Diabetes and female sexual health: an ongoing challenge

Katharine D Barnard[1,2]
PhD, CPsychol, AFBPsS, Health Psychologist

Diana Naranjo[3]
PhD, Associate Professor Health Psychology

Nicole Johnson[4]
DrPH, MPH, MA, National Director, JDRF Mission

Anna Norton[5]
MS, CEO, DiabetesSisters

Renza Scibilia[6]
Manager – Type 1 Diabetes and Consumer Voice

Claire Reidy[2]
PhD, Researcher

Sarah Tutton[7]
DRWF Chief Executive

Daryl Meeking[8]
MD, Consultant in Diabetes and Endocrinology

[1]Faculty of Health & Social Science, Bournemouth University, Bournemouth, UK
[2]BHR Ltd, Portsmouth, Hampshire, UK
[3]Stanford School of Medicine, Palo Alto, California, USA
[4]JDRF, NY, USA
[5]DiabetesSisters, Raleigh, North Carolina, USA
[6]Diabetes Australia, Victoria, Melbourne, Australia
[7]Diabetes Research & Wellness Foundation, Hayling Island, UK
[8]Portsmouth NHS Trust, Portsmouth, UK

Correspondence to:
Professor Katharine Barnard, PhD, CPsychol, AFBPsS, 42 Kilmiston Drive, Portchester, Fareham PO16 8EG, UK; email: katharinebarnard@bhrltd.com

Received: 22 January 2019
Accepted in revised form: 4 June 2019

Abstract

Female sexual health remains a much-neglected area in diabetes clinical medicine; however, it is important for psychological and social well-being as well as reproductive function. We aimed to explore the views of women regarding the impact of diabetes on sexual health beyond pregnancy and reproduction.

We conducted an online survey distributed via social media platforms including Twitter, Facebook and LinkedIn; the survey remained open for four weeks. Questions addressed a range of medical and psychological factors including body image, self-esteem and confidence.

A total of 258 participants, aged 18–73 years, completed the survey. Results show a significant deterioration over the past 20 years, with issues including negative impact on self-esteem (68.6%) and relationships (61.6%), feeling less attractive (57.8%), feeling lonely/isolated (66.3%), worries about fertility (52.7%) and pregnancy (69.4%), and worry about diabetes being passed on to children (79.5%). Medical factors included vaginal infections (77.9%), dyspareunia (51.2%), and general orgasmic problems (57.4%). Almost half (49.2%) were unaware that these problems were more common in women with diabetes. Shorter duration of diabetes was negatively associated with self-esteem ($p<0.002$), loneliness ($p<0.001$), and impact on relationships ($p<0.017$). Those without children and those aged under 35 years were more worried about fertility ($p=0.000$) and pregnancy ($p=0.000$).

It was concluded that sexual health issues continue to pose challenges for women with diabetes in terms of medical and psychological challenges. The psychosocial aspects of diabetes and sexuality, including feeling unattractive both physically and emotionally are widely reported by participants, demonstrating the very damaging and distressing personal consequences.

Practical Diabetes 2019; 36(5): 165–169

Key words

female sexual health; diabetes; sexual dysfunction; psychosocial

Background

Female sexual health remains a much-neglected area in diabetes clinical medicine; however, it is important for psychological and social well-being as well as reproductive function. Sexual health issues for women go beyond pre-conception care and pregnancy. Female sexual dysfunction is associated with both type 1 and type 2 diabetes,[1] with a meta-analysis of 26 studies comparing 3168 women with diabetes with 2832 control participants reporting that the risk for sexual dysfunction was 2.47 times greater for women with diabetes.[2] Contributing factors include interpersonal, social, psychological and biological aspects.

Normal sexual function in women occurs through an interaction between emotional and physical well-being; however, this complex interaction may be modified by disease, anatomic, physiological and/or emotional causes.[3] Given the complex nature of diabetes and its complications in terms of the physical and psychological issues involved, it is unsurprising that female sexual health is markedly affected by this condition. There are no specific guidelines available to support women; however, effective treatment requires psychological and pharmacological approaches. Many women are unaware that treatments are available nor where to seek help.

