

Perception of Patients With HIV/AIDS From Stigma and Discrimination

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Background: Stigma and discrimination among patients with HIV/AIDS cause various problems for the patients and their health systems.

Objectives: The purpose of this study was to explain the perceived experiences of the patients from stigma and discrimination and their roles on health-seeking services among patients.

Patients and Methods: This was a qualitative research using content analysis approach and semi-structured interviews, conducted on patients living with HIV/AIDS, during 2013 - 2014 in Iran. Sampling started purposefully and continued in a snowball.

Results: The experiences of patients with HIV/AIDS from stigma and discrimination led to exploring three main themes and nine subthemes. The main themes were multidimensional stigma, rejection, and insult and discrimination in receiving health services.

Conclusions: Stigma and discrimination play an important role in patients' lives and hinder them from accessing the treatment. The patients' responses to this event by secrecy strategy can be an important factor in the disease prevalence.

Keywords: Discrimination; HIV; Qualitative Research

1. Background

AIDS is regarded as one of the greatest human challenges and risk factors for health (1). Based on the facts and figures issued by World Health Organization (WHO) and Joint United Nations Program on HIV/AIDS, of 35.3 million people living with HIV/AIDS, about six million live in Asia (2). According to the latest figures issued by Iran Ministry of Health, 26120 people have been diagnosed as HIV/AIDS patients (3).

The first patients with AIDS in America were homosexual young men. It is believed worldwide that HIV is mainly transmitted through sexual intercourse. AIDS also occurs mostly to people who participate in unusual sexual activities (4, 5). HIV infection is not socially acceptable in most countries and women living with HIV/AIDS are labeled as adultery (6, 7). These people are stigmatized and pushed out of the community. Stigmatization from the disease deeply degrades the person's personality from a whole to an ordinary and finally to a stigmatized human being (8). Therefore, this person loses social status and gets labels (9). Stigma is created within the society and attached to cultural, social, spatial and historical factors (10, 11). Although it is important to realize where and how stigma has formed in special cultural and political statuses, cultural differences and discrimination should be identified since socio-cultural beliefs, values and morals have structured in cultural backgrounds, which form stigma and discrimination (12).

Stigma and discrimination associated with HIV/AIDS are viewed as one of the greatest challenges mentioned for HIV infection (13). HIV-infected people are considered socially unusual. They are unpleasantly different from the public and threatening to the public (6, 12, 14).

Health-related stigma is a social process which appears as isolation, rejection, blame or devaluation (11). It occurs when the person is treated unequally and unfairly (6). Stigma and discrimination are world events which seriously affect the lives of people with HIV. HIV prevention (15), access to treatment and care (16), disclosure (17), seeking support (18), social interaction (19), identity (18), and people living with HIV/AIDS-infected individuals and their human rights (16) are all influenced by the stigma and discrimination caused by HIV/AIDS. The negative consequences connected to HIV stigma may force the infected people to delay or refuse treatment or hide their disease from others. The fear from stigma causes denial, secrecy, depression and shame. The disclosure of HIV status faces the person with the feelings of shame and self-suspicion (19). Therefore, HIV-infected people who fear from the disclosure of their status because of stigma and discrimination are willing to hide their status. They think disclosing their status may not only create a complicated and stressful situation, but also causes the person to lose family support and health care provision (19, 20). Find-

ings from a study conducted on HIV-positive people in South Africa indicated that 57% of the sample reported their status secretly, 73% had the feeling of guilt due to their positive status, and 43% had the feeling of shame (4). In a study in Botswana, 94% of patients with AIDS kept their status as a secret in the community, 69% hid the situation from the family, and 12% were not satisfied to disclose their situation at all (21). Secrecy and disease denial due to HIV/AIDS stigma may lead to the continuity of risky sexual behaviors (22). The results of some studies indicated that fear can influence the access to treatment and care services and it has been seen as a barrier to help seeking (23, 24). They state that their reluctance to AIDS services is a strategy for protection of the patient and the family from stigma and social isolation (23, 25).

