



## A qualitative investigation into the lived experiences of patients with type 2 diabetes mellitus

Younes Ramazan-Younes<sup>1</sup>, Vian Afan-Naqshbandi<sup>2</sup>, Muaf Abdulla-Karim<sup>3,4</sup>

1 Department of Medicine, College of Medicine, Hawler Medical University, Erbil, Iraq

2 Department of Nursing, College of Nursing, Hawler Medical University, Erbil, Iraq

3 Department of Nursing, College of Nursing, Al-Kitab University Erbil, Iraq

4 Ministry of Health, Kurdistan, Erbil, Iraq

### Original Article

#### Abstract

**BACKGROUND:** Type 2 diabetes mellitus (T2DM) is a chronic disease which afflicts a large number of people all over the world and causes numerous complications to the patients and decreases the quality of their lives. The present study was carried out in order to investigate the lived experiences of patients with T2DM.

**METHODS:** The present study was carried out by a qualitative method. To collect the required data, in-depth semi-structured interviews were carried out with 10 patients with T2DM who referred to Bli Hospital in Mergasour District, the Kurdistan Region of Iraq, in 2018. The interviews were transcribed and analyzed using Van Manen's (1990) hermeneutic phenomenological method, and the themes were retrieved.

**RESULTS:** Based on the results of analyzing the interviews, it was seen that the patients referred to DM as a disease that cannot be treated, which was labelled as "incurable disease". They also referred to the fact that DM had made their life very hard, which was labelled as "difficult life". Moreover, they stated that DM was a silent killer, which was labelled as "silent disease". Finally, they referred to taking insulin shot as addictive, which was referred to as "problem with taking insulin".

**CONCLUSION:** According to the results, the patients' lived experiences were interpreted as incurable disease, difficult life, and silent disease, which requires social and individual support to be tackled. Moreover, alternative medicines should be figured out because insulin injection was referred to as addictive. The results of the present study can be utilized by clinical trials focusing on treating and helping patients with T2DM and enhancing the quality of their lives.

**KEYWORDS:** Type 2 Diabetes Mellitus; Qualitative Evaluation; Lived Experience; Van Manen's Hermeneutic Phenomenological Method

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### Introduction

As a chronic complex condition, diabetes mellitus (DM) has been reported to afflict almost all populations all over the world.<sup>1</sup> It is characterized by high levels of blood sugar resulting from the body's failure to produce or

use insulin effectively.<sup>2</sup> This disease can be associated with numerous complications including gangrenous feet, cerebrovascular disease, coronary heart disease (CHD), retinopathy, and nephropathy.<sup>3</sup>

According to International Diabetes Federation (IDF) (2013), there are three types of DM namely type 1 DM (T1DM), type 2 DM (T2DM), and gestational DM (GDM). In T1DM, the pancreas cannot produce insulin. In T2DM, the pancreas cannot produce sufficient insulin

#### Corresponding Author:

Muaf Abdulla-Karim; Department of Nursing, College of Nursing, Al-Kitab University Erbil, Iraq  
Ministry of Health, Kurdistan, Erbil, Iraq  
Email: uafabdulla82@uoalkitab.edu.iq

or the produced insulin cannot be processed. In GDM, the insulin produced during pregnancy is not effective enough.<sup>4</sup> As reported by World Health Organization (WHO) (2013), T2DM is the most common type of DM and accounts for 90% of DM cases worldwide.<sup>1</sup> For the purpose of the present study, T2DM is focused on.

T2DM is associated with various symptoms including skin infections, genital itchiness, stomach pains and constipation, polydipsia (excessive thirst), fatigue, polyuria (frequent urination), and blurred vision due to dry lens of the eye.<sup>5</sup> However, these symptoms are almost unrecognizable; therefore, this type of DM is called silent killer.<sup>6</sup>

Research has indicated that there are more than 500 million cases of T2DM worldwide and it is estimated that its prevalence will increase over the next 10 years.<sup>7</sup> According to the reports published by IDF (2017), prevalence of DM in Iraqi adults was 7.5% with 1411500 cases in 2017.<sup>8</sup> The increasing prevalence of DM has been attributed to prevalence of obesity and low socio-economic status.<sup>9</sup>

