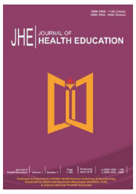
JHE 9 (1) (2024)

Journal of Health Education

http://journal.unnes.ac.id/sju/index.php/jhealthedu



Managing Diabetes: The Need for Support

Udhavana Ramraj[1]✉, Nalini Govender[2], Poovendhree Reddy[1], Raisuyah Bhagwan[3]
Durban University of Technology, South Africa

Article Info

Article History:
Submitted 12 September 2023
Accepted 11 April 2024
Published 29 July 2024

Keywords:
Diabetes, Qualitative; Psychosocial; Treatment and Management

DOI
https://doi.org/10.15294/jhe.v9i1.10060

Abstract

Background: This study aimed to determine the psychosocial aspects of diabetes management and treatment.
Methods: A qualitative research method was used to guide this study. The study population was diabetic patients over the age of 50 years. A semi-structured interview was used to obtain data, which was transcribed and coded and later developed into themes.
Results: Five broad themes emerged from the analyses, viz., patient understanding of diabetes, psychological effects, the impact of diabetes on life, experiences of support, and treatment and management of diabetes.
Conclusion: The findings from this study highlight the personal health and social strain of diabetes, as well as the challenges experienced in terms of the stress and anxieties associated with the disease

✉ Correspondence Address:
Email : udhavanar68@gmail.com

p-ISSN 2527-4252
e-ISSN 2528-2905

INTRODUCTION

Approximately 415 million people worldwide, mostly in low- and middle-income nations, have diabetes mellitus (DM) (Jaacks et al., 2016). The global burden of diabetes on health systems is alarming (Balasubramaniam et al., 2019), since prevalence is increasing exponentially (Gupta et al., 2016). The prevalence of type 2 diabetes, which was once a rare condition in Africa, is predicted to rise by 110% over the next 20 years, from 19.8 million people in 2013 to 41,5 million in 2035 (Motta et al., 2017). Information on the true prevalence of diabetes in South Africa is scarce. However, the most recent International Diabetes Federation (IDF) estimates for 2019 indicate that with an estimated 4.6 million people affected, South Africa had the highest prevalence of diabetes (ages 20–79) and the highest number of deaths attributable to DM (Ikram and Pillay, 2022).

As part of individual treatment and healthcare, effective physician–patient communication, proactive health system and family support are some of the most effective facilitators (Kumar et al., 2022 & Hill-Briggs et al.. 2021). Families are usually the first line of support for those with type 2 diabetes mellitus (T2DM) and play a crucial role in its management and control. However, this support system may demonstrate limited diabetes management knowledge (Scarton et al., 2016). Clinical depression and diabetes distress are common emotional states among diabetics, and they can significantly impair glycemic control, reduce the frequency of blood glucose monitoring, and increase microvascular complications, healthcare expenditure, and use (Van Buren et al., 2018).

Diabetes distress is associated with a lack of social support, and social stigma often prevents people from discussing or seeking help for psychological issues (Seamark and Gabriel, 2018). Family involvement can encourage positive choices and thus assist the patient in identifying and overcoming adherence barriers (Vongmany et al., 2018). It can also positively influence the patient's psychological health, offer financial support, and instil self-belief to follow medical advice, thereby encouraging behavioural changes associated with DM control and management (Vongmany et al., 2018). Incorporating psychological, emotional, behavioural, and social factors into treatment modalities would assist diabetes adherence and self-care (Kalra et al., 2018).

Social support for diabetes self-management may include trained laypeople, community health workers, certified diabetes educators, and people living with diabetes (Fleming et al., 2022). Peer support groups help in the learning process by sharing experiences and observing how others manage their diabetes, as well as offer support and encouragement, mutual guidance, and a decreased sense of isolation. Similarly, Sani and colleagues reported that conventional, passive therapy can be converted into dynamic, efficient patient engagement that enhances self-management in cooperation with the healthcare professional (Sani et al., 2018). Peer support has also been shown in clinical trials to strengthen medication adherence, manage diabetes-related distress, and improve glycaemic control (Powers et al., 2016; Spencer et al., 2018). In studies where support is given by a peer diagnosed with DM, the peer supporters typically experience similar clinical benefit as the peer recipients, demonstrating the benefits of a non-hierarchical, peer relationship (Sani et al., 2018). Understanding the various means of communication between people with diabetic patients and members of their family, partners, friends, and caregivers, including their love, care, and motivation, is thus one of the areas of medical research interest (Dong et al., 2019). In view of a growing interest in the psychological aspects of diabetes management, this study explored the psychosocial aspects of managing diabetes treatment. The phenomenon related to the lack of diabetes management attributes to several factors such as comorbidities, health literacy, access to adequate medical care as well as depression and mental health. It's essential to address these factors through targeted interventions, education, and support to improve diabetes management in older adults (Kumar et al., 2022). The goal of this study was therefore to examine diabetics' experiences of managing treatment and the psycho-social factors related to having DM among patients who are 50 years of age or older in Africa due to the dearth of information available regarding diabetes among this population and the risks associated with it (Werfalli et al., 2016). This specific group of patients were chosen as a result of their heterogeneity as older adults represent a diverse population in terms of health status, socioeconomic background, and lifestyle. Researchers can explore how different factors (such as genetics, lifestyle choices, and comorbidities) impact health and well-being in this age group (Bajenaru et al., 2022)

