

## Living in the Shadow and Light: Iranian Youths' Responses to Diabetes-Related Stigma

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### Abstract

This study aimed to explore the responses of Iranian young people with type 1 diabetes to the diabetes-related stigma. Conventional qualitative content analysis approach guided this inquiry. Volunteered people with type 1 diabetes were recruited by purposeful sampling from one endocrine and metabolism center in Isfahan in 2012. Data gathering was done through 17 individual unstructured in-depth interviews and 3 focus groups. Data saturation was achieved through 33 participants. The data were analyzed using qualitative content analysis. All participants acknowledged stigma and responded it in different ways, which was categorized in two main categories including living in the shadow (hide and seek, missing diabetes, withdrawal) and moving toward light (diabetes disclosure, destruction of the false bubbles). The most response especially for girls was to live in the shadow of silence that can be associated with negative consequences affecting diabetes management. Moving towards the light, suggests that it is possible to help people with type-1-diabetes to achieve a normal life as much as possible. It is necessary to plan the anti-stigma programs and engage them actively to reduce stigma and mitigate or prevent its negative impacts.

**Keywords:** diabetes type 1-related stigma, qualitative research, social stigma, stigma management

### Introduction

Health-related stigma is a complex issues including both social and psychological aspects (Dwivedi, 2008), and causing indescribable suffering to stigmatized people (Van Brakel, 2006). Disability or chronic illness imposes vary degrees of pressure on the person's life, and its-related stigma impose additional burden which is more than the burden is caused by disease (Larsen & Lubkin, 2009). Health-related stigma is not a new issue and has been associated with some diseases such as mental illness, physical disabilities, cancer, tuberculosis (Dwivedi, 2008), and diabetes (Hopper, 1981) since many years ago.

Diabetes-related stigma is much lower than some diseases, and diabetes is one of the most acceptable chronic disease (Berlin et al., 2005). However, it is proposed as an important and striking

phenomenon in many countries especially in Asian countries (Dwivedi, 2008; Goenka et al., 2004) such as China (Tak-Ying Shiu et al., 2003), India (Bharti et al., 2009) in the 21st century.

Evidence showed that Iran is similar to other Asian countries and is not an exception. The secondary findings of Amini (2003), Doosti (2006), Abolhassani (2008) pointed to the experience of stigma in Iranian people with diabetes. Abdoli's study (2008) on the empowerment process of people with diabetes showed that diabetes-related stigma is one of the main barriers to empowerment (i.e., creating a new identity). Moreover, recently Abdoli et al. (in press) conducted a study to explore the nature of the type 1 diabetes (T1DM)-related stigma. They showed that a person with T1DM is stigmatized as miserable human (always sick and unable, death reminder, and intolerable burden), deprived of normal life (Prisoner of "to must", deprived of pleasures), rejected marriage candidate (a busy spouse and a high-risk pregnant).

Several studies showed that stigmatized people respond differently to stigma. Some stigmatized people's responses are isolation, disregarding, secondary gain, resistance, passing, and covering, which are depend on individual characteristics, duration and nature of condition (visible and invisible) (Larsen & Lubkin, 2009). Joachim and Acorn (2000) suggested that people with invisible conditions usually respond to stigma in different way including disclosure, protective and spontaneous, and preventive disclosure. Stress is an integral part of these responses. Henderson (2009) also noted that people with T1DM have three responses to stigma including non-disclosure, disclosure, and addressing myths, while disclosure strategies are not fixed and changes over time.

Since the stigma is a socio-cultural factor that influences the experience of chronic illness, and individuals and groups respond differently to the stigma process, being informed about how people respond to stigma and outcomes of these answers can assist nurses to have a holistic view about chronically ill people and to understand the overall chronic disease experience. It helps them to assess patient's needs considering such aspects as nutritional factors, cognitive status, stress tolerance, values, and beliefs. Nurses' knowledge about these possible answers can provide insight into the coping experiences and targets for strategic interventions. Such information is necessary for nurses to plan for improving patients' coping mechanism and quality of life (Joachim & Acorn, 2000).

