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Sexual health discussions between health care professionals and midlife-older women living with Type 2 diabetes: an interpretative phenomenological study*

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ABSTRACT

Aim: To explore the barriers and facilitators to sexual discussions in primary care according to a sample of women aged 50 and older living with Type 2 diabetes.

Design: A qualitative, interpretative phenomenological analysis study.

Methods: Ten women aged 50-83 years living with Type 2 diabetes were interviewed between August 2016-March 2017. Data were analysed using interpretative phenomenological analysis.

Results: The participants reported changes to their sexual health and well-being, which they attributed to diabetes, menopause, ageing and changes within intimate relationships. Not all changes were considered problematic, but those that were, tended not to be discussed with healthcare professionals. The women assumed that the topic of sex was not broached by professionals due to embarrassment (both their own and that of the healthcare professional), ageism and social taboos around older women's sexual pleasure. The place that sexual health and well-being held in the women's lives also influenced primary care discussions.

Conclusion: These findings demonstrate that social taboos around gender, ageing and sex influenced the barriers to sexual health and well-being discussions in primary care. Facilitators to overcoming these barriers were professional-patient rapport, consulting with a female healthcare professional and instigation of the conversation by healthcare professionals.

Impact: Type 2 diabetes can have a negative impact on women's sexual health and well-being. Prior to this study, little evidence existed of the barriers that older women with Type 2 diabetes faced with regard to sexual health care. This study shows that midlife-older women with Type 2 diabetes can experience sexual health and well-being problems which are neglected within primary care. It also shows that women want their healthcare professionals to explore these

problems. Raising awareness and providing training for healthcare professionals may lead to better provision of sexual health support for midlife-older women with Type 2 diabetes.

Key words: diabetes, sexual health, sexual well-being, primary care, midlife-older women, qualitative, interpretative phenomenology

INTRODUCTION

There are approximately 3.8 million people living with Type 1 (T1D) and Type 2 diabetes (T2D) in the UK which is 9% of the adult population (Public Health England, 2016). Globally, this public health challenge is reflected in the number of people living with T2D 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, 2001). T2D accounts for around 90% of diabetes cases and tends to occur in adults over the age of 40 (Diabetes UK, 2020).

People living with diabetes are prone to macro and micro-vascular complications, having a impact on sexual function/pleasure, for example by causing decreased lubrication in women and erectile dysfunction in men (Copeland et al., 2012; Esposito et al., 2010; Lindau et al., 2007). Primary care healthcare professionals are often considered the first point of contact for non-urgent and chronic health concerns (WHO, 2011). Chronic health conditions, conditions which require ongoing management over a period of years, can have an impact on sexual health and well-being (SHW) (Pangman & Seguire, 2000; Verschuren et al., 2010). Research into SHW and chronic diseases is growing alongside the increasing prevalence of chronic diseases and the realisation that SHW is important for many midlife-older adults living with chronic diseases (Pontiroli, Cortelazzi, & Morabito, 2013; Verschuren et al., 2010). However, the sexually-related concerns of midlife-older adults often go unaddressed in primary care due to embarrassment and not knowing how to broach the topic (Taylor & Gosney, 2011).

There has been little research into midlife-older women's experiences of discussing their SHW needs in primary care settings. T2D is known to have an impact on the SHW of women living

with it, of whom most are aged 40 and older. Therefore, through knowledge of the barriers and facilitators to these conversations we can identify women's SHW needs and the implications for practice.

BACKGROUND

In recent years, there has been increasing recognition of the need to acknowledge the sexual rights of midlife-older adults (Hinchliff & Barrett, 2018). This acknowledgement is due to growing evidence that many midlife-older adults still participate in, or want to participate in, sexual activity (DeLamater, 2012; Gott, 2005; Gott & Hinchliff, 2003; Hinchliff & Gott, 2004; Lee et al., 2015). In this study, SHW is defined using the WHO definition of sexual health (WHO, 2006) in addition to Laumann's definition of sexual well-being as "...the perceived quality of an individual's sexuality, sexual life and sexual relationships" (p.146)

The literature suggests that embarrassment, lack of rapport and acceptance of sexual changes are barriers to SHW discussions between midlife-older patients and healthcare providers (Barrett & Hinchliff 2018; Rutte et al. 2016; Sinković & Towler, 2019). However, exploration of women's SHW on its own terms is essential for recognising gendered differences and to counterbalance the predominantly medicalised and androcentric focus in literature and society (Hinchliff 2014; Lindau & Gavrilova 2010). Sexual difficulties that may have an 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. The quote above, taken from a mixed-methods report published by Public Health England, summarised research intended to gain an understanding of women's experiences of their reproductive health and healthcare. Women aged over 55 years only represent approximately 8% of their sample. The lack of midlife-older women in their sample reflects the tendency in research to focus on SHW in

younger populations. This focus on young people in sexual health research also extends to wider society with social fixations on youth, particularly for women. To begin to address this imbalance in the literature, this study explored the experiences of women at midlife and older. Due to the broad age range, we use the term midlife-older women.

