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Original Article

Can I do…? Life with type II diabetes: A phenomenological study

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Abstract

Background: Diabetes is a chronic disease affects many aspects of daily life. We need a bio-psychosocial approach to patients and their problems in diabetes management. Since patient's beliefs about health and disease will guide self-management measures, a holistic understanding toward subject is necessary. The aim of this study was to identify and describe the lived experiences of patients with diabetes in a qualitative study.

Methods: A descriptive phenomenological framework used to guide the project of inquiry. Eleven volunteered patients (6 men, 5 women) were recruited by purposed sampling from "Glands and Metabolism Research Center" and "Al-Zahra Hospital" of Isfahan in 2006. In-depth unstructured one to one interviews conducted and interview data were transcribed and analyzed for themes using collizi method.

Results: Five themes were identified including; "Why I get", "Disease requirements", "Can I do", "Limitations", "Silent motion towards death". 3 first items belongs to participants' perception about diseases etiology, treatment, and their feeling about their situation, respectively. "Silent movement towards death" and "limitation" pointed to the patients' belief about limitation in nutrition and having a healthy child and nature of disease.

Conclusion: Based on findings, patients' beliefs about their disease and health situation can affect health behaviors and self-management, and act as barriers and facilitators in patient behaviors. Findings suggest considering this factor in self-management preparing program.

Key words: Type II diabetes, lived experience, phenomenology

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Diabetes Type II, as a chronic disease, is epidemic in third thousandth anniversary.[1,2] There are more than 171 million diabetic patients all over the world and is estimated to rise to 366 million in 2030.[2] There are nearly 23 thousand diabetic patients in Isfahan.[3] It is a disease with high morbidity, known as the third cause of disease-related death.[4,5] As its treatment and care expenses are high, appropriate prevention is the only reasonable way for decreasing these excessive expenses.[6] Although complications of diabetes can be prevented or delayed,[7] many studies indicated that diabetes control is undesirable.[8-10] So many factors participate in this status; one of these, is patient related factors, since diabetes is a largely self-managed disease.[11-14] Behavioral research findings denoted that attitudes and illness beliefs have determinants role in patients' healthy behaviors.[15] Patients will benefit from interventions compatible with their interest and experiences.[16] In addition, management methods should be according to the patient life in order to motivate him/her.[17] Understanding of patients' perceptions about health and diabetes will be helpful in developing effective diabetes prevention programs.[18] Researches findings showed that health care providers would ignore patient's needs and worries thoroughly; this indicates the necessity of subtle consultation with patients and depth exploration of patients' health beliefs and attitude (who their

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ability for extent change in lifestyle is affected).[16,19] Since diabetes affected many aspects of daily life, it is necessary to take, into account, a holistic view in diabetic patient assessment[11] and a bio-psychosocial approach to the patients and their problems in its care and treatment.[15] Therefore, exploring the patients' experience for nursing cares, in a holistic manner, can be valuable. Nurses need to concentrate on patient's experiences in order to provide effective strategies in diabetes management. The aim of this qualitative study was to investigate diabetic patients' perception about their illness.

Methods

A descriptive phenomenological framework used to guide the project of inquiry. Volunteered diabetic patients were recruited by purposed sampling from "Glands and Metabolism Research Center" and "Al-Zahra Hospital" in Isfahan in 2006. Patients with any limitation for describing the experiences such as communication, disability or severe illness, excluded from our study. Data gathered by in-depth unstructured one to one interviews and completed by eleven participants. After taking informed consent, each interview was done in a private place in health care centers; each interview lasted about 60 minute in average based on patient's preference. All interviews were audio-recorded. The focus of interviews were questions allowed patients describe their experience such as how the disease changed their life, how it is, and so on; when it was necessary, more detailed questions were asked. However, bracketing done before interview in order to help data trustworthiness. After repeated listening and immersing in first interview, it was transcribed exactly and analyzed (for themes) using Collizi method. Vague statements were adjusted using another interview or calling the participant (step 1). Significant statements were identified and meaning of them were formulated in separate term; then second interview with another participant was performed (step 2 and 3). Similar meanings were sorted in one group and the main theme of each group was extracted (step 4). Finally, a comprehensive description with five main themes obtained. Qualitative researchers evaluated the trustworthiness of data using the criteria of credibility, dependability, confirmability, and transferability. In this study, for improvement of these criteria, peer debriefing, member checks, inquiry audit, prolonged engagement of researcher for data collection and data analysis, and bracketing were considered.

