

Seeking new identity through the empowerment process

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ABSTRACT

Background: All health professionals are responsible for facilitating empowerment among people with diabetes. However, research suggests that health professionals do not have the knowledge and skills to help people with diabetes become empowered. As a result, many Iranian people with diabetes do not become empowered. The aim of the study was to explore and understand how empowerment occurs in Iranian people with diabetes.

Materials and Methods: Grounded theory using individual open in-depth interviews, field notes, and memos was used to collect data from 25 people with diabetes, their families, and health professionals. Strauss and Corbin's constant comparative analysis was used to analyze the data.

Findings: Empowerment is a transitional, perceptual, and continuous process. The process for people with diabetes includes threatened identity when diabetes is diagnosed, reconstructing identity, and integrating diabetes into identity to become an empowered person with diabetes. The empowerment process was influenced by a combination of knowledge, social support, values and beliefs, psychosocial issues, and the nature of diabetes.

Conclusions: Health professionals can help people with diabetes integrate diabetes into their identity and become empowered; however, becoming empowered is complicated and occurs over time.

Key words: Diabetes, empowerment, grounded theory, Iran

INTRODUCTION

Diabetes is a chronic disease and represents a unique experience for each individual who develops diabetes. It affects every aspect of an individual's life and places a significant self-care burden on the individual. In addition, people with diabetes face day-to-day challenges such as insulin injection, following special regimen, etc.^[1] Significantly, being diagnosed with diabetes threatens the person's self-identity, lifestyle, and autonomy.^[2-4] Thus, the individual needs to adapt to a diabetes management regimen.

Diabetes management requires the person to make daily decisions about nutrition, physical activity, regular intake of

medicines, and controlling stress to balance his/her lifestyle and achieve optimal metabolic control.^[5] Historically, health professionals have always tried to "control" people with diabetes by adopting a dictatorial approach: "Do what I say." Today many experts believe the individual with diabetes is responsible for managing their diabetes (diabetes self-care) with the support of the family.^[7-9] Consequently, diabetes management requires a different approach from acute disease management models. Modern diabetes management is embodied in the Chronic Disease Model, which encompasses the individual's key role in making care decisions and the need to accept responsibility for their decisions as well as their social life. Thus, the Chronic Disease Model is an empowerment model.^[10]

Health professionals are responsible for the quality of care and education they provide; however, the ultimate responsibility for diabetes care belongs to the individual.^[6] Researchers believe in understanding how empowerment process in people with diabetes can help the nurses in facilitating empowerment process in people with the disease. Thus, a study was designed to explore the empowerment process with Iranian people with diabetes.

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MATERIALS AND METHODS

A grounded theory method was used to collect the data. In the current study, the researcher used purposive sampling

to select people with diabetes who were willing to share their experiences about learning to live with the disease.

Participants included men and women with various durations of diabetes, level of education, income, and a variety of residential locations. In addition, some participants were selected from the medical staff and some were from the family of the person with diabetes. Data collection continued till saturation was reached.

Potential participants were introduced to the researchers by nurses, doctors, or peers from hospitals, rural health centers, diabetes clinics, doctors' offices, and diabetes association in Iran. Once the participants were informed about the study, one of the researchers explained the study objectives to them and obtained their informed consent to participate in the study. There were three categories of participants: people with diabetes ($n = 16$), family members ($n = 4$), and health care providers ($n = 5$).

People with diabetes

Five men and 11 women, of age range 20-73 years, with type 1 and type 2 diabetes participated. They were a heterogeneous group from different urban and rural regions of Iran, with differing levels of education. Four were single and the remaining were married.

Family members

Three women and one man (25-67 years) participated in the study. They had different levels of education. Three were wives of three persons with diabetes and one was a child. Two lived in rural area.

Health professionals

A heterogeneous group of three physicians and two nurses participated in the study, which consisted of two men and three women, aged 29-57 years. All had worked in diabetes for more than 5 years.

