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Exploring the Problems and Challenges of HIV-Infected Women: A Qualitative Study

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Abstract

Objective: Although HIV-infected women in Iran face many problems, research in this area is limited. This research aims to understand and deeply comprehend the issues and challenges HIV-infected women encounter.
Method: Qualitative research method and content analysis were applied in this study. The participants of the research were HIV-infected women referred to three Supportive Health Centers in Tehran. Among them, 17 participants were selected through the convenience sampling method. The data collection technique was a semi-structured in-depth interview. The collected data were coded and interpreted using thematic analysis.
Results: The results of the interview analysis revealed six categories of "social exclusion", "job problems", "social phobia caused by stigma", "mental problems", "treatment problems", and "coping mechanisms".
Conclusion: The findings of this study indicate that HIV-infected women face many challenges in their individual and social life for social integration and reducing their problems; besides, individual empowerment, structural, and social interventions are also essential. The results of this study can be used in policy-making, the presentation of supportive programs, and social services for HIV-infected women and their families.

Keywords: HIV, Women, Challenges, Stigma.

Introduction

Today, various human societies suffer from HIV/AIDS, which is the most important challenge for public health care systems in the world. The World Health Organization (WHO) estimated the number of HIV-infected people at 36.7 million in 2016 (World Health Organization, 2018).

In Iran, the number of HIV-infected people was 37,650 in 2018, of which 83% were men and 17% were women. The pattern of transmission of the disease and the infection percentage of men and women has changed in recent years, with 32% of women and 68% of men in 2017. The pattern of infection in new cases shows that HIV infection tends to lead to unprotected sex through drug injections; in that, out of the total new cases of HIV infection, 33% was as the result of injecting drugs and 47% through sexual intercourses (Center for Infectious Diseases Management, Ministry of Health of Iran, 2018).

Research showed that people have a hostile perspective on HIV/AIDS. Inaccurate beliefs about HIV transmission through casual social contact, as well as the belief that infected people with AIDS (PWA) deserve the disease, are common in society (Herek et al., 2002). More than half of people have a discriminatory attitude toward HIV-infected people (PLHIV). Stigma and discrimination may deprive PLHIV of access to optimal health services medications (UNAIDS, 2017).

Stigma and discrimination are major barriers to the

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global fight against HIV. AIDS stigma affects the prevention, diagnosis, and treatment of HIV. It puts HIV-infected people at higher risk and vulnerability and impairs their physical and mental health (Kalichman & Simbayi, 2003). This disease in Iran is tantamount to notoriety and sexual harassment. The condition of patients would be affected not only physically, but also psychologically and socially in terms of many social problems, negative public perceptions, and social labels towards them. Besides, it causes rejection and isolation of them.

HIV-related stigma may perpetuate the spread of the disease in several ways. First, the fear of stigma avoids some HIV test (Fortenberry et al., 2002), affects preventive behaviors such as the use of a condom, lack of knowledge that leads to the inadvertent transmission of the disease, and failure to follow up treatment. Also, HIV-infected people are less likely to disclose their illness and are more likely to engage in high-risk sexual behaviors for fear of disgrace and discriminatory behavior (Simbayi et al., 2007).

Although both men and women are affected by stigma, its psychological and social dimensions are far greater for women than men, some of which relate to gender expectations (Colbert, et al, 2010). The degree of moral stigma varies between HIV-infected men and women. For example, women are accused of sexual promiscuity (Bunting, 1996). The economic and financial situation of HIV-infected women is often low (Cook et al., 2002: Ji, Li, Lin, & Sun, 2007). Gender has a moderating effect on coping mechanisms, and HIV-infected women are more likely to resort to maladaptive ways of coping, including avoidance due to environmental and social barriers (Moscowitz et al. 2009).

Different kinds of stigma accompany people with HIV/AIDS throughout their life, like social stigma, self-stigma, and health professionals' stigma (Arias-Colmenero et al, 2020). Internalized stigma in HIV-infected women causes shunned by families (Oskouie, et al, 2017), mental health problems, low social support, reduced quality of life (Rueda, et al, 2016), low Mental Well-Being (Rasoolzadegan, et al, 2020) negative self-image negative, shame (Audet et al., 2013; Earnshaw et al., 2013), isolation, depression, reduced access to health centers, and conflict in high-risk sexual relationships. This matter is not only a serious obstacle to their health but also provides the basis for the transmission to others (Darlington & Hutson, 2017).

