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Fears and Health Needs of Patients with Diabetes: A Qualitative Research in Rural Population

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ABSTRACT

Introduction: Insulin-dependent patients are individuals with chronic disease who are well adapted to living and dealing with any health needs and fears arising. An important aspect in the process of adaptation to chronic illness is the provision of nursing care in the early stages of the disease, because this contributes to its acceptance and the early identification and management of potential complications. **Purpose:** To investigate the health needs and self-management problems faced by patients with diabetes daily, especially those who use insulin. Furthermore purpose of this study was to investigate the fears experienced by patients in the early stage of the disease, but also in its subsequent development and to study possible differences between sexes. **Methodology:** This is a qualitative study, using interpretative phenomenological approach. Fifteen (nine women and six men) insulin-dependent patients, recounted their personal fears and their needs, through semi-structured interviews, which took place in Central Greece. The method used for processing the results is the Mayering one. **Results:** The analysis of the narratives showed that patients have a variety of fears and needs associated with the diagnosis, treatment, expected consequences, prognosis and everyday life in the management of the disease. Most patients express the concept of need as desire. Care needs, psychological support and education to recognize and prevent hypoglycemia. **Conclusions:** Insulin-dependent patients express fears and needs in their daily lives. Nurses providing care aimed at enhancing the level of health, while putting self-care information and training them. Patients want the nurse next to them, so that information is continuous and permanent.

Key words: diabetes mellitus, fears, health needs, self-care, nursing care.

1. INTRODUCTION

Patients with type II diabetes, especially insulin-dependent are usually suffering from diabetes several years before the initiation of insulin therapy. Treatment of diabetes has now as a central character, the patient himself who co-decides with the physician-nurse team. The primary concern is the patient's acceptance of the disease in the early stages and his gradual familiarization with the treatment (1).

According to International Diabetes Federation, at least 285 million people worldwide have diabetes and this number is expected to increase to 438 million by 2030, with two-thirds of all cases living in low or middle income countries (2, 3).

Apart from pharmaceutical care, the nurse also provides psychological care which is necessary for the disease process, both at the individual and the family level. Psychological support for patients, may positively affect the acceptance, the treatment and the course of the disease (4).

Patients have a number of care needs both in early as well as in later stages of the disease. It is important for nurses not to treat all patients with diabetes mellitus the same way , but, to approach, at first the patient as an in-

dividual and then the disease. In this way, we can see the specificities in each individual-patient (5).

According to the literature, the diagnosis itself causes fear which rises in the course of the disease as patients' awareness regarding the disease and its complications increases. The holistic approach of diabetic patients produces positive results, both in the acceptance of the disease, as well as to the recognition of complications, and the protection from them.

2. PURPOSE

The purpose of this qualitative study was to investigate the fears of patients and their families, related to their disease and their specified treatment. Also, we investigated the patients' and their households' needs and feelings regarding the care provided by health professionals and where they consider nursing care is necessary.

3. MATERIAL AND METHODS

Semi-structured interviews with 15 patients with type II were conducted, concerning, the fears that arose and who needed nursing assistance when they were first diagnosed with the disease as well as their decisions regarding to the treatment.

The approach and the localization of the participants took place in the region hospitals, external Diabetes clinics and in private outpatient clinics. The sample selection was based on criteria: patients should have type II diabetes, be insulin dependent, by both sexes and be able to cooperate in the interview. After the patient selection, they were asked whether they accepted or not to participate. Also we verbally explained to them the purpose of the interviews. We approached 33 patients of which only 15 were positive to the research. Many of those who refused, had, at first, been interviewed, but nonetheless, when the final debate approached, they refused to participate. It was observed that those who were more negative, were individuals who were monitored in private clinics and had secretiveness against their disease. They did not even mention the name of the disease, but called it as "the bad" or "this" or "what I have".

The interviews lasted for 20-30 minutes. The discussions were not recorded as the patients reported that they feel comfortable and therefore extensive notes were kept during the interview.

The questions asked were two:

a) Is there something that worried (scared) you when you were diagnosed with diabetes?

b) Do you believe a nurse would be helpful for you?

Participants: 9 out of the 15 surveyed persons were women and 6 men. The oldest patient was 81 and the youngest 36 years old. Of all participants, 12 were over 65 years old and 14 over 60 years old. From research conducted in America it is estimated that by 2025 adults over age 60 will comprise two-thirds of the population with diabetes (6).

