

Rearranging Everyday Lives among People with Type 2 Diabetes in Korea

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Purpose: The purpose of the study was to understand what are the experiences and management of type 2 diabetes in everyday lives among Korean people. **Methods:** A grounded theory method was utilized to explore how people with type 2 diabetes to experience and manage their disease under the Korean socio-cultural context. The data were collected via narrative in-depth interviews with 21 people with type 2 diabetes during 2010-2011 and all interviews were transcribed for verbatim analysis. **Results:** The core category was 'Rearranging everyday lives by accepting diabetes as lifelong annoying companion.' Four stages were identified: ignoring; struggling compromising and conciliating. Each stage illustrates major problems and/or strategies that the participants face in dealing with diabetes. The process illustrates the transference from their ordinary life, in which diabetes or health was ignored, to the health-oriented life, within which diabetes is integrated into their lives. The most difficult barriers they faced in everyday lives include social stigma of diabetes and collectivistic culture in Korea. Within the culture, the group goals are concerned over individual ones, making it harder for the participants to take care of their own health. **Conclusion:** The findings of the study imply that health care professionals may consider the influence of social stigma in caring diabetic patients. Also, the intervention study is warranted to educate Korean people with diabetes to get aware of the sociocultural context and stigma as well as personal difficulties in self-caring diabetes.

Key Words: Experience, type 2 diabetes mellitus, Self-Management, Qualitative research

INTRODUCTION

Diabetes is a major worldwide health problem. In 2012 the World Health Organization[1] estimated that there are 347 million people with diabetes. In Korea, 3.2 million people (10.1% of the population) aged over 30 years or old had diabetes in 2010[2]. It is well known that diabetes, especially type 2 diabetes which comprises 90% of disease cases[1], can be controlled by diet, exercise, and weight control along with medication. However, many people with diabetes find it difficult to follow the treatment regimen. Although some guidelines have been introduced (i.e., Korea National Diabetes Program[3]), half of the Korean people with diabetes failed to control their glycemic level, applying the guide-

lines HbA1c < 7%, and three out of four were overweight or obese[2]. A U.S. study[4] also found low rates of management 45% were non-adherent to medication and 42% ate high-fat food, while only 28% performed moderate or vigorous physical activity. To solve these grave problems, unified global actions should be taken, along with culturally sensitive regional actions against diabetes.

To promote management of diabetes, many studies have dealt with factors influencing diabetes management. Personal factors such as fear and depression[5] were identified to be associated with lack of self-management of diabetes, while self-efficacy[4] and spirituality were associated with high rates of management. Extrinsic factors such as support from family, peers, and health professionals had a positive influence[6]. Numerous intervention studies have also been conducted to facilitate life-

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- This study was supported by the Korea Research Foundation(KRF-2009-322-A00106).

Received: Aug 30, 2014 / Revised: Nov 17, 2014 / Accepted: Nov 28, 2014

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style changes related to diabetes. Self-management education[7], participative group education[8], and a culturally-tailored intervention[9] have been implemented. In spite of these efforts and extensive studies on intervention, it turned out that their effects are sparse or limited[10].

To overcome these problematic situations and to provide more patient-oriented care, health professionals began to view patients as fully responsible for their own care rather than viewing them as passive recipients of health care[11]. And, in order to integrate the essential role of people with diabetes in the health care, many researchers had conducted explorative studies by considering specific socio-cultural context[12,13]. Results of these studies clearly show that self-management of diabetes revolves around specific socio-cultural settings.

Korean culture is considered to be collectivistic, while Western culture is individualistic [14]. Koreans tend to be closely tied to their family, group, and society. Maintaining harmony with others is considered a high value, even put above individual needs, whereas failing to do so is recognized as a sign of moral failure in Korea[15]. However, knowledge on experience of self-management of people with diabetes in Korea in such a cultural context is scarce.

The purpose of the study was to understand how people with diabetes in Korea experience in managing their disease. More specifically, it aimed to examine what kind of meanings Korean people with diabetes have on diabetes, what kind of problems they face in managing the disease, and how they manage these problems in their ordinary everyday life.