METHODS

Study design and site

In order to explore the experiences of patients with diabetes and the management thereof, a qualitative research method was used to guide the current study. This particular methodological approach was selected, because it advances a deeper comprehension of this human condition, in various contexts of a perceived situation (Bengsston, 2016). The purpose of qualitative descriptive research is to provide a concise overview of specific events that individuals or groups of individuals have encountered (Lambert and Lambert, 2012). By using focus groups and interviews as a data collection method, qualitative research emphasizes the essence of a lived experience or phenomenon that can be observed or felt by people with divergent viewpoints (Tomaszewski, Zarestky & Gonzalez, 2020). This study was conducted in Durban, KwaZulu-Natal (KZN), South Africa.

Ethical considerations

Ethical approval was granted by the Durban University of Technology, Institutional Research and Ethics Committee (IREC 122/20) . Following receipt of gatekeepers' permission from the Diabetic Association, participants were recruited based on specific inclusion and exclusion criteria. All participants provided informed consent. All participants were informed that their participation is voluntary, and they are able to withdraw from the study at any given time.

Participant Sampling

The study population (N=16) included Indian, White and African diabetic patients above 50 years. Participants were recruited using a non-probability purposive sampling method through liaison with the Diabetic Association of South Africa. The Association is a welfare organisation with a network of branches, that provides support and information to people with diabetes in South Africa. The Diabetic Association is a member of the International Diabetes Federation (IDF), which represents 146 diabetes organisations in 121 countries and representatives are intimately involved in several working committees on this prestigious body (Diabetes South Africa, n.d para. 3).The non-probability sampling method was appropriate for this study, as it is a technique that is predicated on the notion that any particular constituent will have a chance of being included in the study sample (Etikan and Bala, 2017). Following receipt of ethical approval (IREC 122/20) and gatekeepers permission, potential participants were informed by the senior educator of the Association about the study. Interested participants contacted the senior educator, who subsequently provided the researcher with a list of interested participants with contact information. All participants were provided with a letter of information, consent form and the interview guide prior to participation.

Data Collection

A semi-structured interview was used to collect data until saturation was reached. The interview was guided by guide inclusive of the following broad questions: 1) Can you tell me what you understand by the term diabetes?, 2) what has it been like living with the disease and how has it impacted your personal life?, 3) how do you cope with the stress of managing diabetes? and 4) how does your culture affect management of diabetes?. In qualitative research, interviews are popular data collection techniques used by scientists to understand the human experience, (Bearman, 2019). All participants provided consent to record the interview sessions which were approximately 45 minutes.

Data Analysis

Thematic analysis was used to analyse, interpret and report patterns within the data. All interview recordings were transcribed verbatim and reviewed multiple times by different people, by making notes and documenting potential codes. Once data was coded, several themes emerged, which was then interpreted according to the research objectives.

One strategy a researcher can use to convince readers and themselves that their research findings merit attention is trustworthiness. The traditional quantitative assessment criteria of validity and reliability is refined by the addition of the credibility, transferability, dependability, and confirmability criteria. For the purposes of this study, the trustworthiness criteria used was, as follows:

Credibility: Credibility is concerned with the accuracy of the data or participant perspectives as well as the interpretation and presentation of those data and perspectives by the researcher. The researcher interviewed participants and then transcribed their interviews into verbatim transcripts to preserve their credibility. In order to maintain credibility, this study was also overseen by qualified experts in the field of research.

Transferability: The generalizability of an inquiry is referred to as transferability. Only case- to-case transfer is a concern in qualitative research. Thick descriptions must be provided by the researcher so that those wishing to apply the findings to their research can assess their applicability. In order to support findings, the researcher combined extensive research from reputable journal articles with many references.