The changes in Western society that women over the age of 50 have lived through include the separation of sex from marriage, the relative ease of getting a divorce and second-wave feminism (Arber et al., 2003; Gott, 2006; Watters & Boyd, 2009). However, the social reality is that perceptions and judgement of midlife-older women's sexual behaviour remain relatively conservative compared with those relating to men and younger generations (Bristow, 2015; Giami & Hekma, 2014; Rowntree, 2014; Thorpe, Fileborn, & Hurd Clarke, 2018; Weeks, 2010; Woodsprings, 2016).

In addition to the social environment, physical changes that women living with T2D may experience also have an impact on SHW. Neuropathy, linked to diabetes, can lead to vaginal dryness, pain during or after sex and anorgasmia in women. (Baldassare, Alvisi, Berra, & Meriggiola, 2015; Copeland et al. 2010; Esposito et al., 2010; Lindau et al., 2007; Ogbera, Chinenye, Akinlade, Eregie, & Awobusuyi, 2009; Rockliffe-Fidler & Kiemle, 2003). Despite knowledge that these sexual changes can occur, sexual problems are one of the most under recognised complications in diabetes care (Verschuren et al., 2010). 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). The inclusion of discussions of sexual problems is encouraging but whether healthcare professionals incorporate this into practice remains unknown.

Currently, people living with T2D in the UK are invited to attend an annual review by a General Practitioner (GP) or practice nurse (NICE, 2015). Under National Institute for Health and Care Excellence (NICE) guidelines, during these appointments, patients receive advice regarding their diet and exercise patterns. Healthcare professionals also screen for and manage potential complications of diabetes (NICE, 2015). The annual review, along with additional appointments, suggests that healthcare professionals have frequent contact with patients providing opportunities for sexual discussion between midlife-older women with T2D and healthcare professionals. However, the extent to which the sexual issues of midlife-older women living with T2D are being addressed, remains unknown.

There is a lack of qualitative research on midlife-older women's sexual issues in the context of T2D. This study was conducted to address that gap. Given the barriers that both primary care nurses and GPs face when it comes to sexual health of midlife-older female patients (Hinchliff & Gott, 2011) and the lack of acknowledgement about T2D on sexual well-being, the findings are important for women's health and primary care practice.

THE STUDY

Aim

To explore the barriers and facilitators to sexual discussions between healthcare professionals and women aged 50 and older living with T2D.

Design

An interpretative phenomenological analysis (IPA) methodology was used. IPA was developed in the mid-1990's within the discipline of psychology (Smith, Jarman & Osborn 1999; Smith 1996). The exploratory, in-depth nature of an IPA approach, facilitates insight into and

comprehension of the lived experiences of participants (Willig 2008). IPA is increasingly used in health-related research, where there is an intrinsic focus on patient care, as researchers realise that it is a useful tool for challenging assumptions and the biomedicalisation of sex (Balls 2008; Clarke 2009; Smith 1996; Smith 2011; Tiefer 2007). IPA has been used in the field of SHW and specifically female SHW (Holt & Slade 2003; Lavie & Willig 2005; Sanders & Carter 2015). However, to the best of our knowledge it has not been applied to midlife-older women and SHW.

Participants

The sampling strategy included English speaking women aged 50+, with a diagnosis of T2D. The lead researcher recruited participants from Diabetes UK meetings, community organisations and through word of mouth in a city in the North of England. 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). Three additional women showed interest in the study and then later declined to participate due to “personal reasons”. The final sample consisted of ten women aged between 50 and 83 years with T2D (Table 1).

Data collection

In-depth, semi-structured individual interviews took place between August 2016 and March 2017, at the participant’s home or office at the University of Sheffield. Interviews lasted between 30 minutes and one hour 50 minutes. Of the ten participants, seven were interviewed in their homes, one at the University and two at their place of work. Giving the women a choice of where to be interviewed meant that the interview took place in a setting they considered convenient and felt comfortable talking about issues of a personal nature, as well as reducing the interviewer-interviewee power imbalance.

The semi-structured interview schedule (Supplementary file 1) allowed for flexibility and the phrasing of sensitive questions. It permitted the researcher to prompt when required and check that no areas of interest had been omitted (Eatough & Smith, 2008). The interview questions were developed from a scoping review of the literature (conducted as part of a PhD: see Ejegi-Memeh 2019 for further details). Questions focused on participants' definitions of SHW, the place of SHW in their lives, the impact of diabetes on their SHW and help-seeking for sexual issues. The lead author kept a reflexive diary, which has been used to develop the reflexive account included in Supplementary file 2.

Ethical considerations

Ethics approval was obtained from the University of Sheffield, where the authors work (approval number 008690). Potential participants were provided with an Information Sheet and Consent Form. Participants were made aware that even if they signed the Consent Form, 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, analysis would have begun, and their interview would contribute to findings. One copy of the signed Consent Form was kept by the participant and the other by the lead researcher (in a secure locker). Verbal consent was also audio-recorded before the interview commenced as further confirmation of voluntary participation (Smith et al., 2009). The interviews were transcribed and anonymized and kept in a password protected file. The recordings were erased after transcription.