A further complicating factor is that women with diabetes are at increased risk of developing depression[4] which is the most well-established risk factor for female sexual dysfunction in women with diabetes[1,5,6] and which can impact on all stages of sexual functioning.[1] In addition, psychological challenges in diabetes may negatively impact on sexual function, including low self-image, tiredness and dependency on others.[7,8] Diabetes in itself has negative psychological effects on sexual function beyond any

medical aspect,[7,9] with women viewing themselves as less attractive and less happy. They also report less satisfaction with their sexual partner, sex life in general, lubrication and orgasm.

Twenty years ago, a study by Meeking *et al.*,[10,11] involving 161 patients, reported medical issues related to pregnancy (43%), contraception (33%), dyspareunia (painful intercourse), general orgasmic problems (50%), and genito-urinary infection (23%). Meeking *et al.* further reported a number of psychological issues including low mood, anxiety and poor self-image. Furthermore, loss of self-esteem, loss of attractiveness, loneliness or isolation, and relationship difficulties attributed to diabetes were common. Additional diabetes-attributed factors affecting sexual health for women included tiredness, anxiety/worry, anger/irritability and depression. It is unclear the extent to which these problems persist and the impact they have on women today.

The aim of the current study was to explore the impact of diabetes on female sexual health in terms of medical and psychological aspects, relationships and help-seeking behaviours with a view to developing appropriate support resources if required.

Methods

A questionnaire study delivered online via social media platforms was conducted. Participants were women with diabetes of any type or duration. Data were collected via links on Twitter, Facebook and LinkedIn over a four-week recruitment period. Institutional ethical approval was obtained from Bournemouth University and informed consent was received prior to survey completion. The survey contained 54 items including free-text response questions so that participants could provide further detail to their responses if desired. Most questions replicated those in the Meeking 1998 study.[10]

The questionnaire was piloted with four women with diabetes prior to use to ensure the final version was acceptable and relevant. No revisions were suggested nor made to the final version. Descriptive and inferential

Variable		No.	%
Age	• Under 25 years	41	15.9
	• 25–34 years	82	31.8
	• 35–44 years	69	26.7
	• 45–54 years	42	16.3
	• 55–64 years	21	8.1
	• 65+ years	3	1.2
Marital status	• Divorced	8	3.1
	• Married/partnered	190	73.6
	• Single	60	23.3
Number of children	• 0	149	57.8
	• 1	34	13.2
	• 2	48	18.6
	• 3	14	5.4
	• 4	9	3.5
	• 5	2	0.8
	• 6	2	0.8
Duration of diabetes	• 1–3 years	14	5.4
	• 3–5 years	13	5.0
	• 5–10 years	43	16.7
	• 11+ years	188	72.9
Diabetes therapy/ treatment	• Insulin (always)	233	90.3
	• Diet only	1	0.4
	• Tablets	13	5.0
	• Insulin (used to take tablets only)	11	4.3

Table 1. Demographic data for all survey participants (n=258)

Variable	Meeking study (%)	Current study (%)
Psychological		
Diabetes has led to a loss of self-esteem	36.0	68.6
Diabetes makes me feel less attractive	34.0	57.8
Diabetes has led to loneliness or isolation	40.0	66.3
Diabetes had led to worry about fertility	31.0	52.7
Diabetes has led to worry about pregnancy	43.0	69.4
Diabetes has led to worry about passing it on to children	75.0	79.5
I have discussed my concerns with a health care professional	66.0	57.4
Medical		
Vaginal infections	23.0	77.9
Dyspareunia	43.0	51.2
General orgasmic problems	47.0	57.4

Table 2. Comparison of results obtained from the Meeking *et al.* 1998 study[10] versus the current study

statistical analyses were conducted using SPSS.22 with content and thematic analyses carried out on the free-text responses. Two researchers experienced in qualitative research methods analysed the free-text responses and conducted thematic and content analyses thereof.

Results

We received 258 completed survey responses from women aged 18–73 years of whom 212 (82.2%) were sexually active. Demographic data are presented in Table 1.

The results showed a statistically significant deterioration in psychosocial outcomes in the current study compared with data presented in the Meeking study (all p<0.001); see Table 2.

A shorter duration of diabetes (<10 years) was negatively associated with self-esteem (p<0.002), loneliness (p<0.001), and impact on relationships (p<0.017).

Table 3 summarises participants' responses to the current survey regarding the psychosocial impact of diabetes.