Dependability: Researchers must ensure that the research process is logical, traceable, and clearly documented to achieve dependability. The methodology that the researcher provided was comprehensive and described each step of the research process. Before putting together, the final dissertation, the researcher engaged in a number of steps and processes. A proposal was completed, approved, and given the seal of ethical approval by the gatekeepers before the study could proceed.

Confirmability: Confirmability is concerned with demonstrating that the researcher's interpretations and findings are clearly derived from the data, necessitating a justification for the researcher's conclusions and interpretations. A journal for reflection was used for this. In addition, the researcher recorded her interactions with the study participants, her personal values and beliefs and how they might have affected the study, as well as procedural notes on what was done and why. Each interview's transcription was kept by the researcher, who then went through them all to identify themes and draw conclusions.

RESULTS AND DISCUSSION

Of the 16 participants recruited, six were White, five African, and five Indian. Majority (n=9) were Christian and there was an equal distribution based on gender. Five broad themes emerged from the analyses, viz., patient understanding of diabetes; psychological effects; impact of diabetes on life; Experiences of support; and treatment and management of diabetes.

Theme 1: Patient understanding of diabetes

Theme 1 highlighted the patient's knowledge of diabetes, based on individual perceptions Two of the participants had a general idea that it refers to "high levels of sugar in the blood, as indicated below:

> "To me, it is when you have too much sugar in your body. I do not know much about it, but it is when your sugar is high in your blood." (P7)
>
> "I believe diabetes refers to excess of sugar in the blood, you know…when people say "my sugar is high" then you know that they are diabetic, yes that is what I understand by term diabetes." (P12)
>
> "I think it refers to high sugars, everything to do with sugar and glucose control, that's what I understand by it." (P4)

As indicated in the excerpts above, participant understood that diabetes refers to having "high blood sugar levels", however they lacked knowledge regarding how the disease is caused or how it affects them. This lack of adequate training and knowledge regarding their understanding is indicative of a general basic understanding. This is consistent with the findings from the Centre for Disease Control and Prevention (2020), which stated that diabetes results in excess blood sugar levels. According to a study carried out in the Eastern Cape, South Africa, participants reported a below-average knowledge and awareness of various aspects of diabetes care, including dietary changes, glucose testing, use of insulin, physical activity, identification of complications, and screening (Owolabi et al., 2022). Similar findings were reported in a study conducted in Poland where the participants had insufficient knowledge of diabetes (Sekowski et al., 2022). Diabetes patients' often experience major psychosocial discomfort and limited physical activity participation due to chronic medication use (Silva et al., 2018), and thus having sufficient knowledge is essential in empowering them to potentially overcoming such obstacles.

One participant reported being only familiar with information disseminated by their healthcare practitioners, as outlined below:

> "I only know what the doctors told me…I remember going to the clinic for some other issues and when they did tests, they told me I'm diabetic…I never learnt about it myself." (P11)

Our findings suggest that many participants are dependent on medical practitioners for gaining knowledge. It is evident that the perceptions and knowledge level regarding the management of diabetes is likely to influence the way in which they approach treatment, side effects, and the associated psychosocial and/or psychological effects. The results of our study corroborates the findings reported by Owolabi et al., (2022), who highlights the lack of communication and understanding between healthcare providers and diabetics regarding their knowledge. Similar results were demonstrated by a Vietnamese study, who reported that diabetics received minimal information and guidance from health care providers, which consequently resulted in uncertainty regarding their personal management (Gammeltoft et al., 2022).

Theme 2: Psychological effects

The second theme that emerged from the data was associated with the emotions, feelings and fears associated with DM management. Participants 5, 7 and 16 shared the following regarding their feelings:

> "Dealing with it has been difficult, people don't understand. They judge you. They don't realise that it's a 24/7 disease and it's a difficult disease….. I always felt anxious around other people, just waiting for them to pass a negative comment." (P5)
>
> "You know my life was easier before I found out I had diabetes. Living with disease unknowingly did not put so many restrictions on me. Now we must watch our food, take tablets… it's too much." (P7)
>
> "Even though I didn't know much about diabetes, my life was more smooth sailing you know, because prior to finding out…I didn't have to worry about what I eat or get all hyped up if I miss my medication…it places a burden on you." (P16)

The findings as reflected in the excerpts confirm that many participants experienced diabetes related stress once diagnosed. This may be attributed to various factors, including the implementation of changes to both dietary and physical lifestyle, incurring additional costs due to procuring medication, and their risk of DM related complications especially in those with underlying conditions.

