

Lived experience and impact of oral phosphodiesterase-5 inhibitors among patients with type 2 diabetes mellitus complicated by erectile dysfunction: A qualitative study

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ABSTRACT

This study explored the experiences of men with Type 2 Diabetes Mellitus (T2DM) who also experienced erectile dysfunction (ED) and delayed seeking medical treatment. Using a phenomenological approach, in-depth interviews were conducted with 15 male patients, aged 18 and above, who had been using phosphodiesterase-5 (PDE5) inhibitors for at least three months. Thematic analysis of the interviews, framed by sexual script theory, identified three key themes. Patients reported feelings of sexual distress, a perceived loss of manhood, and inadequacy as husbands, which negatively affected their wives and relationships. Many initially believed that alternative therapies could cure ED, delaying their pursuit of conventional medical treatment. However, after complementary treatments failed, they recognized the benefits of PDE5 inhibitors. These medications significantly helped patients regain sexual strength, self-esteem, and satisfaction in their relationships. This study underscores the profound impact ED has on the sexual well-being of men with T2DM and highlights the importance of PDE5 inhibitors in improving sexual function and restoring intimacy within couples. It also emphasizes the need for early intervention and education on the effectiveness of medical treatments for ED.

Keywords: phosphodiesterase-5 inhibitors; qualitative research; diabetes mellitus; erectile dysfunction

INTRODUCTION

Diabetes mellitus (DM), characterized by impaired glucose tolerance, is commonly associated with various complications, including erectile dysfunction (ED). Both type 1 and type 2 DM are linked to a significantly increased risk of ED, with studies reporting global prevalence rates ranging from 38% to 86.1%.¹ A recent study in Pakistan involving 319 patients with type 2 DM found an overall ED prevalence of 65%, with 19% experiencing severe ED.²

The study aims to explore the experiences of men with Type 2 Diabetes Mellitus (T2DM) who also suffer from erectile dysfunction (ED), focusing on how they perceive and are affected by ED, particularly after using phosphodiesterase-5 (PDE5) inhibitors. It uses a qualitative, phenomenological approach to examine the social, emotional, and relational impacts of ED, as well as how PDE5 inhibitors influence their sexual well-being and relationships. The research also seeks to fill a gap in existing studies, particularly in Malaysia, where limited research addresses the experiences of men with both T2DM and ED. The study aims to provide insights into their experiences, emphasizing the importance of early intervention, education, and the benefits of treatments like PDE5 inhibitors.

LITERATURE REVIEW

Erectile dysfunction (ED) is a common health problem among diabetes patients. It is often missed in patient evaluations due to factors such as a lack of consideration, false patient beliefs, or the embarrassment

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experienced by both clinicians and patients.³ This contributes to high rates of ED, with many patients unaware of the actual condition they are experiencing. Further barriers to treatment include time constraints, availability of medications and geographical challenges, particularly for patients living in rural areas. Limited access to healthcare facilities, long travel distances, and the time required to visit clinics can make it difficult for these individuals to seek timely treatment.⁴

In Malaysia, cultural and psychosocial factors partially influenced their perceptions and attitudes toward ED and its treatment.⁵ Malays regarded ED as an illness and felt that its impact on their relationship with their spouse was significant. Thus, motivating them to seek treatment. In comparison to the Chinese and Indians, they perceived ED as a less severe issue. The Chinese believed that psychosocial problems, low self-esteem and anxiety were the causes of ED, and they tended to be more accepting if it was attributed to aging. Indians attributed ED to fate and experienced a lesser impact on their relationship.⁵

Much of the research has centered on the attitudes and responses to ED and what leads to men seeking or avoiding the treatment. The well-documented consequences for men with ED include a loss of self-esteem, mental health problems, and decline in sexual and overall quality of life.⁶ However, there has been limited research focusing on the experiences and impact of PDE5 inhibitors on patients with both DM and ED in Malaysia. Recent data is lacking concerning the experiences and effects of PDE5 inhibitors in Kelantan. Therefore, this study aims to delve into the meaning of living with ED, the experiences individuals have before initiated treatment, and the influence of PDE5 inhibitors on sexual well-being and marital relationships among patients with DM and ED.

