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Original Research Article

Exploring the pathway from recognising symptoms to receiving a type 2 diagnosis among adults: a grounded theory study

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ABSTRACT

Background: The rising incidence of type 2 diabetes in Zimbabwe is linked to notable delays in diagnosis after symptoms emerge. Early detection, even before symptoms appear, is vital for clinical, social, and public health purposes. Although epidemiological data indicate an increase in cases, little is known about how patients perceive and respond to initial signs of diabetes. Gaining insight into this pre-diagnosis phase is essential for developing strategies to promote earlier detection and better engagement with healthcare services. This study examined the pathway from symptom recognition to a diagnosis of type 2 diabetes.
Methods: The study was guided by a constructivist grounded theory approach. Twenty-eight semi-structured interviews were conducted with individuals diagnosed with type 2 diabetes at selected community pharmacies in Harare.
Results: A theoretical category, 'learning I have diabetes,' emerged from the data analysis. 'Learning I have diabetes' is a non-linear process marked by interconnected milestones, such as recognizing symptoms, seeking information, health-seeking, experiencing negative emotions, denying the diagnosis, and ultimately accepting it. The theoretical category outlines the social processes, from recognizing bodily changes and investigating behaviours to diagnosing type 2 diabetes.
Conclusions: The process from recognising symptoms to receiving a type 2 diabetes diagnosis is intricate and not straightforward. It is influenced by psychological, socio-cultural, economic, and relational factors that affect health-seeking behaviours. This study indicates that culturally tailored awareness campaigns, enhanced primary care screening, and targeted information sharing can promote earlier diagnosis and help prevent diabetes-related complications.

Keywords: Constructivist grounded theory, Diagnosis, Symptoms, Type 2 diabetes

INTRODUCTION

Type 2 diabetes (T2D) continues to be a significant global health challenge with profound economic, social, and political effects. Its rates are increasing more rapidly in developing countries than in developed countries. In 2015, Africa was the only continent where infectious diseases caused more morbidity and mortality than T2D.[1] However, this pattern is rapidly changing as Sub-Saharan Africa (SSA) faces an escalating T2D burden.[2,3] By 2030, an estimated 40.7 million adults in SSA will have T2D- representing a 162.5% increase from 15.5 million in 2017- if efforts to improve diagnosis and treatment are not intensified. The rise in T2D prevalence in SSA is anticipated to outpace that in other regions globally.[4] These alarming statistics highlight the significant threat that diabetes poses to both human health and economic stability in SSA.

The burden of type 2 diabetes is rising in Zimbabwe, yet many people face significant delays between experiencing symptoms and getting a formal diagnosis.[5] For example, the prevalence of diabetes in Zimbabwe has increased sharply over the past 40 years, impacting around 850,000 individuals in 2018.[6] Projections indicate that by 2035, more than 1.2 million Zimbabweans will have T2D unless urgent strategies are introduced to address the crisis.[7]

Zimbabwe lacks a national health insurance system, resulting in high healthcare costs. For example, managing diabetes costs about US$1,300 annually, and complications from diabetes can add roughly US$2884 per year per patient.[8] The absence of universal healthcare coverage in Zimbabwe starkly contrasts with the UN sustainable development goal 3, which aims to expand access to healthcare, improve care quality, and reduce financial hardship for patients.[9] The high costs of diabetes management and the lack of universal coverage pose significant barriers to healthcare access, potentially harming patients' quality of life unless targeted measures are taken to reduce disparities in diabetes care.

The IDF has highlighted that nearly 50% of people with T2D worldwide are unaware of their condition, representing a significant portion without diagnosis or treatment.[10] In SSA, three in five people with T2D are still undiagnosed, and 75% die before age 60 due to diabetes-related complications.[10] These delays contribute to late presentation with advanced complications, increased healthcare costs, and poorer long-term outcomes.[11] Detecting the disease early, even in the absence of symptoms, is vital for clinical, social, and public health reasons. It enables prompt intervention, reducing the risk of microvascular and macrovascular complications and ultimately lowering healthcare costs and resource use.

