

Perceptions of Diagnosis of Diabetes among Newly Diagnosed Diabetes Patients – A Qualitative Study

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Abstract

This research aims to explore the contextual barriers and beliefs surrounding the recent diagnosis of diabetes mellitus type II from the viewpoint of patients. Thirty-two individuals diagnosed with diabetes mellitus II were interviewed to understand the circumstances leading to their diagnosis and to identify any obstacles hindering early detection. Grounded theory qualitative methods were employed for the analysis of the interviews. The diabetes diagnosis in the interviewed patients commonly resulted from chance discovery, symptom recognition, or patient-driven initiatives. Despite having a familial predisposition to diabetes, many patients had limited awareness of diabetes symptoms before diagnosis. Frequently, symptoms were incorrectly attributed to other factors. Notably, concerns related to fear and trust were not prominent among these patients. There appears to be a lack of awareness among individuals with undiagnosed diabetes regarding the significance of reported symptoms. Clinicians need to remain alert to identify individuals at increased risk of diabetes, and the implementation of screening programs should be considered.

Keywords: newly diagnosed diabetes, diabetic symptoms, diabetes education, qualitative, patient attitude.

1. Introduction

The prevalence of diabetes is acknowledged as an important global health issue (Fralick et al., 2022), which affects various body systems leading to increased rates of morbidity and mortality (Zakir et al., 2023). Diabetes is characterized as a complex and progressive disease; it demands effective management necessitating the implementation of diverse risk management strategies (Bereda, 2022). Among metabolic disorders, diabetes mellitus stands out as the most prevalent, with approximately 451 million individuals aged 18–99 years affected by it. This number is projected to increase to 693 million by the year 2045 worldwide (Dehghan et al., 2022). The condition arises from either a lack of insulin or its inefficiency, leading to a state of elevated blood sugar levels, known as hyperglycemia. Diabetes gives rise to various complications and mortality (Zakir et al., 2023).

In recent decades, the global prevalence of diabetes has surged significantly, reaching epidemic proportions (Alqahtani et al., 2023). According to the latest data from the International Diabetes Federation (IDF), approximately 9.1% of adults aged 20 to 79 years, totaling 463 million individuals, are affected by diabetes (Ogurtsova et al., 2022). Additionally, an estimated 374 million people have impaired glucose tolerance which increases the risk of developing diabetes later in life (Alqahtani et al., 2023). Alarmingly, half of the adults with diabetes (approx. 232 million), remain undiagnosed, potentially leading to complications as their condition goes untreated (Sardu et al., 2019). It is expected that this number will increase to 578 million in 2030 and 700 million in 2045. In Saudi Arabia, current estimation shows that there are 4 million diabetic patients (Almutairi & Abbod, 2023).

There is growing global attention towards diabetes, with a particular focus on Type II diabetes. This evaluation serves as a valuable tool for gauging the effectiveness of global policies, programs, and clinical interventions aimed at addressing diabetes (Ali et al., 2022). Contrary to the conventional belief associating diabetes primarily with affluent and developed regions, there is substantial documentation of high prevalence rates in developing countries (Ogurtsova et al., 2022).

Between 1990 and 2010, the disease's ranking decreased from 15th to 9th place, indicating a substantial 92.7% increase in burden over two decades (Babakhanian et al., 2022) The surge in diabetes prevalence in recent years is

attributed to factors like an aging population, genetic predisposition, obesity, and unhealthy lifestyles. In 2014, the prevalence of diabetes in individuals aged 18 and above stood at 8.5%, marking a significant rise over the past thirty years, particularly in low- and middle-income nations (World Health Organization, 2016; Babakhanian et al., 2022).

Over the past three years, there has been a tenfold rise in the incidence of diabetes cases in Saudi Arabia (Gollapalli et al., 2022). There has been a rise in diabetes rates in Saudi Arabia, marking the condition as an important public health concern. Approximately 17.1% of Saudi adults in 2022 were estimated to be affected by diabetes (Alwadeai & Alhammad, 2023). This prevalence represents a substantial increase from the 2.1% to 9% range recorded in the 1980s (Aljulifi, 2021).