By following the six steps of qualitative research, perceptual outline of qualitative research (first step), research question (Step 2), sample determination (Step 3), data collection (step 4), data analysis (step 5), presentation / writing (step 6)}, an attempt was made to investigate the problems as perceived by the patients themselves (7).

Our sample members were residents of Central Greece which was chosen because of its accessibility and its climate diversity.

The method used for processing the results is the Mayering method for qualitative research (8).

4. RESULTS

From the collected responses by the population under investigation, we found that nursing care is necessary, both in the early and in later stages of the disease. The patient feels great safety and relief when the nurse is beside him to inform and encourage him for any changes that will occur. The analysis of both questions which were set showed the following:

A. Fears

Fears for life itself

Diabetes is related with a reduction in life expectancy and high morbidity due to specific complications associated with micro vascular (retinopathy, nephropathy and neuropathy), and increased risk of macro vascular (ischaemic heart disease, stroke and peripheral vascular disease) diseases and low quality of life (9).

"I was worried ... .If my condition will become worse .... I felt very healthy ... and I was afraid that I would not continue to be so ...", "At first I was not scared at all ....because I did not know ... now that I learned the more anxious I have became... for my life".

According to researches, mortality is higher among people with diabetes, and the rate varies with age, sex, time and cause of death (10, 11).

Diabetic patients are individuals at high risk, studies support the fact that vaccination against influenza should be offered to all of them. Vaccination can greatly reduce the risk of serious complications in people with diabetes. Influenza vaccine has been shown to reduce diabetes-related hospital admission by as much as 79% during flu epidemics (12).

Fears for Complications

Randomized clinical trials and prospective epidemiological studies have shown that lifestyle changes, such as healthy eating patterns, weight loss, quitting smoking, increased physical activity and patient education can help delay or prevent diabetes complications [13]. *"I was very anxious. I knew from my family...it harms nearly every organ of the body".*

"My mother went blind due to diabetes...she had retinopathy...I am really scared... being unable to see is really bad". Although, persons with diabetes mellitus are 2.5 times more likely to have retinopathy than non-diabetic, the actual number of individuals with retinopathy is threefold higher in the non-diabetic (14).

One of the participants has both legs amputated and uses a wheelchair. When asked about his initial fears he replied *"...If I knew my fate ... and maybe a little fear could be good for me ... I did not expect to be so destroyed..."* [15]. *Another patient recounts, "I was afraid ... because diabetes brings other problems ... as hypertension... and in our family we have high blood pressure".*

".. My body will become more sensitive.... I will often get sick ... ". The deregulation of diabetes associated with infection requires special attention when treating patients with diabetes (16).

Fears for work

Patients with diabetes are afraid of the social impact of the disease such as deterioration of the economic and occupational life situation. *'When I first heard of diabetes diagnosis my mind went to my business ... would I be able to continue to work ...? ".Diabetes is a way of life and that's how it should be treated by everyone. Activities of daily living don't stop with the diagnosis of the disease; instead, patients should manage to continue their daily lives and daily routines as before. But, there are professions which have certain peculiarities that the diabetic patients are prone to. "... I was a driver and I made long trips ....immediately after I was diagnosed with my illness ... I stopped working ... I could not drive.... I feared of hypoglycemia ...".* Research done, indeed, shows that drivers with diabetes are vulnerable to face unfortunate incidents while driving. These can be linked to hypoglycemia (17).

Fears for family

A great concern for most participants as they were all parents, except the younger one who was expectant mother–was if their children and grandchildren had inherited a predisposition to the disease. *"... We have now lived our lives ....should not to happen to our children... ".*

"When I learned that I have diabetes, it was shortly after my engagement .... I was afraid that would never have children ... I did not want to be guilty of the misfortunes of my fiancé...we were informed and now we are happy ... we expect to have our baby. "

Many diabetic women planning a pregnancy, exhibit increased anxiety about their fertility. There is no reason to believe that diabetic women with good glycemic control are less fertile than non-diabetics. There are just some signs that poor glycemic control can affect the regularity of ovulation. Maternal morbidity is increased due to complications. "Hydramnios", the incidence of this state among diabetic pregnant women is 10 times higher than in the general obstetric population.