Despite the this fact that it is necessary to identify responses of people with diabetes to stigma, and the significant role of these information in the planning to improve the quality of life, there is no study to address it directly. Few existing studies have examined just the role of disclosure in diabetes management (Henderson, 2009) or factors affecting the disclosure of type 2 diabetes (Kohinnor et al., 2011). Evidence also suggests that no study has been conducted specifically to explain responses of Iranian people with diabetes to stigma, while stigma is a social process that is different in various cultures. Such cultural differences affect both what is stigmatized and how stigma does manifest (Weiss et al., 2006). It is not clear how people with diabetes respond to the stigma.

### **Purpose**

This study aimed to explore responses of young people with T1DM to stigma.

### **Methods**

#### ***Design***

Conventional qualitative content analysis approach guided this inquiry. Qualitative content analysis is a research method that has been used widely in health studies in recent years, and aims to provide knowledge and understanding of the phenomena under study. Conventional content analysis is used in studies that focused on describing a phenomenon especially when there is limited existing theories and literature on it. In this way, the researchers avoid preconceived categories. Data ob-

tained directly from participants; and categories and their names flow from data inductively (Hsieh et al., 2005).

### ***Participants***

Volunteered people with T1DM who could communicate verbally were recruited by purposeful sampling from an endocrine and metabolism center in Isfahan (Iran) in 2012. Sampling continued until data saturation. Finally, 33 participants (21 female, 12 male) participated in the study. Participants aged 20-37 years; their diabetes history was 2-24 years; and their education level varied from high school to post-graduate. 13 people were married.

### ***Data collection***

Data gathering was done through individual unstructured in-depth interviews and focus groups. Each interview was began with an open question (how do you answer to other people's reactions to diabetes) and were continued based on participant's initial responses to explore their responses to T1DM-related stigma. Finally, 17 individual interviews with 10 female and 7 male participants with different demographic characteristics was done. Each interview lasted 40-80 minutes based on participants' preference.

Focus groups were also used to better achieve the objectives of the study. 5-6 participants from both sex, with different educational level, marital status and diabetes history were in each focus group. In focus groups, the researcher acted as a facilitator and encouraged participants to express their experiences and responses to stigmatizing situations. Finally, three focus groups were formed and lasted 90-165 minutes. All interviews and focus groups were audio-recorded.

### ***Data analysis***

The data were analyzed using qualitative content analysis, which was described by Elo and Kyngäs (2008). In this model, analysis is done using three steps i.e., open coding, creating categories and abstraction. For this purpose, after repeated listening, each recorded file was transcribed verbatim, and all the participants' descriptions and stories were read to achieve a general understanding. Then the text was reviewed for open coding. In this step, notes and headings were written in the texts while reading it, and as many headings as necessary were written down in the margins to describe all aspects of the content. Then, categories were grouped. One heading encompassing all codes was considered for each category. Finally, the groups and classes as possible were placed in larger classes to achieve new knowledge and understanding and full description of the content.

### ***Trustworthiness***

Researchers used prolonged engagement for data collection and data analysis. In addition, peer debriefing (all authors discussed data analysis process), member checks (vague statements adjusted using another interview or calling the participant; and extracted concepts were returned to the participants and examined) for enhancing credibility. Inquiry audit by an independent qualitative researcher was done for enhancing dependability and confirmability. Researchers tried to select different participants and describe fully study design for enhancing transferability.

### ***Ethical consideration***

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

## **Results**

Findings indicated that all participants acknowledged diabetes-related stigma and responded it in different ways. The responses was categorized in two main categories including living in the sha-

dow (hide and seek, missing diabetes, withdrawal) and moving toward light (diabetes disclosure, destruction of the false bubbles).

In fact, some participants have perceived strong diabetes-related stigma in their life and have tried to escape the stigma in the shadow of long silence. While others have considered it as a transient cloud that must not pay attention to it or must try to remove it and enjoy of life light. This group was not silent and they have seen themselves as agents who can change others' view about diabetes and people with diabetes.

### *1- Living in the shadow*

In most cases, participants have attempted to hide their disease because of fear of stigma (especially as a miserable human) from the diagnosis time. They quite deliberately and consciously have kept illness as a secret in the family using a long silence. They reported three different strategies (hide and seek, missing diabetes, and withdrawal) to keep diabetes as their life secret.

