

ORIGINAL ARTICLE

Sexual dysfunction, an invisible complication of diabetes – an exploratory study of the experiences of premenopausal women with Type 1 diabetes

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Abstract

Background: Survey data suggest that women with Type 1 diabetes mellitus have a higher prevalence of sexual dysfunction (SD) compared with women with Type 2 diabetes or without diabetes. However, little is known about how women with Type 1 diabetes experience SD or its impact on their lives. This exploratory study sought to elicit women with Type 1 diabetes's experiences of SD and identify their ideas on how SD could be better addressed in diabetes care.

Method: A qualitative study using semi-structured interviews was conducted at a diabetes centre in South West of England hospital. A purposeful sample of six women with Type 1 diabetes (<50 years of age) and experience of SD were interviewed. The interviews lasted 20–30 min and were analysed using Interpretive Phenomenological Analysis.

Findings: The study identified four superordinate themes: barriers to sex, impact of SD, personal support and ideas for improving support with SD. The majority of the themes were underpinned by diabetes specific factor such as hypoglycaemia, body image and diabetes management (technology and glucose regulation). This study found that women's perspectives on their sexual identities and behaviours were mediated by emotional and interpersonal issues. This study also highlighted the lack of support provided by healthcare professionals (HCPs) in addressing SD.

Conclusion: The findings indicate that SD is a complex issue that needs to be given more attention by HCPs, so that the women can approach sex positively in their lives. HCPs need to be enabled to initiate conversations around SD in their consultations.

Keywords: *Type 1 diabetes; sexual dysfunction; psychological health; qualitative research*

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Type 1 diabetes mellitus is associated with multiple potential complications, including microvascular (retinopathy, neuropathy and nephropathy) and macrovascular (cardiovascular disease, peripheral vascular disease and stroke) complications and psychological morbidities.¹ An additional and somewhat understudied complication of diabetes is sexual dysfunction (SD). The limited available studies report greater prevalence of SD in women with Type 1 diabetes compared with women with Type 2 diabetes and women without diabetes.^{2–4} The majority of these studies have been epidemiological studies based on questionnaire surveys. Hence, limited evidence is available about the lived experiences of SD and its effect on the quality of life of women with Type 1 diabetes.

Whilst there are no standard diagnostic criteria for SD,³ it is generally defined in terms of deficits in sexual

desire, arousal and the ability to orgasm.^{4,5} It has also been suggested that SD involves psychological and socio-cultural processes.⁶ Hence, SD is a complex and multifaceted problem, and its aetiology in women with Type 1 diabetes incorporates both biological and psychosocial factors. Changes in structures within the genitourinary system due to vascular and neuropathic damage may lead to decreased hydration of the vaginal membrane causing dyspareunia and impede sexual response and arousal.^{7,8} It has also been identified that psychological factors, diabetes medications and comorbidities may exacerbate SD in women with Type 1 diabetes.⁹ Women affected by Type 1 diabetes are mainly young women who are relatively free of age-related complications, and therefore, SD could have a major impact on their quality of life with the reoccurrence of sexual disappointment and emotional discomfort. In terms of the impact of SD,

associations with diminished quality of life and relationships as well as increased levels of depression and anxiety have been reported in women with Type 1 diabetes experiencing SD.^{1,2}

However, despite the high prevalence and negative sequelae of SD in women, it is largely a hidden problem associated with social embarrassment that is often unaddressed by healthcare professionals (HCPs).⁶ The lack of recognition given to SD in women with Type 1 diabetes may also be related to the fact that very little is known about how it impacts on the lives of women. Male SD, in contrast, particularly erectile dysfunction, is a more commonly recognised issue. Hence, it is important that we develop a fuller understanding of SD in women with Type 1 diabetes, so it can be considered in diabetes consultations. This study aimed to explore the lived experience of SD in women with Type 1 diabetes and its impact on their lives, and to elicit suggestions from them as to how they could be better supported by HCPs in addressing this aspect of their lives. It is hoped that the outcomes of the research will provide a platform for further inquiry in this field, which has not been extensively studied.

Methods

This study used Interpretive Phenomenological Analysis (IPA) approach to explore the psychological and emotional elements of women’s experience of SD and Type 1 diabetes. The ideographic element of IPA enables an in-depth exploration of each individual’s experience and understanding of the phenomena of interest. This study addressed the following research questions:

- How do women with Type 1 diabetes experience SD?
- What do women with Type 1 diabetes feel would improve the care they receive in relation to SD from their diabetes team?

