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ORIGINAL ARTICLE

Breaking stigma within us: the role of people with type 1 diabetes in overcoming diabetes-related stigma

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Abstract This study explored the strategies to overcome type 1 diabetes-related stigma at the individual level in Iran. This paper is part of the findings of an action research study, which was designed in Iran in 2012 to plan and implement a program for overcoming diabetes-related stigma. Participants were 44 people with type 1 diabetes. Unstructured in-depth interviews, focus groups, email, short message service (SMS) and telephone interview was used to extract strategies to overcome the diabetes-related stigma. Due to the qualitative nature of the data in this phase of the action research, data were analyzed using inductive content analysis approach. Findings showed that in the viewpoint of people with diabetes, their behaviors and reactions are important factors in their resistance to diabetes-related stigma, reducing social stigma, and avoiding its harmful effects. They referred to the interconnected strategies as disease acceptance, accepting social stigma, reinforcing spirituality, enhancing self-esteem and self-confidence, effective self-care activities, and forming real and distant groups. Individual interventions are important steps to initiate overcoming diabetes-related stigma, and social activities will not be successful without them. They are much more economical and more practical than social level measures. These findings can help healthcare teams to integrate anti-stigma strategies in their routine care plan to reduce stigma as well as providing diabetes management.

Keywords Anti-stigma interventions · Diabetes type 1-related stigma · Qualitative research · Stigma management · Iran

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Introduction

Diabetes is a chronic disease with potential impact on all aspects of life [1]. The experience of living with diabetes is an ongoing dialog process with the self and the world [2], which is associated with damaged individual's identity due to destruction of different aspects of life [3]. Identity is a social and interactive product indicating one's sense of self as a unique and different from others on various aspects [4]. Others can share in identity formation through some process such as stigmatization. Stigma is an attribute that makes a person different from others to be a less desirable kind. Thus, she/he is reduced in others' minds from a whole and usual person to a tainted, discounted one [5].

Health-related stigma is based on an enduring feature of identity conferred by a health problem or health-related condition [6]. The specific nature of illness-related stigma depends on three elements: the blame on the individual for the

illness, the threat the illness represents to others, and the threat the illness represents to individual competence [7].'

Diabetes-related stigma has proposed as an important phenomenon in many countries especially in Asian countries [8–14]. Iran is not an exception. Some unpublished [15–18] and published works [19, 20] pointed to the experience of stigma in Iranian people with diabetes.

Diabetes-related stigma is particularly severe since diabetes is a chronic and life-threatening condition [11]. It has various negative effects. Diabetes-related social stigma as well as self-stigma has adverse impact on the mental health and feeling of wellness of people with diabetes [11]. Diabetes nondisclosure [21], insulin therapy-related problems [12, 22], non-adherence to self-care [23], and reduced marriage chance [22] are only some negative effects of diabetes-related stigma on quality of life and well-being of people with diabetes. It is due to the complexity of stigma and its impact on social and psychological aspects [11].

People with diabetes need a stigma-free identity for effective diabetes management. It is necessary to consider diabetes-related stigma to promote diabetes care. Several authors and organizations [11, 13, 24] have emphasized on the necessity of efforts to reduce diabetes-related stigma. Evidence has suggested that efforts to reduce the stigma can be effective. Therefore, if we reduce diabetes-related stigma, it would be possible to mitigate or prevent its negative consequences.

Despite numerous calls for stigma reduction, no study has been conducted to explore interventions to overcome type 1 diabetes (T1DM)-related stigma. Several approaches have mentioned for other stigmatizing conditions, but stigma reduction strategies at the individual level are defined differently and they have different emphasis [25]. On the other hand, these approaches are not specifically related to diabetes, and it is impossible to develop generic stigma reduction interventions for all health conditions, given the specificity of these conditions and the complexity of factors related to each person's experience of stigma [26]. Interventions that are not based on cultural values and beliefs may not be successful, and it is necessary to develop culturally sensitive interventions. This study explored the ways to overcome T1DM-related stigma at the individual level in Iran.