Data analysis

To gain an in-depth understanding of the phenomenon under study, the analysis process followed Smith et al's (2009) seven steps approach (Table 2). This involved analysing each participant's account in-depth before moving onto the next. Each transcript was read at least twice, to

facilitate immersion in the data and help with exploratory coding. Exploratory coding involved noting descriptive, linguistic and conceptual aspects within the accounts. These codes helped to develop the emergent themes.

Connections across the emergent themes were searched for and themes grouped into subordinate themes and superordinate themes. This meant that each participant account was assigned discrete sub and superordinate themes. The process was repeated with each participant. Going through these steps in a systematic way was useful for providing a structure for the women's lived-experiences of SHW to come to the fore. An exploration of how themes connected across and between the participants was undertaken to develop overarching superordinate themes. The overarching superordinate themes brought together recurrent and related topics. Three superordinate themes were developed (Figure 1); two of which are discussed below.

Rigour

The first author SEM (PG Cert/MSc/BSc/RN), collected and analysed the data as part of their PhD. To ensure trustworthiness, credibility, transferability, dependability, confirmability and reflexivity were considered (Korstjens & Moser, 2018; Lincoln & Guba, 1985). Credibility checks were integrated throughout and the study adhered to Yardley's criteria for assessing the quality of qualitative research (Yardley, 2000). Iterative questioning and prolonged engagement through asking the participants several distinct questions related to their SHW discussions with healthcare professionals ensured the in-depth exploration of the topic with participants.

Transferability was achieved through 'thick' descriptions of data and context (see Findings and Table 1). Dependability was achieved through thorough descriptions of each methodological decision made during the research process. Confirmability was achieved through the inclusion of rich descriptions using data extracts in the Findings and reflexivity (see Supplementary File 2 –

Reflexive account). Furthermore, both co-authors (SH, MJ) analyzed the first interview so that comparisons about interpretations could be made. Further evidence of rigour is provided in the COREQ checklist (Tong, Sainsbury & Craig, 2007) (see Supplementary File 3).

FINDINGS

The superordinate themes discussed below are ‘Patient- healthcare professional relationship’ and ‘Sense of control over SHW and healthcare’. Each theme has subordinate themes, which describe the convergences and divergences within participant accounts.

Patient-healthcare professional relationship

The relationship that participants had with their healthcare professionals influenced their decision whether to discuss SHW and how comfortable they were in doing so. Particular aspects influenced whether and how SHW discussions took place in practice including (the subordinate themes) ‘Being listened to and having health conversations’ and, ‘healthcare professional characteristics’.

Being listened to and having health conversations

The participants’ willingness to discuss SHW was influenced by their previous consultation experiences with healthcare professionals. How professionals 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.

(Debra, 69 years)

The participants expressed a desire for healthcare professionals 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. Crucially, regarding SHW, some participants suggested that their healthcare professionals would not discuss SHW without being prompted. Indeed, a perception of professional reluctance to engage in SHW discussions was present, with some participants suggesting that healthcare professionals would expect patients to bring up SHW concerns:

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 three participants reported that they had engaged in conversations with their healthcare professionals about T2D and sexual changes. The remaining participants had not been asked about their SHW by healthcare professionals, demonstrating the infrequency with which conversations about sex took place in practice with midlife-older women with T2D. Most participants were unaware of a possible link between T2D and SHW, reflected 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 ... and it should have been really thinking about it.

(Isobel, age 83)

Healthcare professional characteristics

The participants' had preferences for discussing SHW with healthcare professionals who had certain characteristics, generally for discussing sexual issues with female healthcare professionals. There was diversity within the sample with some participants feeling more strongly than others about only seeing female healthcare professionals:

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)

Age also influenced SHW discussions in the form of perceived ageism. Some participants, particularly those in their 70s and 80s, assumed that healthcare professionals had not previously brought up SHW with them because they held ageist views:

... well, probably they just look at me and think "No, she's not having any [sex]".

(Isobel, age 83)

It was evident that assumptions about healthcare professionals' feelings about discussing SHW shaped the participants' willingness to discuss SHW. Some discomfort was linked to the perceived awkwardness of the healthcare professional around sexual discussions. Some participants assumed that, particularly their male healthcare professionals, would be uncomfortable discussing SHW and they did not want to cause this feeling. This was particularly salient in the accounts of participants who had known their healthcare professionals for a considerable amount of time and thus reflects the complexities around the patient-healthcare professional relationship:

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)

Sense of control over SHW and healthcare

The participants' sense of control, both in everyday life and during consultations with their primary care healthcare professionals, influenced their decisions around whether to initiate sexual discussions. These issues are discussed in the subordinate themes 'Adapting to SHW circumstances' and, 'Balancing pragmatism and embarrassment'.

