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Original Article

Exploring the strategies to overcome diabetes-related stigma in patients' family: A qualitative study

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Abstract

Introduction: Asian countries, including Iran, experience diabetes-related stigma. Since a stigma-free identity is necessary for optimal diabetes management, the necessity of efforts to reduce diabetes-related stigma has been emphasized. This study aimed to explore the strategies to overcome diabetes-related stigma at the family level in Iran.

Methods: Seventy-four volunteered people (people with diabetes, family members, non-diabetic people, and healthcare personnel) participated in a qualitative content analysis study to extract the anti-stigma strategies. Data collection was done until data saturation through unstructured in-depth face-to-face interviews, focus groups, Email, short message service (SMS), and telephone interviews. All audio-recorded and transcribed verbatim data were analyzed using the conventional content analysis approach.

Results: Participants were raised "empowering families of people with diabetes" that would be possible through "family education" and "family-group formation". Educating families about "stigmatizing behavior", "coping skills", "accepting the person with diabetes as the main responsible person for disease control", and "diabetes" is necessary to help families by creating a free-stigma atmosphere. All the training could be programmed in peer groups of families to facilitate goal achievement.

Conclusion: Some obtained strategies have been suggested for other stigmatizing conditions like tuberculosis or mental health. However, it must be noticed that every condition is specific and also each stigmatized person is unique and is affected by complex factors. So it is impossible to develop generic stigma reduction interventions for all health conditions. Most studies on stigma have considered families a part of society and have proposed general strategies for them.

Introduction

Many countries, especially Asian countries, have faced diabetes-related stigma.[1-7] Literature[8-11] delineated the experience of diabetes-related stigma in Iran. Stigma affects the quality of life and well-being and can lead to diabetes nondisclosure,[12] insulin therapy-related problems,[5,13] non-adherence to self-care,[14] and reduced marriage chance.[13] Stigma as a complex issue and its effects on social and psychological aspects[4] is a significant barrier to improving care for individuals with type 1 diabetes mellitus (T1DM).[15] People with diabetes in Iran respond to stigma like others affected persons.[12]

The necessity of efforts to reduce diabetes-related stigma has been emphasized to create a stigma-free identity.[4,6,16] Several de-stigmatizing strategies have been mentioned for other stigmatizing conditions. However, it must be noticed that every condition is specific and also each stigmatized person's experience is unique and is affected by complex factors. So it is impossible to develop generic stigma reduction interventions for all health conditions.[17] Stigma is context-based and roots in relationships.[18] Stigma is a social construct and therefore differs widely across societies.[15] Effective interventions must be designed based on cultural values and beliefs. Research papers by Doosti Irani et al[19,20] describe strategies at the individual and social levels for combating diabetes-related stigma. So, this paper aimed to explore the strategies to overcome diabetes-related stigma in patients' families in Iran.

Methods

This paper is a qualitative content analysis study as a part of an action research study designed in Iran to explore and implement a de-stigmatizing program for o diabetes-related stigma.

Sampling method

People with diabetes, family members, non-diabetic people, and healthcare personnel were recruited. All candidates were selected purposefully from volunteered eligible people and invited to participate to reach maximum variation. Inclusion criteria included people living with T1DM in Isfahan who were 18 years old or

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older, lived with T1DM for a minimum of 1 year, referred to the selected diabetes center, and were willing to share their experiences. Exclusion criteria included people with a psychiatric disorder or unable to share their experiences. The inclusion criteria for individuals without diabetes (with or without having a family member with type 1 diabetes) were willing to participate in the study. All health care providers at the diabetes center were eligible because of their experience in diabetes care.

Participants

Seventy-four people, including 44 people with T1DM (25 women, 19 men; age 19-50 years; a history of diabetes of about 2-35 years; high school education up to PhD), 12 family members (2 men, 10 women; high school education up to bachelor's degree), 15 non-diabetic people (9 women, 6 men; age 18-55 years; with elementary education up to graduation) without a relative with type 1 diabetes, and 3 healthcare personnel in the selected endocrine center (3 women with BSc to MSc degree) were recruited.