Participants and setting

The participants were purposively sampled from women with Type 1 diabetes attending the diabetes centre of a hospital in South West England, from the beginning to the end of March 2020. Following the IPA approach, women were purposively identified to include cases, which are rich in information and have experienced the relevant phenomenon (SD). The women were identified based on the inclusion and exclusion criteria outlined in table 1.^{10,11}

IPA methodology requires a sample of 6–10 participants; homogenous to the phenomena of interest is required.¹² In this case, the sample was selected from women with Type 1 diabetes who identifies as having SD. A sample of six women was identified to enable an in-depth exploration of the women’s experiences with sufficient informational power for the analysis. To ensure sample homogeneity, the women were identified using a short screening questionnaire, as follows:

- Do you experience any anxiety or difficulties in having an intimate relationship with your sexual partner?
- Do you find it difficult to enjoy sexual relationships?
- Do you find intercourse unpleasant or uncomfortable in any way?

Data collection

In-depth semi-structured interviews were undertaken following an interview topic guide (Table 2) with further probing and exploration to expand the generated understanding of the study phenomena. The interview guide was developed based on existing literature. The interviews were conducted in a quiet room within the hospital and were audio recorded using two digital, password-protected voice recorders. A total of six interviews were carried out with six participants. Five interviews were conducted face-to-face, whilst the last interview was conducted over the phone due to COVID-19 lockdown measures.

Data analysis

Data were analysed according to the six steps of IPA identified by Smith et al.¹² (see Fig. 1).

Following this process, each interview was analysed independently by one researcher (RH) with themes subsequently checked by a second researcher (AF). Each interview was coded using three commentaries: descriptive commentary (what is said); linguistic commentary (tone and expression) and conceptual commentary (the significance of what is said). These codes were used to generate themes, first for each participant and then integrated across participants to generate superordinate themes following the concept of ideography in IPA. The analysis was performed using the NVivo 12 software.

The audiotaped data were precisely transcribed by the researcher who listened to and transcribed it twice. The researcher read and reread the transcripts to ensure that the analysis of data produces an accurate report of what the participants have said in the interview. Dependability was enhanced by asking a nursing colleague to assess the transcribed data and taking their recommendations into consideration.

Table 1. Inclusion and exclusion criteria

The inclusion criteria	The exclusion criteria
Type 1 diabetes mellitus for more than 1 year	Age <18 years
Aged 18–50 years	Age >50 years to avoid conflation with menopausal symptoms
Have a sexual partner	Have no sexual partner
Able to communicate verbally and in writing in English	Unable to communicate in English
Able to provide an informed consent	Unable to provide an informed consent

Table 2. Interview topic guide

Main questions	Additional questions	Clarifying questions
1: Can you tell me about your experiences of intimate relationships with others?	Did you have any problems? Do you have a long-term partner?	Do you consider your relationship to be normal? Can you tell me a bit more?
2: Can you tell me about any difficulties you have experienced in your sex life since you were diagnosed with diabetes?	Is it difficult to keep your BG levels under control on sex days? Do you have fear of hypos?	Do you have a BG target in sex days? If yes, is it something you recommend? Why? If not, do you think you need to? Why?
3: In which way do you think that diabetes has impacted on the quality of your sex life?	Were you more reluctant to meet a new partner?	Do you know about SD as a complication of diabetes? Have you ever discussed SD with your partner?
4: What is the effect of the problem on your relationship with your partner?	If you had diabetes later in life, do you experience SD more since you were diagnosed with diabetes?	Do you see SD as a problem in your personal life? If yes Does it cause you to be distressed? Can you tell me about any previous experience?
5: What type of support did you have from your healthcare professionals?	Have ever thought about raising the issue of SD in your follow-up appointments?	If yes, what factors prevents you from raising the issue? If not, is it because you do not see it as a problem?
6: In your opinion, how should a problem of this kind be addressed in clinical care?	Would you rather your healthcare professionals discussed SD in your follow-up appointments? Why? Or would you prefer that this is left for you to raise if concerned?	Do you have any suggestion? Do you find the subject embarrassing?

BG, blood glucose; SD, sexual dysfunction.

Ethical approval was granted by the South West England NHS ethics committee (REC ref: 20/SW/0005).

Findings

A total of six women were recruited and interviewed during March 2020. They had a median age of 33 (range 30–47 years), they were all non-smokers, and had male partners. The women were given pseudonyms to maintain their confidentiality, and their details are summarised in Table 3.