Adapting to sexual health and well-being circumstances

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. This suggested fluidity of SHW across the life-course. It was within the context of their current lives that the women decided how, or whether, to embrace these changes. There was

recognition of the 'ebb and flow' of SHW circumstances throughout life, so even if SHW had not previously been considered a central feature in their lives, it could be at a later date:

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, 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 indicated that sexual desire disparities within intimate relationships could present a problem. None had ever discussed sexual desire with a healthcare professional. It was clear that there were occasions when their sexual desire within their intimate relationships was higher than their partners, when they were not sexually active or when other life events took priority over their sexual needs. In these instances, women satisfied their sexual desire by masturbating or dealt with the situation by deprioritising their SHW needs. However, the findings demonstrated that while many participants could recall times in their lives when their sexual desire had been high or low, often they were unconcerned which provides an additional explanation for why they did not seek professional:

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)

The participants often perceived a reduction in sexual activity as a common effect of ageing (but not did not link it with T2D). As in the case of sexual desire, the participants did not consider it distressing so long as their level of sexual desire and activity was appropriate within the context of their life and/or intimate relationship. Thus, help from professionals was not always required 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...our sex life isn't as active as it was when we were younger but just normal, you know what I mean, I don't feel I'm hard changed.

(Grace, age 63)

Balancing pragmatism and embarrassment

All participants discussed ways they self-managed their T2D, e.g. through dietary choices to manage their weight and this provided further evidence of their independent approach to health. This approach was evident in their frequent use of the phrase "I just get on with it", applied to changes such as vaginal dryness, which the women tolerated rather than sought professional help. Some participants expressed that professionals needed to bring up SHW as many patients, particularly midlife-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 issues had a negative impact on SHW for participants. Use of the words “*suffer*”, “*pain*” and “*agony*” made it clear that there were SHW problems that women tolerated rather than sought help for. Reasons the participants gave for these issues not having been treated included not wanting to take medication or healthcare professionals 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 healthcare professional had talked about vaginal bleeding:

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 an omission of discussion around Isobel’s vaginal dryness. It suggests that when professionals do not ask direct questions about specific SHW issues, patients may be reluctant to bring them up and so tolerate their SHW problems. Some participants linked this reluctance to gendered social expectations from their upbringing:

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)

Some of the older participants also lacked the language to discuss their sexual concerns. They struggled to use the words “*sex*”, “*vagina*” or “*vulva*”, instead using phrases such as “*down there*” or preferring to gesture to their genital area without using words at all. This demonstrates

how difficult it can be to broach these issues to their healthcare professionals, presenting another potential barrier to asking for help.

Not all sexual issues were tolerated however, with a pragmatic approach of the participants facilitating some discussions. The participants often based their decision of whether to bring up SHW issues on the perceived severity of the issue and treatment options that their professionals 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 severity of vaginal bleeding after sexual intercourse allowed her to overcome her embarrassment and raise the issue with her GP. Women in their 50s and 60s often discussed seeking professional help to manage menopausal symptoms. Seeking help for smear tests, fertility and sexually transmitted infections was considered essential to preserving good general health and so the women often overcame feelings of embarrassment to address these issues with professionals.

DISCUSSION

The findings demonstrate previously unexplored barriers and facilitators to SHW discussions between healthcare professionals and women with T2D. Aligning with a systematic review on the sexual health of midlife-older adults, the current study found that acceptance, lack of rapport and embarrassment were barriers to SHW discussions between midlife-older patients and healthcare providers (Sinković & Towler, 2019). However, the current study’s findings add to

the existing body of evidence through showing that midlife-older women's decision making around seeking help for SHW issues are more complex than previously thought. Linguistic, social and knowledge elements contributed to barriers and facilitators to SHW discussions between healthcare professionals and midlife-older women living with T2D.

A lack of language to broach the topic may present a barrier to sexual discussions in primary care. There is an ongoing societal silence surrounding the SHW of older women demonstrated in the lack of anatomically correct language that many women used to describe issues relating to their genital areas. This linguistic absence was linked to social taboos ingrained from childhood. Without the language to describe experiences, women's abilities to discuss SHW issues may be limited (Davidsen, 2013). This may present an issue for women in their 70s and 80s in particular. Many midlife-older women may not want to discuss their SHW but informing them of their sexual rights and providing opportunities for them to discuss their SHW is an essential aspect of care (Barrett & Hinchliff, 2018).

Weeks (2010) suggests that the social construction of sexuality has influenced the current generation of midlife-older women's approach to SHW. Historically, sexual activity has been firmly linked with reproduction and not pleasure or well-being (Gott, 2005; Hirst, 2013). Consequently, many heterosexual midlife-older women have grown up with a sense that discussion of their sexual pleasure is taboo. The findings show that the social environment where the women were brought up continues to influence their discussion in primary care around sexual pleasure and desire.

Gendered expectations may also intersect with women's awareness that there is a social expectation to be sexually inactive during midlife-older age (Hinchliff & Barrett, 2018; Woodsprings, 2016). This social expectation may lead to the feeling that it is inappropriate for

midlife-older women to have and want to discuss, SHW needs. Awareness of ageism may also lead to women to assume that issues around sexual desire and pleasure are inappropriate topics for consultations.