Methods

This paper presents the part of the findings of an action research study, which was designed in Iran in 2012 to plan and implement a program for overcoming T1DM-related stigma. Action research is a way for people engagement to share their experiences and to learn through collective reflection and analysis. It considers local cultural beliefs and is an appropriate approach to address stigma.

Researchers contacted all people with T1DM referring to the selected diabetes center in Isfahan (Iran). All candidates until data saturation were invited to participate in this stage. Since this issue was important for them, nobody refused to participate.

Candidate participants were 44 people with T1DM (25 female, 19 male; 19 to 50 years; a history of diabetes about 2 to 35 years; high school education to PhD). Participants' characteristics are shown in Table 1. Unstructured in-depth interviews (18 sessions), focus groups (4 sessions), email, short message service (97 SMS was received) and telephone interview (10 interview) was used to extract individual level strategies to overcome the T1DM-related stigma (Table 2).

Individual interviews were the main data collection method. Participants were asked to reflect on the stigmatizing attitude and behaviors, and to respond to three open questions (How people with diabetes can help to reduce stigma? How people with diabetes can help to reduce the self-stigma? How people with diabetes would be more strong against stigma?). Detailed questions were asked based on participant's initial responses to encourage them to fully describe each mentioned strategy. Interviews lasted between 40–80 min based on participants' preference. Focus groups were also used to explore

Table 1 Participants' demographic characteristics

	Variable	Number
Age (years)	19–20	1
	21–30	38
	31–40	4
	41–50	1
Diabetes duration (year)	2–5	8
	6–10	15
	11–15	10
	16–20	9
	21–25	1
	26–30	0
	31–35	1
Sex	Male	19
	Female	25
Education	Under diploma	2
	Diploma	12
	Associated degree	3
	Bachelor degree	23
	Master degree	3
	PhD	1
Marriage status	Single	27
	married	17
Employment	Student	18
	Employed	12
	unemployed	14

Table 2 Main findings

Obtaining required skills for living with diabetes	Disease acceptance
	Accepting social stigma
	Reinforcing spirituality
	Enhancing self-esteem and self-confidence
	Effective self-care activities
Forming peer group	Forming real groups
	Forming distant groups

more strategies. Five to six participants from both sex, with different educational level, and marital status were invited in focus groups. The main researcher acted as a facilitator. Focus groups were lasted 90–165 min. Finally email, SMS, and phone was used to collect the other possible strategies.

The first author acts as an interviewer. She was PhD candidate who experienced in qualitative research as well as interviewing. 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 transcripts. Data collection continued until data saturation which was happened after 28 interviews (18 individual interviews and 10 telephone interviews) and there after the 4th focus groups had not any extra information.

Due to the qualitative nature of the data in this phase of the action research, data were analyzed using conventional content analysis approach. Analysis was conducted concurrently with data collection. This approach involves three steps including open coding, creating categories, and abstraction [27]. After repeated listening, and reading the transcripts, the text was reviewed for open coding. Notes and headings were written in the margins. It was repeated several times, and as many headings as possible were written down to describes all mentioned strategies. After that, all the strategies were written on another sheet, and strategies were grouped. One heading encompassing all strategies was considered for each category. Finally, the groups and classes as possible were placed in larger classes. Research team members (six persons) were responsible for data analysis. They 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 data analysis. Moreover, peer debriefing (all authors discussed data analysis process), member checks (all extracted concepts were returned to the participants and examined) was used for enhancing credibility. Inquiry audit by an independent qualitative researcher was used for enhancing dependability and confirmability. Researchers tried to select different participant for enhancing transferability.

Ethical committee of Isfahan University of Medical Science approved the project of inquiry. Researchers selected volunteered participants after informing volunteered about research objectives. They obtained verbal consent for voice recording. Participants were assured that all stories will be confidential, and they are free to quit at any time they wish.