Diabetes mellitus often evades detection for an extended duration due to the gradual development of hyperglycemia, with early stages exhibiting symptoms that may not be severe enough for patients to recognize the classic indicators. The prolonged subclinical phase of the condition is linked to heightened morbidity and mortality, increasing the risk of macro and microvascular complications.³ Positive attitudes of patients toward diabetes management play an important role in modifying their behavior to regulate blood glucose levels compared to those with negative attitudes (Mansy et al., 2022).

Unrecognized diabetes poses significant risks like coronary heart disease, stroke, and peripheral arterial disease, alongside microvascular conditions like kidney disease, peripheral neuropathy, and retinopathy (Tomic et al., 2022). Previously, the identified shortcomings in the healthcare system include; a lack of essential infrastructure for diabetic care as a barrier that contributes to suboptimal processes and outcomes for individuals with diabetes. Despite the ongoing prevalence of the traditional complications linked to diabetes mellitus, there is a decline in the rates of these conditions, attributed to advanced management of diabetes mellitus (Tomic et al., 2022). Conventional guidelines outlined in programs like the National Diabetes Prevention Program (Draznin et al., 2022) advocate weight loss through energy deficits to enhance insulin sensitivity and slow disease progression.

These differing treatment priorities by patients and healthcare providers highlight the need for a deeper understanding. Therefore, the present study aims to explore the context barriers and beliefs related to recent diagnoses of diabetes mellitus type II from the viewpoint of the patients. Furthermore, the study examined the prior health experiences and how these patients interpreted symptoms upon being recently diagnosed with diabetes mellitus type II.

2. Method

2.1 Study Design

The present study has employed qualitative research methods that help in investigating patterns of meaning from the data, frequently articulated in the participants' language (Pope & Mays, 1995). The qualitative researcher's responsibility is to identify patterns within these expressions (and actions) and present them for scrutiny, all while maintaining proximity to the participants' original experiential framework. This qualitative study involved in-depth interviews with a cohort of adult patients recently diagnosed with diabetes. This approach allowed patients to articulate their interpretations and viewpoints, facilitating the identification and exploration of themes and hypotheses that might not have been initially foreseen.

The employment of grounded theory qualitative methods enabled us to deeply explore the context surrounding recent type II diabetes diagnoses to shed light on this complex process. The data collection approach provides rich insights into the sociological phenomenon under observation (White & Cooper, 2022).

2.2 Study Sample

The participants for this study were recruited from the Family Medicine Clinics and Primary Health Care clinics at the Health Care Specialty Center (HCSC) which is part of King Abdulaziz Medical City in Riyadh KSA, from February to September 2022. The sample of this study comprised 32 patients for qualitative analysis. Most of the patients were soldiers in the National Guard or their family members, most were intermediate social class and the health care system is free governmental health care services. Enrollment of patients was through file review of all diabetic patients referred to the health educator by the family physician or the Primary Health Care doctor in HCSC.

The study included patients who had received a diabetes diagnosis in the preceding six months to share their perspectives on the experience of being diagnosed. The time frame for diagnosis was confined to the six months leading up to the interview to gather their most vivid recollections of transitioning from undiagnosed to diagnosed diabetes. Both genders were included in the study. However, patients <18 years, diagnosed with gestational or type

1 diabetes, and diagnosed more than 6 months were excluded from the study.

2.3 Study Procedure

The data for this study was gathered through face-to-face interviews utilizing a semi-structured interview questionnaire (Appendix I). Each interview was for 15 to 20 minutes and conducted within the healthcare setting. Most of the questions are open-ended questions that enable the patient to express his or her perceptions, feelings, ideas, concerns, beliefs, and expectations about being diabetic. These questions are collected from previous studies that investigate the same issue.