Another reason for being dominated by fear from the beginning was their family; they did not want to be a burden to their children. Most of them knew that their illness has a direct impact on the whole family as in the province there is still the institution of family, consisting of a grandfather, a grandmother, a father, a mother and children living under one roof. *"I really tire my bride ... she has never gone taken a holiday, and has never left home .... She injects me.... I do not know how ".*

Fears of stigmatization

Most of the patients we approached were negative to participate in the survey. They avoided accepting that they suffered from diabetes and even hardly they answered if they were insulin-dependent. They didn't answer to the question if something scared them, because their biggest fear after the diagnosis was not to be learned by the neighbors, the family and acquaintances. In the province the patient's stigmatization is a bigger problem than the disease itself. *"... I was ashamed of my children.... What will the neighbors say? ...I was strong ... was running for everyone ..."* are the words of one of the surveyed women. Most participants had suspicions and fears during the conversation if anyone was listening and find out their secret.

None of the patients mentioned the problems and fears that arise in both men and women for the possible impairment in their sexual life.

Fears for deprivations

Many of the patients participated in this study had related diabetes with deprivations. With the main deprivation considered was food. Mostly, the majority of women referred to that. It was the nature of women to be occupied by food and the kitchen that makes them more vulnerable and stressed about food issues. *"I was scared a lot!!!!...I panicked when I heard it.....the worst existing disease.....to want to eat and that to be prohibited.....in the summer you see the fruits and you turn away..."* (a big sigh and a long pause).

The limitation of food in diabetic patients shouldn't be forced for glucose regulation, although some limitations can be imposed on them in order to control body weight mostly concerning overweight patients. If the patient is overactive some additional meals between the main ones is likely to be needed. In the evenings close to bedtime, the overconsumption of carbohydrates is usually discouraged (18).

B. Needs–Wishes

In the survey which was conducted in response to the question *"in what way they believe a nurse would be useful» most patients, expressed this sense of the need mainly as a desire. They expect nurses to be helpers in their Fight. They want them not only as fully qualified professionals but also "as their own person",* who will always be there for them.

Needs for Psychological Support

Nurses should understand the patient's feelings and expectations which might be hidden behind words and sentences, as many times the cognitive and emotional content of the patient's words is presented verbally or non-verbally disguised or completely falsified. *"I want a person who I can call mine.... with knowledge, who I can trust... always there when I need him...".* Therefore, during their conversation, the nurse should not just listen to what the patient says, but also to understand the different tones and intensity of his voice and the various nonverbal facial and eye expressions. For the above purpose, devoting sufficient time and attention to the needs of patients is required in order to express his thoughts, fears and concerns about his condition. Psychological support, which is also provided to certain groups of people with diabetes, during visits at home is of very high importance. Such groups are newly diagnosed insulin-dependent diabetes patients (which usually develops in young people) during visits at home is of very high importance. *"... I started insulin last week ... everything is mountains to climb ... I need support now at the beginning ...".* Additionally, the nurse who works and cares for people with diabetes, should be a source of advice for other nurses and health professionals, providing to them the necessary information and alternatives useful for solving complex problems with final aim the alleviation of mental stress of these people (4).

Needs for training

The instruments that can be used by nurses for better education of diabetics include : interview, speeches given to groups of diabetic patients and their families, various forms and brochures with pictures and detailed explanations provided in a language understandable to the patient regardless of their educational level and their social class.

The success of a diabetes-training program depends on the willingness of the diabetic to be trained. Sometimes the trainer comes across indifference, pessimism, negative mood or psychological disruption which can impede knowledge acquisition in patients with diabetes (19).

The success of an individualized diabetes care plan requires the incorporation of training as an integral component of diabetes therapy. The goal of each educational intervention is the promotion of self-care and the prevention of complications (20).

Needs for technique learning

The term technique for many of the patients of this study, especially those who were recently diagnosed, is referred to a daily act and it needs some kind of training in order to perform. Such actions are insulin injection, the self-examination for blood glucose test even the urine test. Insulin-dependent patient must on a daily and periodic bases undergo, in an outpatient setting, with laboratory tests, such as:

Glucose of capillary blood, by a small device and the appropriate test strips. The frequency of the tests depends on the difficulty of regulation of diabetes. In some patients the daily control is required, with 3-4 daily measurements. The examination of urine sugar nowadays tends to be replaced by capillary blood tests. Glycosylated hemoglobin every three months (HbA1c). Many of the patients in the study were curious about…. *"What is Glycosylated hemoglobin"…….. Many of them couldn't pronounce it and referred to it as "……..the new blood test…"* Moreover, many patients of this study were asking *"…is it an important examination as blood sugar…"*

The first thing that a diabetic must been trained to is the self-examination for blood glucose test. It is a test that should be conducted many times during the day and mostly when the patient senses that something is wrong with his blood glucose value. The majority of the patients always have questions about this simple examination, *"… can I have blood sample from all of my fingers…?".* Regardless how simple the self-monitoring of blood glucose is, there is always a technique that must be applied. Washing hands with soap and water and drying them out and using the first drop of blood. If washing the hands isn't possible and if there isn't any visible stain or exposure to product that contains sugar, then to use the second drop after wiping the first drop is acceptable. The external pressure may lead to unreliable results. It does matter which finger is used (21).