Data collection

Data collection was done through 26 sessions of unstructured in-depth face-to-face interviews lasting between 40 and 90 minutes, 10 focus groups that lasted 90-165 minutes, 97 e-mails, 11 short message service (SMS), and 14 telephone interviews to extract strategies to overcome the diabetes-related stigma. Individual interviews were the main data collection method. The focus groups were used to complete the obtained information. Finally, all participants were told if they remembered a different approach, they could give it via e-mail or SMS.

The main goal was to explore strategies to overcome diabetes-related stigma. Since participants referred to the family role and interventions in the family, we focused on it and asked detailed questions based on participants' initial responses to encourage them to describe each mentioned strategy. Then anti-stigma interventions at the family level were categorized separately and presented here.

The first author acts as an interviewer who is experienced in qualitative research as well as interviews. All interviews, focus groups, and telephones were audio-recorded and transcribed verbatim. Vague statements were checked through telephone or re-interview. The participants' identification information was removed from the transcripts. Data collection continued even after data saturation.

Data analysis

Qualitative conventional content analysis approach was followed concurrently with data collection. Open coding, creating categories, and abstraction were done.[21] Repeated listening and reading of the transcripts were done for open coding, and as many headings as possible were written down to cover all mentioned strategies. Then strategies were grouped and labeled. Finally, the groups and classes were placed in larger classes if possible. Research team members read and coded each transcript separately. Lincoln and Guba's Evaluative Criteria were used for trustworthiness. Researchers used prolonged engagement (about 12 months) for data collection and analysis. Moreover, peer debriefing (all authors discussed the data analysis process), and member checks (all extracted concepts were returned to the participants and examined) were used to enhance credibility. An inquiry audit by an independent qualitative researcher was used to enhance dependability and confirmability. Researchers tried to select different participant to enhance transferability.

Results

Findings portray an image in which a family, for the first time, teaches a person with diabetes that diabetes is a stigmatized condition and sometimes family stigmatizes him/her. In this situation, he/she deals with diabetes-related public/social stigma alone and without family support. Therefore, participants were raised interventions/strategies that express "empowering families of people with diabetes" that would be possible through "family education" and "family-group formation".

Family education

Based on the findings, families should be trained about "stigmatizing behavior", "coping skills", "accepting the person with diabetes as the main responsible person for disease control", and "diabetes". This education helps the family to provide a supportive and stigma-free atmosphere (not reinforcing stigma) and to reduce diabetes-related stigma. Although family support plays an important role in the life of every child and teenager, but sometimes the family also reinforce diabetes-related stigma. They make diabetes a major concern for patients. This is where the "family education about stigmatizing behavior" is necessary. A 24-year-old man with diabetes said:

"Families should be taught about hope and how to deal with person with diabetes. Family must look at diabetes with open eyes. They must thank God since there are some diseases such as cancer and AIDS worse than diabetes. They should not say: 'Oh you will not be ok anymore. You experience diabetes complications. You cannot get married.' They must say that life is in God's hands. Hope empowers you and decreases your problems."

Therefore, families need training about stigma and stigmatizing behaviors to avoid leaving their child who is challenged with diabetes alone. Rejection and stigmatization of the child lead to losing the family as a safe and important support. Participants' statements indicated that family' behavior usually teaches that "diabetes" is a problem that should be hidden. They teach their children that diabetes is associated with the stigma that provides shame and embarrassment. They highlight the disease and give their child a life that is every moment with fear

of disclosing diabetes. For example, in a focus group, most families said that just parents know their child's disease. Then, a 42-year-old mother said:

"At the time of diagnosis, Family's role is very important. When diabetes was diagnosed for my son, we tried to behave in a manner that he did not feel any obstacle… for example, we took him a restaurant. I wanted to tell him that the problem might not be very important ...Even his father brought insulin and injected it for him in public; … I mean, we did not hide it."

Families need to know about the impact of their behavior on children. They must avoid discrimination among children since it causes embarrassment and weaknesses. Finally, one of the participants stated that non-stigmatizing behaviors in the family also help to reduce the public stigma and empower the child for disease acceptance. A 27-year-old man with diabetes said:

"Changing a family's view can reduce stress, increase collaboration, and change neighbors, and relatives' views. Family can help a child by offering practical solutions, decreasing great compassion, showing no discrimination and distinction between the person with diabetes and other family members, raising the child's self-esteem, and encouraging the child."

