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RESEARCH ARTICLE

‘I accept his manhood is on life-support’: A qualitative understanding of the impact of diabetes on sexual relationships among men and women living with type 2 diabetes and their partners in South Africa

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Abstract

Aims: To explore the impact of diabetes on sexual relationships among men and women living with type 2 diabetes. People living with type 2 diabetes (PLWD) and their partners in Cape Town, South Africa.

Methods: As part of a larger study developing an intervention to improve type 2 diabetes mellitus (T2DM) self management, we conducted in-depth individual interviews with 10 PLWD and their partners without diabetes about experiences living with T2DM, between July 2020 and January 2021. We used inductive thematic analysis.

Results: Both PLWD and partners felt that their sexual relationships and desires changed post-diagnosis, in ways beyond biomedical issues. Although couples' reports on the quality of their sexual relationships were concordant, most participants had not communicated their sexual desires and concerns with each other, causing unhappiness and fears of disappointing or losing their partner. Participants felt uninformed about sexual dysfunction but had not discussed this with their healthcare provider, leading to increased anxiety.

Conclusion: PLWD and their partners need more informational support to increase their understanding of diabetes-associated sexual dysfunction and to decrease fears and anxiety. Strengthening communication within couples on sexual issues may empower them to find solutions to problems experienced. This may improve couples' relationships and quality of life, and indirectly result in better self management of T2DM.

KEYWORDS

diabetes intervention, diabetes self management, qualitative research, relationships, sexual health, type 2 diabetes

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1 | INTRODUCTION

With a prevalence estimate of 15.3% for people 25 years and older and the most common cause of mortality among women, type 2 diabetes (T2DM) contributes significantly to the already large burden of non-communicable diseases in South Africa.¹ Most people living with T2DM in South Africa have poor levels of glycaemic control and face daily challenges to manage their condition, leading to complications and poor health outcomes.¹ Among these complications is sexual dysfunction, whereby erectile dysfunction (ED) and ejaculation problems are most commonly reported.² In Africa, the prevalence of ED in men living with T2DM is between 68% and 73%,³ but little is known about other sexual disorders occurring in both men and women with T2DM, including reduced sexual desire, orgasmic dysfunction and sexual pain.⁴ Sexual dysfunction is problematic. It can have negative psychological effects and increased stress levels for the individual, leading to poor self management of diabetes and can have impact within relationships.^{5,6}

Sexual dysfunction in both men and women living with T2DM continues to be under-recognised and under-treated.⁷ In part, this is due to the failure to address this complication of T2DM in clinical guidelines. The American Diabetes Guidelines (2022) only address sexual dysfunction in a single paragraph, discussing the possible treatments for ED, including vacuum devices and penile prostheses.⁸ The guidelines in South Africa (2017) are more detailed, linking glycaemic control to ED in men living with diabetes and describing the potential impact of ED on psychological state and depression.⁹ It also provides a screening questionnaire for ED and options for treatment.⁹ However, neither guideline acknowledge the possible impact that sexual dysfunction may have on relationships or address female sexual dysfunction. There is also limited evidence available for healthcare providers (HCPs) in South Africa that provide guidance on the biomedical and psychosocial aspects of sexual dysfunction.¹⁰ Furthermore, sexual dysfunction in both men and women living with diabetes are rarely discussed during consultations, especially in the public health system, used by the majority of PLWD.¹¹

Couples with a satisfactory sex life have a better relationship and improved health outcomes, even when living with chronic illnesses, including diabetes.¹² Sexuality also determines quality of life and intimacy between two partners and can influence communication and understanding within relationships.¹³ Furthermore, sexuality is a shared pleasure in relationships and fosters intimacy and bonding.¹⁴ For people living with T2DM with a partner, having a strong spousal relationship is important, as partners play a crucial role in both the medical self management

What's new

- We explored the impact of type 2 diabetes mellitus (T2DM) on the sexual relationships in couples where one partner is living with T2DM in Cape Town South Africa.
- Reported challenges were loss of libido, erectile dysfunction and decreased intercourse frequency, leading to stress, anxiety and frustration between partners.
- To improve the relationship between couples and self-management, diabetes awareness about sexual well-being is needed inside and outside clinical settings.