Despite rising prevalence indicated by epidemiological data, little is known about how individuals in Zimbabwe recognise, interpret, and react to initial signs of diabetes.[5] Understanding this pre-diagnosis phase is essential for creating interventions that promote earlier detection and engagement with health services.

In Zimbabwe and many parts of the SSA region, many individuals overlook early diabetes symptoms or attribute them to stress, physical activity, ageing, spiritual beliefs, or cultural ideas.[12] Socioeconomic hardships may prevent or delay seeking medical help, and the use of traditional remedies or healers often delays diagnosis of T2D.[13] Conversely, advice from family, community stories, and familiarity with chronic illnesses can promote earlier detection and treatment of diabetes. At the healthcare system level, limited diagnostic tools, long wait times, financial barriers, and inconsistent screening practices influence how quickly people are tested and diagnosed.

The factors delaying T2D diagnosis are interconnected, forming a dynamic pathway influenced by personal meaning, social interactions, and structural constraints. Yet, current research provides a limited understanding of how these elements evolve and interact over time. A GT approach is well-suited for investigating this area because it helps develop an explanatory model grounded in participants' experiences.[14] This model illustrates the sequence of events, decision-making processes, and contextual influences shaping the journey from symptom recognition to diagnosis.[15] By building an empirically grounded theoretical framework, the study can pinpoint key mechanisms that either facilitate or obstruct timely diagnosis. It will also identify critical intervention points and produce evidence to inform culturally sensitive awareness initiatives, community involvement, and enhancements in primary-care screening processes. These insights are vital for improving early detection and decreasing diabetes-related complications in Zimbabwe.

This study's objective was to examine the experiences of patients with type 2 diabetes, focusing on their journey from initial symptom recognition to finding out about their diagnosis of T2D.

METHODS

This study used a constructivist grounded theory (CGT) approach, aligning with the researcher's view of reality and the study's goals.[15] The CGT epistemology- that knowledge is shaped by cultural, historical, and social influences- guided this choice. The method also highlights the researcher's active role in co-creating the core theory.[15] Incorporating symbolic interactionism, CGT helped develop a theoretical understanding of patients' self-reported lived experiences, from symptom recognition to T2D diagnosis.

Study setting, sampling, and data collection

The study was conducted in Harare, Zimbabwe, from October 2023 to January 2024. Participants were deliberately recruited from community pharmacies specifically selected for this research. Pharmacy management teams agreed to host interview sessions and display recruitment flyers after receiving formal written requests. The lead researcher personally approached potential participants to invite them to join. Participants received an information sheet detailing the study's aims and procedures and were given at least 1 week to review it and decide whether to participate before follow-up. They read and signed the consent form before data collection began, and they were told they could withdraw at any time without explanation. To ensure confidentiality, all personal identifiers were removed from responses, and each participant was assigned a unique code pseudonym. The inclusion and exclusion criteria for the study are detailed in Table 1 below.

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. Initially, eight individuals with T2D who met the inclusion criteria were selected through purposive sampling. The lead researcher conducted semi-structured, open-ended interviews to gather detailed accounts of their experiences from symptom recognition to their T2D diagnosis. Each interview, lasting 40-60 minutes, was held in designated consultation rooms at community pharmacies and audio-recorded and transcribed by the researcher. Participants received £10 to cover transportation and related expenses.

As the research progressed, questions were refined to investigate new concepts emerging from initial data collection and analysis.[16] Data collection and analysis were conducted concurrently, following CGT principles, despite the process's nonlinearity.[15,16] Theoretical saturation occurs when additional data no longer yield new insights or reveal further aspects of core categories.[15] Data collection continued until theoretical saturation was achieved.[15] In total, twenty-three participants contributed, resulting in twenty-eight interviews.

