ORIGINAL ARTICLE Exploring Sexual Life Experiences and Perceptions of Women with Diabetes: A Qualitative Study

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Abstract

Background: Sexual life can be affected through different aspects of living with diabetes. This study aimed to explore the perception and experiences of Iranian women with diabetes at reproductive age regarding the impact of diabetes on their sexual life.

Methods: This qualitative study was conducted from August 2018 to February 2019 in five diabetes centers in Tehran. Purposeful sampling method was used to select the participants, and data were collected by in-depth semi-structured interviews. Data were analyzed manually using the conventional content analysis method. Data saturation occurred after interviewing 24 women with diabetes.

Results: Three themes were identified. The first theme was "diabetes-related threatened sexual life" with three categories: change in sexual functioning, negative sexual self-evaluation, and concern in sexual relationships. The second theme was "diabetes treatment challenges in sexual life," which included two categories: adverse effects of diabetes treatment in sexual life and the psychosocial distress related to diabetes treatment. "Couples' relationship adjustment to diabetes," was identified as the third theme, including four categories: the need for spouse's understanding of living with diabetes problems, perceived need for spouse's support, perceived need for intimacy, and the need to cope with diabetes-related childbearing challenges.

Conclusion: According to the participants' perception and experiences, in addition to sexual problems, diabetes had affected their sexual life through diabetes treatment challenges in sexual life and the way the couples' relationships adjust to diabetes. Therefore, sexual problems screening and providing counseling services in community-based diabetes care planning are recommended.

Keywords: Diabetes complications, Diabetes mellitus, Qualitative study, Sexual dysfunction, Sexual life

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INTRODUCTION

Diabetes is a serious health-threatening disease, with a rapidly rising prevalence worldwide.¹ The prevalence of diabetes in Iranian women was reported about 11/9%.² Sexual dysfunctions have been considered a common complication of diabetes in men and women.³ The prevalence of sexual dysfunction in women with diabetes was reported to vary from 17% in an Italian study to 95.4% in a study from Iran.⁴

Decreasing clitoral and vaginal engorgement and vaginal lubrication due to diabetes-related atherosclerosis can inhibit the females' sexual responses.⁵ Also, depression, diabetes-related hormonal changes, and neural and vascular damages have been introduced as the causes of female sexual dysfunction.⁶

It should be noted that diabetes is not only a metabolic disease with biological symptoms, but often it is accompanied by psychological distress, and sociocultural and relational problems.7 Thus, beyond sexual functioning, sexual life can be affected through different aspects of living with diabetes.8 Sexual life is an important aspect of quality of life.9 It has been defined as a whole of a person's sexual activity and relationship.¹⁰ Interpersonal factors have been introduced as the most important determinants of female sexual satisfaction.¹¹ Consideration of sexual life quality as a concept related to satisfaction with sexual life can provide comprehensive information in this regard.8 However, limited attention has been paid to the sexual life of women with diabetes. A few studies on this topic are quantitative and have compared the scores of sexual life quality in women with and without diabetes.12 Most studies have focused on sexual dysfunction in women with type 1 or 2 diabetes mellitus (T1DM or T2DM), and the results are controversial. Several studies showed a higher prevalence of sexual dysfunctions in women with diabetes than healthy women,¹³⁻¹⁵ while some studies have reported that sexual functioning in women with diabetes is similar to healthy women.^{16, 17}

For promoting the quality of sexual life in

women with diabetes, it is essential to provide a general understanding of how diabetes may affect sexual life in this group of women. As qualitative research provides an in-depth insights into perceptions, behaviors, and experiences of individuals,¹⁸ this qualitative study aimed to explore the effects of diabetes on the sexual life of women who live with diabetes.

METHODS

This qualitative study was conducted from August 2018 to February 2019 after receiving necessary permissions from the authorities of the diabetes clinics. Five diabetes clinics (three public diabetes clinics and two private diabetes clinics) in different locations of Tehran were selected as the research sites. The participants were selected from married, non-pregnant, Iranian women of reproductive age (15-49 years, before menopause) with T1DM or T2DM with at least the ability to read and write. Diabetes diagnosis and type were considered based on medical records. The women in the lactation period and those with known psychiatric disorders were excluded from the study. One of the women who met the inclusion criteria refused to participate in the study because she did not feel comfortable talking about her sexual life.

