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Original Research Article

Barriers and factors influencing how adults with type 2 diabetes perceive their risk of developing diabetes-related complications: a qualitative study

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ABSTRACT

Background: Delayed diagnosis and poor management of type 2 diabetes can lead to severe acute and long-term complications, such as early death or disability. Research evidence has shown that without consistent and effective self-management practices, individuals with type 2 diabetes face a higher risk of avoidable complications. These self-management practices are mainly influenced by individuals' perceptions of the risks linked to diabetes complications. Due to poor self-management practices particularly in Sub-Saharan Africa, it is crucial to identify the barriers and enablers that shape patients' perceptions of their risk of developing complications.
Methods: Twenty-three individuals with type 2 diabetes were purposively and theoretically sampled from purposively selected community pharmacies in Harare, Zimbabwe, between October 2023 and January 2024 and participated in semi-structured interviews.
Results: The analysis of the data revealed that participants perceived risk of complications differently: some perceived a higher risk, while others perceived a lower risk, based on the meanings they ascribed to living with type 2 diabetes. Facilitators to perception of risks of complications were: (i) having personal risk experiences; (ii) information-seeking; and (iii) engaging in health-seeking behaviours. In contrast, barriers to perception of risks of complications were: (i) holding cultural or religious beliefs; (ii) being in denial about the illness; and (iii) lacking knowledge about diabetes.
Conclusions: This study explored the factors shaping patients' perceptions of risks for developing diabetes-related complications. It offers important insights into risk perception research in resource-constrained environments and assists healthcare providers and policymakers in developing strategies to support those at higher risk of such complications.

Keywords: Barriers, Complications, Constructivist grounded theory, Facilitators, Risk perception, Type 2 diabetes mellitus

INTRODUCTION

Type 2 diabetes (T2D) has become a significant public health concern due to its high incidence, associated complications, and rising mortality rates, particularly in developing countries where these issues are more severe than in developed nations.[1] Developing countries, especially in Sub-Saharan Africa (SSA), have experienced an extraordinary increase in T2D prevalence, rising from 4 million cases in 1980 to 23.6 million in 2021- an increase of 490%.[2] If no effective strategies are implemented, T2D cases in SSA are expected to double, reaching 54.9 million by 2045.[2,3] In Zimbabwe, T2D cases have increased over the past four decades, with

many individuals remaining undiagnosed or poorly managed due to socio-economic challenges and inadequate healthcare systems.[4] Poor management and delayed diagnoses of T2D may lead to complications and place a heavy burden on public health systems, creating significant socio-economic challenges for affected individuals and communities.

Effective diabetes self-management practices are vital for preventing diabetes-related complications and improving health outcomes and quality of life.[5] There is growing concern that without regular efforts- such as foot and eye exams, blood glucose monitoring, physical activity, healthy eating, medication adherence, and weight control- people with T2D face a higher risk of preventable complications.[3] Furthermore, a review highlighted that diabetes self-management in SSA was poor, representing a public health threat to individuals and the healthcare system.[6] There is a compelling need to raise awareness and promote better diabetes self-management practices to diminish this public health threat, including the spread of the disease and its negative impact on individuals and healthcare systems due to diabetes-related complications.

Significantly, behavioural adherence to diabetes self-management is strongly influenced by individuals' perceptions of the risks associated with T2D complications.[5,7] For example, health decisions often involve weighing risks and benefits; underestimating risks can decrease motivation for healthy actions, while overestimating risks might lead to adverse health outcomes.[5,8] Furthermore, previous research shows that risk perceptions are influenced not only by individuals' ability to understand numerical threat data but also by their personal experiences.[5,8] Additionally, perceptions of their risk for diabetes complications significantly influence individuals' motivation to adopt healthier lifestyles.[7] Many individuals with T2D are unaware of the full range of possible complications.[9] Therefore, healthcare professionals need to prioritise educating patients about their risks of developing diabetes-related complication to encourage prevention. Moreover, as the prevalence of T2D and its complications rises in Zimbabwe, it becomes increasingly important to understand how individuals perceive diabetes risks. To the best of our knowledge, there is limited recent research on how Zimbabwean populations perceive the risks associated with diabetes complications or how these perceptions influence future health behaviours.

