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Attitudes, Knowledge, and Perceptions of Patients Regarding Type-2 Diabetes in Jordan

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Abstract

Introduction: Poorly controlled Type 2 diabetes is considered a major public health problem and associated with adverse outcomes in Jordan. Good diabetes knowledge may facilitate adaptation of healthy behaviors and improve patients' adherence to their diabetes management plans. **Purpose:** To gain an in-depth understanding of attitudes, perceptions and knowledge of patients which underpin their behaviors in Jordan. **Methods:** 8 focus groups with 38 patients with poorly controlled Type 2 diabetes were conducted. The focus group sessions were audio recorded and transcribed. Thematic analysis was employed to analyze the qualitative data. All transcripts were uploaded into the qualitative data analysis software pack NVivo. **Results:** Patients reported the different ways in which they were diagnosed with Type 2 diabetes. Most of the patients visited the health facility after experiencing signs and symptoms of diabetes, often for some time before seeking medical help. Stress and family history were perceived as causes of developing diabetes and reasons for poorly controlled diabetes. Fatalistic beliefs were shared when the patients were talking about the causes of diabetes, the reasons for developing diabetes and their inability to control their blood glucose levels. Patients also associated fatalistic attitudes with religious beliefs and the power of God as illness being in God's hands. Patients' responses also showed a poor understanding of the basic knowledge of diabetes. **Conclusions:** Effective health education programs need to be tailored to meet the individual needs of patients. Patients need to be provided with accurate information about medications, side effects and therapeutic effects. An educational program may rectify misconceptions among patients.

Keywords

Type 2 Diabetes, Attitude, Knowledge, Adherence, Fatalism

1. Introduction

Globally, there are 425 million people who have diabetes, and this number is expected to increase to 629 million by 2045 [1]. Diabetes mellitus is a significant health problem in the Middle East region; including in Jordan where 11.8% of the population is reported to have diabetes [1].

Several studies have shown that diabetes knowledge is important to change management behaviors among patients in Jordan [2] [3] [4] [5] [6]. However, knowledge alone is not enough to change behaviors, and it should be complemented by behaviors and positive attitudes towards diabetes and the treatment plan [7].

In Jordanian literature, most of the researchers evaluated either diabetes knowledge [2] [8] or patients' behaviors [9] alone which is identified as a short-fall. Knowledge, attitudes and behaviors are required to be explored together to provide a holistic understanding of the reasons behind poorly controlled Type-2 diabetes mellitus (T2DM). Poor glycemic control is defined as an HbA1c greater than or equal to 7% [10]. HbA1c levels less than 7% (good glycemic control) are recommended for people with diabetes, as it is linked with a reduction in microvascular and long-term macrovascular complications [10].

This study aimed to explore the knowledge, attitudes and perceptions of patients regarding Type-2 diabetes. The qualitative methods utilized in this study gave patients the opportunity to express their feelings and concerns regarding their condition. To date, there are no published qualitative studies identified from Jordan regarding patients' attitudes and perceptions of their condition.

2. Materials and Methods

This study was conducted in a large comprehensive health care center in Jordan between July and December 2016.

Inclusion criteria included patients diagnosed with Type 2 diabetes who had an HbA1c greater than or equal to 7%. Inclusion criteria also included patients with type 2 diabetes who lived in the selected city and attended the selected health care center to receive diabetic care. It has been reported that patients with Type-2 diabetes need one year since diagnosis to understand and monitor their disease [3]. In order to avoid an unnecessary additional burden for patients who had been newly diagnosed, the inclusion criteria included patients who had been diagnosed with Type-2 diabetes for more than one year.

The prevalence rate of Type 2 diabetes in Jordan rises after the age of 40 years in both sexes [11]. Globally, 374 million out of a total of 425 million people with diabetes (all types) are aged more than 40 years old [1]. This study included patients with Type-2 diabetes older than 40 years. Additionally, the study participants needed to be able to communicate in Arabic, to understand and be able to give informed consent and be willing and able to participate in a focus group. The exclusion criteria included patients who had severe speech or hearing difficulties, patients with type 1 diabetes or gestational diabetes, and patients with good glycemic control levels HbA1c less than 7%.