Data were collected using purposeful sampling through in-depth interviews. The interviews were conducted by the first author, who was a Ph.D. candidate in reproductive health. She had passed sexual health and qualitative research methodology courses before this study. Before beginning the interviews, the interviewer introduced herself to the participants, explained the purposes of the study and obtained their permission for audio-recording. In-depth and semi-structured interviews were held in a private room that had been considered at each research site. Only the interviewer and participant were present at the time of the interviews. The interviews began with general questions; then, a few open-ended questions were asked during the interviews. For instance: "Explain about your sexual relationships in the condition of living with diabetes, please," or "Can you tell me about your sexual experiences and feelings in this condition, please?" The participant's responses were used to create the following exploratory questions to deepen the data. Probing questions were used to provide further detailed data. For instance: "Please explain more about that," "What happened after this experience?", and "Explain your feeling at that time, please."

At first, three interviews were done, transcribed, and coded by two researchers. These interviews were held to find potential interviewing and coding problems. The interviews began with general open-ended questions, and each interview session lasted 50-60 minutes and an average of 55 minutes.

One participant was re-invited for complementary information. After in-depth interviews with 24 participants, data saturation was achieved, and performing more interviews could not lead to new data or themes. All data, including recorded interviews, and non-verbal, verbal and field notes, were collected and converted to textual data sheets on the same day of the interview. The data organization was performed manually. The data analysis was conducted using the qualitative conventional content analysis based on Graneheim and Lundman's approach.¹⁹ Based on this method, after reviewing the text repeatedly to obtain a correct general understanding of the content, we considered the whole transcribed text as the unit of analysis. Then meaning units were identified and coded based on explicit and latent concepts. The codes were compared, categorized based on their differences and similarities, and then were labeled (category). Finally, by comparing the categories and identifying their characteristics and classification, the themes were formed.

Lincoln and Guba's criteria for qualitative research were used for the rigor of data collection.²⁰ The research team members reviewed the process of coding and analyzing the data repeatedly. Also, prolonged engagements with data and data analysis helped establish the credibility of the study. The researchers interacted with the respondents to confirm the interpretations of the extracted codes. Maximum variation in sampling was used in this study, so the participants were selected from diverse backgrounds in terms of age (within the reproductive age), therapy type (oral medications, insulin injections, and insulin pump), social status, and educational levels to achieve transformability.

This study was approved by the Tarbiat Modares University ethics committee, and the ethics code assigned to this study is IR. MODARES.REC.1397.012. Written informed consent for participation and voice recording was obtained from each of the participants. The interviewer ensured the participants that their personal information would remain confidential, this study would not affect their treatment process, and they could withdraw from participation at any time.

RESULTS

A total of 24 women with diabetes participated in this study. 41.7% of the participants had T1DM, and 58.3% had T2DM, with an age distribution between 23 and 43 years, with an average of 35 years (Table 1).

Twenty-four subcategories, nine categories, and three themes resulted from the data analysis as follows: "diabetes-related threatened sexual life," "diabetes treatment challenges in sexual life", and "couples' relationship adjustment to diabetes" (Table 2).

1. Diabetes-related Threatened Sexual Life

The first theme, diabetes-related threatened sexual life, included three categories: "change in sexual functioning", "negative sexual self-evaluation", and "concern in sexual relationships."

1.a. Change in Sexual Functioning

According to the participants' explanations, low desire, insufficient lubrication, orgasmic problems, and dyspareunia were experienced

Number	Age	Education	Job	Diabetes Type	Type of diabetes treatment
1	35	Bachelor	Nurse	1	Insulin pump
2	37	Bachelor	Teacher	1	Insulin Injection
3	24	Diploma	Housewife	1	Insulin pump
4	41	Diploma	Housewife	2	Oral medication
5	35	Ph.D.	Manager	2	Insulin Injection + Oral medication
6	40	Diploma	Housewife	2	Insulin Injection+ Oral medication
7	43	primary	Housewife	2	Insulin Injection+ Oral medication
8	28	Associate	Employee	1	Insulin Injection
9	39	Bachelor	Teacher	2	Oral medication
10	38	Primary school	Housewife	2	Oral medication
11	39	Diploma	Hairstylist	2	Oral medication
12	23	Diploma	Housewife	1	Insulin Injection
13	40	Diploma	Housewife	2	Oral medication
14	42	Primary school	Housewife	2	Oral medication
15	25	Diploma	Housewife	1	Insulin pump
16	42	Bachelor	Employee	2	Insulin Injection+ Oral medication
17	41	Secondary school	Housewife	2	Oral medication
18	39	Diploma	Housewife	2	Insulin Injection+ Oral medication
19	23	Bachelor	Employee	1	Insulin pump
20	40	Secondary school	Housewife	2	Oral medication
21	27	Diploma	Employee	1	Insulin Injection
22	29	Primary school	Housewife	2	Oral medication
23	36	Diploma	Tailor	1	Insulin Injection
24	34	Diploma	Housewife	1	Insulin Injection

