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How do Saudi diabetic patients perceive their illness? A multicenter survey using revised-illness perception questionnaire

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Abstract:

BACKGROUND: Illness perception questionnaires for various medical conditions have become more useful in recent years. However, very few have used this to address the issue of type 2 diabetes in Saudi Arabia.

MATERIALS AND METHODS: This study was conducted among type 2 diabetic patients attending primary healthcare centers and Al Kharj Military Industries Corporation Hospital in Al Kharj, Saudi Arabia, during November 24, 2016, to April 24, 2017. SPSS used for analysis that included descriptive statistics, *t*-test, and a one-way analysis of variance (ANOVA).

RESULTS: A total of 500 questionnaires were distributed, and 383 of them were returned; response rate about 77%. Majority of participants (80.4%) were educated, 69.5% were married, and 51% were females. About 57% were on OHA, and 57% had no other chronic disease. Most participants perceived that diabetes was hereditary (75%), and 62.4% thought it is due to diet or eating habits. About 80% participants believed that there is a lot they can do to control symptoms. About 73% participants believed they have the power to influence diabetes, whereas 78% think there is very little that can be done to improve diabetes and treatment can control diabetes. The Cronbach's alpha value for identity, timeline (cyclical), and emotional factors were relatively high, showing that these scales had a strong level of internal consistency.

CONCLUSION: Saudis with type 2 diabetes mellitus had adequate knowledge of their disease. They agreed that diabetes was likely to be permanent and would have major consequences on their lives.

Keywords:

Diabetes, illness perceptions, Saudi Arabia

Introduction

Type 2 diabetes is a serious common chronic disease resulting from a complex inheritance-environment interaction together with other risk factors such as obesity and sedentary lifestyle.^[1,2] Type 2 diabetes and its complications constitute a major worldwide public health problem, affecting almost all populations

with high rates of diabetes-related morbidity and mortality.^[3] Type 2 diabetes mellitus (T2DM) are often accompanied by complications, such as cardiovascular diseases, diabetic neuropathy, nephropathy, and retinopathy.^[4] With its associated complications, diabetes lowers the quality of sufferer's lives and generates enormous economic physical, cognitive, social, and psychological burdens.^[5]

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Furthermore, diabetes mellitus is becoming more prevalent worldwide,^[6] as it increased from 4.7% to 8.5% in 2014.^[7] In the Middle East and North Africa, it reached 9.1% in 2015,^[8] while in Saudi Arabia, it was as high as 23.9% in 2013.^[9] According to a study conducted by the World Health Organization, Saudi Arabia is the second highest in ranking in the Middle East, and is seventh in the world for the rate of diabetes in the population. It is also estimated that around seven million of the population are diabetic and almost three million have symptoms of prediabetes.

Perception of health is an important facet of health, which depends on the presence of a disease and its possible impact on health-promoting behaviors. Undoubtedly, self-perception plays a crucial role in self-management behaviors in people affected by diabetes. Perception of health, to some extent, can have effects on self-care, management of the condition, and some areas of the quality of life of these people who have diabetes. Illness perception questionnaires for various medical conditions have become more useful in recent years: ^[10] they examine the perceptions patients have of their disease; ^[11,12] they look at the name of the disease, its symptoms and ideas about its causes. ^[13] Some studies have been done with this kind of questionnaire; ^[14-17] including a few for diabetes mellitus. ^[6,18] However, very few have addressed this issue for type 2 diabetes in Saudi Arabia. ^[18]

The aim of this research was to examine type 2 diabetic patients' perception of the disease in Saudi Arabia; to help give health providers a better understanding of what patients feel about their disease, and help with their treatment and future medical care. It is important for patients to grasp various outcomes in chronic diseases, including the quality of life and self-management. ^[10]

Materials and Methods

A cross-sectional study was conducted over a 5-month period (November 24, 2016, to April 24, 2017). The study was conducted in Al Kharj Military Industries Corporation Hospital (AKMICH) and five other primary health-care centers (PHCCs) in Al Kharj on the targeted population of all type 2 diabetic patients in Al Kharj governorate. To minimize bias, the questionnaire was distributed to a representative sample of the target population of both male and female type 2 diabetics who attended PHCCs and AKMICH in Al Kharj governorate. A multistage random cluster sampling technique was employed in the PHCCs, according to their geographic divisions in five districts (middle, northern, southern, western, and eastern) with two to three in each. We randomly chose five PHCCs in total, one PHCC in

each district. Eligibility criteria included being Saudi, having had T2DM for at least 1 year, aged 18 years or more, with no cognitive impairment that could interfere with communication or comprehension of questions, the ability to read and write in Arabic. They should have no visual impairment that could interfere with self-reporting, and a willingness to participate in the study. Extremely ill patients and pregnant women were not eligible.