Data collection

Unstructured interviews were used to collect the data using open questions such as "talk about your life after being diagnosed with diabetes," and they were gradually focused on specific subjects. The interviews were tape-recorded and immediately transcribed verbatim and analyzed as original data. The duration of the interviews ranged from 15 to 50 min. In addition, television programs and documents such as conferences, seminars, and newspapers (e.g., programs and newspapers regarding Diabetes Week and World Diabetes Day) were used as appropriate data, and were analyzed by the same method as interview.

Data analysis

Data collection and data analysis occurred concurrently. Data analysis was undertaken using constant comparative analysis (Strauss and Corbin, 1998) and consisted of three stages: open coding, axial coding, and selective coding.^[38]

In open coding phase, the tape-recorded interviews were transcribed and reviewed carefully several times. Researcher reviewed the data line by line, examined the main sentences and concepts of each line or paragraph, and gave it a code. Coding was done using participants' or researcher's words. In the open coding stage, a preliminary classification was done. In addition, based on similar properties and dimensions of the codes, they were put together. Main classification of data was done through axial coding phase. Codes and initial open coding categories were compared with each other and conceptually similar codes were placed around a joint. Researcher placed the codes around a common base with focus on conditions, action and interaction, and outcomes.

Furthermore, the researcher used continuous comparison to define the relation between classes and search-underlying process in the data.

Rigor

After coding the data, the transcripts and codes were examined by the participants and the co-researchers. The researchers discussed similarities and differences in their coding and compared the categories with original transcripts, searching for data that supported or rejected the categories. The researchers continued the iterative process of categorization until a consensus was reached. Spending enough time and being involved with participants enabled the researchers to confirm the data credibility. The confirmation process was continued by three external experts to assess the audibility and establish dependability.

In the present study, in order to evaluate reliability, auditing was used. In this method, an external expert^[39] carefully reviewed the data and documents. Therefore, the whole process, from beginning to end of the study, was described in detail in order to make the external expert be able to audit in accordance with these documents.

In addition, the authors tried to provide a rich description of information for readers to evaluate the applicability of data in other fields, which would indicate transferability.^[39]

Ethical considerations

The Ethics Committee of Shahid Beheshti University of Medical Sciences granted approval to conduct the study.

The aim of the study was explained to all participants. In addition, they gave oral informed consent to participate and to be audiotaped. The participants were assured that their information would be only available to the research team. Moreover, their confidentiality would be maintained at all stages of the research and in publication of findings. In addition, participating in the study was voluntary and they could withdraw at any time they wanted.

FINDINGS

The findings showed that the empowerment process in Iranians with diabetes is a continuous developmental and psychological transition from threatened identity to integrating diabetes into their identity. During the process, individuals tried to achieve a partly normal life but felt they were caught between trying to revive their previous identity and gaining a new identity. Threatened identity was the main social problem that the people with diabetes experienced and ends through empowering process. Empowerment is a lifelong process, which involves gaining a new identity and integrating diabetes into their identity. In fact, acquiring a new identity appeared to be the main factor associated with empowerment in the present study.

The findings highlighted empowerment in three main categories:

- Threatened identity (“fear of becoming different,” “being out of control”)
- Reconstructing pre-diabetes identity (“having doubt,” “silent trust,” “accepting diabetes as reality,” “struggling with diabetes”)
- Gaining a new identity (“moving between ability and inability,” “redefining diabetes,” and “living within boundaries”).

Phase 1: Threatened identity

The threatened identity was the main social problem in people with diabetes and was due to their “being different from earlier” in all personal, social, and vocational aspects. When the participants were asked to tell the story of their life with diabetes, all of them recounted the moment they were told that they had diabetes. Years after diagnosis, they remembered every minute of that day and even their first plasma glucose level. Being diagnosed was a great shock and threatened their identity. They remembered feeling stressed and anxious, and felt they had lost control over their lives. Threatened identity as the starting point of empowerment process included the classes of “fear of being different” and “being out of control.”