Table 1: Characteristics of the study participants

frequently. One of the participants, who had suffered diabetes for five years, explained:

"I feel, my sexual desire has reduced dramatically in comparison to before diabetes. During sexual intercourse, I feel vaginal dryness, which makes it all painful for me." (P4)

One of the participants explained how her sense of sexual stimulation had changed:

"I don't feel aroused like the way I used to get stimulated during intercourses. I feel that my genital sensations have diminished." (P18)

A participant with T1DM also said:

"I don't reach orgasm. Even if I reach, I feel like it's too weak." (P8)

1.b. Negative Sexual Self-evaluation

Participants explained how their sexual selfevaluation had been changed by living with diabetes. Being concerned about the husband's negative attitude about having a partner with diabetes, disqualification of herself as a sexual partner, feeling of unattractiveness due to poor body image (diabetes-related weight loss or weight gain) were frequently reported by participants. A participant explained:

"I am worried about my husband's feelings related to my sexual problems after diabetes. I feel he compares me with healthy women." (P18)

A participant described how she evaluates herself as a sexual partner:

"I feel sorry for my husband. I have not been a good sexual partner for him. If he had married a woman without diabetes, it would have been better for him. I often do not have enough energy to accept my spouse's request for sex." (P12)

One of the participants described her feelings regarding her body image and said:

"Due to uncontrolled diabetes, I have lost so much weight that I hate looking at my own body. I feel I'm sexually unattractive." (P7) 1.c. Concern in Sexual Relationships

The data revealed that participants were sexually dissatisfied due to feeling concerned

Theme	Category	Subcategory
1. Diabetes-related	1.1. Change in sexual	1.1,1. Reduced sexual desire
threatened sexual life	functioning	1.1.2. Reduced arousal/ Insufficient lubrication
		1.1.3. Orgasmic problems
		1.1.4. Sexual pain problem
	1.2. Negative sexual	1.2.1. The concern of husband negative attitude
	self-evaluation	about having a partner with diabetes
		1.2.2.Disqualification of herself as a sexual partner
		1.2.3. Feelings of unattractiveness
	1.3. Concern in sexual	1.3.1. Concern about the fluctuation in blood sugar
	relationships	during sex
		1.3.2. Concern about urinary infection after sex
		1.3.3. Concern about genital infection after sex
		1.3.4. Concern about unplanned pregnancy
2. Diabetes treatment	2.1. Adverse effects of	2.1.1. Diabetes medicines side effects in sexual life
challenges in sexual life	diabetes treatment in sexual	2.1.2 Problems with using diabetes medication in
	life	sexual relationship
	2.2. The psychosocial distress	2.2.1. Distress with diabetes medication
	related to diabetes treatment	2.2.2. Perceived stigma towards the need for
		insulin therapy
3. Couples' relationship	3.1. The need for spouse's	3.1.1. Need to spouse' understanding of diabetes
adjustment to diabetes	understanding of living with	complications
	diabetes' problems	3.1.2. Need to spouse'understandig about the
	2.2. Demois 1 10	effects of diabetes on sexual responses
	3.2. Perceived need for	3.2.1 Reflection of spouse's behavioral reactions
	spouse's support	towards diabetes on sexual life
		3.2.2. Reflection of spouse's involvement in diabetes care on sexual life
		3.2.3. Influence of spouse empathy in diabetes care on the sexual relationship
	3.3. Perceived need for	3.3.1. The dominance of sexual intimacy on
	intimacy	diabetes-related sexual problems
	intimacy	3.3.2. Importance of intimate couple relationship
		in sexual life
	3.4. The need to cope with	3.4.1. Couple's conflicts about childbearing related
	diabetes-related childbearing	to diabetes
	challenges	3.4.2. Negative feelings resulted from adverse
		effects of diabetes on pregnancy

Table 2: Extracted subcategories, categories, and themes

about having sexual relationships. These concerns included blood sugar fluctuation during sex, and concern about urinary infection after sex, genital infection after sex and concern about an unplanned pregnancy.

One of the participants said:

"I have unpleasant experiences of sudden drops in my blood sugar's level during sex. I am worried about these symptoms." (P16)

One of the participants explained how she is worried about urinary infections after sex.

"As I have diabetes, I feel sex causes urinary infection for me. I am worried about the unpleasant feeling of pain and burning in urination." (P19)

A participant explained her experiences of recurrent infection:

"I am worried about having sex. I have a recurrent vaginal infection after sex." (P11)

Unplanned pregnancy was introduced as a source of concern in sexual relationships by several participants. One of the participants explained:

"As I have diabetes, I am worried about being pregnant with uncontrolled blood sugar, during sex. I know that uncontrolled diabetes has negative effects on the fetus." (P15)

2. Diabetes Treatment Challenges in Sexual Life

The participants described how the adverse effects of diabetes treatment and the psychosocial distress related to diabetes medication affected their sexual life.