This study, therefore, aimed to examine the barriers and enablers that influence T2D individuals' perceptions of their risk of developing diabetes-related complications. Identifying the factors that shape patients' perceptions of risk of developing T2D-related complications can offer valuable insights to healthcare providers and policymakers, ultimately promoting better self-management practices, enhancing health outcomes and quality of life.

METHODS

This study employed the constructivist grounded theory (CGT) qualitative approach, reflecting the researcher's philosophical stance.[10] The choice of CGT was guided by its ontological assumption of multiple realities, shaped by participants' experiences and perspectives and influenced by their varied demographic, social, cultural, and political backgrounds.[10] Moreover, this approach emphasizes the researcher's active role in interpreting the meanings participants ascribe to their experiences of living with T2D in their own situations, and actions in their own social contexts.[10]

Study setting, sampling, and data collection

The study was conducted in Harare, Zimbabwe, from October 2023 to January 2024. The setting for the study was community pharmacies (CPs) that were purposively recruited to both recruit and host the study participants. The participating CPs consented to the display of the study recruitment flyers and participant information sheets (PIS), which outlined the study's objectives and procedures. The inclusion and exclusion criteria for the study are detailed in Table 1.

Table 1: Participant inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
Diagnosis of type 2 diabetes	Absence of type 2 diabetes
18 years and above	Type 1 diabetes
Resides in the city of Harare	Aged below 18 years
Male and female	Resides outside Harare
Accessed community pharmacies in Harare for type 2 diabetes management	Accessed community pharmacies outside Harare
Absence of type 2 diabetes complications (renal dialysis, blindness, stroke)	Did not utilise community pharmacies for diabetes care
Mental capacity to make informed consent	

The study employed two sampling methods: purposive and theoretical sampling. Purposive sampling involved recruiting eight adults with T2D to identify themes for further analysis. Participants were provided with PISs and given at least seven days to decide whether to participate. Those who agreed signed consent forms and were informed they could withdraw at any time without giving a reason. To protect confidentiality, personal identifiers were removed from responses, and pseudonyms were assigned. In-depth, face-to-face, semi-structured interviews explored their experiences with diabetes self-management. Each interview lasted between 40 and 60 minutes, was audio-recorded, and transcribed by the lead researcher. Data collection and analysis were performed simultaneously following CGT principles, despite the non-linear process. Participants received US$10 to cover transportation and related expenses.

As themes emerged, we applied theoretical sampling guided by Charmaz's CGT principles, recruiting additional participants and exploring less-developed categories. This process included reviewing memos, field notes, and raw data to find overlooked information, as well as recontacting some participants for additional interviews. Saturation was reached when no new insights or elements of the core category appeared. Overall, 23 participants took part in 28 interviews.

Ethics

The study was approved ethically by Nottingham Trent University's School of Health and Social Care and the Zimbabwe Medicines Research Council Ethics Committees (MRCZ/A/3096). Participating community pharmacy managers granted access to, and use of, their premises once ethical approval had been granted.

Data analysis

As the lead researcher, the author manually analysed the data by thoroughly reviewing all interview transcripts, memos, and field notes collected during the study.[10,11] The research utilized Charmaz's CGT data analysis framework, which involves three interconnected coding stages: initial, focused, and theoretical. These stages were applied iteratively rather than in a strict sequence.[10] Coding was performed immediately after data collection to categorize and summarize interview details. The author switched between initial and focused coding as new insights arose.[17]

The focused and theoretical stages facilitated the identification of key categories. The constant comparison method was employed to detect similarities and differences within the data, refining the analysis and developing a theoretical understanding of participants' perceptions of their risk of developing diabetes-related complications.[11]

RESULTS

Twenty-three participants with T2D were interviewed for this study. Their demographic details are shown in Table 2.