HIV/AIDS stigma and discrimination have a crucial impact on the life of people living with HIV/AIDS and can be an important barrier for voluntary test and consultation (5, 26). In a study on 482 males who had sexual intercourse with males, it was found that 82% of the participants never preferred to do HIV tests. The feeling of shame, fear and embarrassment were the barriers for reluctance to health care seeking of risky people and their stigma (25).

In Iran, HIV/AIDS is regarded not only as a medical but also a social problem. This can delay the treatment and cause a lot of troubles for patients and their families. Reduction of stigma and discrimination has been emphasized in the health system as an emergency preference because of the increase of AIDS in the Iranian population and its opposition with support, treatment and prevention. The importance and the impact of stigma and discrimination related to the disease in Iranian culture on one hand and the impact of cultural differences on patients' health-seeking attitudes and support services given by the health care system on the other hand composed the framework of this qualitative study. The interrelatedness of stigma and discrimination with the socio-cultural context led the researchers to outline this study.

2. Objectives

The aim of the study was to explain the perceived experiences of patients from stigma and discrimination and their roles on health-seeking services among patients during 2013 - 2014 in Iran.

3. Patients and Methods

The present study was a qualitative research using conventional content analysis. All qualitative studies consider a whole view of human phenomenon; so, this can be one of the most appropriate methods for studying people's experiences as a social phenomenon. Qualitative conventional content analysis is a method that can clarify the concealed patterns from the inside of data content (27).

In this study, the criteria focused on the participants' ability to speak and understand Farsi, have a good physical, mental and cognitive condition, and in-

tend to take part in the study. The domain of the study included the Clinics of Education Hospital and AIDS Research Center affiliated to Tehran University of Medical Sciences. Sampling started purposefully and continued in a snowball. Thereafter, to make the concepts and categories more abstract, we applied theoretical sampling with inclusion of the patients' families and health professionals. All the participants were highly satisfied with participation when the aim of the study was described to them. For collecting the data, deep interviews and semi-structured interviews in a face-to-face manner were conducted. The interviews started with an open-ended question, like: "What were your challenges in your social interactions with others?" Afterwards, considering the participant's answer, the researcher formed probing questions to be asked. All the interviews were performed in Farsi by the first writer. Each interview lasted 45 - 90 minutes. The setting for each interview was the participant's choice. Finally, 18 personal interviews with 13 patients, three family members and two health professionals were completed (Table 1). Data collection continued till data saturation. At the data saturation point, no new data could be obtained by the interviews (28). With the participant's agreement, the interview was recorded on a tape. For data analysis, the following eight steps were used: preparing the data; determining on the conceptual units; coding the units; coding the whole text and matching the codes to the text; developing the generated codes and categories based on similarities, revising categories and re-comparing with the data for solidity of the codes; creating themes and comparing the categories and reporting the findings (27). MAXQDA 2007 software was used for data analysis (Table 2).

Lincoln and Guba's 4-item criterion was used for assessing the accuracy of this study. Prolonged engagement and member check were used for creditability. To assure the researcher's perception from the data, a brief version of the participants' interviews were returned to the participants. Peer check was applied for confirmability of the data. In this way, the whole coded data and categories were reviewed by supervisors and peer advisors. The audit trail was applied for dependability of the data. In this study, the researcher kept the original data, categories and subthemes till the end of the research process. In this study, sampling was accomplished with the highest variance in age, gender, level of education, and the duration of infection. This can help the transferability and stability of the data (29).

For this study, a legal permit was received from the Tarbiat Modares University Research Ethical Committee with the number D- 52/3535. In addition, written agreements were taken from the participants after full description of the research aim, data collection method, data record, safety and comfort at the time of interview, their right to leave the program, and keeping their names and the data as a secret.