The recommended focus group size is 6 to 10 people [12]. Small group size stimulates discussion and encourages participants to share their ideas and enables the facilitator to explore any tensions, disagreement or conflicts between group participants. A minimum number of four focus groups were planned with more if needed to reach data saturation. Eventually, eight focus groups with 38 patients were conducted. Focus groups (FGs) were conducted by a principal researcher aided by an assistant with a small group of patients (4 - 6) with poorly controlled Type-2 diabetes. This sample size was considered adequate for addressing the research aim and objectives.

Informed consent was gained before any data collection from participants and before commencing the focus groups. All participants were informed that they had the right to accept or refuse the audio recording of their discussion and interviews.

Ethical approval was obtained from the College of Human and Health Sciences Ethics Committee at Swansea University in the United Kingdom. This study was conducted in a comprehensive health care center managed by the Primary Care Department of the Ministry of Health in Jordan.

The focus group sessions were audio recorded and transcribed. Thematic analysis was employed to analyze the qualitative data. To support the data analysis process, all transcripts were uploaded into the qualitative data analysis software pack NVivo.

3. Results

All focus groups were conducted in the comprehensive health care centre. Eight FGs (n = 38) were conducted with a mix of males (n = 16) and females (n = 22) with poorly controlled Type 2 diabetes (Table 1). The number of participants per focus group ranged from 3 - 6, the average duration was 70 minutes.

Themes

Analysis of the collected data revealed 4 main themes related to attitudes, knowledge and perceptions of patients regarding Type-2 diabetes; 1) reasons for developing diabetes, 2) knowledge of T2DM and its complications, 3) patients' perceptions and attitudes of insulin and self-monitoring blood glucose (SMBG), and 4) misconceptions.

Main theme 1: Reasons for developing diabetes

Many patients talked about life events that led to the patient's diagnosis or occurred before the diagnosis was confirmed by the doctor. Six male patients and three females (9/38, 25%) held fatalistic attitudes.

Whatever happens, happens

"Whatever happens, happens" was an expression that a few patients (3/38, 8%) mentioned expressing their fatalistic beliefs and attitudes towards diabetes and its management:

I got diabetes because of psychological distress. I was a diabetes carrier, and it happened because of the psychological thing. Anything you are a carrier with will appear (Female patient 3. Focus group (FG) 4).

Table 1. Sociodemographic and relevant characteristics of people with Type-2 diabetes (n = 38).

Demographic characteristics	Frequencies	Percentage (%)	Missing data
Gender			
Male	16	42.10%	
Female	22	57.89%	
Age (years)			
40 - 50	13	34.21%	
51 - 60	12	31.57%	
61 - 70	9	23.68%	
≥71 years	2	05.26%	
Highest level of education			
No education	4	10.52%	
Primary	7	18.42%	
Secondary school	12	31.57%	
Diploma	7	18.42%	
University degree or higher	8	21.05%	
Duration of Type-2 diabetes (years)			5
1 - 5 years	16/33	48.48%	
6 - 10 years	8/33	24.24%	
≥10 years	9/33	27.27%	
Type of Type-2 diabetes treatment			6
Diet only	2/32	06.25%	
Oral hypoglycemic tablets	19/32	59.37%	
Diet and oral hypoglycemic tablets	1/32	03.12%	
Oral hypoglycemic tablets + herbs	1/32	03.12%	
Insulin and oral (combined)	9/32	28.12%	
Family history of diabetes			4
Yes	26/34	76.47%	
No	8/34	23.52%	
Smoking status			
Current smoker	12	31.57%	
Past smoker	4	10.52%	
Non-smoker	18	47.36%	
Monthly income in Jordanian Dinar (JD)			10
≤299 JD	2/28	07.14%	
300 - 500 JD	20/28	71.42%	
501 - 1000 JD	5/28	17.85%	
≥1000 JD	1/28	03.57%	

Difficulties in adhering to the diabetes management behavior plan induced six patients (6/38, 15%) to express feelings of resignation, hopelessness and fatalistic beliefs to justify their difficulties:

I gave up testing for a year, and I did not buy strips. Now when I get up, I have shakiness, and when I test my blood glucose, I also got bored and as this sister said “the death is once, whatever happens, happens” (Female patient 5. FG 3).