"…I don't need to check for my blood glucose …I can understand either is very high or low…" is the most frequent and dangerous excuse! In the best case only very high or very low values can be perceived. *"… I have an insulin injection five times per day, I don't do it on my thighs… because there bleeding…".* Many of the patients expressed their need for information regarding insulin injections, *" …are they any secrets so they do not hurt….sometimes they can be very painful…" .*

"…What exactly happening to the point that insulin is injected and it becoming red and itchy…" was the question of a young patient who participated in this study.

Both, patient and his family should monitor injection areas always, for differences in the points. Moreover, they should inform the nurse about every minor or major difference detected, because a slight impairment at an early stage can be easily handled rather than a more extensive one. The main problems are hypersensitivity, lipodystrophy and lipoatrophy (19, 22).

Needs for diet and exercise

The diet of a patient with type II diabetes does not differ at all from the diet of a healthy individual, if they are following the traditional Greek lifestyle. According to this lifestyle, obesity did not exist in Greek villages until a few decades ago. Many of the patients who participated in this study were obese people, especially women. The energy consumption includes the basic metabolism, the caloric effect the metabolism of foods and muscular work [23].

"… I want to learn how to eat correctly… I have to lose weight…", the most obese among patients states *"I have to lose a lot of weight…my feet are aching……..I find it hard to walk…".*

Nurse must respect the religious specifics of each patient and its fasting periods. *"I want to fast ... but I'm afraid that may turn out to be harmful ..."* this is the desire of a patient who is diabetic and is very religious person. We cannot depriving from patients their desires and especially the religion ones. The Faith of each person gives him strength, and by raising this force he can overcome the difficult life events.

Need for knowledge about Hypoglycemia

Hypoglycemia is the most frequent and more severe side effect of insulin therapy, but it can happen after the administration of hypoglycemic tablets. The fear of hypoglycemia and the effects of severe and extended hypoglycemia on the brains functions that are reversible, but under certain circumstances may become permanent, are a key obstacle in the regulation of diabetes. All patients who participated in our study had a medical history with enough episodes of hypoglycemia,*"I find it difficult to calculate the dose .... I often have hypoglycemic episodes…..".*

Among patients with diabetes type II, the higher frequency of hypoglycemic episodes is, in those who are using insulin and less in those patients who are using tablets.*"….. I often have hypoglemic episodes ... my jaw is numb or I'm sweating…..".*

In such a way a patient describes the hypoglycemic symptoms (24).

The importance of every patient with diabetes to always carry a badge or a feature that says he is diabetic should be noted. This characteristic may save his life in an impending hypoglycemia. Hypoglycemic symptoms can imitate those of alcohol abuse. *"I forget a lot and I want someone to remind me the time ... and what to do ...".*

The patient was located at the city hospital and the cause of her hospitalization was the deregulation of diabetes, due the fact that she didn't had been administrated

with insulin for days. When her insulin supplements had finished she and her relatives weren't able to replace them.

Dementia is a frequent phenomenon in diabetic patients, especially in those with a certain age. According to research that has been conducted, middle age patients with type II diabetes, have a more severe reduction compared with those without diabetes. Therefore cognitive function should be evaluated and assessed in middle aged people with type II diabetes (25, 26, 27).

Need for Communication

One of the essential points that indicated by this study was the need for communication, expressed by all participants as well as their relatives. Most of them wished if we could keep in touch with them in the future. *".. Now that "help at home" ended..... those girls would come and helped us.... Now where do we find some support ..."*The "Help at Home" program serves a large number of people who are living in remote areas of large municipalities. It offers nursing, household service's and entertainment and it make the best possible use of all resources that are available. It is addressed to lonely people who are facing various forms of difficulties and provides employment to a significant number of people; in addition, it strengthens incentives to remain in their place than seeking work in urban centers.*"... I do not want to leave my home..... There, a nurse may come to help us ..... with injections ... the food ... and keep us company ..."* (28).