Many studies have highlighted embarrassment as a barrier to SHW discussions between midlife-older adults and healthcare professionals (Hinchliff & Gott, 2011; Rutte et al., 2016; Sinković & Towler, 2019). However, the current study shows that women may want to avoid, not only their own embarrassment, but that of their healthcare professionals and that this presents a barrier to SHW discussions. It suggests that if professionals were confident and unembarrassed around discussing SHW and that it was a standard part of care provision, that this could normalize these conversations and make it easier for midlife-older women to discuss these issues in practice.

The current study showed that women often attribute sexual changes to age or menopause rather than T2D and may mean that women do not discuss changes with their professionals. Other studies of women living with T2D report high rates of never having been asked about SHW by their healthcare professionals and being unaware of an association between sexual problems and T2D (Rutte et al., 2016). Therefore, this study highlights a disconnect between existing evidence of SHW issues being linked to T2D and the women's lack of awareness of T2D on women's SHW (Baldassare et al., 2015; Copeland et al. 2010; Esposito et al., 2010; Lindau et al., 2007; Ogbera et al., 2009; Rockliffe-Fidler & Kiemle, 2003). Increasing women's awareness around this aspect of T2D care may motivate some women to seek help for problematic SHW issues.

Limitations

The findings are based on a sample of 10 women living with T2D in one area of the UK. They are not intended to be generalizable beyond this setting; however, they may be transferable to other women of this age group. The sample was diverse in terms of age, ethnicity and gender of

intimate partner and we need to acknowledge the potential differences in responses from those aged in their 50s and 70/80s. However, future studies in this area should strive to include 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. Two women of South East Asian background agreed to participate but later declined. Future studies which aim to recruit an ethnically diverse sample should ensure their research strategies and study design are culturally-sensitive.

T2D can be a life-threatening condition for some. The women included in the sample were all in reasonably good health and none were living in institutions. The inclusion of women who were in poorer health may have illuminated differences in women's experiences of SHW discussions.

There was no participant checking of the findings but five knowledge exchange events were held. Events were attended by a range of stakeholders and provided an opportunity for attendees to feedback on the findings.

Implications for practice

The findings strongly indicate that the barriers to effective SHW care may be overcome by letting women know that it is a legitimate area of discussion for primary care consultations and that they won't be judged negatively. In this way, they are given permission to raise the topic. Additionally, once these conversations have been initiated, exploration may be required in more depth as the findings show that women may be comfortable bringing up an issue such as vaginal bleeding but less for issues linked to desire and pleasure. Awareness that some midlife-older women may perceive ageism and feel constrained by gender norms is important so let women know that they can discuss SHW if they wish but also offer a female healthcare professional if they would be more comfortable.

Finally, the availability of more information for patients to know of the potential impact of T2D and its medications on SHW may make it easier for them to identify issues which are linked to their T2D and to initiate conversations around these issues in the future.

CONCLUSION

Frequent primary care appointments mean that midlife-older women living with T2D in the UK have ample opportunity to address SHW issues. However, the findings show that this is not always happening in practice. The barriers identified in this study can be overcome by awareness raising for women living with T2D, education and training for healthcare professionals and permission giving approaches in primary care. As life-expectancy increases, along with diagnoses of T2D, the issues raised in this paper are important to address now.

Conflict of Interest statement

No conflict of interest has been declared by the authors.

References

- Arber, S., Davidson, K., & Ginn, J. (2003). *Gender and Ageing: Changing roles and relationships*. Open Univesity Press.
- Ashworth, P. (2008). Conceptual Foundations of Qualitative Psychology. In JA Smith (Ed.), *Qualitative Psychology: A practical guide to research methods* (2nd ed., pp. 4–25). SAGE Publications.
- Baldassarre, M., Alvisi, S., Berra, M., & Meriggiola, M. C. (2015). Changes in Vaginal Physiology of Menopausal Women with Type 2 Diabetes. *The Journal of Sexual Medicine*, *12*(6), 1346–1355. <https://doi.org/10.1111/jsm.12906>
- Balls, P. (2008). Phenomenology in nursing research: methodology, interviewing and transcribing. *Nursing Times*, *105*(32–33), 30–33.
- Borrell, K., & Karlsson, S. (2003). Reconceptualizing intimacy and ageing. In Sara Arber, K. Davidson, & J. Ginn (Eds.), *Gender and Ageing: Changing roles and relationships* (pp. 47–62). Open University Press.
- Bristow, J. (2015). *Baby Boomers and Generational Conflict*. Palgrave Macmillan.
- Brocki, J. M., & Wearden, A. J. (2006). A critical evaluation of the use of interpretative phenomenological analysis in health psychology. *Psychology & Health*, *21*(1), 87–108. <https://doi.org/10.1080/14768320500230185>
- Clarke, C. (2009). An introduction to interpretative phenomenological analysis: a useful approach for occupational therapy research. *The British Journal of Occupational Therapy*, *72*(1), 37–39.
- Copeland, K. L., Brown, J. S., Creasman, J. M., Van Den Eeden, S. K., Subak, L. L., Thom, D.