The research employed multiple data collection techniques, including field notes, demographic questionnaires, memo writing, and voice recordings. Using various methods improved data quality, as noted by Creswell.[17] Field notes were recorded after each interview, and memos documenting emerging ideas were maintained throughout data collection and analysis to support the findings. The study ensured participant confidentiality and data anonymity by preventing participant identification at all stages.

Ethical approval

The study received ethical approval from the Nottingham Trent University School of Health and Social Care and the Zimbabwe Medicines Research Council Ethics Committees (MRCZ/A/3096). It followed the standards outlined in the 2013 Declaration of Helsinki.

Data analysis

The principal researcher manually reviewed all interview transcripts, memos, and field notes collected during the study. This CGT approach followed Charmaz's framework, comprising three interconnected coding stages: initial, focused, and theoretical.[15] These stages were iterative rather than linear. Coding was conducted immediately after each data collection to categorize and summarize the interview data. The researcher switched between initial and focused coding as new insights emerged.[15,16] The focused, theoretical coding stages identified key categories. The constant comparison method was used to identify similarities and differences in the data, enhancing analysis refinement and fostering new ideas.[16] Continuous peer review from the research team provided ongoing support throughout the process.

RESULTS

The demographics of the participants in the study are presented in Table 2.

Table 2: Demographics of participants.

Demographics		Count (%)
Gender	Male	12 (52.17)
	Female	11 (47.83)
Age (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)

Learning I have diabetes

The theoretical category 'learning I have diabetes' explicates the meanings participants ascribed to the

processes of symptom recognition and learning about a type 2 diagnosis. The following sub-themes explained this theoretical category: i) recognising symptoms; ii) information searching; iii) health-seeking; iv) being in denial; v) experiencing negative emotions; and vi) accepting the diagnosis.

Recognising symptoms

This sub-theme highlights when participants became aware of bodily changes. For some, it was a signal to investigate further, while others did not understand or ignored these changes. They reported symptoms such as unexplained weight loss, frequent urination, and intense thirst. The following excerpts illustrate how participants initially recognised these symptoms.

"I was feeling thirsty and drinking plenty of water. I also felt tired most of the time. Despite eating a lot of traditional food, I was frequently hungry, and surprisingly, I was losing weight without dieting." (Nicodimus)

The study showed that participants found their symptoms both worrying and frustrating. A leading source of their frustration was not recognising that these symptoms indicated a long-term illness. It also revealed that many participants had no previous knowledge of diabetes when they first noticed bodily changes. After identifying their symptoms and understanding their importance, they started seeking information from various sources to make better health choices. This process, from recognising symptoms to gathering information, was complex, with different participants ascribing different meanings to their symptoms and reacting in various ways regarding their health.

Seeking information

The study revealed that participants sought information about their symptoms to inform their health decisions. They used various sources, including family and friends, the internet, and health facilities. Factors like socio-economic background, education level, socio-cultural influences, and age influenced their choice of information sources.

"*I had no idea what my symptoms meant. I was too frightened to talk to friends or family members about them. I decided to visit my local pharmacy because you do not need an appointment or money to speak with the pharmacist. My pharmacist gave me information about T2D, and I found it very helpful. I left the pharmacy feeling well-equipped to manage my condition on my own."* (Chiwoneso)

Many participants in the study used various sources of information to understand their symptoms, which played a crucial role in their health-seeking behaviours. The ease of access to healthcare facilities was also a significant factor affecting participants' decisions on where to seek information about in their bodily changes.

Health-seeking

The study demonstrated that health-seeking behaviour involved individuals seeking medical care for T2D symptoms. The results showed that simply providing education and information about illnesses often did not sufficiently motivate participants to access healthcare. It also emphasised that various complex factors- such as gender, socio-cultural and socio-economic backgrounds, education, and knowledge- significantly influenced health-seeking actions across different settings and over time. Early health-seeking was linked to quicker diabetes treatment and lifestyle changes, whereas delays often resulted in poorer health outcomes.