Results

Participants pointed to the several strategies as the starting point that can be implemented for people with diabetes (at individual level), and can help their resistance, and social and self-stigma reduction. According to the participants, without strategies at the individual level, other actions at other levels (family, organization, community) will not produce significant outcomes. Individual level strategies include "obtaining required skills for living with diabetes," and "peer group formation".

Obtaining required skills for living with diabetes

One mentioned basic strategy to deal with stigma is to create a strong and impenetrable fortress for people with T1DM. It means that they must obtain required skills for living with diabetes (including disease acceptance, accepting social stigma, reinforcing spirituality, enhancing self-esteem and self-confidence, and effective self-care activities).

Disease acceptance

Disease acceptance was mentioned as an important strategy to resist against stigma. It facilitates accepting others' view. A 27-year-old woman stated

> Diabetes is hard to accept for many diabetics. Before people accept our diabetes, we ourselves must accept it…If I accept my diabetes; I am not concerned about others' view. It will be easier for me.

Accepting social stigma

Another strategy is to use a way through which the stigmatized person consider stigma as a natural phenomenon and neglect or ignore it. They believed that changing community' attitude or complete eradication of social stigma is time-consuming and sometimes impossible. Therefore, they considered its ignoring as an appropriate strategy. One 22-year-old man said

> We must accept that stigma exists in our society. We cannot eradicate it. This is true not only for diabetes

but for everybody who is physically or mentally disabled. People pity us. Just do not be sensitive.

Reinforcing spirituality

Reinforcing spirituality was another strategy, which strengthens them through increasing their hopes and coping. God facilitates disease acceptance and helps them to tolerate and accept others' stigmatizing behaviors and attitude. One 23-year-old man said

> If you believe in god and be closer with God, you get less frustrated. At least you say that God has a good reason for my diabetes, and I must stand it.

Some participants mentioned that Allah will punish people who are stigmatizing and Allah would test stigmatized people. For example, a woman said

> I am always thankful any time whether in good or bad days, even in the worst situations. Allah wants it to be. It does not matter what others say. Allah will finally punish them.

Enhancing self-esteem and self-confidence

Participants mentioned "enhancing self-esteem and self-confidence" as another strategy, which help them resist stigma and even help to change others' attitudes. For example, a 28-year-old woman referred said

> we must learn that do not pity ourselves, and instead give ourselves self-confidence, gradually other people understand that there is no need for pity…I'm so independent, and happy that others cannot believe in my diabetes….

A 22-year-old man portrayed a beautiful image. He explained

> We should believe in our abilities…if I'm feeling defeated and disappointed, I will open a wound. Then if others pity me, it seems that others pour salt on my wound. Indeed we should not open that wound for ourselves…This is how you make a strong fortress for yourself.

Effective self-care activities

The fifth strategy was effective self-care activities to achieve the optimal diabetes management. Participants mentioned that mainly T1DM-related stigma is rooted in diabetes complications especially long-term complications. Then, it is necessary to take good care to reduce stigma in the community. For this purpose, they require the correct and enough about self-care behaviors. For example, a 27-year-old woman said

> Perhaps stigma is our fault. People fear when they see an old man/woman who is blind due to diabetes… We should try to change people's attitude through good self-care.

Another participant said

> Every day you hear that somebody goes for dialysis, or has a diabetic foot sore. Its solution depends on us. People with diabetes should take care of themselves to avoid such situations.

Forming peer groups

Most participants referred to the effectiveness of peer groups in disease acceptance, enhancing self-esteem and self-confidence, and learning self-care activities. Many participants stated that they attend in this study to see someone who has T1DM. They noted that it could eventually reduce stigma, particularly self-stigma. They suggested two ways for forming peer groups including "forming real groups" and "forming distant groups". Peer group was mentioned as a quick and highly effective way to learn the required skills for living with diabetes.