The study applies Sexual Script Theory (SST) to understand the experiences of men with diabetes and erectile dysfunction (ED), and the impact of PDE5 inhibitors on their lives. Simon and Gagnon⁷ proposed that sexuality is shaped by social processes rather than just biological factors, with scripts guiding behavior on three levels: sociocultural scenarios, interpersonal scripts, and intrapsychic scripts. These scripts are influenced by illness, treatment, and perceptions of sexual importance, as well as by traditional gender roles and self-acceptance.⁸ The study's findings are important for improving sexual health in patients with both diabetes and ED, especially given the lack of qualitative research in this area.

METHOD

Study design

This qualitative study employs a phenomenological framework, originally developed by Edmund Husserl, to explore the lived experiences of men with diabetes and erectile dysfunction (ED) who use PDE5 inhibitors (Reeves et al., 2008). Phenomenology seeks to understand and describe these experiences as they manifest in consciousness, without assuming any social realities. By focusing on both the 'what' and 'how' of living with ED and using PDE5 inhibitors, the approach provides a deep understanding of participants' personal stories, using methods like epoché and intuition to capture their experiences in detail.⁹

Instruments

The study used two tools: a sociodemographic form and a semi-structured questionnaire. The semi-structured questionnaire, based on the research objectives and phenomenological framework, aimed to explore the experiences of men with Type 2 Diabetes Mellitus (T2DM) and erectile dysfunction (ED). A pilot study was conducted with three T2DM patients to test the content, length, and clarity of the interview guide. The feedback from the pilot study, reviewed by qualitative research experts, did not result in any changes, and the pilot data were excluded from the final analysis.

Data collection procedure

Patients with Type 2 Diabetes Mellitus (T2DM) experiencing erectile dysfunction (ED) were identified from the Men's Health Clinic registration list at a government clinic in Peninsular Malaysia between August 2021 and August 2022. Eligible participants, aged 18 and above and on PDE5 inhibitors for at least three months, were invited to participate through letters, email, phone, or WhatsApp. Patients with anatomical penile deformities, a history of undescended testes, premature ejaculation, or using supplements for ED were excluded. Interested participants were contacted by the researcher for further explanation and to schedule interview appointments.

On the interview day, the researcher (K.N.R) reiterated the study's purpose, obtained written consent, and had participants complete a sociodemographic form. The interviews took place privately in a consultation room using a semi-structured guide, ensuring privacy to encourage open discussion about the sensitive topic

of erectile dysfunction (ED). Participants were informed that the interview aimed to explore their experiences with PDE5 inhibitors, including their thoughts, feelings, expectations, and outcomes. They were asked to share their journey with diabetes and ED, leading to their use of PDE5 inhibitors. The interviews lasted about an hour, conducted in either English or Malay, and were audio-recorded for transcription and analysis. Data saturation was reached after interviewing 15 participants.

The interviews were transcribed verbatim and shared with participants for feedback. The transcripts were then entered into Nvivo software for analysis. The emerging themes were reviewed and refined in collaboration with qualitative research experts (RM and SBI) to ensure rigor. Additionally, six participants reviewed the findings to confirm that the interpretations accurately reflected their experiences, and all agreed with the results. The study received ethical approval from the Human Ethics Committee at Universiti Sains Malaysia (USM/JEPeM/21040314).

RESULTS

A total of fifteen men were interviewed in this study (Table 1), ranging in age from 30 to 73 years, with a mean age of 57.1 years. All participants were married, with two of them having more than one wife. Most participants had uncontrolled DM with an HbA1c level of more than 6.5% and suffered DM complications, including retinopathy, nephropathy, neuropathy and diabetic foot. All participants had a history of or current health conditions, which included hypertension, dyslipidemia and obesity.

Three main themes emerged in the lived experience and impact of PDE5 inhibitor among DM patients with ED: (i) Mental distress following ED, (ii) The influence of socio-cultural in managing ED, and (iii) PDE5 inhibitors provide new hope for couples' sexual life

Themes I: Mental distress following erectile dysfunction

Most participants had emotional changes following ED. Younger or newly married participants were more affected than the older ones. Living with ED affected not only the men's self-esteem but also the mental health of the participants' wives, and these emotions could potentially harm their marital relationship.