Results

Eleven participants with type II diabetes interviewed. There were between 30 to 70 years old and six of them were male. Their education levels varied between diplomas and BSc. Three patients were retired, five workers, and three housekeepers.

Five main themes identified including: "Why I get", "Disease requirements", "Limitation", "Silent motion towards death", "Can I do".

The first theme was "Why I get". It belongs to participants' attitude toward the cause of disease. They mentioned many different reasons for it including stress, inheritance, sedentary life, gluttony, and disturbance in insulin secretion.

> "*I got it because I was sad, I had problem, and I had experienced psychological shock in my life. My husband is a liar. I know those lies who told me have resulted in my disease...* (P: 5)".

The second theme was "Disease requirements". It belongs to anything patients believed that they should have done for their disease. They mentioned stress, medication, diet, and exercise as effective factors in disease management.

> "*Although I am referred to the diabetes center according to the planned schedule and I took my medications, but at the first step I am on a diet, I mean I am compliant to my diet really good, I am walking every day, I don't eat or eat a little of sweet things, so I can control my disease. These are principle in diabetes* (P: 6)".
>
> Another participant said "*When I am angry or worry or when I have any concern I feel burning in my toes, and after I get relax I will be OK* (P: 3)".

Another theme in our study was "Limitations". One of the major participant's experiences was limitation. They feel that they had limitation in diet and having a healthy child

"*… you had many limitations; now you want to have a baby but you can't… you know that diabetes would affect your fetus so you should not have a baby… I myself could not have a child for this reason* (P: 11)".

Another one told about her limitation in other word: "*Many limitation…Oh, diabetic patient have many limitations. For example, I should eat tomato, cucumber, cabbage and like these…it is not good. If I eat an orange or sweet, my blood sugar will rise…so I cannot* (P: 10) ".

"Silent motion towards death" was a theme that most participants emphasized on it as an important experience. They pointed to the impalpable effects of diabetes on their body. They mentioned that diabetes means gradual process leading toward complications and finally death. It seems that patients who felt powerlessness in diabetes management emphasized it more strongly.

"*…When you put a cube sugar in a glass of water it dissolve, like a diabetic patient…* (P: 10)".

Tenth participant gave another example in this issue: "*As doctor said… it is like a burned house, like a house in fire that everything in it such as television set and carpet is burning but its foundation will be remaining. Diabetic patient's body is the same. Every organ is burned but its appearance is ok and seems intact, but you know it is not efficient anymore* (P: 12)".

The last theme was "Can I do". Participants expressed two ideas (power and powerlessness) about their ability for diabetes management. Some stated that potential complications of diabetes can be prevented and it is possible to have a normal life with diabetes by compliancy to the therapeutic regimen.

"*Actually diabetes is a terrible disease if you know about its outcomes. Well these complications are almost obvious such as effects on eyes, kidney, leg ulcer, etc. yeah it is true these are. Nevertheless, well if there is a diabetes control, there will not be a problem. If you control it to prevent its complications or if you think that you will not experience complications, there will not be a problem* (P: 3)".

Some believed that in spite of all efforts, diabetes is uncontrollable. Therefore, they found themselves powerlessness. Especially patients who had negative experiences about disease outcomes in their relatives expressed it.

"*Diabetes is not a good disease. It is worse than a cancer, you know why. Cancer affects an organ or a system but diabetes affects all body. Diabetes is a process and you cannot stop it. Doctors suggest this truth too. Yeah it is true that you can control sugar but it is harmful and destroys organs. When I got disease my doctor told me this truth, he said that diabetes gradually affects all parts of my body for example my heart, eye, kidney, stomach, hand, foot. He told me that diabetic patients would reach to the situation that even God cannot help them.* (P: 12)".

Discussion

Diabetes affects all aspect of daily life. Participant's experiences and participating in educational classes cause them to have some beliefs and perceptions about their disease and situation. Five main obtained themes of this study reflect this experience.