Most participants (69.4%, n=179) had not sought help from a health care professional for sexual health related medical problems. Overall, 77.9% (n=201) of participants were unaware of any treatments available. Almost half (49.2%) were not aware that any of these problems were more common in women with diabetes. Table 4 provides details of the survey results regarding the negative impact of diabetes on sexual activity.

Over half of participants (52.7%, n=136) reported having worried that diabetes may affect their fertility, with 69.4% (n=179) having worried about diabetes affecting their ability to become pregnant. Participants aged <35 years were over three times more likely to be worried about fertility (OR=3.15) than those aged >35. This relationship was statistically significant (p=0.000). Furthermore, participants aged <35 years were also over five times more likely to be worried about pregnancy (OR=5.08) than those >35 – again, statistically significant (p=0.000). Those without children were twice as likely to be worried about fertility (OR=2.49) and almost twice as likely to be worried about pregnancy (OR=1.82). These differences were both statistically significant (p<0.001).

	Not at all: no. (%)	Mildly: no. (%)	Moderately: no. (%)	Greatly: no. (%)
Diabetes has led to a loss of self-esteem	81 (31.4)	74 (28.7)	58 (22.5)	45 (17.4)
Diabetes makes me feel less attractive	109 (42.2)	69 (26.7)	50 (19.4)	30 (11.6)
Diabetes has led to loneliness or isolation	87 (33.7)	71 (27.5)	51 (19.8)	49 (19.0)
Diabetes has had a negative effect on my relationships with a partner/potential partner	99 (38.4)	86 (33.3)	41 (15.9)	32 (12.4)
Diabetes has had a positive effect on my relationships	159 (61.6)	49 (19.0)	30 (11.6)	18 (7.0)

Table 3. The psychosocial impact of diabetes: results of the current survey

	Not at all: no. (%)	Mildly: no. (%)	Moderately: no. (%)	Severely: no. (%)
Tiredness	21 (8.1)	72 (27.9)	98 (38.0)	60 (23.3)
Anxiety/worry	49 (19.0)	63 (24.4)	86 (33.3)	45 (17.4)
Anger/irritability	52 (20.2)	67 (26.0)	93 (36.0)	35 (13.6)
Depression/hopelessness	61 (23.6)	60 (23.3)	70 (27.1)	48 (18.6)
Lack of time/inconvenience	60 (23.3)	79 (30.6)	71 (27.5)	35 (13.6)
A reduction in pleasure from sex	101 (39.1)	57 (15.9)	49 (19.0)	41 (15.9)
Increasing difficulty/inability in achieving orgasm	93 (36.0)	59 (22.8)	43 (16.7)	51 (19.8)
Lack of desire/interest	80 (31.0)	66 (25.6)	43 (16.7)	60 (23.3)
Vaginal/urinary infections, cystitis or thrush were reported to have interfered with sexual relationships by 203 participants (78.7%).				

Table 4. Negative impact of diabetes on sexual activity: results of the current survey

Three-quarters of participants (76.4%, n=197) reported that their diabetes-related medications had not negatively impacted on their sexual relations, despite concerns regarding injection sites and visibility of medical devices. Many (42.2%, n=109) participants reported that a doctor or nurse had not discussed pregnancy planning with them. Two-thirds of participants (67.4%) reported that diabetes had not affected their choice of contraception. Participants with children were not more concerned about passing on diabetes than those without children (p=0.409).

A selection of the free-text responses is presented below. Content analyses are shown in Table 5, with the key themes for each of the individual items showing the number of responses falling under each theme for each item. Results show that 'loss of self-esteem' and 'feeling less attractive' are mostly associated with difference from others/loneliness/stigma and lack of understanding as well as body-image, feeling judged and the presence of technology. 'Loneliness/isolation' and 'negative effect on

relationships' are associated with difference from others and low mood/burnout/tiredness.

Loss of self-esteem

'Made me feel worthless and broken.' (Participant no. 181.)

'I'm broken. I broke myself. The roller-coaster that we sometimes ride despite the insulin, exercise, food and everything else makes it seem like we're failing, even though we're doing our best.' (Participant no. 251.)

'Embarrassed, misunderstood, criticised.' (Participant no. 253.)

