

Original Article

Emotions, Thoughts and Experiences of Diabetes Patients: A Qualitative Study

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Abstract

Background: Diabetes affects individuals physically, mentally, socially and financially.

Aims: The aim of this study was to determine what it means for patients to live with diabetes mellitus, to reveal patients' feelings, thoughts and wishes, and to examine their perspectives and coping strategies regarding the disease.

Methodology: This work is a qualitative study. The sample consisted of 37 patients. After the data were collected, content analysis was performed.

Results: Out of the patients in the study, 3 main themes with 10 subthemes emerged from the content analysis. The results showed that diabetes adversely affected the participants' lives; they experienced psychological, physical and social problems related to the illness; and they exhibited a fatalistic approach feeling convinced that everything comes from God and feeling thankful in coping with these problems.

Conclusions: Diabetes patients deal with the difficulties they experience that a holistic nursing approach is required.

Keywords: diabetes, meaning of the disease, coping, qualitative study.

Introduction

Diabetes mellitus (DM) is a complex and chronic disease with multiple complications leading to increased mortality and poor quality of life. Insulin-dependent Type II diabetes mellitus (DM) causes significant morbidity and mortality in the long term. DM prevalence is constantly increasing all over the world and in our country. The rising prevalence of Type II diabetes mellitus (T2 DM) is a major healthcare challenge globally. The burden is highest in developing countries where more than 80% of the people live with diabetes (International Diabetes Federation, 2015). The prevalence of DM is on the increase globally (International Diabetes Federation, 2015; Mozaffarian, Benjamin & Go, 2015). Approximately, 6.4% of people

worldwide suffer from DM, and this figure is anticipated to rise to 7.8% by 2030. A prospective study conducted in Turkey found that the prevalence of DM reached up to 13.7 % and increased by 40% in the last decade (Satman et al., 2013).

Diabetes is a new life experience for the individual. How the individual perceives the disease, the meaning of the disease, illness and treatment compliance, and psychosocial difficulties are some of the issues that need to be addressed. Mental, emotional, social and psychosexual problems and conflicts arise because this is a lifelong disease and requires a continuous controlled lifestyle (Collins et al., 2009; Wu et al., 2011; Kucuk, 2015; Celik et al., 2015).

In addition to major complications such as cardiovascular disease, adult blindness and end-stage renal failure, diabetes also causes the development of diabetic foot due to self-care deficiencies. DM is reported to be responsible for 50% of all lower extremity amputations (Demir, Akinci & Yesil 2007). Individuals diagnosed with diabetes suffer more severe and work-limiting symptoms (e.g. neuropathy) (Minor & MacEwan, 2016). Apart from these complications of DM, in insulin-dependent T2 DM, life-threatening complications such as hypoglycemia/ hyperglycemia/ketoacidosis may also develop in association with inadequate compliance with medications. Individuals diagnosed with diabetes often have a negative perception toward their lives (Demir, Akinci & Yesil, 2007).

Mental status is effective in the course of the emergence of diabetes, and diabetes as a physical illness and its complications has an impact on mental health (Kucuk, 2015). The prevalence of depression is approximately 10% higher in patients with DM and also lifetime prevalence of depression in type II DM has been found to be as high as %30. (Minor & MacEwan, 2016; Barnes & Hong, 2012). Depressive symptoms were also shown to be associated with impaired health-related quality of life. Furthermore, patients with DM are at increased risk for suicide (Minor & MacEwan, 2016).

In order for the individual to manage diabetes, he or she should adapt to diabetes and early diagnosis and appropriate treatment of psychopathology need to be addressed in a psychosomatic, behavioural and social unity. Adopting a team approach, patients need to be trained about developing healthy lifestyle behaviours, disease management, medication compliance and strategies to cope with the challenges. Nurses should adopt a holistic approach in dealing with individuals diagnosed with diabetes. While assisting individuals with their metabolic controls, nurses should also carry out applications to support their mood (Collins et al., 2009; Wu et al., 2011; Chung et al., 2014; Kucuk, 2015; Celik et al., 2015).

