequently absent (Gilleard & Higgs 2000; Pruchno 2012). The reasons for this absence, which I have discussed in the previous section, are complex, and were only revealed through the in-depth exploration of the women's lifeworlds. The link between historical, socio-cultural and personal factors, and the SHW of older women, is recognised in the literature (Calasanti & Slevin 2006; Hinchliff & Gott 2008; Pruchno 2012). However, this thesis is the first to consider how these aspects are specifically linked to SHW discussions in primary care and why these discussions do or do not take place in practice.

This thesis has achieved a level of detailed analysis that studies using other qualitative methodologies, such as thematic content analysis, have not reached (Rutte et al. 2016). An example of this less nuanced analysis comes from a study of the sexual needs and care preferences of people living with T2D by Rutte et al. (2016). The researchers developed themes around the participants' sexual needs and their experiences of SHW discussions with HCPs but did not explore factors influencing participants' decisions of whether to discuss SHW or not, as has been done in the current thesis. Within the current thesis, the detailed data collection and subsequent analysis led to the exploration of the factors influencing the participants' decisions of whether to discuss SHW or not. As discussed, identified factors included the place of SHW within the women's lives, taboos around older women's sexuality and wanting to preserve the feelings of the HCPs.

A non-phenomenological qualitative methodology may not have permitted the identification of the host of factors identified within the current thesis. For example, by focusing on how women tolerated SHW issues in their personal lives and so did not discuss them with their HCPs, IPA was conducive for allowing me to examine the existing literature and suggest why this may be so. Currently, one mixed-methods study on the sexuality of women living with T1 and T2D includes an IPA approach (Rockliffe-Fidler & Kiemle 2003). This study is included in the scoping review of the literature presented in Chapter Two. Within that study, IPA was used to enrich quantitative data on sexual 'function'. Within the current thesis, IPA was used to bring forth baby boomer women's perspectives and experiences of SHW discussions in

primary care consultations. Thus, the aim of the current thesis was distinct and builds on findings from the previous study in two ways. First, the level detailed analysis has enabled the identification and exploration of the link between SHW in the lifeworld and SHW discussions in primary care, a link that has not previously been identified in any other studies in this area. Second, the current thesis focussed on SHW discussions with HCPs as well as SHW itself, meaning that its focus is unique.

## **Section Two summary**

Within this section, I have stated the theoretical and methodological contributions to knowledge of this thesis. The theoretical contributions highlight how areas of intersection may conflate to produce SHW inequalities for baby boomer women living with T2D whilst also recognising the crucial diversity that exists within the SHW needs of baby boomer women living with T2D. The methodological contributions to knowledge focus on the novel use of IPA and how an IPA approach enabled a close connection with the participants' accounts while permitting the exploration of existing literature and my own interpretations.

## **Summary of Discussion Chapter with a synopsis of the barriers and facilitators to SHW communication in primary care settings**

Chapter Five presented an empathetic reading of the women's accounts, while the current chapter has provided a more critical and speculative reading of those accounts. Current literature, theories and the contribution of IPA have been used to produce this more critical approach. In the first section of the current chapter, the complexities and nuances of SHW discussions in primary care have been examined in great detail to elucidate the various barriers and facilitators that had not previously been considered in this population. Exploring historical, socio-cultural and personal factors through the use of IPA, the diverse experiences of SHW of this cohort have been captured and informed a deeper understanding of their SHW than previously before. In the second section of the current chapter, the contributions to knowledge that this thesis makes are stated. Within the Discussion chapter, the thesis aim has been achieved and four of the five research questions posed in Chapter Two have been addressed<sup>7</sup>:

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<sup>7</sup> The fifth, and final research question 'What are the implications for practice?' is addressed in Chapter Seven

**Primary research question**

What do baby boomer women (aged 50-75 years with T2D) consider to be the barriers and facilitators to SHW communication in primary care consultations?

**Secondary research questions**

What do baby boomer women consider important to their SHW?

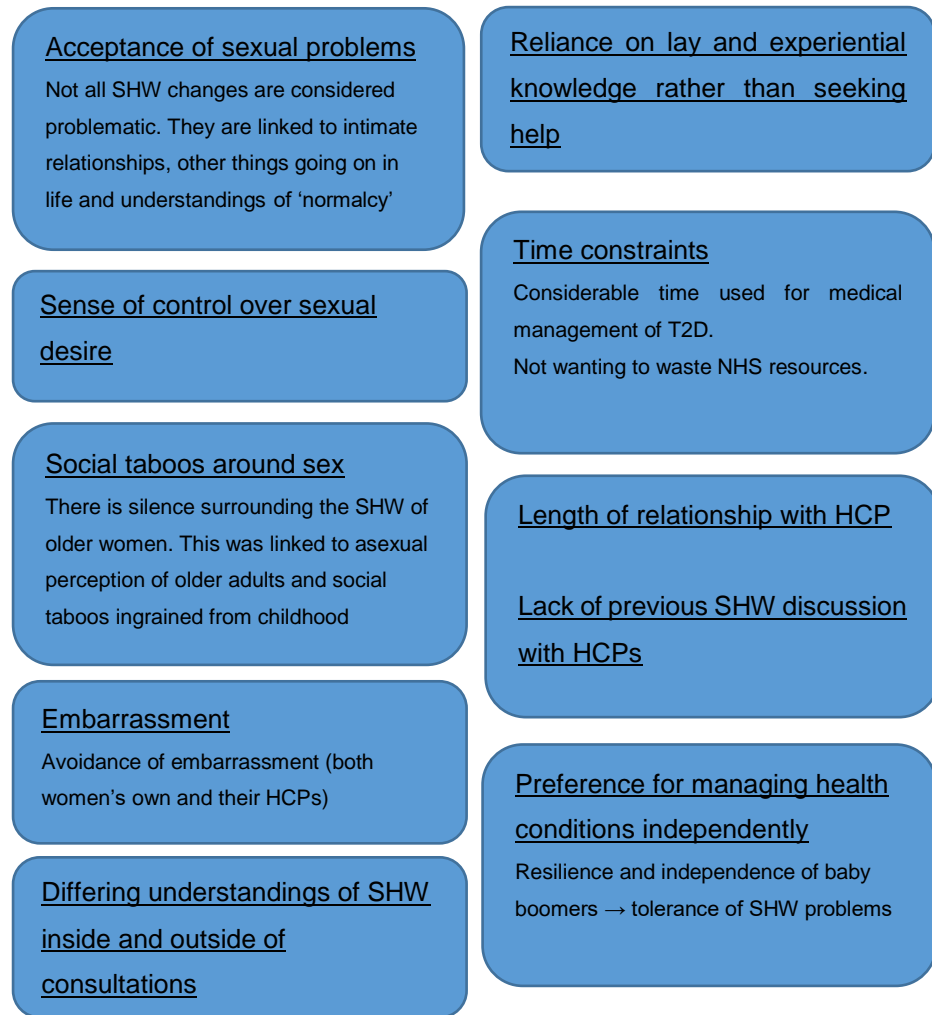
Which factors influence the decision to discuss (or not to discuss) SHW within primary care consultations?

What role does the HCP play in SHW communication?

Below, I have provided a synopsis of the barriers and facilitators to SHW discussions between older women living with T2D and their HCPs. This paves the way for the thesis to consider the implications of this research for primary care practice and research (see Figure 3 – Synopsis of barriers and facilitators to sexual health and well-being communication in primary care).

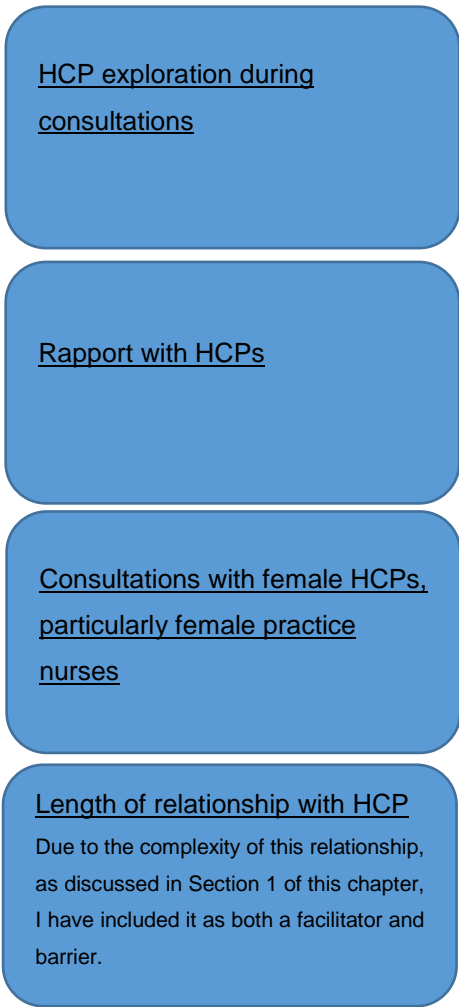
**Figure 3 – Synopsis of barriers and facilitators to sexual health and well-being communication in primary care**

**Barriers**



Barriers and facilitators to SHW communication between older women with T2D and their HCPs

**Facilitators**



# CHAPTER SEVEN – IMPLICATIONS FOR PRIMARY CARE PRACTICE AND RESEARCH

## Introduction

In this chapter, I address the final research question “What are the implications for practice?” As this thesis is focussed on the primary care context, the implications for health care practice and improving patient care have been woven into the thesis design (Reed et al. 2017). Experts argue that for qualitative health research to have practical utility it needs to illuminate concepts in new ways and provide in depth interpretative explanations of phenomena (Miller 2010; Sandelowski & Barroso 2003). The current thesis has done this.

The first section of this chapter describes the knowledge exchange activities undertaken with the general public and healthcare professionals (HCP). The knowledge exchange activities raised awareness of the thesis findings, in both the community and in HCP circles. These knowledge exchange activities ensured the dissemination of the thesis findings.

The aim of the knowledge exchange activities with the general public was to discover how the thesis findings were understood outside of academia. The test of academic research and health-focussed research specifically, is how applicable it is in real-world contexts (Pentland et al. 2011; WHO 2012). Therefore, it was important to learn about the reception of the findings by the general public. Knowledge exchange activities with the general public also enabled me to compare their views with those identified from the thesis participants. It was important for realising the transferability of the thesis findings and their potential impact in real-life settings. Furthermore, in discussing the thesis findings with younger women, those not living with T2D and men, I was able to explore the meanings of the findings from various perspectives and consider the implications of the findings.

The aim of the knowledge exchange activities with the HCPs was to disseminate and receive feedback on the thesis findings. These activities also provided HCPs with an opportunity to gain insight into their patients' perspectives and to reflect on their sexual health and well-being (SHW) discussions with their patients (Kearney 2001; Miller 2010). Kearney (2001) describes how in-depth qualitative research can encourage HCPs to see the patient experience in a new light. In discussing the thesis findings with HCPs, during knowledge exchange activities they were presented with a new perspective regarding the SHW needs of their baby boomer female patients with Type 2 diabetes (T2D). In light of the thesis findings, HCPs may now interpret the silence of their older female patients as linked to social taboos around sex (and the other barriers discussed above) rather than assuming sexual disinterest on the part of the patient. I discuss this point below. These knowledge exchange activities contribute to the transferability of the thesis findings, a point which I discuss in the next chapter. Further evidence of the health care implications of this research lies in the educational session that I designed and delivered to practice nurses. This educational session is discussed at the end of the first section of this chapter.

The second section of this chapter discusses the implications for primary care practice and research. These implications have been developed through linking the thesis findings with feedback obtained during the knowledge exchange activities. The implications for primary care practice are to put baby boomer women's SHW on the T2D agenda and to increase the awareness of available SHW resources. Suggestions for future research focus on the development of an intervention study to improve SHW communication in practice and a call for the inclusion of more diverse samples.

## **7.1 Section 1 – Knowledge exchange with the general public and HCPs**

Knowledge exchange is described as an interactive process by which researchers, research users and the wider community share knowledge (Kiefer et al. 2005; Mitton et al. 2007). Knowledge exchange activities were held in community centres, cafes, offices and classrooms in South Yorkshire. They took place between March and November 2018 and lasted from 30 minutes to one hour depending on the scope of the discussion and feedback provided by attendees. I prepared a leaflet and a



PowerPoint presentation for the knowledge exchange activities. Depending on the setting and number of activity attendees, I either presented the PowerPoint, distributed and talked through the leaflet, or presented the thesis findings without any visual aids. Throughout the sessions, I took notes which led to the development of this chapter. Table 3, below, provides information about the knowledge exchange attendees, the setting for the activity and the way in which the thesis findings were communicated.

**Table 3 - Knowledge exchange activities**

	<b>Demographics</b>	<b>Group size (approx.)</b>	<b>Date</b>	<b>Setting and length of session</b>	<b>How were the thesis findings communicated?</b>
<b>The general public</b>					
Sheffield And District African Caribbean Community Association (SADACCA)	Female, 30-85, some living with T2D	20	March 2018	Community centre, 1 hour	Leaflet
Sheffield 50+ Hub	Male and female, 50 and above, some living with T2D	15	May 2018	Community centre, 30 mins	PowerPoint
Sheffield Feminist Network	Female, 20-70, some living with T2D	8	November 2018	Café, 30 mins	PowerPoint
<b>HCPs</b>					
Geriatrician	Female, 30s	1	September 2018	Café, 1 hour	Verbal
General Practitioner (GP)	Female, 30s	1	September 2018	Café, 1 hour	Verbal
Academic GPs	Male and female, age 30-50	6	October 2018	Office, 1 hour	PowerPoint
Academic practice nurses	11 females, 1 male, age 20-60	12	November 2018	Classroom, 1 hour	PowerPoint

### **7.1.1 Knowledge exchange with the general public**

During knowledge exchange activities with the general public, I engaged in discussions with adults, both male and female, older and younger, with and without T2D (see Table 3 – Knowledge exchange activities). This engagement enabled the differences and similarities between attendees' experiences, and the thesis findings, to come to the fore.

Older adult attendees identified with the research findings in that many of their HCPs had not asked them about SHW. Furthermore, older women attendees expressed that HCPs assumptions of the sexual disinterest of older women may be one reason for the omission of SHW discussion within consultations. This concurs with the thesis discussion around the area where age and gender intersect presenting a barrier to SHW discussions in primary care, through the reinforcement of social taboos around female sexuality. Older women felt that these taboos were still prevalent and that society nor HCPs recognised their SHW needs. One reason that women attendees gave for this lack of recognition was the social devaluing of women as they get older. They saw evidence of this in the paucity of information discussing what happens at, and after, menopause and its potential impact on SHW or other health conditions that they may have, such as T2D.

Attendees reported a lack of information regarding the potential impact of T2D and the side-effects of medication (both for T2D and other conditions). Women attendees, in particular, expressed frustration that they had to report side effects experienced to their HCPs rather than HCPs telling them about potential side effects when the medication was prescribed. As above, they felt that this was linked to their age and gender. One attendee, around 50 years of age, discussed that she and her daughter were on the same medication and yet their HCP frequently asked her daughter about SHW whereas the attendee was not asked. The lack of information provided by the HCP was interpreted by the attendee as an assumption of sexual disinterest in older women. The discussion during engagement activities around the assumption of

women's sexual disinterest led attendees to comment on their parents' approach to SHW discussions. Similarly, to the research participants, attendees drew intergenerational comparisons in regards to changing social norms around the acceptability of SHW discussions.

The attendees concurred with the thesis findings that the social norms of the previous generation continue to influence the prevalence of taboos around sex. Contrastingly, some of the baby boomer women expressed a sense of liberation in talking about sex when involved with the feminist movement when they were younger. In this way, the varied social groups that women were a part of in their youth may provide insight into their current approach to talking about sex. This reiterates the importance of idiographic research that focuses on individual women's lives, as discussed in the previous chapter.

In both the Sheffield 50+ Hub group and the SADACCA group, Black, Asian and Minority Ethnic (BAME) women alluded to the ways that cultural differences potentially influence how older women discuss SHW. In the Sheffield Feminist Network group, no BAME women were present but members discussed how socio-economic status may impact on how comfortable women felt about their sexuality. Their inference was that women from working-class backgrounds might feel more inhibited than women from middle-class backgrounds. They did not suggest reasons for this potentially increased inhibition but used their own familial experiences to illustrate the point. The attendees at all three general public activities expressed that their familial experiences and upbringing continues to influence comfort levels around discussing SHW, and with whom.

All women during the knowledge exchange activities expressed a preference for discussing SHW with female HCPs. Younger participants disclosed that they may not specifically ask for a female HCP for SHW concerns, but that they would not be able to speak as freely with a male HCP. One attendee, however, expressed that the female HCPs that she encountered had been less sympathetic than male HCPs. In her experience male HCPs had been more sympathetic during consultations, alluding to

the role of rapport, as found in this thesis. The attendees' preference for female HCPs was not only for their own comfort but also for that of the HCP. The female attendees discussed feeling uncomfortable discussing SHW when they saw their male HCPs become visibly uncomfortable (blushing) in consultations, which aligns with the thesis findings of women wanting to preserve the feelings of their male HCPs. The attendees also identified with the more practical barriers to SHW discussions found by the thesis research, such as a lack of time during consultations.

Time constraints presented a practical barrier to discussing wider health concerns. Some women during the knowledge exchange activities described preparing what they wanted to discuss with their HCPs before their appointment because of this constraint. They stated that they had to be quite assertive sometimes if they wanted to cover their concerns within a single consultation. Particularly as they had experiences of HCPs asking them to choose which issue they wanted to deal with and requesting that they make additional appointments for other issues. Structuring appointments in this way may make it challenging for patients to broach the topic of SHW, especially if women consider sexual changes to be a normal part of ageing. One woman stated that she did not know any women over the age of 50 who had not experienced sexual changes. This highlights the transferability of the thesis findings to other populations of women (see Chapter Eight – Strengths, limitations and reflexivity).

Throughout exchanging knowledge with the general public, I considered how women living with and without T2D may differ from each other. The first potential difference identified links to the increased likelihood of women living with T2D experiencing SHW changes. At the beginning of knowledge exchange activities, I informed attendees that evidence suggests that older women living with T2D may have more frequent episodes of thrush and increased vaginal dryness than other women of the same age. Given this information some attendees suggested the incorporation of questions about women's SHW into routine T2D care, echoing a suggestion from Grace, one of the thesis participants (see Chapter Five – Findings, Super theme 3: Subtheme 1). The second difference identified was that baby boomer women may have more frequent appointments with practice nurses and therefore, more opportunities to discuss their

SHW. These frequent appointments were found to be a facilitator to SHW discussions between the women and their HCPs within this thesis. However, the third difference is that there may be less time available to address issues unrelated to the biological management of T2D given that consultations often focus on this issue.

As discussed in Chapter One – Background, the Quality Outcomes Framework (QOF) is used to determine the care provision in the majority of primary care settings within the UK. For diabetes care, there are 18 indicators that HCPs are required to address within consultations. This is more than any other health condition and potentially leaves little time for SHW discussions with T2D consultations compared with consultations for other conditions (NHS Digital 2018). The attendees expressed frustration that men's sexual health is on the QOF whereas women's sexual health is omitted (NHS Digital 2018). HCPs attendees shared this frustration. I return to this point in the following section. There were other areas where the thesis participants, the general public and HCPs perspectives aligned.

### **7.1.2 Knowledge exchange with healthcare professionals**

While the women's SHW experiences and discussions are at the core of this thesis, knowledge exchange activities were considered essential for sharing the thesis findings with HCPs and gaining their perspectives of SHW discussions within their consultations. As shown in Table 3, the thesis findings were presented to a range of HCPs, with varied ages, sexes and clinical foci, which ensured that I received varied feedback. Within the group sessions, GPs and practice nurses, who had significant expertise in the area of caring for women living with T2D debated their clinical experiences with each other. Observing their discussion afforded me insight into the diversity within HCPs experiences. The format of the knowledge exchange activities also provided HCPs with the opportunity to discuss and debate their perspectives on SHW care, enabling their professional development.

The acceptance of their level of SHW by the thesis participants created debate within the HCP knowledge exchange activities. Some GPs stated that SHW should be “*pushed up the agenda*” in primary care and others argued that if older women had adapted to their SHW circumstances, that it was unnecessary to focus on it. However, similarities were drawn with the recent history of men’s sexual health. The HCPs expressed that before the advent of sildenafil, a medication to treat erectile ‘dysfunction’, erectile ‘dysfunction’ was seldom discussed within consultations. However, once male patients realised that help was available, GPs saw more male patients broaching the topic of erectile ‘dysfunction’ within consultations. This difference in the interpretation of the thesis findings highlights how individual factors between HCPs likely impacts on the SHW services and advice that women are offered in practice. However, T2D care in primary care is standardised by the aforementioned QOF.

The GP attendees stated that the QOF criteria shapes the questions that they ask their patients living with T2D within consultations. GPs referred to the omission of female SHW from the QOF indicators. This omission was given as a reason for why they often did not ask female diabetic patients about their SHW. They discussed that the QOF promoted the paternalistic model of health care through directing the content of consultations. Their concern was that the QOF increased potential for overlooking aspects of importance to the patient. This suggested that HCPs recognise that aspects of importance within patients’ lifeworlds may not be addressed within consultations. The large number of QOF indicators associated with T2D care reflects, first the complexity of T2D management in primary care, and second, the extensive amount of care that HCPs are expected to provide within the space of a single consultation (Calvert et al. 2009).

HCPs discussed the difficulty in addressing multiple issues within a short consultation with their patients. They expressed that this issue specifically applied to their consultations with patients living with a chronic disease, such as T2D. They wanted their patients to broach aspects of importance to them within consultations but the limited time was identified as a barrier to SHW conversations, aligning with the thesis

findings. HCPs were aware of the importance of SHW across the life span but also that most patients with T2D had complex health needs which required considerable time to manage. Therefore, given the limited available time and the large number of health concerns to cover, quality of life issues were considered the “*cherry on the top*” of consultations. There was a discussion about longer consultations and the positive effect that this could have for addressing holistic aspects of patient care, particularly if patients have waited a few weeks for an appointment and have several issues to address in the space of one consultation.

Both GPs and practice nurses identified the longer consultations that older women with T2D have with practice nurses (compared with their GPs) as being conducive to more frequent, and more exploratory, SHW discussions. This supports the thesis findings around lack of time as a potential barrier, and frequent appointments as a facilitator, to SHW discussions. While the length of the consultation was identified as a facilitator to SHW discussions, practice nurses attendees also considered the nature of their consultations with their baby boomer women living with T2D. The practice nurses suggested that their consultations were perhaps less medicalised than consultations with the GPs precisely *because* they had more time to ask exploratory questions of their patients and then explore any issues that patients brought up. This suggests that differences between GP and practice nurse consultations may be due to differing lengths of consultation rather than an inherent difference in the role of GPs and practice nurses identified during data analysis.

Just as the participants’ life experiences factored into their comfort discussing SHW, the same was evident for HCPs with some expressing discomfort in discussing their own SHW with their HCPs. This reflects the very human act of using one’s personal experiences to gauge how the other may feel about discussing SHW. This discomfort also acts as a reminder that HCPs have their own personal views and lifeworlds that influence discussions in consultations. The personal views of those providing sexual education, in many contexts, not just primary care, can potentially supersede guidance on best practice (Hirst, 2013). Formation of these personal views are complex but one



factor which appeared to make HCPs more comfortable discussing SHW with their older patients was professional experience in the area of sexual health.