Feeling of loss of manhood

The participants who suffered from ED had not able to perform sexually, and this can be very frustrating. They expressed a deep blow to their ego and sense of themselves as real men when they had ED. For example, one participant, P1, remarked: *"Having this is stressful because it is important for men like us, and it feels like we are not men if it does not work."* (P1)

When the younger participants had ED, due to uncontrolled diabetes this can be even more distressing for various reasons such as unable to perform sexually, he also worried about the ability to have another child. P4, a teacher and a father of one daughter express their frustration. *"I felt quite distressed. I thought I wanted to have another child, because I am still young. However, considering my situation, it is difficult."* (P4)

Feeling of inadequacy as a husband

When the participants were not able to perform sexually well, they might have the feeling that they were inadequate as a husband. The participants expressed shame, guilt and sad about not satisfying the wife's desires and showing concern towards the wife. P7, P2 and P10 among those who expressed this concern. *"I felt ashamed and guilt with myself as a husband. Because it is my responsibility as a husband to provide for my wife. However, I could not fulfil this responsibility because I had erectile dysfunction."* (P7)

They also felt a sense of inadequacy which caused them to think of themselves as inferior to others. For example, P10 stated. *"I knew that I could not fulfil her sexual desire. When a few of my friends talked about this topic, I just kept quiet because I felt inferior to them."* (P10)

Consequences to wife

Since sex is a two-way relationship, ED affects both participants and wives. Thus, depending on the behaviors and reactions of the participants to this problem, the wives' responses can be different, such as dissatisfaction, disappointment, or refusal to have sex. P7 reported about his wife. *"She was not satisfied and easily disappointed when we had sex. Over time, we rarely have sex. Furthermore, when I asked to have sex, she would refuse or look for an excuse."* (P7)

However, older age wives, especially those who already have menopause, were not affected so much when their husbands had ED. This is because estrogen level in menopause women is low, and this can give impact on sexual function such as lower desire and make harder for them to become aroused. P3 said, *“I think women are different from men. When she is old and reaches menopausal age, she is okay if we cannot have sex because of my erectile dysfunction.”* (P3)

Similarly, P8 also expressed that his wife who also already menopause many years ago, was so understanding and could accept his fate of having ED. P8 expressed, *“I am grateful because my wife was quite understanding of my situation. She gave me a lot of encouragement. So, if I did not have sex with my wife was not a big deal. She said if I could, she was okay. However, I could not. She is also okay because she also not interested, I feel relief.”* (P8)

Theme 2: The influence of socio-cultural in managing erectile dysfunction

All participants preferred to seek complementary treatments for an average of two to three years before pursuing medical treatment at the clinic. They obtained information from friends, social media, and relatives. Reasons for this choice included feelings of shame in discussing sensitive issues like erectile dysfunction, a desire to try complementary treatments first, and the convenience of obtaining supplements through online shopping or from neighboring countries such as Thailand and Indonesia.

Alternative therapy is believed to cure erectile dysfunction

Most participants believed in the effectiveness of complementary medicine for treating various diseases, including erectile dysfunction (ED), which is commonly used among Malaysians. They reported using various complementary treatments such as kratom water, traditional massage, herbal creams, and supplements in both liquid and capsule forms. Kratom water was thought to enhance energy levels, reduce anxiety, and induce euphoria, but participants discontinued its use due to side effects like dizziness. Participant 13 shared insights into their experiences with traditional medicine. *“Some people suggested to me to drink kratom water. I tried to drink it, but it had no effect on me. It just made me feel dizzy.”* (P13)

Traditional massage using oil and cream are common in Malay culture to stimulate the nerves and clear the blood circulatory path, thereby enhancing the blood flow to organs. Five participants mentioned using massages for their ED treatment; however, none improved after a few sessions. For example, P1 mentions that: *“Before I came here, I went for massages to get the blood flowing. It is just a general massage, not specific to that part. After massages, my back pain and body pain improved, but not that ‘thing’.”* (P1) Few participants have tried pill in capsule and supplements in bottle. They brought from friends who asked them to try to solve their problem. *“My friend sells the herbal pills; he said I can try first maybe it can help. So, I tried a few times only but then I was afraid it can damage my organ.”* (P5)