Table 1. Demographic Features of Participant

Characteristic of Participants	Values
Gender	
Male	9
Female	4
Age	Mean = 26.15 (min: 17-max: 52)
Marital Status	
Married	4
Single	8
Widowed	
Occupation	
Housewife	2
Unemployed	5
Businessman	4
Employee	1
Faculty member	1
Education	
Elementary	4
High school diploma	7
Bachelor	1
Master	1
Ph.D.	1
Infection duration	5 months to 12 years
Characteristic Theoretical Sampling	
Family Member	
Mother: 42 years old; high school diploma; house wife	
Father: 46 years old; bachelor; military staff	
Father : 48 years old; high school ; businessman	
Health professional	
Female: infectious disease specialist	
Male: bachelor; bachelor of health	

4. Results

Interviews with 13 patients, three family members and two health professionals helped us to access the complete information, repetition and saturation of data. From the researched data, after removing the overlapping items, 224 codes were obtained. The main extracted concepts in this study involved three basic themes and nine subthemes. The main themes were multidimensional stigma, rejection, and discrimination and insults in health services (Table 2).

4.1. Multidimensional Stigma

The participants mentioned many painful experiences resulted from being labeled as HIV/AIDS-positive patients. This category included such subthemes as social stigma, self-stigma and treatment system stigma.

4.1.1. Social Stigma

The participants claimed that social stigma caused them to be judged wrongly in their social relations. They felt the insulting and humiliating looks by the society. The female patients felt it much more. "People as well as health professionals look at us in an unusual manner. I tried a lot to ignore their behavior and looks. This problem annoyed me so much. In spite of all these misbehaviors, I attempted very hard to bear a healthy child by receiving pregnancy health care on time" (a 24-year-old woman).

Labeling as prostitutes and sexual stigma is important and agonizing for the participants. They understood that most of the people in the society think that AIDS originates from sexual deviances and matches immorality. "The society regards HIV-positive women as prostitutes. Being seen in hospital by an acquaintance or a relative is really painful since they think of me as a street woman who betrays her husband. I gave up the treatment process for this reason" (a 52-year-old woman).

Table 2. The Extraction Process of HIV/AIDS Patients' Multidimensional Stigma

Meaning Unit	Code	Sub-theme	Theme
People of the society degrade you when they find out you are an HIV-positive. As they understand your status, they tell you indirectly that you are an immoral person.	Negative social view of community on patients with HIV/AIDS	Social stigma	
When they told me about my HIV-positive status, they labeled "high-risk HIV-positive" on my bed. I asked about the label. They told "it is a drug abuse label"	Marginalized patient in the hospital	Health system stigma	
In some cases, I prefer not to disclose my positive HIV status when I am in a group. My problem becomes all family's problem. My problem may degrade my family reputation. Even this can affect their job conditions. My brothers have the best social positions. I do not want to devaluate their social statuses.	Belief on family members' social labels	Self-stigma	Multidimensional stigma

Table 3. The Subthemes Associated With the HIV/AIDS Patients' Experiences From Stigma, Discrimination and Rejection

Theme	Subtheme
Multidimensional stigma	Social stigma
	Self-stigma
	Health system stigma
Rejection	Self-isolation
	Family and relatives' rejection
	Friend and community rejection
Discrimination and insult in receiving health service	Discrimination in receiving services
	Insult of health system staff
	Ignorance in giving services

4.1.2. Self-Stigma

Participants reported the feelings of shame and embarrassment because of HIV/AIDS. To be away from stigma, they put mask on their faces when referring to treatment centers. "When I decided to follow treatment, I wore big sunglasses, since I felt shameful of being cured in an AIDS center" (a 32-year-old woman).

4.1.3. Health Professionals

Patients' experiences from stigma indicated that some physicians and health professionals labeled positive patients with HIV with stigma and discrimination. They pushed the patients away from themselves and deprived them from treatment services. "Some of the physicians treated us impolitely. As they knew about our infection, they refused to visit us. The lab professionals misbehaved us" (a 24-year-old woman).

4.2. Rejection

The participants claimed that as they were identified as patients with HIV/AIDS in the community, they faced isolation from family members, relatives and friends, and even social separation, loneliness, hopelessness, social rejection and home-leave. The rejection category had the subthemes as self-isolation, family and relative rejection, and friend and community rejection.

4.2.1. Self-Isolation

The participants reduced and cut their social relations and kept away from the community. They ran away from stigma and concealed their illness. "After finding out my HIV/AIDS infection, I cut my friends not to let them know about my condition and have wrong judgment about me. I like to receive services from AIDS patients' club, but I am afraid of being known by students or colleagues; so, I do not take part in club programs" (a 32-year-old man).