HCPs that had previous experience in sexual health care reported being more comfortable discussing SHW with their patients. One HCP expressed that she routinely asked her patients about their SHW and linked it to the patient's medical condition. She reported using phrases, such as, "Some people living with T2D experience vaginal dryness, is that something that you have found?". In many cases, once she broached the subject, patients would discuss their SHW issues quite openly. She felt that once she had "*opened the floodgates*", the patients then felt able to discuss SHW. Other HCPs expressed ease at discussing SHW changes linked to mood but difficulty in broaching the topic of sexual activity within consultations, echoing the distinctions that the participants made between discussing various SHW issues (vaginal cysts versus sexual desire). Practice nurses recounted experiences of women broaching the topic of SHW at the end of consultations, perhaps due to having built some rapport during the consultation or having built up the courage to discuss SHW.

The HCPs reflected on the language they and their older female patients used in consultations when discussing SHW. Some described using phrases to normalise sexual changes and its discussion, such as "*I've come across this before...*" or "*Some women have reported...Is that something that you have found?*". The HCPs echoed the thesis findings around baby boomer women lacking the language to discuss their SHW. HCPs described some of their older female patients referring to their vulvas using euphemisms or just gesturing downwards. In these situations, HCPs described also using euphemisms to reduce the embarrassment that their older female patients felt, reflecting concerns that the thesis participants had about embarrassing their HCPs. Just as the thesis participants were concerned about how HCPs perceived them, male HCPs expressed concerns about being labelled a "*pervert*" for asking women questions about their SHW.

Body language was also reportedly used by the HCPs to reduce embarrassment. Eye contact was one example that was discussed during two of the knowledge exchange activities. Practice nurses described asking patients about sexual activity while performing clinical tasks, such as, monitoring blood pressure, as they were able to avoid eye contact. They felt that the lack of eye contact made the encounter less embarrassing for both patients and the HCPs. Exploring patients' general health while performing clinical tasks echoed an extract from Grace's account "*...so when you're having your blood taken for instance, our health practitioners sit there and they say, they have a conversation with you at that point*". This suggests that these moments in consultations may provide opportunities for SHW discussions that both the HCPs and patients are comfortable with. However, other HCPs felt that some patients would prefer eye contact for such conversations reiterating how HCPs have the complex role of assessing patients' needs frequently using non-verbal cues in consultations.

The HCPs expressed that their older female patients with T2D consulted them for increased episodes of thrush and vaginosis. However, care provision tended to focus on curing individual episodes rather than discussing the wider implications of the problems, such as the impact on sexual relationships. One HCP was particularly adamant that if SHW was not an issue brought up by the women (with T2D) themselves then it must not be important to them. However, when a fellow HCP asked if she would feel the same about a younger woman, she felt that it might be more relevant to younger women. During the knowledge exchange activities, a general conclusion drawn was that all women living with T2D should be given the opportunity to discuss SHW. This move would simultaneously remove the onus from the HCP to speculate as to which patients have unmet SHW needs, as well as, offset older women's assumptions of ageism.

The thesis findings, and supporting research show that older women may assume that their HCPs hold ageist attitudes and this is a reason that SHW has not previously been broached (Hinchliff et al. 2017). HCPs confirmed that the women's assumptions of ageism reported in this thesis may be correct. They suggested that particularly older male GPs, may be reluctant to discuss SHW with their patients. The GPs in the

sessions recounted experiences of their older male GP colleagues referring their older female patients with SHW issues to other HCPs who they knew were more comfortable discussing SHW in practice. This links with the findings of the complex interaction between the length of the relationship between HCPs and their patients. HCPs concurred with the thesis findings that length of relationship and rapport between patients and their HCPs are important features of the primary care consultation. They also felt that sharing characteristics such as age and culture are important in making patients feel comfortable discussing their SHW issues.

Both the patients' and HCP characteristics were important to the occurrence and nature of SHW discussions. HCPs discussed making assumptions about their patients' SHW needs based, not only, on their presenting health condition but also the patient's socio-economic status, education level, and culture. Within the current research, the participants' social class was collected (see Appendix I – Demographic data collection) but no connections between socio-economic status, education level and SHW discussions were found during data analysis. I suggest reasons for this in Chapter Eight – Strengths, limitations and reflexivity). The HCPs stated that their patients from lower socio-economic statuses tended to unquestioningly accept HCP advice whereas patients from higher socio-economic statuses did not. HCPs also expressed that their patients from higher socio-economic statuses tend to present as more empowered and willing to challenge HCP recommendations. As discussed in the previous two chapters, the majority of thesis participants indicated that they were confident in consultations, challenging HCP decisions when necessary. I recruited six of the ten participants from community organisations and it is possible that people who engage in community activities may feel more empowered and better able to challenge HCP decisions. While I collected data on the participants' socio-economic and educational background, I had not made the connection between those factors and SHW discussions until highlighted by HCPs. Socio-economic status may add another layer of complexity to the areas of intersection highlighted in the previous chapter. I include this point in the 'Implications for future research' section below and also discuss it in the next chapter.

Menopausal symptoms and smear tests provided HCPs with an opportunity to initiate SHW discussions with all women. For those HCPs that had discussed SHW with female patients in the past, the most common SHW issue was vaginal dryness. Although smear tests are only usually recommended for women under the age of 65 (NHS 2018), practice nurses said that they found them to provide a useful opportunity for broaching the topic of SHW with their older female patients. As the consultation was specifically focussed on women's reproductive health, they frequently offered to swab women's cervixes for sexually transmitted infections (STIs) at the same time as performing the smear test. Offering to swab women's cervixes occasionally led to a discussion around STIs.

Many of the HCPs discussed their experiences of discussing and treating their patients' menopausal symptoms. HCPs expressed frustration at women suffering through menopausal symptoms when there was medical help available. They referred to the Million Women study (Million Women Study Collaborators 2003), which linked HRT with high incidences of cancer, as having caused irreparable damage to women's help-seeking for menopausal symptoms. This study was also referenced in the previous chapter. HCPs suggested that many older women do not have accurate knowledge of cancer risks. They discussed resources that they direct their patients to in order to provide information. Resources are discussed in more detail in the second section of this chapter, 'Implications for primary care practice and research'. HCPs, particularly practice nurses, discussed different approaches advocated by different GP surgeries to using HRT to manage menopausal symptoms, and how this impacts on the treatment that HCPs offer their patients. These distinctions indicate that conversations around SHW may also be influenced by GP surgery management, in addition to, individual HCPs.

Most GPs stated that they felt comfortable with issues they could prescribe medication or treatment for, such as lubrication for vaginal dryness. However, they felt less comfortable with relationship issues and low sexual desire. They had concerns about how to treat or where to refer patients with such concerns. However, the provision of medication was given careful consideration by GPs in particular who expressed

concern about the medicalisation of sexuality, with examples drawn from the practice of prescribing medication for premature ejaculation when they felt that it was an issue that frequently benefits from psychological support rather than medication. This reflects HCPs awareness of the potential to medicalise SHW in their practice and aligns with concerns in the literature on the medicalisation of female sexuality and older age discussed in the previous chapter. Lack of knowing where to refer women with SHW issues was also identified as a concern for HCPs. Sexual health services mentioned, such as Relate, a national charity providing relationship support (Relate 2018), were considered inappropriate for sexual desire and relationship concerns. One GP with a special interest in SHW frequently provided advice, directed women to websites and other sources of information and support but most however, avoided SHW discussions if they did not feel that a medical solution existed.

### **7.1.3 Educational session for practice nurses**

In addition to knowledge exchange activities, the practical utility of the thesis findings was also demonstrated through the development of an educational session. I delivered the session, titled “Addressing the sexual health needs of older adults”, to academic practice nurses. The content of the session included discussion around the thesis findings and their experiences of SHW discussions in primary care. I then presented some of the available research and resources may facilitate their SHW discussions within consultations e.g. the Ex-PLISSIT (Permission, Limited Information, Specific Suggestions and Intensive Therapy) model and the IntimAge Project (I discuss these resources below).

Following the educational session, I prepared a scenario, which encouraged students to reflect on their consultations with older women with T2D and consider how they may integrate SHW inquiry into their consultations (see Appendix P - Sexual health and well-being scenario for practice nurses). This scenario was uploaded into their virtual learning environment and feedback received from the programme lead was that the session and scenario were received positively. The session and scenario may have led to the practice nurses reflecting on their practice but further interventions and

research are required to determine the impact of such sessions on HCP practice in primary care. Inclusion of SHW in medical and nursing curricula is frequently cited as important for increasing awareness about the SHW needs of older adults and is indeed one of the implications for primary care practice suggested in the following section (Gott et al. 2004a; Hinchliff & Gott 2011; Hordern & Street 2007).

#### **7.1.4 Triangulation of the thesis findings with the knowledge exchange activities**

Within the following section, I triangulate the thesis findings with the knowledge generated from the exchange activities. I consider how wider society, and the dominant institutions within that society, are important for understanding SHW within primary care from both the perspective of the thesis participants their HCPs. Below I briefly discuss religious, familial and biomedical influences that both HCPs and the thesis participants were influenced by.

It has been argued that religion and family are two powerful institutions which dictate who can have sex with whom (Hampshire 2005; Weeks 2010). These institutions do this by creating definitions of what is 'normal' sexual behaviour and what is 'abnormal', and thereby labelled unacceptable (Plummer 1984; Weeks 2010). Weeks (2010) highlights how the new conservative and religious forces which emerged across Europe in the 1980s emphasised

"...an affirmation of the sanctity of family life, hostility to homosexuality and 'sexual deviance', opposition to sex education and a fierce reassertion of traditional demarcations between the sexes." (p. 2)

The continuing power of these discourses is evident, not only through the women's silence around sex, but also the HCPs reluctance to discuss SHW with their older female patients living with T2D. Evidence of this was shown through HCPs stating that many of their older female patients would not be interested in discussing sex, even if the topic has not previously been broached in practice.

HCPs may be more susceptible to ageism than the general public due to frequently seeing frail, older patients with multiple and chronic diseases (Bowling 2007; MacRae 2018). The thesis participants also showed awareness of ageism within society and their primary care consultations. Evidence of ageism intersecting with sexism was evident in HCPs reluctance to discuss SHW with their older female patients. While this may appear in contrast to the unbiased and equal care that HCPs are expected to provide patients with, it is undeniable that aspects of care that HCPs deem necessary to address within a consultation may sometimes be shaped by social norms rather than the needs of the individual patient.

As stated in Chapter Six, HCPs are in a powerful position because of the status ascribed to medicine and the historical dominance of the biomedical model (Estes & Binney 1989; Marshall 2010; Yuill et al. 2010). During the knowledge exchange activities with HCPs, they did not appear to recognise this power imbalance between themselves and their patients in regards to SHW discussions. The implications of not recognising this power imbalance were that HCPs made assumptions about the issues that female patients considered important, usually linked to function, rather than initiating a discussion.

Historically, medical spaces have been aligned with biomedicine rather than holistic health (May et al. 2006; Yuill et al. 2010). The impact of which was evident in both the women's and HCPs accounts of barriers and facilitators to SHW discussions. Both HCPs in the knowledge exchange activities and the thesis participants viewed sexuality through the lens of biomedicine within primary care consultations. The implications of this were seen in the HCPs descriptions of prescribing medication for erectile dysfunction when, on occasion, they thought this might be an emotional issue rather than one that required a medicinal solution. The implication for the women's SHW was seen in types of concerns that they had previously discussed with their GPs and practice nurses. These were primarily biological. See Chapter Five – Findings.

Considering the thesis findings alongside the knowledge exchange activities has shown that as HCPs and patients are people, they are similarly influenced by the dominant institutions within society. The knowledge exchange activities reflect that HCP preconceptions, influence the dynamic in primary care consultations. Ideally HCPs would become aware of these preconceptions, which would allow them to mitigate these and ensure that older women feel more comfortable discussing SHW.

## **Section 1 Summary**

The general public and HCPs experiences aligned with many of the thesis findings with, time constraints, embarrassment and not knowing how to broach the topic highlighted as barriers to SHW discussions in primary care. In disseminating the findings to the general public, I have demonstrated the transferability of the thesis findings. Whilst not a contradiction to the thesis findings, both the general public and HCPs discussed the patient's socio-economic status as potentially influencing SHW discussions in primary care. I pick up on this interesting point in the following chapter. Within this chapter, similarities and differences between the thesis participants' and other populations (age, gender, no T2D) have been considered.

Knowledge exchange activities with HCPs permitted the discussion of the thesis findings and gave the HCPs space to reflect on their practice. These activities with HCPs afforded insight into how the thesis findings may have implications for primary care practice, thus taking the thesis findings from a theoretical to a practical level. The knowledge exchange activities, thesis findings and the exploration of the existing literature, led to the development of several implications for primary care practice and research.

## **7.2 Section 2 – Implications for primary care practice and research**

### **7.2.1 Implications for primary care practice**

Within the UK, primary care services are organised in such a way that they are the first point of call for non-emergency health concerns. Previous research has identified



that primary care HCPs may not want to broach patients' SHW concerns as they do not consider themselves to have the skills and knowledge to deal with issues that may be revealed through exploration (Gott et al. 2004a; Saunamäki, Andersson & Engstrom 2010). In the following section, I posit two implications for primary care practice in regards to SHW discussions. First to put baby boomer women's SHW on the T2D agenda and second, to increase awareness of available SHW resources.

### **7.2.1.1 Putting baby boomer women's sexual health and well-being on the Type 2 diabetes agenda**

Throughout the thesis, I have provided evidence that older women living with T2D have SHW questions and needs which go unanswered in practice. The routine nature of T2D appointments provides opportunities for general health conversations to take place but this rarely leads to SHW concerns being addressed for many reasons identified by this thesis. Until women's SHW is placed on the diabetes care agenda, which patients are asked about their SHW remains at the discretion of individual HCPs. I suggest two approaches for pushing baby boomer women's SHW up the diabetes care agenda. First, through the inclusion of a QOF indicator addressing female SHW and second, through HCPs asking about the SHW of their older female patients living with T2D.

The inclusion of a QOF indicator which addresses female SHW would encourage HCPs to enquire about the SHW of their female patients living with T2D. There are two indicators about erectile 'dysfunction', one of which specifies that men should be "asked about erectile dysfunction" (NHS Digital 2018). I argue that women should also be asked about vaginal dryness and increased episodes of thrush and vaginosis. I have chosen these aspects of SHW because the evidence provided in Chapter One – Background and Chapter Five – Findings show that they are aspects of SHW which can have a significant impact on women's quality of life and that women living with T2D are more susceptible to. Similarly to the QOF guidelines, the National Institute for Health and Care Excellence (NICE) guidance for management of T2D in adults, states that HCPs should offer men the opportunity to discuss erectile 'dysfunction' and yet any and all aspects of women's SHW is omitted (NICE 2015b). The omission of

women's SHW from these two key documents, which dictate the care of women living with T2D, highlights the disparities in SHW care provision between men and women. However, financial and practical considerations that are beyond the scope of this thesis may prevent the addition of female SHW to the QOF and NICE guidelines. Therefore, I suggest a second approach to putting SHW discussion on the T2D agenda which may be easier to incorporate into existing practice.

The second suggestion for putting baby boomer women's SHW on the T2D agenda is that HCPs ask their female baby boomer patients living with T2D about their SHW. Studies have shown that HCPs are concerned about offending older women by asking about SHW during consultations (Gott et al. 2004a). However, the current findings and other studies show that many older women would not be offended if asked about their SHW (Gott & Hinchliff 2003b; Sadovsky et al. 2006; Sadovsky & Nusbaum 2006). Asking women about their SHW would provide them with an opportunity to discuss their SHW in primary care consultations.

HCPs have additional opportunities for addressing SHW concerns due to the organisation of T2D primary care treatment with the UK. However, the thesis findings and knowledge exchange activities demonstrate that opportunities to address concerns are frequently missed in practice. HCPs asking about women's SHW reduces invisibility and normalises sexual health as a component of general health and well-being (Foley, 2015). The thesis findings demonstrate that while baby boomer women living with T2D may feel confident in most aspects of their health management, embarrassment may be a barrier to initiating SHW discussions. HCP perceptions of baby boomer women as independent and in control of their health may lead to HCPs assuming that women will bring up SHW concerns if they have them.

Women experienced SHW changes, some of which were problematic, that they had not discussed with their HCPs. Lack of information led to most women not knowing of a possible link between their SHW and T2D, which in turn contributed to the lack of discussion. The provision of information to women by HCPs may lead to further exploration. As discussed in Chapter Six – Discussion, some aspects of menopause,

such as mood changes, were brought up by the participants during consultations and others, such as vaginal dryness, were avoided. Knowledge exchange activities with HCPs also reflected that menopause provided an opportunity to broach certain aspects of women's SHW. However, whether these conversations take place or not, appears to be partially linked to HCPs characteristics rather than patient need. Exploration on the part of the HCP can help to dispel assumptions of ageist attitudes which the thesis participants expected to encounter; one way in which to do this is to ask all patients about their SHW regardless of age, gender, sexuality or marital status.

As discussed in the previous chapter, the participants had a range of relationship statuses. Registration for primary care clinics often require women to define their relationship status as "married", "divorced", "single" or "widowed" (Graham et al. 2017). These categories do not reflect the complexities of the relationship statuses of the women in this thesis, with some women sexually active but "divorced" and others, "married" but living apart, or not currently sexually active but thinking about entering into a sexual relationship with someone other than their husband in the future. Some of the thesis participants, who were not currently sexually active, implied that later in their lives, they may be again. Women may benefit from SHW discussions with HCPs even if they are not currently sexually active and awareness that older women may be thinking about becoming sexually active and are not at the end of their sexual lives. Asking all women living with T2D about their SHW would avoid assumptions about patient need (Hillman 2017; Politi et al. 2009; Westwood & Lowe 2018) and simultaneously dispel perceptions that older women may have around their SHW needs being unacceptable to discuss in consultations.

In addition to letting women know that it is acceptable to discuss their SHW concerns in consultations, SHW discussions may also provide women with additional information. The thesis findings showed that women wanted information around sexual changes that they might experience linked to health conditions, and knowledge exchange attendees supported this. There is a body of literature which states that older women with T2D are more likely to encounter increased episodes of thrush and vaginosis than older women without T2D (see Chapter One – Background). The thesis

findings have shown that not all women living with T2D are aware of this increased likelihood. Therefore, it may be beneficial to provide older women living with T2D with additional information around sexual changes that they may experience, even if for some women, sexual changes were unproblematic.

As stated in Chapter Six – Discussion, women may be unconcerned by some SHW changes, such as reduced desire, and may not require professional help but most women expressed a preference for information and exploratory discussions in their primary care consultations. Providing information about the possible effects of T2D and its medication on SHW, would demonstrate to older women that their SHW forms a part of their primary care. The lack of information could be perceived as a breach of their sexual rights as older adults have a “...right to comprehensive sexuality education...and scientifically accurate information” (Barrett & Hinchliff 2018, p. 16). This right is arguably even more pertinent when the individual is living with a chronic disease known to potentially impact on SHW. HCPs have a responsibility to receive their patients’ concerns with openness and to support their sexual expression, in whichever way the patient needs (Jen 2017). These discussions in practice may enable women to critique ageist social norms which reject their sexuality.

One of the key thesis findings is that baby boomer women’s decisions around which aspects of SHW to broach in primary care consultations may be influenced by social and cultural messages about ageing and sexuality (Skultety 2007). It has been recognised that older adults may not have the vocabulary to express sexual issues they may be experiencing so the HCP needs to clarify any clinical terminology (Garrett 2014). To help older women feel more comfortable in clinical settings but also ensure clarity, open-ended questions and a sensitive approach may facilitate discussions.

As shown in Understandings of sexual health and well-being and Chapter Five – Findings, the participants had broad understandings of their SHW. Understanding that definitions of SHW are broad is essential to ensuring the provision of high quality health care. However, some participants did not feel it necessary to discuss within consultations reiterating the importance of not imposing notions of sexual decline nor

over-sexualisation onto older adults (Jen 2017). Therefore, HCPs need to tailor SHW conversations and care to ensure that they are not exerting pressure on patients to remain sexual into their old age or frame a sexual change as a sexual problem if this is not the case. HCPs are in a key position to resist the medicalised discourses emerging about female sexuality. Good SHW communication between HCPs and their patients is less about the discussion of specific sexual acts and more about discovering which aspects patients consider important to their SHW (Graham et al. 2017; Skultety 2007). HCPs can then assess how, if necessary, they can best assist or direct their patients

### **7.2.1.2 Increase awareness of available sexual health and well-being resources**

This thesis found that the participants, both with and without intimate partners, wanted their HCPs to be more proactive and “ask questions” within consultations. They implied that this would encourage them to discuss SHW. However, during knowledge exchange activities, HCPs identified not knowing where to refer patients for low desire or relationship issues as a barrier to SHW discussions. Lack of knowing where to refer female patients experiencing SHW issues may deter HCPs from asking their patients about their SHW. The second implication for health care practice is to increase HCPs awareness of SHW resources. These include resources designed to facilitate SHW discussions as well as resources for addressing patients’ SHW concerns.

While HCPs in the knowledge exchange activities appreciated the importance of information provision and enquiring about potential SHW changes, in practice several attendees found this an awkward conversation to have. There has been a call for HCPs to screen for sexual problems in their older patients and particularly those with chronic diseases and on medication (Taylor & Gosney 2011). Several resources exist which have been designed to facilitate SHW discussions in practice. The Brief Sexual Symptoms Checklist (BSSC-W) (Bijlsma-Rutte et al. 2017) was designed for quickly assessing if patients have any sexual concerns within primary care consultations. A short screening questionnaire could be used to identify sexual dissatisfaction and any SHW care needs. Its implementation would also ensure that all patients were asked

about SHW, removing the potential for selection bias on the part of the HCP. Used on its own, the BSSC-W may encourage a biomedical model of SHW, focussed on symptoms rather than the meaning the sexual dissatisfaction has within the life. However, the 5<sup>th</sup> question, which asks “would you like to discuss it with your GP?” may lead to increased exploration during consultations, something that the thesis participants reported as advantageous for facilitating SHW discussions.

Resources aimed at facilitating SHW discussions between HCPs also exist. IntimAge is a European wide project designed to provide HCPs with learning materials to facilitate SHW discussions with older adults in health care practice (IntimAge 2016). It was developed in 2011 but the extent to which HCPs know about and use the resources remain unknown. It has been suggested that teaching HCPs SHW communication by case-study and role play may be more effective than traditional lectures due to the absence of simple solutions to most SHW concerns (Langer-Most & Langer 2010).

The PLISSIT (Permission, Limited Information, Specific Suggestions and Intensive Therapy) model was designed to assist HCPs in discussing SHW concerns with patients (Annon 1976). More recently, it has been re-named Ex-PLISSIT and adapted for use in people living with chronic diseases (Taylor & Davis 2007). The adapted model has a focus on giving patient Permission to discuss their SHW concerns throughout rather than just once at the beginning. Nurses using the original PLISSIT model found that HCPs often omitted the Permission level (Taylor & Davis 2007). Due to the barriers experienced by women, explored in the previous chapter, such as embarrassment, social taboos around sex and reliance on lay knowledge, it is understandable how a repeated focus on the ‘permission’ aspect of the PLISSIT model would be beneficial for facilitating SHW discussion in consultations. However, HCP concerns about what to do if SHW issues are raised that they do not know how to address are understandable. Therefore, increasing HCP awareness of resources to address their patients’ concerns are also explored.