#### *1-1 Hide and Seek*

People with T1DM often have used "hide and seek" strategy in facing with stigma. They stated how have tried to show themselves normal through hiding in order to prevent diabetes-related stigma. They have sought a safe and private place for hidden insulin injection or blood glucose measurement in unsanitary places such as toilets and sometimes through unsanitary methods. One 27-year-old girl said:

"Sometimes I inject insulin in toilet or car, or under my veil (dress) to hide it. I do it so secret that no one understands."

While "hide and seek" as a game in the real world is associated with positive emotion, but it was full of distress and fear of diabetes disclosure for participants. One 28-years-old participant portrayed beautifully these worries associated with "hide and seek" and said:

"Only my own family and my husband know that I am a person with diabetes...my husband's mother or my husband's families do not know this fact. Therefore, I hide my insulin...But I always have stress that if one day they find insulin what should I say...I always thought that how long I can hide insulin."

#### *1-2 Missing diabetes*

Participants stated that sometimes it was not possible to find a private place to hide their self-care. Therefore, they deliberately miss their diabetes and its care for a while or delay it to sound normal and to escape stigma. For example, one 28-years-old girl with a 9-year history of diabetes said:

"When I go somewhere in which people do not know that I am a girl with diabetes, I do not do anything to inform them...For example, if they give me a piece of cake I eat it to avoid disclosing."

They refused insulin injection to avoid being stigmatized. It seems that they forgot their diabetes for a few hours. Another 27-years-old girl described her deliberately effort to miss diabetes:

"When I go party, I do not take my insulin. If I do so, others see it. So I either do not inject it at all or inject it when I come back home."

#### *1-3 Withdrawal*

A small number of participants, who also were afraid of pity and stigma, have tried to limit their social interactions and to avoid diabetes disclosure or escape stigmatizing situations. 26-years-old participant mentioned that she have just communicated with her close family and husband's family who know her diagnosis. She referred to withdrawal of other people who were unaware of her illness. She said:

“I do not interact with my husbands’ friends who do not know my condition. I go to their house rarely or just when I am sure that, I do not experience hypoglycemia, for example, after dinner. My husband suffers from it.”

They reported withdrawal from not only unaware people but also stigmatizing people who were informed about their diagnosis unintended and spontaneously. One 20-years-old boy referred to the withdrawal of some stigmatizing people:

“I do not show my diabetes. If I go somewhere, even if they know my diabetes I do not say anything about it. Alternatively, I will not go there at all. For example, there is a woman in my family. When she sees me says, “God will heal you”. I really hate this sentence. I hate it. Therefore, when I know that she is in party I leave there or I will go out of her reach.”

### **2 – Moving toward light**

One of the interesting responses of some participants was “moving toward the light”. They have escaped of silence and solitude. They acknowledged the existence of stigma in the community, but either they have revealed their diabetes diagnosis to deal with stigma, or have tried to change people’ view and eliminate stigma by providing an accurate picture of diabetes. This category includes “diabetes disclosure” and “destruction of false bubbles”.

#### **2-1 Diabetes disclosure**

Some participants stated that their silence and secrecy will add to the diabetes-related stigma and will diminish personal identity. They believed that the secrecy teaches others “diabetes is bad thing since everybody hides it”. Therefore, they have ignored the stigma and have considered it natural. They disclosed their condition. One 21-years-old boy said:

“I got diabetes 2 years ago. Everyone in our class knows that I have diabetes. I inject my insulin when I am with my friends...I am not shy to say that I have diabetes...others do not know what is diabetes or how is my condition. Maybe if I was in their shoes I have the same reaction. Therefore, I believe that we must consider these reactions as natural reactions and passed it.”

One 24-years-old boy said:

“Almost all know that I am a person with diabetes. I inject insulin whenever necessary. I know that people’ view is not good about diabetes, but we do not have to pay attention to it. If we try to live according to the people’ view we should kill ourselves.”

Findings showed that girls were often unwilling to reveal their condition. Only male participants reported diabetes disclosure. Girls thought that negative consequences of disclosure for girls are much more than for boys. For example, 26-years-old girl said:

“For girls, the situation is very difficult. Girls may accept to get marry with a boy with diabetes, but boys do not accept a lady with diabetes...Diabetes is easier for boys than girls...For example, my brother who has also diabetes got married easily two years ago. A girl with diabetes cannot do so. Even my own family pities me more.”