- H., Ferrara, A., & Huang, A. J. (2012). Diabetes mellitus and sexual function in middle-aged and older women. *Obstetrics and Gynecology*, *120*, 331.
- Davidson, A. S. (2013). Phenomenological Approaches in Psychology and Health Sciences. *Qualitative Research in Psychology*, *10*(3), 318–339.
<https://doi.org/10.1080/14780887.2011.608466>
- DeLamater, J. (2012). Sexual expression in later life: A review and synthesis. *Journal of Sex Research*, *49*(2–3), 125–141.
- DeLamater, J. D., & Sill, M. (2005). Sexual desire in later life. *Journal of Sex Research*, *42*(2), 138–149.
- Department of Health. (2001). *National Service Framework for Diabetes*. London: Department of Health. Department of Health.
- Diabetes UK. (2010). *Diabetes in the UK: Key statistics on diabetes*. Diabetes UK.
- Diabetes UK. (2020). *Diabetes Prevalence*. Diabetes UK. <http://www.diabetes.co.uk/diabetes-prevalence.html>
- Diabetes UK. (2016). *Your 15 healthcare essentials*. Diabetes UK.
<https://www.diabetes.org.uk/guide-to-diabetes/managing-your-diabetes/15-healthcare-essentials/what-are-the-15-healthcare-essentials>
- Duncan, B., Hart, G., Scoular, A., & Bigrigg, A. (2001). Qualitative analysis of psychosocial impact of diagnosis of Chlamydia trachomatis: implications for screening. *British Medical Journal*, *322*(7280), 195.
- Eatough, V., & Smith, J. (2008). Interpretative Phenomenological Analysis. In C. Willig & W. Stainton-Rogers (Eds.), *The SAGE Handbook of Qualitative Research in Psychology* (pp.

- 193–211). SAGE Publications. <http://eprints.bbk.ac.uk/16386/3/16386.pdf>
- Enzlin, P., Mathieu, C., Vanderschueren, D., & Demyttenaere, K. (1998). Diabetes mellitus and female sexuality: a review of 25 years' research. *Diabetic Medicine*, *15*(10), 809–815.
- Enzlin, P., Rosen, R., Wiegel, M., Brown, J., Wessells, H., Gatcomb, P., Rutledge, B., Chan, K.-L., & Cleary, P. A. (2009). Sexual Dysfunction in Women With Type 1 Diabetes Long-term findings from the DCCT/EDIC study cohort. *Diabetes Care*, *32*(5), 780–785.
- Esposito, K., Maiorino, M. I., Bellastella, G., Giugliano, F., Romano, M., & Giugliano, D. (2010). Determinants of female sexual dysfunction in type 2 diabetes. *International Journal of Impotence Research*, *22*(3), 179–184.
https://www.researchgate.net/profile/Maria_Maiorino/publication/43073985_Determinants_of_female_sexual_dysfunction_in_type_2_diabetes/links/5834241b08ae102f073809c1.pdf
- Flick, U., von Kardorff, E., & Steinke, I. (2004). What is Qualitative Research? An Introduction to the Field. In U. Flick, E. von Kardorff, & I. Steinke (Eds.), *A companion to qualitative research*. SAGE Publications.
- Free, C., Ogden, J., & Lee, R. (2005). Young women's contraception use as a contextual and dynamic behaviour: A qualitative study. *Psychology & Health*, *20*(5), 673–690.
- Gaveras, E. M., Kristiansen, M., Worth, A., Irshad, T., & Sheikh, A. (2014). Social support for South Asian Muslim parents with life-limiting illness living in Scotland: a multiperspective qualitative study. *BMJ Open*, *4*(2), e004252.
- Giami, A., & Hekma, G. (2014). Sexual Revolutions: An Introduction. In *Sexual Revolutions* (Macmillan, pp. 1–24). <https://doi.org/10.1057/9781137321466>
- Giraldi, A., & Kristensen, E. (2010). Sexual dysfunction in women with diabetes mellitus.

Journal of Sex Research, 47(2–3), 199–211.

Gott, M. (2005). Sexuality, Sexual Health and Ageing. In *Rethinking ageing*. Open University Press.

Gott, M, & Hinchliff, S. (2003a). Barriers to seeking treatment for sexual problems in primary care: a qualitative study with older people. *Family Practice*, 20(6), 690–695.

<https://doi.org/10.1093/fampra/cm612>

Gott, M, & Hinchliff, S. (2003b). How important is sex in later life? The views of older people. *Social Science & Medicine*, 56(8), 1617–1628.

Gott, M, Hinchliff, S., & Galena, E. (2004). General practitioner attitudes to discussing sexual health issues with older people. *Social Science & Medicine*, 58(11), 2093–2103.

Gott, Merryn. (2006). Sexual health and the new ageing. *Age and Ageing*, 35(2), 106–107.