Given that the prevalence of diabetes mellitus in Saudi Arabia is 23.9%, and the total population of Al Kharj governorate is 376,325,^[19] the minimum sample size required for a 99% confidence interval with a 5% margin of error was calculated to be 383. The sample size was adjusted to 400 to account for any possible data loss during collection. To compensate for low response and rejection as a result of noneligibility, 25% was added. Thus, the target sample size was 500. We heard from 398 (79.6%) participants with completed questionnaire. After screening, 15 (3%) questionnaires were excluded due to incompleteness leaving 383 (77.6%) questionnaires for further consideration and analysis.

A validated, multiple selection, self-administered illness perception questionnaire, established at University of Bergen, Norway was used as the data collection tool. A version for diabetes available on their website was used with the permission to assess perception of diabetes illness.^[20] The IPQ-R include three sections: identity perception, illness perception, and cause perception. The first comprising 14 yes/no items measure how the patient labels his illness; each item is a symptom the patient might feel he has. A high score indicates a high diabetes identity perception. The second measures seven illness perceptions (timeline perception, cyclical perception, consequences perception, personal control perception, treatment control perception, illness coherence, and emotional representations). For each of the 38 items, the patient indicates his level of agreement using a five-point Likert-type scale (strongly disagree to strongly agree). Six timeline perception items (sample: "My diabetes will last a short time") measure whether the illness is perceived as acute or chronic. A high score indicates that diabetes is perceived as a chronic (long-term) illness. Four cyclical perception items (sample: "I go through cycles in which my diabetes gets better and worse") determine the pattern the patient perceives in the course of the illness. A high score indicates that diabetes is perceived as a cyclical or unstable illness. Six consequence perception items (sample: "My diabetes is a serious condition") measure how serious the illness and its impact on life are perceived. A high score indicates that diabetes is perceived as a serious illness with a negative impact on life, social relationships, or economic status. Six

personal control perception items (sample: "I have the power to influence my diabetes") measure how much the patient thinks he can manage or control the illness. A high score indicates that the patient perceives he has the personal ability to control diabetes. Five treatment control perception items (sample: "My treatment can control my diabetes") measure how effective the patient perceives his treatment is controlling the illness. A high score indicates he perceives his treatment to be effective in controlling diabetes. Five illness coherence items (sample: "I have a clear picture or understanding of my condition") measure the patient's perception of his own understanding of the illness. A high score indicates the patient perceives he has a personal understanding of diabetes and that diabetes is perceived as a clear or unambiguous illness. Six emotional representation items (sample: "When I think about my diabetes I get upset") measure the patient's emotional responses to the illness. A high score indicates more emotional responses to diabetes and that diabetes affects the patient emotionally and distresses him. The last section comprises 18 disparate items, or causes of diabetes, for which the patient indicates agreement on the same Likert-type scale. In this case, responses were dichotomized to yes (strongly agree or agree) or no.

The illness perception questionnaire was translated into Arabic, reviewed by Family Medicine consultants, and then translated back into English. A pilot study of 30 participants was done before the distribution of the questionnaire with no changes: participants had no difficulty in completing them the pilot questionnaires were excluded from the final analysis.

Demographic data on participants (age, gender, education level, occupation, marital status, other chronic diseases, type of treatment [either insulin or tablet], and duration of diabetes) were obtained.

Statistical Package for Social Sciences (SPSS) version 23 (IBM Corporation, Armonk, New York, US) was used for data entry and analysis. The coding methods followed for the identity scale are as follows: scale yes = 1; no = 0 (strongly disagree = 1, disagree = 2, neither agree nor disagree = 3, agree = 4, and strongly agree = 5). Descriptive statistics where frequencies, percentages, mean, and standard to measure the central tendency and distribution of the variables were done, *t*-test analysis was conducted, and a one-way analysis of variance (ANOVA) also implemented.

The study was ethically approved by the Institutional Review Board of College of Medicine, Prince Sattam Bin Abdulaziz University. Letters of authorization were procured from each hospital before the distribution of the questionnaire, and verbal informed consent

obtained from participants. Hard copies of the translated questionnaire were stored in the main hospital and five primary health-care centers in Al Kharj governorate. All the physical and electronic confidential and sensitive material were secured.

Results

The youngest study participant was 18-year-old, and the oldest 85-year-old, with most participants falling between 30 and 70 years of age: age distribution was not skewed. The mean age ($M = 46.0$, standard deviation = 15.94) showed that the sample was middle age on average.

