

# How public perceive diabetes: A qualitative study

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## ABSTRACT

**Background:** Diabetes has a high prevalence in Iran, and its incidence is estimated to increase from 3.5 million adults in 2005 to 5.1 million by 2025. Given the high prevalence of diabetes in Iranians, it is surprising that little is known about understanding of diabetes in the general population. This study aimed to explore how people without diabetes interpreted the disease.

**Materials and Methods:** This study was conducted as a qualitative content analysis, using unstructured and in-depth interviews, with the participation of 21 individuals without diabetes (13 women and 8 men), 18–61 years old, who were selected for this purpose from the cities of Isfahan and Tehran from October 2010 to May 2011. The data were analyzed using latent content analysis method.

**Results:** The participants had different beliefs and ideas about diabetes and most of them gave a negative and black image of diabetes. Although a small number of individuals considered diabetes better than AIDS and cancer, they often took diabetes as blackness, end of romances, and a gradual death.

**Conclusion:** However, the study sample was small. The findings show that the participants' perspective on diabetes is negative and destructive. It seems shaping a new identity in the path of empowerment could be difficult within the social and cultural context. These findings can give an insight to health care providers to realize how important it is to find the public perception about diabetes. They are responsible to change or modify the public view on diabetes by introducing the disease with the help of prominent people and educating individuals in the society on all aspects of living with diabetes, not simply the symptoms and disabilities it brings along.

**Key words:** Diabetes, people without diabetes, qualitative study

## INTRODUCTION

Experience of living with a chronic disease is a progressive and continuous process consisting of an individual's complex dialogs with himself and the world.<sup>[1]</sup> Getting a chronic disease threatens the individual's self-sufficiency<sup>[2]</sup> and disturbs his family life and future perspectives.<sup>[3,4]</sup> Having a chronic illness is like a sudden crisis, an unexpected loss, and an unpredictable event that can distort an individual's image of his future, separating him from the identity he used to have<sup>[5]</sup>; weakness and rupture are the results of chronic disease. Therefore, facing the diseases, most people have neither any control over their lives nor over their bodies, a feeling that counts as a plunge and changes an individual's outlook toward life.<sup>[6]</sup> In fact, chronic diseases attack a person's body, threatening his daily life and gradually destroying his identity.<sup>[7]</sup>

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Recently, some studies have discussed diabetes as an identity problem,<sup>[8]</sup> which can be a treat to a person's individuality and security. The findings of Abdoli's research also showed that threatening one's identity exists as a fundamental problem in all stages of the process of empowerment for people with diabetes, which ends in the integration of diabetes and identity.<sup>[9]</sup> Findings of Abdoli *et al.*'s study in 2011 showed that the first response of people, on being given a diagnosis of diabetes, included fear of being perceived as different and of losing control of their body and life.<sup>[10]</sup> It seems the reaction, however, is influenced by being diagnosed as a chronic disease; it could be affected by public views about diabetes. In fact, people with diabetes often spoke of an existing dread and society's negative views about diabetes, which is often accompanied by labeling the person with diabetes; they would also interpret community's response to diabetes and people with diabetes as a kind of rejection.<sup>[11, 12]</sup> The society's reaction could be affected by public communication with various people suffering from diabetes complications. In addition, Iranian population gets most of the information about diabetes and its complications and limitations through media, such as by TV advertisements and newspapers.<sup>[9]</sup>

On the other hand, interaction is a requirement for integrating diabetes into identity, and others' negative views about

diabetes and people with diabetes can affect the process. In fact, identity as an interactive process needs to be formed through the individual's progressive interaction within his social environment. We believe that health care providers are responsible for how people in the society look at diabetes, which can influence their communication with people with diabetes. They are responsible to facilitate the empowerment process by educating and supporting the people, and attempting to modify, change, or reinforce the population's perception, based on community-based information. Given the high prevalence of diabetes in Iranians, it is surprising that little is known about understanding of diabetes in the general population. Therefore, this study was conducted with an aim to understand how people without diabetes explain and describe the disease.

## MATERIALS AND METHODS

As there was no information about the concept in this context, this study was conducted as a qualitative content analysis. In this study, 21 individuals without diabetes (13 women and 8 men) participated and 4 had a close relative with diabetes in their family. They were 18–61 years old with an education level ranging from illiterates to university graduates; eight of the subjects were residing in two large important cities of Iran, including Tehran (capital city of Iran) and reminders residing in Isfahan (cultural capital city of Iran). The participants were recruited from different areas of the cities by face-to-face interview of the researchers with the people in public places such as parks, metro, or bus stations, and others. The participants were selected for this purpose from December 2010 to May 2011, and sampling was continued till saturation.