In total four superordinate, themes were generated in the analysis, and these are summarised in Table 4 and described in detail below, together with the related sub-themes and data excerpts.

Barriers to sex

Throughout the interviews, the women talked about issues that were described as barriers to sexual activities. These issues formed interrelated subthemes, some of which were related to diabetes with others being more general, as detailed below.

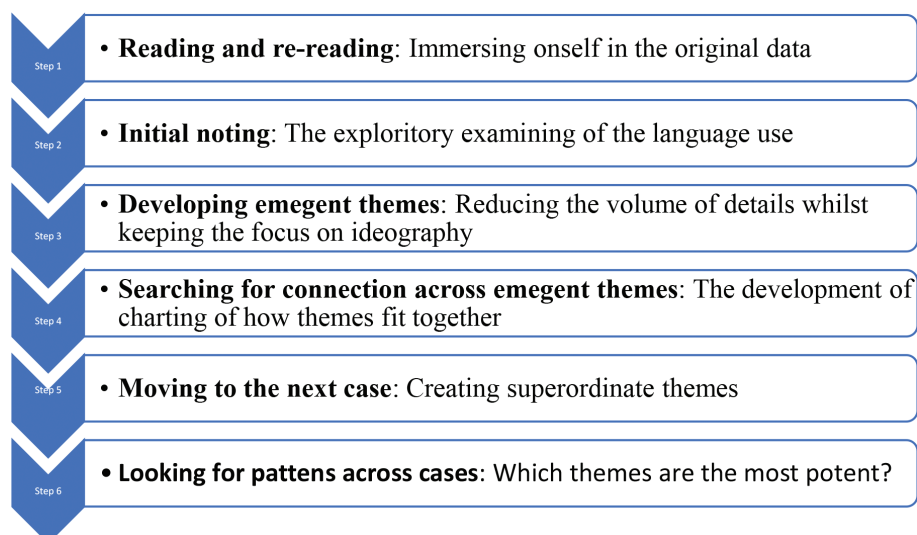


Fig. 1. Interpretive phenomenological analysis steps for data analysis.

Table 3. Patient characteristics

Name	Samantha	Andrea	Beckie	Melanie	Sharon	Jasmine
Age (years)	36	30	47	30	32	34
Age at diagnosis (years)	3	4	30	19	22	2.5
Duration of relationship (years)	14	6	4	6	7.5	12
Number of children	1 (adopted)	N/A	N/A	N/A	N/A	3
Use of contraception	Condom	Birth control pill	Birth control pill	Birth control pill	Pregnancy planning	Coil
Type of insulin	Basal bolus	Insulin pump	Basal bolus	Basal bolus	Basal bolus	Basal bolus
Last recorded HbA1c (mmol)	71	69	52	68	59	80
Marital status	Married	Married	In a relationship	Married	Married	Married
Weight (kg)	64	85.7	104.9	86	105.2	80.7
History of depression, Y/N	N	Y	Y	N	N	N

Table 4. Final themes

Superordinate themes	Sub-themes
Barriers to sex	Sexual drive Diabetes-related body image issues Hypoglycaemia Glucose regulation Age Depression
Impact of SD	Guilt Relationship with partner
Personal support	Partner support HCPs support
Ideas for improving support with SD	Informational support Integrating SD into clinical care

SD, sexual dysfunction; HCP, healthcare professionals.

Sexual drive. A lack of interest in sex and a reduced libido were commonly identified by the women. Beckie (aged 47, Type 1 diabetes for 17 years) reflects on her experience.

Its lack of interest, my body doesn't respond so my boyfriend will try to be intimate, my body shows no interest which can be difficult.

Some of the women questioned the reasons for the lack of sexual desire. Sharon (aged 32, Type 1 diabetes for 10 years) explains:

My libido has gone down as well, although it is hard to tell if it is related to diabetes.... I remember my previous relationship before I was diabetic it was very much me wanting sex.

Samantha (aged 36, Type 1 diabetes for 33 years) believed that reduced libido could be related to hormonal issues.

I thought it maybe hormonal, I know that my hormones impact on my diabetes...I don't know... I think I just have got a barrier up... I don't know whether it is diabetes related but certainly as I got older, I don't feel the same.

she speculated whether this could be related to lifestyle issues

...Again I put that to lifestyle. Me working in the evenings, he's working late, that's quite difficult and also having a 9 year old child.