During knowledge exchange activities, HCPs with professional experience in sexual health care were knowledgeable about existing resources which could address their patients SHW concerns. Online resources and community organisations were highlighted by HCPs as useful. HCPs can direct patients to reliable online resources that may answer questions they may have about their SHW needs. Websites such as “Menopause Matters” and “Age, Sex & You” (Age Sex and You, 2019; Menopause Matters, 2018), provide up-to-date and high-quality information written by HCPs and researchers. Directing patients to online resources would also alleviate the time pressure, identified by thesis and knowledge exchange activity participants.

The thesis findings suggest that women’s groups may provide a source of SHW support as participants reported their ease at discussing women’s health concerns, particularly around menopause, with female friends. The findings from a similar study used focus groups consisting of older women living with T2D and found that this method of data collection was advantageous for women being able to open up after, for some, a lifetime of silence (Sarkadi & Rosenqvist 2003). HCP recognition of women’s groups as a potential source of support and information is important as health beliefs that women may hold may have been developed through discussions with women’s groups (Ayers & de Visser 2017). It is possible that this generation of women benefit from contact with patient or women’s organisations, such as Menopause Café, where women can meet and discuss their experiences of menopause, and access self-care remedies.

A recent move towards ‘social prescribing’ could potentially improve the SHW care that patients are provided with. Social prescribing encourages GPs and practice nurses to refer patients to community organisations, recognising that people’s holistic health and well-being needs can sometimes be better met through community activities (Kimberlee 2013; NHS England 2018; The King’s Fund 2018). It is particularly aimed at individuals with chronic health needs and those with frequent primary care appointments. The potential benefits for social prescribing can be seen in the importance that many participants attributed to dancing and socialising with their intimate partners. Although social prescribing is not currently available to all UK

patients, it is growing in popularity as GP surgeries increasingly recognise the significant benefits for patient care. HCP awareness of community organisations may reduce concerns that they have around not being able to provide patients with a suitable solution to SHW issues that may arise during consultations. This awareness of resources in the community may lead to increased SHW exploration during consultations without an increased focus on biomedical solutions. Increased education and training may encourage SHW discussions in practice (Flaget-Greener, Gonzalez & Sprankle 2015; Graham et al. 2017; Skultety 2007).

## **7.2.2 Implications for future research**

While the thesis findings have shown that silence remains around the SHW of older women, social constructions of ageing and gender are changing. The sexual rights of older adults are being increasingly recognised as important (Hinchliff and Gott 2016). There is also an increasing importance being attributed to gender equality. Therefore, in the future, research which includes the voices of older people and women will hopefully become more common.

I suggest four suggestions for future research. The first three focus on using research to break taboos, and the final one is a call for more inclusive research samples.

### **7.2.2.1 Using research to break social taboos around SHW**

One of the ways in which to break the social taboos around the SHW of older women in wider society is to normalise SHW discussions in primary care contexts. The knowledge exchange activities have shown that some medical and nursing professionals struggle to discuss SHW with older female patients living with T2D. The thesis findings also show that some older women living with T2D are unaware of the possible side effects of their medication. Therefore, developing a tool to facilitate communication between primary care HCPs and baby boomer women living with T2D will ensure that women are routinely asked about their SHW. This tool could normalise conversations around SHW, enhance the confidence with which HCPs feel able to ask about SHW and thus, have a meaningful impact on patient care. The development of



such a tool would have significant social implications and raise awareness of the women's SHW needs and potential ways of addressing these needs.

Social taboos could also be broken through incorporating 'SHW throughout the life course' into the nursing and medical curricula. Just as HCP's practice is influenced by the society in which they live, HCPs also have potential to influence social norms. Thus, an intervention study integrating a life course approach to SHW onto medical and nursing curricula could change the way that SHW discussions are approached in practice. The results from such a study may signal the need for increased education regarding SHW discussions across the life course. Providing holistic SHW education for HCPs could potentially contribute towards changing constructions of ageing and gender within society.

The third suggestion for using research to break social taboos is an intervention study evaluating the impact of HCPs asking their older female patients living with T2D about their SHW. The intervention would involve the incorporation of a question asking older women if they had any SHW issues that they would like to address during their T2D consultation in primary care. Data collected would include qualitative interviews with HCPs and older women living with T2D after the consultations where they had been asked about their SHW. The research findings could provide insight into whether the inclusion of SHW questions in consultations may be beneficial to the care that older women living with T2D receive.

During knowledge exchange activities, several HCPs stated that learning about the thesis findings and discussing their approach to SHW within consultations led to reflection on their SHW discussions. Some stated that they would consider discussing the SHW needs of older women with T2D in the future. While this increased willingness to discuss SHW in practice is positive, the impact of the thesis findings on practice are unknown. Therefore, an intervention study of this nature has potential to provide stronger evidence supporting the need for SHW discussions in primary care settings. This evidence would potentially influence practice and policy. In the Netherlands, Rutte et al. (2015) designed a randomised control trial to assess the effectiveness of a

PLISSIT model intervention for patients living with T2D but the results of this trial remain unpublished.

### **7.2.2.2 Inclusive research samples**

Research that highlights the diversity of the identities and experiences of the baby boomers can challenge the one-size-fits-all model of sexual health promoted by biomedicine (Marshall 2011; Westwood 2018). Until recently, research literature in the area of ageing and sexuality has neglected to recognise sexual and cultural diversity (Gewirtz-Meydan et al. 2018b), through either not collecting data on participants' sexuality or ethnic background or neglecting to include these participants at all. This lack of recognition has promoted the invisibility of certain groups and individuals. Research that contains diverse samples in which sexuality, culture and other aspects of people's identities are considered would widen boundaries of current knowledge.

Qualitative research that recognises diversity in later life is needed. Research which includes both heterosexual and lesbian older women is essential for expanding our understandings of how ageing intersects with gender, sexuality and health (Fredriksen-Goldsen & Muraco 2010; Westwood 2018):

*...without such studies, we are only ever getting partial perspectives on the intersecting ways that ageing, gender and sexuality inform later life.  
(Westwood & Lowe 2018, p. 159)*

The above quote reflects the recent recognition of the importance of sample diversity within research on the experiences of ageing. However, the thesis findings and knowledge exchange activities highlight that in addition to research that is inclusive of sexualities, the inclusion of women without intimate partners, and from different cultures is also necessary. The inclusion of these women ensures that in research, a greater range of voices is heard.

There is also a dearth of literature that explores the SHW needs of older women without intimate partners. This thesis highlighted that women without intimate partners considered their sexual desire and sexual "*function*" to be important to them. Few

existing studies explore what SHW means to older women not in intimate relationships (DeLamater, Koepsel & Johnson 2017; Fileborn, Thorpe, Hawkes, Minichiello, & Pitts 2015). Furthermore, as discussed in the critique of the scoping review in Chapter Two, little known about the SHW needs of older women living with T2D not in intimate relationships. Therefore, there is a need to include older women without intimate partners in future research. This may ensure that their SHW needs are not overlooked, in academia nor practice.

## **Summary of the Implications for primary care practice and research chapter**

In this chapter, the final research question, “What are the implications for practice?” has been addressed. Additionally, through the discussion of the thesis findings with wider audiences, both the general public and HCPs, I have found out about the applicability and relevance of the thesis findings outside of the context of my thesis. Both the general public and HCPs who took part in knowledge exchange activities posited that the integration of SHW discussions into consultations could be beneficial for patient care. The suggestion that the integration of SHW discussions into consultations has also been found in other studies (Bijlsma-Rutte et al. 2017; Rutte et al. 2015, 2016).

The knowledge exchange activities with the general public provided feedback on how the thesis findings were understood outside of academia. Many attendees to the general public knowledge exchange activities identified with the barriers to SHW discussion found by the current thesis. The knowledge exchange activities with HCPs informed HCPs of the thesis findings, and led HCPs to reflect on their discomfort around discussions around sexuality, assumptions of sexual inactivity in older women, a lack of time within consultations and the omission of women’s SHW on key diabetes care directives. The HCP knowledge exchange activities also highlighted that HCPs could benefit from additional information about community and referral resources to provide better SHW care for their older female patients living with T2D. Triangulation

of the thesis findings with the knowledge exchange activities allowed for discussion of the dominant institutions which influence the participants and the HCPs.

The implications for primary care practice developed as a result of the thesis findings and knowledge exchange activities are to put baby boomer women's SHW on the T2D agenda and increasing awareness of available SHW resources. Changing key diabetes care directives in one suggestion for increasing awareness around potential SHW needs of older women living with T2D. However, another way which is easier to implement is to encourage HCPs to ask about SHW. Lack of knowing where to refer female patients for SHW issue was identified as a barrier to SHW discussions during knowledge exchange activities, therefore providing HCPs with information about available resources for older women's SHW may also impact on the SHW care provision in practice.

The suggested implications for future research focus on the design of an intervention study and a call for the inclusion of more diverse research samples. The proposed intervention studies could build on the current findings to develop policy and practice. Research that contains diverse samples in which sexuality, culture and other aspects of women's lives are considered can make an important contribution to current knowledge as this thesis has done. In the next chapter, I consider the thesis strengths and limitations, and provide a reflexive account of the thesis development. At the end of the chapter, the thesis is concluded.

# **CHAPTER EIGHT – STRENGTHS, LIMITATIONS AND REFLEXIVITY**

## **Introduction**

Within this final chapter, the quality of the thesis is discussed through an exploration of the strengths and limitations. To evaluate the quality of the thesis, I use Lincoln and Guba's (1985) criteria for trustworthiness and Yardley's (2000) criteria for assessing qualitative research. This chapter also includes a reflexivity section, where I consider the way in which my role as the researcher influenced the thesis development. Engaging in the process of reflecting on the researcher's role throughout is essential to producing high-quality interpretative phenomenological analysis (IPA) research (Smith, Flowers & Larkin 2009). The final reflexivity section builds on the Preface presented at the beginning of the thesis where I introduced my epistemological position.

## **8.1 Strengths**

### **8.1.1 Interpretative phenomenological analysis approach**

The first key strength of this thesis lies in the adoption of an IPA approach. Studies of SHW discussion have not explored women's experiences of discussing SHW at this level of depth until now. As a result of the sample size of ten, I was able to perform a thorough exploration, and subsequent interpretation, of women's accounts. Through this process, I, along with the women, have co-produced new knowledge. The knowledge produced has been generated from the small, but diverse sample (see Chapter Four – Table 2 – Participant demographics).

As discussed in Chapter Four – Methods, the diversity of the sample was a choice based on the paucity of existing evidence around the SHW and SHW discussions of older women living with T2D. Additionally, the choice of a diverse sample reflects the consideration for representing the voices of underrepresented groups in society in all areas of research, even within studies with small sample sizes. While I made a

conscious effort to recruit women of sexual and ethnic minorities, along with women of working class backgrounds, I was fortunate to find women of these groups who were willing to participate and their inclusion enriched the contribution to knowledge that this thesis makes.

While the sample was diverse, it was also homogeneous in terms of the participants' gender, age range and T2D diagnosis. These shared characteristics ensured that there was a considerable level of homogeneity in the group, a requirement of IPA studies (Smith, Flowers & Larkin 2009). The balance of homogeneity with diversity enabled an exploration of the similarities and differences between the women's accounts. Furthermore, an IPA approach facilitated the minute attention to the participants' accounts that subsequently engendered the identification of convergences and divergences between and within women's accounts.

### **8.1.2 Trustworthiness**

The second key thesis strength lies in its quality, which has been assessed using two measures. From the outset of the thesis development, I have considered how to ensure that the quality has been maintained throughout. In the early stages of the thesis development, I chose to use Yardley's criteria for assessing quality (2000) due to its recommendation specifically for IPA studies (Smith, Flowers & Larkin 2009). Its four principles are sensitivity to context; commitment and rigour; transparency and coherence; and impact and importance. As the thesis developed, I continued to ensure that I adhered to these measures of quality. An extensive description of how this thesis meets these criteria is included in Appendix Q – Yardley's criteria of qualitative research applied.

I also chose to apply a second measure of quality, Lincoln & Guba's (1985) criteria of trustworthiness. The four criteria of trustworthiness in qualitative research are credibility, transferability, dependability, confirmability and reflexivity (Korstjens & Moser, 2018; Lincoln & Guba, 1985). The first four criteria are explored in this section and the final criterion, reflexivity, in the last section of this chapter. I adopted this

second measure of quality to allow for an assessment of the thesis quality using a more commonly used criteria. This allows the reader to judge the thesis quality against existing qualitative research. For the reasons provided, I considered it to be important to include both measures. However, there is overlap of these two measures and to avoid repetition I have included Lincoln and Guba's criteria within this chapter, and Yardley's in Appendix Q. Using both of these assessments ensures a high quality thesis and provides evidence that quality measures specific to IPA and qualitative research have been considered.

### **8.1.2.1 Credibility**

Credibility, assurance that the phenomena under scrutiny has been accurately recorded, was established through various means throughout the research process (Lincoln & Guba 1985). While many factors have been identified as evidence of qualitative research credibility, certain aspects are considered more relevant to measuring the trustworthiness of this thesis, in particular because of the sensitivity of the topic SHW, the IPA methodology and the research expertise of the thesis supervisors. Features identified as most relevant include the adoption of well-established research methods, using tactics to ensure honesty from informants, researcher reflexivity, 'thick' descriptions and frequent debriefing sessions with my thesis supervisors.

This thesis was designed using the seminal IPA text which ensures that it is informed by the foundation principles of IPA (Smith, Flowers & Larkin 2009). As well as including an extensive description and justification of the methods used in this thesis, there has been considerable engagement with the criticisms of IPA (see Chapter Three – Methodology) and how they would be addressed in thesis development.

In addition to the requirements of an IPA approach, the sensitivity of SHW as a topic was also addressed in order to ensure credibility of the research findings. The sensitivity of the topic of SHW and the inexperience that some women had discussing SHW indicated that it was important to ensure that research findings reflected the participants' subjective experiences insofar as possible. Iterative questioning and

prolonged engagement through asking the participants several distinct questions related to their SHW discussions with healthcare professionals (HCP) ensured that I explored the topic in depth with the participants and I used prompts to encourage them to support their responses (Korstjens & Moser 2018; Shenton 2004). The participant transcripts were also studied throughout the data analysis process and beyond to be able to present the scope of the phenomenon and check that interpretations were rooted in the participants' accounts.

Interpretations were also checked through regular supervisory meetings with my doctoral supervisors and their comments on my interpretations of women's accounts which ensured that interpretations were credible (see Appendix L – Transcript extract). Both are academics with years of qualitative research experience in sexual health, gender and diabetes and the regular supervisory meetings, where we discussed interpretations and analysis of the data, contribute to the credibility of research findings. They frequently asked for explanations and justifications for the way in which I had interpreted the data, which ensured 'thick' descriptions of the participant experiences. Over the course of my doctoral studies, I was also able to receive feedback on my interview schedule, data analysis and research findings from IPA experts at workshops that I attended at the University of Dublin and the University of Derby. Furthermore, I received feedback on the research findings from academics within my department and at conferences.

### **8.1.2.2 Transferability**

Transferability concerns applicability of the research in other contexts (Lincoln & Guba 1985). However, there is debate around how best to address this criterion (Korstjens & Moser 2018; Shenton 2004). It is most commonly considered achievable through 'thick' descriptions of data and context. This thesis meets this criterion through the presentation of extensive discussion of the social context of older women with T2D (Chapter One – Background and Chapter Six – Discussion) and detailed accounts of the research process (Chapter Four – Methods, Appendices C – O). It also includes contextual information about the participants and the interview settings (Shenton 2004). However, the main evidence demonstrating the transferability of the findings



from this thesis lie in the rich account of descriptive data, using participant extracts, presented in Chapter Five – Findings. My incorporation of these aspects are intended to enable the reader to make a judgement on the transferability of the thesis findings (Shenton 2004). In addition to research transferability, the thesis also contains practical transferability through the inclusion of BAME women (see Chapter Four – Methods). As discussed in Chapter One – Background, there are high rates of T2D in older women living with T2D meaning that HCPs are likely encounter many patients from these backgrounds in practice. Therefore, inclusion of this population makes the findings more transferable to practice.

### **8.1.2.3 Dependability**

The dependability of the research findings is the degree to which the data analysis is in line with the accepted standards for a particular design and that steps undertaken are described clearly for assessment by external auditors (Guba 1981; Korstjens & Moser 2018). Due to the credence given to the researcher's interpretation in IPA, careful consideration is required when reflecting on this criterion. While I agree that it is crucial that interpretations of the data are based within the data, I argue that there are various valid interpretations of the data (Smith, Flowers & Larkin 2009). Notwithstanding, throughout the thesis, there are supportive quotes (see Chapter Five – Findings) and a transcript extract (Appendix L – Transcript extract) to enable the reader to certify what they have read in this thesis is a valid interpretation of the data. Furthermore, in order to justify *this* interpretation of the data, throughout the thesis I have provided a complete description of each decision made during the research, allowing the reader to examine the processes whereby data was collected, analysed and interpreted. Fulfilment of the criterion dependability is also met through the quality and quantity of reflexivity included in the thesis.

### **8.1.2.4 Confirmability**

Confirmability refers to the inter-subjectivity of the researcher and participants, and the assurance that interpretations are grounded in the data (Korstjens & Moser 2018; Lincoln & Guba 1985). The grounding of interpretation in data is particularly important to explore given the focus on interpretation in IPA research. Korstjens & Moser (2018)

argue that "...interpretation should not be based on your own particular preferences and viewpoints but needs to be grounded in the data" (2018, p. 122). I argue that these two points are not mutually exclusive (Smith, Flowers & Larkin 2009). My epistemological position is that all interpretation of qualitative data is based on the perspective of the researcher which, as discussed in the Preface, was one of my rationales for adopting an IPA approach (also see Chapter Three – Methodology). However, I advocate that interpretations presented in this thesis are grounded in women's accounts and provide explanations for how the researcher's background influenced readings of said data. I have included these in the form of rich descriptions using data extracts (as shown in Chapter Five – Findings), the reflexivity section (see Reflexivity, later in this chapter) and the individual lifeworld and interview reflections (Appendix K). Through linking four of Lincoln & Guba's (1985) criteria of trustworthiness to the current thesis, several strengths of this thesis have been illuminated. However, it is also important to reflect on the thesis limitations in order to provide the reader with accurate context for the work and allow them to review the quality and relevance of the thesis.

## **8.2 Limitations**

Thesis limitations are broadly divided into those pertaining to the sample and those pertaining to concerns around the body of literature that the thesis findings will contribute to. One of the inclusion criteria for the thesis participants was that they spoke and wrote fluent English (see Chapter Four – Methods). The lack of linguistic fluency to express complex SHW issues or the presence of a family member for translate, may mean that patients for whom English is not their first language may face additional barriers to SHW communication that were not detected by this thesis. This area may also warrant further research. Additionally, HCPs encounter a diverse group of baby boomer women living with T2D so the research used to support their practice should reflect the reality of the population that they serve.

I would have liked to include a more diverse sample, specifically underrepresented women and women from South East Asian backgrounds who are more prone to T2D

(Diabetes UK 2010). Their input may have enriched the sample and contributed to knowledge around their SHW discussions. I approached two women of South East Asian background who originally agreed to participate but then declined without providing a reason. All three Black British participants were recruited from the same community group which makes it complex to discern whether similarities stem from shared experiences and discussions in the community group or from related to the influence of ethnic origin on their life experiences.

Most of the women included in this thesis had experienced health changes related to T2D. T2D can be a life-threatening condition for some and older women whose T2D was more advanced were not included in this study. The women included in the thesis sample were all in reasonably good health and none were living in institutions. The inclusion of women who were in poorer health or who were living in institutions may have illuminated differences in the women's experiences of SHW discussions. Their perspective may have contributed to the range of women's voices included in their thesis.

The second limitation is linked to potential source of sample bias. People who were more comfortable discussing their sexuality were more likely to participate potentially introducing selection bias meaning that the thesis findings may not represent the SHW experiences of a wider population of baby boomer women with T2D, however the sample of women is relatively varied in terms of class, race and sexuality. Selection bias may also exist in that six of the ten participants were recruited from community organisations. The fact that they were members of community groups may mean that they were confident individuals. Therefore, the thesis findings may be based on a sample that is more empowered than the general population of baby boomer women living with T2D in the UK. Recruiting primarily from Diabetes UK could also produce a bias in the sample through the women being more openly communicative than women who did not attend a community organisation. This is because women who attend groups may seek social interactions and be more accustomed to talking to others. This potential bias may mean the findings that baby boomer women want to discuss SHW was based on a sample of women who may have been more openly communicative

than a more general population. Nevertheless, the diversity of the sample and recruiting the remainder of the participants not from community organisations, may have offset this potential source of bias.

There is an extensive body of literature warning against associating old age with ill health (Gilleard & Higgs 2000). Given that this thesis focuses on old age and a chronic disease, it has potential to contribute to the body of literature that focuses on old age as being a time of ill health rather than focussing on the positive aspects of ageing or ageing as it is experienced (Bouman & Kleinplatz 2016). However, in conducting an IPA study, I have highlighted the women's lived experiences rather than reinforced the biomedicalisation of ageing and T2D. Having discussed the key strengths and limitations of this thesis, I now turn to the final criterion for trustworthiness, reflexivity. I discuss the way in which it has been applied throughout the thesis.

### **8.3 Reflexivity**

The inclusion of an in depth reflexivity section is not only an important requirement of an IPA approach but also enables the reader to evaluate the thesis quality. Reflexivity, Guba and Lincoln's final criterion for trustworthiness of research, is defined as both reflecting on oneself as a human and the relationship between the researcher and the data (Biggerstaff & Thompson 2008; Guba 1981).

In IPA, the researcher's symbolic interactionist position means that they are aware of their role in the production and analysis of data. The researcher's thoughts, feelings and experiences are legitimate and necessary components for making sense of participant experiences (Biggerstaff & Thompson 2008; Willig 2008b). In addition to reflection being important for IPA research, there has also been extensive literature published concerning the importance of reflection particularly when interviewing women on sensitive subjects (Cotterill 1992; Finch 1993; Oakley 1981). Oakley (1981) reflected on her interviewing experiences with women and the complexity of maintaining the balance between building rapport with the participants whilst ensuring that her knowledge, experiences and perspectives did not overshadow those of the

participants. This highlights the importance of reflecting on the role of the researcher in qualitative research.