'Diabetes has made me extremely self-conscious in all aspects of my life.' (Participant no. 173.)

'Weight fluctuations. Bruises. Devices attached. Diet is hard I feel broken, like I'm defective in some way.' (Participant no. 138.)

Feel less attractive

'People's perceptions are that I'm a high-risk partner and, let's be honest, hypos aren't attractive.' (Participant no. 017.)

'Wearing devices, having scars from cannulas.' (Participant no. 058.)

'I feel that my diabetes is a judgement making me ugly fat.' (Participant no. 133.)

'When my boyfriend sees me having low hypos … When I'm sweaty and shaky and feeling really rough I struggle a bit.' (Participant no. 149.)

'I feel as though I'm less desirable.' (Participant no. 170.)

'I feel as though people wouldn't want to be with me as I am diabetic.' (Participant no. 181.)

Diabetes led to loneliness or isolation

'*My husband is not interested so I cannot discuss it with him, friends do not understand the full complexities.'* (Participant no. 009.)

'Scared of going out … would always just stay in my room.' (Participant no. 018.)

'No-one seems to listen and actually hear what you are saying!' (Participant no. 093.)

'At times, it's like living with a death sentence. Not easy to share that.' (Participant no. 102.)

'I avoid spending time going out because of the temptations or sadness at watching others indulge.' (Participant no. 133.)

'Felt like no one understood it.' (Participant no. 224.)

Question	Difference from others/Isolation/ Stigma/Lack of understanding	Body-image/ Judged/ Presence of technology	Low mood/ Burnout/ Tiredness	Sexual function/ Infection/Loss of enjoyment	Other
Loss of self-esteem	70	81	25	3	26
Feel less attractive	28	140	9	8	17
Loneliness/ isolation	128	5	29	0	17
Negative effect on relationships	75	14	32	22	8

Table 5. Content analyses – questions with summary of free-text key themes, showing number of responses to each theme

Diabetes had a negative effect on relationships with a partner/ potential partner

'Lack of sexual interest is significantly impacting on my marriage.' (Participant no. 249.)

'I resent him for never taking an interest after the initial diagnosis.' (Participant no. 250.)

'Having to explain it all, having hypos and feeling humiliated, hospitalisation, complications, endless blood tests and meds, feeling disgusting is not conducive to a healthy relationship.' (Participant no. 159.)

'…my partner is often very worried about my diabetes and is more anxious about my blood sugars than I am when all I need is for him to be calm.' (Participant no. 129.)

'I take anger out on him.' (Participant no. 084.)

'Don't love my husband any more.' (Participant no. 051.)

Discussion

A total of 258 women participated in the survey. Sexual health issues continue to pose challenges for women with diabetes both in terms of medical issues and psychological challenges. The psychosocial aspects of diabetes and sexuality, including feeling unattractive both physically and emotionally, are widely reported by participants with the free-text data demonstrating the very damaging and distressing personal consequences.

The psychological challenges posed by sexual health issues for women with diabetes remain particularly concerning, with considerable deterioration in several areas. Loss of self-esteem, feelings of unattractiveness and loneliness/isolation were highly prevalent both in the Meeking study and considerably worse in the current study. These debilitating psychological consequences are severely limiting for women. It is perhaps unsurprising that almost two-thirds of current study participants reported that diabetes had a negative effect on their relationships with a partner or potential partner. Furthermore, such self-loathing and despair negatively impacts on women's life choices as their expectations are reduced, including academic attainment, employment opportunities and social relationships.[12]

There are some similarities and notable differences between the data reported by Meeking 20 years ago and medical issues data reported here: for example dyspareunia increased from 43% to 51.2%, general orgasmic problems increased from 47% to 57.4% and vaginal infections increased from 23% to 77.9%. While more women in the current survey had sought medical advice for difficulties with sexual function (30.6% compared to 17%), this did not seem to have impacted on the number of women who were aware that treatment was available (22.1% in the current study compared with 20% in the Meeking *et al.* study). Despite treatments being available, it is unknown what

treatment recommendations were made for the 30% of women who sought medical advice.

