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Original Article

Social Identity and HIV Stigma: A Phenomenological Study

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Abstract

Introduction: The purpose of the present study was to explore how HIV stigma is constructed in the social relationships between healthy people and AIDS-affected people and how the social identity of those who suffer from it is stigmatized. Moreover, given the public negative assessment of AIDS that forms stigmatized and devalued identities for AIDS-affected people and their families, this study examined the impact of HIV stigma on the successes and opportunities of AIDS-affected people.

Methods: This study employed a qualitative research method based on an empirical phenomenological approach. The data were collected using in-depth interviews and the interviewees were selected using purposive sampling. Accordingly, 15 AIDS-affected people living in Tabriz in 2017 were interviewed. The interviews were recorded, transcribed, and analyzed using Colaizzi's method.

Results: The findings of this study indicated that AIDS-affected people use five main strategies to manage HIV-related stigmas in their social relations. These strategies include concealment, denial, social isolation, informed group membership, and normalization.

Conclusion: The results revealed AIDS-affected people can continue their normal life and have relationships with healthy people by accepting the reality of their illness. However, the most frequently used strategy by AIDS-affected people to manage their social relationships is the denial of their disease when other people directly ask about it. Even in places such as barbers and hairdressing shops, dental clinics, and hospitals with the high possibility of infecting other people, AIDS-affected people are more likely to conceal their disease, contributing intentionally or unintentionally to spreading AIDS in the community.

Keywords: AIDS, Stigma, Phenomenology, Experimental phenomenology, Social identity

Introduction

Acquired Immunodeficiency Syndrome (AIDS) is the deadliest infectious disease and the fourth leading cause of death in the world (1). Iran is recognized as one of the most dangerous countries in the world in terms of Human Immunodeficiency Virus (HIV) infection (2). Besides, AIDS is one of the major problems in human societies, due to the high rates of injury, the high cost of infectious care, the creation of social problems, and the targeting of the young population of the community (3). Many people, especially the young, are at risk for the disease. One of the most important concerns for affected patients is the stigma that some people in the community are ruthlessly attaching to HIV patients making their living conditions more difficult and unbearable. Therefore, AIDS is not just a health problem but also a social issue. Being affected by AIDS naturally follows two key concepts

of social identity and stigma. The concept of social identity is defined as "the relatively stable perception of one's self concerning other individuals and groups that evolves through an individual's social relations with others in the process of socialization" (4). AIDS-affected people also acquire a spoiled social identity that is studied in sociology as a stigma. Abachi and Behravan define social stigma "as a "significant discredit" quality of one's life from the point of view of others, arguing that the result of this view is unfair behavior that stigmatizes the negative feeling or perception of the person being stigmatized when belonging to a group." (5). As Santuzzi et al. pointed out, it is very difficult for a stigmatized person to have a positive body image because they receive cues from the environment that lead them to believe they are ominous (6). Thus, a stigma forms when a person is made believe to have a trait or characteristic that implies, he or she has a devalued social identity in a social context (7). The concept of stigma is closely related to labeling theory. Labeling is a process in which personal and social characteristics are described by negative labels (8). The most important outcome of labeling is the drastic change in one's personal and social identity, including attitudes and perceptions related to embarrassment, disgrace, Shame and disgrace is related to social stigma. (9). Stigma, therefore, refers to a feature or trait that is highly defamatory (10). It should be noted that the stigmatizing power of a trait is rooted not in its essence but in social relations" (11). There are considerable differences between cultures and times in terms of what is the cause of stigmatization (12). As such, the major negative impact of stigma is not only related to its physical consequences but rather its social and psychological consequences that shape the interaction between the stigmatized person and ordinary people.

Goffman defined stigma as "Refers to a trait or attribute that is defamatory or disgraceful." (13) and is a weakness, a defect, and a discrepancy between virtual and actual identities (14). According to Goffman, stigma can be both visible and invisible (15). AIDS is also a hidden stigma because at least it does not have any apparent symptoms at initial stages. AIDS-affected people are not accepted by the community because of the stigma people attach to them (16). An important point to note here is that not all AIDS-affected people consider themselves victims. Some AIDS-affected people replace their victimized and self-blamed status with a self-awareness that results in changing their behavior in social relationships and adopting strategies to manage this situation in society (17). As a result, AIDS-affected people may apply stigma management strategies (18).

In their study, Ntoh Yuh et al. (19) show that AIDS-related stigma results into many negative emotions and behaviours directed toward HIV infected and affected people. Stigma is multidimensional in nature affect the individual, families and communities alike. In another study, Taub et al. (20) interviewed twenty-four AIDS-affected people and found that the respondents used different stigma management strategies such as deflection and normalization. Heidari et al. (21) studied the social consequences of stigma in women with AIDS. Finally, Sassani et al. (22) examined the lived experiences of AIDS patients of social stigma. In most of these studies, stigma theory reminds us that stigmatized people may be the only bad luck groups that have become accustomed to justifying their behavior, externalizing it, and facing their internal fears and insecurities. Thus, according to the stigma theory, a stigmatized person is not considered a complete human being and, according to the same perception, is exposed to various forms of discrimination against him. AIDS-affected people are present in all societies and are usually targeted by stereotypes and discriminatory attitudes and treatments, so that many of them, despite their abilities and talents, cannot function as healthy persons in different domains of their lives. Accordingly, the present study aimed to explore the strategies employed by AIDS-affected people in their daily social relationships to cope with HIV stigma. As such, the most important questions addressed in this study are as follows:

1. What strategies do AIDS-affected people use in their daily social relationships to avoid the possibility of facing discrediting behavior and reduce the stress caused by HIV stigma?
2. Does stigma affect the successes and opportunities of AIDS-affected people?
3. What are the attitudes and behaviors of healthy people toward AIDS-affected people?