<https://doi.org/10.1093/ageing/afj050>

Hinchliff, S, & Barrett, C. (2018). Introduction to the Sexual Rights of Older People. In C. Barrett & S. Hinchliff (Eds.), *Addressing the sexual rights of older people* (pp. 1–13).

Routledge, London.

Hinchliff, Sharron. (2014). Sexing Up the Midlife Woman. In I. Whelehan & J. Gwynne (Eds.), *Ageing, Popular Culture and Contemporary Feminism* (pp. 63–77). Palgrave Macmillan.

Hinchliff, Sharron, & Gott, M. (2004). Perceptions of well-being in sexual ill health: what role does age play? *Journal of Health Psychology*, 9(5), 649–660.

Hinchliff, Sharron, & Gott, M. (2011). Seeking Medical Help for Sexual Concerns in Mid- and Later Life: A Review of the Literature. *The Journal of Sex Research*, 48(2–3), 106–117.

<https://doi.org/10.1080/00224499.2010.548610>

- Hirst, J. (2013). Sex Education Sexuality, Society and Learning “It’s got to be about enjoying yourself”: young people, sexual pleasure and sex and relationships education. *Sex Education, 13*(4), 423–436. <https://doi.org/10.1080/14681811.2012.747433>
- Holt, R. E., & Slade, P. (2003). Living with an incomplete vagina and womb: an interpretative phenomenological analysis of the experience of vaginal agenesis. *Psychology, Health & Medicine, 8*(1), 19–33.
- Korstjens, I., & Moser, A. (2018). European Journal of General Practice Series: Practical guidance to qualitative research. Part 4: Trustworthiness and publishing. *European Journal of General Practice, 24*(1), 120–124. <https://doi.org/10.1080/13814788.2017.1375092>
- Kralik, D., Koch, T., & Telford, K. (2001). Constructions of sexuality for midlife women living with chronic illness. *Journal of Advanced Nursing, 35*(2), 180–187.
- Lavie, M., & Willig, C. (2005). “I Don’t feel like melting butter”: An interpretative phenomenological analysis of the experience of inorgasmia. *Psychology & Health, 20*(1), 115–128.
- Lee, D. M., Nazroo, J., O’Connor, D. B., Blake, M., & Pendleton, N. (2015). Sexual Health and Well-being Among Older Men and Women in England: Findings from the English Longitudinal Study of Ageing. *Archives of Sexual Behavior, 45*(1), 133–144.
- Lindau, S. T., & Gavrilova, N. (2010). Sex, health and years of sexually active life gained due to good health: evidence from two US population based cross sectional surveys of ageing. *British Medical Journal, 340*, c810. <https://doi.org/10.1136/bmj.c810>
- Lindau, S. T., Schumm, L. P., Laumann, E. O., Levinson, W., O’Muircheartaigh, C. A., & Waite, L. J. (2007). A study of sexuality and health among older adults in the United States.

New England Journal of Medicine, 357(8), 762–774.

Mahieu, L., Van Elssen, K., & Gastmans, C. (2011). Nurses' perceptions of sexuality in institutionalized elderly: a literature review. *International Journal of Nursing Studies*, 48(9), 1140–1154.

NCD Risk Factor Collaboration. (2016). Worldwide trends in diabetes since 1980: A pooled analysis of 751 population-based studies with 4.4 million participants. *Lancet*, S0140-6736(16), 618.

NICE. (2015). *Type 2 diabetes in adults: management: What your diabetes care team will do*. NICE. <https://www.nice.org.uk/guidance/ng28/ifp/chapter/What-your-diabetes-care-team-will-do>

Nolte, E., & McKee, M. (2008). *Caring for people with chronic conditions: A health system perspective*. Open University Press.

Nowosielski, K., Drosdzol, A., Sipiński, A., Kowalczyk, R., & Skrzypulec, V. (2010). Diabetes mellitus and sexuality - Does it really matter? *The Journal of Sexual Medicine*, 7(2pt1), 723–735.

Ogbera, A. O., Chinenye, S., Akinlade, A., Eregie, A., & Awobusuyi, J. (2009). Frequency and correlates of sexual dysfunction in women with diabetes mellitus. *The Journal of Sexual Medicine*, 6(12), 3401–3406.

Pangman, V. C., & Seguire, M. (2000). Sexuality and the chronically ill older adult: A social justice issue. *Sexuality and Disability*, 18(1), 49–59.

Phillipson, C., Leach, R., Money, A., & Biggs, S. (2008). Social and cultural constructions of ageing: The case of the baby boomers. *Sociological Research Online*, 13(3).

<https://doi.org/https://doi.org/10.5153/sro.1695>

Pontiroli, A. E., Cortelazzi, D., & Morabito, A. (2013). Female sexual dysfunction and diabetes:

A systematic review and meta-analysis. *Journal of Sexual Medicine*, *10*(4), 1044–1051.