The effect of lifestyle and tiredness was described by Melanie who recalls how tiredness affects her sex drive

I don't have a high sex drive really... I am probably not the best wife maybe because I get so tired sometimes, I just want to go to sleep.

Diabetes-related body image issues. Body image was identified as a barrier to enjoying sexual activities by some of the women. These issues related to visible diabetes technologies (pumps and sensors) and visible diabetes-related tissue changes (lipohypertrophy). Melanie (aged 30, Type 1 diabetes for 11 years) describes how having a continuous blood glucose monitoring sensor attached to her arm impacts her self-esteem and makes her feel less attractive.

I look at my body and think, who on earth would find this attractive? ... I have the libre on and I get embarrassed.... I don't want to wear it...

Visible tissue changes at injection sites can affect the women's body image negatively.

It affects me that people see the injection sites on my stomach..., I just hate my body at the moment, that really affects it (SD). Sharon (aged 32, Type 1 diabetes for 10 years)

Hypoglycaemia. The women described how they regulated their sexual behaviour in relation to potential hypoglycaemia by avoiding sex and that the fear of hypoglycaemia impacted on their ability to enjoy it.

I am perhaps more cautious if I know my levels have been low and perhaps, less willing to have sex if my blood levels are low. Samantha

Some women felt that hypoglycaemia can spoil the experience.

I have had a couple of episodes where I had hypos during sex, completely ruin the moment (laughs).
Melanie

Glucose regulation. Another subtheme that emerged from the interviews related to the women's concern of how sex might impact on their glucose levels, making it difficult to have a satisfying sexual experience. Beckie recalls:

...Because I am more in tune now with my diabetes than I've ever been I think it is even more so on my mind, the consequences of being intimate.....you then get scared of losing this control and whether that sexual intimacy forms part of that control.

Age. Although the ages of the participants were relatively young, the issues around reduced sexual function were repeatedly linked to age. Beckie (aged 47) recalls:

I think as I got older it became different.... When I was married and younger, life was easier... I think sex life wasn't really a problem.

Samantha (aged 36) reflects on her previous experiences, which makes her question whether her age has impacted her sexual desire negatively. She says:

Because I know what I used to be like when I was 18–25 years old, it is very different now.

She goes onto acknowledge that she is not old, implying that age is not the only reason

.....I don't know if it is related to age although I am not old.

Depression. For some women, their mood and the use of anti-depressant impacted on their sexual desire. Andrea states:

I'm on citalopram which could have something to do with it.....that's probably got a lot to do with it because I've been on them for so long, longer than our relationship, but I don't think that's the full reason behind it.

Impact of SD

The women's accounts show that the experience of SD had an emotional impact with feelings of guilt and a negative effect on their relationships.

Guilt. The women expressed feelings of guilt associated with their inability to engage intimately with their partners. Sharon (aged 32) refers to the pressure it puts her under to maintain an adequate relationship with her husband:

I think it is just a lot of pressure on our relationship at the moment...If I don't want to, it makes him feel upset.

Guilt was also associated with a sense of failure and frustration at not being able to have a normal sex life. Melanie (Aged 30) reflects:

...in a way perhaps, I should be more willing, sometimes I get frustrated with myself....

Relationship with partner. The women describe the impact of SD on their relationships with their partners and how it can create tension. Beckie (duration of relationship 4 years) says:

...I think there is a constant issue because as much as you can cuddle somebody, hold hands and kiss them, ultimately there is a fully grown male who wants more than friendship, it does affect us hugely.

On the other hand, having an understanding partner can help reducing the effect of the problem. Samantha (duration of relationship 14 years) recalls:

....I think overall it does affect our relationship but I wouldn't say enough to push to a breaking point. We can talk about it

Personal support

The women identified that having the opportunity to discuss sexual issues in a supportive environment was important in how they managed difficulties with intimacy. The two main sources of support identified by the women were their partners and HCPs.

Partner support. The women reflected on the role of the support they get from their partners in comforting and helping them to manage the problem. Samantha (duration of relationship 14 years), who clearly appreciates her husband's support, says:

.... we know each other really well and I can talk to him about things and he can talk to mehe will listen to me if things aren't comfortable then that's fine. I do have a good relationship.

Melanie (duration of relationship 6 years) shares this view and values her partner's understanding

.....Because he is so good to me then when I perhaps don't want to then I feel awful, it is like I've rejected him but he never gets upset, never queries it, he understands.