The study revealed that participants' perceptions of risk differed: some had a higher risk, while others had a lower risk, depending on the meanings they ascribed to living with T2D. The main findings are organized into two themes: factors that facilitate and barriers that hinder perception of risk to developing diabetes complications. The themes and subthemes are presented in Table 3.

Table 2: Demographics of the study participants.

Demographics		Count (%)
Gender	Male	12 (52.17)
	Female	11 (47.83)
Age in years	20-40	15 (65.21)
	41-60	8 (34.79)
Marital status	Married/partner	14 (60.86)
	Single	6 (26.08)
	Divorced	2 (8.69)
	Widow	1 (4.34)
Residential status	High density	7 (30.43)
	Medium density	13 (56.52)
	Low density	3 (13.04)
Educational status	No formal education	1 (4.34)
	Secondary education	6 (26.08)
	College	7 (30.43)
	University	9 (39.13)
Employment status	Employed formal	12 (52.17)
	Informal employment	7 (30.43)
	Unemployed	4 (17.39)
Smoking status	Smoker	1 (4.34)
	Non-smoker	22 (95.65)
Alcohol consumption	Yes	6 (26.08)
	No	17 (73.91)
Years lived with a diagnosis of diabetes	Less than 1 year	2 (8.69)
	1-3 years	9 (39.13)
	4-6 years	6 (26.08)
	7-10 years	4 (17.39)
	Over 10 years	2 (8.69)

Table 3: Themes and subthemes.

Themes	Subthemes
Facilitators of the perception of risk of developing diabetes-related complications	Information-seeking Engaging in health-seeking behaviours Having personal risk experiences
Barriers to the perception of risk of developing diabetes-related complications	Holding cultural/faith beliefs Being in denial about the illness Lacking awareness about diabetes

Facilitators of the perception of risk of developing complications

Facilitators to the perception of risk of developing diabetes complications are elements that influence patients' behaviour and health choices. They also directly impact whether patients seek medical assistance and how they manage potential risks.[12] The factors that enhance the perception of risk are diverse, and our study highlights the following: (i) having personal risk experiences; (ii) information-seeking; and (iii) engaging in health-seeking behaviours.

Having personal risk experiences

The participants' experiences of caring for or living with friends and family exposed them to risk, resulting in negative emotional reactions. These experiences made them more resilient when facing a T2D diagnosis and heightened their awareness of the potential complications of T2D.

"*As a family, we cared for my father and grandmother, both affected by type 2 diabetes. They experienced multiple stages of the illness and had several hospitals stays. By the time my grandmother died, she was blind. Caring for them heightened my awareness of my own risk of complications. I have researched extensively on the topic and prioritise my health" (Linda).*

"*My father-in-law had diabetes and endured significant suffering from the disease. He lost his leg because of it and eventually needed renal dialysis. Despite his health problems, he continued drinking alcohol. His suffering deeply affected me, and I would never want to experience the same. Since being diagnosed with diabetes, I have altered my lifestyle". (Nicodimus)*

The study showed that participants felt emotional distressed from caring for family and friends with diabetes-related complications. These experiences heightened their fears about the worsening of their own illness and the perceived higher risk of complications.

Information-seeking

The study findings indicated that participants were actively seeking information about their condition and methods to enhance self-management practices and health outcomes. This information-seeking behaviour increased their awareness of the risks related to diabetes complications.

"I aimed to improve my well-being and manage my illness better by gathering information from various sources. This helped me understand different aspects of type 2 diabetes, including its complications. I became conscious of my dietary management and ensured I attended all routine diabetes reviews at the hospital. I also became more aware of the risks associated with developing diabetes-related complications". (Yolanda)

The study found that some participants sought information to better manage their diabetes and improve their overall quality of life. Notably, seeking information raised their perception of the risks of complications, as they became more aware of the issues and the evidence-based self-management practices.