The minimum time period for which participants had lived with diabetes was 1 year, while the maximum time period was 40 years. The duration was skewed with a few participants having lived with it for more than 20 years although the median duration was 6 years. The number of study participants (220, 57.4%) using oral hypoglycemic agents (OHA) was higher than those on insulin, with or without OHA. More than half of the study participants (51.4%) were unemployed and those with no chronic disease (56.9%) was more than those with only one. Those who were educated (80.4%) were significantly more than those who were not (19.6%); results are shown in Table 1.

Table 1: Sociodemographic characteristics and disease profile of study participants (n=383)

Variable	N %	Mean (SD)
Age		
18-30 years	81 (21)	46.0 (15.94)
31-45 years	114 (29)	
46-60 years	120 (31)	
61-75 years	50 (13)	
76-90 years	18 (4)	
Gender		
Male	187 (48.8)	8.3 (6.08)
Female	196 (51.2)	8.7 (7.30)
Education		
Educated	308 (80.4)	10.9 (7.33)
Not educated	75 (19.6)	6.7 (5.62)
Marital status		
Single	117 (30.5)	7.5 (6.09)
Married	266 (69.5)	12.7 (7.59)
Employment status		
Employed	186 (48.6)	6.4 (4.81)
Unemployed	197 (51.4)	9.4 (7.22)
Diabetes medication		
OHA	220 (57.4)	6.4 (5.18)
Insulin with or without OHA	163 (42.6)	10.5 (7.39)
Chronic diseases		
No	218 (56.9)	6.0 (5.40)
Yes	165 (43.1)	11.9 (6.88)

OHA=Oral hypoglycemic agent, SD=Standard deviation

A Student's *t*-test showed that the mean duration between male (48.8%) and female participants (51.2%) was not statistically different. Unemployed study participants (51.4%) demonstrated a higher mean duration of illness compared to participants who worked (48.6%), and a *t*-test showed this difference to be statistically significant. Study participants who were on insulin (42.6%), with or without OHA (57.4%), had a higher mean duration of illness than participants on OHA; a *t*-test showed this difference to be statistically significant as well. Participants with a chronic disease (43.1%) had a longer duration than participants who had no chronic disease (56.9%); a *t*-test revealed this difference to be statistically significant. Moreover, participants who were not educated (19.6%) also had had the disease for a longer time period than those who were educated (80.4%); a *t*-test showed the difference to be statistically significant.

The shortest period the participants had had the illness was 31–45 years: those over 61 years had had it for a longer duration. A one-way ANOVA was used to find out the significant difference of the mean in age categories, as it also showed that the mean in age categories was statistically different ($F [4378] = 28.13, P = 0.000$).

The descriptive statistics and Chi-square results of each symptom, along with the belief that the symptom was associated with diabetes are shown in Table 2. Chi-square tests were used to discover any association between symptoms, or the belief that it was associated with diabetes, as the test showed an association with some symptoms. These symptoms included loss of strength (26.7%), dizziness (36.5%), sleep difficulties (42.2%), upset stomach (39.9%), stiff joints (48.2%), weight loss (48.6%), and nausea (50.6%).

Table 3 shows that most participants believed they could do a lot to control symptoms (80.4%) and that what they did could determine whether diabetes got better (80.2%) or worse and the course of diabetes depended on them (80.2%). Almost two-thirds of the participants believed they had capacity to influence diabetes (72.6%), 77.8% thought there was very little that could be done to improve diabetes and 22.7% thought treatment could control diabetes.

More participants understood that what led to diabetes was hereditary (75.5%), diet or eating habits (62.4%). There was fair agreement that aging (46.7%), behavior (43.9%), poor medical care in the past (39.9%), as well as stress or worry (40.5%) also contributed. The level of agreement for other causes was low as shown in Table 4.

The Cronbach's alpha values for identity (0.87), timeline (cyclical; 0.19), and emotional factors (0.61) were relatively high showing that these scales had a

Table 2: Association between experience of any symptoms since diabetes, and the belief that these symptoms are related to diabetes