Aim of the study

The aim of this study was to determine what it means for patients to live with diabetes, to reveal patients' feelings, thoughts and wishes, and to examine their perspectives and coping strategies regarding the disease. The results from this study

could help individuals diagnosed with diabetes manage, adapt to and cope with the disease.

Methodology

This qualitative research used a phenomenological research framework. A semi-structured interview addressed the perceptions of patients with DM regarding the disease. Data were collected by asking the participants three questions on the In-depth Individual Interview Form. Data were analysed using the continuous comparative method of Colaizzi (Colaizzi, 1978).

Qualitative research is different from conventional/quantitative research methods in terms of research questions, objectives, sampling processes, and data collection and analysis methods. Unlike quantitative research, data in qualitative form is not usually represented in numbers. The primary aim of qualitative research is to provide the reader with a descriptive and realistic depiction of the topic in question. Therefore, data collected in qualitative research should be elaborate and in-depth, and the opinions and experiences of the individuals involved should be presented in as direct a way as possible. Qualitative methodology allows a much richer description of the fears and problems encountered by patients than is possible with quantitative methods. The qualitative research technique provides useful methods to understand and appreciate the complexity of patients' medical, emotional, and social needs, as well as their health beliefs and attitudes. Patient care or research protocols for individuals or groups of individuals can be informed by the results. Finally, qualitative research can be used to generate hypotheses for subsequent quantitative research (Colaizzi, 1978; Kumbetoglu, 2005; Vaismoradi, Turunen & Bondas, 2013).

Research Participants

The study population consisted of all of the patients treated for T2 DM at the Department of Endocrinology of Mersin University Faculty of Medicine Hospital (n=350). The study sample consisted of patients who came to the department of endocrinology of the same hospital for follow-up appointments due to their DM diagnosis. The participants were 18 years old or older, had been diagnosed with DM at least 6 months prior, used insulin, and agreed to participate in the study.

In qualitative research the choice of sampling is aimed at reason. In selecting the sample for the

purpose, participants are selected who can give detailed information on the purpose of the research (Streubert & Carpenter, 1999). Therefore, the sample of our study has been chosen for the purpose of learning more about the experiences of patients DM diagnosis. The study used a sampling approach that required continuous data collection until the concepts and processes that help answer the research question begin to repeat (saturation point). In light of this, the researchers decided that they reached a sufficient number of data sources when the emerging concepts and processes began to repeat one other (Kumbetoglu, 2005). Therefore, the study sample consisted of 37 patients.

Data collection

Data were collected by conducting individual in-depth interviews with each of the patients in the study sample in order to explore what living with DM meant for the patients. We also wanted to reveal the patients' feelings, thoughts and desires (Kumbetoglu, 2005). There were three questions on the Individual In-depth Interview Form: (a) What does it mean for you to live with diabetes mellitus? (b) What are your thoughts/experiences about using insulin? (c) What do you recommend in order to live with this disease in a more harmonious way? A total of six patients were given a pre-application in order to assess the usability of the Individual In-depth Interview Form. The form was then revised in light of the pre-application. The individual in-depth interviews were conducted in the meeting room of the endocrinology department. During the interviews, the patients and researchers sat next to each other or face-to-face. All of the conversations in the interviews were recorded using a voice recorder, with the exception of one participant who did not agree to be recorded. In that case, the researcher wrote down the participant's responses. All of the data obtained during the interviews were kept confidential so that they could be used for scientific research. The interviews lasted 50-60 minutes on average.