While all qualitative research requires the researcher to reflect on their role in the research process (Biggerstaff & Thompson 2008; Finlay 2009, 2002), the interpretative nature of IPA requires a more intensive discussion of my position to delineate why I have made sense of the women's accounts in the way that I have and how this influenced the final thesis. Just as the participants' SHW was understood in relation to the context of their lives, e.g. intimate relationships, familial responsibilities and other health issues, my understandings of their accounts is also in response to my own lived context making it an essential component of the thesis. To ensure that I was reflecting throughout the research process, I kept a reflective journal (see Chapter 4 – Methods). The process of writing the journal helped me first, to reflect on the ways in which my experiences, beliefs and feelings affected recruitment, data collection and interpretation of the data collected and second, to assess how my personal characteristics as the interviewer may have impacted on the experiences that participants chose to share with me in interviews. This section examines the process of reflexivity throughout, from recruitment, data collection, data analysis, knowledge exchange activities and the thesis writing process, overall.

### **8.3.1 Reflexivity and recruitment**

Recruiting the women myself, rather than asking other HCPs to recruit on my behalf, could have reduced the selection bias reported from other studies included in Chapter Two – Scoping review of the literature (Bijlsma-Rutte et al. 2017). When in the initial phases of recruitment, I realised that my own preconceived ideas about how older women may feel about discussing sex were influencing who I approached to discuss the study with. Often it was not an intentional decision but I realised that I was approaching women who I felt would be open to discussing sex. These assumptions were based on their clothes, the way they spoke and other arbitrary factors but I learnt that often my assumptions were unfounded. Some women that I assumed would not want to participate, were keen to participate and had plenty to contribute. Other women

that I approached and thought that they would not have any problem discussing SHW said that they would prefer not to participate and looked visibly uncomfortable. Once I became aware that there was no visual way to ascertain whom the willing participants were and that my assumptions may be preventing potential participants from contributing to this study, I began to ask more women to participate. This early experience of recruitment led me to reflect on whether assumptions that HCPs hold may also influence with which patients they discuss SHW. It gave me a more personal understanding of how it may be challenging for HCPs to broach the topic of SHW with some of their patients.

My own assumptions around why potential participants chose not to participate were also important. I had the opportunity to ask a woman who decided not to participate in the research why this was so. During the recruitment phase, when asked if she would like to participate, she originally agreed and then some days later, declined. She gave her reason as “*personal*” and I assumed that the topic embarrassed her. After one of the knowledge exchange activities, over a year later, she later approached me and discussed SHW very openly which gave me the opportunity to ask why she declined to participate. Her reason was that she did not feel it fair on her husband to disclose intimate details about their relationship which reiterates the thesis findings around the complexity of the topic of SHW, the central role that intimate relationships play in SHW discussions and the protection of male intimate partners’ feelings.

### **8.3.2 Reflexivity and data collection**

The process of identifying potential participants helped me to develop a relationship with them. Then once the interview had commenced, I built on this rapport which enabled me to bring up SHW in a way that I felt appropriate for that individual. For some participants this was later in the interview than others. Whilst I had my interview guide, I used my judgement when in the interview, balancing issues that the participants wanted to discuss with staying focussed on the research area. However, I was careful not “lead” participants in a particular direction as the thesis aim was to obtain their experiences. As I conducted more interviews, pored over transcripts and

reflected on my technique, I began to be able to differentiate between leading questions and questions that enabled the participants to evoke a particular experience which reflected an area of importance for them. Consistent with a phenomenological approach, the women were experiential experts and the flexible inductive method allowed for them to describe their lived experiences and issues that they considered pertinent to our discussions (Shaw 2010). As I became more comfortable with the subject area and interviewing, I became less dependent on the interview schedule meaning that the interviews became less structured and more participant led, permitting the participants to reflect more freely during interviews. However, I often referred to the schedule for the phrasing of sensitive questions and to re-focus the interview.

I found that my previous professional experiences (see Preface) made me comfortable discussing SHW with the participants but that I was more accustomed to discussing it with younger adults. While I considered myself open-minded, I realised that prior to interviews I was nervous about discussing SHW with older women. I was nervous because I did not want to embarrass them. This brought to light my preconceptions about older women being embarrassed to discuss SHW. In practice, once I had brought up SHW, usually any awkwardness between myself and the participants dissipated. In two of the interviews, however, I sensed that the women were uncomfortable discussing sex (see Cath and Ellie in Appendix K – Individual lifeworld and interview reflections). This may have been because these interviews took place at the place of work, for one participant, and the home of the other where one of her children was in the vicinity. While I was assured by both women that we could not be overheard, having a family member in the house may have led the participant to feel inhibited. Alternatively, it is possible that they were just not that comfortable discussing SHW.

While conducting interviews, I found that adopting an open, friendly approach allowed the women to feel more comfortable and forthcoming with their experiences of discussing SHW. I can recall two of my earlier interviews where the interview had been concluded, the voice recorder switched off and I adopted a more casual tone with the

women. At this point, the women began to talk about aspects of their SHW in detail and I asked for their permission to turn the voice recorder back on so that we could continue the interview. This showed that sometimes it was advantageous for the women to see me as more relatable and in subsequent interviews, I attempted to balance 'giving participants voice' with giving enough of myself in the interview so that they felt able to express their experiences (Larkin, Eatough & Osborn 2006; Larkin, Watts & Clifton 2011). The choice to disclose more of myself helped the participants feel more able to disclose more of themselves. This enabled more of a reciprocal relationship between myself and the participants which was advantageous for the richness of the data collected from the women (Oakley 1981). I had control over what I chose to disclose to participants but there were some visible aspects of my character, some of which I introduce in the Preface, of which I had no control and may have influenced what the women chose to discuss with me during their interviews.

I was pregnant while doing the interviews and while this was not something that I disclosed to all participants, some of them knew either because it had come up in a conversation prior to the interview, or in later interviews, because it was visible. When the subject of my pregnancy came up, especially in the interviews with women with children, it appeared to create a more relaxed atmosphere within the interview, as exemplified below:

*I: Ok, you said you've got [many] children.*

*Isobel: (laughs and point to my bump) Is that your first one?*

*I: Second (laughs)*

*Isobel: You'll get there (laughs)*

*I: (laughs) I don't know if I want to!*

*Isobel: I don't blame you, two is nice!*

And Ellie, a participant who initially struggled to discuss SHW, asked if I had children and the interview became noticeably more relaxed once she discovered we had a shared experience. I feel that for some women my pregnancy may have, if not, reduced the power imbalance certainly increased rapport:



*Ellie: You know (pause) have you had children?*

*I: Yes*

*Ellie: Right well, yes, once you've had children you've had your feet up in the stirrups and the man with the light, you know (laughs) After that, yeah...just get on with it, get the baby out (laughs)*

I intentionally did not disclose that I trained as a nurse in the information sheet so that the participants would not perceive me as an HCP. The perception that I was a nurse could perhaps elicit some of the barriers that I was attempting to identify. Initially, I was also reluctant to disclose other details about myself as, while I recognised that it is impossible to make oneself completely neutral in the qualitative interviewing process, I wanted to limit the extent to which my personality, beliefs and feelings influenced the answers the women gave. However, it has been argued that this attempt to distance oneself from the interview and subsequent interpretation rarely functions in practice (Oakley 1981) and that reciprocity is actually a vital component of interviewing women.

There is extensive literature about the power imbalance that exists between researcher interviewers and their participants and consideration of this is important for recognising the implications for the data produced (Finlay 2002; Ribbens 1989; Rodríguez-Dorans 2018; Willig 2013). Kvale (2007) argues that a clear power imbalance is inherent in all interview settings, with the interviewer more powerful than their participants are. Examples of this are given as the researcher devises the interview schedule, dictates the pace and topic area of the interview. However, I feel that my age and race altered the power imbalance that is reportedly inherent in interviews between women, in favour of researchers. Extensive research exists on women interviewing women and the benefits that this 'insider status' can have in the interview situation (Cotterill 1992; Oakley 1981). However, some claim that an 'outsider' status can facilitate understanding in interviews and analysis.

There is a small body of literature which focuses on the experiences of black women undertaking qualitative research (Jefferies & Generett 2003) but how this impacts on

the interview setting, both from the perspective of the interviewer and the interviewee, has not previously been explored. Few, Stephens & Rouse-Arnett's (2003) article on white women interviewing black women emphasizes the importance of educating oneself on the culture and history of informants in order to gain the 'insider' status which I discuss briefly above. Having been born and educated in the UK, and always having lived in predominantly white areas means that I had an in depth knowledge of the social and cultural background of the White British participants and an understanding of the experiences that they described, even if I did not always identify with them. Here, empathy again becomes important in order to understand their experiences rather than making sense of my own.

Throughout my PhD I have become more aware of intersectionality and the impact that social power can have to marginalise, sometime inadvertently, those who are visibly different (Crenshaw 1991). This awareness contributed to decisions regarding the recruitment. There is little research on black women interviewing black women but the evidence that does exist suggests that we may have the advantage of 'insider' status encouraging Black women to open up in interviews when discussing sensitive topics (Few, Stephens & Rouse-Arnett 2003). Certainly sharing race facilitated discussion between myself and the Black British participants, as one participant explicitly expressed so and others alluded to it. However, I have not been able to find literature exploring power balances between black interviewers and white interviewees.

While I have identified that being a black woman may have facilitated rapport in the interview with black women, reflection on how being black may have influenced the interview with the White British women also requires consideration. The main argument for insider status being advantageous within interviews, is that because of shared characteristics or experiences the participants may feel better able to disclose their thoughts to the interviewer (Dwyer & Buckle 2009). However, I perceive benefits to being an outsider. For example, being able to ask questions that may seem obvious without participants assuming I know the answer due to being from a shared ethnic culture or age cohort. I cannot see myself through their eyes and know the influence that my colour had on women's ability to open up. I do however, feel that I had good

rapport with my participants, demonstrated in the length and detail of our interviews. In addition to race, I have considered the impact of age, in relation to the participants' interview experiences.

Isobel, the oldest participant, referred to me as “*young*” during her interview and apologised for talking about sexual problems she had had. This showed her discomfort in discussing SHW with someone younger, perhaps with an older female interviewer she would not have felt it necessary to apologise. Cotterill (1992) identified in interviews between younger researchers and older women, older women may “set boundaries” (p. 600) thus preventing the exploration of certain topics. I acknowledge that the women may have set boundaries but this was perhaps due to the sensitive nature of SHW and the lack of previous experience discussing the topic rather than the age disparity between the participants and myself. Reflecting on age, race and lived experiences, both my own and the participants' were essential for recognising the role that these aspects had on data collection. This reflection subsequently influenced the writing up process and the final thesis.

### **8.3.3 Reflexivity, data analysis and writing up**

One concern throughout data analysis and writing up was the extent to which I could interpret women's accounts whilst still staying close to their original meanings. As stated throughout, this thesis was designed to ‘give voice’ to participants and this is recognised as a key aspects of phenomenological inquiry (Davidsen 2013; Larkin, Watts & Clifton 2006; Smith, Flowers & Larkin 2009). However, the women's accounts contained, what I considered to be, contradictions. For example, Isobel's declaration that she had been content with her level of SHW but then later describing sexual intercourse, as having been incredibly painful and that she did not discuss this with her intimate partner. Discrepancies within, and between, accounts were analysed in a ‘suspicious’ way (Ricoeur 1970) searching for the deeper meaning in what women were saying and why they may perceive themselves to have good SHW if I did not perceive this to be the case (Willig 2013), which led me to reflect on how to interpret these discrepancies.

As discussed in Chapter Three – Methodology, and Chapter Six – Discussion, while a feminist approach was not adopted for the thesis, its development has undeniably been influenced by my feminist identity and findings have potential to contribute to the body of feminist scholarship. The disparity in the literature between the SHW of men and women living with T2D, along with the paucity of knowledge in the area were the motivating forces for deciding to focus on women. However, my belief that women deserve SHW care equal to that of men throughout the life span was what compelled me to dedicate this thesis solely to women’s experiences. During the early phases of data analysis, through reflection and feedback given from my supervisors, I realised that I was interpreting women’s experiences from a feminist standpoint, sometimes problematizing aspects of women’s lives that I felt highlighted gender inequalities within society. My interpretation of the women’s accounts reflected a desire to rectify the perceived imbalance between men and women, even if the participant did not consider the aspect problematic. I dealt with this by making notes on the transcript, writing in my reflexive diary and discussing it with my supervisors. Henceforth, I endeavoured to become more empathetic and ‘believing’ of women’s accounts and their perceptions of sexual and relationship satisfaction, reiterating Ricoeur’s tension between suspicion and empathy when interpreting accounts (Ricoeur 1970). This experience accentuated the complex distinction involved in presenting women’s experiences on their own terms in Chapter Five – Findings, and then providing a more interpretative account within Chapter Six – Discussion.

Mindful of the power imbalances that are inherent within interview, discussed above, I reflected on my position in regards to the interpretation of the women’s accounts and the power that I had, as the researcher, in the interpretation of accounts (Kvale 2007). I thus recognised that the thesis presents a co-construction of knowledge, comprising of the participants’ interpretations of their experiences, and my interpretations of their accounts. The interplay between the part and the whole, the hermeneutic circle, comes to the fore when reflecting on this relationship (Larkin, Eatough & Osborn 2011). I was mindful of the potential to *misinterpret* women’s accounts and so frequently reflected on my interpretations, through repeated returning to transcripts, writing reflexive diary

entries and discussions with my supervisors, to ensure that sound conclusions had been reached. In order to justify my interpretations, participant extracts have been included in the Chapter Five – Findings which details the nuances of the interview experience (where they took place, the pauses, reflecting on my feelings about the interview and how I felt about the participant). This means that while the thesis represents an interpretation, influenced by my life experiences and preconceptions, said interpretations are firmly grounded in the words of the women. Recognition of my subjective interpretation is essential for awareness that I am a product of the historical and cultural climate in which I live and my interpretations are inextricably linked to my past and current experiences (Gagnon 1990; Shinebourne 2011a). Both the participants and I perceived the requirements and habits of intimate relationships to have changed over the course of the last century with younger people having more independence and communication within their intimate relationships.

As expected in IPA (see Chapters Three and Four), the relevant pre-conceptions that I held came to the fore-ground during the data analysis (Smith, Flowers & Larkin 2009). This manifested as applying my own definitions for what a “good” intimate partnership was onto participants. Though my epistemological position does not regard bracketing as entirely possible, it is essential to be aware of said pre-conceptions at every stage of research in order to ensure transparency and a justification for analysis. My interpretations of the women’s accounts brought to light my own, previously unexplored, understandings of SHW, lived experience and identity.

It is possible that my focus on the intersections of age and race, discussed above, mean that other differences between myself and my participants, such as social class and education level were overshadowed in my analysis. I was of a higher level of education than most of my participants but this was not an aspect that I reflected on deeply during data analysis, as evidenced (by its absence) in my reflexive diary. In fact, I only considered the impact of education level after HCP feedback received during knowledge exchange activities. Two observations exist in regards to class; the first is that I am unable to define my own social class so positioning myself in regards to my participants is problematic. A researcher that identified more strongly with a

certain social class may have focussed more on social class differences than myself during data analysis. The second observation is that within this thesis, social classification was self-defined and many women found it difficult to decide which social class they were in, perhaps because the boundaries of social class are not as clearly delineated as other demographic categories such as, ethnic origin or gender of partner. While I do not dispute that class may impact on SHW discussions in primary care settings, I felt uncomfortable about drawing conclusions about it.

### **Summary of the strengths limitation and reflexivity chapter**

The strengths, limitations and reflexivity section has presented a balanced and in-depth discussion of the thesis qualities and limitations which facilitate a critique of the thesis. Key strengths of this thesis lie in its IPA approach, which have allowed for novel contributions to knowledge to be made, along with the description of how it fulfils two measures of quality (Guba 1981; Yardley 2000). In addition to these reflections of quality, the reflexivity section demonstrates that consideration has been dedicated to rationalising research development and the interpretation of women's accounts presented within this thesis.

## **Thesis conclusion**

This thesis has presented an in depth exploration of the SHW discussions of baby boomer women, living with T2D, in primary care settings. In relation to the broad research aim, research questions were developed and addressed to explore more specific areas of interest. These can be summarised as, aspects of importance to the women's SHW and barriers and facilitators to SHW discussions.

Complexities around SHW and its discussion in primary care consultations have been highlighted, with historical, social and personal factors influencing the women's decisions around which aspects of SHW to discuss with their HCPs before even stepping into a consultation. Furthermore, the thesis findings demonstrate that while many barriers exist to SHW discussions in primary care settings, that sexual changes are subjective, context dependent and may not always require a medical solution. Through the sample choice, the IPA approach and the detailed levels of analysis, the thesis makes theoretical and methodological contributions to knowledge. The contributions presented within this thesis provide novel insight into SHW discussions within the primary care context, and the factors around why these decisions may or may not take place.

As there is a paucity of qualitative research which focusses on the SHW of baby boomer women living with T2D, this thesis has contributed to understandings about this cohort of women. Furthermore, it has taken the research from a theoretical realm to a practical one through the extensive knowledge exchange activities which have disseminated the thesis findings and received the perspective of the general public and HCPs. Overall, this thesis has provided evidence that in depth and idiographic approaches to qualitative research can make significant contributions to understanding the patient need and experience.

## **Critical reflection on my theoretical position**

The theoretical contribution to knowledge presented in Chapter Six highlights the areas of intersection in the lives of baby boomer women living with T2D and how these influence their SHW and SHW discussions. Within this final section, I critically reflect on my theoretical position regarding the social constructions of older women's sexuality, constructions of sexuality and ageism and the significance of the biomedical model. This reflection focuses on the women's negotiation of previous and current social norms and expectations within intimate relationships, the women's rejection of the medicalisation of their SHW and the differentiation between their SHW and health when making decisions around which aspects of SHW to broach with their HCPs.

### **Taboos and expectations from the women's youths**

The social construction of sexuality has influenced baby boomer women's approach to SHW (Weeks 2010). Historically, our patriarchal society has prioritised the SHW needs of heterosexual men, with women in Western countries expected to satisfy their husbands' sexual needs (Barrett et al. 2018; Bradway & Beard 2015; Hinchliff & Gott 2008; Tiefer 1995, 2001; Wood et al. 2007). Consequently, many heterosexual older women have grown up with a sense that it is their duty to engage in sexual activity with their husband. For context, one example, lies in that marital rape was not criminalised until 1991 within the UK (The Law Commission 1992). The thesis findings show that the social environment in which baby boomer women were brought up continues to influence SHW discussions. However, the findings also provided evidence that the baby boomer women's approach to their sexuality changed over time, aligning with literature stating that the sexual needs of women are beginning to be recognised by society (Bradway & Beard 2015; Laumann et al. 2006).

The tension between the historical expectations that were placed on women in regards to their heterosexual intimate relationships and the perceived increasing equality within heterosexual intimate relationships was evident in the women's accounts. This tension is one of the contributions to knowledge that this thesis makes. The thesis findings show that baby boomer women perceive there to be increased gender



equality within the heterosexual intimate relationships of younger generations but that they may not enact this within their own intimate relationships due to the sense of duty, discussed above. However, the thesis findings have shown that rather than a sense of duty to engage in penile-vaginal sexual activity, it is a commitment to their intimate partners' needs, whether that be engaging in sexual activity or not (particularly when the intimate partner is unable or unwilling).

The first example of when baby boomer women felt a sense of commitment to their intimate partners was when they engaged in painful or unwanted penile-vaginal sexual intercourse with their intimate partners. This supports other qualitative research findings on women's sexual well-being (Gott & Hinchliff 2003; Hinchliff et al. 2012; Loe 2004; Sandberg 2013). The second way provided a more novel contribution to the existing literature. A sense of commitment was also present within the thesis findings when women wanted to engage in sexual activity with their male partners but did not express it to their male partners. Their desire to maintain harmony in the relationship and preserve the feelings of their male sexual partners was prioritised over their own sexual needs. Therefore, the contribution of this thesis to the literature is that older women may have sexual needs which they do not act on, or at least do not verbalise. They may do this in order to maintain harmony within their intimate relationships or to adhere to the assumptions of older women and asexuality that exist within society.

### **Ongoing reliance on narratives of asexuality in older adults, and older women in particular**

The findings from this thesis have captured what baby boomer women living with T2D consider important to their SHW and their experiences of discussing SHW with their HCPs. Hinchliff and Gott (2016) emphasise differences in language between cohorts and through using a qualitative IPA approach, this research has captured the specific words and phrases that baby boomer women use to describe aspects of importance to their SHW. Consulting with baby boomer women and listening to them explain SHW as they understand it challenges damaging generalisation about 'sexy oldies' and

sexual disinterest that exist within society (Gott & Hinchliff 2003; Hinchliff & Gott 2008; Tiefer 1995).

The double standard of ageing, where older men stay sexy but older women lose sex appeal and are expected to lose desire, has been explored within the literature (Rowntree 2014; Sontag 1972; Wood et al. 2007). While this double standard of ageing and assumptions of sexual disinterest are discussed as pertaining to the social construction of ageing and gender, the thesis findings show that these assumptions that older women may not be interested in sex are also evident within medical encounters.

This "...humiliating process of sexual disqualification" (1972, p. 287) that Sontag describes as executed by society, can be offset through HCPs asking their older female patients about their SHW. Through asking about SHW, HCPs can challenge the social construction of the sexual invisibility of baby boomer women. This thesis has presented the nuanced and complex lived experience of baby boomer women living with T2D in primary care encounters without presenting an overly sexualised or medicalised image of baby boomer women. In doing this, it has revealed the continuing dominance of the biomedical model underpinning sexual health, and primary health care more generally.

### **Biomedical model underpinning primary health care**

The thesis findings show a continuing focus on the biomedical aspects of ageing and the medical management of chronic illnesses. These overshadowed the holistic aspects of women's lives. This aligns with existing literature concerned with the medicalisation of women's sexual changes (Cacchioni & Tiefer 2012; Gott 2005; Graham et al. 2017; Tiefer 2007). This thesis has added to the body of literature challenging definitions of women's sexual 'dysfunction' (Gott 2005; Hinchliff & Gott 2011, 2004, Tiefer 1988, 2001, 2007). It has done this by asking women to discuss their SHW needs, and providing a detailed analysis of which issues they would seek

help for, why and why not. It therefore has permitted women to define what is a 'problem' using their own lives, and those around them, to define their normal (Faccio et al. 2018).

Part of allowing women to define their normal is also about accepting their choices around what they consider acceptable within their intimate relationship and sexual lives, even if this is in contrast to what is considered sexually empowered. Feminist research has been undoubtedly instrumental in challenging the language and definitions of women's sexual health and illness (Wiederman 2005) and the lives of many women have been enriched by the contribution of feminist research. However, there is little literature exploring that some women are content to live with the aforementioned sense of duty, and to prioritise the feelings of their intimate male partners. I argue that it is important to research these areas but if some women are content to accept this arguable inequality within their intimate relationships, it may be an abuse of power to insist that they change their intimate relationships to adhere to newer, more liberal social norms. Care must be taken with this position, as there is a danger that it will perpetuate the gender inequalities. I counterbalance this argument later within this section, by highlighting the crucial role of the HCP in informing baby boomer women of their sexual health rights (Barrett & Hinchliff 2018) and that they do not have to passively accept their SHW or intimate relationship concerns.