Symptom	Believe symptom is related to diabetes		χ^2	p-Value
	No N (%)	Yes N (%)		
Pain				
Yes	201 (61.1)	50 (58.8)	0.146	0.70
No	128 (38.9)	35 (41.2)		
Sore throat				
Yes	261 (67.3)	16 (61.5)	0.361	0.55
No	127 (32.7)	10 (38.5)		
Fatigue				
Yes	128 (67.4)	165 (73.7)	1.97	0.161
No	62 (32.6)	59 (26.3)		
Nausea				
Yes	176 (50.6)	48 (72.7)	10.96	0.001
No	172 (49.4)	18 (27.3)		
Breathlessness				
Yes	171 (45.7)	22 (55.0)	1.25	0.318
No	203 (54.3)	18 (45.0)		
Weight loss				
Yes	84 (48.6)	146 (60.6)	5.89	0.015*
No	89 (51.4)	95 (39.4)		
Fatigue				
Yes	128 (67.4)	165 (73.7)	1.97	0.161
No	62 (32.6)	59 (26.3)		
Stiff joints				
Yes	163 (48.2)	51 (67.1)	8.86	0.003*
No	175 (51.8)	25 (32.9)		
Sore eyes				
Yes	156 (45.3)	40 (57.1)	3.25	0.072
No	188 (54.7)	30 (42.9)		
Wheezing				
Yes	175 (47.4)	24 (53.3)	0.561	0.454
No	194 (52.6)	21 (46.7)		
Headaches				
Yes	149 (60.8)	108 (63.9)	0.41	0.524
No	96 (39.2)	61 (36.1)		
Upset stomach				
Yes	111 (39.9)	75 (55.1)	8.55	0.003*
No	167 (60.1)	61 (44.9)		
Sleep difficulties				
Yes	125 (42.2)	67 (56.8)	7.18	0.007*
No	171 (57.8)	51 (43.2)		
Dizziness				
Yes	50 (36.5)	168 (60.6)	21.45	<0.001*
No	87 (63.5)	109 (39.4)		
Loss of strength				
Yes	40 (26.7)	114 (43.2)	11.17	0.001*
No	110 (73.3)	150 (56.8)		

strong level of internal consistency; it also showed that the timeline (acute/chronic; 0.19) and treatment control scales (0.22) were low, thus showing internal consistency of these scales. Cronbach's value of coherence (0.54) and consequences scales (0.50) were low, showing a moderate level of internal consistency [Table 5].

Table 3: Study participants' views about diabetes (n=383)

Views about diabetes	Strongly agree or agree Percentage
Will last a short time	24.5
Is likely to be permanent rather than temporary	60.3
Will last for a long time	51.4
Will pass quickly	12.5
I expect to have this diabetes for the rest of my life	59.0
Is a serious condition	53.3
Has major consequences on my life	65.3
Does not have much effect on my life	25.3
Strongly affects the way others see me	36.8
Has serious financial consequences	40.2
Causes difficulties for those who are close to me	44.9
There is a lot which I can do to control my symptoms	80.4
What I do can determine whether my diabetes gets better or worse	80.2
The course of my diabetes depends on me	80.4
Nothing I do will affect my diabetes	21.9
I have the power to influence my diabetes	72.6
My actions will have no effect on the outcome of my diabetes	23.5
Will improve in time	43.9
There is very little that can be done to improve my diabetes	77.8
My treatment will be effective in curing my diabetes	22.7
The negative effects of my diabetes can be prevented (avoided) by my treatment	76.0
My treatment can control my diabetes	77.5
There is nothing which can help my condition	13.6
The symptoms of my condition are puzzling to me	42.0
My diabetes is a mystery to me	23.0
I do not understand my diabetes	32.4
My diabetes does not make any sense to me	33.4
I have a clear picture or understanding of my condition	16.7
The symptoms of my diabetes change a great deal from day to day	57.7
My symptoms come and go in cycles	62.9
My diabetes is very unpredictable	59.5
I go through cycles in which my diabetes gets better and worse	77.3
I get depressed when I think about my diabetes	42.8
When I think about my diabetes I get upset	49.6
My diabetes makes me feel angry	29.2
My diabetes does not worry me	43.9
Having this diabetes makes me feel anxious	54.0
My diabetes makes me feel afraid	42.6

Discussion

The study sample of participants belonged to the age range of 18 years to 85, the youngest participant aged 18 and the oldest aged 85. Thus the possibility of age bias was reduced, making the findings generalizable across an age spectrum of the population. Male participants were 48.8% and female participants made up 51.2%, which meant there was fair balance, with little preponderance of one gender. This equitable distribution of the genders would, therefore, make a generalization of the findings possible. To further minimize risk of bias in the sample population, study participants were carefully selected by their educational, marital, and employment status.

We did not find a significant difference in the length of time male or female participants had lived with diabetes. Although this suggests a similarity in its occurrence among men and women, it cannot be concluded that risk factors are similar. More research is needed to determine this issue.