Data analysis

As a part of the data analysis, the voice recordings were transcribed first. After that, the raw data were obtained by combining the

transcripts with the observations. The transcripts were then entered into Microsoft Word, resulting in a total of 54 pages. Colaizzi's continuous comparative method was used in the qualitative analysis of the research data (Colaizzi, 1978). The raw data were read multiple times before being grouped. Because it was impossible to interpret the vast majority of this data in numbers, the researchers noted that the results could not be generalized and they were limited to the participants of this study. For a qualitative analysis of the data, a content analysis was performed considering not only the words themselves, but also how common the comments expressed by the participants' responses were, the number of the participants making the same comments and using the same words, the actual meaning underlying the statements and the authenticity of the participants' responses. The patients' responses were evaluated separately for each one of the topics discussed. The responses of the patients were combined by considering the differences and similarities between them. After the raw data generated were read separately and carefully by each of the researchers, the data were processed (i.e. coding of meaningful concepts and themes). Themes were identified by combining the coded data. For the analysis of the data obtained, two experts with experience on qualitative research were asked for their expert opinions on the given raw data. As a result of the data analysis, three main themes and 10 subthemes were identified (Colaizzi, 1978; Kumbetoglu, 2005; Vaismoradi, Turunen & Bondas, 2013).

Trustworthiness

Some additional methods (e.g. participant verification, peer verification) are used to help verify the results for the sake of validity and reliability in qualitative research. Receiving confirmation from the participants to confirm the findings is significant for establishing the validity and reliability in qualitative research. It is also essential to provide direct quotations from the individuals interviewed and to explain the results based on these (Yildirim & Simsek, 2005). The above-mentioned criteria are met in this study.

Table 1 Themes and subthemes of patients' perspectives

Themes	Subthemes	(n=37)
Theme 1: Experiences during the diagnosis stage	Emotions experienced when diagnosed with diabetes	9
	Meaning of diabetes for patients and the reason for having diabetes	35
	Disease acceptance and rejection	18
Theme 2: Experiences after the diagnosis stage	Diabetes limits life chances	28
	Psychological problems associated with diabetes	35
	Physical problems associated with diabetes	28
	Social problems associated with diabetes	9
Theme 3: Management of and coping with diabetes	Fatalistic approach to the disease	9
	Readjustment of life after diabetes diagnosis	19
	Problems associated with the use of insulin	28

Ethical considerations

Before commencing the study, written approval was obtained from the Mersin University Scientific Research Evaluation Committee (approval number: B.30.2.MEÜ.0.01.20.10-11.903.07/93), and the Office of the Chief Physician of the hospital where the study was carried out. When the patients came to the hospital's department of endocrinology, the researchers informed the patients about the study and the patients gave their verbal consent for participation.

Results

As a result of the content analysis carried out on the data obtained through the qualitative study regarding the meaning of living with DM, three main themes and 10 subthemes emerged (Table 1). Out of the patients in the study, 52% were

female, 48% were married, and the mean age was 32 years.

Theme 1: Experiences during the diagnosis stage

Emotions experienced when diagnosed with diabetes

One-fourth of the patients in the study reported that they felt nothing, gave no reaction, or felt shocked when they were diagnosed with diabetes. However, three-fourths of the participants stated that their initial feeling was a deep sorrow followed by feelings of grief, anxiety, despondency and gloom. One of the patients expressed the feelings when diagnosed with diabetes:

“I was terribly taken aback. I had no choice but to accept that I had diabetes. At first, I cried, screamed and thought it was just a

nightmare. I threw away my handbag and started to cry” (49 years old, Women, Primary School Graduate, Unemployed).

Meaning of diabetes for patients and the reason for having diabetes

Nearly all the patients attached a negative meaning to diabetes and described it as a cruel and insidious disease that damaged vital organs without causing any noticeable painful symptoms. Similarly, more than half of the patients reported that they considered this disease as an evil friend they had to live with. One of the patients said:

“I see diabetes as a worm eating a tree inside. It does not cause any pain. Yet, it harms many organs” (70 years old, Male, High School, Police).

Disease acceptance and rejection

Half of the participants reported that they accepted the disease, they had to live with this disease, they began to use medications and insulin regularly, they believed they would live longer when they led their lives in accordance with the requirements of this disease and paid attention to their diets. The patients whose family members or friends were diagnosed with diabetes (only three patients) stated that they accepted the disease more easily.

“I accepted it. I am living with the disease almost like we are dancing. I do not feel worn or daunted and I have moved on. I totally accepted the disease and I do not feel pessimistic at all” (67 years old, Male, High School, Unemployed).