Health-seeking behaviours

The study findings showed that, despite the impact of socio-economic and cultural factors, some participants still chose to seek healthcare from medical institutions rather than traditional or faith healers. Those who opted for medical care experienced better diabetes outcomes and had greater awareness of the risks associated with diabetes-related complications.

"When I experienced bodily changes, I sought help from my GP. My GP was supportive because he provided all the information, I needed to manage my condition and helped me understand the risks of developing diabetes-related complications. I became knowledgeable about my illness and learned to recognise early signs or problems in my body before they worsened, allowing me to seek help from my GP promptly". (Henry)

"I developed a solid professional relationship with my local pharmacist, who supported me in managing my illness and understanding of the diabetes-related complications. His information was helpful, which improved the overall management of my condition". (Tanaka)

The study found that participants who accepted their type 2 diabetes diagnosis were more likely to seek medical care, leading to improved health outcomes. As part of their health-seeking behaviour, some participants gained knowledge about the illness, which increased their perceived risk of developing diabetes-related complications.

Barriers to the perception of risk of developing diabetes-related complications

Participants had different perceptions of their risk for diabetes complications. While many acknowledged they were at risk, they often felt unsure about how to prevent or delay these issues or what steps to take. Barriers to developing a clear risk perception include various factors, with our study highlighting the following: (i) holding cultural or religious beliefs; (ii) being in denial about the illness; and (iii) lacking knowledge about diabetes.

Holding cultural/religious beliefs

Some participants saw their lives as predetermined, trusting that God controls everything, which related to the concept of inevitability. From a cultural standpoint, others thought that the illness was caused by witchcraft and needed traditional treatment methods. While other participants felt helpless and less responsible for their predicament, viewing the illness as part of God's plan and perceiving a low risk of diabetes complications.

"*I believe everything happens for a reason. It's all part of God's plan that I have this illness, and I am unaware of any complications related to it. If there are complications, they are part of God's plan, and the Lord's power will resolve them*". *(Wonder)*

Whatever happens, it will happen. I'm not concerned about complications, if they ever occur". (Ngoni)

Being in denial about the diagnosis

The study findings showed that some participants refused to accept their type 2 diabetes diagnosis, which negatively affected how they managed their condition. Those who denied their diagnosis perceived a lower risk of developing diabetes-related complications.

"*I have never heard of this illness before and have never met anyone with it. I want to believe it is all related to witchcraft. I don't believe in the illness itself, and I am unaware of any complications associated with witchcraft, other than the practice of sending bad spirits back to their sender*". *(Tadiwa)*

Some participants showed a clear detachment from their new health reality; despite experiencing bodily changes, they believed the illness was a curse caused by evil spirits and denied the existence of complications linked to the disease. Overall, they were in denial about their diagnosis and underestimated the risks of diabetes-related complications.

Lacking knowledge about diabetes

The study findings showed that some of the participants lacked knowledge and awareness of diabetes-related complications and showed little responsibility or motivation to understand how serious the illness could be on their overall health and well-being.

"I am not aware of any possible complications associated with the illness". (Grace)

"I lack knowledge about diabetes-related complications, and I have never considered them, nor do I know where to find such information". (Nyarai)

"I lack the resources to research the diabetes-related complications and cannot afford medical consultation fees. As a result, I am entirely unaware of the complications associated with the illness". (Tafadzwa)

DISCUSSION

Poorly managed T2D can lead to both immediate and long-term health problems, often resulting in hospitalisation, disability, lower quality of life, and early death.[5] This research identified factors influencing how participants with T2D perceive their risk of developing diabetes-related complications. Facilitators include having personal risk experiences, proactive health-seeking, and information-seeking behaviours. Barriers included having limited knowledge of diabetes, being in denial of the diagnosis, and having cultural or religious beliefs. Importantly, evidence from prior research has shown that individuals with a better understanding of T2D were more aware of their risk of complications than those with less knowledge.[13] This aligns with the health belief model, which posits that positive health behaviours are driven by perceived or expected benefits. However, while risk information can encourage behavioural change, humans often make irrational choices.[14] Even when aware of risks, individuals tend to underestimate the overall danger.[15] Therefore, effective diabetes policies should focus on educating all diagnosed patients about the treatment benefits and risks, particularly regarding long-term organ damage.