Study participants who had chronic diseases had lived for a significantly longer period with diabetes than those who had no chronic diseases. One possible explanation for this finding is that diabetes is associated with other diseases, therefore, people with other diseases were at a higher risk of developing diabetes at an earlier age. The Centers for Disease Control and Prevention reported that 45–64-year-old were at the highest risk of developing diabetes,^[21] but that lifestyle risk had also placed a

younger population at a high risk of developing diabetes. Because of this variation in environmental factors, more research is required to understand high-risk factors in the population.

Uneducated participants had lived with diabetes for a significantly longer period than educated participants had, although it is difficult to delineate the main reasons for this difference (whether it was due to differences in income, lifestyle, or quality of life of the employed and unemployed populations). An example is the Fenwick *et al.* study of the factors associated with knowledge of diabetes in patients with a higher level of education and those with little education.^[22] Furthermore, Gulabani *et al.* found that only 10.8% knew that diabetes could be prevented.^[23] More research is similarly required to understand relevant differences in risk factors of the huge burden of diabetes management on families and health-care systems.^[24]

Table 4: Study participants' perceptions about the cause of diabetes (n=383)

Cause	Strongly agree or agree Percentage
Stress or worry	40.5
Hereditary - it runs in my family	75.5
A germ or virus	19.8
Diet or eating habits	62.4
Chance or bad luck	26.9
Poor medical care in my past	39.9
Pollution in the environment	12.3
My own behavior	43.9
My mental attitude, for example, thinking about life negatively	23.0
Family problems or worries	25.3
Overwork	28.5
My emotional state, for example, feeling down, lonely, anxious, empty	23.0
Ageing	46.7
Alcohol	13.3
Smoking	15.1
Accident or injury	8.4
My personality	20.6
Altered immunity	19.3

According to a study conducted by Thongsai, patients' views or perceptions of their illness seem to be a major variable affecting their health behavior and problem management. Their study indicated that patients with type 2 diabetes who have either a positive or a negative illness perception could benefit by attending their appointment. Therefore, the study advised that factors that influenced participants' attendance of their appointment should be assessed regardless of their illness perceptions.^[25]

Although diabetes had been associated with older populations, this study found it in younger populations as well although the older population had lived with it for a longer period. This study found that 60 years of living with diabetes was more than double the time that those aged 45 years or less had lived with it. Due to the high economic and social costs of managing diabetes, more studies of the younger population are required to understand and reduce its risk factors.

According to a study conducted by Al-Amer *et al.*,^[6] the sequence between self-efficacy and illness perception was mediated by depression. Therefore, they suggested devising strategies to promote self-efficacy and illness perception that will be helpful in developing a customized diabetes health plan for the affected patients. Participants associated loss of energy, dizziness, sleep difficulties, upset stomach, stiff joints, weight loss, and nausea with diabetes. These symptoms are associated with diabetes itself, or with the side effects of the medication, which showed that patients had appropriate knowledge of their disease. It is important to educate patients during management on how to identify and manage symptoms, since those with a good understanding of the disease were able to identify the most probable causes, including eating habits and hereditary factors. This knowledge fostered views that were more consistent with reality.

More patients agreed that diabetes was likely to be permanent rather than last for only a short time. This is in line with findings of Gulabani *et al.*, who found that slightly more than half of the study participants knew

Table 5: Study participants' perceptions about diabetes illness based on the Revised Illness Perception Questionnaire Scale

IPQ-R	Number of items	Possible score range	Mean (SD)	Cronbach's alpha
Identity	14	0-16	4.42 (3.57)	0.87
Timeline (acute/chronic)	6	6-30	18.14 (2.60)	0.19
Timeline (cyclical)	4	4-20	13.30 (2.96)	0.74
Consequences	6	6-30	17.22 (3.58)	0.50
Personal control	6	6-30	19.28 (2.71)	0.41
Treatment control	5	5-25	15.51 (2.16)	0.22
Emotional	6	6-30	16.03 (4.37)	0.61
Coherence	5	5-25	12.75 (3.42)	0.54

IPQ-R=Revised Illness Perception Questionnaire, SD=Standard deviation

there was no cure.^[23] More patients agreed that diabetes would have major consequences on their lives, but that they could definitely manage it better. This finding was consistent with the results of a study by Al-Maskari *et al.*,^[26] which found that patients in the United Arab Emirates, had a positive attitude about self-care.

Conclusion

Saudis with T2DM had adequate knowledge of their disease. They agreed that diabetes was likely to be permanent and would have major consequences on their lives. Successfully managing diabetes was possible, as this study found many patients who had lived with it for over 20 years.

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Conflicts of interest

There are no conflicts of interest.

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