While the person with diabetes is challenged with the acceptance of diabetes, the family also must move with him/her and accept their child with the disease. Diabetes rejection by the family will be an obstacle to achieving objectives. Accepting and coping with diabetes is so poor in the family that they often cry by observing the insulin injection. In this situation, the majority of people with diabetes expressed that they avoid injections in the presence of their parents. Therefore, participants mentioned "teaching coping skills to families" as a solution. 23-years old participant with diabetes said:

"Education must help families to recognize diabetes as a disease rather than as an obstacle to live."

A 28-year-old woman with diabetes said:

"It is necessary to give information ...Families are the first ones that must be informed. The family can transfer fear of the future to their child. This fear can break any child and give him/her a sense of loneliness. I never inject in front of my mom because she cries. So, when my mom cries, I can guess what the rest do."

Family education must be in a manner that they accept that self-care is the child's responsibility. Parents should not constantly limit and control her/him. In other words, "teaching families about accepting the person with diabetes as the main responsible person for disease control" is essential. A 28-year--old woman without diabetes said:

"I think it is a disease that the affected person knows what he/she should do. You should not repeatedly advise them what to do. If you do so, it seems that you put a camera above her head, and they are in control. There is not a sense of freedom. Now, if you want to take care of them, do it indirectly. Tips are said and they know them. Therefore, please do not repeat them every day."

One of the diabetes center's staff (a 50-year-old woman) said:

"A woman said: "my son tells me you need to test your blood sugar because you may have diabetes". … yes Mothers are really sensitive ... really worried. We must teach them about this matter. They must not focus on food directly and in this bad way."

Participants expressed that their family bars them from programs like camps. A 28-year-old man with diabetes said.

"Invite family ... Especially those mothers who are sympathetic and repeatedly say hey, do not do this, do not do that. They must inform."

They are calling for proper and explicit family education about "diabetes' and its control. This information can decrease families concerns and provide more support to the patients. So stigmatizing context will decrease.

One of the diabetes center staff said:

"Once, a young woman came here and said: "My aunt has a 4-yearold girl with diabetes. Yesterday, she ate a bunch of grapes. My aunt screamed why she ate grapes; her blood sugar would rise. Finally, she cried, and said that oh my god what should I do, this grape will affect my daughter's eyes and kidneys... please help my aunt. She does not have the correct information". We as a healthcare team must tell her that do not worry, she needs a grape too. You must check her blood sugar and regulate insulin. It is impossible to tell your child not to eat grapes, bananas, etc."

Family-group formation

Participants' statements show that family groups can be formed to help the family adaptation and empowerment. For example, a 51-year-old father (father of a girl with diabetes) suggested periodical family meetings to be held for the families of affected persons:

"A meeting, for example on Fridays, which all families can come can be helpful for learning from each other… Now, we are a large family (families with an affected person) that deals with diabetes. This large family must be gathered as a group and must be educated."

Another 21-year-old participant said:

"It will be good if families know each other, and learn together… my mom is very nervous, he always has stress, he calls me frequently and say how are you…if families see each other and talk, it may be helpful, especially in the time of diagnosis."

Discussion

Based on the results, some families stigmatize the person with diabetes or frighten him/her of the existence of public stigma and extend the public stigma. Therefore, the findings indicate the necessity of anti-stigma interventions for the family to "empower families of people with diabetes" through "family education" and "family-group formation".

Educating families about "stigmatizing behavior", "coping skills", "accepting the person with diabetes as the main responsible person for disease control", and "diabetes" is necessary to help families by creating a free-stigma atmosphere (not an atmosphere reinforcing stigma). These interventions will help to reduce the diabetes-related stigma.

The findings show that families should recognize the stigmatizing behaviors to avoid them, since these behaviors seem so ordinary in many cases such that they will not impose stigma on the person. In most cases, participants (who expressed that they hide their diabetes and fear to disclose it) mentioned that family members keep their diabetes secret and by doing so, they are taught that diabetes is an embarrassing and shamming condition. Since families' behaviors prevent the person with diabetes from accepting diabetes or even force them to keep diabetes a secret in the family that is the main source of support, family education about coping skills is necessary.