2.4 Thematic Analysis

The transcripts from the interviews underwent thematic analysis, with each investigator independently examining them. Regular meetings were held among the three investigators, consisting of two family physicians and a health educator with expertise in qualitative methods. During these sessions, the team discussed emerging themes, reached consensus, and determined subsequent steps in sampling and questioning. Through the interviews with patients, socio-demographic barriers to diabetes diagnosis were identified, revealing racial disparities in undiagnosed diabetes. The assessment of the interview process's completeness was based on the point where new interviews failed to yield additional information.

2.5 Ethical Consideration

The researchers assured the ethics committee that all patients were informed and sought consent for their participation in this study. Explicit permission was obtained from the participants for the transcription of the interviews. It is imperative to note that the data and information acquired from the patients were exclusively utilized for this research. Patients were contacted following approval from the Department's Research Ethical Committee.

3. Results

Most of the patients recruited in this study were interviewed on the same day of diagnosis, and only 9 were diagnosed within 3 months of their interview. The patients' average age ranged between 33 to 71 years, with a mean age of 53 years. All of them are Saudi citizens and National Guard dependent. Educational attainment ranged from illiterate to high school. Healthcare was provided at the primary care level and was free of any charges. The analysis revealed prevalent themes among the majority of the participants that are summarized below;

3.1 Methods of Diagnosis

Individuals reported diverse paths to their diabetes diagnosis, with many experiencing it through accidental discovery, in response to distinct symptoms, or as a result of their proactive efforts. Notably, five participants underwent diagnosis after voluntarily opting for testing due to the recognition of symptoms that they associated with diabetes. One patient stated that;

“I always felt thirsty...even if I drink a whole bottle of water...my family advise me to have chick up.” (Patient 7)

Eight patients received their diabetes diagnosis upon the discovery of elevated blood glucose levels during routine laboratory examinations conducted for the monitoring of other medical issues. The statements of patients in this context have been listed below;

“The rheumatologist, while conducting laboratory work for my rheumatoid disease, identified elevated blood sugar levels. Consequently, he referred me to family medicine for further evaluation and management.” (Patient 10)

“I am known hypertension. I used to have blood work every 6 months. Then they discover that am diabetic.” (Patient 13)

“My physician used to ask for some tests every 6 months to monitor my gland problem (hypothyroidism)...and in one day he told me that my sugar is too high.” (Patient 22)

“It was accidental finding of high blood sugar when I went to emergency due to scorpion bite.” (Patient 4)

Nineteen patients received their diabetes diagnosis as a result of symptoms reported during acute care visits. The patient stated that;

“I have been having this pain and burning sensation in my legs for a long time...so the doctor raises the possibility of diabetes.” (Patient 16)

“I had this bad ear infecting...because of that the doctor advised for more tests.” (Patient 1)

“I felt dizzy twice in one week ... when I complained to the doctor ... he suggested some labs” (Patient 30)

Furthermore, it was noted that none of the patients went through a specific diabetes screening program.

3.2 Patients' Concerns

Six out of 32 patients were worried about the diagnosis, some of them were concerned but not worried, however, most of them had never thought about it.

“I was worried about my general health.” (Patient 2)

“I have a history of gestational diabetes. I was worried...I asked my doctor to do blood work for diabetes.” (Patient 6)

“I was worried about diabetes, am known to have gestational diabetes, so I do ask the doctor to do blood work for me.” (Patient 12)

“I can't say that I was worried about diabetes, but I was having some concerns because my age is above 60years and I consider myself obese.” (Patient 11)

3.3 Awareness of Diabetes Symptoms

Most of the patients admitted that they were not aware of any symptoms of diabetes before they met their family physician. Only seven of 32 patients were aware of diabetic symptoms

“I was complaining from the generalized body each and low energy and I think this is related to diabetes because I have a history of gestational diabetes before so am aware of the symptoms.” (Patient 6)

Most of the participants noticed one or more of the following symptoms: dry mouth, thirst, fatigue, frequent urination, loss of weight, and loss of energy, and most of them did not link it to diabetes until seen by the family physician.