A male patient used religious expressions to shift the responsibility for his own condition to God or Allah in Arabic, and that diabetes was from God. He also emphasized the role of religious beliefs and faith in controlling his condition and attributed developing diabetes to a higher power “Allah” as a sign of coping and acceptance of his condition:

As I told you according to the instructions that I received from the center I try to apply them because if I don't apply them, I will stay with the same disease. I want to beat the disease and thanks, Allah it is Allah's willing. When I am a patient with diabetes, it is from Allah (Male patient 5. FG 8).

Proactive screening for diabetes

Family history was reported as the primary risk factor associated with the development of diabetes among two-thirds of the patients (26/38, 70%) in this study. However, proactive screening for diabetes was reported by 5 (20%) of the 26 patients with a positive family history:

My mother has diabetes and her sisters too. So when I was visiting my friend, I tested my blood glucose and I didn't have my breakfast yet, and the test was high 130 so directly I said it is family history that has a role. Then I did fasting blood sugar (FBS), and it was high too so then I have started treatment for diabetes (Female patient 1. FG 7).

Many patients supported the female patient's view in the previous quote that a family history of diabetes increased their susceptibility to developing diabetes:

I was always stressed and family history too. I was a diabetes carrier, and it happened (Female patient 3. FG 4).

The reaction to classic symptoms of diabetes

A reactive approach to the symptoms of diabetes was adopted by a half of the patients in this study (19/38, 50%) as a response to the signs and symptoms of diabetes. Half of the patients in this study reported to the health facility seeking medical help after diabetes symptoms had been detected, and its complications had already developed:

Ten years ago, I ate so many sweets then my eyes became blurred. After that, I went to the clinic, and they told me I have diabetes, and my first fasting blood glucose was 300 (Male patient 1. FG 1).

Five patients (13%) were diagnosed with diabetes following a routine check-up or visiting the hospital for non-diabetes related reasons. Lack of awareness linked to the patient's ignorance of diabetes symptoms resulted in a delay in gaining a diabetes diagnosis and taking no action:

I don't know what I was feeling in some things such as frequent urination, but

I thought of prostate enlargement rather than diabetes. Coincidentally, I did regular blood tests because I have hypertension for a long time and my blood glucose was high (Male patient 4. FG 6).

“Suddenly” was mentioned by many patients in this study to describe how they were diagnosed with diabetes. Patients believed that the onset of diabetes symptoms happened suddenly without experiencing any obvious symptoms:

I got diabetes suddenly when I was 25 years old (Male patient 2. FG 5).

Is there emotional diabetes?

Many patients expressed the view that psychological distress caused the onset of diabetes. Over a third of patients (n = 13) in this study perceived that having psychological distress was the main cause of diabetes. Female patients (n = 9) were twice as likely to perceive stress as a cause of diabetes than males (n = 4). Many patients talked about the stressful life events that preceded their diagnosis of diabetes:

I came here, and I was sick then the doctors asked me to do tests, and they told me you have diabetes. I had HbA1c done, and they told me you have emotional diabetes (Female patient 4. FG 8).

Many patients perceived that developing diabetes was unavoidable because of experiencing stress and having a relevant family history:

My parents had diabetes, and I got diabetes because of psychological shock (Male patient 3. FG 2).

Main theme 2: Patients’ knowledge of Type-2 diabetes and its complications

All patients were asked questions during the FG discussions to explore their knowledge of Type-2 diabetes and its complications.

Patients’ knowledge of Type-2 diabetes

Most of the patients were able to express their knowledge of diabetes. The common perception that age is the discriminating factor between Type-2 diabetes (older patients) and Type-1 diabetes (younger patients) was mentioned by a few patients:

There are two types of diabetes, Type-1 and Type-2. Type-1 diabetes is common among children, and Type-2 diabetes occurs with the old age due to bad eating and drinking habits, weakness in the heart muscle and sadness (Male patient 1. FG 2).

Family history and stress were reported by patients as the main reasons for the development of diabetes:

Family history such as parents had diabetes is another risk factor for diabetes. Majority of patients may experience psychological shock which increases blood sugar then end up with having Type-2 diabetes (Male patient 1. FG 2).