Perceive benefit of conventional medicine after the failure of complementary medicine

All participants started to get medical treatment when they realized their ED worsened or did not respond to the complementary treatment. Most of them got information regarding the men’s clinic in our center and the availability of treatment by their treating doctor when they come for diabetes follow-up. For example, P8 who was asked by his treating doctor whether he is suffering from ED and was referred to men’s clinic. *“After I got erectile dysfunction, I came to the hospital to see the doctor. However, it is a long journey. Before I came here, I had tried many alternative medicines, and none of them could treat my condition until one day the doctor asked me about erectile dysfunction problem and refer me to this clinic.”* (P8)

Theme 3: PDE5 inhibitors provide new hope for couples’ sexual life

Participants explained the effect of PDE5 inhibitors on their physical and psychological self- being. Most participants expressed that the medication was effective in treating ED.

Regain sexual strength and self-esteem

Majority participants felt relief after taking oral PDE5 inhibitors. They thanked God that they got their strength back as man. They felt more confident and energetic when they tried to get close to their wife, and this medication gave them new hope. The participants now can come out of the sadness bubble and this boosting their self-esteem and confidence. *“Syukur (thanks God), doctor, this medication has improved my*

sex performance. This medication is amazing. Suddenly you feel your pride has come back and you are a man again.” (P8)

Restore couple satisfaction

Many participants were seen as satisfied after taking the medicine. Many of them claim their wives also happy with the improvement and advice to continue taking the medication.

“Alhamdulillah, after taking medicine, I could do the ‘work’, and my heart was happy. The feeling of sadness and disappointment that I had felt before was gone, and I could say that I felt satisfied when my wife also satisfied.” (P11) “It’s getting better, doctor. In the past, if I asked her for sex, sometimes she refused to. Now, I could say that she rarely refused and looked happier. She even said that she was satisfied with my performance.” (P1)

DISCUSSION

This study reveals the profound impact of erectile dysfunction (ED) on men with Type 2 Diabetes Mellitus (T2DM), affecting not only their physical health but also their emotional well-being and relationships. ED disrupts their sexual lives and strains marital relationships, often causing feelings of frustration and emotional disconnection. Participants reported poorly controlled diabetes and a long disease history, contributing to the severity of ED and complicating their sense of masculinity and intimacy. The findings highlight the importance of comprehensive care that addresses both the physical and emotional dimensions of ED in diabetic patients.

Sexual Script Theory was utilized to examine the impact of erectile dysfunction (ED) on men with Type 2 Diabetes Mellitus (T2DM) across three levels: intrapsychic, interpersonal, and sociocultural.⁸ At the intrapsychic level, ED leads to significant emotional distress, resulting in feelings of inadequacy and lowered self-esteem. Interpersonally, this distress affects relationships, causing tension and dissatisfaction with partners. Sociocultural, societal expectations and cultural beliefs about masculinity and sexual performance exacerbate feelings of inadequacy, hindering men's willingness to seek help and treatment. This interplay of factors underscores the complexity of men's experiences with sexual dysfunction.

The participants described that their feelings of inadequacy as a man and a husband are paramount significance at an intrapsychic level. In our study, participants explained that they perceived it as their responsibility to provide sexual satisfaction to their partners. Consequently, they conveyed feelings of shame, depression, guilt and self-blame due to their unable to fulfil this role due to the restrictions imposed by their ED. Yafi F et al.¹⁰ in their paper also reported that most men with ED will experience depression and anxiety, subsequently affecting the men's overall quality of life.

