Abstract

We aimed to explore how elderly immigrants from Bosnia and Herzegovina living in Sweden described their daily lives from the moment they received a diagnosis of diabetes mellitus, as well as their mental health.

Material and methods: Our study has a qualitative design. Data was collected between March and September 2013 through face-to-face interviews using open-ended questions. A qualitative content analysis method was used for analysis and interpretation of data in accordance with the Graneheim and Lundman method (2004). The participants were eight women and seven men, aged between 50 and 86 years (mean 71.4), emigrated from Bosnia and Herzegovina and diagnosed with diabetes mellitus type 2 in Sweden. They had lived in Sweden between 10 and 18 years.

Results: The participants diagnosed with diabetes mellitus type 2 experienced a lot of problems and difficulties with the disease. They felt shock and fear because they were aware that they would never be free from the disease. Changing lifestyle, eating habits and activity level were described as difficulties by participants. The combination of the disease and language difficulties made the situation more difficult for the study group. More than 50 % of the participants had experienced some kind of depression.

Conclusions: Health care professionals need to be aware of the various ethnic groups in Sweden. The health care system must adjust to the needs of ethnically diverse patients instead of the other way around. Effective and simple routines and facilities are also necessary when communicating with patients speaking a foreign language. Difficulties in daily life can result in more difficulties regarding their diseases. Health care professionals need to have more knowledge about social and cultural factors that may influence interaction with patients from other linguistic and ethnic backgrounds. Mutual understanding between professional and patient has a significant impact on health outcome.

ABBREVIATIONS

DM: Diabetes Mellitus

INTRODUCTION

Due to the wars, hunger, natural disasters and persecution during the last decades, millions of people have been forced to leave their own countries, cross language and cultural boundaries and resettle in other parts of the world [1]. The number of people with diverse cultural and linguistic backgrounds has increased considerably in Sweden, which has created a challenge for health care professionals [2]. In this context, encounters between health care professionals and patients from other cultures have become progressively complex and sometimes problematic [3,4]. In today’s societies transcultural nursing is a crucial aspect of health care activities and a new concept with its own separate area in nursing science [5,6]. In developing the theory, the fundamental issue was to identify factors that influence the quality of care for patients with different cultural and linguistic backgrounds. In this context, religion, cultural values, politics, economics,
environment, world view, history, language and gender were considerable factors. The main purpose of developing this theory is to explain diverse and universal culturally based care factors influencing the health, well-being, illness or death of individuals or groups. Health care professionals and patients’ mutual understanding is essential to provide transcultural nursing, and factors influencing care for patients with other cultural and linguistic backgrounds must be avoided [5,6]. The role of language in providing care across cultural and linguistic borders is important. Health care providers’ understanding of their own cultural values, attitudes and beliefs has a significant effect on understanding of other cultures [7].

Bosnia and Herzegovina refugees

Until 1991 Bosnia and Herzegovina was geographically and politically a part of former Yugoslavia, but after a period of war, it became an independent state. As a result of conflict or war, many people from Bosnia and Herzegovina have been forced into exile. During the war violence and ethnic cleansing were often deliberately used to drive people from their homeland where they were born and had lived for generations [8]. Because of war the whole social and economic structure was destroyed, and there was no hope to receive social and economic support. In this war a large number of civilians were affected brutally by the former Yugoslavia army and were exposed to extreme threats and intense feelings of powerlessness [9,10]. Thousands of people experienced traumatic events during this ethnic conflict. Many of them still suffer from the effect of the violence from the enemy during this war [11]. The traumatic effect of violence has had significant negative impact on their lives and their psychosocial well-being in their resettlement countries [12]. Immigration to Sweden was dominated by labour immigrants from Northern European countries as post-war immigration up to the 1970s. However, later it changed to refugees and asylum seekers mostly from Iran, Iraq and former Yugoslavia [11,12]. After the 1970s, like in many other European countries, immigration to Sweden increased dramatically. Immigration is now the main source of the increase in the Swedish population. According to Swedish official statistics in 2013, 23.3% of the Swedish population of 9.7 million had a foreign background and 15.4% were born outside the country. In the last ten years, labour migration associated with European Union regulations and immigration to join family has increased. In 2013, 115,845 persons immigrated to Sweden, which is an increase of 3% compared with 2012. Of them, 64% are men and 36% women [13]. Unlike many immigrants who have left their homes because of economic reasons or to join family members already settled in another country, refugees have fled their home country in order to survive. Although both immigrants and refugees have a number of common difficulties, refugees usually experience more negative events that affect their well-being in their resettlement countries [14]. The immigrants from Bosnia and Herzegovina living in Sweden are on the fourth place after Finland, Iraq and Syria. There are 57,904 individuals from Bosnia and Herzegovina living in Sweden [15].