Patients’ perception of diabetes complications

Approximately a third of patients (11/38, 30%) in this study had already developed complications at being diagnosed with diabetes which induced them to learn more about their condition. All patients were able to list a number of examples of diabetes complications:

I suffered from complications which diabetes destroyed my retina, kidneys and heart (Male patient 1. FG 3).

Approximately half of the patients (18/38, 50%) identified that retinopathy and nephropathy were the most common complications of diabetes. This perception was attributable to the high prevalence of kidney and eye problems among patients. Kidney and eye problems were the main complications among seven patients (20%) with complications. Oral health problems and hypoglycemia were only mentioned once by two patients.

A few patients used different phrases such as “gate for other diseases”, “silent cancer”, “cumulative for all body systems” and “irreversible damage” to describe how they felt towards diabetes:

I learned that diabetes opens the doors for other diseases-the gate of other diseases in the body such as the poison in the body and it hurts the body so much (Female patient 3. FG 8).

Other patients’ experiences with complications made patients aware and conscious of the seriousness of diabetes. For example, a male patient who was talking about his fear of developing complications:

I am terrified of seeing my uncles’ sons who are the same age as me, and some of them lost their legs or have renal failure. Eventually, the patient with diabetes will lose his legs or have the renal failure which forces me to follow the diet too much and decrease the sugar (Male patient 4. FG 4).

Main theme 3: Patients’ perceptions of insulin and self-monitoring blood glucose (SMBG)

Nearly a quarter of the 38 patients in my study managed their condition by insulin therapy. However, a few patients expressed their concerns about the use of insulin in their treatment plan.

Fear of painful injections, an indicator of poor glycemic control and hypoglycemia were the main barriers reported among the patients. Fear of injections was also associated with patients’ resistance to accepting insulin to be added to their treatment program:

Because I don’t want the doctor to add insulin to my medication regimen as end stage, I do not tell her about the increase in my blood glucose levels. I only take tablets because it is hard to inject myself. No (Female patient 4. FG 3).

Many patients in this study did not test their blood glucose (BG) levels at home despite a quarter of them taking insulin. A few female patients reported that they avoided glucose testing due to the emotional anxiety testing caused them. None of the male patients reported this feeling of anxiety associated with glucose testing. Other reasons than stress such as the cost of the strips and needle phobia were reported. Fear of self-testing was linked to stress and avoidance behavior among a few female patients:

From the things that make the patient unhappy the excess doing self-monitoring tests which when you eat the sugar is low while during fasting the sugar is high. These readings make you stressed. Self-monitoring makes patients psychologically stressed then sugar increases (Female patient 3. FG 4).

Most of the patients waited to test their BG until either they felt symptoms of diabetes or they did not feel well (reactive approach):

If I see myself being tired due to increase or decrease in blood glucose, immediately I test my blood glucose, so the glucometer is so good if it is available. Now I don't test my blood glucose (Male patient 2. FG 5).

Main theme 4: Patients' misconceptions of diabetes and its management

Many patients shared their beliefs and perceptions of diabetes in this study. Patients' perceptions affected their level of adherence to their management plan. Two main misconceptions were expressed by patients; medications and the seriousness of the condition.

Negative beliefs about medications were held by one-sixth of the patients (6/38, 15%) in this study. Metformin was associated with side effects; therefore, the prescribed Metformin was not taken regularly:

I decrease the amount of Metformin that I take per day. For instance, if I take three times a day, I feel back pain, and it affects kidneys, so I take one or two tablets a day according to my comfort (Female patient 3, FG4).

Adherence to the treatment plan was affected by patients' perceptions of medications' side effects and their short-term benefits:

Insulin and tablets are temporary not for a week or a month. When insulin and pills are taken in the morning, they are only for one day. Insulin and tablets are not a treatment because they cannot cure diabetes (Male patient 5, FG 4).

There was a lack of awareness among patients that chronic conditions such as Type 2 diabetes cannot be managed and cured only by medications. Another patient also talked about a machine to cure diabetes:

I heard the news there is the machine that is invented in America to remove diabetes? (Male patient 2. FG 1)

Taking medications based on experiencing symptoms of diabetes was mentioned by a few patients (3/38, 8%):

When I work, I forget to take medications because I don't feel tiredness or thirsty or fatigue. Even during winter, I don't feel that I have diabetes at all and I don't take tablets for 20 days (Male patient 4. FG 4).