(including medication use and diet) and emotional self management, which regulates stressors caused by the disease.^{15–17} However, to the best of our knowledge, there are no studies in Sub-Saharan Africa investigating the link between sexual health and self management in couples of which one partner is living with T2DM. This article seeks to address this gap, as we aim to qualitatively explore the impact of diabetes on sexual relationships among men and women living with type 2 diabetes (PLWD) and their partners in urban South Africa.

2 | METHODS

2.1 | Study design

This is a secondary analysis of in-depth qualitative interviews aimed at exploring barriers to T2DM self management among people living with T2DM (PLWD) and their partners in Cape Town, South Africa. The interviews were conducted as part of a larger study, Diabetes Together, aiming to develop a couple-focused intervention to support self management of T2DM among heterosexual couples with one partner living with T2DM in South Africa.¹⁸ The Diabetes Together intervention was a joint project between the University of Cape Town (UCT) and University of Southampton (UoS).

2.2 | Recruitment

Participants were recruited from low-income neighbourhoods in Cape Town, South Africa between June 2020 and February 2021. All participants lived in townships with a predominantly black African and coloured population, including Khayelitsha, Gugulethu and Langa. For

recruitment, we used snowball method because we had no access to clinics during the SARS-CoV-2 pandemic, leveraging our relationship with the community working group linked to the Diabetes Together intervention and other community-based networks. PLWD were first screened and when eligible, invited to the study and requested to ask their partner to contact the study team. When the partner contacted the study team, they were screened for eligibility and, after providing informed consent, both the PLWD and partner were interviewed separately. Eligibility required one partner to be living with T2DM and be in a relationship for at least 6 months with someone not living with type 1 or type 2 diabetes and attending public healthcare.

2.3 | Data collection

The author team developed two topic guides, one for the PLWD and one for the partner (Appendices S1 and S2). The topic guide prompted PLWD and partners to share experiences of living with T2DM, their lifestyle habits and speak about fears of complications. To understand more about the impact of T2DM on sexual relationships, we included the following question: 'Some people who have diabetes, say that it affects their sexual health ... how is this for you?'. Due to the COVID-19 restrictions, all interviews were conducted telephonically by Buyelwa Majjkela-Dlangamandla (BM), an experienced diabetes educator. Interviews lasted between 18 and 90 min and were audio-recorded. Nonzuzo Mbokazi (Nmb) Myrna van Pinxteren (MvP), Melinda Onverwacht (MO) and BM transcribed the interviews verbatim and quality control was conducted by researchers from the University of Southampton (KS and NM). We did not reach data saturation, as the Diabetes Together study moved on to phase 2.¹⁸

2.4 | Data analysis

Interview transcripts were analysed using an inductive thematic analysis approach, guided by Braun and Clarke.¹⁹ Initially, MvP familiarised herself with the data by reading and rereading the transcripts, and then created a codebook with developing themes. These themes were discussed with the larger research team, leading to further interpretation of the content and context of these themes. A fellow researcher, Lucy Lynch (LL), was the second coder with whom MvP discussed the themes and nuances in the data, until consensus was reached. All data were explored for differences between PLWD and their partner for each theme and for

differences between men and women. We also looked at differing experiences between PLWD who were newly diagnosed and those who were living with diabetes for longer.

2.5 | Ethics

Ethical approval for the Diabetes Together study was obtained from the Human Research Ethics Committee at the University of Cape Town (reference 031/2020) and the University of Southampton (Ethics and Research Governance Online 53875).²⁰ All data were stored on a password-protected computer and anonymised before transcription and analysis. Sharing of non-anonymised data between UCT and the UoS was done using SafeSend links.