METHODS

1. Design and Sample

The Strauss and Corbin's grounded theory method, which is an inductive approach, was used to understand how people with type 2 diabetes manage their disease in Korea. This study utilized the data from a five-year project, "Interdisciplinary Research and Development of Illness Narrative Database: Based on Linguistic Methodology," supported by the Korea Research Foundation in 2009~2013. A sample of 50 people with diabetes was recruited nationwide by introductions of health professionals, self-help groups, online advertisement, as well as snowball sampling in the project. For theoretical sampling, maximum variation sampling was utilized to collect experiences on diabetes from a wide range of peo-

ple, including varying age, gender, education, economic status, duration of illness on the basis of concepts. This study used the data from 21 of 50-samples in the project, as the theoretical saturation was accomplished when no new information seems to emerge during analysis in the data[16].

2. Human Subjects Approval

Approval to conduct the study was obtained from the Human Subjects Review Committee [IRB No.0910/001-002] at the university. The subjects were reached by phone and asked whether they would like to participate in the study, after the purpose of the study was explained. Before the interview began, all participants signed a written consent form that explained their rights as research participants. It included statements that their participation was voluntary, that they could refuse to answer any of the interview questions, and that they had the right to withdraw from the study at any time. A small payment was given to each participant as a token of gratitude.

3. Data Collection

All of the participants were interviewed by one of four trained interviewers at their choice of place, such as their home or office, during 2010~2011. Semi-structured narrative interviews were conducted with open-ended questions, such as "Please tell me about your experience as a person with diabetes." Each interview lasted about one hour or until the participant had no more to talk about. Since the project was to produce a website (www.healthstory4u.co.kr) of the DIPEX of Korea, interviews were video-recorded (five of them were audio-taped at the request of the participants) and transcribed verbatim.

4. Method of Analysis

Constant comparative analysis was applied throughout the entire coding process [16], although the data collection and analysis were not performed at the same time. First, the transcribed data in Korean were read line-by-line to identify significant statements related to the experiences with diabetes. Meanwhile, codes that reflected the significant statements were generated in English by three investigators who are bilingual. Further analysis was conducted in order to develop categories, of which properties and dimensions were based on

the codes. Connections between the categories were made by utilizing a coding scheme that involved conditions, strategies, and consequences. In the selective coding, a core category that indicates basic social psychological process was constructed, while the data were analyzed repeatedly to verify categories and subcategories and to confirm that no new categories emerged. Memos and diagrams were also utilized to obtain analytic ideas throughout the analytic process.

To ensure rigor of the study, the criteria of credibility, fittingness, auditability, and confirmability were utilized [17]. The credibility of the data was enhanced by using narrative in-depth interviews that reflected the participants' own perspectives and experiences. Theoretical saturation of the data from 21 participants and investigator triangulation [18] added to the overall credibility. Fittingness was enhanced by providing demographic and illness-related data of the participants along with various incidents and events in the texts. Auditability was ensured by providing analysis procedures in detail and by showing conclusions explicitly linked with displayed data. Confirmability, which refers to a freedom from possible research biases, was achieved by undertaking the strategies discussed above.

5. Researchers as Research Instruments

The researchers are experts on the qualitative research and have studied the qualitative research con-

tinuously since receiving PhD with qualitative methods in their dissertation. Especially, the researchers are proficient in both Symbolic Interactionism and Grounded Theory that have published numerous research studies and focus on expanding and studying Grounded Theory through academy of qualitative research.

RESULTS

Interview data from 21 participants were included in the study. The average age of the participants was 57.3 years, ranging from 39 to 75 years. Fifteen were male and 17 were married. Eight each had high school education and college education, respectively. Nine were in the middle socio-economic class and eight were in the lower class. The average duration since diagnosis was 12.0 years. Most of them had experienced hypoglycemia, and eight had several complications such as diabetic neuropathy, retinopathy, and diabetic foot ulceration. Twelve participants took an oral hypoglycemic agent, six used insulin, and three used a combination of an oral hypoglycemic agent and insulin.

After constant comparative analysis of the data, a core category emerged as 'accepting diabetes as a lifelong annoying companion' (Figure 1). The core category illustrates the transferring process from living an ordinary life in which ignoring diabetes to a health-oriented life of accepting diabetes although it is annoying.