Patients expressed their perceptions of the severity of diabetes. The onset age of diabetes and type of treatment were perceived by patients as indicators of the severity of the condition. Diabetes was regarded by a number of patients as a "mild illness":

If diabetes comes after the age of 50, it is normal. It does not cause complications, and it does not affect (Female patient 6. FG 1).

A few patients (3/38, 8%) referred to diabetes as "sugar" disease; therefore, they associated diabetes with simple sugar only:

Really I do not eat sweets, and I do not know how I got diabetes (Female patient 6. FG 1).

A male patient was not aware of the nature of chronic condition management. He thought that diabetes could be cured and reversed by taking medications:

If the blood glucose becomes controlled, can the patient stop taking medications? (Male patient 3, FG 7)

4. Discussion

This study aimed to explore the knowledge, attitudes and perceptions of patients regarding Type-2 diabetes. The qualitative methods utilized in this study gave patients the opportunity to express their feelings and concerns regarding their condition. Furthermore, to gain an in-depth understanding of attitudes, perceptions and knowledge of patients which underpin their behaviors. To date, there are no published qualitative studies identified from Jordan regarding patients' attitudes and perceptions of their condition.

Fate was seen as a reason for patients believing that they did not have control over their own condition. Furthermore, patients used different statements related to fatalism such as "God's will", "inevitable condition" and "death is once" during FG discussions. Diabetes was perceived as an inevitable condition especially among patients who had a positive family history and went through stressful life events prior to diagnosis.

Patients displayed strong beliefs in an external locus of control regarding their diagnosis of diabetes. In any behavior change approach to health promotion, these patients could be seen to be contributing to developing diabetes because they did not look after themselves especially with respect to maintaining a healthy lifestyle [7]. Although most Arabs strongly believe in fate and destiny due to the religious faith they are also encouraged to believe in self-responsibility. Responsibility towards one's health is emphasized in the Qur'an and the Islamic Hadith [13].

The overwhelming power of fate was perceived by patients to justify their difficulties in controlling their BG levels. "Hopelessness" was mentioned which is viewed as an indicator of fatalism and associated with poor adherence, decreased quality of life and poor BG levels [14] [15]. The patients' expressions of fatalism were consistent with the three main dimensions of diabetes fatalism; emotional distress, hopelessness and powerlessness [14].

A few patients pointed out that all life circumstances were controlled and predetermined by "God", but at the same time, they acknowledged that they should take responsibility for their condition. This implied patients believed they had little or no personal control over their fates. Similarly, most of the participants acknowledged the importance of visiting the doctor and following medical instructions, but also they believed that God was responsible for whether their condition got better or worse in Saudi Arabia [16].

Many of the Qur'an's phrases and Islamic beliefs encourage patients to take responsibility for their own health and maintain a balance between physical, psychological and spiritual aspects which is consistent with the concept of wholeness and internal locus of control [13] [16]. Most of the participants viewed illness as a "will of God" and shared the same belief that is "whatever happens,

must happen” in Jordan [13]. For Muslims, most of the life events including developing illness and recovery are explained regarding “God’s will” [17].

Up to two-thirds ($n = 26$) of patients in this study had a family history of first degree relatives mainly their parents with the disease which added another risk factor for developing diabetes among them. Family history was the most common risk factor reported by patients in this study. Similarly, a study reported that 126 (70 %) had a family history of diabetes as a first-degree family member in Jordan [5].

Approximately half of the patients in this study suffered from the symptoms of diabetes before the diagnosis of diabetes was confirmed by the doctor. These patients mentioned that they already had a family history and hypertension which increased their chances of developing diabetes. Patients perceived that diabetes occurred suddenly but in reality less than 50% of B-cell function remains effective at the time of diagnoses of Type-2 diabetes [18]. That means Type-2 diabetes develops gradually rather than suddenly. Patients were not aware of having diabetes until the symptoms were worsening and their bodies were not able to cope with these symptoms.