2.a. Adverse Effects of Diabetes Treatment in Sexual Life

Some participants mentioned the adverse effects of diabetes medication, such as headache, nausea, sleepiness, problems with using diabetes medication in their sexual relationships affected their sexual life.

A participant with T2DM discussed the side effects of her diabetes medicines and said:

"I take oral medicine to control my blood sugar, and I have nausea and headache. I feel exhausted. I've lost my sexual interest under these conditions." (P13)

One of the participants with T1DM who used an insulin pump discussed her problems with using insulin pump during sex and said:

"I cannot tolerate my insulin pump during sex. Sometimes, it gets disconnected during sex. It negatively affects our sexual relationships." (P15)

2.b. The Psychological Distress Related to Diabetes Treatment

The participants explained about their psychological problems with diabetes medication, such as feeling depressed or anxious due to the need for lifelong medication. Also, the participants who did use insulin described their perception of stigma towards insulin therapy. An Insulin pump user participant, while looking down and wiping her tears, explained her feelings of embarrassment and low self-confidence due to wearing an insulin pump in sexual relationships:

"My self-confidence has decreased. I feel very embarrassed because I have to wear an insulin pump even in my sexual relationships. I hate its vibration sound at that time." (PI)

3. Couples' Relationship Adjustment to Diabetes

The third theme included the need for the spouse's understanding of living with diabetes-related problems, perceived needs for spouse's support, perceived need for intimacy, and the need to cope with diabetes-related childbearing challenges.

3.a. The Need for Spouse' Understanding of Living with Diabetes' Problems

Based on the extracted data, the husband's understanding of diabetes problems highly affected the couple's relationship. Participants described how her spouses' understanding of problems with diabetes and spouse' understanding about the effects of diabetes on sexual responses affected their sexual life. A participant mentioned:

"I need my husband to understand my problems with diabetes. Sometimes my mood changes rapidly, and I cannot control my anxiety or anger. This situation has negatively affected our relationship and even our sexual relationship." (P14)

Also, a participant explained:

"I am not interested in sexual relationships. My husband does not know that I need more sexual stimulation than before to be aroused." (P4)

3.b. Perceived Need for the Spouse's Support

Some participants described how their husbands' involvement and empathy in diabetes care had affected their relationship. One of the participants explained her feelings in this regard:

"My husband never asks about my treatment process, and these behaviors have resulted in a poor relationship between us, I am not satisfied to have sex with him, while my health is not important for him." (P20)

3.c. Perceived Need for Intimacy

Based on the participants' explanations, the dominancy of sexual intimacy on sexual problems related to diabetes and the importance of intimate couple relationships in sexual life had been perceived. One of the participants explained:

"I can easily talk to my husband about the changes in my emotions due to diabetes or even the changes I feel during sex. Although I have sexual problems, I am satisfied with my sex life." (P5)

A participant described how their intimate relationship in the context of living with diabetes improved their sexual life.

"The intimacy between my husband and I gives me the strength to accept this disease better because I'm sure that he will do his best to help me without knowing my diabetes as a weakness... our intimacy in this situation affects our sexual relationship positively." (P3)

3.d. The Need to Cope with Diabetes-related Childbearing Challenges

Childbearing was threatened by living with diabetes based on the participants' perceptions. They perceived the need to cope with these challenges in their sexual lives. This perception came from the couple's conflicts about childbearing due to the concern about diabetes complications in pregnancy, and negative feelings come from adverse effects of diabetes on pregnancy.

A participant explained:

"I am very anxious. Despite my diabetes problems, my husband insists on having another child ... Our relationship is challenging". (P21)

Also, one of the participants described her feelings after a complicated pregnancy experience.

"I don't like to have sex. I had uncontrolled blood sugar, and my baby was born with a congenital heart defect. I feel guilty. ...my husband blames me a lot, and I can not forgive myself." (P23)

DISCUSSION

This study aimed to find out the effects diabetes on sexual life by exploring the perceptions and experiences of women with diabetes. The results revealed three themes of diabetes-related threatened sexual life, diabetes treatment challenges in sexual life, and couples' relationship adjustment to diabetes.

The findings of this study are in the same line with the biopsychosocial model. Biological, sociocultural, psychological, and interpersonal factors can all affect sexual functioning.²¹ The results of this study revealed that the way the participants perceived their sexual life was mainly affected by the physical, psychological, and sociocultural dimensions of living with diabetes.