4.2.2. Family and Relative Rejection

The participants' experiences suggested the family's

unwillingness in having relations with them. When people around knew about the patients' HIV infection, they forced the patients to leave the house and let them alone.

"My father is a physician. When he got informed of my positive HIV status, he forced me to leave the house and did not let me live with the family again. He explained that I was a threatening being for the family members, especially for my sisters. This kind of behavior led me to depression and caused me to delay my treatment" (a 30-year-old man).

4.2.3. Friends and Community Rejection

The participants mentioned friends and community awareness as one of the most humiliating experiences. "I was pushed away by the community since I was five years old. My classmates humiliated and mistreated me. My chair was taken away from others. None of my classmates were allowed to get in touch or even have a talk with me. The teacher would punish them" (a 17-year-old man).

4.3. Discrimination and Insult in Receiving Services

Almost all the participants encountered challenges while receiving health and medical services. Most of the patients mentioned such problems as discriminatory behaviors offered by physicians, health professionals' unwillingness in giving services to them, lack of cooperation in acceptance of patients with HIV in hospitals. The "discrimination and insult in receiving services" category had subthemes as: "discrimination in giving services", "insult and humiliation by health professionals", and "ignorance in giving services".

4.3.1. Discrimination in Receiving Services

Most of the participants mentioned the experience of discrimination in receiving temporary and clinical services.

"One month ago, the doctor ordered to hospitalize me in the Psychiatric Ward, but they did not take the actions due to my positive HIV status" (a 17-year-old man).

"One day, I visited a gynecologist for my internal infec-

tion. As she found out about my disease, she did not examine me and left for a reason. I went to another one. This time I did not say anything about my disease. She prescribed some medications. I did not dare to ask about the contradictory side effects of HIV medications with the newly given ones" (a 32-year-old woman).

4.3.2. Insult and Humiliation by Health Professionals

Most of the participants experienced receiving the services along with insult, humiliation, devaluation, mistreatment and wrong pre-judgment.

"I referred to a dentist for my tooth pain. He refused to provide any services to me. In the presence of other patients, he tore out my record file and put it in the trash" (a 32-year-old woman).

4.3.3. Ignorance in Giving Services

The participants experienced lack of attention in care and treatment needs and long-time waiting. "After my cesarean section in hospital, they put the label "positive HIV" on my bed. No one came to check me for some time. I felt my rights are ignored as a human" (a 24-year-old woman).

5. Discussion

After passing of three decades from HIV/AIDS epidemic, HIV stigma is still the main issue for HIV-infected patients (30). Although United Nation (UN) AIDS emphasized on stigma reduction programs for prevention and control of HIV/AIDS in public health areas, rare studies have been conducted in this field (31).

The purpose of this study was to clarify the HIV/AIDS patients' perception and experiences from discrimination and its role on health service reception. The ideas obtained from this research involved three main themes and nine subthemes. The main themes were multilateral stigma, rejection, and insult and discrimination in receiving services.

Lekganyane et al. (32) believed that stigma inevitably led to discrimination. It started from a nonsense cycle through which people talked about the fear of their disease and infection disclosure. Gaudine et al. (8) described four themes about stigma: separation from others, the experience of rejection, anger of being viewed as a social patient, and disease concealment. These stigma themes included three important aspects, as shame and shyness, different behaviors, and stigma due to the fear of transmission and recall. Deacon et al. (33) identified four kinds of stigma including discrimination, expected stigma, self-stigma, and secondary stigma. Stigma is often multi-dimensional (33). Liamputtong et al. (34) described three kinds of stigma associated with AIDS: self-stigma, perceived stigma and enacted stigma.

AIDS is a health and medical phenomenon with broad economic, cultural and social aspects. Its stigma targets the social status of infected people. An HIV/AIDS-infected

person lives a life full of fear, pain, hopelessness and indecision. He/she also has a disappointing image of the disease and near-death image. In spite of all those mentioned, he/she receives discrimination, devaluation, rejection and preconception from the community. In this study, however, stigma was associated with cultural backgrounds. This means that, in addition to the patient, his/her family is influenced by the community negative attitudes. This social reaction results from the idea that HIV/AIDS-infected people have got infected as a result of immoral sexual behaviors. As homosexual behaviors contradict Islamic beliefs, they are not confirmed by our society. Therefore, this can intensify the complexity of HIV/AIDS stigma in the community. Since homosexual behaviors oppose Islamic socio-cultural rules, they have a religiously stigma base which creates assertive judgments and thus, they are not socially accepted.