Forming real groups

Mentioned real groups were group meetings and camps. Participants believed that these groups help to resist stigma through decreased sense of loneliness, increased empathy, and disease acceptance. They tended to meet successful people with diabetes that can communicate their experiences. They believed that the introduction of those people would give them hope. In addition, they can learn diabetes self-care. A 28-year-old woman referred to group meetings and said

> Meetings with other youths with diabetes are necessary…I think if we motivated if we see successful people with diabetes, people who did not give up everything and try to reach success..

"Camp" also can be used for their interaction. A 27-year-old man said

> Camp is very good in which we can have fun as well as using our diabetic friends' experiences. People with high self-esteem could enhance others' self-esteem.

Forming distant groups

Distant communication contexts such as blogs were another tool that can contribute to link people with diabetes together. One 28-year-old woman said

> Blogs can use for the information and emotion exchange among diabetics. It helps them to see that they are not the only ones struggling with diabetes. Finally it brings self-esteem.

Another participant explained about its content:

> Its contents can include the correct definition of diabetes, its prevention, appropriate strategies for its control, practical solutions to improve attitude, and report on successful people. In addition it must provide a place for people communication.

Discussion

Findings showed that in the viewpoint of people with T1DM, their behaviors and reactions are important factors in their resistance to T1DM-related stigma, reducing social stigma and avoiding its harmful effects. They referred to the interconnected strategies including disease acceptance, accepting social stigma, reinforcing spirituality, enhancing self-esteem and self-confidence, effective self-care activities, forming real groups, and distant groups. They mentioned that this is important to initiate individual level strategies, and social activities will not be successful without them. Others similarly wrote that the most promising approach to reducing HIV, mental illness, and TB stigma might be to empower individuals to resist stigmatizing external judgments, while working to change community norms about the disease [28].

"Disease acceptance" was one strategy. Based on this strategy, if people accept and integrate diabetes as a part of their own identity, they can resist social stigma and even their behavior may help to reduce the social stigma. This finding is not clearly mentioned in other studies. Royal Tropical Institute briefly noted that one of the individual level interventions to overcome the stigma of leprosy and tuberculosis is understanding and acceptance of the disease [29]. Another study, which has not specifically addressed stigma, indicated that people who perceiving diabetes in negative terms, as a stigmatizing condition or as a domain of underperformance will experience more psychological consequences [30].

"Accepting social stigma" was another solution. This finding is consistent with Kingdon and Turkington' study. They used a cognitive behavioral approach to help people reframe stigma as a normal event. The interventions were well-received by consumers and seemed to yield more acceptance of their illness (cited in 31). In addition, another study indicated that participants avoid confrontation and passively accept or ignore stigmatizing behavior. This passive way of protecting one's self [31] was a coping strategy with the stigma not an anti-stigma intervention. However, our participants believed that people with diabetes should use this approach actively along with other measures, and healthcare workers must offer it to people with diabetes.

"Reinforcing spirituality" was another strategy. It seems natural given the significant role of God and the religious context of Iran. God is the greatest supporter in the religious and cultural context of Iran. Resorting to religion, faith, and spirituality as a coping strategy has been noted in other studies [32]. Spirituality was showed as a coping strategy in HIV-related stigma [31] and might reduce the negative effects of HIV stigma on depression [33]. However, there are differences in the findings of current and other studies. Stigma-related literature often stated that stigmatized people were punished for their sins and so got a disease (e.g., AIDS) [34]. While in current study, disease and society' reaction is considered as a divine test. The Muslim religious verses indicate that stigmatization is abominable [35] and God support the patient (steadfast) people [36]. Therefore, participants believed that God helps them to tolerate others' behavior, and God will reward them for their tolerance, and will punish stigmatizers.