### Data collection

Data were collected through unstructured and in-depth interviews. After initial consent was obtained from people in the public areas, those who agreed to participate in the study were invited for an interview. The interviews were conducted everywhere based on the participants' choices. The interview started with the open question of "what comes into your mind when you hear the word diabetes?" and then gradually focused on more specific items. The average duration of the interviews was 40 min and was recorded by an MP3 player.

### Data analysis

A qualitative latent content analysis was used to analyze the data in the present study. In this method, the researcher does not use previous theories or research before the analysis for developing the initial codes, but rather looks for hidden meanings in data. As the analysis proceeds, planning initial codes, revising, and refining take place.<sup>[13]</sup>

Accordingly, the main researcher studied each interview line by line thoroughly in the first 24 h, underlined the key words and sentences, labeled each with a code, and then started integration and summarizing, wherever codes with similar meanings fell under the same category. Based on the aforementioned, primary data classification was obtained. Then, the research team tried to perform the same classification process on each class that was once applied to all codes. When all the data had been coded and a compromise on levels had been reached, saturation of each class was examined.

### Rigor

Member checking was undertaken to ensure the data were trustworthy and validated the researchers' interpretation of the data. After one researcher initially coded, the data participants and co-researchers re-examined the transcripts. In addition, the credibility of the findings was established by having other researchers independently analyze the raw data and their interpretations were compared with those of the study researchers, to arrive at a preliminary category list.

### Ethical issue

Potential participants were informed that participation in the study was voluntary and they could withdraw at any time, their confidentiality would be maintained, and that no individual's identity would be disclosed in any publication arising from the study.

## RESULTS

Participants had different explanations and ideas about diabetes, and their responses suggested existence of a negative and black image of diabetes in the communities. The mentioned themes include: diabetes: blackness, end of romances, a gradual death, and better than AIDS or cancer.

### Blackness

A number of participants described diabetes as blackness that devastates a person's body and life. One of the participants explained:

*"I see diabetes as something like a mass, a mass of dust and horror; it seems like when this blackness and dust is spread through your body, you become more miserable with each part of your body that it gets to. I see diabetes very frightening."* (Female, 35 years old)

Another participant likened diabetes to "leprosy," a disease similar to a black mass that devastates and darkens the lives of people:

*"Diabetes is a black and scary mass that eats you up like leprosy. It's so dark and horrifying that I don't see a need to*

explain it to you. I can see how it has darkened my mother's entire life." (Female, 31 years old)

Another participant related its darkness to its sly nature: "I think diabetes is a black spot. A disease that associates with many other issues and diseases, you know, it's very sly, so very much." (Female, 28 years old)

### End of romances

A number of people went to the extent of interpreting diabetes as the end of relationship and romances. For those people, diabetes is a destructive factor that affects the person with diabetes familial and social relations. One of the participants talked about the movie in which diabetes caused a family founded on love to perish:

"I watched a movie about diabetes where the child in the family started to suffer from diabetes and caused the family to perish away. It made the man and woman, who were once in love, get divorced. That's when you feel like diabetes means the death of a relationship, the end of love. When seeing all that you feel like diabetes has the power to demolish a family." (Female, 42 years old)

One more participant spoke of her experience wherein diabetes put an end to a relationship with love:

"I know a girl who could not marry the love of her life. They adored each other, but the boy's family saw diabetes as gloom, trouble, and illness. They tried hard enough but could never get their families to agree. Diabetes was the only cause that took their life filled with love away." (Female, 33 years old)

### Gradual death

The destructive image of diabetes was excessively vivid, making it appear as a silent and gradual killer, as some of the people had believed that diabetes was the messenger of pain, grueling suffering, and gradual death.

"Diabetes is like a backpack on your shoulders that weighs more each passing day. It is the starting point of misery, and there's no end to it but death." (Male, 22 years old)

One more participant told us of the things that come to his mind on hearing the word "diabetes," when he equated diabetes with death:

"The first thing I think of on hearing diabetes is death. When I hear someone is suffering from diabetes, I imagine he will lose his legs, become blind, and finally die." (Male, 27 years old)

Another participant put diabetes next to a gradual death, explaining:

"Diabetes for me means a chronic disease... it means trouble... it means despair... it is a disease that kills you in time, a silent death that shortens one's lifetime and robs them of their abilities away." (Female, 37 years old)

One other participant put in plain words:

"Diabetes is a disease that wipes you out completely. It's true that they say it's a silent death or a silent disease. It slowly spreads throughout all the parts of the body, and the person finally dies." (Female, 37 years old)