Fear of being different

Fear of becoming different was an important aspect of threatened identity phase. Participants were afraid of

being labeled, having insulin injections, and diabetes complications. In the midst of diagnosis distress that ranged from several days to several years, they constantly asked “Why me?”

Participants wanted to maintain their self-identity, but diabetes reminded them that “they are not the same, they are different now.” Participants were afraid of being labeled as “a diabetic” and of social rejection as a consequence of having diabetes.

“Because society can’t accept a person with diabetes easily, at first, I was too scared of being rejected by the society... fear of getting rejected and losing my chances of marriage, I was deeply upset and cried all the time. I was thinking I became labeled now, labeled with being sick.” (A 22-year-old girl).

The fear of being different was closely linked with the concern about losing control of their lives and body.

Being out of control

Being out of control triggered fear and anxiety, and participants felt that they would be overwhelmed by diabetes forever. In situations when the nature of the disease was disturbing, the sense of losing control intensified.

“When my doctor said I had diabetes, I had a strange feeling. I said to myself diabetes is going to kill me.” (A 51-year-old female).

Threatened identity led people to the next stage of the empowerment process, which was revival of for pre-diabetes identity.

Phase 2: Reconstructing pre-diabetes identity

When people with diabetes found their identity threatened and experienced fear of being different, they used various strategies to restore their previous identity. At first, they selected doubt or silent trust, but eventually they admitted there is no escape from reality and they need to accept diabetes in their life. In fact, restoring pre-diabetes identity was a conscious and active response to the threatened identity. Focusing on diabetes led to insecurity that was “by overcoming diabetes, I’m the same person as before.”

Reconstructing pre-diabetes identity encompassed four subcategories: “having doubt,” “silent trust,” “accepting diabetes as reality,” and “struggling with diabetes.”

Having doubts

Participants described doubting the diabetes diagnosis or passively complying with health care providers’

recommendations when they were still in shock of diagnosis, as the first strategy to keep their pre-diabetes identity. Society's negative attitude to diabetes, aggressive symptoms of the disease, and visiting different doctors to find the one who would "call off the diagnosis of diabetes" were common.

"When the doctor said I have diabetes and it is a chronic and incurable disease, I went to the next one, next, and next, once again.... I hoped to find a doctor who would say the diagnosis was wrong." (A 73-year-old male).

Silent trust

In contrast to minimizing the threat or denying, some people passively accepted and trusted the diagnosis and entrusted themselves to the doctors' hands. The participants minimized the threat to their identity by accepting the diabetes and hoped for a cure from the doctors in whom they had strong faith because they regarded doctors as the holy men.

"I was very sick. My doctor said I need to follow diabetes diets and exercise as well. After that I followed his prescription step by step. You know, I trust my doctor; he is like an Imam to me. I believed him." (A 41-year-old female).

The next stage was accepting diabetes as a reality and attempting to integrate it into their lives.

Accepting diabetes as a reality

In this stage, the participants accepted diabetes and the fact that there was no cure. Accepting diabetes meant "diabetes is a disruption that I have to tolerate." Participants wanted to be the person they were before they had diabetes and often chose to isolate themselves from social activities; particularly, young people kept their diabetes a secret to avoid negative reactions of other people.

"It does not feel good when others know I have diabetes. I think if they know, their reaction towards me would change." (A 21-year-old female).

Struggling with diabetes

Participants tried to restore their pre-diabetes identity by achieving tight glycemic control. Some participants referred to combating diabetes. "You have to combat diabetes, avoid its domination over you. You have no choice, but it is too difficult" was a common reply in the interviews. Therefore, participants used a range of strategies to combat diabetes – some used positive attitudes, prayer, and trust in God, as well as learning from peers.

"When I want to go walking, I tell myself that walking helps me control my diabetes. Then I start walking... With prayer,

I try to relax myself and control my blood sugar... and I always listen to other people with diabetes to learn more about diabetes." (A 56-year-old female).