I argue that within discussions between baby boomer women living with T2D and their HCPs, the women's sense of responsibility towards their HCPs should not exist if they have SHW issues that they would like to address. The knowledge exchange activities showed that HCPs may be unaware of the power imbalance between their older female patients living with T2D and themselves in regards to SHW discussions. Particularly, as I discuss further down, if they appear confident in discussing other aspects of their health. This sense of commitment to HCPs feeling (shown through avoiding SHW discussions in order to not make their, usually male, HCP feel uncomfortable) demonstrates a need for HCPs to give permission to baby boomer women living with T2D to discuss their SHW needs. This nuanced argument both

promotes the need for providing the opportunity for baby boomer women to discuss SHW whilst rejecting the medicalisation of their SHW.

What the findings from this thesis add is that while baby boomer women may reject the medicalisation of their SHW, they may also benefit from a space to discuss SHW within medical encounters. Offering conversation rather than medication is also important to balance permissions for baby boomer women to discuss their SHW without unintentionally promoting the notion that remaining sexually active is the gold standard of ageing (Hinchliff & Gott, 2016). The narrative of the sexy oldie emerged alongside the medicalisation of sexual health (Gott, 2005) both narratives, discussed in Chapter One, emerged in response to an increasingly sexualised culture. However, presenting baby boomer women as disempowered in the face of the biomedical model, which continues to underpin primary healthcare, is overly simplistic. The findings from this thesis show that baby boomer women successfully reject the medicalisation of SHW and resist conforming to these narratives if they do not fit within the context of their lives. Evidence of this was shown in that they felt able to reject the suggestions of their HCPs and prioritised their own knowledge of their bodies over than of their HCPs. This empowered, agentic image of the baby boomer woman within primary care settings is not frequently presented within the literature. Nevertheless, within consultations, baby boomer women may show agency in terms of health (rejection of suggestions from HCPs), but less so in regards to SHW. This is also a key contribution to existing literature which has considered the power imbalance between HCPs and their older patients (Estes & Binney 1989; Evans & Robertson 2009; Foucault 1963; Turner & Samson 1995; Twigg 2004) but has seldom explored the influence of gender and generation on the power dynamics within consultations.

Tiefer argues that as feminists, our focus should be on "...providing and supporting education and consciousness raising rather than health care..." (Tiefer 1995 p. 201). I argue that providing education, healthcare, and raising consciousness in the area of older women's SHW are not mutually exclusive. Within this thesis, through interviewing women on their previous experiences of SHW discussions and asking them about their SHW needs, I have provided an exploration of the SHW needs and

their SHW educational needs. Through an exploration of the existing literature, I have shown that HCPs have the potential to raise consciousness and acceptability around the SHW needs of baby boomer women. They also have potential to provide education on possible SHW changes which can, not only educate but also, raise consciousness and acceptability around the SHW of baby boomer women.

Within this section, I have critically reflected on my theoretical position. The thesis contributions show that baby boomer women living with T2D actively negotiate previous and current social norms and expectations within their intimate relationships. This negotiation within their world outside of the consultation, also influenced the medical consultation. Within consultations, there was a rejection of the medicalisation of their SHW but women did want to be asked about their SHW. Baby boomer women living with T2D are agentic and may feel able to discuss many aspects of their health. However, due to power imbalances, historical and current social norms, SHW is often perceived as distinct facet of health.

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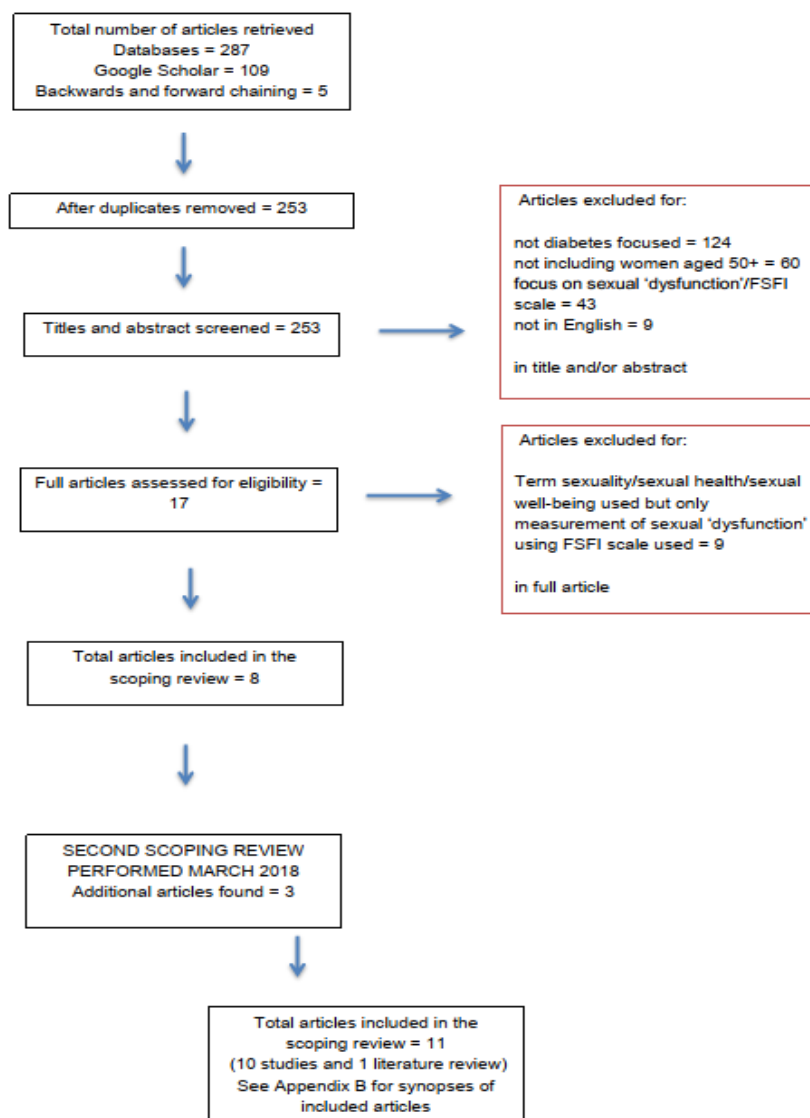
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# APPENDICES

## Appendix A – Flow diagram of literature inclusion process



## Appendix B – Synopses of scoping review studies

Study reference and country	Aims	Sample size and characteristics	Data collection and analysis	Key findings and notes
<p>(Bijlsma-Rutte et al. 2017) Screening for sexual dissatisfaction among people with type 2 diabetes in primary care. The Netherlands Article added in March 2018</p>	<p>To determine the prevalence of sexual dissatisfaction, sexual problems and need for help using a screening instrument</p>	<p>N=786 33.5% of their sample were women living with T2D. Median age of women 61</p>	<p>Quantitative methods. Screening questionnaires</p>	<ul style="list-style-type: none"> <li>- 52.8% of women experienced little or no sexual desire</li> <li>- lack of lubrications was a cause of sexual dissatisfaction for 45.8% of women</li> <li>- Other issues linked to sexual dissatisfaction were pain and/or cramping, clitoral sensation and orgasmic problems</li> <li>- Sexual satisfaction/dissatisfaction more important to participants than sexual 'function'</li> <li>- 47.2% of sexually dissatisfied women reported a need for help</li> <li>- Gender difference highlighted in regards to sexual dissatisfaction and help seeking with women less likely to discuss their sexual dissatisfaction with their GPs</li> <li>- Age not associated with a need for help</li> <li>- Increased duration of dissatisfaction associated with a decreased need for help</li> <li>- Authors encourage the use of short sexual health screening questionnaires in practice</li> </ul> <p>Knowledge gaps highlighted: Why women who were sexually dissatisfied, did not want to talk to their GPs about it. And also, why</p>

				other women who were sexually dissatisfied did want to talk to their GPs about it
(Bjerggaard et al. 2015) Prevalence of sexual concerns and sexual dysfunction among sexually active and inactive men and women with screen detected type 2 diabetes	To examine the prevalence of sexual concerns among sexually active and inactive men and women with type 2 diabetes and of sexual dysfunction among the sexually active	N=414 of their sample were women living with T2D between the ages of 40 to 69	Quantitative. FSFI with additional questions about sex	<ul style="list-style-type: none"> <li>- Key strength: They included sexually inactive women in the first part of the study</li> <li>- High rates of macro-vascular problems found in sexually inactive women</li> <li>- Reasons for lack of sexual activity given as no interest, health problems (their partners or their own) making it difficult to engage in sex, lack of an intimate partner</li> <li>- High number of sexually inactive women reported that their sexual life did not meet their sexual needs (42%) but a low number reported that a good sex life was important to them (10%)</li> </ul> <p>Limitations: No information on the sexual orientation of participants, high non-responder rate</p>
(Celik et al. 2015)	To detect the	N=423	Quantitative with data	<ul style="list-style-type: none"> <li>- Women with diabetes had low sexual quality of life score</li> <li>- More sexual 'dysfunction' found in women with T2D than T1D diabetes</li> </ul>

Sexual dysfunction and sexual quality of life in women with diabetes: The study based on a diabetic center. Turkey	prevalence of sexual function and sexual quality of life in women with diabetes	Women with diabetes. Sample had a mean age of 50	analysed through statistical tests	<ul style="list-style-type: none"> <li>- The majority (60-2%) of women expressed decreased sexual desire and reduced sexual activity after diabetic diagnosis</li> <li>- Suggest that age and menopausal status may be relevant to sexual quality of life</li> <li>- Suggest social factors e.g. employment status, may be relevant to sexual health</li> <li>- Social context of sexuality in Turkish society may have caused women to hide sexual problems</li> </ul> <p>Limitations: Exact age range is not specified</p>
(Copeland et al. 2012) Diabetes mellitus and sexual function in middle-aged and older women. USA	To examine the relationship of diabetes to sexual function in middle-aged and older women	N=2270 Women aged 40-80 with and without diabetes	Quantitative methods. Self-administered questionnaires analysed by statistical tests	<ul style="list-style-type: none"> <li>- Insulin treated diabetic women reported less sexual activity, less sexual desire and satisfaction than non-insulin treated women and non-diabetic women</li> <li>- Sexual activity in women negatively impacted by diabetes and diabetes medication</li> <li>- Diabetes and its complications affect lubrication and orgasm more than sexual desire, interest and subjective arousal</li> <li>- Suggest that attitudes, expectations and approaches to sexual activity may affect SHW</li> </ul> <p>Limitations: Psychological and relationship factors not taken into consideration</p>
(Erten et al. 2014)	To examine	N=38	Mixed methods.	<ul style="list-style-type: none"> <li>- Their definition of sexuality: Drive, arousal, vaginal lubrication, orgasm and satisfaction from orgasm</li> </ul>

Sexual lives of women with diabetes mellitus (T2) and impact of culture on solution for problems related to sexual life. Turkey	sexual lives of women with diabetes mellitus and impact on solution for problems related to sexual life	Women aged 40-66 with T2 diabetes	First stage: Surveys and questionnaires analysed by statistical tests Second stage: Semi-structured interviews analysed by content analysis	<ul style="list-style-type: none"> <li>- High rates of sexual 'dysfunction' found in the quantitative component</li> <li>- Relationship factors featured heavily in women wanting to please their partners</li> <li>- Importance of discussing sexual health problems with HCPs in order to improve sexual health outcomes</li> </ul>
(Lindau et al. 2010) Sexuality Among Middle-Aged and Older Adults With Diagnosed and Undiagnosed Diabetes A national,	To describe sexual activity , behaviour and problems among middle age and older adults by	N=1993 Adults aged 57-85 with and without diabetes	Quantitative. Survey analysed by logistic regression	<ul style="list-style-type: none"> <li>- 61% of men and 33% of women with diagnosed diabetes were sexually active</li> <li>- Women with diabetes less likely than men with diabetes and women without diabetes to be sexually active</li> <li>- Older women with diabetes as likely to have sexual problems as older men but less likely to discuss it.</li> <li>- Fewer older women with diabetes able to reach orgasm in comparison with older women without diabetes</li> <li>- Nothing documented on the effect of medication on the sexuality of older women</li> <li>- Focus on HCPs discussing sexual health problems with older men rather than older women</li> </ul>

population-based study. USA	diabetes status			<ul style="list-style-type: none"> <li>- Women with diabetes less likely to masturbate than women without diabetes suggesting a reduction in sexual drive</li> </ul> <p>Limitation: while the title states sexuality, there is perhaps a focus towards biomedical aspects of sexual health</p>
(Rockliffe-Fidler and Kiemle 2003) Sexual function in diabetic women: a psychological perspective. UK	To assess psychological factors likely to impact on the sexual functioning of diabetic women	N=43 women with diabetes for the quantitative component N=8 women with diabetes for the qualitative component	Mixed-methods. Survey analysed by statistical tests and semi-structured interviews analysed by IPA	<ul style="list-style-type: none"> <li>- Women with T2D found to have significantly more problems with the psychological aspects of sexual function, desire, satisfaction and enjoyment scores compared to women with type 1</li> <li>- Anxiety related to sexual activity due to thrush</li> <li>- Women separated by age. Women over 50 less sexually preoccupied and lower sexual self-esteem</li> <li>- Women with T2 diabetes mentioned weight as an important factors in how they viewed themselves sexually</li> <li>- Suggest research into how women see themselves sexually is lacking</li> <li>- Suggest addressing sexual health issues in the name of secondary prevention</li> </ul> <p>Limitations: potential recruitment bias through HCPs only recruiting participants that they were comfortable discussing sex with, lack of ethnic minorities</p>
(Rutte et al. 2016) Type 2 diabetes patients' needs for	To explore the needs and preference for care concerning	N=700 self-reported questionnaire using Female Sexual Function	Mixed methods. Statistical tests run in SPSS for quantitative	<ul style="list-style-type: none"> <li>- Only 35% of women aware of an association between T2D and sexual issues (63% of men were aware)</li> <li>- Participants struggled to discuss sexual concerns with their HCPs</li> <li>- Participants had the view that only worth discussing it with HCPs the HCP can offer a solution</li> </ul>



<p>preferences for care concerning sexual problems: A cross-sectional survey and qualitative interviews. The Netherlands (Article added in March 2018)</p>	<p>sexual problems in both men and women with type 2 diabetes</p>	<p>Index for quantitative component. Participants between the ages of 40-75  N=11 semi-structured interviews with women for qualitative component (mean age 61)</p>	<p>component. Thematic analysis for qualitative component</p>	<p>- Participants suggested the integration of sexual discussions into routine diabetes care Limitation: Even though their quantitative data reported significant differences between men and women, much of the discussion of the qualitative data is not separated by gender Knowledge gap highlighted: given the significant gender differences found in knowledge level around sexual changes and T2D, and feelings about discussing it with GPs, suggests that further research into women's experiences of primary care</p>
<p>(Sarkadi and Rosenqvist 2001) Contradictions in the medical encounter: Female sexual dysfunction in</p>	<p>To explore the effects of T2D on "womanhood and intimacy" and investigate whether women</p>	<p>N=33 Women aged 44-80 with T2D</p>	<p>Qualitative. Focus groups, observer data and a structured questionnaire Content analysis</p>	<p>- Personal characteristics of a GP (young age, male sex, shy personality) shown to have the greatest influence on whether sexual health matters were discussed - Shame and embarrassment of the women considering sexual health to be a taboo, time constraints and lack of privacy determined whether sexual matters were discussed or not were barriers - Women not considering primary care HCPs as sexual counsellors - Suggests they may not see SHW as a "medical" matter therefore need physicians to broach the subject</p>

<p>primary care contacts. Sweden</p>	<p>wish to receive medical attention for their sexual disturbances</p>			<ul style="list-style-type: none"> <li>- Contradiction: GPs expect patients to receive and answer questions and patients expecting GPs to ask</li> <li>- Disparity 1: patients believe HCPs to be capable of treating 'dysfunctions' but fail to report them</li> <li>- Disparity 2: Physicians have a fear of intrusion and so do not ask</li> <li>- None of the participants had been told about the possibility that diabetes could affect sexual functioning</li> <li>- Interesting use of the word intimacy rather than sexuality throughout the study</li> </ul>
<p>(Sarkadi and Rosenqvist 2003) Intimacy and women with T2 diabetes: An exploratory study using focus group interviews. Sweden</p>	<p>To explore how women perceive diabetes as affecting their social and sexual intimacy and if they wished to receive professional attention</p>	<p>N=33. Women aged 44-80 with T2 diabetes</p>	<p>Qualitative. Focus group interviews and a structured questionnaire</p>	<ul style="list-style-type: none"> <li>- Shame of sexual problems: Barrier to discussing sexual health with HCPs, purchasing effective self-care remedies such as lubrication</li> <li>- Shame and guilt of diabetes: perception of being a self-inflicted disease</li> <li>- Speculation as to cause of sexual problems: Menopause vs. diabetes vs. normal ageing</li> <li>- Desire to discuss sexual health needs with other women</li> <li>- Role of interviewer influencing the actions of the women</li> <li>- Women not being told that diabetes could have an effect on their SHW. They had however heard of impotence. Their sexual disturbances viewed as "invisible" compared to men</li> <li>- Physical contact and social interaction more important than penetrative sex</li> <li>- Discomfort of discussing sexual health needs with GPs</li> </ul>

	for any sexual disturbances			<ul style="list-style-type: none"> <li>- Focus group advantages: able to gather many opinions in little time, rare and welcome opportunity to discuss sexuality with other women in similar situations. Disadvantage: existing power relationship within the group</li> <li>- The sum of diabetes, menopause, social norms and gender roles and their effect on sexuality more important than establishing causality</li> <li>- Female sexual desire described as “brushed under the carpet” in comparison with male sexual desire</li> <li>- In order to separate sexual health and dysfunction from the wider definition of sexuality, they use the term ‘intimacy’</li> </ul> <p>Limitations: Participants part of a self-referred diabetes education group. Their participants were possibly more likely to be healthy, white... etc. Selection bias</p>
(Whitehouse 2009) Sexuality in the older female with diabetes mellitus—a review of the literature. USA	Review the literature in the area of sexuality in older women with diabetes	n/a	Literature review	<ul style="list-style-type: none"> <li>- Indirect (psycho-social) effects of diabetes on female sexuality: mood, adjustment and family relationships related to reduced desire, mental arousal, feeling unable to relax, reduced enjoyment</li> <li>- Sexual dysfunction found to be more prevalent in women than in men yet less literature exists and women less likely to report</li> <li>- Sexual activity found to be a predictor of QoL</li> <li>- Physical, social, emotional and relationship factors impact on sexuality</li> <li>- Menopause: physical and psychosocial changes</li> <li>- Mixed findings on type 1 vs. T2 effect on sexuality</li> <li>- HCP communication: Importance of the right language in sexual health interactions, importance of physicians age in decision to discuss sexual</li> </ul>

				health problems, thinking the HCP should initiate discussions, lack of time/opportunity - Limitations of the literature reviewed: Medication overlooked, ethnic minorities lacking
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## Appendix C – Letter of approval from University Ethics



Downloaded: 15/11/2018  
Approved: 22/08/2016

Stephanie Ejegi-Memeh  
Registration number: 140147472  
School of Nursing and Midwifery  
Programme: Nursing and Midwifery PhD

Dear Stephanie

**PROJECT TITLE:** Baby Boomer women with Type 2 diabetes: An Interpretative Phenomenological Analysis of their experiences of sexual communication in primary care  
**APPLICATION:** Reference Number 008690

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 22/08/2016 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 008690 (dated 18/07/2016).
- Participant information sheet 1019543 version 3 (18/07/2016).
- Participant consent form 1019545 version 2 (12/07/2016).

The following optional amendments were suggested:

*Please consider the points made by the reviewer in sections D5 and E1: (D5) It may be wise to agree a strategy for a participant raising or reporting either of these two things in the interview 1. A past experience of primary care that may be negligent or malpractice 2. An indication that they have an unreported health problem that their primary care team is unaware of. Whilst these are unlikely they may happen and its worth having a strategy ready e.g. a person to report/discuss the issue with. I suggest discussing this with the supervisory team (E1) If either of the 2 issues above occur you may need to break confidentiality - it may be worth stating this here.*

If during the course of the project you need to [deviate significantly from the above-approved documentation](#) please inform me since written approval will be required.

Yours sincerely

Parveen Ali  
Ethics Administrator  
School of Nursing and Midwifery

## Appendix D – Letter of approval for minor amendment to ethics submission



The School Of  
Nursing  
And  
Midwifery.

30<sup>th</sup> January 2017

Stephanie Alero Ejegi-Memeh  
6 Talbot Place  
Sheffield  
S2 2SS

Head of Department  
Dr Tracey Moore

School of Nursing and Midwifery  
Barber House Annexe  
3a Clarkehouse Road  
Sheffield  
S10 2LA

**Telephone:** +44 (0) 114 222 2046  
**Email:** parveen.ali@sheffield.ac.uk

Dear Stephanie

**Project Title: Baby Boomer women with Type 2 diabetes: An Interpretative Phenomenological Analysis of their experiences of sexual communication in primary care (008690)**

I am writing to you following your request for minor amendments to your ethics submission Number 008690 previously approved on 22<sup>nd</sup> August 2016.

I am pleased to inform you that the amendment submitted on 23<sup>rd</sup> January 2017 has been approved. This amendment related to:

- Recruiting from the Sheffield and District African Caribbean Community Association (SADACCA).

As the recruitment process will not change from the original recruitment process stipulated in your original Ethics application and the amendment raises no ethical concerns, I am able to grant approval for this amendment.

Yours sincerely

**Parveen Ali**  
**Ethics Administrator**  
**School of Nursing and Midwifery**

## Appendix E – Participant Information Sheet



### **“A study exploring sexual communication of women between the age of 50 and 75 with type 2 diabetes in primary care”**

I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and please contact me if you have any questions or require any further information. You can find my details at the end of this information sheet.

#### What is the purpose of the study?

This is a study about how women between the age of 50 and 75 with Type 2 diabetes communicate with their General practitioners and practice nurses about their sexual health, well-being and intimacy.

#### Why have I been invited?

You have been invited because you are a woman who is between the age of 50 and 75 and you have Type 2 diabetes. I would like to talk about your sexual health, well-being and intimacy and any experiences, thoughts and feelings you might have had about discussing it with your general practitioner or practice nurse.

#### Do I have to take part?

You can decide if you want to participate. I will explain the study, go through this sheet with you and you may ask any questions that you may have. If you decide that you would like to participate, you will be asked to sign two consent forms to show that you agree to take part. I will keep one copy and you will keep the other. If you decide that you do not wish to take part, you can withdraw at any point without giving a reason.

#### What will the study involve?

This study will involve one interview which will last between 30 minutes and one hour at the place and time that is most convenient for you, either a room at the University of Sheffield or your home. I will be the only other person present during the interview.

There will be approximately 10 other participants involved in this study who will be interviewed separately.

We will begin your interview with some general questions and then move on to discussing sexual health, well-being and intimacy and communication with your GPs and practice nurses. If you feel uncomfortable discussing any topic area, please let me know.

What are the possible disadvantages and risks of taking part?

Talking about sexual health, well-being and intimacy may be upsetting for you. If you do not want to continue, we can stop the interview at any point. If you feel that you want additional support after the interview, I will be able to advise you on who to contact.

What are the possible benefits of taking part?

The study may not have direct benefits to you but the knowledge gained from the study may help improve the care of other women with Type 2 diabetes

Will my taking part be anonymous?