<https://doi.org/10.1111/jsm.12065>

Public Health England. (2016). *3.8 million people in England now have diabetes - GOV.UK.*

<https://www.gov.uk/government/news/38-million-people-in-england-now-have-diabetes>

Public Health England. (2018). *What do women say? Reproductive health is a public health issue.*

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/731891/What_do_women_say_reproductive_health_is_a_public_health_issue.pdf

Ravanipour, M., Gharibi, T., & Gharibi, T. (2013). Elderly women's views about sexual desire during old age: A qualitative study. *Sexuality and Disability*.

<https://doi.org/10.1007/s11195-013-9295-7>

Rockliffe-Fidler, C., & Kiemle, G. (2003). Sexual function in diabetic women: A psychological perspective. *Sexual and Relationship Therapy*, *18*(2), 143–159.

Rowntree, M. R. (2014). “Comfortable in my own skin”: A new form of sexual freedom for ageing baby boomers. *Journal of Aging Studies*, *31*, 150–158.

<https://doi.org/10.1016/j.jaging.2014.09.006>

Rutte, A., Welschen, L. M., van Splunter, M. M., Schalkwijk, A., De Vries, L., Snoek, F., Enzlin, P., Nijpels, G., Elders, P., & Petra, J. M. (2016). Type 2 Diabetes Patients' Needs and Preferences for Care Concerning Sexual Problems: A Cross-Sectional Survey and Qualitative Interviews. *Journal of Sex & Marital Therapy*, *42*(4), 324–337.

<https://doi.org/10.1080/0092623X.2015.1033578>

Sanders, C., & Carter, B. (2015). A qualitative study of communication between young women with disorders of sex development and health professionals. *Advances in Nursing*.

<https://doi.org/http://dx.doi.org/10.1155/2015/653624>

Sarkadi, A., & Rosenqvist, U. (2001). Contradictions in the medical encounter: Female sexual dysfunction in primary care contacts. *Family Practice*, 18(2), 161–166.

Sinković, M., & Towler, L. (2019). Sexual Aging: A Systematic Review of Qualitative Research on the Sexuality and Sexual Health of Older Adults. *Qualitative Health Research*, 29(9),

1239–1254. <https://doi.org/10.1177/1049732318819834>

Smith, J, Jarman, M., & Osborn, M. (1999). Doing Interpretative Phenomenological Analysis. In M. Murray & K. Chamberlain (Eds.), *Qualitative Health Psychology*. SAGE Publications.

Smith, JA. (2011). Evaluating the contribution of interpretative phenomenological analysis.

Health Psychology Review, 5(1), 9–27. [https://www-tandfonline-](https://www-tandfonline-com.sheffield.idm.oclc.org/doi/pdf/10.1080/17437199.2010.510659?needAccess=true)

[com.sheffield.idm.oclc.org/doi/pdf/10.1080/17437199.2010.510659?needAccess=true](https://www-tandfonline-com.sheffield.idm.oclc.org/doi/pdf/10.1080/17437199.2010.510659?needAccess=true)

Smith, Jonathan., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. SAGE Publications.

Smith, Jonathan. (1996). Beyond the divide between cognition and discourse: Using

interpretative phenomenological analysis in health psychology. *Psychology and Health*,

11(2), 261–271.

Taylor, A., & Gosney, M. A. (2011). Sexuality in older age: Essential considerations for healthcare professionals. *Age and Ageing*, 40(5), 538–543.

<https://doi.org/10.1093/ageing/afr049>

- Thorpe, R., Fileborn, B., & Hurd Clarke, L. (2018). Framing the sexual rights of older heterosexual women. In Catherine Barrett & S. Hinchliff (Eds.), *Addressing the Sexual Rights of Older People* (pp. 29–41). Routledge, London.
- Tiefer, L. (1995). *Sex is not a natural act and other essays*. Westview Press.
- Tiefer, L. (2007). Beneath the veneer: The troubled past and future of sexual medicine. *Journal of Sex & Marital Therapy*, 33(5), 473–477.
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International journal for quality in health care*, 19(6), 349-357.
- Tuffour, I. (2017). A Critical Overview of Interpretative Phenomenological Analysis: A Contemporary Qualitative Research Approach. *Journal of Healthcare Communications*, 02(04). <https://doi.org/10.4172/2472-1654.100093>
- Verschuren, J. E. a J., Enzlin, P., Dijkstra, P. U. P., Geertzen, J. H. B., & Dekker, R. (2010). Chronic disease and sexuality: A generic conceptual framework. *Journal of Sex Research*, 47(2), 153–170.
- Watters, Y., & Boyd, T. V. (2009). Sexuality in later life: opportunity for reflections for healthcare providers. *Sexual and Relationship Therapy*, 24(3–4), 307–315.
<https://doi.org/10.1080/14681990903398047>
- WHO. (2011). *Sexual and reproductive health: Core competencies in primary care*. WHO.
www.who.int/reproductivehealth
- Willig, C. (2008). Phenomenological methods. In C. Willig (Ed.), *Introducing qualitative research in psychology: Adventures in theory and method* (2nd ed., pp. 39–53). McGraw

Hill Open University Press.

Woodsprings, N. (2016). *Baby boomers: Time and ageing bodies*. Policy Press.

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health*, 15(2), 215–228.