In this stage, participants' focus on combating diabetes affected their ability to live as normal as possible. Despite their coping strategies, they felt powerless to win the diabetes combat and sometimes experienced hopelessness. They said something like this "I'm going to die because I'm a diabetic." Finally, the participants understood they need to move ahead and live with a new identity as a person with diabetes.

Phase 3: Gaining a new identity

The final phase of the empowerment process in people with diabetes is gaining a new identity, which is constantly communicating with earlier stages, and includes the following classes: "moving between ability and inability," "redefining diabetes," and "living with boundaries." Through a developmental transition and a cognitive process, participants found that reviving pre-diabetes identity is not possible with diabetes; more precisely, because of the chronic and complicated nature of diabetes, their former identity is threatened. Sometimes they experience drop of blood glucose and sometimes they need change in medications. Furthermore, they would be overwhelmed by the long-term complications of diabetes and sometimes are required to use insulin in front of others. In this way, they demanded integration with identity and reconstructing a new identity.

Through gaining a new identity, those with diabetes believe in becoming different to themselves and to others. Along this way, they try to be a person looking for a new identity, instead of being a patient searching for the lost identity, and experiencing a normal life like normal people in the shadow of an identity with diabetes. In fact, in this stage he/she admitted that "I am the same person although I have become different." In other words, gaining a new identity was the phase of change in which concentration on the disease reversed to concentration on self. At this stage, they tried to embrace diabetes and enjoy having a normal life as much as possible by taking care of themselves.

This final stage of empowerment process included "moving between ability and inability," "redefining diabetes," and "living within boundaries."

Significantly, this stage reflected acceptance and integration with diabetes into the self: "I am the same person, however, I became different." Participants changed their focus from the disease to themselves as they learned to live with diabetes and enjoy living with the limitations.

Moving between ability and inability

Trying to manage diabetes was difficult because of the complex nature of the disease. Thus, participants' comments reflected constant movement between feeling of control and feeling of diabetes in control. For example, one participant compared himself to a lion, which suggested control, but his next words reflected his feeling of lack of control over his diabetes.

"Sometimes I have experienced severe hypoglycemia that led me to thinking I was going to die... Diabetes affected me too much but I controlled it like a lion... Being diabetic is like somebody who's drowning in disease, pain and suffering until death." (A 73-year-old male).

Redefining diabetes

As part of the empowerment process, participants redefined what diabetes meant to them. Most participants viewed it as a chronic, devastating, and dreadful disease that made them feel their life was out of control and reduced their quality of life. The negative view of diabetes was reinforced by their inability to control their blood glucose, disempowered peers with diabetes, and the pervasively negative public portrayals of diabetes. However, some participants felt the diagnosis of diabetes represented an opportunity for them to positively modify their lifestyle. They believed diabetes changed their lives, but the change was positive and improved the meaning of lives. For example:

"Diabetes changed my manner towards life and having important goals for living. Before that I was just a lazy boy with no clear end in my head. But, now I'm very successful as I tried to do the best with my time, love myself much more than before, and as a result, I'm happier and healthier now." (A 27-year-old male).

Living within boundaries

Moving between ability and inability and redefining diabetes was an essential part of the empowerment process, as participants began to understand how diabetes affected their body and life and that they could manage the disease. Thus, they began to accept the limitations of living with diabetes and find value in their lives. They were able to reshape their identity and take care of themselves, which meant "bringing limitations into life, and reducing the distance between diabetes and self." In this stage, participants concentrated on themselves instead of their diabetes and attempted to enjoy their lives. One participant said, "My insulin and me are not apart." She went on to describe working to integrate diabetes into her identity.

"Diabetes could not limit my life or isolate me. I go everywhere, but with my insulin package. I tell my mom

that my insulin and I are integrated friends (she smiles)." (A 21-year-old female).