Becky compares her experiences with her previous and current partners. She feels the lack of support can negatively affect the women's sexual desire. She reflects:

...My ex-husband was quite good maybe that's why there were no issues but if you had no real support or anyone to talk to.... and especially if your partner shows no real support then it is a huge problem.... He finds it difficult to have conversation about sex which doesn't help whereas I would talk about anything.

HCPs support. The women expressed mixed experiences in the support they received from their HCPs and their

confidence or willingness to seek support. Melanie felt supported by her team and able to raise her concerns, but she prefers discussing issues around SD with a familiar HCP:

I haven't seen my GP (General Practitioner) for a long time I see my diabetes nurse at the surgery, and the sexual health nurse, I would rather speak to them rather than my GP.

Becky felt her GP would not be able to help her with sexual issues. She says:

If I went to my GP and had that conversation would they have any information about SD in Type 1 diabetes in women? no, they would probably put it down to my age or hormones or something.

Ideas for improving support with SD

Overall, the women felt that there was a need for more information and awareness of SD as an issue for women with Type 1 diabetes. They also identified that there should be more opportunities for women to discuss SD in clinical care.

Informational support. The women suggested that having literature on SD for women with Type 1 diabetes in the form of leaflet or a website would help in raising awareness of the issue and encourage the women to seek help. Melanie believes having the right information would have enabled her to be more aware of her status, she says,

.... I feel like people should be made aware of it first because until today, I've never thought about it

Beckie realises that the lack of knowledge of SD was exasperated by the lack of literature, she states

Literature should be made for women like for men because there is not anything out there.

Integrating SD into clinical care. The women believe that HCPs could help raise awareness of SD by asking the patients about their sexual function as part of their routine diabetes care. When asked about her views on how the problem should be addressed, Samantha believes HCPs should ask the question. She says,

...I think asking the question helps. I never would've thought that my diabetes would have a link to sexual issues I don't know if it does.

This view was shared by Melanie who said,

I think it would be important that it was raised by yourselves because a lot of people are nervous to speak about anything sexual.

Discussion

This study highlighted that SD is a significant problem, which is generally not attended to by HCPs. Approaching the issue of SD by utilising a qualitative method has allowed

the women to voice their concerns and give ideas on how to address the issue of SD in clinical settings. This study showed that the women experienced a range of barriers to have a fulfilling sexual relationship with their partners. Some of these barriers were diabetes specific (hypoglycaemia, diabetes technology, body image and glucose regulation), and whilst others were more generic (age and loss of sex drive), the women often related these to diabetes. Previous studies have also identified that diabetes specific issues can mediate sexual behaviour. Santos et al.¹⁴ identified that managing hypoglycaemia had a negative impact on women's enjoyment of sexual intercourse. Whilst previous studies have highlighted how body image can impact on women with Type 1 diabetes's sexual behaviour, this has been in relation to an increased BMI,¹⁵ which is also a common issue in women without diabetes.¹⁶ This study has revealed that in addition to the general issues women may have about their bodies, visible diabetes technology (pumps and sensors) and lipohypertrophic tissue changes can also be a factor. Similar findings were reported in a survey study by Robertson et al.,¹⁷ which looked at the impact of wearable technologies on sexual activity in people with Type 1 diabetes. Their survey of 285 people with Type 1 diabetes (53% were women) found that wearable technologies impacted on sexual activity with women having to make behavioural adjustments to compensate for their technology. Insulin pumps were also reported as a difficulty during sexual intercourse in a qualitative study by Santos et al.¹⁴ Therefore, considering the impact of such technologies with women on their sexual relationships is an important consideration, and this should include helping women incorporate these technologies positively into their intimate relationships in addition to technical information on how to manage such technology during intercourse.

Some of the women were concerned that sexual activity may elevate glucose levels affecting their diabetes control. Whilst previous studies have shown a positive correlation between HbA1c and SD,^{3,18,19} further exploration of this is required as there could be multiple explanations for these associations. Overall, the message would seem to be that it is important to elicit from women how diabetes related thoughts, technology and issues of glucose regulation might be impacting on their sexual relationships.

Depression is a common problem in people with diabetes, and previous studies have reported that it can contribute to SD.^{1,2,13,18,20} The women also reported fatigue impacts on their sexual desire, and fatigue is also a common problem in diabetes which can be related to high or low glucose levels.²¹ Hence, another consideration in exploring sexual issues with women could be comorbid depression or fatigue.