The present study findings showed sexual life was threatened through changes in sexual functioning, negative sexual self-evaluation, and concern in sexual relationships based on the participants' statements. Decreased sexual responses and feelings of dyspareunia were reported frequently. These findings are in line with the results of several previous studies.^{5,22,23} However, it is in contrast with some studies results that showed sexual functioning in women with diabetes had been similar to that of the control group.^{16, 17} Differences in the results of the studies can be due to differences in the method of research and life skills in couples.

In this study, negative sexual self-evaluation in this group of women was highlighted as an influencing factor in sexual life. Although these findings are in line with previous studies that reported higher negative sexual selfconcept scores,²⁴ and a deep feeling of physical and emotional unattractiveness in women with diabetes,^{5, 25} this study also shed new light on other factors perceived as influencing factors in negative sexual self-evaluation.

Concern in sexual relationships (worries about genitourinary infection, blood sugar fluctuation, and unplanned pregnancy) was another diabetes-related problem in sexual life. Previous studies have discussed some of these problems in women with diabetes.^{26, 27} The findings contrast with a descriptive study that found, people with diabetes were often not concerned about hypoglycemia in their sexual relationships.²⁸ It shows that specific education in this regard is essential.

In the current study, adverse effects of

diabetes treatment and the psychological distress related to diabetes treatment resulted in diabetes treatment challenges in sexual life. Adverse effects of diabetes treatment were related to diabetes medicines side effects in sexual life and problems with using diabetes medication in sexual relationships. Most published studies in this regard are quantitative and assessed related factors to sexual functioning. These studies reported that diabetes treatment type is associated with sexual dysfunction or sexual satisfaction in women with diabetes. Only a few studies have focused on how diabetes treatment affects sexual functioning.^{29, 30} A study confirmed different effects of anti-glycemic agents on sexual functions.³¹ In line with the present study findings on problems with using diabetes medication in sexual relationships, a study reported that about 50% of insulin pump users reported that the insulin pumps interfere in their sexual relationship.⁵ Psychological distress related to diabetes treatment on sexual life has received less attention. In the present study, participants explained problems with diabetes medications type, especially insulin pumps, during sexual relationships. In contrast, a study results showed no statistically significant differences in anxiety and sexual behavior between the insulin pump users and the controls.³² This difference can be due to concern about stigma related to attaching pumps in our participants. Feelings of embarrassment and negative body image due to wearing the attached pump were reported by participants in this study. It has been reported that people with TIDM or T2DM who are on intensive insulin therapy are more likely to experience stigma.³³ These findings confirmed the importance of assessing diabetes treatment challenges in sexual life in diabetes treatment and care services.

The present study indicated that the participants have perceived their sexual life was affected by how the couple's relationships adjusts to diabetes. These results are in the same line with those of a study that revealed that marital adjustment had increased the quality of sexual life in women with diabetes.12 A study showed lower marital adjustment and sexual functioning in women with diabetes than healthy women. Also, a positive relationship has been reported between sexual functioning and marital adjustment in women with diabetes.³⁴ A study results revealed a correlation between dyadic adjustment and sexual life quality in women with diabetes, and their spouses also emphasized the necessity of partner involvement in diabetes care.¹² Another study showed how relationship adjustment had bidirectional effects on sexual and reproductive health experiences.²⁷ The results of a study showed an association between high-quality partner support and happiness in the relationship.³⁵ In the present study, the participants' statements reflected that in addition to the spouse's support, intimacy, and understanding of living with diabetes problems, they need to cope with diabetesrelated childbearing challenges. These results are consistent with a study that reported that 52.7% of participants were worried about their fertility and pregnancy outcomes. This finding can be due to the cultural importance of childbearing in Iran. The findings of a qualitative study confirmed the importance of childbearing in Iranian culture.³⁶

An advantage of this study was using the qualitative method to provide insight into the diabetes-related problems in sexual life and understanding the underlying reasons. As a limitation, this study recruited only married women, and also, as the subject of our study is influenced by cultural, social, and even financial factors, the generalization of these findings might be limited to similar communities.

CONCLUSION

The present qualitative study showed how sexual life is threatened by living with diabetes and affected by challenges of diabetes treatments and how the couple's relationship becomes adjusted with diabetes based on the participants' statements. Therefore, efforts to address or better adjust to each aspect can reduce the negative impacts of diabetes on sexual life. Considering sexual dysfunction screening and counseling services (for women with diabetes and their husbands) in the diabetes care system can improve the quality of sexual life in women with diabetes

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