Families must be educated in such a way that they accept a person with diabetes as the primarily responsible one for their diabetes control, and constantly not control them and not deprive them of participating in social activities. All of this depends on the correct understanding of the true nature of diabetes. Results showed that all the training could be programmed in peer groups of families to facilitate goal achievement.

Only two documents have mentioned the importance of family-level interventions to reduce diabetes-related stigma. Dwivedi showed that a very high-quality counseling session for people with diabetes and their family members in the diabetes centers was essential to help to combat stigma ultimately. Dwivedi points out that the consultation by stressing that "diabetes is not a disease but is a metabolic disorder", and calling patients "a person with diabetes", and not a "diabetic" will be effective in reducing stigma. These consultation sessions also help to adapt to changes in their lifestyle.[4] Oskouie et al mentioned that if the parents of children with diabetes shared their experiences, the diabetes-related stigma would be decreased.[22]

In other diseases-related stigmas, consulting with family and attracting their support was mentioned as a way to overcome the stigma. For example, the Royal Tropical Institute Report states that consulting with family is a strategy to reduce the stigma of mental illness and tuberculosis.[23] Lodder states that interventions for families often try to teach the family that AIDS is not transmitted through casual contact, and an affected person is able to work.[24]

In overcoming leprosy-related stigma, family counseling and support for people with leprosy have been reported as a solution.[25] Also, participants of Lekganyane and du Plessis' study mentioned family support as a way to cope with the stigma of AIDS. They suggest that interventions should be designed to help families to support people with AIDS. They call nurses to express the psychological support, which people with HIV require. Their families can use this education.[26]

D'Souza mentions that families of children with epilepsy may consider epilepsy as something shameful and it is necessary to train families about epilepsy and its management.[27] Puhl and Latner conclude that parents are one of the sources of stigma in children with obesity and overweight.[28]

Apart from the above studies, we did not obtain studies (both in diabetes and in other areas) that referred to strategies to overcome stigma at the family level. It seems that most studies on stigma have considered families a part of society and have mentioned general strategies for them. For example, Mittan writes that stigma is taught by the family's behaviors of children with diabetes. Before we are parents and even contemplate marriage, culture has placed its values in us. Therefore, educational programs about epilepsy should address the entire community.[29] This is true even in the case of the healthcare system; the healthcare systems also have been identified in many studies as a part of society. However, in the current study, participants stressed the role of the family as the first society in which a person with diabetes often finds him/her, so the family must be addressed.

Conclusion

Overall Educating families about "stigmatizing behavior", "coping skills", "accepting the person with diabetes as the main responsible person for disease control", and "diabetes" is a new finding in this study. Although other studies have partially addressed these findings, they generally refer to consultation with family and education about the nature of disease and they do not specify details, especially for diabetes. It must be considered that Iranian families have a tight relationship with each other as well as their children and adolescents. In Iranian culture, parents have full control over the children till they become adolescence. It means that family is the first and the last society that people face. So, the family can largely affect people with type 1 diabetes. Our finding is extracted from the individual experiences of Iranian participants who live in Iran. They are fitted to this culture, so there is more hope for their effectiveness and sustainability. However, the findings can be generalized to other communities with different contexts and cultures, but they must be cautioned due to the inherent limitations of qualitative studies and action research.

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Ethical Approval

The ethical committee of Isfahan University of Medical Sciences

Study Highlights

What is current knowledge?

- Diabetes as a chronic disease is associated with stigma. Many destigmatizing strategies were addressed for stigmatized health conditions but not for diabetes and not for family members.

What is new here?

- Empowering families of people with diabetes is a way to reduce the diabetes-related stigma. Family improvement would be possible through "family education" about "stigmatizing behavior", "coping skills", "accepting the person with diabetes as the main responsible person for disease control", and "diabetes" and "family-group formation".

approved the project of inquiry. Researchers selected the participants who volunteered to participate after introducing themselves and informing them about the research objectives. Then, they obtained verbal consent for voice recording. Participants were assured that all stories would be confidential and they were free to quit whenever they wished.

Conflict of Interest

There is no conflict of interest.

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