Our interview will be audio-recorded and after the interview I will transcribe (type out) our discussion onto a computer. When I transcribe our interview, I will use a false name and make sure that no details that could identify you are included.

The recording and computer will be kept in a locker that only I have access to and the computer will be password protected to make sure that your information will be protected. Only the researcher and her supervisory team (Dr. Sharron Hinchliff and Dr. Maxine Johnson) will have access to the recording. The recording will be destroyed one month after I have transcribed it.

My copy of your consent form will also be kept in the locker to ensure your confidentiality.

What will happen if I don't carry on with the study?

If you withdraw from the study, during the interview or up to one month after the interview, all your data will be destroyed. One month after the interview, withdrawal will not be possible.

What if there is a problem?

Please contact me if you have a concern about any aspect of this study. My contact details are at the end of this information sheet.



If you feel that I have not answered your concerns adequately or you would like to speak to someone else, please contact Dr. Sharron Hinchliff or Dr. Maxine Johnson. Their contact details are also at the end of this information sheet.

What will happen to the results of the research study?

After I have analysed the interviews, I will present the findings to health care professionals, will write a report and the results may be published in journals and presented at conferences. It will not be possible to identify you from any work that I present or publish. Please contact me if you would like a copy of your interview transcript and/or any publications.

Who is organising the research?

I am a PhD student at the University of Sheffield and this study forms part of my PhD programme.

Please do not hesitate to contact me if you would like further information.

Thank-you for your time.

Yours sincerely,

Researcher

Stephanie Ejegi-Memeh  
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Sheffield  
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0114 222 0850

## Appendix F – Informed Consent Form



### INFORMED CONSENT FORM

Title of Project: **A study exploring sexual health, well-being and intimacy communication of women between the age of 50 and 75 with type 2 diabetes in primary care settings**

Name of Researcher: Stephanie Ejegi-Memeh

Please initial box

1. I confirm that I have read the information sheet dated ..... for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

3. (If appropriate) I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers.

4. I agree to take part in the above study.

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Person  
taking consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

## **Appendix G – Sexual Health Support sheet**

### **Contact details for support agencies**

#### **Age Better Sheffield via Sheffield Mind**

Edyta Bancer  
57 Wostenholm Road,  
Sheffield S7 1LE  
0114 258 4489 extension 106  
therapy@sheffieldmind.co.uk

This is a free counselling service for people over 50 who are experiencing social isolation. You can contact them yourself or ask your GP or practice nurse to refer you.

#### **Gail Evans**

Cornerstone Counselling and Therapy  
99 Murray Road,  
Sheffield S11 7GH  
0114 267 8613  
[info.cornerstone@gmail.com](mailto:info.cornerstone@gmail.com)

This is a counsellor with extensive experience of sexual therapy. This service is not free. Please contact the therapist for more details.

#### **Psycho-sexual counselling**

Porterbrook Clinic  
Dr. Kevan Wylie  
Clinical Lead  
75 Osborne Road,  
Sheffield S11 9BF  
0114 271 6671  
[mail@porterbrookclinic.org.uk](mailto:mail@porterbrookclinic.org.uk)

This service is free but requires a referral from your GP or practice nurse.

**Sheffield Domestic & Sexual Abuse Helpline & Assessment Service**  
0808 808 2241

**Sheffield Rape and Sexual Abuse Centre**

Helpline: 0808 802 0013

Office: 0114 2412766

This is a free helpline. The opening hours are Monday: 10am - 12noon, Tuesday and Thursday: 1 – 3pm then 6 – 8pm. For information outside of these hours, call the office number.

**Sheffield Women's counselling and Therapy Service**

44 Daniel Hill

Upperthorpe

Sheffield S6 3JF

0114 275 215

This service is free but has a waiting list. They will not be accepting new clients until October 2016 but you can call or email now to add your name to their waiting list.

**VIDA**

Violence against Women and Girls

Knowle House,

4 Norfolk Park Road,

Sheffield, S2 3QE

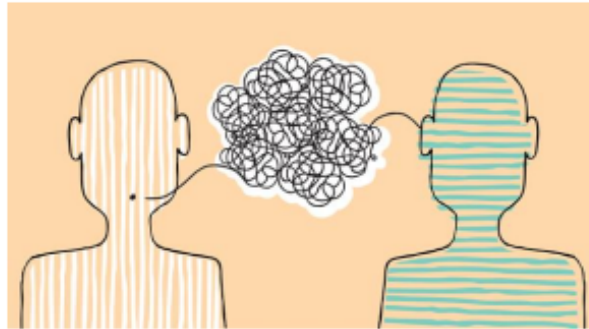
0114 275 0101

[www.vidasheffield.org.uk](http://www.vidasheffield.org.uk)

This is an organisation that has advice and runs free groups for women who have experienced domestic or sexual violence. No referral is necessary, just visit the website or call for more information.

## Appendix H – Recruitment Leaflet

**Are you a woman living with Type 2 diabetes?**



**Can you spare 30 minutes to talk about intimate relationships, well-being and health communication?**

I am a PhD student at the University of Sheffield. The purpose of this study is to learn about the intimacy and well-being needs of women with Type 2 diabetes and improve GP surgery services. Everything we discuss will be treated in confidence.

Meetings can take place either at the University of Sheffield or your home, whichever is most convenient for you.

I am looking for women to take part who

- Were born between 1940 and 1965
- Have Type 2 diabetes
- Are able to speak, read and write fluent English

All experiences welcome

**Want to take part? Contact Stephanie Ejegi-Memeh**

**[saejegi-memeh1@sheffield.ac.uk](mailto:saejegi-memeh1@sheffield.ac.uk)**

**07563927604**



## Appendix I – Demographic questionnaire

Participant Identification Number:

Date of birth: .....

Postcode: .....

Education level: .....

Employment status: .....

Social class: .....

Ethnic origin: .....

Religion: .....

Children: .....

Relationship status: .....

Gender of partner: .....

Duration of Type 2 diagnosis: .....

Length of time in UK, if not from birth: .....

## **Appendix J – Interview schedule**

As you know, I've asked you here today to take part in an interview about the sexual health, well-being and intimacy of women over the age of 50 with type 2 diabetes and communication with GPs and practice nurses. This means that although I have a list of topics, I hope that the interview will be more like a chat with you doing most of the talking. If I ask a question that you don't understand or that you're unsure of, please let me know. Sometimes in these interviews, people feel that they have been talking too much but don't worry as I really want to know about your personal opinions and experiences and if we go off track, I will ask some questions to get us on the right track again. Sometimes questions I ask may sound a bit obvious but I ask them because I don't want to take anything for granted. I hope that you will be able to be open and honest with me and I will try to be as non-judgemental about the things we talk about. If you want to stop the interview at any point, please let me know and we can stop. I'm happy to answer any questions that you might have about me but I'd rather we waited until the end of the interview.

Are you happy to begin?

(Demographic questionnaire)

What first came to your mind when you saw the interview subject?

How do you define sexual health and well-being?

What do you consider important to sexual health and well-being?

What does good sexual health mean to you?

Can you tell me what place sexual health and well-being has in your life at the moment?

*Prompts: Tell me more about x? Why is that important to you?*



Have you had any changes in your sexual health and well-being since your diabetes diagnosis? What do you think that they might be related to?

*Prompts: Do you see yourself differently? In what way?*

Have you ever sought help for sex and diabetes? Or sex generally?

Who do you talk about sexual health and well-being with?

*Prompts: Partner, friends, family, GP, practice nurse, other professionals*

Have you had conversations with your GP or practice nurse on sexual health issues?

If so, how did they go?

*Prompts: Would you feel comfortable discussing it? Who would you feel most comfortable discussing it with. How did/would it feel?*

What do you think would make discussing your sexual health and well-being with your GP or practice nurse easier?

How do you think your GP or practice nurse feels about your sexual health?

*Prompt: Why do you think that?*

Can you think of any ways of improving services?

Is there anything you'd like to add?

Thank-you for your time.

### General prompts

*Can you tell me a bit more about that?*

*What do you mean by...?*

*How did that/does that feel?*

*How so?*

*Why do you think...?*

*Can you tell me a bit more about that?*

*Can you explain in which way?*

*Can you give me specific examples?*

*And what were your thoughts on that?*

N.B. If the participant uses other terminology e.g. “being intimate”, “sexuality”, the researcher can ask them what they mean and adopt this same term instead of “sexual health”

This is not a strict interview schedule to be adhered to. The researcher should add questions and additional probes as they find appropriate and as areas of interest develop.

## **Appendix K – Individual lifeworld and interview reflections**

### Participant 1: Ann

Ann was a retiree in her mid 70's. She had been married for many years. She was not currently sexually active but affection played an important role in her relationship. Both her and her partner enjoyed dancing and this appeared to be important to the intimacy in her relationship. She had a very good relationship with her partner and they spent lots of time together. Throughout the interview she spoke using the term "we" rather than "I" and several times began speaking about her partner when I had asked about her opinion or experiences. Her partner and their relationship appeared to be inseparable from her as an individual. She explicitly stated that she did not have a problem discussing SHW and yet on many occasions during the interview, I would ask a question related to SHW and she would change the topic. I am not sure if this was due to discomfort in discussing SHW or that part of her nature was a tendency to digress in conversations, having described herself as "you get me talking and it's hard shutting me up!"

She had been diabetic for nearly 20 years and had recently started on some new medication which she was concerned were affecting her mood which was subsequently affecting her relationship. She asked me if this was possible and explained that she had never spoken to healthcare professionals about this. She had many good and bad examples of communication experiences that she had had with healthcare professionals. In the past she had moved practice because the diabetes nurse, someone with whom she was in regular contact with, "got on her nerves". Our interview was one of the longest at nearly two hours. She was very happy to participate and discussed various aspects of her life that she considered important at length.

### Participant 2: Bev

Bev was a retired woman in her late 60's who had recently started studying. She was married but currently separated from her husband. She stated that they were still

“involved” but did not disclose whether this meant that they still had an emotional or physical relationship. She described her SHW as good but said that having sex wasn’t good for her mental health as she tended to have complicated relationships which ended badly. She felt that sex was frequently a source of sadness and disappointment for her.

She expressed her reluctance to discuss SHW with healthcare professionals even though she was very happy with her HCPs and it did not appear difficult for her to discuss SHW with me during the interview.

While she described her relationship with her HCPs as “excellent”, she perceived the GP surgery as a place for diagnosis but liked to inform herself from other sources, such as friends and books and then decide a course of treatment, as demonstrated in trying to control her high cholesterol and T2D with lifestyle changes rather than the medications that she was offered on diagnosis. She was very newly diagnosed.

### Participant 3: Cath

Cath was a woman in her early 50’s who lived with her children. She was in a relationship with a man who had problems maintaining an erection and so was not sexually active at the time of the interview. This had had an impact on their relationship and her SHW. She had been living with diabetes for a long time and was content with the management of it.

She appeared timid from the outset and I am not sure if this was due to nervousness about the topic area or if that was her personality. We had the interview in her home whilst one of her children were in a different room. During the interview I felt that she was not entirely comfortable with participating. This was demonstrated in her body language and the short answers that she gave to questions initially. As tended to happen during interviews, she gradually became more relaxed and provide insight into her perspective as the interview went on. I think the discomfort she felt may have been

due to the fact that one of her children were in the vicinity and also the fact that she is a very private person.

#### Participant 4: Debra

Debra lived with her husband. In addition to diabetes, she had other health problems which were currently taking priority. She made clear to me that diabetes was a source of annoyance in her life. This was because she felt that she has done all the right things to avoid T2D e.g. diet and exercise. Because of illnesses not related to diabetes, she described sex as being “on the back burner” at the moment. However, she expressed that communication and physical contact were important to her SHW. We met at Debra's home and she was very welcoming.

Once we started the interview, she appeared to struggle to define SHW. As she had worked in sexual health, I found this surprising. It made me realise that she perceived her personal sexual health as distinct from professional definitions of SHW. In fact in that initial period when struggling, she used professional references to aid her. Throughout the course of the interview she relaxed and began to discuss issues around SHW e.g. her relationship in a more open fashion. I feel that this was one of the richest interviews as it highlighted the centrality of relationships to SHW and the place that sex has in her life at the moment and why. She also highlighted the role of comorbidities in the lives of many older women living with T2D. Although she wasn't the first participant to talk about comorbidities, the way she spoke about them made their importance clearer to me than previously.

#### Participant 5: Ellie

Ellie was a woman in her late 50's who was in a long term relationship with a man. From the outset, she was clearly someone for whom control was important.

I found this interview challenging. We met at a private room at her office. She was very willing to talk to me but from the outset it was clear that control was very important to her, demonstrated in her desire to make it clear to me that diabetes did not define her and that it was not related to any other aspect of her life. She had had severe adverse

reactions to diabetes medications. Initially, when I probed, she was reticent to disclose her "inner" thoughts but after she'd gotten used to the interview style, I feel that she opened up. I think that this is evident in the analysis. During (and shortly after) the interview, I felt that it hadn't been very rich but on analysis, there is a lot of depth and complexity within this interview. At certain points, she alludes to certain things but does not quite want to talk about it further. Once I had seen it in her interview, I felt I could see it in other interviews, this "it's not a problem" "I just get on with it" attitude to SHW and health in general, which became a prominent aspect of the thesis findings.

#### Participant 6: Fiona

Fiona in her mid-fifties, was not currently in a sexual relationship and had not been sexually active for over 25 years. She lived alone and did not have any children. Even though she was not in a relationship, she considered herself to be "healthy sexually". She spoke about the importance of masturbation to her for "dealing with" her feeling of desire. She had not found that diabetes, ageing nor menopause had impacted on her SHW. However, side effects of medication that she was taking for comorbidities had affected her SHW. In addition to T2D, she also lived with obesity, high blood pressure and other health problems. These comorbidities meant that she had been taking daily medication for many years and regularly used primary care services. While she struggled with her health problems, she considered herself to have a good relationship with her HCPs.

She was very open in discussing SHW within the interview, even though we had the interview at her place of work. This openness in discussing SHW with me was also reflected in her comfort in discussing SHW with her HCPs. During the interview she spoke extensively about how openly she was able to discuss SHW with her parents and some of her siblings.

#### Participant 7: Grace

Grace was a self-employed women in her early 60's. She described herself as White British and middle class. She had step-children that she described as being like her own. We had the interview at her home. She was married to a woman. She was

sexually active with her partner, and though less so than in previous times in their lives, she was happy with their level of sexual activity. During her interview she spoke extensively about her attitude towards health and health care in general which was quite enlightening. She had not had any problems related to her sexual health but recognised that other women of her age may have done. She felt able to bring up SHW and had plenty of suggestions for how to improve the sexual health communication with HCPs. She had not broached the subject of SHW with her HCP in relation to diabetes and HCPs hadn't either.

Right at the beginning of the interview she began talking about her parents perceptions of the health service and how important continuity was to them. When expressing her own opinions and desires of the health service, she appeared to perceive that the health service had changed significantly and that continuity that her parents historically experienced now did not exist.

#### Participant 8: Hazel

Hazel was a retiree in her late 60's who lived alone and migrated from the Caribbean when she was a child. The interview took place at her home. She had more than one child and had been single for many years after a divorce many decades ago. She was not currently sexually active. Since having being diagnosed with T2D nearly a decade ago, she had frequent episodes of thrush and vaginosis for which she attended regular GP/practice nurse appointments. In addition to diabetes, she also had sickle cell trait, a condition which predominately affects people of Afro-Caribbean descent. She gave this as a secondary reason for joining a surgery with Afro-Caribbean GPs. Her first reason was a preference of a shared culture between herself and her HCPs. I think being an Afro-Caribbean woman myself also made it easier for her to talk freely during our interview.

I felt nervous about this interview due to my preconceived ideas about Afro-Caribbean women being more reserved towards SHW discussions. Due to my nervousness, I was pleased when she brought up the subject of sexual health early on in the interview as it made it provided and opening for me to ask about her SHW. I was happy with the

interview and although she had a lot to say, she needed encouragement. When analysing this interview I realised that my interview style was like driving a car around an unknown city with no map and no idea of where I was going! Some avenues (of questioning) led to dead ends and we'd have to reverse and try a different avenue. While this style is evident in most interviews, it was especially noticeable in interviews like this one where the participant needed some encouragement to express their views.

#### Participant 9: Isobel

Isobel was a retiree in her mid 80's who lived alone. She migrated from the Caribbean when she was in her early 20's. She had several children. The interview took place at her home. Her husband had died 15 years ago and since that time she had not had any romantic relationships.

Being the oldest participant, I was interested to see if there were any differences around her perception of SHW compared to that of the other, younger participants. When I first brought up the topic of SHW, she laughed and appeared to find it surprising that I would ask someone of her age about it. However, once she'd gotten over the initial surprise, she had plenty to say about SHW and some really interesting data came out of the interview. For me, this showed how bringing up SHW may work with other older adults in practice. Perhaps when SHW is brought up by HCPs, patients may initially be shocked but then may actually want to discuss it. While many participants spoke about when they were younger, in this interview she expressed that she was more "outspoken" and "assertive" compared to previous times in her life when she was "reserved" and she attributed this increased ability to speak out to "getting older".

#### Participant 10: Joanna

Joanna was a retiree in her mid-60's who lived alone. She migrated from the Caribbean when she was in her early 20's. She had several children. The interview took place at her home. She was married but lived separately from her husband due to his mental health problems. She said in the interview that she felt more like his carer than his wife. Even before living apart, they had not been sexually active for over 20



years as her husband had experienced erectile 'dysfunction' as a result of his own T2D diagnosis. In addition to T2D she had other health problems.

This interview was one of the longest at nearly two hours. During the first half she spoke extensively about her husband and his health. At times I would ask a question about her thoughts, feelings, experiences and she would give an answer which pertained to her husband. It was very clear that her caring for her husband was an important part of her life at the moment. However, as we continued the interview she eventually opened up more and began to express her own thoughts, feeling and experiences.

# Appendix L – Transcript extract

Debra

<p><i>But would seek help if need be</i></p> <p><i>Issue of discussing STI/infections with HCP</i></p> <p><i>Self as health information resource</i></p> <p><i>Reluctance of discussing 'other' aspects of SHW w HCP</i></p> <p><i>Problem? + issue</i></p> <p><i>Solution based help seeking</i></p>	<p>Debra: If I felt that I'd got a problem, I would bring it up, yeah.</p> <p>I: What sort of problem would you speak to your GP for?</p> <p>Debra: Erm...well, I think if...I don't know really. If...from the sort of infection point of view, that would be not a problem at all, I mean if I got thrush or something that wouldn't be a problem. Although I could probably treat that myself (laughs)</p> <p>I: (laughs) perks of the job</p> <p>Debra: But that kind of thing, that wouldn't be any problem at all. Sort of, sexual health around the sort of, erm...loss of libido or that sort of thing, er...disparity in sexual appetite between me and my partner or whatever, that sort of thing then if it were a problem, (long pause) I'd probably read a book (laughs)</p> <p>I: (laughs)</p> <p>Debra: But no, if it were a problem and I thought there was help out there, and because I was in that field and I kind of, I know time passes and I know things change but if I thought that there was something that I thought might be helpful then I would ask about it and we'd talk about it</p> <p>I: Are you talking...when you say "something" are you talking....</p>	<p><i>① What Debra would feel able to talk about problem "a problem" - ② a problem - concrete + specific</i></p> <p><i>③ see GP role as infection control, aware</i></p> <p><i>④ easy to discuss infections</i></p> <p><i>⑤ self as source of health/disease info</i></p> <p><i>⑥ more difficult to discuss Libido, disparity in sexual appetite</i> <i>↳ more less biological aspect of SHW</i></p> <p><i>⑦ suggests its not a problem</i></p> <p><i>⑧ book as source of health info</i></p> <p><i>⑨ rather a book than talk to GP - demonstrated in long pause reluctance.</i></p> <p><i>⑩ would only discuss if she felt Dr had a solution, not just for discussion sake</i></p> <p><i>⑪ if it were a problem she thought Dr. could solve</i></p> <p><i>⑫ "if it were a problem" repeated 3 times</i></p> <p><i>⑬ is there a threshold of how much of a "problem" something is before it gets discussed.</i></p> <p><i>⑭ good discussion = help</i>    <i>⑮ "we'd talk about it" - equal partnership = GP</i></p>
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*Look for a solution herself*

*they have discussion rather than Dr giving answers*

Debra

communication differences = she doesn't know what her partner wants in terms of intimacy.

Sexual side-effects of medication

<p>Would seek help if needed.</p> <p>Would want to 'solve' the problem</p> <p>Adaptation of sex live depending on partner</p> <p>Health affecting</p> <p>Poor partner communication</p> <p>Health problems disrupting SHW</p>	<p>Debra: If there was a...erm...medicine or a new...or a method of counselling or er...some therapy that might help then then I would ask about it and I would talk to the GP about it and yeah, I mean and if, if I said there was a problem and he suggested something, then I'd probably go ahead and try it. But I haven't..I don't ...I can't remember a time when I've sort of had to bring it up because I haven't really had...a sort of problem. I mean I think because both of us have had health problems you know when John had his heart problems you know, there were....I didn't expect...I didn't expect much intimacy and I don't think he wanted it but he never shares anything anyway, so I don't know but that's the way it seems so...but it...I mean if there was some problem where we were...unhappy because we weren't on the same wavelength or whatever I think we'd talk about it</p> <p>[00:31:05]</p> <p>I: Ok so earlier on you mentioned that earlier on your problems are taking centre stage, erm and you know is there a disparity in your sex drives now or is that not really a problem? (pause) like when he was ill, you didn't really expect erm...intimacy from him when you say intimacy are we talking about sex? We're not talking about hand holding or things like that</p> <p>Debra: No, no...sex. I think. Yeah. (long pause) Yeah, sex. Erm...(long pause) I think...only when I started on this medication I got very tired very quickly so erm...I probably wasn't really awake enough (laughs) but erm...yeah, I think because of what we've, the problems</p>	<p>Dependent on HCP suggestions</p> <p>Repetition of problem. Quite vehement that there's no problem</p> <p>Reciprocity. Levels of sex drive more or less equal</p> <p>Lack of partner communication impacting on their SHW</p> <p>If the problem made them unhappy - key is contentment w level of SHW</p> <p>How much does the "problem" affect the happiness by partner</p> <p>More important to be on the same wavelength than external perceptions of normality/normality sexually</p> <p>Composite/confusing questions</p> <p>Practical barriers to sex? Medication as a barrier to sex?</p>
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Debra

Intimacy note  
 'sex' - OK  
 about 'it'

Comparison between  
 state of sick  
 selves + well selves

Adapting to  
 each other  
 sexual needs

Concept of  
 problem defined  
 by actors in  
 relationship

Sexual desire  
 differences -  
 fluctuate  
 across the  
 ship.

Importance of  
 finding "normalcy"  
 balance/stability  
 in relationship  
 throughout  
 life span

we've had we've probably not, not, as not as  
 sort of sexual or as we would have been. We  
 still have cuddles and hugs and things  
 but...er...er...most of the time, that's as far as  
 it goes, erm...but it's not a problem. I'm pretty  
 sure it's not a problem for John and it's  
 certainly not a problem for me and I don't and I  
 don't think we're, no, I don't think it is a  
 problem. I mean I think when we first, when  
 we first got together, erm, or no, not when we  
 first got together, but after a bit, after we'd  
 been married for a while...