“I was complaining from dry mouth, but I did not think that dry mouth has any relation to diabetes.” (Patient 1)

“I notice frequent urination but I did not know that it is connected to diabetes until the doctor told me.” (Patient 3)

“I have symptoms of dry mouth, loss of weight, and joint pain but I did not know that it is the symptoms of diabetes.” (Patient 7)

“I was complaining of headaches, fatigability, and thirst, but I do not know it is linked to diabetes.” (Patient 13)

“I was complaining from thirst and dry mouth, I was not aware it's related to diabetes until the doctor told me.” (Patient 5)

Some patients believed that these symptoms highlighted something else like summertime, aging, hard work, etc, and not diabetes.

“I feel fatigued all the time...I thought that this because of caring for my five children” (Patient 15)

3.4 Family History of Diabetes

Nineteen out of 32 patients had a family history of diabetes; either one family member or more. The majority of these family members were closely related, with many also noting the presence of diabetes and its complications among friends and spouses. Yet it didn't cause enough worry for patients having diabetes; it was not the reason for many physicians to ask for blood work.

“Yes, my mother is diabetic but I never thought that diabetes runs in the family!” (Patient 13)

“Yes, my father was diabetic, he died a long time back, but this is not the reason for the doctor to have my blood work.” (Patient 9)

A significant number of patients demonstrated limited awareness of diabetes symptoms. When questioned about diabetic symptoms, twenty-five patients acknowledged that they were not acquainted with most of these symptoms before consulting with a doctor or diabetic educator. The answer given by patients upon asking them about any other family members with diabetes is given below;

“Three of my brothers have it; one of them is using insulin ...also my uncles...I'm not sure if my father had it before he died” (Patient 8)

While asking about their family members' taking medication, the patient responded;

“They all complained that their diabetes is never right...some time it is high and other time it's low” (Patient 8)

To answer what extent were the patients familiar with diabetes before their diagnosis, one patient stated that;

“Nothing... but I know that some people are treated with tablets and some with insulin.” (Patient 8)

Upon asking patients about any information, they heard from their bothers or the media about diabetic symptoms, the patient stated that;

“Maybe I did hear something ...but at the time of the diagnosis I did think about it” (Patient 8)

3.5 Family Experience with Diabetes

Nineteen out of 32 patients had a family history of diabetes. The patients were asked specifically about their feelings when they were diagnosed and if their feelings had anything to do with their family history of diabetes. Most of them were not affected by their family's experiences. Only four patients reported bad feelings when they received the news about the diagnosis of diabetes.

“My mother's experience did not affect my thinking toward diabetes.” (Patient 7)

“More than one person in my family is diabetic, although it would not affect me.” (Patient 6)

“Everything is from God; my mother is diabetic but her history has not affected me when I have been diagnosed.” (Patient 13)

3.6 Medical History

Twenty-four out of thirty-two patients were known to have other medical problems such as hypertension, osteoarthritis, hyperlipidemia, gestational diabetes, liver disease, and otitis media. Patients thought that the physicians did investigate them because of their other complaints.

“I am known to have hypertension, and every person I meet was telling me diabetes came with hypertension, so I ask my doctor to do blood work for diabetes.” (Patient 14)

“I am known to have hypertension and my doctor followed my blood work every 6 months.” (Patient 13)

“I was following up with my doctor for hypothyroid and hypertension when she discovered am diabetic.” (Patient 12)

“I was doing blood work to my liver when they discovered high blood sugar.” (Patient 11)

“I have no medical problem, but I have a history of gestational diabetes.” (Patient 6)

3.7 Relation to Doctor

The patients were also questioned about possible barriers to their diagnosis. Most of them have a good experience with the medical system in a family medicine clinic. They do trust the doctor and the system.