T2DM can have various negative effects on the patients' lives. For example, life expectancy among patients with T2DM is reported to be 15 years shorter than others.<sup>10</sup> Patients with DM have been reported to suffer from various psychological complications including anxiety, depression, sexual dysfunction, or eating disorders.<sup>11-13</sup> In addition to the mentioned psychological complications, DM can lead to numerous physiological problems including pain in the legs, toes, feet, arms, hands or fingers, numbness, indigestion, wasting of the feet or hand muscles, urination problems, nausea or vomiting, constipation, diarrhea, and dizziness.<sup>14</sup>

Given the abovementioned complications and problems caused by T2DM, quality of life among patients with the disease can be negatively affected.<sup>15,16</sup> In this regard, research has suggested that a range of factors such as

attitudes, available healthcare, biology, and behavior can be effective in controlling DM and its associated complications.<sup>17</sup> Most studies dealing with T2DM have focused on the causes and therapy methods;<sup>16,18,19</sup> however, effectiveness of the proposed therapies depends on the patients' personal characteristics, experiences, life conditions, and requirements.<sup>20,21</sup> Therefore, it is highly significant to achieve deep understanding of the lived experiences of patients with T2DM in order to provide them with better healthcare services and improve the quality of their lives.

In this regard, the present qualitative study was aimed at investigating into the lived experiences of patients with T2DM who referred to Bli Hospital in Mergasour District, the Kurdistan Region of Iraq, in 2018.

## Materials and Methods

**Study design:** In order to carry out the present study, a qualitative method using Van Manen's hermeneutic phenomenological method was employed.<sup>22</sup>

**Participants:** The study sample consisted of 10 patients with T2DM who had referred to Bli Hospital in Mergasour District in 2018. They were selected by a convenience sampling method. The patients were chosen based on some inclusion criteria such as being officially diagnosed with T2DM, lack of other chronic diseases, and willingness to participate in the study. Some of the patients who referred to the hospital were not included in the study based on the exclusion criteria such as having other chronic diseases and lack of willingness to participate in the investigation. The participants were 6 men and 4 women with an age range of 38 to 56 years. They were all from Mergasour District. Table 1 presents the patients' socio-demographic and clinical data.

**Data collection:** In order to collect the required data, in-depth semi-structured interviews were carried out with the participants from November 2018 to December 2018.

**Table 1. Socio-demographic and clinical data of patients**

Socio-demographic and clinical variables		n (%)
Sex	Female	4 (40)
	Male	6 (60)
Age (year)	30-40	4 (40)
	41-50	4 (40)
	51-60	2 (20)
Place of residence	Urban	7 (70)
	Rural	3 (30)
	Illiterate	3 (30)
Education level	Primary	2 (20)
	High school	3 (30)
	University	2 (20)
Religion	Islam	10 (100)
Ethnicity	Kurdish	10 (100)
Employment	Employed	6 (60)
	Unemployed	4 (40)
Disease duration (year)	< 5	6 (60)
	> 5	4 (40)
Current treatment	Insulin injection	8 (80)
	Metformin	2 (20)

All of the interviews were conducted in a relaxing small room at Bli Hospital. In order to elicit as much information as possible from the participants, friendly relationship was established with them, and they were ensured that their information would be confidential. Moreover, they were given sufficient time to consider and answer the questions raised by the interviewers. Also, the women were interviewed by a female interviewer and the men by a male interviewer in order for the

patients to feel more comfortable and relate their lived experiences with more details. The interviews were led by asking predetermined questions beginning with general questions such as "How is it like to suffer from type 2 diabetes (T2DM)?", "When did you notice you had T2DM? How did it feel?", or "What is it like to have T2DM?" followed by more specific questions such as "How has T2DM changed your life?" or "What have been the effects of T2DM on your daily life?". Each interview lasted for about 55-70 minutes. Following the participants' permission, all interviews were recorded and then transcribed and translated for further analysis.

**Data analysis:** In order to analyze the transcript of the interviews, the six methodological activities proposed by Van Manen (1990)<sup>22</sup> were employed (Table 2).

In order to make sure about the accuracy of the translated transcripts, they were compared to the recorded interviews several times. Afterwards, the themes depicting the patients' lived experiences were extracted by breaking down the interviews into words, phrases, and sentences by utilizing holistic, detailed, and selective approaches. The transcripts were reread and scrutinized several times in order to thoroughly understand the experiences of patients with T2DM.