Whilst age is associated with a reduction in sexual activity in the general population, the participants identified age as factor contributing to SD despite being relatively young. It has been reported that sexual activity peaks during the ages of 20–40 years,²² and most women

in the study were in their early 30s. Data from previous studies on the association between age and SD are ambiguous.^{2,23} It may be that the excess glucose exposure associated with Type 1 diabetes precipitates age-related changes such as neuropathy causing vaginal dryness.²⁴ The extent to which age or diabetes-related phenomena contribute to this perception needs further consideration.

Relationships, particularly with partners, were identified as having a mediating effect on how women managed their concerns about sexual intimacy. Again, this is not unique to women with diabetes, and relationship quality has been identified as a predictor of SD.²⁵ However, previous studies have found that the quality of marital relations was significantly lower in women with Type 1 diabetes compared to women without diabetes due to the impact of diabetes.^{2,26} Therefore, the influence of problematic relationship status on SD in women with Type 1 diabetes may be greater, and the association between the SD and the quality of the relationship may be interrelated. This emphasises the need to support women in addressing intimacy with their partners and/or involving partners in such discussions.

Improving support with SD

In terms of improving the support for women in relation to SD, the most important message from the study is that women would find it helpful if SD was included in their routine clinical care, rather than having to initiate the conversation themselves. Clearly, this would need some consideration as to how to do this constructively and sensitively. Previous studies have reported that most women avoid discussing sexual health problems with their HCPs due to embarrassment.²⁷ There is also the fear that their sexual problems are not seen as a medical condition by HCPs and therefore considered unimportant.²⁸ It was identified that the women may prefer to have this conversation with their diabetes specialist nurse rather than raising the issue with their consultant or GP. In this case, the diabetes specialist nurse is a female, and the GP is a male. This may be a gender-related issue or reflect the time and depth of the relationship they have with the nurse.^{29,30} Feldhaus-Dahir²⁷ identified that women prefer discussing their experiences of SD with a HCP that they know and trust. Clinical teams may need some additional training in how to address SD sensitively in clinical consultations, recognising that women may be more comfortable in talking about sexual issues with someone of the same gender and similar age. This study has also highlighted the need for more information and supportive resources on SD in diabetes that women can access through different media. It is not clear if all women in this study have access to sexual health nurse and whether this could impact the findings.

Study limitations

It is important to acknowledge this study as a small-scale exploratory study, involving a few women from one

clinical service who were screened for evident SD. As such, this study only provides a sample of perspective on the views and experiences of sexual issues in women with Type 1 diabetes, limiting the potential transferability of the findings to the wider population. Nevertheless, the findings do concur with the limited previous research on this topic. In addition, this study has mapped out some of the different elements and potential drivers of SD in this population. These factors provide a starting point for future research into how we can better support women with Type 1 diabetes in achieving a fulfilling sex life.

A potential source of bias in this study to consider was that the researcher was known to the participants as their diabetes specialist nurse. This could have led to the women censoring some of their comments particularly in relation to support from HCPs. However, this limitation could also be seen as an advantage, as the women may have found it easier to talk about their sexual issues with someone they were familiar with. Also, the women may have seen this study as an opportunity to express their views on how their care should be delivered.

Another limitation is that the women were all in heterosexual relationships, and this excluded any exploration of SD in homosexual relationships; also, women did not provide details of SD in the context of the physical nature of the sexual relationships. These limitations should be considered in any future studies.

Conclusion

This study highlighted that SD is an important and multifaceted problem in women with Type 1 diabetes, with diabetes specific issues playing a significant part in their experience of SD. The participants felt that SD is generally not attended to by HCPs, and the women were not confident that their HCPs would address their sexual health needs effectively. Women expressed preferences for discussing sexual issues with a HCP of the same gender with whom they were familiar; they would also like more access to information on diabetes and sexual relationships. There is also the need to consider the training provided to HCPs, so that they feel more comfortable in initiating a conversation around SD. This training should include information on common sexual health issues in women with Type 1 diabetes and communication training. Further studies are required to identify how sexual issues can be better addressed in diabetes care. In-so-doing, giving the sensitivity of the problem, to bring women with Type 1 diabetes, their partners and HCPs together to develop supportive interventions to address this neglected, distressing and common problem would be an important consideration.

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No conflict of interest or funding to declare.

Authors' contributions

RH undertaken the participant interviews and analysis. AF advised on the study design, supervised the analysis and edited the manuscript.

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