“This is my 1st visit to National Gourd clinic, I have a good experience with them before, that's why I came again to them.” (Patient 7)

Some patients were concerned about the appointment problems and delay in seeing the doctor but reported that these concerns were not the barrier to their seeking care for the problem.

“Everything is organized ...but because of the pressure of patents sometimes...there is a delay in the appointments.” (Patient 9)

“I do not have any bad experience with the medical system; I do know they have a lot of pressure. And I do trust the doctors.” (Patient 17)

None of the patients said that time and schedule with their jobs and professional duties were a potential barrier to receiving care. Some of the patients wished to be followed by the same doctor each follow-up visit.

“I do trust the doctor and the medical system; I wish I have my follow-up with the same doctor each visit.” (Patient 12)

“I have a good relation to my doctor; I wish I could see her every visit.” (Patient 2)

4. Discussion

The findings from this in-depth exploration of the circumstances surrounding the diagnosis of individuals recently identified with type II diabetes indicate a significant likelihood that a considerable number of people with this condition remain undiagnosed. This lack of awareness about the significance of their symptoms appears to be a contributing factor. Among those with multiple significant risk factors for diabetes, the diagnosis of the condition often occurred by chance. The views of these patients suggest that the proactive implementation of diabetes screening due to their high-risk status was not a widely practiced approach.

Most of the patients deny that fear or worry about diabetes affects having a physician consultation, even (surprisingly) in those with a family history of diabetes. A similar study revealed that recognition of depression signs holds significance within clinical settings as individuals experiencing such symptoms might be hesitant to engage in discussions about self-care (Beverly et al., 2012). There is a necessity for interventions and evidence-backed strategies to enhance both the management of depressive symptoms and communication between physicians and patients regarding self-care. In the present study, the patients refused to have any issues of trust or communication with the health caregiver as a barrier. Moreover, the cost of medical care is not a concern for the patients. The present study signified that the main barrier to having early medical consultation for diagnosing diabetes is the nature of diabetes symptoms.

The individuals are more likely to neglect or misinterpret the signs leading to missed diagnosis of potential conditions like type II diabetes when confronted with the unclear symptoms characteristic of early-stage diabetes, coupled with a limited understanding of these manifestations. The deferment of seeking medical attention is likely as long as patients remain unaffected by the consequences of diabetes and do not perceive a decline in their well-being.¹⁷ The individuals are prone to transition from perceiving themselves as in good health to recognizing an unwell state, after experiencing diabetes symptoms impacting their daily life facilitated by familial, social, or media influences. Consequently, seeking medical consultation becomes more probable. There is an increase in patients' perceived vulnerability that substantiates the effectiveness of educational initiatives (Dadkhah et al., 2018).

Conveying information about the unclear symptoms is likely to pose challenges in communication. Certain patient groups may experience delays in diagnosis due to their interpretation of early, indistinct symptoms and limitations in expressing them, both personally and when seeking lay consultation from their family and peers (Vaishnavi & Mishra, 2021). Individuals undergo the subjective experience of "illness," while physicians and healthcare providers engage in diagnosing the corresponding "disease." In this healthcare interaction, physicians play a crucial role in translating the patient's sociocultural explanation of the illness (Mariman et al., 2023). The occasional disparity between these clinical realities carries implications for how we conceptualize, categorize, and respond to diseases (Mariman et al., 2023). Importantly, a considerable proportion of "illnesses" may not come to the attention of a physician, potentially leading to further delays in diagnosis.

The study findings suggest the need for increased community awareness regarding diabetes and education regarding the significance of certain ambiguous symptoms. At the community level, it is suggested that both patients and physicians may benefit from reminders about the importance of diabetes screening, particularly for individuals at risk of the disease. It is noteworthy American Diabetes Association (ADA) has a significant positive impact on patients across the globe in collaboration with WHO (Fleming et al., 2020).