### Better than AIDS and cancer

There were a few people who did not have an optimistic view of diabetes; however, they considered it to be better than suffering from AIDS and cancer. One participant said: "I think diabetes is better than other diseases like AIDS or cancer. There's a different thing about it, which you may not be cured, but will not die of it either. But God forbid if they tell you you're suffering from AIDS or cancer, that's the end of you. Well, diabetes is much better." (Male, 35 years old)

Another participant explained:

"It's a disease that you can get along with. It's not like AIDS where they think you might have moral issues." (Female, 33 years old)

Another participant claimed:

"Diabetes is not a disease for someone to hide. It's not as bad as if one has cancer, or AIDS... People don't look upon diabetes as they do upon AIDS or cancer. Diabetes is more common." (Female, 28 years old)

### DISCUSSION

The results of other studies in different societies show that negative attitude toward diabetes is an issue that has been brought up frequently in different communities as well. The results of a study on public perception of diabetes in Kenya showed 51% of the community's population had negative views on diabetes.<sup>[14]</sup> The trails of negative attitudes can be seen in another study carried out in 16 cities in Virginia, USA.<sup>[15]</sup>

In addition, although diabetes is referred to as an interpersonal matter,<sup>[16,17]</sup> which influences social interactions<sup>[16,18,19]</sup> and brings along numerous problems,<sup>[17]</sup> at times resulting in divorce, sexual problems, infertility,<sup>[20]</sup> and sometimes fear of marriage<sup>[11,21,22]</sup> or negative effects on marriage,<sup>[21,22]</sup> none of the studies put diabetes synonymous with end of romances as bold as the findings of this study. From the study participants' point of view, diabetes is a disease that steals the opportunity of a love-filled life from individuals with diabetes and causes the families to break up in many cases. High expenditure related to diabetes control and management, the sufferings undergone by the person with diabetes as well as the family members because of close family relationship in Iranian community, and a prominent belief that a person with diabetes cannot get married and

have healthy children could be considered as some special contextual factors in the community.

In comparison with people with diabetes in other studies, the participants in the present study talked about diabetes more negatively; however, there are some similar points of view. Abdoli<sup>[11]</sup> in a study conducted in Iran highlighted that people with diabetes look at diabetes as a defect point and as a dreadful disease. The negative view about diabetes was also reported in other studies. Kyngas *et al.*<sup>[23]</sup> undertook a study where people with diabetes referred to the disease as a “habit,” a “little devil,” a “nightmare,” “stress,” “prison,” “death,” and “hell.” In addition, in the present study, the participants described diabetes as a gradual and silent death. Interpreting diabetes as a silent death among people is notable, since the term “silent death” is used for diabetes in medical articles. The results of the present study as well as those of a study by Abdoli (2011)<sup>[11]</sup> concerning the interpretation about diabetes show that the disease is a silent death for people in a community just as it is for the people suffering from it. Likewise, diabetes was also considered a serious, life-threatening disease that gradually causes the people to die.<sup>[16,24]</sup> However, the participants described diabetes as being better than cancer and AIDS; in the studies by Corondo *et al.*<sup>[16]</sup> and Abdoli,<sup>[11]</sup> people considered diabetes as being worse than AIDS and cancer, which can lead to death if not properly controlled.

The findings of the present study show that there were not many positive views about diabetes. In contrast, the study of Abdoli, in 2011,<sup>[11]</sup> found some people with diabetes had more positive attitude as they imagined diabetes as a high-risk baby that needed to be cared for and nurtured and an opportunity that gave their life order and goals. The findings of the another study in Japan show that people with diabetes consider the disease a positive alteration and an opportunity to enjoy a new social network as well.<sup>[25]</sup> Lo<sup>[20]</sup> found that Australian people with diabetes have a positive self-image and take charge of their lives with diabetes by being innovative, self-caring, and making positive life changes to manage their diabetes.

### Limitations and strengths of the study

The findings provide insight into how people without diabetes understand the illness. On the other hand, the study sample was small and was carried out in one national context. Thus, as with other such qualitative studies, caution is needed in generalizing the findings to either Iran as a country or other countries around the world. We believe that it is necessary to conduct a population-based survey to confirm the finding.

## CONCLUSION

The study shows that the participants' perspective on diabetes is negative and destructive. Therefore, shaping a new identity in the path of empowerment could be difficult within the social and cultural context. These findings can help the health care providers to realize how important it is to know about people's view on diabetes and try to change the public perception by introducing the disease with the help of prominent people and educating individuals in the society on all aspects of living with diabetes, not simply the symptoms and disabilities it brings along.

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