Methods

This study employed a qualitative research method. Qualitative research methods are useful for demonstrating people's thoughts and attitudes toward complex social activities (23). Qualitative methods can provide tools for discovering issues that we do not deeply understand (24). Thus, this study used an experimental phenomenological approach to understand the problem under analysis. To understand the social world and its phenomenological needs, the world must be described as rooted in the objective

experiences of real people (25). One of the assumptions and principles of empirical phenomenology is to have experience as the only way to describe one's lived experiences (26). Empirical phenomenology deduces the common aspects of different lived experiences (27). The data were collected in this study through in-depth interviews. Besides, purposive sampling was used as the size of the original population was not predetermined (28). Purposive sampling has been designed to increase the understanding of individuals and groups (29). This is because the purposive sampling method is one of the most common sampling methods in which the participating groups are selected based on predefined criteria for specific research questions (30). Thus, in purposive sampling, the information of an informant is used to select cases with a particular purpose in mind (31). For this purpose, fifteen AIDS-affected people living in Tabriz in 2017 were invited to be interviewed and were asked to describe their experiences with their disease. The interview time was on average 50 to 110 minutes for each participant. The data collection process continued until data saturation (32). Data saturation occurs when patterns in the data are repeated. In other words, interviewing more would not result in new findings or patterns. Colaizzi's seven-step method was used to analyze the data. Thus, in the first step, the interviews were transcribed and then reviewed several times to come up with a general understanding of their contents. In the second step, for each of the interview transcripts, an interpretive summary was written to extract its latent meanings and themes. In the third step, the researcher talked to the participants to extract the themes. In the fourth step, the transcribed interviews were reviewed to gain a general sense of the transcript and to find the essential elements. In the fifth step, the basic relationships between the themes and the essential elements were understood and organized descriptions were extracted. In the sixth step, the transcripts were summarized to find out the key data from the themes extracted from the transcripts. Qualitative categories, initial themes, and final themes that were more harmonious were organized, and the core concept of the categories was extracted. Finally, in the seventh step, the important statements directly related to AIDS were extracted in the form of rich comprehensive description. (The details of the interviewees are given in Table 1).

Results

The present study identified five main strategies used by AIDS-affected people in their social relationships and daily lives. According to Figure 1, these strategies are detailed as follows:

1. **Concealment:** AIDS-affected people are exposed to considerable social pressure as they are afraid that their true identity is revealed every moment. Therefore, to create and maintain a constant image of themselves and avoid being differentiated from other people, they are constantly playing a role to conceal their disease. For instance, Participant 13 stated, "*I got married for three years and was not aware of my illness. Otherwise, I would never get married. Only my older brother knew I had HIV. I don't talk about my illness. I usually say I have back pain*". Another participant described his experience of HIV as follows, "*Only my mother and my old brother know about my illness, and I hide it from the rest of my family members and all my friends. If my family members and relatives knew about my illness, they would reveal it publicly and it would stand out a mile, which would be a great disgrace*" (Participant 3).

Table 1. The participants' demographic data

Code	Gender	Age (year)	Education	Marital status	Occupation	HIV transmission	HIV infection period
1	Male	45	Illiterate	Married	Unemployed	Intravenous drug abuse	3
2	Male	32	Elementary school	Single	Baker	Intravenous drug abuse	2
3	Male	23	Illiterate	Single	Self-employed	Intravenous drug abuse	2
4	Male	52	Illiterate	Single	Self-employed	Sexual relation	1
5	Male	42	High school	Single	Unemployed	Intravenous drug abuse	2
6	Male	49	Elementary school	Single	Self-employed	Intravenous drug abuse	2
7	Male	32	Elementary school	Single	Self-employed	Intravenous drug abuse	2
8	Male	40	High school	Married	Self-employed	Intravenous drug abuse	5
9	Female	32	High School diploma	Married	Unemployed	Sexual relation with the husband	5
10	Female	44	Middle school	Divorced	Housewife	Sexual relation with the husband	3
11	Female	28	High School diploma	Married	Housewife	Sexual relation	6
12	Female	36	Illiterate	Single	Unemployed	Intravenous drug abuse	5
13	Male	42	High School diploma	Single	Unemployed	Intravenous drug abuse	3
14	Male	33	Associate's degree	Married	Worker	Intravenous drug abuse	2
15	Female	33	High School diploma	Single	Unemployed	Sexual relation	5

2. Denial: Revealing the disease will cause AIDS-affected people to be defamed and stigmatized. These people try to show only one aspect of their identity that is acceptable for other people. When they are asked about their disease, they will deny it, except for a few people who are not afraid of revealing their disease. Even in places such as barbers and hairdressing shops, dental clinics, and hospitals with the high possibility of infecting other people, AIDS-affected people are more likely to conceal their disease. According to Participant 2, "*It would be very terrible to reveal the disease. If I tell someone that I have HIV, they will treat me differently and reject me. I will only tell a person if I am going to marry her*". Participant 5 narrated his experience in this way, "*Once I went to the emergency ward when I told the nurse that I had AIDS, all the doctors and nurses left there and I had to get out of the emergency ward with embarrassment. Now, if I go to a hairdresser or a dentist, I won't tell them about my disease*".