"It took me approximately 4 to 5 months before I sought medical help. I initially believed there was some form of witchcraft affecting my life, so I turned to traditional and spiritual healers. They occasionally provided me with herbs and anointed water to use at home. Eventually, I realised these methods were not helping, and after collapsing at home, I decided to seek assistance from my local clinic." (Tafadzwa)

Participants highlighted the significance of their symptoms, what they represented, and their efforts to seek treatment. Their social and cultural backgrounds shaped how they coped with and managed their symptoms. Additionally, the participants came from diverse socio-cultural and educational backgrounds, leading to different understandings of the illness.

Being in denial

This study characterises denial of a T2D diagnosis as participants refusing or avoiding accepting their new health status because it conflicts with their understanding of symptoms. Influencing factors include their medical and psychiatric histories, cultural backgrounds, personal coping strategies, symptom interpretations, and fears of possible reactions.

"*I cried when I found out about my diagnosis of T2D. I was 31 years old at the time of my diagnosis. I outrightly denied the existence of this illness. I squarely placed the blame for my ill health on witchcraft. This was so because I only got ill when I started a new job, and my immediate relatives were jealous of my new job. I consulted the traditional healers, and they all agreed with me that the illness was started by a jealous relative who could not stomach me being successful. I refuse to accept this diagnosis of T2D. I will continue to engage my traditional healers until this illness has been sent back to the sender."* (Sonia)

The study's findings show that the period after a T2D diagnosis and the start of treatment was difficult. Some

participants refused to accept their diagnosis, attributing it to witchcraft, misdiagnosis, or simply rejecting the illness altogether. This denial often caused delays in seeking medical help. Providing participants with information about diabetes was essential in helping them accept their condition and pursue appropriate care.

Experiencing negative emotions

Receiving a T2D diagnosis can act as a stressful event, causing psychological distress. Several participants reported feeling negative emotions such as guilt, shame, shock, low mood, and anxiety after learning their diagnosis. The emotional effects on these individuals are demonstrated in the excerpts below.

"*I was feeling low, guilty, and ashamed for several weeks, avoiding leaving the house and social interactions. I experienced deep loneliness and a sense that life was meaningless, as everything seemed worthless. I believe my reactions were influenced by a lack of information and understanding about the illness. Furthermore, I think the clinic did not sufficiently prepare me for receiving such difficult health news. Counselling might have helped me better accept my new health situation".* (Wonder)

The study revealed that participants experienced negative emotions like anxiety, anger, worry, and depression after their T2D diagnosis. These emotions affected their willingness to seek health services and accept treatment, and they found it difficult to cope with these feelings. Consequently, successful T2D management should go beyond medical treatment to include emotional and psychological support as essential parts of a holistic care plan.

Accepting the diagnosis

For several participants, accepting a T2D diagnosis involved adjusting to the illness while managing its uncertainties, unpredictability, and adverse effects. Acceptance was a multifaceted process in which participants understood their condition, maintained optimism, adapted their lifestyles, and employed strategies to cope with and live with T2D. However, acceptance does not imply losing hope of someday living without the disease or being satisfied with their present situation. It also does not mean they are happy with the lifestyle changes brought on by the illness.

"To me, being diagnosed with T2D is like any other health condition. I see it as a test from God to strengthen my faith. My trust in God is firm, and I stay optimistic, believing in His supreme authority. I continued praying regularly and accepted my new health situation, beginning to take my medication. My prayers keep me focused and positive." (Linda)

The study found that participants who accepted their T2D diagnosis could live with the condition while experiencing few negative emotions. Acceptance did not mean losing hope or feeling defeated, nor did it mean being happy about the health changes caused by T2D. Instead, accepting the diagnosis was a complex, ongoing process that involved challenges such as feelings of relief and doubt. Many also experienced episodes of insecurity and hopelessness. Embracing the diagnosis may have enhanced their quality of life and lowered the risk of diabetes-related complications.