Our study found that participants' information-seeking behaviours were shaped by factors such as education, socioeconomic status, diabetes knowledge, and age. This supports earlier findings that personal and socio-economic factors influence how individuals search for health information.[16] Prior research indicates that adults with higher education levels generally demonstrate more effective online health information-seeking behaviours than those with lower education levels.[13] Moreover, studies highlight that T2D, is significantly affected by socioeconomic factors that influence health outcomes.[26] Removing barriers to access can greatly enhance patients' diabetes knowledge, lower the risk of complications, and improve their quality of life. Additionally, research shows that the primary reason for seeking information is to help individuals with T2D manage their diagnosis and health concerns.[13] Tackling health literacy barriers is essential since they limit access to critical health information. Providing relevant information boosts patients'

understanding of symptoms, treatments, and necessary lifestyle changes, a vital public health approach to improving diabetes management and reducing complications.[17]

The literature on public health promotion supports the study's findings, indicating that participants' health-seeking behaviour is mainly influenced by the presence of symptoms, a T2D diagnosis, perceived threats of disease progression and its consequences, and the perceived benefits of seeking healthcare. These factors elevate their perceived risk of complications.[18] However, many with T2D initially experience no symptoms, which can diminish the urgency to seek medical care and lead to denial of the diagnosis- posing a significant obstacle to effective management and the prevention of complications.[19] Furthermore, limited awareness of the condition often causes underestimation of its severity and risk of progression, resulting in poor health-seeking behaviours and worse health outcomes.[20] Therefore, public health promotion strategies are crucial to fostering early diagnosis and treatment of T2D. Such initiatives can help prevent complications and lower overall management costs. Additionally, participants' health-seeking behaviour significantly influenced their acceptance of T2D and its outcomes, consistent with prior research.[20] Engaging in proactive health-seeking behaviours can decrease dependence on screening, early detection of symptoms, and diagnosis, leading to improved diabetes self-management and health outcomes.[18] It also enhances diabetics patients' awareness of potential complications, thereby reducing the onset of diabetes complications.

Our research indicates that those with a deeper understanding of T2D- often gained through family and social networks- tend to perceive higher risks of complications, consistent with earlier studies.[21,22] An ethnographic study of SSA immigrants in the UK reported similar patterns, highlighting their experiences with severe diabetes-related complications and deaths within their families.[22] These experiences, built up from caring for loved ones with T2D over the years, shaped their attitudes toward lifestyle choices and heightened their understanding of the disease's severity. Consequently, they became more health-conscious and aware of the risks. However, merely perceiving risk may not be sufficient for individuals with T2D to change their self-management behaviours. With positive expectations of outcomes and strong self-efficacy, there is potential to improve health behaviours and sustain positive changes through self-regulation strategies.[23] Thus, public health policies should incorporate more family-centred approaches in personalised healthcare programs to improve quality of life and health outcomes.

Previous research indicates that cultural and religious practices significantly affect how individuals manage diabetes, especially concerning diet and exercise.[24] In many developing nations, such as those in SSA and the Arab world, being overweight is often seen as a sign of status, while weight loss is discouraged.[25] Our study shows that cultural and religious beliefs influence participants' self-management practices, including limiting their knowledge and health literacy, fostering misconceptions, and leading to non-adherence to treatment. These findings are consistent with previous studies.[26] For instance, some participants, motivated by their faith, sought oils and water blessed by church leaders to treat their diabetes, which harmed their health and caused acute complications and hospitalisations. As in a scoping review that identified Christian healing practices in Cameroon, such as prayers, communion, oil anointing, and fasting, as part of diabetes self-management, our results show that many participants believed that 'diabetes prayers' and 'anointed oils' could cure T2D and perceived a low risk of complications.[27] While these practices may improve emotional and psychological well-being, they can also impede effective self-management by delaying medical care and increasing the risk of complications.[18] Incorporating religious and cultural perspectives into diabetes management could improve outcomes by promoting resilience, community engagement, and social support.[28] Furthermore, existing research emphasises that healthcare providers should respect patients' religious beliefs in diabetes care, as such beliefs about origins and prognosis influence treatment responses.[29] Our findings highlight that religion and culture are central to shaping perceptions of diabetes risk, which is vital because all cultures have health belief systems that define the causes of illness and influence understanding, management, and coping mechanisms.[29] This insight is particularly relevant for patients with diabetes in socio-economically disadvantaged regions like SSA, where limited resources heavily affect self-management practices.