Many diabetic patients often experience guilt, anxiety, shame, and despair when diagnosed since the cause of T2DM is perceived by society and/or healthcare practitioners to be linked with poor lifestyle choices. As shown in the excerpts above, many felt judged by family or peers after being diagnosed. Feelings associated with judgemental attitudes may result in depression and as thoughts that "they're not good enough". One participant reported "feelings of being ashamed" as they felt they were unable to consume preferred meals. Another expressed deep frustration, as they believed others perceived their symptoms as pretence. Words can either positively or negatively affect an individual and consequently affect their health, as previously reported (Dickinson and Maryniuk, 2017). It is possible that criticism and experiencing negative comments and attitudes from peers/family may exacerbate the stress already experienced with being newly diagnosed (Dickinson et al., 2017). Our findings mirrors that reported by

Dickinson (2018), who confirmed that diabetic adults felt blamed and judged by friends, family, and the general public based on the language used. Many diabetic patients often experience internalized stigma, as described by feelings of negative emotions such as failure, guilt, and blame and consequent self-judgment , which may be similar to that described by our participants.

Theme 3: Impact of diabetes on life

Theme three highlights the impact of diabetes management on life, as depicted by participants 7, 12 and 14 below:

> "It affected my vision; I sometimes feel very weak especially when I'm working and then I have to take some time to feel better then get back to work. This happens a lot." (P7)
>
> "After my amputation, driving became difficult and due to that I had to stop work. I always think if I could have avoided it, but the thing is, a small injury (which I didn't even know happened) caused me to lose a limb, I mean how could I have avoided that? It really has made a significant impact on my life; I even struggle to walk up the stairs in my house so every time I need to move around, I have to call for my wife or our helper." (P12)
>
> "I was a very big sportsman back in the day, and after my diagnosis, I became very sedentary. I couldn't strain myself and sports was something that I really enjoyed. When I had to stop, I felt very disheartened." (P14)

The excerpts reflect that the quality of life and subsequent management of these participants was negatively impacted by DM. Each participant highlighted the emotional changes and consequent the limitations that DM imposes to their personal life, indicative that it negatively affects their quality of life. Our findings concur with that reported by Diaz et al., (2016), who evaluated the quality of life of Brazilian patients. Their findings confirm physical and emotional factors as central predictors of poor quality of life, with 77.2% endorsing the emotional impact (Diaz et al., 2016). Other studies reported the experience of disrupted lifestyles due to limitations on daily activities such as driving or go shopping without assistance, as it required prior planning (Coffey, Mahon and Gallager, 2019).

The findings also suggest that the participants experience difficulties navigating through social media and society as a whole, which subsequently limit their engagement and enjoyment at social gatherings. It is possible that non-diabetics lack empathy towards diabetics as they may not have the necessary understanding regarding diabetes.

Theme 4: Experiences of support

Theme four was derived from data related to the support that participants received from their families and social support groups. Participants 1, ,7, 9 and 10 highlight the support that families and support groups provide.

> "Aside from my family, I form part of a support group for type 1 diabetics. It's comforting knowing that there are others with similar problems as you and we help each other with stories of our personal experiences. We even have a WhatsApp group now and we communicate there." (P1)
>
> "My husband does not know much about diabetes, but he always makes sure I take my medication. When I am not well, he helps me and takes care of me. He is very good and caring. My husband and my child are the only family I have" (P7)
>
> "You know as much as they say family is family (and I know that), but I think what helps me more is the support I receive from individuals with the same condition as me because we understand each other on our bad days. Look, I am not disputing the fact that my family is there for me…but I also have to give credit to the diabetes focus group that I joined about 2 years ago, these members have really helped me on my diabetes journey." (P9)
>
> "My wife and kids are very supportive. My wife makes sure my diet is followed and makes sure my medication is taken on time. My wife also makes sure I hit the gym when I'm supposed to." (P10)

The data emanating from the excerpts indicates the efforts taken to improve the quality of life and is suggestive that they prefer to share their experiences with those who share similar encounters, so they understand their feelings . As evidenced in the data, this type of support helped the affected individuals gain the strength and motivation to have a positive mindset to cope with their diagnosis which significantly decreased their feelings of depression and anxiety. Additionally, the data highlight the importance of support groups, and its potential role in improving quality of life. A recent study reported the significance of trained laypeople, community health workers, certified diabetes educators, and people living with diabetes as integral social support structures (Fleming et al., 2022).