Diabetes mellitus (DM)

Nearly 6% of the world’s adult population suffers from diabetes mellitus, and it constitutes a global public health concern. In Sweden almost 400,000 persons are diagnosed with DM [15]. Previous studies about diabetes and immigrants showed that immigrants from culturally and linguistically diverse backgrounds experience considerable difficulty in adjusting to a diagnosis of DM and its management. These studies have also indicated how culture and the experience of immigration affect a person’s experience of the health care system in his or her resettlement country [16-18]. In one study about stress and diabetes, the authors showed that most stress was caused not by the physical symptoms of the disease but by the barriers these imposed on performing social and cultural duties expected of their communities and the lack of control over their lives [17]. Previous studies showed also that prevalence of depression in patients with diabetes is twice compared with those without the illness, many people with diabetes suffer depressive symptoms and distress, which is associated with disease complications and mortality, and depression, may be very important risk factor for developing diabetes [19-21]. The aim of the present study therefore was to explore how elderly immigrants from Bosnia and Herzegovina living in Sweden and diagnosed with diabetes mellitus type 2 in Sweden described their daily lives from the moment they received diagnosis, as well as their mental health.

MATERIALS AND METHODS

Participants

Our study is based on a qualitative design, as the study aimed to describe and analyse how patients experienced the Swedish health system. Inclusion criteria were subjects/persons coming from Bosnia and Herzegovina who were more than 50 years old, had lived in Sweden more than ten years and had a diagnosis of diabetes mellitus. Twenty persons were invited to participate in the study, of which 15 participants agreed to participate. Three of the participants declined participation without explanation, and two of participants moved back to Bosnia and Herzegovina during the study period. Accordingly, 15 persons participated in the study: eight women and seven men, aged between 50 and 86 years. All participants had lived in Sweden between 10 and 18 years (Table 1). The first author of the study (FK) made appointments for all interviews.

Data collection

Data was collected through individual face-to-face interviews by the first author (FK) using open-ended questions, following an interview guide inspired by Kvale [22]. The interviews were performed between March and September 2013. They began with small talk. The opening question was “Can you please tell me about the moment you received diagnosis of diabetes?” and “Could you please tell me about your experiences to live with diabetes?” The initial question was supplemented with other short questions like “Could you please tell me more about this?” or “What do you mean by this?” Participants were contacted through Bosnian Culture Association in Gothenburg. Written information about the aim of the study was sent to all of them before interviews. Additionally, information about the interview’s practical issues and participants’ right to withdraw from the study if they wanted was delivered before the interviews started. Interviews were conducted at the participant’s private home and lasted between 60 and 90 minutes. The language of the interviews was the participants’ mother tongue, which made it possible for
them to speak freely using their own words, and the interviewer encouraged the informants to answer questions as thoroughly as possible. The interviews were audiotapes, transcribed and translated by one of the researchers (FK). In order to obtain the participants' depression level, a few minutes after the interview was finished, the participants completed the DASS 21 scale [23]. The first author (FK) translated the scale into Bosnian because the participants could not understand Swedish. Categories in the scale were: No depression 0–9, mild 10–13, moderate 14–20, severe 21–27 and extremely severe 28+ (Table 3).

Data analysis

As the aim of the study was to find out the participants' experiences of DM, a qualitative method that stayed close to the nature of the data was needed. In this context we found content analysis in accordance with Graneheim and Lundman (2004) an appropriate method to analyse and interpret the collected data. This method makes it possible to compact a large amount of data into a limited number of subcategories and categories. Additionally, this method is capable of including interpretations of latent content. In the first step, the text was read carefully in order to identify the informants’ experiences and conceptions of DM and its effect on their daily lives. In the second step, in order to build meaning units consisting of one or several words, sentences or paragraphs containing aspects related to each other and addressing a specific topic moved together and more abstracted. In the third step, the condensed text was further abstracted and labelled with a code. Finally, codes that addressed similar issues were moved together, subsequently into subcategories. Subcategories, which focused on the same problem, resulted in categories [24].

Ethical considerations

According to Swedish law, there is no need for an ethical board review if written consent has been obtained from the participants and if there is no physical intervention involved in the study [25]. However, the study conformed to the principles outlined in the Declaration of Helsinki [26]. Participants were informed that participation was voluntary and that confidentiality would be maintained. Written informed consent was obtained from the participants.

RESULTS AND DISCUSSION

The analysis resulted in two categories and five subcategories based on how the participants described their lives in Sweden. These categories, together with the subcategories, are presented in (Table 2).