I: How long have you been together?

Debra:

I: OK. So you were saying,

Debra: So I think when, no, when we'd been  
 married for a bit, I think then there were times  
 when our, erm...our desire for sex was  
 different and sometimes one or other of us  
 would be quite grumpy because of it but then  
 things sort of got into a pattern and settled  
 down and then I think we were kind of OK, then  
 John had his heart problem first and that sort  
 of upset the apple cart a bit and then I think  
 we were sort of...again, not getting back  
 where we were before but to a sort of more  
 steady time and then er...it was me. And now  
 it's, we're sort of just reaching a time when we  
 can't really, we can't really do anything at the  
 moment because I won't know until I have this  
 scan around Christmas time to know whether  
 the treatment I'm having is making any

Comparison between how sick self + well self (alternative, what their sex life would have been like)

reiterate that it's not a problem

Importance to her that it's not a problem for both not ju

Think up about past sexual habits

"I'm pretty sure" "I don't think"

due to lack of communicable

I'd remove this for anonymity reasons.

sexual history

found a pattern. Rhythm in relationship

settled down. how does this term relate to back women

refers back to the "new normal" that she spoke of before

"steady" - reliability, continuity, stability

health problems in the way of her sex

sexual continuum - looking for the balance like has nothing to do w external

perceptions their normal

Debra

more of future  
of sex  
r-ship.  
Again, not  
a problem  
to not have  
sex.

<p>Concept of Problem Contextually defined</p>	<p>difference or not and because I'm taking the pain killers regularly, I don't get any pain which is the way I knew I'd got something wrong. Erm..so I don't really know whether its, how things are going so we're sort of at an 'impasse'. As I say putting one foot in front of the other and waiting to see so er...yeah. So I think, yeah, I think we're at a different level but it's not a, it's not a problem level.</p> <p>I: I understand. You've explained it very well</p> <p>Debra: (laughs)</p> <p>I: so which part of your relationship are important? Sex has gone on the back burner</p> <p>Debra: yeah</p> <p>I: But which aspects would you say are important now?</p>	<p>① health less than SHW at a dead end</p> <p>② context w the level?</p> <p>N.B ← term she introduced earlier in the interview</p>
<p>Physical contact SHW + health generally inextricably linked</p> <p>— or different?</p> <p>Poor partner communication important to SHW</p>	<p>Debra: I think, I think the cuddles and the hugs are important. I think erm...I think er for both of us perhaps there are times when we sort of read things or hear things or there's things on television that is sort of pertinent to our problem, you know, individually...</p> <p>I: To your health problems?</p> <p>Debra: yeah, to our health problems, individually that we need to share, and so I think and I need to, I would like to be able to share without John saying that he can't do anything about it. It's probably a man thing but he feels if there's a problem that he needs to</p>	<p>③ physical contact important to SHW</p> <p>④ when she discusses her partner's feelings, she's unsure</p> <p>⑤ move from discussing SHW to health. Demonstrate how low health impacts on SHW</p> <p>⑥ feels it an unfulfilled "need"</p> <p>⑦ communication is important to her + a source of frustration within her relationship</p> <p>⑧ excusing him because of his gender?</p>



## Appendix M – Table of emergent and subordinate themes (example)

Subordinate themes	Emergent Themes	Page	Transcript extract
	Compromising relationship with doctors	12	So but yeah, but I think probably thought well we're going to have a battle here (laughs) so no, I mean, he said, yes, that's fine, let's see what it is in 3 months or whatever and as I say, the parameters were down within normal limits and he said that was OK and I could carry on which I did.
	??	12/13	Erm...I don't think I have, that I've ever felt it necessary. Erm... If I felt that I'd got a problem, I would bring it up, yeah (on discussing SHW with GP)
Dynamics of relationship	Relationship as paramount to SHW (sex and STIs as secondary)	4	I think more about the...erm...sort of sex being part of a good relationship rather than erm...sort of health being associated with infection, not like sexually transmitted infections. Not that bit but just sort of...yes, just part of a good relationship, I suppose.
Dynamics of relationship	Regards good relationship as prerequisite for good sex	5	I think you're far more likely to have erm...good sex if there is a good relationship within that. I mean there are people that, that have sex without a relationship and seem to thrive but ... I tend to feel that they're not, that they're the exception rather than the rule, I think generally people are much happier if they've got a relationship.
Dynamics of relationship	Regards good communication as a prerequisite for good relationship	5	as long as it's er...a good communicating relationship,

Dynamics of relationship	Reciprocity in relationships, "communication" again	6	Things like respect and trust. Erm....and erm...honesty. I think erm...sharing
Dynamics of relationship	Communication as conflictive in relationship with partner	6/7	I try to share what I'm feeling, John's not very good at that, he doesn't have feelings so he doesn't share them.
Dynamics of relationship	Poor partner communication	14	but he never shares anything anyway, so I don't know but that's the way it seems so.
Dynamics of relationship	Physical contact important to her SHW	15	We still have cuddles and hugs and things but...er...er...most of the time, that's as far as it goes, erm...but it's not a problem.
		16	I think the cuddles and the hugs are important.
Dynamics of relationship	Poor partner communication important to SHW (or wanting better communication with partner?)	16	we need to share, and so I think and I need to, I would like to be able to share without John saying that he can't do anything about it.
		17	I'm just asking to be heard so sometimes that's, that's that can be a bit difficult and I think it is sort of important if he'll listen without saying I can't do anything about it. So yeah, that would be, that's important that I'm heard, yeah.  I want to be able to say what I'm feeling ...
Dynamics of relationship	Sharing and respecting feelings important to SHW	17	So I think the sharing is important and respecting feelings is quite important.
Health problems impacting on relationship	Health problems overshadowing SHW	6	it doesn't take a very prominent position erm...just now so there are erm...because of my health problems.
Health problems impacting on relationship	Health dictating relationship course but it's resilient	7	new sort of normal and new sort of status quo with...we sort of went along and this sort of...(laughs) it's been like this since but I think it's

			just beginning to straighten out again but it's not where it was before. It's erm...it's <i>different</i> whether its better or worse I don't know but it's <i>different</i>
Health problems impacting on relationship	Health problems highlighting weaknesses in the relationship	8	...It gets reaffirmed frequently...now. Over the past few years, 5 years (since diagnosis), I suppose.
Health problems impacting on relationship	Health problems disrupting SHW	14	I think...only when I started on this medication I got very tired very quickly so erm...I probably wasn't really awake enough (laughs) but erm...yeah, I think because of what we've, the problems we've had we've probably not, not, as not as sort of sexual or as we would have been. We still have cuddles and hugs and things but...er...er...most of the time, that's as far as it goes, erm...but it's not a problem.
Health problems impacting on relationship	SHW and general health inextricably linked	16	I think, I think the cuddles and the hugs are important. I think erm...I think er for both of us perhaps there are times when we sort of read things or hear things or there's things on television that is sort of pertinent to our problem, you know, individually
Meaning of diabetes	Perception of diabetes as a reflection of an unhealthy lifestyle/undeserved/chronic	9	I was really cross about the diabetes because I thought I'd done all the right things to put off the diagnosis, me mum was a diabetic but she was very broad and very short and never did any..you know any exercise and never watched what she eat. Had all the wrong things and then didn't take tablet. You know, didn't really look after herself at all and I sort of felt that if I did all the right things, then it wouldn't happen or if it did, it wouldn't happen yet so when it happened, then I was really,



			really cross because I thought I'd been doing what I should and it shouldn't have come so that was quite hard...
Meaning of diabetes	Significant anger at diabetes diagnosis (because she felt it was undeserved?chronic? can't get "rid" of it	9	<p>the cancer one I just sort of accepted, you know got <b>rid</b> of that so that was alright erm, I'm just taking the tablets but I was really cross about the diabetes</p> <p>I was really cross about the diabetes ... I was really, really cross because I thought I'd been doing what I should and it shouldn't have come so that was quite hard,</p> <p>Well, I'm still a bit cross</p>
Meaning of HCP interaction	GP knowledge of her important	11	he knows me quite well
Meaning of HCP interaction	Negotiating relationship with GP	11	he agreed... we've had a battle about statins. I said no way, absolutely no way am I taking statins and erm...we've had several talks about it but I've said no.
Meaning of HCP interaction	Assertive in medical interaction	11	we've had several talks about it but I've said no. I'm not having it...
Meaning of HCP interaction	Previous professional experience entering GP interaction	12	I did suggest (to her previous patients) that they went to see if there was an alternative that they could take, John's on an alternative but it did a lot of damage, I mean I know not all patients are the same but I think that the effect on muscles is far greater than we're given to believe in the data sheets. I don't think people report it often enough. I think GP's ought to report it more and they don't. They don't use the yellow card system as it should be used.

Meaning of HCP interaction	Self as assertive	12	Well, we're going to have a battle here (laughs)
Meaning of HCP interaction	Listening/discussion as crucial to her HCP encounters	18	I could have tossed ideas around with her and another one that I sort of got on quite well with and I knew she would listen. Well i think the listening bit is the important bit and being heard, that bit
Meaning of HCP interaction	Building of relationships with HCPs	18	The GP that I usually see, I wouldn't have any problem about speaking about anything...he'll listen
Meaning of HCP interaction	Listening as crucial for HCP interaction	18	he's a very popular GP and I think it is because he listens
Meaning of HCP interaction	Experience important to her HCP perceptions	19	there is one or 2 new GPs that I haven't seen so I don't know about them but certainly all the ones that have been there a very long time I think would have the same sort of attitude and er...I wouldn't have any problems or anything like that
Meaning of HCP interaction	Continuity important to HCP relationship	19	this time I went it was <i>another</i> one again, a new one and I then I think I need to...I think I would have reservations about talking to somebody new
Meaning of HCP interaction	Listening as crucial to HCP relationship	19	I would need to know that they would...listen to me
Meaning of HCP interaction	Assessing of HCPs through discussion of non-SHW discussion	19	I think I would have reservations about talking to somebody new about things because I would need to know that they would a) listen to me and b) take me seriously and c) you know, have erm...knowledge to know whether it needed referral or not. erm...and until you I mean not that they are the things I talk about when I go but I think you can get a good idea of what they...certainly whether they're going to listen and whether they're going to take you seriously by just a couple of consultations about just ordinary, everyday things that you might go with

Meaning of HCP interaction	HCP communication as a conversation	19	we've had all the discussions about the cholesterol,
Meaning of HCP interaction	HCP relationship/history as important to her	23	we've had all the discussions about the cholesterol, about the diabetes about everything so he <i>knows</i> all about that and he <i>knows</i> about the cancer
Meaning of HCP interaction	Listening as crucial to HCP communication	24	So this doctor has sort of listened to all of this and he knows me very, very well
Meaning of HCP interaction	Feeling known as important	24	He knows, you know, he knows work and what the problems that I had at that time at work. He knows about erm...ID, my son
Meaning of HCP interaction	Defines poor GP care as not listening	27	he was just not listening at all and he was just a horrible person
Meaning of HCP interaction	Indirect experiences with HCPs affecting relationship with HCP	28	and being (her sons) NOK he should have acted on what I said but he didn't
Sense of control over body/health	Categorization of disease	3	then I thought that probably my new diagnosis would mean that I wasn't suitable
Sense of control over body/health	Sense of loss of control	10	The medication for the cancer upsets your blood sugar...my HbA1c had gone up and it was suggested I had another check in 3 months, which I've just had and it's gone up a lot again and I'm not doing anything different, you know I haven't changed my diet or anything
Sense of control over body/health	Trying to avoid medication	10	so it looks like I've...I'm going to have to go on some medication which (quietly) I don't want to do.
Sense of control over body/health	Sense of control over body	10	I said, well let me have a go at doing it myself and I lost some weight...and it was controlled and it's been fine and when I had my HBA1C done before the July one, at the beginning of of the year, it was

			in normal range so so I...you know it was OK, not to have medication
Sense of control over body/health	Uncomfortable with lack of control over diabetes	11	but now it's all gone haywire so I'm going to have to so (quietly) I'm still a bit miffed about it
Sense of control over body/health	Feeling of loss of control over diabetes	11	it just reflects that the whole thing has gone a bit haywire
SHW as fluid	Position of SHW as fluid/not fixed in life/relationship	6	...I suppose, the way to put it would be that it's on the back burner (laughs) it is not really erm...it doesn't take a very prominent position erm...just now
SHW as fluid	Position of SHW as "moveable" currently	7	So it's not really, you know, yeah, it is just sort of there in the background but not sort of...
SHW as fluid	Adaptation of relationship to health status	7	...(long pause) I think it has changed erm...now I think that we've sort of reached a new sort of normal and new sort of status quo
SHW as fluid	Problem (or not) defined by couple	13	if it were a problem,
SHW as fluid	Adaptation of SHW expectations depending on partner and health	14	I haven't really had...a sort of problem. I mean I think because both of us have had health problems you know when John had his heart problems you know, there were...I didn't expect...I didn't expect much intimacy and I don't think he wanted it but he never shares anything anyway, so I don't know but that's the way it seems so...but it...I mean if there was some problem where we were...unhappy because we weren't on the same wavelength or whatever I think we'd talk about it

SHW as fluid	Comparison between SHW of sick and well selves	15	I think because of what we've, the problems we've had we've probably not, not, as not as sort of sexual or as we would have been.
SHW as fluid	Adapting to each others sexual needs/problem defined by actors in the relationship	15	I'm pretty sure it's not a problem for John and its certainly not a problem for me and I don't and I don't think we're, no, I don't think it is a problem.
SHW as fluid	Importance of finding "normalcy"/balance/stability/pattern in relationship throughout the life span	15	I think then there were times when our, erm...our desire for sex was different and sometimes one or other of us would be quite grumpy because of it but then things sort of got into a pattern and settled down and then I think we were kind of OK, then John had his heart problem first and that sort of upset the apple cart a bit and then I think we were sort of...again, not getting back where we were before but to a sort of more steady time
SHW as fluid	Problem (or not) defined by couple	16	So I think, yeah, I think we're at a different level but it's not a, it's not a problem level
SHW as fluid/relationship dynamics	Reluctant adaptation/acceptance to partners communication barriers/to his SHW needs(?)	8	it took me a long time to get used to the fact that if John has feelings, he doesn't share them...he doesn't talk to me about feelings, it took me a long time to get used to that erm...he never shares his feelings. So erm and I think I've given up guessing so there's only sort of my feelings that I try to share though sometimes he doesn't want to know but I...having said that, I've learnt that that's how he is now so that's OK. I can accept that and respect that he's different, you know, different to me (laughs) and that's not going to change erm...

SHW perceived as function/dysfunction in HCP interaction	Ease of discussing SHW infections with HCPs	13	...from the sort of infection point of view, that would be not a problem at all, I mean if I got thrush or something that wouldn't be a problem.
SHW perceived as function/dysfunction in HCP interaction	Reluctance of discussing "other" aspect of SHW with HCPs	13	Sort of, sexual health around the sort of, erm...loss of libido or that sort of thing, er...disparity in sexual appetite between me and my partner or whatever, that sort of thing then if it were a problem, (long pause) I'd probably read a book (laughs)
Use of alternative health resources	Defining SHW from an external position	3	I used to work in sexual health so I ...and erm...psycho sexual medicine
Use of alternative health resources	Defining SHW from an external position	4	more like doing interviews because I erm...worked I was a member of the ID psycho-sexual medicine which...works on the principle that if whatever problem there is between a patient and their partner is reflected in the relationship between the interviewer and the patient.
Use of alternative health resources	Self as a source of health management	10	I said, well let me have a go at doing it myself
Use of alternative health resources	Use of previous professional knowledge for current SHW references	11	when I was doing psychosexual medicine at ID erm...the number of people I saw, that were on statins that put their muscle weakness down to either low testosterone or ageing was just...like every other patients and they're taking statins and if you questioned it, they'd say well yes it has come on since then, since I started statins
Use of alternative health resources	Self as health information resource	13	Although I could probably treat that myself (laughs)
Use of alternative health resources	Solution based help seeking	13	if I thought that there was something that I thought might be helpful then I would ask about it and we'd talk about it

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## Superordinate and subordinate themes

### 1/ ATTITUDE TO SELF/BODY

#### Meaning of diabetes

Significant anger at diabetes diagnosis (because she felt it was undeserved?chronic? can't get "rid" of it  
Perception of diabetes as a reflection of an unhealthy lifestyle/undeserved/chronic

#### Sense of control over body/health

Sense of control over body  
Sense of loss of control over body  
Uncomfortable with lack of control over diabetes  
Feeling of loss of control over diabetes  
Trying to avoid medication  
Categorization of disease

### 2/ SHW POSITIONING

#### Health problems impacting on relationship

Health dictating relationship course but it's resilient  
Health problems overshadowing SHW  
Health problems highlighting weaknesses in relationship  
Health problems disrupting SHW  
SHW and general health inextricably linked

#### SHW as fluid

Adapting to each others sexual needs/problems defined by actors in the relationship  
Position of SHW as fluid/not fixed in life/relationship  
Importance of finding "normalcy"/balance/stability/pattern in relationship throughout the lifespan  
Position of SHW as "moveable" currently  
Problem (or not) defined by couple  
Adaptation of SHW expectations depending on partner and health

Reluctant adaptation/acceptance to partners communication barriers/to hi SHW needs(?)

Adaptation of relationship to health status

Comparison between SHW of sick and well selves

#### Dynamics of relationship

Poor partner communication important to SHW (or wanting better communication with partner?)

Sharing and respecting feelings important to SHW

Relationship as paramount to SHW (sex and STIs as secondary)

Regards good relationship as prerequisite for good sex

Regards good communication as prerequisite for good relationship

Communication as conflictive in relationship with partner

Physical contact important to her SHW

Reciprocity in relationships, "communication" again

Poor partner communication

### 3/ HEALTH, HEALTHCARE PROFESSIONALS AND HEALTHCARE SYSTEM

#### Use of alternative health resources

Use of previous professional knowledge for current SHW references

Defining SHW from an external position

Defining SHW from an external position

Self as health information resource

Self as a source of health management

Solution based help seeking

#### Meaning of HCP interaction

Listening/discussion as crucial to her HCP encounters

Building of relationships with HCPs

Listening as crucial for HCP interaction

Experience important to her HCP perceptions

Continuity important to HCP relationship

Listening as crucial to HCP relationship

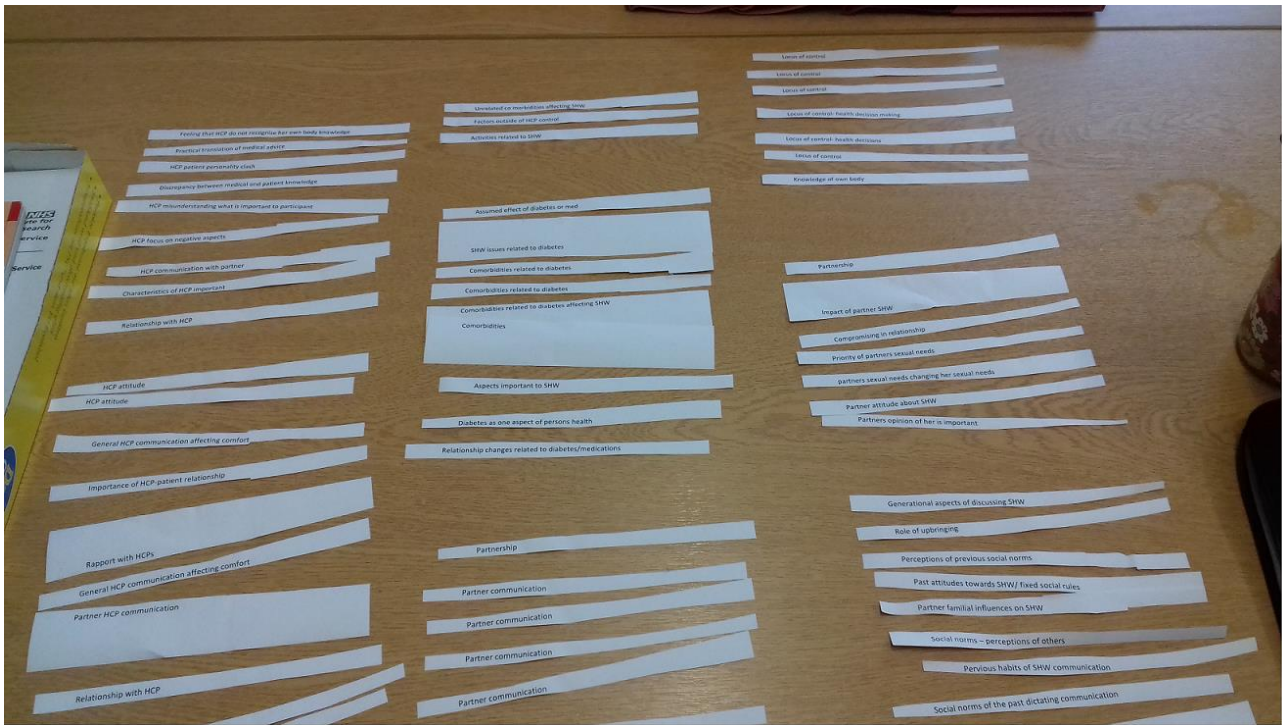
Assessing of HCPs through discussion of non-SHW discussion



HCP communication as a conversation  
HCP relationship/history as important to her  
Listening as crucial to HCP communication  
Feeling known as important  
Defines poor GP care as not listening  
Indirect experiences with HCPs affecting relationship with HCP  
Compromising relationship with doctors  
Self as assertive  
Assertive in medical interaction  
Negotiating relationship with GP  
GP knowledge of her important  
Previous professional experience entering GP interaction

SHW perceived as function/dysfunction in HCP interaction  
Reluctance of discussing "other" aspects of SHW with HCPs  
Ease of discussing SHW infections with HCP