This study found that many participants denied their T2D diagnosis, which led to delays in treatment, poor self-management, and a higher risk of complications. Previous research indicates that prolonged illness denial can harm health by causing treatment delays, poor medication adherence, lower risk perception, and refusal to start necessary therapies.[30] Another study showed that denial is a major barrier to proper self-management practices and can lead to both acute and chronic complications.[31] Although literature suggests that denial is a common initial reaction to grief, applying strategies to help individuals accept their new health status is vital to prevent negative health outcomes.[32] Acceptance of a T2D diagnosis is linked to awareness, education, social support, socio-cultural influences, and a heightened perception of risk for complications, while denial is influenced by factors affecting how participants perceive the importance of their lifestyle and perceived risks. Hanif et al[33] described denial as the refusal to accept an intolerable situation or emotion, viewing it as a defence mechanism that protects the ego from anxiety. Although denial may provide temporary relief, a previous study warned that persistent denial could indicate pathology.[33]

Notably, patients with T2D are 2-4 times more likely to die from cardiovascular issues than those without diabetes.[34] This underscores the importance of early diagnosis and acceptance in improving health outcomes and shaping patients' perceptions of risk.

Previous research shows that increasing knowledge and education about diabetes and its complications can improve self-management practices and reduce health risks.[35] However, this study found that some participants were unaware of diabetes and its dangers. This aligns with a previous study, among ethnic minorities in London, UK, where high T2D rates were linked to limited understanding of the disease's risks and complications.[33] Our findings reconciles with previous studies, indicating that participants do not see a T2D diagnosis as seriously as cancer and view HIV/AIDS as more severe than diabetes.[33,36] Moreover, Afaya reported that over half of the study population lacked adequate knowledge about diabetes complications.[33] Similarly, Obirikorang found that, although some participants recognised certain complications, their understanding was superficial-consistent with our study results.[37] Other studies show that T2D patients often have only a vague awareness of the link between T2D and heart disease, supporting our findings.[38,39] Participants' knowledge affects how they manage their diabetes.[40] Therefore, identifying knowledge gaps and providing educational resources are vital for improving self-management practices and awareness of potential diabetes-related complications.

Implications for practice

Healthcare professionals should incorporate patients' cultural and religious beliefs into their self-management practices to support a patient-centred approach to diabetes care. Additionally, HCPs ought to address the main issues identified in this study within educational and intervention programmes to enhance patients' knowledge, awareness, and self-management practices.

The study's conclusions are limited to the participants' social and economic backgrounds and may not generalise to the wider population or other contexts. Additionally, geographical limitations and sample-size constraints in selecting study sites led to the exclusion of potential participants. Despite the limitations, mixed-methods research could be conducted in the future to explore the influencing factors by increasing the sample size and enhancing the representativeness of participants.

CONCLUSION

Public health policymakers and healthcare professionals should raise awareness of T2D in the general population and strengthen awareness of diabetes-related complications to improve health outcomes. This will help deepen their understanding of diabetes-related complications and enable them to accurately assess their risk of developing them. The study indicated that risk perception is a complex, evolving process influenced by various factors and requires a comprehensive strategy. Such an approach aims to empower patients with T2D to better manage their condition and enhance their quality of life.

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