**Table 2. Six methodological activities in Van Manen's method**

#	Van Manen's methodical activities	The researchers' activities
1	Turning to the nature of lived experience	Given the high prevalence of T2DM in the region and its negative effects on the patients' quality of life and finally the need for developing effective approaches to improve the patients' daily lives, the researchers decided to carry out an investigation into the lived experience of the patients with T2DM.
2	Investigating experience as we live it	Selecting the patients with T2DM
3	Reflecting on the essential themes which characterize the phenomenon	Using thematic analysis
4	Describing the phenomenon through the art of writing and rewriting	Writing and rewriting to create a phenomenological text
5	Maintaining a strong and oriented relation to phenomenon	Discussing the themes in relation to the phenomena
6	Balancing the research context by considering parts and whole	Moving between transcripts and themes

T2DM: Type 2 diabetes mellitus

**Trustworthiness:** In qualitative studies, the level of adequacy or soundness is referred to as trustworthiness.<sup>23</sup> To ensure trustworthiness of a qualitative study, it is necessary to describe the data analysis procedure and justify the reliability of the results.<sup>24</sup> The trustworthiness in the present investigation was ensured by establishing a good relationship with the patients and obtaining their trust, benefiting from the comments made by the field experts, conducting the interviews at suitable time and place, and going over the transcripts for several times. In addition, the researchers have been active nurses in the field for years; therefore, their reliability can be ensured.

**Ethical considerations:** In order to make sure about the observation of the ethical considerations, necessary approval was obtained from the Ethics Committee of College of Medicine, Hawler Medical University, Erbil, Iraq (No. 4 on 12-11-2018). Furthermore, the study's objectives, data collection method, and confidentiality of the collected information were explained to the participants. Moreover, the participants were given the right to quit the study whenever they wanted to. In addition, informed written consent was obtained from the patients. In order to keep the collected data anonymous, each patient was given a unique code (patient 1, patient 2, etc.), and the confidentiality of the data was ensured by keeping the files containing the collected data in a safe place.

## Results

Analyzing the patients' lived experiences led to elicitation of 4 main themes namely "incurable disease", "difficult life", "silent disease", and "problem with taking insulin".

### *Incurable disease*

Most of the participants were fed up with their frequent referral to physicians and hospitals and referred to the fact that their disease was untreatable. In this regard, patient 2

stated: "Since I was diagnosed with diabetes, I have been always in hospitals and clinics. I have taken so many medicines, and I'm really tired of taking medicine. I want to get rid of this disease, but I know that there is no final cure for it, and it's so sad to have an incurable disease."

Referring to having taken various medicines to control his blood glucose, patient 6 said: "My blood sugar cannot be controlled by any means. I don't eat much, and I take all medicine prescribed by my doctor, but my blood sugar is still very high. My disease cannot be cured. It's so frustrating and worrying."

Being completely frustrated and tired of taking medication and losing hope, patient 8 revealed: "I've been on medication for more than 5 years, but there has been no sign of being cured forever. I'm sure there is no final treatment. I know this disease will be with me until I die. Death is the only cure for it."

### *Difficult life*

The second theme that emerged from the patients' lived experiences was their difficult life conditions. In this regard, patient 3 said: "I haven't enjoyed my life at all since I was diagnosed with this disease. My life is full of worry and concern about my future. It's so difficult to live with such a disease."

Regarding difficult life conditions, participant 7 stated: "Living with diabetes is the most difficult thing ever. It has affected all aspects of my personal, social, and familial life. When you're suffering from diabetes, you no more enjoy your life like ordinary people, you always need to be careful about what you do and what you eat, and it's really saddening."

Also, patient 10 said: "Diabetes has made my life so difficult. Apart from all worry and concern it has given me, I can't live like a normal person anymore. Since I was diagnosed with it, everything in my life has changed, my eating and my sleeping habits, my free time activities, and so forth."