DISCUSSION

The theoretical concept, 'learning I have diabetes,' derived from this study, clarifies the contexts behind patients' experiences of T2D diagnosis and how these influence the timing of diagnosis. It reflects the evolving nature of life as patients experience, interpret, and explore their symptoms. Moreover, this concept provides HCPs with a valuable framework for understanding the complex interplay between context, relationships, and self-perception that drives help-seeking behaviour and the eventual diagnosis.

'Learning I have diabetes' emphasises the complexities faced by patients with T2D and how these complexities shape their beliefs and subsequent life with the illness. The process of 'learning that I have diabetes' was intricate and influenced by multiple perspectives and personal stories, shaping their understanding, thoughts, and behaviours.[18] This learning developed through interconnected themes, though not in a strictly linear fashion- they follow the pathway from recognising symptoms to adopting health-seeking behaviours, culminating in a T2D diagnosis. As shown in previous research, some individuals denied their diagnosis, while others feared potential complications related to diabetes.[19] It is essential to provide support to those struggling with a T2D diagnosis, as this may improve health outcomes and reduce risks of diabetes-related complications.

Recognising symptoms prompted participants to identify issues with their health. Previous research indicated that symptom recognition served as a cue for patients to determine when to engage in self-management practices.[20,21] Emerging evidence indicates that some patients have a reduced capacity to detect and interpret symptoms.[20] Difficulty in recognising symptoms can delay early detection of T2D, increasing the risk of complications. Therefore, recognising symptoms is essential for T2D self-management and plays a crucial role in enhancing patients' quality of life.

Study participants were diagnosed with T2D after noticing their symptoms, highlighting delays in screening. Similar findings on delayed diagnosis have been reported in the literature on type 2 diabetes.[22,23] Previous research shows that most T2D patients experience delays of up to 10 years in clinical diagnosis after the onset of hyperglycaemic symptoms.[24] This delay may be even longer among Zimbabweans, where access to T2D testing

and diagnosis is often limited. Early management of hyperglycaemia is frequently overlooked because the undiagnosed phase is asymptomatic, leading to microvascular damage by the time of diagnosis.[24] Disparities in healthcare access and limited screening may contribute to the high rate of undiagnosed diabetes and related complications.[23,25,26] For instance, the IDF estimates that Africa has the highest proportion of undiagnosed T2D among adults aged 20-79 years, at 59.7%.[7,10] Undiagnosed diabetes and its complications impose significant financial burdens on individuals, families, and healthcare systems due to repeated resource use. Therefore, developing strategies to improve healthcare access for high-risk populations and prioritising diabetes screening as a crucial public health measure is essential.

Health information seeking involves individuals looking for knowledge about their health, symptoms, risks, and ways to improve their well-being.[27] Studies show that people with chronic conditions who receive information about their illness are more likely to take responsibility for their health and achieve better health outcomes.[28] However, knowledge alone does not automatically cause behavioural changes or health improvements.[29] It is important to understand each person's view of their diabetes, their management approaches, and how education can influence their condition.

In this study, participants looked for information about their symptoms before being diagnosed with T2D. This supports previous findings indicating that patients often seek information beforehand, either to decide whether to consult a healthcare professional or to prepare for their appointment.[30] Another study also found that individuals with long-term conditions often gain knowledge about their symptoms before diagnosis.[31] Making health information widely available and easy to access should be a top healthcare priority, especially in low-income countries where disadvantaged groups frequently lack reliable access to education and resources for managing chronic illnesses.

Research showed that health-seeking behaviour is a complex process influenced by factors at the individual, family, and societal levels, aligning with earlier findings.[32] In this study, it was also associated with participants' symptoms, social network interactions, healthcare provider contacts, and diabetes diagnosis. The WHO states that practising 'good' health-seeking behaviour can prevent illnesses, facilitate early detection of diabetes, improve its management, and lower complications and costs.[26]

The literature on public health promotion confirms that participants' health-seeking behaviour is primarily driven by bodily changes.[33] However, many people with T2D are asymptomatic at diagnosis, which may lead them to delay seeking care or deny their condition, posing a significant barrier to effective management and increasing the risk of complications.[34] Therefore, public health strategies are essential to motivate early diagnosis and treatment of T2D. Such efforts can help prevent complications and reduce the costs associated with managing them.