3 | RESULTS

3.1 | Participants characteristics

We interviewed 10 couples, five couples with a female living with T2DM, five with males living with T2DM (Table 1). The median age of participants was 51.5 years (interquartile range: 42.8–60.3). Four couples spoke English and Afrikaans as their primary language and six couples were speaking isiXhosa. All PLWD were living together with their partners and had been diagnosed during the relationship. The duration of diabetes ranged from 6 months to 35 years in the PLWD of whom five were also living with other chronic illnesses, including hypertension (4) and neuropathy problems (1). Four of 10 partners reported chronic conditions, including HIV (2), osteoporosis (1) and back problems (1).

The data analysis generated four main themes: (1) Experiences of sexual dysfunction; (2) Sexual dysfunction causing strain in relationships; (3) Lack of communication between partners about sexual health and intimacy; and (4) Accepting sexual dysfunction when living with diabetes.

3.2 | Experiences of sexual dysfunction

When asked about their experiences of living with, or being in a relationship with someone with diabetes, eight out of 10 PLWD identified sexual difficulties as one of the challenges, with half of them without being prompted. Although most PLWD, both male and female, felt supported by their partner and appreciated the help when following diabetes dietary guidelines, taking medication regularly and living a healthy lifestyle, they acknowledged that living with T2DM had changed their intimate relationship.

| Study ID | Gender | Age range (years) | Language | Duration diabetes | Duration relationship (years) |
|----------|--------|-------------------|-----------|-------------------|-------------------------------|
| 001D | Female | 60–70 | Xhosa | 12 years | 12 |
| 001P | Male | 70–80 | Xhosa | No diabetes | 12 |
| 002D | Female | 50–60 | Xhosa | 10 years | 10 |
| 002P | Male | 50–60 | Xhosa | No diabetes | 10 |
| 003D | Male | 40–50 | Afrikaans | 15 years | 21 |
| 003P | Female | 40–50 | Afrikaans | No diabetes | 21 |
| 004D | Female | 50–60 | Afrikaans | 35 years | 37 |
| 004P | Male | 60–60 | Afrikaans | No diabetes | 37 |
| 005D | Female | 40–50 | Xhosa | 9 years | 14 |
| 005P | Male | 40–50 | Xhosa | No diabetes | 14 |
| 006D | Male | 70–80 | Afrikaans | 18 years | 42 |
| 006P | Female | 60–70 | Afrikaans | No diabetes | 42 |
| 007D | Male | 60–70 | Xhosa | 6 months | 20 |
| 007P | Female | 50–60 | Xhosa | No diabetes | 20 |
| 008D | Female | 30–40 | Xhosa | 6 months | 19 |
| 008P | Male | 50–60 | Xhosa | No diabetes | 19 |
| 009D | Male | 40–50 | Xhosa | 5 years | 12 |
| 009P | Female | 40–50 | Xhosa | No diabetes | 12 |
| 010D | Male | 30–40 | Xhosa | 6 months | 8 |
| 010P | Female | 20–30 | Xhosa | No diabetes | 8 |

TABLE 1 Participants' characteristics.

We only got one problem, the sexual problem. That is the problem we had. It has been a problem of this year.

P002D (female, 51, T2DM for 11 years)

Feeling uncomfortable about the topic, several PLWD and partners used euphemisms to describe their own sexual dysfunction or their partners' lack of interest. 'Not having an appetite', 'not being in the mood' or 'things have changed' were the most common phrases used when speaking about sexual relationships.

It's like, you love eating chocolates. Your appetite has changed. It is not the same anymore, it is decreased.

(female, 43, partner)

Male and female partners also noticed a change in their sexual relationships but were hesitating to bring this up during conversation.

Although half the PLWD interviewed were living with additional chronic illnesses, both men and women attributed their sexual problems to diabetes.

At first, living with diabetes was just like normal life, later, I saw the negative impact of it.

As like I said like ermm ... sex drive wasn't there.

P003D (male, 46, T2DM for 15 years)

More recently diagnosed male PLWD also experienced ED, which might be attributed to uncontrolled diabetes and feeling physically ill.