VanLandingham et al. (2005) claimed that there were different reactions toward HIV/AIDS-infected people and their families (35). Their reactions were more positive compared to the past. Stigma alters during the time. The past stigma may not be the today stigma. It was found that Thai people have got more positive attitudes toward HIV/AIDS-infected females (34, 35).

We found out that by taking cultural backgrounds into account, women are exposed to more stigmas. Women living with HIV are blamed of sexual deviances and adultery. Several studies have implied that women have been more vulnerable to stigma, especially when HIV/AIDS is mentioned as a transmittable sexual disease (14, 35). HIV/AIDS is under negative judgement due to immoral behaviors of prostitutes. Stigma may appear because of sexual misuses or adultery. It may cause rejection and degradation (9).

Discrimination in rendering the services to patients with HIV/AIDS is one of the critical outcomes of stigma. This can negatively affect care and treatment fields and act as a major barrier for infected patients to receive services. Discrimination itself has many effects on the society. It cannot weaken the HIV stigma. It can cause other problems. Nondisclosure of HIV/AIDS and concealment of HIV/AIDS is a strategy used in response to this discrimination (36). Concealment of the disease from health professionals may lead to a rise in the number of infected people and the disease prevalence. The bad looks of the community to patients with HIV have caused the patients not to introduce themselves to health professionals and physicians while referring to treatment centers. They have found out that they will face rejection or discrimination while receiving services if their disease is disclosed. Discrimination means to distinguish between HIV-positive people and other patients. Not tracing the treatment process by patients is the result of discrimination and rejection. This can create a cycle of health and social issues.

Participants of the study explained their experiences associated with giving services and insult and degradation from health professionals. They also mentioned their

experience about bad behaviors of most general practitioners or dentists and gynecologist. Most participants stated that not being accepted by the physician caused them to ignore or delay the treatment process. Some claimed that they concealed their disease to receive services in subsequent visits with physicians. Multisocial prejudices toward people with HIV/AIDS not only have reduced the social supports offered by health professionals but have also created various types of discriminations such as judgment attitudes, avoidance from patient, rejected treatment, health care services and unwanted disclosure in health care centers. Along with the present study and the discrimination problem in offering medical and dental services, a study in Nigeria was conducted. The results of the study focused on the discriminatory attitudes towards HIV-infected patients, given by dentists (37). A study in Kenya highlighted the fear of being infected among midwifery caregivers, which concluded social stigma and discrimination for patients (5).

As it was noted, stigma and discrimination can appear as big barriers for HIV/AIDS-infected people, which hinder them from accessing health, medical and care services. The results of this research can inform patients, families and health givers of practical aspects of HIV/AIDS stigma and discrimination. They may assist them to reduce the outcomes and complication of their disease by planning and support.

As HIV/AIDS infection is increasing in Iran, it is necessary to plan and practice proper strategies for eliminating wrong conception among public, families and medical teams, by which stigma and discrimination could be reduced to the least extend. According to the findings obtained, HIV/AIDS stigma has had an unpleasant impact on the society and it has been a barrier for the participants to access and gain equal social and medical rights. Studies have indicated that insufficient knowledge, misconceptions about the transmission ways, and the fear of being infected may lead to inappropriate social behaviors towards these patients. Showing sympathy and empathy with patients and creating a cultural background for the public as well as a general knowledge about HIV/AIDS can create positive attitudes for patients' health care. In this way, their social difficulties can be lessened.

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Authors' Contributions

Mandana Saki was involved in the study interviews, extracting and encoding the data, data analysis and drafting the article. Sima Mohammad Khan Kermanshahi and

Eesa Mohammadi were involved in revising the codes and data analysis and reviewing the content critically. Minoo Mohraz was involved in final revisions and critical reading.

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