# Appendix N – Visual grouping of emergent themes



# Appendix O – Master data table for superordinate theme 3

**Key**  
 Green= repeated extract  
 Purple= contrasting example  
 Red=Move to another subordinate theme?

Superordinate theme	Subordinate themes	Participant Number and Pseudonym									
		P1: Ann	P2: Bev	P3: Cath	P4: Debra	P5: Ellie	P6: Fiona	P7: Grace	P8: Hazel		
Relevance attributed to SHW in different contexts	Sources of SHW information/discussion (partner)	"I feel he can talk to me about it and I you know if I...was (long pause) upset about anything" Ann, pg 38	"A man can say and do and act with you just how they want and they don't seem to understand" Bev, pg 12	"Erm...not always that openly, I think he's a little bit shy about it really" Cath, pg 6	"I think you're far more likely to have erm...good sex if there is a good relationship within that...as long as it's er...a good communicating relationship" Debra, pg 5	"I think I'm more embarrassed to discuss it (sex) with my partner than I am with a stranger (motions towards me) (laughs)" Ellie, pg 11 "but that's...we don't discuss it (laughs)" Ellie, pg 12		"It is that something you can discuss with your partner? Grace: Yes, oh yes" Grace, pg 10		with...and talk" Isobel, pg 19 "he never complained or said anything. I: Because you would say...I don't want to have sex... Isobel: I didn't want to say that... I: So you wouldn't say that...? Isobel: No...Isobel, pg 20 "You wouldn't discuss it with your partner? Isobel: No because he was, he wasn't er...shouldn't say it, he wasn't a person that would sit and discuss. But to tell somebody else from outside, I couldn't because you know, you're not like XXXX, I probably wouldn't. Not even a friend." Contrast example Isobel, pg 9 "It is strange because a lot of people have a lot of symptoms. Some people get angry, some friends say they get angry, they're easy to get angry, annoyed, it affects them in different ways. I have a friend, oh my god, even when it's cold, she'll be opening every window because she's always hot and we are wrapping up. She had to wear a catch.	"Because when we both went to see them, I just sat, I sat there and I thought I wish this floor would open and swallow me in, I felt uncomfortable talking about things like that and I think he did as well and then the relationship between us wasn't brilliant" Joanna, pg 39
	Sources of SHW information/discussion (friends/literature/self)	"I used to have a really good friend and we used to ring one another up very frequently and have a mean at one another." Ann, pg 18	"I'm told that it's (sex) meant to be good for you at my age you know, a friend of mine tells me all the time." Bev, pg 18/19 "when I had emotional problems I went, I did courses, an alternative therapy, not to be a therapist, but I've done loads and loads of things and that's my way of coping and I've managed to get by on that" Bev, pg 7	"I'd probably be more likely to talk to a close friend about it first. Yeah, definitely, I've got one or two good friends so...probably discuss it with those." Cath, pg 16	"then if it were a problem, (long pause) I'd probably read a book (laughs)" Debra, pg 13	Very clear about not wanting to discuss it with anyone (including friends)		"we've got plenty of friends that we could have that sort of conversation with or that they might have with us if there was something wrong or whatever so, yes, there are plenty of people that we talk to about everything so that would just be one of the everything's that you might talk about" Grace, pg 27		"And of course with your female friends you do talk about stuff because like the women's group. Many are widowed or divorced or single and erm...when I go out with some of my friends from work, some of them are divorcees as well and stuff like that so we do talk openly..." Joanna, pg 49	
	Understandings of SHW through family	"we didn't at home...(talking about sex)" Ann, pg 13 "Because ladies just didn't talk about, if I...I didn't talk to her generation...because we just didn't... Well sort of never did coz we were brought up never...not to talk about that sort of thing. Like "down there" you just didn't" Ann, pg 32 "moving in together) you just didn't do that" Ann, pg 34	"I think my mother didn't have a very happy sexual relationship. She always made it out to be bad or wrong...(her mother) she never talked about sex" Bev, pg 21 "masturbation) I didn't really understand it years ago and now it's about that sort of quite openly talked about and things...it's all there for you to enquire about these days" Bev, 19 "I think I've always thought its (sex) just something that you have to do."			"So from the point of view of not discussing sexual relationships, my parents were very prudish and erm...when we watched television if whatever we were watching boobs came out or something the telly would be turned off because we don't talk about that...we don't...so I was brought up very prudish. Ellie, pg 20 "I think it was just how I was brought up." Ellie, pg 20	"I must admit my parents did bring me up to be open. They were a very happy and open couple so... So that (discussing SHW with HCPs) wouldn't be a problem." Fiona, pg 4 "My dad used to go to the chemist for me to pick up my prescriptions for contraceptives. He used to go and pick up my sanitary towels and tampons... You know, like they used to send us to Sunday School but only so that they could have that alone time together and that kind of."	"I don't know, I suppose it's the way I've been brought up really. You know, you don't, it's not nice to discuss thing like that with a man and it doesn't matter that he's a male doctor, he's trained in all of these things, I still don't feel comfortable talking about my thrush with him." Hazel, pg 23	"I love how these young people are, my children and everybody have a partner and everything, I love that but it wasn't like that." Isobel, pg 19	"so if I want a relationship I'd have to be very, very discreet, I couldn't let anybody...and the kids don't want me...they say "What do you want a man for at your age?" Joanna, pg 44 "I have a really good relationship with my kids, especially my FAMILY MEMBER) I can say anything to him and his wife, you know. We talk about anything sexual and anything like that but the other one goes "Mum! Mum!" and rolls her eyes. Yeah, I say sexual things to (MALE FAMILY MEMBER) and (FEMALE FAMILY MEMBER) but it's affected him sexually, it make him...so we didn't do anything for 20 odd years." Joanna, pg 12 "You know when you switch off, you just switch off completely so it wasn't a major problem as such and because I went through such a bad menopause, I wasn't interested. The feeling is there now and again but I wasn't bothered" Joanna, pg 12 "I don't think they could...they could accept somebody else... So I shut down, this is how I deal with it." Joanna, pg 44 "So	
Relevance attributed to SHW in different contexts	Acceptance of SHW/"managing" sexuality	(on husbands low libido) "I did you know, I used to like...sex and what have you (removed to preserve anonymity) but...(long pause 6 seconds). It's just not a problem." Ann, pg 22 "it's (sex) not dreadfully important... to both of us now but must admit that I...did you know, I used to like...sex" Ann, pg 22	"I just think that it's not worth it and I don't feel that...erm...I don't feel like I want sex. I can live without it. I don't think about it. I don't think about masturbate or anything like that. I never have really." Bev, pg 21	"Yeah, I mean the sex life at the moment is just non-existent really erm...so yeah, just either accept it or...he's reluctant to get help so..." Cath, pg 6	"(on lack of penetrative sex) I'm pretty sure is not a problem for John and it's certainly not a problem for me" Deb, pg 15	(referring to her low libido) "I: So you mentioned, for example, your libido but I know XXX for a long time, you said 20 years. Is that something you would discuss with the GP or... Ellie: Not as a problem. It is what it is" Ellie, pg 11 "I...erm...don't initiate because I don't want to put pressure on him because his libido has declined and he has commented on that so...yeah...so maybe sometimes I don't simply because, you know, I don't want to put any pressure on him" Ellie, pg 12	"as I've, as we've got older we've, I mean I would imagine, I mean I don't know, that our sex life isn't as active as it was when we were younger but just normal you know what I mean don't feel I'm hard changed or you know that there's anything stopping that." Grace, pg 10 "I get a feeling that there's more of a stigma for men talking about sexual health in a way that there isn't for women. I may be wrong, it's a perception, it's my perception but I think I	all of that so that dryness causes problems as well. I: Have you found that you've had more dryness? Hazel: Of recent, yeah. In the last few years, yeah. I am (LATE 60's) though... I: So you said that you'd been experiencing some vaginal dryness in recent years, do you do anything? Or have the doctors suggested anything? Hazel: No, no. When I get the thrush episodes, they give me pessaries and stuff for that but no, I don't use them...I wouldn't use HRT as well. "	"lucky (for not having menopausal symptoms)" Isobel, pg 18 "for me it (sexual intercourse with vaginal dryness) was pain and agony and I bear with it" Isobel, pg 20 "I used to have, I used to feel guilty when he wanted to have sex with me because, it I wasn't enjoying it" Isobel, pg 19 "I used to have, I used to feel guilty when he wanted to have sex with me because, it I wasn't enjoying it" Isobel, pg 23		

<p>Relevance attributed to SHW in different contexts</p>	<p>Perception of diabetes and comorbidities (including menopause) impacting upon SHW</p>	<p>"he thinks because I am now...you know...I explode a lot more and shout at him for things and then I'm really sorry because I know it's not his fault, I know it's me being...and I apologise and he says...I have to ask you as well. Are the pills I take because I'm not on insulin or anything. Can they affect mood?" Ann, pg 8 "I don't think about it (SHW) now. I've got a lot more problems health wise" Ann, pg 30 "at one stage when</p>	<p>Mental health condition of husband</p>	<p>"horrendous hot flushes, trouble sleeping which is nothing fresh for me really, I do have trouble sleeping anyway but it was the hot sweats and night sweats and irritability and just I found it hard to put a smile on my face really I was quite down about things so yeah, touch wood, I've been a lot better since I've been on the tablets so..." Cath, pg 5 NOT DIRECTLY RELATED TO SHW "No I haven't personally</p>	<p>"it doesn't take a very prominent position erm...just now so there are erm...because of my health problems." Debra, pg 6 "only when I started on this medication I got very tired very quickly so erm...I probably wasn't really awake enough (laughs) but erm...yeah, I think because of what we've, the problems we've had we've probably not, not, as not as sort of sexual or as we would have been." Debra, pg 14</p>	<p>"so I can remember distinctly speaking to my doctor about increased er...libido (caused by a medication taken for an additional health problem) and er...it was acute stimulation, even sitting on a chair would cause problems" Fiona, pg4</p>	<p>"I just have to be more...aware of my lifestyle choices. What I eat erm...make sure I take some sort of exercise. Sexually, I've had a lot of episodes of thrush. Yeah. And vaginosis. As well." Hazel, pg 4 "Hazel: Yeah, when it's a bit high on the high side, it tends to flare up. I: And how does it affect you, the thrush? Hazel: Just the itching. I: And the vaginosis? Hazel: Like a fishy smell." Hazel, pg 5 "It is, the itchiness, yeah and it still comes up. I think it's related to fact that I</p>	<p>"And then it comes back within like, a month or...a month will go and there's none and the next month it will come back with a big flow..." Isabel, pg 19 "You know, I wouldn't because, at first, you well, like your vagina went really dry. Really dry, you're a young girl but I have to tell you, it's important." Isabel, pg 18 "[during the menopause, because of the vaginal dryness] I wasn't enjoying it [sex], it wasn't comfortable" Isabel, pg 19</p>	<p>"He's been a diabetic for over 30 years or so. He's been longer than me. Well, it's affected him sexually. It make him...so we didn't have...we weren't doing anything for 20 odd years...he was impotent" Joanna, pg 12/13 "I went through such a bad menopause, I wasn't interested. The feeling is there now and again but I wasn't bothered..." Joanna, pg 12I had a such, heavy bleeding, really such heavy bleeding and stuff and then it eventually stopped but that put me off any sex and everything at the time."</p>
<p>Relevance attributed to SHW in different contexts</p>	<p>Professional help seeking attitude to SHW</p>	<p>Reluctance to discuss SHW with me</p>	<p>(on discussing SHW) "I wouldn't talk about it unless it was really important, it was affecting me or something" Bev, pg 6</p>	<p>DIVERGENCE "I'd definitely consider it GETTING HELP AS A COUPLE), yeah, definitely erm, but you know what men are like they're a bit stubborn sometimes especially when it comes to anything like that" Cath, pg 6 "if I had a problem and it was big enough, I'd want it sorting" Cath, pg 11 "I've been on the tablets since the beginning of August, I've been brilliant but I've was having horrendous</p>	<p>"Debra: If I felt that I'd got a problem, I would bring it up, yeah. I: What sort of problem would you speak to your GP for? Debra: Erm...well, I think if...I don't know really. If...from the sort of infection point of view, that would be not a problem at all, I mean if I got thrush or something that wouldn't be a problem. Although I could probably treat that myself (laughs)" Debra, pg 13 "Sort of, sexual health around the sort of, erm...loss of libido or that sort of thing, er...disparity in sexual appetite between me and my partner or whatever, that sort of thing then if it were a problem, (long pause) I'd probably read a book (laughs)" Debra, pg 13 "If there was a...erm...medicine or a new...or a method of counselling or</p>	<p>"So yeah, I went to see them but...you have to discuss with them how often you have intercourse and all that kind of thing, yeah, ok it's something private you don't really want to discuss but there's no problem in discussing it really" Ellie, pg 10</p>	<p>"If I had an issue but there would have to be something wrong. You know, I'm not a...you know, I don't know. Erm...if I felt there were something not right, then I would go straight away but I don't think erm...its not...I wouldn't. It wouldn't cross my mind to have that a part of a conversation. Do you know what I mean?...if for instance, I don't know maybe a, I found my...any sort of sexual activity uncomfortable or something, then I'd go to find out what was wrong</p>	<p>"Good sexual health is about knowing your body, knowing when there's any sort of changes and that you can be aware of and that you can get treatment for." Hazel, pg 16 "I: Do you talk to her about the thrush and the vaginosis? Hazel: Oh yes. She makes sure that erm...I had a list of things that concern me and that I tackle that list on a personal basis...I have that list to guide me as to what I need to do and on that list was the vaginal itching, that was one of the priorities and I've been to the doctor about it...as I</p>	<p>"I would be able to, I think at...erm...at the time was at [REMOVED TO PRESERVE ANONYMITY] [HOSPITAL] for it and he's had all sort of stuff, Viagra and all things but it just put me off. It was a turn off." Joanna, pg 13 "I went back to see her, she had all the tests and stuff done, gave me tablets to stop the bleeding, that didn't even work and it went on. She put me back on the pill, and I thought to myself, I can't be doing with this at my age, erm, messing about with pill taking so I said that I'm stopping it. I said to her 'I'm coming off</p>
<p>Relevance attributed to SHW in different contexts</p>	<p>SHW as function/dysfunction in primary care consultations</p>	<p>"So I happily went to my GP and asked what that was... it was just something that needed seeing to" Ann, pg 30 "I used to take the Pill...That's what they called them in my day and I used to go there and I had no problems...you know discussing...things like that" Ann, pg 17 "they</p>	<p>"Just making sure that you get your smears and erm...I've had erm...coils fitted periodically, I've not got one in at the moment because I've just started on er...HRT." "Yeah, erm...so I had obviously tests that I didn't have any sexually transmitted</p>	<p>"from the sort of infection point of view, that would be not a problem at all, I mean if I got thrush or something that wouldn't be a problem. Although I could probably treat that myself (laughs) Debra: But that kind of thing, that wouldn't be any problem at all. Sort of, sexual health around the sort of, erm...loss of libido or that sort of thing, er...disparity in sexual appetite between me and my partner or whatever, that sort of thing then if it were a problem, (long pause) I'd probably read a book</p>	<p>"Sexual health, I suppose, OK, the first thing that does come to mind is that er...I had er a polyp a couple of years ago" Ellie, Pg 3 "I don't think about my sexual health, I'm in a long term relationship erm...I don't get...I have had a worry years ago about transmitted diseases but my sexual health right now, I have no worries about."</p>	<p>"Provided I'm careful with partners and I regularly check should I have various partners that I've not contracted any erm...STDs or anything like that and or just the actual function of...because you're older do you need more lubrication and things like that so..." Fiona, pg</p>	<p>"if for instance, I don't know maybe if, I found my...any sort of sexual activity uncomfortable or something, then I'd go to find out what was wrong but I wouldn't be going for anything else" Grace, pg 5 "when I was about 30 I tried to conceive myself and couldn't so there was a bit of a discussion about that</p>	<p>"(on recurrent thrush) Yeah, yeah. And he did say that it's because of the diabetic situation." Hazel, pg 5 "Good sexual health is about knowing your body, knowing when there's any sort of changes and that you can be aware of and that you can get treatment for. And as I said, the worst thing I have is the thrush. Hmm, and vaginosis and</p>	<p>"Well, I went to him about the erm...heavy periods but I didn't tell him about that [vaginal dryness] part (laughs)" Isabel, pg 19 "I always had to go in and a...smear test." Isabel, pg 8 "No she was, she said when the result come back she says "Oh, have you had any itching?" and I said "Yes, I have" and she said "Well, you have a bit of thrush</p>

## **Appendix P – Sexual health and well-being scenario for practice nurses**

### **Scenario**

Gemma is a 71 year old retiree who lives alone. She is married but has been living separately from her husband for many years due to a mental health issue which causes him to experience frequent violent outbursts. Before living apart, they had not been sexually active for many years as her husband had experienced problems maintaining an erection. He lives nearby and she visits him regularly. She has an active social and family life but misses intimacy so while not currently sexually active, she may become so in the future. She has experienced vaginal dryness since she went through the menopause 15 years ago and while it causes her some discomfort, she has never sought help for it. Neither she nor her healthcare professionals have ever broached the topic of sexual health in consultations.

Gemma has Type 2 diabetes and high blood pressure so she has frequent appointments with you to monitor these conditions. She has been your patient for over a year and you have built up good rapport, often having a brief chat about her husband, children and other aspects of her life during her appointments. Towards the end of today's routine diabetes check-up, you ask her if there is anything else that she would like to discuss and she mentions that she has been "in a terrible mood lately". She asks if it could be linked to her Type 2 Diabetes medication. She also suggests a few other things that her mood change may be linked to, one of which is feeling lonely.

### **Discussion points**

How might you respond to Gemma's question?

How would you decide which issues (e.g. vaginal dryness, relationship with her husband, potential new relationships, mood changes, loneliness) to broach with her?

How might you initiate a conversation about her sexual health and well-being needs? And, which phrases might be useful?

What information do you think might be useful for Gemma? Are there any resources or sources of information outside of consultations that she might find useful?

## Appendix Q – Yardley’s criteria for assessing the quality of qualitative research

Criteria	Considerations for this study
<p>Sensitivity to context</p> <p><i>knowledge of the existing literature, relevant socio-cultural factors, the sample choice, recognition of the relationship that exists between the interviewer and participant</i></p>	<p>Primarily, literature in the area of the SHW of older women with T2D was explored to identify knowledge gaps (see Chapter One and Chapter Two), the process of which ensured that I had knowledge of some of the relevant socio-cultural factors.</p> <p>For both methodological and theoretical reasons, the inclusion criteria for this study required women between 50 and 75 years. This age range was chosen in order to consider issues that may affect this particular cohort and due to the suggestion that IPA studies should endeavour to recruit homogenous samples to allow for an idiographic exploration (see Chapter Three – Methodology). One participant included in the study was not within the age bracket and her inclusion is justified for methodological and practical reasons. In IPA participants are selected for the access the particular perspective that they can provide and while this participant may have had different social experiences in her youth to some of the younger participants, stark differences in approaches to SHW communication were also found between participants who were around the same age (Ellie, age 58 and Fiona, age 54) suggesting that factors other than age are also implicated. Her inclusion was also justified due to practicality in that I intended to recruit 10 participants, I was coming to the end of my allocated recruitment period and she volunteered to participate.</p>

Exploration of the sensitive topic of SHW within interviews required me to establish a rapport with participants and put them at ease. The demographic data collection (Appendix I – Demographic questionnaire), which I began each interview with, allowed me to develop a rapport with the participant from the outset and encourage them to express their thoughts and feelings about SHW. One criticism of phenomenology more generally, is that it is suited to participants that can articulate the nuances of their experiences (Tuffour 2017)(see Chapter Three – Methodology – Criticisms of IPA). However, through the collection of rich and extensive interview data in which I asked participants for clarification, when necessary, the women’s perspectives became clearer. The nuances of their experiences also came to light through my interpretation of their accounts.

I have considered the relationship between participants and myself in Chapter Eight – Strengths, limitations and reflexivity (potential power imbalances, importance of rapport, etc.). During data collection, wider experiences of SHW, conversation and ideas around primary care emerged within interviews which reflects entry into the lifeworld of women living with T2D. Giving the women freedom to direct interview discussions enhanced the sensitivity to context of this thesis through reflecting aspects which were important to the women and also allows understandings the wider context in which SHW conversation. Placing these SHW conversations within the context of the life of the participant allowed for the importance placed on SHW, and its discussions, to emerge.

	<p>Verbatim extracts were included throughout Chapter Five – Findings in order to support interpretations. During and after data analysis, I continued to explore literature on the theoretical underpinnings of qualitative research, phenomenology and IPA were explored to facilitate the interpretation of the data.</p>
<p>Commitment and rigour</p> <p><i>dedication to the in-depth analysis and subsequent interpretation of the data</i></p>	<p>Yardley's second principle is commitment and rigour. This principle is fulfilled through my dedication to the in-depth analysis and subsequent interpretation. However, this principle also refers to the care with which interviews were conducted. During the interviews, I did not take written notes as I wanted the participant to know that I was giving them my full attention. I feel that this lack of writing notes not only meant that I was able to attend to participant's words more closely but also contributed to the rapport between the participant and myself.</p> <p>I conducted all the interviews, listened to them various times, re-read them, in part and whole, various times. In this way, I demonstrated my commitment to the idiographic requirements of IPA. Rigour was demonstrated through the adaptation of the semi-structured interview schedule (Appendix I – Interview schedule) during interviews depending on the experiences and personality of the participant. This ensured that at the end of the interviews, I felt that I had a clear understandings of participant experiences.</p> <p>Rigour was also demonstrated through my decision about the sample characteristics (see Sensitivity to context, above). The small sample size permitted a depth of analysis that would not have been possible, given the time constraints of my PhD programme, if more participants were included in this thesis. IPA was able to detect these other aspects of life that other methodologies may not have as the interplay</p>



	<p>between SHW and other aspects of life was revealed through the intense focus on topics present in the women's accounts.</p> <p>The depth of analysis is shown in the Findings and Discussion chapters where descriptions and interpretations of accounts is clear and supported through verbatim extracts. To further enhance the rigour of this thesis, my supervisors consistently reviewed my data analysis and interpretations and provided feedback. I also devised a table to show which participants extracts corresponded to which super and sub-ordinate themes in order to ensure that I was reflecting the idiographic experience for each participant. In addition to verbatim extracts demonstrating a justification for interpretations, reflections that are presented throughout this thesis also shed light on the perspective that I have presented in this thesis.</p>
<p>Transparency and coherence</p> <p><i>coherence of data interpretation the clarity with which the research is presented</i></p>	<p>In describing, and providing evidence in the appendices, of the steps specific to thesis, readers can understand decisions made. These include the choice of research question, the design of the interview schedules, the selection of participants and the process of data analysis. Discrepancies in data that contradict patterns has also been included in Chapter Five – Findings which adds to the richness of the data and gives the researcher the opportunity to assess conclusions drawn from the analysis of the data.</p> <p>This thesis also presents transparency of methodology and the language used and interpretations included make it clearly identifiable as an IPA thesis. Thesis chapters have been drafted and re-drafted and reviewed by supervisors and postgraduate peers for clarity of written expression. Careful</p>

	<p>consideration has been given to which information is presented, in which format and where in order to enhance the coherence of the thesis.</p> <p>Reflexivity, presented in the thesis Preface and Chapter Eight – Strengths, limitations and reflexivity, support Yardley’s third principle; transparency and coherence. These elements demonstrate reasons for my interpretations through elucidating my position as the researcher and interpreter of accounts. In order to further enhance the transparency of this thesis overall, it has been written and organised manner that is easy to understand and with decisions around methods and methodology clearly justified and explained. This was important as while extensive guidance for undertaking IPA studies exists (Brocki &amp; Wearden 2006; Eatough &amp; Smith 2008; Smith 1996; Smith et al. 1999, 2009), the specific steps involved in this particular thesis have been explained in detail in the Chapter Four – Methods as the flexibility of IPA as a methodology means that each study follows a different process.</p>
<p>Impact and importance</p> <p><i>how important the research will be and who it will affect</i></p>	<p>The primary care context of the thesis means that its findings have significant implications for clinical practice. I propose that the thesis findings have the potential to improve the care of older women living with T2D through providing understandings of how older women living with T2D perceive their care.</p> <p>The ‘Contribution to knowledge’ has shown that this thesis has made an important contribution to the knowledge of SHW discussions between baby boomer women with T2D and their HCPs.</p>

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The practical and empirical implications of this research are discussed at length in Chapter Seven – Implications for primary care practice and research, demonstrating the transferability of the thesis findings.
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