3. Social isolation: Places and occasions where there are a number healthy people are always a source of stress and anxiety for AIDS-affected people. That is why a majority of such people resort to mystification most of the time. Accordingly, they limit all their contacts and social relationships to the necessary cases and avoid unnecessary contacts and relations. In general, three groups of people are aware of their disease: Some members of the family, the people who have the disease themselves, and the people who consciously interact with affected people. Accordingly, Participant 5 stated, "*I have cut off relationships with my family members and relatives, and I have no contact with them. I only interact with some people here* [the clinic]". Similarly, Participant 7 stated, "*I live alone and have almost no contact with anyone outside this clinic. I don't feel like having any relationship with anyone*".

4. Informed group membership: People close to a stigmatized person can be called the informed group; those who show empathy with his/her stigma. That is, they are ordinary people but whose special position has made them aware of the secret of the stigmatized person's life without mediation and they sympathize with him/her. As a case in point, Participant 1 stated, "*Here we all feel at home. We can open our hearts to other people and have no fear of each other. Doctors don't run away from us. But when you are out of here you have to hide your identity*'. Similarly, Participant 10 stated, "*This clinic is the only place where everyone feels comfortable with others. It is easier to tolerate illness when one finds a person who has the same disease. I can say things I can't say to my sister to the doctors and counselors in the center*".

5. Normalization: All the efforts and strategies used by people stigmatized with AIDS aim at preventing differentiation from other people. They understand well that identity is one of the key criteria for distribution and the allocation of amenities and opportunities. Having a distinct identity as an infected person means losing life opportunities and being exposed to discrimination. Normalization is actually a reaction of people with HIV shown to others who have rejected them. Participant 12 described her experience as follows, "*I did not know much about the disease before. I was able to get some useful information about it in some books and brochures that were available in the center. I found out that the disease was not as dangerous as they say*". Participant 15 said, "*When my family became aware of my illness, they hurt me a lot. Everyone hates us. They want to reject and hurt us. Even our family members and relatives*".

Figure 1. Five strategies used by AIDS-affected people

Discussion

As it was stated earlier, one of the objectives of the present study was to find out the strategies used by AIDS-affected people in their daily social relationships to avoid the possibility of discrediting behavior and reducing the stress caused by HIV stigma. The results of this study

indicated that the most important strategies frequently used by AIDS-affected people to manage this stigma in their social relationships and daily life are denial and concealment. Based on concealment strategy, to create and maintain a constant image of themselves and avoid being differentiated from other people, they are constantly playing a role to conceal their disease. Moreover, revealing HIV infection will cause affected people to be defamed and stigmatized. Hence, based on denial strategy, these people try to show only one aspect of their identity that is acceptable for other people. Social isolation as another strategy used by AIDS-affected people means they limit all their contacts and social relationships to the necessary cases and avoid unnecessary contacts and relations. As another strategy, the membership in informed groups is essential for people stigmatized with AIDS. An informed group includes people who show sympathy for affected people to have a role in tolerating their stigma. The last strategy used by the participants was normalization. Accordingly, AIDS-affected people try to avoid differentiation from other people. These people try to show that they have no shortcomings compared to healthy people and can continue their lives like others. In line with the present study, Ahmadnia et al. (33) showed that AIDS-related stigma causes physical problems, social isolation, fear of losing one's job, and loss of family support. Similarly, Sassani et al. (22) showed AIDS patients experience a wide range of problems due to AIDS stigma following their awareness of their disease. Likewise, Behravan et al. (34) showed that HIV stigma originates from stereotyped beliefs and perceptions. Furthermore, Sassani et al. (22) found that concern about the HIV stigma and its concealment from others can negatively affect the family structure and force the patient to resort to social isolation. Finally, Babapur & Bahavarnia (35) found that as AIDS is associated with stigmatizing the patient, it can severely affect the patient's economic and social status.

Conclusion

The results of this study showed the most frequent strategy used by people with AIDS to manage their social relations was denial as the disclosure of the disease causes these people to be defamed and stigmatized, represented as a type of deviant behavior. Consequently, other people may perceive AIDS-affected people as disabled and dangerous. These people try to show only one aspect of their identity that is acceptable for other people. When they are asked about their disease, they will deny it, except for a few people to whom they are not afraid of revealing their disease.

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Conflict of Interest

There was no conflict of interest in this study. This study was funded by Payame Noor University.

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