There remains a lack of education around diabetes risks in terms of pregnancy worries and anxiety associated with hereditary risk of diabetes on potential children. Concerns regarding the passing on of diabetes to children remained static at 79.5% (compared to 75%). Worries about fertility increased considerably from 31% to 52.7% and worries about becoming pregnant also increased (from 43% to 69.4%). As can be seen from the data, there are clear sub-group differences in the current study. It appears women's willingness to discuss these concerns with health care professionals has barely changed over the decades, with 57.4% in the current study compared to 66% in the Meeking study.

Pre-conception care and pregnancy support have received much focus over recent years. Developments in diabetes technologies such as continuous glucose monitoring systems and clinical trials in automated insulin delivery during pregnancy have resulted in improved glycaemic control and quality of life for women with diabetes. Broader sexual health issues, however, have received scant attention yet remain a widespread problem.

The strengths of the current study include the large number of participants and replication of previous research, enabling comparisons to be drawn across a 20-year period. The inclusion of quantitative and free-text data provides both overall numbers but also the meaning behind those numbers, which demonstrates the depth of the negative impact that sexual health issues has on the everyday lives of women.

The study is not without limitation, however, with self-selecting participants potentially not being representative of the broader population of women with diabetes. Data were collected via social media internet recruitment and so may not have included those without regular access to the internet. Office for National Statistics data show that over 90% of households have internet access; however, this still excludes 10% of the population and diabetes affects all sectors of society. Furthermore, these data are predominantly explorative in nature and, despite the free-text response options, may have limited participants' ability to report broader issues that may affect their sexual health.

KEY POINTS

- Sexuality is a defining aspect of oneself. It goes beyond conception care and pregnancy
- Sexual health is an integral part of overall health, well-being and quality of life
- Diabetes has been shown to have a significant detrimental effect on sexual health and well-being
- Women report feelings of isolation, low self-esteem, poor body image and loss of enjoyment or engagement in sexual activity
- It is clear that there is a need for support/resources to be readily available as well as heightened health care professional awareness to help individuals

Conclusion

Further research is required, and we are currently conducting in-depth qualitative research to better understand the needs and desires of women in order to develop resources, as well as developing tools to assist health care professionals to initiate conversations regarding sexual health issues with their patients. Cultural factors will surely play a role and these should be considered in future research.

Acknowledgements

We would like to thank all of the women who participated in the survey.

Declaration of interests

There are no conflicts of interest declared.

References

1. Enzlin P, *et al.*; DCCT/EDIC Research Group. Sexual dysfunction in women with type 1 diabetes: long-term findings from the DCCT/EDIC study cohort. *Diabetes Care* 2009;32(5):780–5.
2. Pontiroli A, *et al.* Female sexual dysfunction and diabetes: a systematic review and meta-analysis. *J Sex Med* 2013;10(4):1044–51.
3. Vaccaro C, *et al.* Female sexual function and the clitoral complex using pelvic MRI assessment. *Eur J Obstet Gynecol Reprod Biol* 2014;180:180–5.
4. Schram MT, *et al.* Depression and quality of life in patients with diabetes: A systematic review from the European Depression in Diabetes (EDID) research consortium. *Curr Diabetes Rev* 2009;5(2):112–9.
5. Rockliffe-Fidler C, Kiemle G. Sexual function in diabetic women: A psychological perspective. *Sexual & Relationship Ther* 2003;18(2):143–59.
6. Enzlin P, *et al.* Prevalence and predictors of sexual dysfunction in patients with type 1 diabetes. *Diabetes Care* 2003;26(2):409–14.
7. Kennedy SH, Rizvi S. Sexual dysfunction, depression and the impact of antidepressants. *J Clin Psychopharmacol* 2009;29(2):157–64.
8. Basson R. Human sex-response cycles. *J Sex Marital Ther* 2001;27(1):33–43.
9. Schreiner-Engel P, *et al.* The differential impact of diabetes type on female sexuality. *J Psychosom Res* 1987;31(1):23–33.
10. Meeking DR, *et al.* Sexual dysfunction and sexual health concerns in women with diabetes. *Sexual Dysfunction* 1998;1:83–8.
11. Meeking DR, *et al.* Sexual dysfunction and sexual health concerns in women with diabetes. *Pract Diabetes* 2013;30(8):327–31a.
12. Department for Work and Pensions. Fulfilling potential: Building a deeper understanding of disability in the UK today. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/320509/building-understanding-main-report.pdf [accessed 18 September 2018].