Despite T2DM being a degenerative condition, most patients manage their illness via family support, indicative of a positive impact on patient attitudes toward self-care (Kristianingrum, Wiarsih and Nursasi, 2018). As revealed in the excerpts, the perceptions of a diabetic regarding family support, greatly influences how well they are able to manage their condition. Several studies highlight the relevance of family involvement or support from family, which appears to enhance the self-care behaviours of diabetic patients' and promote favourable clinical outcomes, like reduced HbA1C levels (Gomes et al., 2017; Huang et al., 2014; Pamungkas, Chamroonsawasdi and Vatanasomboon, 2017 and Wichit et al., 2017). These findings emphasises the importance of encouragement and family participation in improving management of T2DM. Similarly, Mogre and colleagues highlighted the value of family support in implementing changes in diet self-care behaviours and demonstrated that those without such support often experience difficulties in adhering to dietary modifications (Mogre et al., (2019).

Family involvement especially focussing on increasing physical activity, eating healthy and providing emotional support to the affected individual, has a greater potential in improving diabetes management. This in turn may motivate patients to reinforce their efforts to manage their condition and subsequently decrease the emotional strain associated with management.

Theme 5: Coping with treatment and management of diabetes

The fifth theme emerged during analyses highlighted the coping mechanisms associated with the treatment and management of T2DM. Participants 6 and 16 reported the following:

> "I don't like taking my insulin shots in front of people, it makes me feel really uncomfortable, people stare. That's kind of annoying you know." (P6)
>
> "Personally, it hasn't really affected me much but if my daughter isn't there, I always feel edgy and forget about some of the important things like my medication for one." (P16)

As evidenced in the data, the participant's experiences differed regarding treatment adherence. Participants reported being forgetful at times to take their medication, which subsequently results in feelings of stress at their non-adherence and its probable impact on their quality of life. Also evident in the data, is that family support positively influences adherence, as they rely on family members for simple reminders, even though they may not be aware of it intentionally.

The findings from this study is similar to that reported by Holmes-Truscott et al., (2016), who highlighted feelings of "awkwardness" when using insulin in public, which consequently contributed to insulin non-adherence. Self-stigma such as feelings of embarrassment, guilt, or failure, as well as concerns regarding indifferent treatment, can significantly influence the psychological barriers associated with insulin use. The fear of using insulin can potentially result in personal failure, poor health outcomes, as well as feelings of embarrassment over how others view insulin injections (Holmes-Truscott et al., 2016). Some T2DM patients who take insulin are reported to also experience psychological insulin resistance and thus impairs their ability to effectively administer insulin (Holmes-Truscott et al., 2018 and Allen et al. 2017). Many patients view the administration of insulin treatment as a personal failure to deal with the illness (Nam et al., 2011), whilst others who received effective insulin treatment experienced feelings of fear and guilt (Jacksonman and Pettus, 2014). The fears associated with the use of insulin, viz., personal failure and deteriorating health, as well as embarrassment over how others view insulin injections (Holmes-Truscott et al., 2016), is likely to negatively impact how well a person adheres to medication and may increase their risk to other consequences if proper care is not taken.

Similarly, our results highlight feelings of "awkwardness" when using insulin in public, which possibly contributes to insulin non-adherence. Individuals' self-stigma (such as feelings of embarrassment, guilt, or failure) and worries about being treated differently because of their diagnosis, can significantly influence their decisions and psychological barriers to insulin use. This undeniably influences medication adherence and can exacerbate the risk of severe clinical outcomes. Peer and family support is essential in mitigating poor adherence and thus enhancing effective management of the patient.

CONCLUSION

The findings from this study highlight the personal health and social strain of diabetes, as well as the challenges experienced in terms of the stress and anxieties associated with the disease. We also demonstrate that diabetes affects the psychological well-being of the patient due to the constant fear of its debilitating health effects.

Initiatives to increase information on diabetes is recommended as it has potential to effectively assist in disease management. Healthcare and medical practitioners also have an important role in influencing diabetes management and medication adherence. Further research must be conducted with regards to healthcare practices and diabetes management. Diabetes mellitus treatment and prevention efforts are further impeded in South Africa by the country's health system prioritising infectious diseases (e.g. human immunodeficiency virus and acquired immune deficiency syndrome, tuberculosis and maternal and child health services. Providing support to diabetics has been shown to positively influence treatment. Individuals in this study expressed that diabetes has impacted their lives in a significant way and those around them. Significant quality gaps continue to exist and persist in the management of DM. Through effective management, the impact of this rapidly emerging health burden can be reduced.

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