Getting the diagnosis

Diagnosis of a chronic illness is not pleasant for the person who delivers the news or for the patient who is ill. All patients in our study come from a country where a war ended approximately 18 years ago. All patients have suffered and experienced unpleasant moments throughout their lives. Being diagnosed with a disease was experienced by all our patients in different ways, but all of them were shocked. In the analysis of the text in the present
study, reactions to the diagnosis were different for all of our participants. However, common to all of participants in the study was that they were in a state of shock. Some of the participants felt anger, rim and heat; some felt that they had ended up on another planet and experienced it so negatively that they cried for a few days after the diagnosis.

**Getting a shock**

The diagnosis of the disease came to all participants in the present study suddenly. None of the participants was prepared for the diagnosis. All remember the diagnosis day very well. Some of them said that they will remember this day for the rest of their lives. And many participants compared this day with all their experiences of war in their home country.

About the diagnosis day, one participant said, “I just looked at my doctor without saying a word; it was hard to hear.”

A woman said, “I did not think the doctor was talking about me. I thought the doctor was talking about another patient.”

One man said about the diagnosis news, “I was not feeling well and I thought I had died in the moment.”

One of the participants said the following: “When my doctor told me that I had diabetes, I started to cry. It felt very exacting.”

**Getting information about diabetes**

Although they had difficulties and horrible experiences of the diagnosis, all of the participants in the present study wanted to know more about their disease and methods that could improve their lives’ quality. All of participants in our study stated that it was very important to be informed about their disease. However, information about their illness was usually poor and incomplete.

Most of the participants described the information about diabetes as limited. Difficulties in meeting a doctor and lack of information in their mother tongue were the other negative factors that they mentioned.

About the disease information, a participant said, “I had been waiting to see my doctor for six months. When I met her, she only had a few minutes.”

A woman said about his time with doctor, “We never meet the same doctor when we return to the health care centre.”

Some of the participants wanted to get the information at home in their mother tongue and read this.

One participant said, “I remember everything that doctor said when I’m in the hospital, but I forget it all when I came home…I have no written information.”

War in the home country and problems related to war and ethnic conflict were mentioned as impact factors that hinder participants from getting involved in social activities and learning the language.

None of the informants knew more than a few Swedish words and were thus unable to communicate in Swedish. They expressed their anxiety concerning lack of knowledge in the Swedish language and mentioned that the Swedish language was the key to participate in their new society.

One participant said, “When I got an appointment to visit my doctor, my interpreter was late, and the nurse tried to talk to my doctor without the interpreter, but our consultation was without any results.”

Another participant said, “Knowing a language is a treasure”.

**Being afraid**

A few months after the patients diagnosed with diabetes felt the shock, participants in our study gathered information about the disease and other problems associated with it. All participants in the present study felt fear and anxiety. Some of them were very depressed about their disease. All participants in our study thought about the future; they thought about their children and grandchildren as well as the complications of the disease like amputation and other health-related consequences.

About their fears for the future a man said, “My wife has been sick for a long time. I have to take care of her. If something happens to me, my children will suffer…I will die.”

One patient was so worried about his situation that it was difficult to talk about, but he said this: “I experienced terrible and ugly things during the war; what more could happen than this? I go blind, my leg is amputated and then I die. It’s horrible.”

**Changing lifestyles**

The result of the study revealed that after a few months, patients were aware of their disease and its diagnosis. They understood that they must change their lifestyle completely. Patients reported that they were never free of the disease and that the disease was present all the time. For patients using insulin, it was hard to stand all the time, check blood counts and inject insulin into the body. Most of the patients had a fear of using the insulin pen. Life was not the same anymore, and patients said they had to end many things they were doing before the diagnosis of the disease.

**Changing eating habits**

Changing lifestyles for participants meant changing eating habits. All patients mentioned that they experienced the situation as very difficult. For some of them, this was more difficult than when they received the actual diagnosis of the disease. Many of participants expressed that it was difficult to affect diabetes. It’s hard to learn some things at an adult age, particularly when one is old and sick. Furthermore, it was more difficult when one resettled in other country with diversity in language and culture.

A man said, “I usually eat meals that are imported from my home country...difficult without food from Bosnia...Now I must eat a special diet, but it is very difficult.”

One woman said, “You need to think about your illness all the time, think about sugar value, in tablets or insulin, thinking about food and how much to eat... It is terribly difficult...Like in a prison.”

Regarding language difficulties and cultural differences, a participant said, “I live alone and cannot speak Swedish. To speak Swedish is something that could help me and make the life easier...the weekend is usually for relaxing but it is a shadow of death.”
Being more active

Participants in our study were aware that they would have to be more active, which for many was very difficult. Many of our patients had other diseases that could hinder them from being more active.

One participant said, “I have two sons in Bosnia but here I am totally helpless. When I need it, I can’t think to go out and run or walk.”