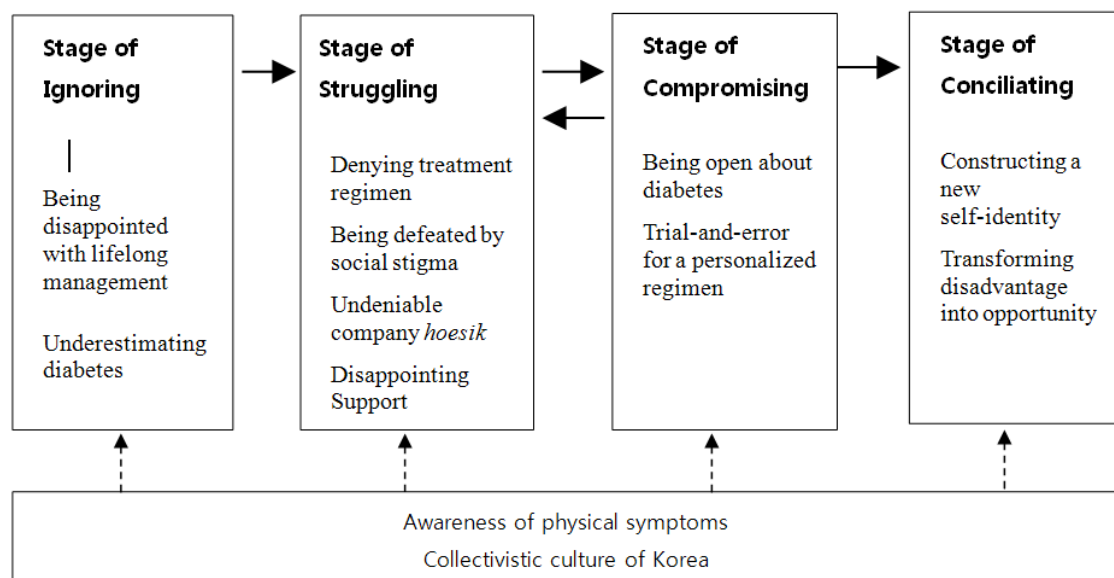


Figure 1. The process of rearranging of the everyday life on accepting diabetes as a lifelong annoying companion.

There is no cure in diabetes. So, I need to deal my diabetes in order to live alongside it until the end of my life. It is like my wife living with me. Sometimes she bothers me, but I cannot change her, so I pat her softly to make her more agreeable with me. (Participant 9)

The transformation process takes a long period of time, from five to 20 years, proceeding in a rough and difficult way. Four stages were identified in the process: ignoring struggling compromising and conciliating. Each stage represents a way of dealing with diabetes, as the meaning of diabetes changes from a manageable disease to a horrible disease and finally to a disease that can be coaxed into being managed with confidence. In Figure 1, the bidirectional arrow between the stage of struggling and compromising indicates that each stage does not proceed straightforwardly to the next, with participants sometimes reverting to the previous stage in challenging situations. Among the 21 participants, most of them were in between the stages of struggling and compromising, and only four were in the stage of conciliating. The awareness of physical symptoms and the collectivistic Korean culture were found to be major factors influencing all of the stages.

1. Stage 1: Ignoring

The stage of ignoring includes two paradoxical aspects: disappointment with lifelong management of diabetes and underestimation of diabetes as a serious disease.

1) Being disappointed with lifelong management

All of the participants were disappointed with the diagnosis of diabetes, mainly because they had heard that it was a lifelong disease requiring radical lifestyle changes. The most stressful part was that they would not be able to eat the food they wanted during the rest of their life, and that they would have to exercise regularly, which they did not enjoy. As this disappointment continued, some of them became anxious and even depressed.

I was anxious when I was diagnosed because diabetes requires lifelong treatment. I had trouble deciding whether I should accept the fact and get treatment or if I should ignore it... I felt terrible. Why me? Why for the rest of my life? I was depressed, so I drank more and smoked more than before, and I

did not tell anybody for a year. (Participant 21)

2) Underestimating diabetes

At diagnosis, most participants experienced symptoms like excessive thirst or fatigue. However, after taking some medication they no longer experienced any physical symptoms. This led them to simply forget managing their disease. Most of them only took medicine and did not follow other regimens such as diet and exercise. A few of them had even discontinued medication after a couple of months. They consoled themselves by simply thinking that they could manage the disease if they set their mind to it in the future.