Many of participants had found in the face of the institution "help at home", willing nurses who visited them in their homes daily, looked after them, and were give by them and their families psychological support.

Needs for recognition and addressing complications

Another very common and important reason for hospitalization is the diabetic foot. The patient needs to be aware for it prevention and how to avoid this complication. *" ... My feet are frozen....and in pain for the last three days....."*, words of a patient that is participating in this study. It would appropriate point out some measures to prevent diabetic foot. As mentioned above, nurses have an important role in the prevention of complications in the lower limbs of patients with diabetes. For this purpose, the provision of information and training of these patients should focus to:

The daily control of lower limbs and foots, due to decreased sensation, it is possible that the patient has injuries, which he didn't feel (10, 29, 30, 31, 32).

In conclusion, by adopting those instructions, diabetic patients can prevent complications in the lower limbs, essentially.*"I did not believe all the problems that diabetes can bring.... ... can get to me ...Now I have asthma..... I had a Coronary Stent procedure ... and now something is wrong with my leg.....Why is it like this..."* words of a patient that had a diabetic foot. As we can see the complications don't relate different patients but each patient can deal with several of the known complications of diabetes.

Diabetic nephropathy complicates 20-40% of diabetics and is the leading cause of end stage renal disease. *"..... I have kidney's problem ... my legs and hands are swelling ... I'm afraid that I going to be under dialysis ... ."*

The everyday needs

"...I'm living in a village on a mountain ... and we stay cut off for may days during the winter...", *"... I can't come often to the city ... It's far away and it's cold ..."*

The peculiarity of the region was expressed by three patients, who there were living in mountainous villages. Those patients did not have access to a nursing facilities cause of the weather conditions and they were remaining cut off by snow for weeks thus without medical-nursing care and medication. The extreme weather events that are prevailing in central Greece are making the need for nursing care necessary.

".....not to long ago I mistook my insulins and I got severe hypoglycaemia..... fortunately my son was there and rushed me to the hospital ...", words from a patient, indicating how crucial, the daily life of diabetics can be. Even a little mistake can be very crucial for life. In province the institution of the family is still preserved, and most diabetics, are still close to their children. Those people have someone younger supervising and helping them. But there are also people who are alone and facing several daily problems.

5. CONCLUSIONS

This study was conducted with semi-structured interviews and with a few participants thus, the results cannot be generalized for the overall population. However, this research's findings are supported by relevant studies, which are reporting similar results. The results indicated that patients with diabetes are exposed to a variety of fears and needs, related to the diagnosis, treatment, expected impacts, prognosis and the daily management of the disease. Their fears were related to the complications and the effects on their lives like any other chronic disease, which cause the patients to a diffuse fear for their daily life and life in general.

The Chronically ill patients are people who have learned to handle their disease better than anyone and often even than scientists. *"... I have become an expert..."* those are words of the chronically ill patients and of all of the participants of this research. This phrase *"I have become an expert"* indicates the patients' development of skills in order to address their diseases in an expert way. Self care and management are goals set by care providers and especially nurses. A successful training program is one that through it the patient was ready to take on initiatives. Family support and the roles that family members have is an integral part not only for the patients training but also for the psychological support (33, 34). Women tend to be more open to provide information and discuss regarding their disease opposed to men who tend to be more cautious. The elderly had to deal with complications and younger patients had more hypoglycaemia. Men were more occupied by issues regarding their work and the possibility o a disability or an inability caused by the illness (17).

The fear of inheritance and for their family is the same for both sexes; moreover a major question for the patient is whether diabetes is a disease with no borders and limitations to societies and all social groups (19).

Most of the patients were in need for psychological support from nurses. Nurses were by their side, from the early stages of their disease, providing information regarding

self-care. Self-care training is a continuous struggle in diabetic care. New treatment methods, new medication, new formulations of insulin, changes in the way of thinking, age perceptions and specificities developed by alignment problems, makes us aware that the skills acquired by diabetic patients are not permanent but they are put under a continuous evaluation and modification throughout the course of his life. The reduction of diabetes and the prevention of his complications could also reduce the cost of hospitalization. The gain that will come from such reduction could be spent on research programs and drug discovery for diabetes and other diseases that plague the modern era (6, 35, 36, 37).

CONFLICTS OF INTEREST: NONE DECLARED.

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