Theme 2: Experiences after the diagnosis stage

Diabetes limits life chances

Three-fourths of the patients reported that diabetes affected their lives adversely, their lives changed drastically and they felt restricted because they had to follow a strict diet, receive a limited menu of foods allowed wherever they go, check their blood sugar levels on a daily basis, make endless medical control visits, take their drugs and insulin with them when they go out, preserve their medication at a particular temperature, stay at home instead of working because they are sick, and find someone else to do the housework.

“Diabetes is the worst disease because you cannot eat what you want. You are always on a diet because your blood levels instantly rise when you step out of your diet. Even the slightest cut on your skin does not heal immediately. I have to keep extra insulin in my siblings’ and mother’s refrigerators so that I do not have to carry it with me and it does not lose its effectiveness... I can’t take insulin with me to everywhere I go. Travelling is difficult for me because I have to store insulin at a cold temperature” (49 years old, Women, Primary School, Unemployed).

Psychological problems associated with diabetes

Nearly all of the patients stated that they mentally felt bad, they were quick-tempered but regretted behaving angrily, they cried and they did not want to stay home alone because of diabetes. In addition, one-fourth of the patients reported that they were worried about increasing blood sugar when they ate something and they were concerned about possible damages caused by the side effects of diabetes on their organs. However, only three of the patients stated that they lost their joy of life and they did not have any desires in life. Among the patients who experienced mental health problems due to diabetes, one said:

“I act angrily because of diabetes. I cannot stand anything my spouse would say, and I get angry so easily. I overreact even to trivial things” (53 years old, Women, University, Nurse).

Physical problems associated with diabetes

Three-fourths of the patients complained about feelings of burning, tingling and numbness in their hands and feet and stated that they experienced weakness, fatigue and vision problems due to diabetes. One-fourth of the patients reported scarring of their feet, and one-third of them stated that diabetes negatively affected their sexual lives. Indicating the physical expression of a patient is the problems encountered due to diabetes.

“The effects of diabetes are felt on my eyes, and my feet sore all the time. I struggle with the pain until morning. Apparently, my foot nerves are dead and there are scars under my feet... This is why I cannot sleep until morning. My hands are numb and tingly” (53 years old, Women, High School, Unemployed).

Social problems associated with diabetes

Among the patients, nine of them reported that they experienced social isolation, got away from the people, wanted to be alone and did not want to pay visits to friends or relatives, and their social lives were adversely affected. Similarly, three patients stated that their working lives were adversely affected and they had financial problems and bureaucratic difficulties because of their conditions.

“I began to stay home more and more each day. I cannot do anything outside without assistance. My social life was completely reset” (35 years old, Male, University, Unemployed).

Theme 3: Management of and coping with diabetes

Fatalistic approach to the disease

One-fourth of the patients stated that they adopted a fatalistic approach feeling convinced that everything comes from God and feeling thankful in managing and coping with diabetes. On the other hand, three patients said they used complementary treatment methods. One of the patients who exhibited a fatalistic approach in coping with diabetes said;

“I have never questioned where this illness came from. Some people just hate it, but can you hate what comes from God? If God wills, it could be worse. I said to myself it is nothing but God’s will. Some people, I hear, do not accept it. But can you turn down what God has given to you. I accept my illness and think of others in worse conditions than mine... Thank God I can meet my basic needs all by myself ” (67 years old, Women, Unemployed, Illiterate).

Readjustment of life after diabetes diagnosis

More than half of the participants stated that they readjusted their lives by doing exercises, going for walks, paying particular attention to nutrition and diet, visiting their doctors, and regularly checking their blood sugar. One of these patients said;

“I think I will live long if I learn to live with it and be careful. I am getting my meds regularly. I’m trying to pay attention to what I eat. For example, I eat butter and honey once a week. I eat nuts and hazelnuts ... I go for walks

regularly” (62 years old, Women, University, Teacher).

Problems associated with the use of insulin

Three-thirds of the patients stated that they experienced problems affecting their quality of life because they have to take insulin regularly and take it with them at all times, they have to follow cold chain procedure, they do not want to take insulin in front of others, they have difficulties while traveling, they have skin dents on their fingers caused by checking sugar levels three times a day, they have problems on insulin injection sites and they sometimes forget to get insulin.