In spite of long time living with diabetes, participating in diabetes related class and attending in health care centers, most participants believed that some stresses that they experienced before their diagnosis resulted in their disease. Some participants mentioned inheritance, sedentary life, gluttony, and disturbance in insulin secretion as the causes of disease. Mullenax showed that in spite of participating in educational programs, most participants believed that diabetes is formed due to stress, inheritance and eating lot in childhood. Although patients gave definition for diabetes, they showed some degree of confusion about type of disease, its etiology, etc.[20] Vinter et al reported that although all patients in their study were informed about the stage of their illness and its treatment, most of them showed incomplete and inaccurate knowledge not only about diabetes, but also about occurring metabolic changes and possible complications. Some patients even considered that diabetes

was a common condition in older age, and therefore saw no need for it to be treated.[21]

According to the participants' statements, stress is leading to the failure of non-pharmacologic therapies and blood sugar increase. Therefore, for these reasons they tried to keep a distance from it and take their worries away. In their view, diet and exercise were more important than medications but try to compliance to all of them. Most participants in Vinter et al study referred to the diabetes as a disease requiring changing in habits, lifestyle, diet quantity and quality, and exercise.[21] Similarly, Dutton et al explained that 75% of participants reported that exercise was extremely important for diabetes control, and only 2% reported that it was slightly or not at all important. Sixty percent reported that it was probable to prevent future complications.[22] Mullenax described that participants were aware about exercise role as an important factor in diabetes management.[20] Lai et al showed that all participants even those who objected to scientific medicine agreed that dietary restriction is beneficial. They believed that dietary regimen is more compatible with natural life than synthetic medication and in addition is more important. Most of them thought that exercise benefits are more than its harms. They had ambivalent attitudes towards medication. Some saw it as an effective factor for diabetes control and some had concerns about its adverse effects.[23]

Base on participant's statement, it seems that they felt limitation because of limitation in eating everything that they want, and having no satisfaction during eating due to fear of blood sugar increasing. Appropriate education can help patients eat foods in a regular dietary program. Choe et al (2001), Wenzel et al (2005), and Sayer et al (2005) also reported feeling of limitation but it was related to the functional limitation and energy decrease not diet and having a healthy child.[24-26]

Motion towards death was another significant feeling in participant's experience. Similarly, Mullenax (2004) and Hornsten et al (2005) found that participants consider diabetes as a disease resulting in amputation, blindness, renal failure, and inevitable death. Some participants described themselves unable and defeated while others believed that they can control their life despite disease and are able to affect disease.[20,27] Hornsten et al (2005) showed that in some participant's opinion, control means behavioral changes and integrating disease to life, and for others diabetes means a progressive process despite all efforts and for the rest it is like a campaign.[27] Participants in Mullenax's study (2004) defined diabetes as an incurable but controllable disease.[20]

Findings of our study showed that patient' beliefs about diabetes and their situation is effective on their health behaviors and self-management, and can act as barriers and facilitators in patient behaviors. Other studies referred to the association between patient's attitude level toward disease and self-management. Weaker attitude toward disease accompanied with more HbA1, complications, and less compliance to dietary regimen.[28] Patient's feeling of influence on the disease course is an important psychological factor affecting patient adherence to treatment.[29] Belief of powerlessness is a disaster. Patients with this feeling quit their self-care.[30] Nagelkerk et al (2006) said that the most frequently reported barriers were lack of knowledge of a specific diet plan, lack of understanding of the care plan and helplessness and frustration from lack of glycemic control and continued disease progression despite adherence.[31] McCord et al found that most patients who feel have suitable knowledge about disease, have more compliancy. However, patients who did not compliance with therapeutic regimens believed that diabetes would not affect their life outcomes.[32]

Therefore, it seems that patients should believe that their behavior can affect outcomes, diabetes is a manageable disease, and every affected person would have a good life with it. Findings can provide appropriate information for nurses in order to provide optimal disease control, increase patient's quality of life, and decrease expenses. For this goal, it is necessary

for nurses to evaluate of patients' beliefs and identify feeling such as powerlessness or efficacy in order to plan an individualized effective care plan

Also, the authors declare that have no conflict of interest in this study and they have surveyed under the research ethics.

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