When I was young, I overlooked diabetes and did not recognize its severity and the importance of treatment, even though my blood sugar was very high. (Participant 3)

2. Stage 2: Struggling

The stage of struggling illustrates the conflicts resulting from a wide gap between recognition of the need for treatment and actually performing self-management.

1) Denying treatment regimen

All of the participants made strenuous efforts to follow the regimen, including diet and exercise, as they began to experience more physical symptoms and/or complications. However, they realized that the diet was unrealistic and even useless, because they could not stop the desire to eat a large amount of food, especially when their blood sugar levels were not controlled. Given that the diet was so hard to follow, they began to feel helpless some felt depressed and even suicidal., They felt the exercise regimen was unrealistic as well. They struggled for moderation in eating and exercise, but it did not come easily to them. Thus they slowly began to perceive diabetes as a horrible disease, not as a controllable disease as they had perceived it in the previous stage.

I know I should follow exactly what the doctors recommend, but in reality, it does not make any sense. It is impossible to follow... It is beyond my control, I even thought that it was better to die rather than to live like this. Whenever I went to bed, I was worried whether I could survive tomorrow. I acted like I was fine in public, but I had no meaning

in my life.(Participant 1)

2) Being defeated by social stigma

One of the barriers to following the treatment regimen was the stigma attached to diabetes. In Korea, diabetes is considered to be a disease related to bad habits. Because of this deeply ingrained stigma, they found it hard to disclose their diabetes. Hiding their condition and keeping their integrity and pride were more important than seeking support from others.

It is known that diabetes comes from an undesirable lifestyle, so it is hard to be open about it. In order to get advice and support, I had to expose the embarrassing part of myself to others. That was hard.(Participant 10)

3) Undeniable company ‘hoesik’

In Korea, there is a tradition in the workplace of dining out together, called ‘hoesik’(literally, dinner with coworkers). Hoesik is considered an extension of work, usually mandatory. In this hoesik culture, there is a ritual that when a person offers a drink, he or she should not decline it because the gesture from the other is considered to be a good favor. If they refuse it, it is considered impolite, especially when it is offered by someone senior to them. If they want to avoid being excluded from the group, they have no choice but to go along with them. Therefore, following the diabetic regimen was risky for all of the participants.

If I am forced to drink alcohol at a company hoesik, I cannot avoid it. Others would be disappointed if I say no, but my health would get worse if I drink. In these situations, I just take the drink to get along with others and to blend in.(Participant 8)

As their physical conditions were getting worse, however, they recognized that not following the regimen was more risky and they began to be trapped between physical health and social acceptance.

I think diabetes and social life is like tight-rope-walking... If you want to be a leader, you have to attend hoesik and also encourage members to drink. But if you do this, it gets hard to maintain your health. It is like walking a fine line between the two. If I keep my health as first priority, I cannot make a living and I will lose my purpose in life.(Participant 1)

4) Disappointing support

Although the participants did not want to disclose their disease, they exposed it to family members and close friends. However, they felt that others were not supportive of the management of their disease. For example, one participant was devastated when she heard her husband saying "Why are you so concerned with your diet?" At the same time, they wanted others to view them as perfectly healthy beings. That is, they themselves became a paradox: a person with a disease aiming to be perfectly healthy. As a result, they were too sensitive to accept others' attention and support, and tried to accommodate the unhelpful behavior of others, rather than trying to make themselves understood. In the end, they had to fight with diabetes all by themselves without the appropriate support of others.

3. Stage 3: Compromising

This stage illustrates how the participants overcame the many obstacles that they had failed to master in the previous stages and found their own treatment regimen that fit them best.

1) Being open about diabetes

All of the participants began to recognize that they had to open up about their disease to others, although it was a shameful confession, in order to get support and to relieve their emotional tensions.