“I have to take insulin with me wherever I go. I cannot go to a place without a refrigerator. I do not know what to do if I cannot find one. I would not have a problem if there were a pill, so I’m having trouble when planning a trip” (53 years old, Male, High School Unemployed).

Discussion

The aim of this study was to determine what it means for patients to live with DM, to reveal patients’ feelings, thoughts and wishes, and to examine their perspectives and coping strategies regarding the disease. Three main themes emerged from the data analysis: experiences during the diagnosis stage, experiences after diabetes diagnosis, and management of and coping with diabetes. The majority of the patients stated that they had feelings of shock, denial, excessive stress, sadness, grief and anxiety when they were first diagnosed with diabetes but they came to accept it in time and believed that everything came from God. However, half of the patients reported they could not accept or adapt to the disease, they adopted an indifferent attitude towards it and they simply ignored and rejected it. Jeragh-Alhaddad et al. (2015), found that the patients had feelings such as denial and ignoring when they were first diagnosed, they thought everything was ordained by God and they tended to use faith- and emotion-oriented coping strategies. Hood et al. (2009), stated that the patients had the biggest shock when they started insulin treatment. Also, research found that religious acts such as seeking refuge in God, believing that God protects and prayers had an important place in coping with illnesses (Abolghasemi & Sedaghat 2015; Patel et al., 2015). This point of view is quite common in Islam, too. The results of both our study and

other evidence suggest training and counselling designed to improve patients' positive health behaviours as well as their compliance with drug-dietary recommendations should involve strategies that take into account patients' beliefs and values. The majority of the patients described DM as a cruel and insidious disease that damaged the body and it was caused by distress, sadness and stress. In a study by Patel et al. (2015), the patients thought DM developed on the grounds of genetics, improper diet, and psychological and mental reasons. In the same way, the patients in a study by Abolghasemi & Sedaghat (2015), described DM as a mysterious internal problem damaging the human body. In the light of this, our results are consistent with the literature results. Most of the patients also had problems that adversely affected their quality of life because they had to follow a strict diet, receive a limited menu of foods allowed wherever they go, check their blood sugar levels on a daily base, make endless medical control visits, take their drugs and insulin with them when they go out and preserve their medications at a particular temperature, and they do not want to take insulin in front of others, they have difficulties while traveling and they sometimes forget to take insulin. Kneck et al. (2011), found that their patients' social lives were restricted because they had to adjust their everyday lives or social activity plans in line with DM needs (e.g. blood sugar checks, adjusting insulin doses and times, preparing dinner menus and doing exercise). Abolghasemi & Sedaghat (2015), found that the patients could not make proper diet plans as health professionals made particularly hard-to-follow diet recommendations and, therefore, they were not able to plan social activities due to diet restrictions. Patients' compliance with medication and dietary recommendations and development of self-management skills is critical to effective control and management of DM. Developing patient-specific, simple and easy-to-adapt plans for the training and counselling to be offered to DM patients will improve both the effective management of the disease and patients' quality of life. Nearly all of the patients stated that they mentally felt bad, they were quick-tempered and they were concerned about possible damages caused by the side effects of diabetes on their organs. Also, one-third of them reported that they experienced social isolation, got away from the people, and wanted to be alone and, therefore, their social lives were adversely affected. In a