#### **2-2 Destruction of the false bubbles**

Those who have chosen to move toward the light in spite of stigma believed that T1DM-related stigma is rooted in misinformation that is like bubbles surrounding the true nature of life with diabetes. They have tried to disclose the disease and at the same time, to deal with the stigma through destruction of false bubbles. They have attempted to improve people’s knowledge. They have begun to convince them that people with diabetes (including them) are not different from others and they can enjoy a normal life by diabetes management. One 23-years-old boy said:

“We had a neighbor who was just familiar with diabetes complications. He thought that I will die soon because of its complications...I talked with him for a long time. I said diabetes do not like this...I gave him a book about diabetes. Finally, his view has changed completely.”

They believed that people with diabetes should gain a correct understanding of their disease and transfer this true picture to others. In fact, they have attempted to raise others' awareness about diabetes and changed their negative views slowly. A 21-years-old boy said:

“People with diabetes must first understand themselves and learn about their disease and transfer this information to family, friends, and those who are around them. In this way community' awareness rises slowly. It will reduce their negative views about a person with diabetes as low as possible.”

### **Discussion**

Results showed that Iranian youths with diabetes have reacted differently to stigmatizing process. They have moved from shadow of silence toward the light. “Hide and seek” was one of the most significant strategies in dealing with diabetes-related stigma. Those who chose hide and seek, have not neglected self-care behaviors even in public, but always have searched a private place for self-care behaviors to keep their diabetes as their life secret. Other studies did not explicitly mention this hide and seek game but findings of Pyatak's study (2010) showed that some participants do diabetes management increasingly private so they do not attract others' attention. Abdoli (2008) also wrote diabetes-related stigma leads to diabetes concealment. In addition, Tak-Ying Shiu et al. (2003) pointed out that some inject in unsanitary places such as toilets to avoid social stigma in Hong Kong.

In current study, missing diabetes in public was another participants' response. Indeed, they forgot diabetes for a while to be sound normal and without diabetes in public' eye. In this case, they did not perform self-care behaviors, or delay it. Tak-Ying Shiu et al. (2003) also noted that some people omitted blood glucose self-monitoring, delayed some injection every time they cannot hide self-care activities from the public to avoid social stigma. Others stated that an adolescent with diabetes may refrain from taking a necessary insulin shot while out with peers to do not look different from peers (Wilson, 2005). Paterson and Thorne (2000) wrote adolescence with diabetes deny diabetes in public to avoid feelings of difference, rejection and isolation. Several authors also referred to diabetes concealment in people with diabetes, their care providers and their failure to perform self-care behaviors in public (Goenka et al., 2004; Tak-Ying Shiu et al., 2003; Amini, 2003; Abolhasani, 2008; Abdoli, 2008; Abdoli et al., in press; Kohinor et al., 2011; Kruger & Spollett, 2009; Wysocki & Greco, 2006; Scollan-Koliopoulos et al., 2007; Sato et al., 2003)

Moreover, withdrawal was another participants' response to social stigma of diabetes. They have tried to hide their diabetes through maintaining physical distance from others and avoiding interaction with others. By keeping distant, they ensure that time will not have be spent with others, since the more time spent with others the more chance of unanticipated events that may necessitate disclosure of secret (Dodor, 2009). Other studies showed social withdrawal and avoidance of social activities as a response to diabetes-related stigma (Tak-Ying Shiu et al., 2003; Kruger & Spollett, 2009; Weiler & Crist, 2009). In addition, withdrawal in our study is similar to isolation, which was described by Goffman (Larsen & Lubkin, 2009).

Diabetes concealment was the most common characteristic of strategies in the first category i.e., living in the shadow of silence. Charmaz (1991) stated that the most important reason for youth and adults' doubt in disease disclosure is the risk of losing acceptance. She believed youth and adults feel they are rejected, stigmatized, and ignored if they disclose condition. They not only have to control their feelings about disclosure but also have to control others' responses. Non-disclosure is a strategy to protect one's identity from stigma (Henderson, 2009). In other words, participants' attempts to hide diabetes through hide and seek, missing diabetes, and withdrawal are in fact an attempt to deal with the stigma and maintain normal identity. Therefore, when people are stigmatized,