If you have diabetes, you should not be ashamed of it or hide it. You should take action to acquire information from others and to express your feelings by being open.(Participant 17)

By accepting themselves as different from others and by opening up about their disease, the participants were able to confront others by explicitly saying that they had to follow the treatment regimen for their health. They were also able to avoid social gatherings with friends or coworkers to control their diet despite the suffering of isolation. As they became more assertive towards family members in following the regimen, the family became a real source of support.

2) Trial-and-error for a personalized regimen

As the physical symptoms worsened, the participants began to realize that they were accountable for their own health and tried to develop their own treatment regimen. First of all, they closely monitored whether the

diet and/or exercise really made their glucose level rise or fall, strictly evaluating each trial., With this active engagement in actions and feedback, through countless evaluations, they were able to establish a regimen that was suitable to their own needs. With this personalized regimen, they finally gained the confidence to control their disease.

Only I can make the right regimen for myself. An important thing to realize is that I, not a physician, am the expert on my body. Although you make endless mistakes with trial and error, you must go through the tests. For example, I drank a cup of alcohol then checked my blood sugar at home. I also checked my blood sugar when I didn't have a drink. I get to see the difference. You have to feel the change or difference directly for yourselves... Experiment with it, test it and compare the data! You can recognize 'what is right!' It results in the most rational and realistic regimen.(Participant 16)

4. Stage 4: Conciliating

This stage illustrates the willingness to end the struggle with diabetes and to conciliate it instead. This is a peaceful and harmonious stage with a new identity as 'a person with diabetes.'

1) Constructing a new self-identity

All participants in this stage accepted diabetes as their companion, although it was annoying, by devoting themselves to following their personalized regimens. Establishing their own self-management strategies that fit in the context of their own everyday lives, they were able to reconstruct a meaningful sense of self, shifting successfully to their new identity as a person with diabetes. With renewed self-identity, they were more empowered to be assertive when it came to their health. They did not struggle anymore to protect their pride, but instead, were firm when following their diabetic regimens without any embarrassment or hesitation. They also acquired a balanced attitude towards diabetes that is, not being afraid of diabetes but not being ignorant either.

You should not take diabetes lightly but you should not be afraid of it either. You should think of it as a companion, keeping a reasonable distance.(Participant 9)

2) Transforming disadvantage to opportunity

By gaining the confidence to control the disease, the participants were able to achieve a state of mental harmony. New hope and altruism were nourished as well. They were also able to advocate for health not only for their family but also for their friends. They persuaded others with diabetes to change their whole eating pattern, for example, eating lots of vegetables and brown rice instead of white rice. They also persuaded non-diabetics to eat homemade meals rather than eating out. They persuaded others to get regular health screenings whenever they had opportunities to talk about health and diabetes.

DISCUSSION

The results of the study demonstrated that the adjustment process of illness among people with type 2 diabetes in Korea was not easy but very confusing one with various trivial obstacles arising in everyday life. This study also identified 'rearranging everyday lives by accepting diabetes as a lifelong annoying companion' as a core category, implying a final phase to be successfully managing diabetes. This core category is similar to 'diabetes is my companion'[19], which was identified as a major theme in Mexican people with diabetes. It is also somewhat similar to 'disciplining a dog' suggested by Ingadottir and Halldorsdottir[13] in Iceland.

The four stages identified in the study are comparable to the phases of comprehending, struggling, evaluating, and mastering in the Netherlands[20], and the process of integrating lifestyle changes for people with type 2 diabetes in the U.S.[21]. They are also comparable to the constructs, such as 'the process of integration'[22] and 'transition' model[23,24] suggested for people with chronic illness. These similarities suggest that people with chronic illness, including diabetes, progress toward conciliation, integration, or mastering regardless of social contexts and cultures.

This study findings show psychosocial difficulties in managing diabetes. The disappointment with the disease is consistent with the work of Manderson and Kokanovic[25], which described diabetic people as worrying all the time. 'Underestimating diabetes' is similar to the irrational thinking and inaccurate risk assessment and biases[26]. It is also similar to the notion that people with diabetes were vulnerable due to the lack of symptoms and lack of perceived seriousness of diabetes[21]. 'The stage of struggle' in this study resembles 'weathering the storms' in another study of chronic illness[22].