The results of Sweileh's (2019) study, based on the Scopus data about stigma and AIDS discrimination from 1980 to 2017, showed that despite increasing research on stigma and discrimination in the last decade, the total number of publications on HIV and the number of infected people are negligible in general. Lack of information and research on HIV-infected people, especially women in Iran, has led to the ignorance of the public and policymakers in this area, and therefore, conducting research in this area and addressing the issues, problems, and concerns of these patients can be the beginning of a change in attitudes toward AIDS and the beginning of paying attention to those affected individuals along with preventing the spread of the disease. The range of harms and limitations for the infected patients, especially women, is very high, given the patriarchal culture that prevails in society, which requires an in-depth study of their challenges, issues, and appropriate solutions. This study aims to provide preventive and supportive solutions to reduce these problems by identifying and analyzing the issues and challenges of HIV-infected women.

Method

Participants and Procedure

The present study was conducted using qualitative content analysis. Participants in this study were HIV-infected women who went to three centers in Tehran (Sun House, Navid Hamrazi Iranian, & Pouyan Positive Club) in 2019 to receive support and health services. Inclusion criteria for participants included:

• Willingness to participate in research,

• Have enough time and opportunity to collaborate and conduct an interview,
• Ensure that you get HIV through specialized tests,
• Be at least 18 years old at the time of the research, and
• No mental disorder.

After winning the trust of the participants, the interviews were conducted by the researchers. Using the purposive sampling method and the theoretical saturation criterion, 17 semi-structured interviews were conducted. Before the interview, women's trust and confidence were taken to record the interview. On average, each interview lasted about an hour. During the interview, it was tried to clarify the experience, challenges, issues, problems, and consequences of the disease as much as possible. The location of the interviews varied according to the circumstances of the interviewees, and the point was that the interview should take place where external factors did not interrupt the interviewees and the interviewee's feelings were expressed in continuity. First, the recorded interviews were carefully done and typed, then the text was coded. The thematic method was used for data analysis. Categories and codes for each interview were compared with the next interview to identify the properties and relationships between them, and then similar categories were conceptually and characteristically merged, located around a joint axle, which then formed a wider category that was related to other categories.

The trustworthiness of this study was evaluated by three criteria of creditability, dependability, and conformability. Credibility was assured via the triangulation strategy – in addition to semi-structured interviews, field notes, and the researchers' prolonged engagement in the subject matter. Dependency was provided by peer reviews and group member checks. Conformability of the data was accomplished by the researcher, who conducted thorough reviews to gather ideas from other researchers and maintained the study documents.

Ethical statement

In this study, ethical considerations were observed. Information was provided on research objectives, potential losses, benefits, information users, how to publish results, and participants' rights. Participants were assured of confidentiality and anonymity. All participants in the study were given informed consent without any coercion, threats, bribery, or seduction. The information was kept in a safe place confidential and only the research team had access to it.

Results

Among participants, only one was single, and others were married, divorced, or living with their partners. All participants had no college education and their average age was 45 years. Only one person was employed and the rest were unemployed or fired. By analyzing the information, classes, and concepts, the following categories and concepts were obtained as the problems of HIV-infected women.

Social Exclusion

HIV-infected women have been shunned not only by strangers but also by their families, relatives, and friends since their diagnosis and disclosure. They face the discriminatory behavior of others in using public facilities. Lack of knowledge about HIV has led to unconventional treatment towards these people and the loss of their citizenship rights which is one of the most important needs of social life.

> 'My daughter goes to school. Her classmates tell her that she is ill and she can't seat near them. The community treats such a child and someone who is sick like a parasite.'

Job Problems

HIV-infected women have faced serious problems in providing necessities of life and treatment costs after the disclosure of their disease. They lose their

jobs and sources of income. One of the main reasons for discriminatory treatment towards HIV-infected people in the workplace is the lack of knowledge and awareness about the disease and how it is transmitted.

> 'I was working. I had a good income. I was careful that no one understood my illness, but because I was hospitalized for a while because of this disease, and when I returned, I was fired.'