it is natural for them to attempt to hide the stigmatizing attribute and to attempt to pass as “normal”. However, hiding is not always an effective strategy to cope with stigma, and constant alertness is required to ensure that stigmatizing attribute will not expose and so can create additional anxiety and isolation (Nicolé Fick, 2005). Pyatak (2010) also argued that secrecy in diabetes management is caused tension. Non-disclosure means loss of emotional and social support (ILEP, 2011). In fact, the use of secrecy and withdrawal reduce the number of safe and reliable social networks (Larsen & Lubkin, 2009). Goffman wrote isolated individuals compensate their limited interactions and relationships with joining peer groups. Nevertheless, in the present study, participants usually have not actively sought peers. They just limited their relations to their own family in which the risk for being stigmatized was low. However, the social relationships outside of the family have potential impact on diabetes self-management in both positive and negative fashion and one aspects of self-care is appropriate social support (Wysocki & Greco, 2006).

Disease disclosure may appear to be a simple process, but decision-making on this issue is very complex for people with chronic diseases (Henderson, 2009). Some participants have tried to deal with the stigma and move towards the light by disclosing diabetes and destruction of the false image of diabetes. They have disclosed their diabetes voluntarily. In fact, they mentioned voluntarily disclosure as their strategy to deal with others’ stigmatizing behavior. In this respect, Charmaz (1991) and Cast et al. (1999) referred to disclosure as a way to prevent being stigmatized. Protective disclosure and preventive disclosure has been mentioned in other studies. But diabetes disclosure in our participants’ consciously movement is different since protective disclosure is preplanned and is limited to certain people and preventive disclosure includes both disclosure and concealment (Joachim & Acorn, 2000), While participants in this study have revealed diabetes voluntarily and for all those who interact with them.

In Kohinor et al.’ study it seemed few participants with a long history of diabetes disclosed their diabetes to people outside their families. Goffman believed that voluntary disclosure show adjustment and those who well adjusted and are comfortable with their own identity and have been dealt with stigma for a long time choose consciously to disclose their condition and do not invest their efforts to response to others’ reactions (Larsen & Lubkin, 2009). However, participants in this study did not rely only on diabetes disclosure. They have tried to correct others’ false information about diabetes and self-care behaviors and to show that normal life with diabetes is possible. In fact, they have chosen to take an active role in reducing diabetes-related stigma and move towards the light and a life free of stigma. It is a finding that less is mentioned in literature and needs special attention.

Although some studies such as Kohinor et al.’ study (2011) did not reported gender differences in diabetes disclosure, the considerable point in current study is that, there was a gender difference in responding to stigma. Often boys have chose to voluntary disclose diabetes and to destruct false bubbles of diabetes as a strategy to deal with the stigma, while almost all girls chose to live in the shadows. Bharti et al. (2009) wrote that T1DM is considered a social stigma for girls and many parents try to hide their daughter’s condition from friends and relatives. Some wrote that concerns about the inability to marry, which is an important feature of stigma in South Asia, are not as important elsewhere (Weiss et al., 2006). It seems that less girls’ decision for disclosure is rooted on stronger social stigma for them. Recent Abdoli et al.’ study (in press) showed that one of the most highlighted stigma for girls with T1DM is “rejected marriage candidate” and is often due to ability for pregnancy and the expected role of a woman in Iranian society. It seems that living in the shadows and hiding diabetes is a way to avoid being stigmatized, being different and reducing chances of marriage in a society in which there is no positive view about diabetes and people with diabetes.

### **Conclusion**

One of the most responses especially for girls was to live in the shadow of silence. It can be associated with using unsanitary methods and places for injections, delay, or failure to inject insulin in public, loss of social support, stress, and fears that are all the negative consequences of using incorrect strategies in dealing with diabetes-related stigma, which can affect on diabetes management and their quality of life. However, moving towards the light, which is used by some male participants, suggests that it is possible to help Iranian people with T1DM to achieve a normal life as much as possible through planning and implanting anti-stigma programs. It reminds us that it is necessary to engage them actively in these programs. It can reduce stigma and mitigate or prevent its negative impacts.

### **Limitations of the study**

Limitations of this study are due to the nature of qualitative research in which perceptions of low number of participants is explored. In addition, the study was carried out in Iran. Therefore, it is impossible to claim that the results of the study can be generalized to all patients with T1DM without caution.

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### **Contributions**

Study Design: MDI, SA

Data Collection and Analysis: MDI, SA, SP, NSF

Manuscript Writing: MDI, SA, SP, NSF, MA

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