DISCUSSION

The three-stage process of threatened identity, reconstructing pre-diabetes identity, and gaining a new identity does not necessarily mean that all people experience all phases in the same way and empowerment ends with an identity which is associated with diabetes. It seems that people were constantly wandering between the three stages more than belonging to a certain stage. Review of the medicine and nursing research suggests that most researchers focus on empowerment process in diabetes, considered from the point of view of effective diabetes management, achieving metabolic control and preventing diabetes complications, self-efficacy, and healthy behaviors.^[7,17,40] However, some people believe in empowerment as a process, which continues from passive acceptance to the successful control of the disease,^[42] while others describe empowerment as a continuum of disability to ability.^[21] However, the participants in the present study experienced an internal cognition process which was expressed as "finally I realized." The findings of this study considered empowerment as a process of changing identity due to the highlighted role of identity in Iranian culture, which helps the people live their life by integrating the disease with peoples' identity. A handful of studies have emphasized on integrating the identity with the disease and its positive impact on empowerment process. Kralik mention a two-step process titled extraordinary and ordinary in living with chronic illness.^[14] In this way, Cheri *et al.* describe a three-step process of empowerment, which consists of having diabetes, starting point, and a part of individual itself.^[42] In addition, Aujoulat *et al.* believe that empowering includes integration of contrasting aspects of itself with an effort to rebuild a sense of self-worth by separating themselves from disease and merging disease with themselves as a part of their being.^[43]

Moreover, similar to the results of other studies,^[44,45] the findings of the present study demonstrated that empowerment is a complex positive concept that is associated with growth and development. Contrary to the definitions that defined empowerment just as patients' active participation in treatment,^[46] or accepting responsibility for diabetes management,^[17,47] our findings indicated that although participants pointed out successful control of the disease as a sign of empowerment, to them, empowerment was not just control of diabetes and its complications. They really seek actual mastery over life as a part of empowerment, which is given as the definition of empowerment in some studies.^[15,48] However, participants were not convinced by dominance over life and having a normal life as much as possible with limitations which were caused by diabetes. In contrast, they

demanded pleasure, satisfaction, and security as well. A few articles have had a psychological and societal perspective toward the concept of empowerment. For example, the research findings of Chang *et al.* defined empowerment as having desire toward life, discussion about self-care goals, and revitalizing their sense about themselves.^[49] According to Chamberlin, endless growth positive thinking about an individual's being, and overcoming labels are indicators of empowerment.^[44] In the same way, the results of Wahlin *et al.*'s study showed that to them, empowerment is to enjoy life. In addition, positive environment promotes a sense of worth and security.^[50] On the other hand, experts believe in empowerment as ranging from mere mental sense to actual mastery over life.^[15,51] However, the results of this study showed that for people with diabetes, empowerment is a combination of reality and feeling. Dominance over life is the real part, and sense of pleasure, safety, and sense of value is the emotional part of empowerment.

Limitations of the study

This was a small study carried out in the national context of Iran. Thus, caution is needed when generalizing the findings to all Iranian people with diabetes and to other countries as well.

CONCLUSION

Health care providers may be able to facilitate the empowerment process in people with chronic illnesses, as the people face with tremendous challenges in the empowerment path, the easiest of which is educating and supporting them in different steps of empowerment process. The findings of the study can be used to design an empowerment approach in order to care Iranian people with diabetes and can provide nurses and other health care providers with a deeper understanding of how Iranian people with diabetes view their lives and their sources of strength. In addition, the study has identified different aspects for future research about diabetes empowerment, such as designing an empowerment program based on integrating diabetes into identity, effects of spirituality on empowerment, and diabetes-related stigma in Iran.

ACKNOWLEDGMENTS

The authors would like to thank Sahid Beheshti University for its financial support for the project and all participants who attended the study as well.

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How to site: Abdoli S, Ashktorab T, Ahmadi F, Parvizy S, Dunning T. Seeking new identity through the empowerment process. *Iranian Journal of Nursing and Midwifery Research* 2014;19:145-51.

Source of Support: Shahid Beheshti University of Medical Sciences, Grant No: 95, **Conflict of Interest:** Nil.