The primary rationale behind advising against population screening is the insufficient evidence supporting the fact that early detection leads to a reduction in morbidity and mortality (Harris et al., 2003). Despite this, it is established that proactive management of confirmed disease significantly decreases the likelihood of complications (Aljulifi, 2021). Nonetheless, the ADA recommends that healthcare providers are more careful in the detection of diseases and screening, particularly among individuals with significant risk factors (Aljulifi, 2021). These factors include belonging to specific minority groups or having a family history of diabetes, which were prevalent characteristics among the participants in the present study. It could be helpful not only to emphasize to patients with these risk factors that they are more susceptible and eligible for screening but also to promote the idea of screening for diabetes based on risk factors within primary care practices.

While this study has yielded valuable insights, it is important to acknowledge certain limitations. For instance, the study's qualitative analysis approach is the first limitation that focused on exploring the context from the participant's perspective and may not readily extend to broad generalizability across diverse settings. Despite this limitation, the study serves as a hypothesis-generating strategy, providing valuable information that could contribute to a more universally applicable investigation. Another limitation pertains to the perspective of patients from which the information was obtained. Consequently, the actual screening practices of physicians remain unknown. While patients initiated the diagnostic process based on their experiences, it is crucial to recognize that this retrospective sense-making might influence the accuracy of their accounts. Furthermore, the study's sample was drawn from clinics catering exclusively to National Guard dependents, a demographic characterized by unique features such as relatively lower educational levels and average income. This distinct profile may impact the generalization of the study's findings beyond this specific population.

In conclusion, the timely identification and management of diabetes are critical factors in preventing both microvascular and macrovascular complications associated with diabetes. A comprehensive understanding of the

patient's journey from the recognition of symptoms to the formal diagnosis of diabetes, holds significance for clinicians and policymakers alike, providing valuable insights to refine the strategies in diabetes care. This study has highlighted the potential value of targeted educational efforts directed at individuals with an elevated risk of diabetes. Enhancing awareness and knowledge regarding diabetes symptoms may facilitate early consultations with healthcare providers among those experiencing initial signs of the condition. As a result, prioritizing improved education for at-risk individuals emerges as a promising avenue for enhancing the early detection of diabetes.

The study recommended that healthcare initiatives should concentrate on the development and implementation of educational interventions tailored to high-risk populations. These interventions should emphasize the importance of early symptom recognition, encouraging timely medical consultations, and contributing to a proactive approach to diabetes detection. Future research should focus on assessing the efficacy of such educational programs, examining their impact on patient behavior and health outcomes, and exploring their adaptability across diverse healthcare settings. By refining and expanding educational strategies, it is possible to advance a more comprehensive and effective approach to diabetes diagnosis and care.

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Informed Consent

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Data Availability Statement

The data that support the findings of this study are available on request.

Competing Interests Statement

The authors declare that there are no competing or potential conflicts of interest.

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Appendix

Appendix I: Interview Questions

1. Tell me about how you were diagnosed with diabetes.
2. Were you worried that you might have diabetes and asked that your doctor do a test to see if you had it? Why?
3. Were you having problems that caused the doctor to test for diabetes?
4. Did you have certain other diseases that worried you or your doctor that led to your being tested for diabetes?
5. Did you have other people in your family with diabetes and did that worry you or your doctor and lead to your being tested for diabetes?
6. How worried were you that you might have diabetes before you knew for sure? Why?
7. Did you have symptoms of diabetes before your diagnosis? What were they?
8. Did you recognize them as symptoms of diabetes at the time? How did you know?
9. How did knowing about your family's experience with diabetes influence you as far as coming to the doctor when you were first diagnosed with
10. diabetes?
11. How is your relationship with your doctor? Tell me about it.
12. Do you trust the medical system in general?

Any past bad or good experiences with the health care system that influenced your decision to go to the doctor?

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