"Enhancing self-esteem and self-confidence" was another strategy. It helps people to show that they are not miserable human and can live well. Most literature referred to the relationship between stigma and self-esteem in different condition such as overweight, AIDS, and mental illness. They concluded that stigma result in low self esteem, and an outcome of reducing stigma is promoted self-esteem. It seems that stigma has been considered as an independent variable that predicts self-esteem. However, based on our findings, helping individuals to promote self-esteem lead to their resistance. In addition, self-esteem is widely assumed to play a vital role in children and adolescents' adjustment to chronic illness. It is recognized both as an outcome variable—an index of mental health—and as a predictor and regulator of beneficial health behavior [37]. Therefore, given the multiple roles of self-esteem, it is better to began effective measures to promote self-esteem in people with diabetes.

"Effective self-care behavior" was another strategy. Some participants stated that they avoid self-care in public to avoid stigma, but all participants believed that effective self-care to prevent diabetes complications will reduce social stigma. This issue has been less discussed in the literature. Self-care was considered to be a trigger to empower persons, increase self-esteem and social status, and, as a consequence, reduce stigma [29, 38]. Most literature mentioned stigma as a barrier to self-care [39, 40]. However, current findings indicated that despite the social stigma, not only active participation in self-care and effective diabetes management is possible but also it is an effective way to fight stigma.

Last strategies were "forming distant and real groups" that actually helps people to gain required skills for living with diabetes and through them deal with the stigma. The effects of real groups were mentioned in other studies. For example, the effectiveness of club and social networks in reducing stigma and managing the stress of living with stigma are listed in tuberculosis [10], leprosy [25], and AIDS [31, 32]. A possible explanation is that these clubs reduce social isolation and offer an environment in which stigmatizing condition is highly visible and accepted [10]. These can help to enhance their confidence, cope with the stigma, and make an effort to eliminate the stigma encountered [25]. Despite numerous studies emphasized on the impact of peer groups particularly on stigma reduction unfortunately, the Iranian health system has not provided necessary structures and context for people with diabetes to communicate, and there are only about 18 diabetes associations for people with diabetes in Iran.

Participants also pointed to the distant groups through weblog. The literature exploring the impact of the Internet on diabetes management is limited. Websites and e-mails had a major impact on the women's ability to manage transitions because they made it easier to access information, reduced their sense of isolation, and informed them about different approaches to health services [41]. It seems that this strategy is welcomed, since diabetes type 1 affected young people.

Finally, it can be concluded that although many of the findings were mentioned sporadically in other studies, none of the previous studies have directly addressed T1DM. On the other hand, anti-stigma individual level interventions are rare, and it seems that the health system is responsible to initiate interventions at this level. People with diabetes are effective agents, which should try to obtain required skills for living with diabetes and to form peer groups. T1DM-related stigma is in the social (family, health system, and society) and individual level, but trying to overcome the stigma at the individual level and strengthening people with diabetes is an important step. These actions not only help them to resist stigma and reduce its negative effects but will also help to reduce the social stigma in the long term. The individual level interventions are much more economical and more practical than social level measures.

In this study, the active participation of people with diabetes and their recommended strategies were discussed. When the strategies are derived from individual experiences and are culturally fitted, there is more hope for their effectiveness and sustainability. The results of this study can help healthcare teams to integrate anti-stigma strategies in their routine care plan to reduce stigma. We have been looking forward to observe the effectiveness of these strategies in this ongoing action research.

Limitations of this study are due to the inherent limitations of action research and qualitative studies. Therefore, the results cannot be extended without cautious to other communities.

Conflict of interest The authors declare that have no conflict of interest.

Author contribution MD wrote the research proposal; conducted interviews; read, coded, and analyzed the transcripts; and wrote the manuscript. SA read, coded, and analyzed the transcripts and wrote the manuscript. SP and NSF discussed about data analysis and reviewed/edited the manuscript. MA reviewed/edited the manuscript. All data were accessible for all authors, and they can take responsibility for the accuracy of this report.

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