‘Denying treatment regimen’ in this stage is comparable to the unrealistic treatment regimens which was identified as a barrier to self-management[27].

‘Constructing a new self-identity’ was important for continuing to practice their personalized treatment regimen in this study, and it is very similar to the studies[21, 24] identified self as essential concept in managing diabetes. ‘Transforming disadvantage into opportunity’ is consistent with the studies[12, 28] that described positive experiences of diabetes. It is also similar to finding meaning or purpose in people with chronic illness[22, 29].

Despite of many similarities with previous studies, however, this study further elaborated in detail on how the Korean cultural and contextual factors influenced to these negative and positive experiences. ‘Hoesik’ is such a big part of Korean interpersonal relationships, and it was identified as a major barrier to self-management. This result is somewhat different from the concept of ‘normalization’[23], which suggests that people with diabetes are not to emphasize that they are different from others. However, this study showed that, in Korea, it is necessary for people with diabetes to accept themselves as different from others. Collectivistic interpersonal relationships kept the participants from identifying themselves as different from others. Thus, differentiation rather than normalization might be encouraged for people with diabetes in a collectivistic culture, at least in the early stage of illness.

The stigma of diabetes was another major barrier, resulting in denial and negative emotions such as frustration, depression, and even suicidal thoughts. Stigmatization was found to be a barrier among African-American women[30], but not much in other ethnic groups. This difference might come from socio-cultural factors where awareness of diabetes is relatively low and social stigma is high, such as in Korea.

There are a few limitations to this study. First, this exploratory study was conducted in Korea. Thus, the applicability or usefulness of the findings related to social-cultural factors could not be expanded to the individualistic cultures. Translation of data from Korean to English would, in some instances, alter the meaning of the experiences described by the participants. Finally, there is the potential for reactivity of the participant to the interviewers as well as the analysis bias as with any qualitative study.

Suggestions for future research include intervention studies integrated with social and cultural factors when assisting people in identifying their own problems. Another important research area is exploring family dy-

namics in these contexts. Cross-cultural studies are needed to compare how much cultural factors influence self-management of people with diabetes, as they might suffer more in a collectivistic culture, where the interest of the group precedes the interest of individuals. The results of this study will guide the development and modification of culturally sensitive educational programs for diabetes. By focusing on the process of managing diabetes, this study would help to identify more sensitive strategies to employ in educational programs and nursing care. Counseling to relieve patients’ disappointment and burden must be included in interventions, especially in the initial stage. On the other hand, the positive and integrative attitude and experience that were identified in the later stage could be drawn upon as a role model for people with diabetes who have trouble accepting and managing their disease.

Social stigma toward diabetes in Korea must be recognized and eliminated on societal and group levels. Self-help group activities would be useful in supporting patients when they disclose their disease in order to achieve a valued self-identity as a person with diabetes. Trial-and-error for self-development of a personalized treatment regimen became the basis for the empowerment to perform self-management in this study. This reinforces the need for patient-centered programs developed for patients to be active in their own care.

CONCLUSION

This exploratory study has provided insight into the lives of people with diabetes in Korea, demonstrating the major problems in their everyday life as well as the process of managing their disease. This study identified many issues in each stage, including social and culturally specific aspects to self-management in a collectivistic culture. It clearly points out that education and counseling programs will not be successful in assisting patients with diabetes in establishing good self-management practices unless such programs take into account social and culturally specific issues.

The results of this study will guide the development and modification of culturally sensitive educational programs for diabetes with rich information about psychosocial adjustment in Korea. Patient narratives of diabetes and their descriptions could be used on instructing patient-centered care to improve relationships between people with diabetes and health professionals and to narrow the gap between the services provided and the needs of people with diabetes.

Suggestions for future research include intervention studies integrated with social and cultural factors when assisting people in identifying their own problems. In addition, it would be useful to conduct cross-cultural studies to compare how much cultural factors influence the adjustment of people with diabetes, as people with diabetes might suffer more in collectivistic culture where the interest of group precedes over the interest of individuals.

Acknowledgement

We thank people with diabetes who participated in the study for their contribution.

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