This study revealed that many participants often deny their illness, which causes delays in seeking treatment and raises the risk of diabetes-related complications. Previous research indicates that prolonged denial can harm health by delaying treatment, reducing medication adherence, and refusing necessary therapies.[35] Furthermore, another study showed that illness denial is a significant barrier to adopting effective self-management for asthma control and preventing severe attacks.[36] It was also observed that in T2D patients, denial was associated with poor glycaemic control. While literature suggests that illness denial is a common initial reaction to grief, implementing strategies to help individuals accept their new health status is crucial to avoid adverse health outcomes.

For some study participants, denying a T2D diagnosis acted as an important coping mechanism as they adjusted to their health changes. This denial allowed them to process feelings of frustration, fear, and uncertainty at a manageable pace, which aligns with findings from a study on cancer patients.[36] Furthermore, earlier research indicates that denial of illness can serve as an adaptive coping strategy by reducing the emotional strain of receiving a chronic illness diagnosis.[37] Previous studies have shown that the emotional distress and overall burden from a T2D diagnosis may contribute to diabetes complications.[37,38] Therefore, implementing public health strategies that provide emotional support to newly diagnosed individuals is crucial to preventing diabetes-related complications.

The study showed that many participants felt negative emotions after learning they had T2D. For most, this diagnosis was life-altering, causing feelings like self-blame, health loss, fear, shock, guilt, panic, denial, frustration, hopelessness, and grief. If these emotions are not managed, they can cause mental health issues such as depression, anxiety, and stress, which may interfere with diabetes self-management.[38] The results align with previous research showing adverse emotional reactions in T2D patients.[39] Earlier research also suggests that 60-70% of those with T2D face psychological problems like depression, stress, anger, and burnout.[40] Therefore, early detection of mental health risks and provision of emotional support from HCPs should be essential components of T2D self-management to enhance quality of life.

This study deepens understanding of diabetes management using a constructivist grounded theory approach that highlights participants' personal experiences. It captures their perspectives directly, supporting the creation of patient-centred support strategies. However, because the findings are rooted in the participants' social and economic context, their

broader applicability is limited. Despite this, the study provides a foundation for larger research efforts to further examine these issues. Participants were recruited from specific community pharmacies in Harare's CBD, so patients who did not use these pharmacies were excluded. Future studies should aim for a more diverse sample to enhance the reliability of the results.

Implications for practice and research

This study aims to expand the limited understanding of how people in Zimbabwe recognise, interpret, and respond to early signs of diabetes. These insights can contribute to developing more patient-centred support systems, helping individuals move from symptom awareness to a T2D diagnosis and effective management. Additionally, these findings could inform the development of targeted screening programs for T2D and raise public awareness of its signs and symptoms. Understanding patients' difficulties with symptom management and their denial of diagnosis can help healthcare providers design practical, culturally sensitive support strategies. Future research should investigate the feasibility of continuous, personalised, or group support for newly diagnosed T2D patients in primary care settings. It is crucial to identify the specific concerns of individuals before and after diagnosis, especially those from socially disadvantaged backgrounds to better tailor support.

CONCLUSION

The understanding of 'learning I have diabetes' among the study participants reflected the meanings they associated with symptom recognition to discovering their T2D diagnosis. Factors such as socio-cultural influences, socio-economic status, limited health literacy, and personal attitudes affected their health-seeking behaviours, which led to either early or delayed diagnosis. Identified lived experiences from participants' perspectives can facilitate earlier detection and pinpoint crucial intervention points for culturally sensitive awareness campaigns, community engagement, and improvements to primary care screening pathways. Personalised support is vital for individuals transitioning from symptom recognition to obtaining a T2D diagnosis and managing it effectively.

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