I heard that when you live with diabetes, you tend not to get erection. Yah I have those difficulties. I still have those challenges as am I still waiting to see that change. Yes, it is still a bit of a challenge. This is not an easy situation.

P010D (male, 35, T2DM for 6 months)

While we did not ask this participant from whom he received information about ED, careful reading of other interviews revealed that PLWD and partners felt underinformed about the impact of diabetes on sexual relationships. This PLWD's partner also noted that his sexual behaviour had changed, which made her feel insecure and anxious.

I know something has changed, but I am not sure exactly. We are happy sometimes,

sometimes he feels down and loses interest. Then, I go home and stay there for a while. I ask myself, is the problem with me or him?
P010P (female, 28, partner)

Another recently diagnosed female PLWD remarked that not she, but her partner noticed that something had changed but could not pinpoint the exact cause of experienced problems. Loss of libido was described by the majority of couples in the study, but only one couple shared their concerns with a HCP. Reflecting on his interactions with the health services, this male PLWD, who had been living with T2DM for 18 years, remarked:

I went to the doctor, explained it to him, and he give me injections, as I don't use the tablets. But since the beginning of the year, everything went downwards. But my wife does not worry about it, that I am not that person anymore. And it is because of diabetes. Luckily my wife understands.
P006D (male, 73, T2DM for 18 years)

Other participants were either uninformed about the link between T2DM and sexual dysfunction or were hesitant to speak about their sex life when visiting the health services.

3.3 | Sexual dysfunction causing strain in relationships

All couples were concordant in describing their sexual relationship and highlighted similar events and patterns. For female PLWD, reduced sexual desire was the most mentioned, leading to a decline in frequency of sexual intercourse. Out of the five females, two were explicit about the impact that reduced sexual appetite had on their relationship.

I am not as active as in the beginning. For example, my sexual activity with my husband. That sexual desire and drive does not exist anymore, it has become prevalently scarce (laughing).
P005D (female, 46, T2DM for 9 years)

Her partner also acknowledged feeling disappointed when being rejected.

It is difficult with the sex, to the extent that we end up having a quarrel. When I am in the

mood for sex and she will tell me she is not interested or she will leave me in the lurch without reaching an orgasm ... I get angry and I will go and sleep on the couch.
P005P (male, 49, partner)

The other woman living with diabetes explained that her partner also acted frustrated about the change in sexual desires and 'struggled' to accept the situation, which caused friction in the relationship. Both women stressed the impact their loss of libido had on their relationship and tried to explain that their reduced sexual desire was a result of diabetes, not a lack of interest in their partners.

Male PLWD were also insecure about their reduced sexual health and wondered how this might impact their relationship. Some of them felt very stressed if they were not able to 'perform' in the bedroom. For men, having sex was mainly synonymous with having penetrative intercourse. However, one participant spoke about the importance of creating alternative ways to be intimate in the bedroom.

We now need to think of different ways to be intimate. I am also not 16 anymore, and now we are accustomed to doing things a little differently. Sometimes there is sexual frustration, but we are coping.
P003D (male, 46, T2DM 15 years)

3.4 | Lack of communication between partners about sexual health and intimacy

While all couples spoke openly about their experienced problems with the interviewer, in-depth analysis revealed that sexual insecurities were not discussed between partners. For male PLWD, not feeling comfortable talking about sex made them feel insecure and anxious. One male PLWD, who was still trying to understand the implications of living with T2DM, was worried about discussing his decreased sexual appetite.

What I mean is that sometimes I find out that I have loss of libido. May be my partner will not understand. I think she has fears when we have to have intimacy.
P010D (male, 35, T2DM for 6 months)

Referring to his inability to get an erection, he hesitated to discuss this with his partner. However, his partner also noticed that things were different.

What has changed that I have noticed is when we have to have sex, he is not in the mood, but I am. Sometimes he is in the mood but all of a sudden he would say there is something wrong with his waist, and he would get up and go drink water. When he comes back, I am fed up and I just go to sleep.