One woman said, “All of my relatives and children are working and I can’t go out alone... What other people will think of me if I walk alone each day?”

DISCUSSION

Being an immigrant in another country with severe problems at the beginning of a new life demands replaced position that requires rapid adaptation and adjustment to a new health care system. The analysis of the material in our study identified several negative factors during the course of immigrant’s contact with health care professionals in Sweden. The present study highlights how the elderly participants experienced being diagnosed with diabetes mellitus, the limitation of the information about the disease and how the diagnosis changed their lives. Due to the inclusion criteria and the demographic factors of participants in the present study, participants may have had varied experiences about the moment they received diagnosis and their contact with health care professionals in Sweden. In this study we analysed how elderly immigrants from Bosnia and Herzegovina living in Sweden described their daily lives from the moment they received a diagnosis of diabetes mellitus and how it has influenced their mental health.

The results of the present study showed that receiving information about a diabetes diagnosis was experienced as very difficult by all participants. The participants felt that the information about the disease came as a shock; it was unexpected and that they believed that their lives were over. The feelings were shared, from feeling the heat to crying for days. Most patients believed that they would be bound to the disease and not have freedom at all. The findings in our study are in the line with Wilkinson et al. [27] who interviewed 47 patients that received a diagnosis of diabetes mellitus (<1 year). The authors in this study showed that people expressed a range of emotions at diagnosis. The participants diagnosed with diabetes were surprised and upset to be diagnosed. Only a small number of participants in the study reported that they didn’t worry about the diabetes diagnosis [27]. Another study with 49 patients with type 2 diabetes (Vinter-Repalust et al.) showed the shocked reactions of the participants who received the diagnosis [28]. Another study with participants from Somalia showed that the participants irrespective of gender did not immediately respond with shock or other strong emotion when they received the diagnosis diabetes mellitus. The answers between men and woman were different and the findings differ in how they experience the diagnosis and how they described their health beliefs [29]. This may be typically to the Somalia culture and the participants coming from this part of world.

Our findings also revealed that all of participants in our study emphasised the importance of information about their disease and that contact and communication with health care professionals wasn’t preferred. They wanted to know more about the disease and meet the same doctor every time, and they were very sad that they couldn’t understand the Swedish language. However, they were interested about information after the shock phase was over. The findings can be seen in one of our previous studies about dissatisfaction with preoperative information on elective total hip replacement (Krupic et al.) [30]. Health care professionals must be aware that caring for patients with diabetes and who have an immigrant background may be difficult because after a person moves to a new country, a social network doesn’t exist, and the person must learn how to manage the disease and find their social identity and network. It is very difficult, however, if participants don’t speak the native language. The structure of the Swedish health care system focuses on disease and treatment, and each visit is limited on time, which can lead to frustration and anger and difficulties in communication with care providers regarding information about disease and involvement in treatment [31,32]. The results of the present study also showed that the disease also meant changing lifestyles, eating in a different way and being more active. All participants in our study described that this was very difficult, and not all patients experienced this as a great burden. Our findings are in the line with the study of Vinter-Repalust et al. [28], who showed a number of difficulties for patients diagnosed with diabetes mellitus. While their families tried to help them to change their diet, it often happened that they ate food that was not recommended. In one similar study with 25 patients with diabetes type 2, the authors described that the patients felt like victims when they were eating. They felt that everyone had their eyes on them, so they chose suitable food and drink. The authors also reported differences in emphasis between participants and health care professionals [33]. In our study, the elderly participants born in Bosnia and Herzegovina and diagnosed with diabetes mellitus type 2 in Sweden tended to have low mental well-being.

Even though the number of participant is small, but participant interest in the study’s subject and their opportunities’ that speak in the mother tongue resulted in saturated data. One limitation of our study was that we interviewed the participants in their homes, and sometimes the participants had guests. In two cases, children of the participants joined the participants during the interview period. These circumstances may have affected the answers and may have made the participants less open and more nervous.

CONCLUSION

Because of the large scale of migration during the last decades, Sweden has become a multicultural and multi-ethnic society. This creates a challenge for health care professionals regarding care and treatment of patients from various ethnic groups in Sweden. In order to give adequate and equal care to all patients, the health care system in Sweden must adjust to the needs of ethnically diverse patients. Communication with patients speaking a foreign language requires effective, simple routines and facilities. Unpleasant moments and difficulties in daily life are factors that may affect diseases negatively. Although the biological nature of diseases is the same in all cultures, how
to express health and disease and understanding them differ from culture to culture. In this context, health care professionals' knowledge about other cultures, as well as awareness of cultural diversity's impact on psychosocial well-being is essential to deliver health care services to immigrant patients.

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