study by Zhang et al. (2016), 46.1% of the patients diagnosed with DM had depression symptoms and 65.5% had anxiety symptoms. Trento et al. (2015), found that long-term insulin use caused depression. Also, Abolghasemi & Sedaghat (2015), suggested that patients faced symptoms of severe anxiety and depression regarding possible future complications associated with DM and found a positive relationship between emotion-oriented coping and depression and anxiety. In a study by Goerge & Thomas (2010), the most feared complication among the patients was hypoglycaemia, the disease clearly reminded its existence every day, it impaired the quality of life and the only relief was through death. The patients in a study by Abu Hassan et al. (2013), had negative beliefs about the use of insulin such as needle phobia, injection pain, shame, social stigma and restrictions on lifestyle. In a study by Kav et al. (2015), one in three (37.5%) of participants had depression symptoms. Anxiety and depression impair quality of life by making it difficult to regulate blood sugar level (pathophysiological challenge) and introducing difficulties in achieving self-care and complying with medication/dietary recommendations (behavioural challenge). Therefore, individuals with symptoms of severe anxiety and depression should be referred to consultation liaison units. Jeragh-Alhaddad et al. (2015), found that members of family or significant others preparing meals appropriate for DM and reminding medication time or blood sugar checks made the patients feel good and not alone. Therefore, the inclusion of family members or significant others in the training and counselling applications to be offered to patients could promote both patients' adaptation and self-care and the sense of mental wellbeing. The majority of the patients complained about feelings of burning, tingling and numbness in their feet and vision problem due to DM. One-third of them stated that diabetes negatively affected their sexual lives. One-fourth of them reported festering sore in their feet due to diabetes. Inability to regulate blood sugar level in diabetes can cause damage in nerves as well as in small and large blood vessels and this can lead to the development of complications such as renal insufficiency, cardiovascular diseases, sensory loss, and visual impairments (Turkish Endocrinology and Metabolism Association, 2013). The literature showed that similar complications might arise in majority of patients

(Erten et al., 2013; Jeragh-Alhaddad et al., 2015). In addition to systemic complications, DM can cause sexual dysfunction due to its effect on neurogenic, psychological and vascular system. For example, in a study by Erten et al. (2013); 47% of the patients experienced sexual problems. Similarly, Papazafiropoulo et al. (2015), found that DM negatively affected sexual lives of individuals and their families in the study reported. In this regard, our results are consistent with the literature results. More than half of the participants stated that after diagnosed with diabetes they rearranged their lives by doing exercises, going for walks, paying particular attention to nutrition and diet, visiting their doctors, and regularly checking their blood sugar. On the other hand, very few patients reported that they used herbal treatments to regulate blood sugar level. Research showed that readjustment of lifestyle in order to regulate the use of insulin and to control blood sugar level was important but patients could not always perform these changes, they could not establish effective communication with health professionals and they did not receive counselling in accordance with their needs (Kneck et al., 2014; Celik et al., 2015; Abolghasemi & Sedaghat 2015). Peeters et al. (2015) found that most of the patients did not use their medication regularly because, as the patients claimed, they did not know it was a chronic illness, they used multiple drugs, they had inadequate communication with health professionals and they did not have confidence in medication. Edwal et al. (2008), suggested that periodical follow-up and collaboration by health professionals played a key role in patients' adaptation to their new way of life. The patients in a study by Oftedal (2014), considered practical support such as preparing food menus appropriate for DM, making daily diet plans, doing exercises and going for walks with members of family/significant others are vital for themselves and the management of the disease. The literature showed that both periodical patient follow-up and communication by health professionals and the inclusion of family members or significant others in the training and counselling process to be offered to patients are critical to the effective management of the disease and patients' adaptation to the disease. Also, the literature showed that herbal treatments were more commonly used in blood sugar control especially in Asian and Muslim communities (Jeragh-Alhaddad et al., 2015; Patel

et al., 2015). In our study, few patients reported that they used herbal treatment to regulate their blood sugar level. Patients could be warned not to use this type of treatment without consulting a health professional and, more importantly, to be aware of the fact that such treatment would not replace proper medication.

Conclusion

In conclusion, the patients in our study stated that diabetes adversely affected their lives; they experienced psychological, physical and social problems related to the illness; and they adopted a fatalistic approach feeling convinced that everything came from God and feeling thankful in coping with these problems. Also, after being diagnosed with diabetes, more than half of the participants rearranged their lives by doing exercise, going for a walk, paying particular attention to nutrition and diet, visiting their doctors, and regularly checking their blood sugar. Nurses should adopt a holistic approach in dealing with individuals diagnosed with diabetes. Finally, offering patients training activities about coping with stressors that can affect blood sugar level could improve patients' quality of life.

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