### *Silent disease*

The third theme that the patients referred to was the fact that T2DM is labeled as a silent killer because the patient does not feel the disease in

the early stages until serious complications start to appear. In this regard, patient 1 said: *"Few years ago, everything was ok with me, I didn't feel any pain, but for a while I started to feel so tired and restless, my body was so itchy, I had constipation almost all the time, so I went to the doctor, and I was diagnosed with diabetes. I was told that I had the disease many years ago, and I was so shocked."*

In the same regard, patient 5 said: *"It's so difficult to be told that you have had a disease for many years, but you haven't noticed. It's really unbelievable. I wish I had never known I had the disease."*

Also, patient 4 said: *"Seemingly, I had no problem and I was quite well until that really sad thing happened. I lost two of my sons. I underwent a mental trauma, and right after that, I was diagnosed with type 2 diabetes. I don't know how I have developed that nasty disease."*

#### *Problem with taking insulin*

The last theme that was obtained from analyzing the patients' lived experiences was the fact that they had problem with taking insulin as a medicine. In this regard, patient 9 said: *"I think that I'm addicted to insulin. Every time I inject insulin, I feel that my body needs more, and when I intentionally postpone my injection, my body starts wanting it. I prefer to take some oral medication."*

## Discussion

As a result of analyzing the transcripts of the interviews carried out with the participating patients with T2DM, four main themes namely "incurable disease", "difficult life", "silent disease", and "problem with taking insulin" emerged.

During the interviews, some of the patients revealed their worries about incurability of their disease and uncontrollable level of blood glucose. In their qualitative study focusing on the diabetic patients' ideas of illness course, Lai *et al.* reported that the participating patients considered DM as a chronic incurable disease which led to serious complications including renal injury, leg amputation,

blindness, and poor peripheral circulation.<sup>25</sup> Similarly, in relating their experiences with DM, the patients participating in the study carried out by Natarajan referred to DM as an incurable disease.<sup>26</sup> Moreover, the patients with DM in the study carried out by Selman *et al.* referred to DM as an incurable progressive disease.<sup>27</sup> The same theme has been reported by the study carried out by Abazari *et al.*<sup>28</sup>

The second theme that emerged from analyzing the patients' lived experiences was difficult life. By referring to the limitations caused by DM, the patients stated that they had not enjoyed their lives since their diagnosis with T2DM. In their study of lifestyle changes as a result of T2DM among women from western Sweden, Ahlin and Billhult observed that the lifestyle of women with DM became more difficult and overwhelming,<sup>29</sup> which is in line with the second theme of the present study. The patients participating in the investigation carried out by Svedbo Engstrom *et al.* also referred to their hard time dealing with the complications and limitations resulting from their DM. These patients stated that support from others could help them overcome the difficulty of dealing with the disease.<sup>30</sup>

The third theme that emerged from the patients' lived experiences was silent disease. DM has been referred to as a silent disease or killer in different studies including those carried out by Carolan *et al.*,<sup>31</sup> Abdoli *et al.*,<sup>32</sup> and DiZazzo-Miller *et al.*<sup>33</sup> Since the symptoms of T2DM are not apparent in the early stages of the disease until serious complications develop, this disease is called a silent killer.<sup>6</sup>

The final theme emerging from the patients' lived experiences was labeled as problem with taking insulin. In this regard, one of the patients stated that insulin taking was addictive and she preferred to take oral medicines. Participants of some previously studies stated that insulin injection was

addictive.<sup>34-36</sup> Moreover, in their study of exploring Brazilian and Canadian patients' perceptions for insulin therapy in T2DM, Guimaraes et al. reported that the patients with DM in their study referred to insulin injection as drug addiction.<sup>37</sup>

There were two limitations in the present study. The study setting was the first limitation because all of the participants were selected from a public hospital in Mergasour District, which can have an influence on the results and their generalizability to other settings particularly to private hospitals where patients might have different experiences, resulting in different outcomes. Also, the participants' ethnicity and culture made another limitation. All of the participants were Muslim Kurds with the same culture and religion. As a result, the findings may not be quite generalizable to other cities and towns in the Kurdistan Region and Iraq where Kurds, Arabs, and other ethnicities live.

### Conclusion

The results of the present study indicated that while relating their lived experiences, the patients with T2DM referred to their experience with the disease as "incurable disease", "difficult life", "silent disease", and "problem with taking insulin". According to the results, future treatments should be based on the patients' lived experiences. In this regard, they need to be socially and individually supported in order to help them overcome their belief about the incurability of their disease, the difficulty of their lives, and the silence of the disease and its complications. Patients with T2DM should also be provided with alternative medicines instead of insulin injection.

### Conflict of Interests

Authors have no conflict of interests.

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