P010P (female, 28, partner)

Although female partners appeared to be more sympathetic about loss of libido or ED changing their sexual relationship, the lack of communication caused tension, which led to distrust and frustration in couples' relationships. One male partner expressed to the interviewer that he was often disappointed when his girlfriend was not interested in sex but would not discuss this with her.

Yes, as a human being, at some point, you will say "I do understand" in front of her, but sometimes, inside, you heart says that "why now? why am I stuck with it (the erection)?"

P008P (male, 52, partner)

Several PLWD also reported using mood swings and grumpiness as an excuse to not have intercourse, instead of openly discussing their lack of libido or potential erection problems, which further contributed to the lack of communication and honesty between partners.

3.5 | Accepting sexual dysfunction when living with diabetes

Despite the sexual difficulties experienced by most couples in this study, this did not always lead to friction in the relationship. For female partners, having a stable and supportive relationship was more important.

Yes, we have those problems, but nothing is going to change simply because he is living with diabetes. I cannot leave him now on the bed and say I am going to someone else I am not interested.

P007P (Female, 59)

Here, female partners reassured the interviewer that marital commitments outweighed the experience of sexual problems. One couple, who actively sought help from their HCP and tried injections to stimulate an erection, spoke openly and concordantly about the impact of

diabetes on their sex life. For the partner, injections felt unnatural, and she discouraged him to use them.

I am actually not bothered by it. It does not affect me. As long as we love each other, that is fine with me. I do not have a problem with it. It is just part of my life, but it is not my whole life

P006P (Female, 65, partner)

Although her partner still expressed feelings of guilt, her reassurance made it easier to accept his ED. Reflecting on this, he remarked that:

Since the beginning of the year, everything went downwards. But my wife does not worry about it, that I'm not that person anymore. I know quite a few men that got that problem with their wives. Luckily my wife understands.

P006D (male, 73, T2DM for 18 years)

Here, open communication between partners and being informed about the impact of T2DM on sexual health were key in couples' ability to reaching consensus in their relationship.

4 | DISCUSSION

To the best of our knowledge, studies about sexual relationships and diabetes in couples in South Africa are underexplored. Overall, PLWD felt supported by their partners in their diabetes self management, but both PLWD and their partners had experienced negative impact on their sexual relationship. Male PLWD reported ED, and both female and male PLWD reported a loss of libido, which they attributed to diabetes. Although couples independently shared similar details of the T2DM impact on their sex relationship with the interviewers, most men and women, PLWD and partners, had not discussed their experiences and concerns with each other. This lack of communication led to friction in their relationship and stress and anxiety among the PLWD. Despite the common reporting of sexual dysfunction by couples in our study, the participants appeared to be uninformed about sexuality and T2DM, and little reference was made to exploring options to improve their sexual well-being. Instead, participants, often reluctantly, accepted that sexual dysfunction was part and parcel of living with diabetes, despite the stress and anxiety among PLWD and relationship friction that this caused.

By actively including partners, the findings expand a small body of qualitative literature exploring the impact of sexual dysfunction on the well-being of PLWD or supporting PLWD in Sub-Saharan Africa. The anxiety and insecurity linked to ED is supported by Cooper et al. who conducted a study of sexual well-being in men with T2DM in Sub-Saharan Africa and found that men's experiences of sexual dysfunction impacted their gender identity, emotional intimacy with partners and sense of security in the relationship.²¹ Similar results were reported in a study exploring diabetes illness demands on couples in Botswana.²² The impact of diabetes on sexual relationships was also described in another T2DM self management study conducted in a peri-urban township in South Africa, whereby PLWD noted the impact as both physically, and emotionally, hereby referring to loss of libido and reduced interest in sex.²³ Although female sexual dysfunction in diabetes is understudied, women with T1D in a Norwegian study pointed to a loss of libido and vaginal dryness as complications of diabetes, resulting in challenges in the relationship between partners.²⁴