At the interpersonal level, this study reveals that ED not only exclusively affects men but also their wives and marital relationships. Men with ED in Malaysia have expressed a lack of confidence and insecurity in pleasing and satisfying their partners.¹¹ Since the early 2000s, literature has mentioned the effect of ED on causing female sexual dysfunction in their partners. A study by Greenstein et al. reported that 55% of wives had trouble achieving orgasm and reduced libido.¹²

A study in China showed a significant correlation between female dyspareunia and males with ED.¹³ These findings correlate with our study, where wives expressed feelings of disappointment, dissatisfaction, and a refusal to engage in sexual activity. The literature also reports a decrease in female sexual satisfaction and the frequency of orgasms in women significantly reducing after their partners developed ED.¹⁴

On the other hand, participants mentioned that older age and menopausal wives were not significantly affected if their husbands had ED. Sexual problems in women increase with age, especially after menopause. Menopausal women experience problems such as reduced libido, decreased lubrication, difficulty in arousal, and orgasm.^{15,16} This is attributed to the physiological changes in women's hormone levels during menopause, particularly the reduction in estrogen, which plays a crucial role in regulating women's sexual responses.

Participants in the study reported positive effects from consuming PDE5 inhibitors, particularly in restoring sexual strength and boosting self-esteem, which also influenced their intrapsychic level. Research by Edwards et al. indicated that men experienced significant improvements in confidence, pleasure, erectile function satisfaction, and satisfaction with medication after using PDE5 inhibitors.¹⁷ Additionally, a systematic review by McCabe and Althof¹¹ found that treatment with PDE5 inhibitors led to notable improvements in confidence, self-esteem, and depression symptoms, enhancing interpersonal relationships between the men and their wives.

Another important interpersonal finding in this study is that treating men with ED with PDE5 inhibitor significantly restores couple satisfaction. Heiman *et al.* found that men treated with PDE5 inhibitor had improved erectile function, increased frequency of sexual intercourse, improved sexual satisfaction and emotional well-being. Their partner also had a greater frequency of satisfactory sexual intercourse and enjoyment.¹² PDE5 inhibitors often reduce the worry about ED and help to facilitate a return to sexual intimacy, particularly in motivated couples and lead to a greater sexual pleasure and enrich the lives of both men and women.¹⁸

On a sociocultural level, the present study found that all participants preferred complementary medicine as the initial approach to treat ED, typically two to three years before seeking conventional treatment. A study reported that high prevalence of complementary medicine use among the general Malaysian population, with as many as 34% of the survey population reporting using complementary medicine to treat or prevent diseases.¹⁹ The main reason the participants in this study used complementary has been documented as feeling shame to discuss the sensitive issues about ED with other people and the supply is easily available through online shopping and from neighboring countries such as Thailand and Indonesia.

In our study, participants sought conventional medicine after the failure of complementary medicine, showcasing the dynamic interaction between the sociocultural factors with the interpersonal and interpsychic scripts. They expressed that PDE5 inhibitors were more effective in treating ED. Sildenafil, tadalafil and vardenafil have all been shown to be effective treatments for T2DM patients with ED.^{14,15} Consistent with our study, Tomlinson *et al.*¹⁶, found that successful ED treatment improves self-confidence and self-esteem.

The strength of this study lies in its use of a phenomenological framework combined with one-on-one in-depth interviews, which allowed participants to openly share their experiences regarding the sensitive topic of erectile dysfunction (ED). The data gathered are valuable for clinical practice, offering insights into the various factors that influence ED and contribute to emotional challenges in individuals.

The study faced limitations due to the cultural taboo around discussing sexual issues in Malaysia, leading to muted responses from some participants during interviews. Another limitation is the small sample size of 15 participants, which may limit the generalizability of the findings to broader populations. As qualitative research often prioritizes depth over breadth, the results should be interpreted with caution, and further studies with larger, more diverse samples are recommended to validate these insights. Furthermore, the study only included patients using PDE5 inhibitors, excluding those who may not seek treatment, potentially missing different perspectives and barriers. Last but not least, our study only includes married men, the findings may not fully represent the experiences of men with different marital statuses or those without partners. Expanding the participant pool to include a more diverse range of marital backgrounds could provide a broader understanding of erectile dysfunction and its impact on various demographic groups.

CONCLUSION

In conclusion, patients with T2DM who experience ED have shown that ED adversely affects their sexual lives, causing emotional disturbances and relationship problems. However, these men expressed hope for treatment. The assessment and exploration of the impact of ED in men with T2DM should be initiated by healthcare professionals who directly support this population during their consultations.

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