Patients believed that they developed diabetes due to their grief caused by a family member’s death or due to other stressors. These patients were overwhelmed by the influence of stress as a dominant cause of diabetes despite the presence of other risk factors such as family history, obesity and a sedentary lifestyle. These participants’ responses reflected an external locus of control by attributing the cause of the disease to factors outside their control [19].

Patients’ responses showed that they perceived the threat of diabetes complications was high, but despite this, they were not making changes to their lifestyle. Most patients were also aware that high BG levels caused damage to all body systems. Therefore, knowledge alone was not enough to stimulate and trigger the patients to take action and change their habits. These findings are consistent with another study that found the level of patients’ compliance with behaviors to reduce the risk of retinopathy was low, despite the high level of awareness about diabetic retinopathy in the study [20].

Patients considered insulin as a “last resort” when all other types of treatment were no longer effective. Therefore, patients associated insulin therapy with a serious stage of diabetes and the development of complications. These patients’ perceptions of insulin are supported by another study in Jordan [3].

These patients tested their BG when they experienced obvious symptoms. This implies that patients did not view self-monitoring as an important element in diabetes management. These feelings and perceptions could explain in part why only a few patients in this study tested their BG at home. These findings are supported by another study in Kuwait that found patients only did self-monitoring when they felt extreme symptoms [21]. Adherence to the medication regimen was affected by experiencing side effects. Some patients reported feeling uncomfortable due to experiencing a number of unwanted effects of

Metformin. Weight loss, back pain and kidney problems were the most common side effects reported by patients. A number of patients either refused to take Metformin or reduced doses due to its side effects. This implies a form of intentional non-adherence to their treatment plan. Concerns about side effects of the medications and fear from insulin injections affected adherence to medication regimen among patients with Type-2 diabetes in Jordan [6].

Patients perceived that medications are only to relieve symptoms without any curable and longtime effects. They emphasized more the short-term effects of medications rather than the long-term benefits to avoid diabetes complications. Similar findings were reported in Oman [22].

Lack of noticeable signs and symptoms of diabetes encouraged patients to not adhere to the treatment plan. These denial attitudes were therefore seen as a barrier that influenced patients' motivation to adhere to treatment plan. Similar misconceptions were reported in Saudi Arabia [23].

Patients thought that Type 2 is a mild form compared to Type 1 diabetes. Lack of noticeable signs and symptoms of Type 2 diabetes made patients think that diabetes is not a serious illness. The type of treatment was also perceived as an indicator to assess the severity of diabetes. Diabetes managed by only oral tablets was perceived as a mild condition. This implies that patients with insulin treatment had a severe form of diabetes and may also be a factor which led to their reluctance to start insulin therapy. Therefore, treatment mode was mentioned as an indicator of the severity of diabetes as patients who take oral tablets think their diabetes is not serious. These perceptions are similar to patients' beliefs in Malaysia that insulin is only given for severe diabetes [24].

There was a poor understanding of the etiology of diabetes among patients. Diabetes was perceived as a short-term condition (acute disease) that is supposed to be cured following taking medications only. These perceptions were also affected by the media that takes advantage of these patients to provide a "cure" for diabetes. These wishing beliefs contributed to poor adherence to treatment plans and increased the risk of developing complications among patients.

Patients associated the cause of diabetes with a high intake of sugar. This perception comes from the word "diabetes" and is translated by many patients in Arabic to "sugar". Similarly, most patients preserved that excessive sugar consumption was the primary reason for developing diabetes among them [25].

5. Limitation of the Study

This study was conducted in one large sized comprehensive health care center in a large city in Jordan. The target sample was patients who accessed the primary care services provided by the selected center. The sample size ($n = 38$) was small and may not be representative of all patients with poorly controlled Type-2 diabetes in Jordan. However, the study findings and inferences may be generalised theoretically to other patients with poorly controlled Type 2 diabetes in similar contexts.

6. Conclusion

There is a poor understanding of the basic knowledge of diabetes among patients in this study. Effective health education programs need to be tailored to meet the individual needs of patients. Patients need to be provided with accurate information about medications, side effects and therapeutic effects. An educational program may rectify misconceptions among patients.

Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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