4.1 | Recommendations for practice

Literature suggests that social support and strong relationships are directly associated with better diabetes self management and health outcomes.²⁴ Thus, there is a need to actively include the possible impact of T2DM on sexual health when educating PLWD and their partners. Ideally, this education should be provided soon after diagnosis, as three recently diagnosed participants noticed a change in sexual appetite and ED but were unable to clearly describe their symptoms to the interviewer. When addressing dysfunction, health providers should also stress that depending on age and other co-morbidities, sexual dysfunction can be reversed when T2DM is controlled and patients are adhering to a healthy lifestyle.²⁵ Female PLWD should also be informed about vaginal lubrication and vaginal moisturisers to help with vaginal dryness. Crucially, there is a need to educate health workers, including community health workers and health promoters, to enable them to engage respectfully, and in culturally appropriate, sexual health discussions with PLWD and partners.²⁶

Several authors have recognised the emotional stress experienced by PLWD, and as health workers largely focus on control of blood sugars, PLWD get insufficient opportunities to discuss everyday challenges of living with T2DM, which can include sexual dysfunction.²⁷ Therefore, conversations about sexual health and diabetes between HCPs and couples on a regular basis are recommended but might be difficult to realise in the

South African public health system, as clinics are overburdened and understaffed.²⁸ However, querying PLWD about sexual dysfunction yearly and educating patients and partners in the consultation room with posters and take-home pamphlets are a low-cost solution to sensitise couples about diabetes and sexual health. Self reported questionnaires on sexual dysfunction—to be filled in in the waiting room—could also be used as conversation starters with HCPs.²⁹ When time permits, consultations on sexual health and diabetes for female PLWD can be integrated with education about menopause and women's sexual well-being.³⁰ For male PLWD, the literature on the impact of prostate cancer and sexual dysfunction can provide guidance on how to approach the topic of ED in a clinic space, as studies stress the need to encourage a realistic appraisal of experienced sexual problems, encouraging new ways to be intimate and including partners in conversations about ED and sexual health.³¹ Additionally, prostate cancer studies recommend creating an accepting healthcare environment that is sensitive to men's vulnerabilities and offering individual and couples sex therapy to patients.³¹

Alternatively, community-based activities can be introduced, within peer-to-peer support groups, which proved effective interventions to improve self management of both PLWD and people living with HIV, but were largely discontinued during the COVID-19 pandemic. Group interventions such as the Diabetes Together programme might be another option, as the piloted workshops included gender-divided dialogues on sexual health, which were well received by both PLWD and partners.^{18,27} The Diabetes Together programme was designed to support couples with communication skills that guides them through difficult conversations, which can be used to address sexual dysfunction and sexual well-being. Billboards, pamphlets and text-based mobile health messaging can provide further diabetes health education to the community.²³

4.2 | Strengths and limitations

Strengths of this study included the in-depth nature of the interviews which were conducted separately with PLWD and partners, which allowed them to be honest about their sexual well-being and allowed concordance in reports between partners to be explored at the time of analysis. We also include a varied sample of participants in terms of age, educational level, language and duration of diabetes. Although the study was conducted during the COVID-19 pandemic and PLWD were identified as particularly at risk, we still engaged with 10 couples telephonically. Limitations included possible selection bias during recruitment, as we could only enrol couples

who both consented to be enrolled in the study. We are also unable to report on experiences from PLWD in rural communities, as this study was in urban Cape Town. Lastly, the interviews did not only focus on sexual well-being but T2DM self management overall, and thus follow-up questions regarding sexual relationship reports was limited.

4.3 | Conclusion

This article adds to a small existing body of literature exploring the impact of diabetes associated sexual dysfunction on the relationships of PLWD and their partners. We highlight that although partners within couples reported similar experiences of sexual dysfunction within their relationship, these experiences and related fears were not always discussed between partners. There is a need to provide more information to PLWD and their partners on the potential impact of T2DM on sexual relationships for men and women and available solutions, both within health settings and in the community. Strengthening communication between couples, promoting open dialogue about their sexual lives with their partner is also likely to improve couples' relationships and quality of life, and indirectly result in better self management of T2DM.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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