Treatment Problems

Most of the time, patients' individual and medical rights are not respected, and they have experiences of discrimination and repulsive behavior by health care providers, which were so humiliating that some of the patients stopped their treatment. The experienced stigma of infected women in relation to health care providers falls into three categories: problems with the treatment process (inappropriate treatment, counseling, care, and education to the patient and the patient's family), professional relationships with the patient (inappropriate interactions with the patient and his family and judging and spreading rumors about the patient), and lack of modern medical services about the disease, lack of financial support, physical space and inappropriate equipment of the centers, and the reluctance of the officials to engage in social activities related to HIV /AIDS. Besides, most of the patients are of lower economic and social classes. They face many problems in the provision of ancillary costs of treatment (transportation, proper nutrition, and dentist ...).

> 'Most of the time, when I go to the hospital or clinic, they know that I am sick, they behave badly. Their look and behavior are annoying.'

Mental Problems

Good mood and mental health are essential for all patients, especially HIV due to the weakness of their immune system and the harmful effects of stress, while HIV-infected women suffer from the stigma of the disease. Rejection by society faces many psychological problems. Depression, anxiety, fear of the disclosure of their disease and humiliating behavior of others, shame, and guilt are common examples of the psychological problems of HIV-infected women.

> 'I was very shocked at the moment of hearing the name of my disease. I went to my home and for about 6 months I was not out of my room at all. I was depressed.'

Social Phobia Caused by Stigma

Infected patients with HIV need a lot of social support and consider this factor as one of their most important needs during their treatment and personal life. However, HIV-infected women are terrified of the stigma of the disease and the community's rejection of it. Those whose illness has been disclosed are afraid of annoying and being insulted by humiliating behaviors, and those who have not yet revealed their disease are afraid of it and afraid of being discredited.

> 'I can't go to the community because I'm afraid of the disclosure of my disease. I don't know how people would think of me after understanding my disease.'

Coping Mechanisms

HIV-infected women reacted to both rejection and discriminatory behavior in both active and passive (avoidant) ways. Actively, they tried to overcome the problems and communicate with others by creating positive thinking and optimism about the future and appealing to religion. But HIV-infected women passively avoided contact with others through secrecy and self-isolation, for fear of HIV/AIDS stigma and degrading and discriminatory behavior. Many patients were forced to hide their illness to advance their treatment and life plans.

> 'I didn't want anyone to know my illness at all. I was really scared of their judgment. They easily told me that I had an illicit affair. Even hearing of the matter made me very upset. I feel better when I pray.'

Discussion and conclusion

The findings of this study show that one of the most important problems of HIV-infected women is social exclusion, which stems from stigma and lack of knowledge and awareness of people with the disease. According to other studies, HIV-infected women had a negative experience, and the disclosure of the disease has led to their families, friends, and strangers shunning; besides, they lost social support (Herek et al., 2002; Brown et al., 2003: Rueda, et al, 2016, Oskouie, et al, 2017). Heavy discrimination against society and the psychological pressure imposed on HIV-infected women cause them to hide from society and their families. This finding is consistent with the results of studies carried out by Audet, et al. (2013). According to their study, HIV increases women's self-isolation. Infected women with social isolation use social isolation as an avoidance mechanism. Based on the socio-cognitive approach, people's perceptions of stigma in cognition affect their social interactions (Parker & Aggelton, 2003). Many studies have also shown that women with a spouse who uses alcohol and drugs are confronted with exclusion and isolation (Orford et al, 2013 & Fathi, et al, 2020). Shunning causes women to live alone and to have no support in society. The results of a study by Kalichman and Simbay (2003) also showed that HIV stigma caused people to feel socially disapproval. This has many negative consequences, including mental and emotional distress, the ineffectiveness of treatment, continued behavioral abnormalities, and so on.

Another common problem of HIV-infected women is job loss and discrimination in the workplace. Many women living with HIV, hide their illness for fear of discrimination, and if exposed to the disease due to the lack of awareness of others of the ways of transmission and negative attitude towards the disease, they face discriminatory behaviors and rejection of their colleagues and often lose their jobs. This finding is consistent with the results of the studies of Herek et al., (2002) and Brown et al. (2003). According to the studies, HIV-infected people are discriminated against in the workplace due to the disclosure of the disease and lose their jobs.

The findings also found that HIV-infected women had many medical problems, including inappropriate and discriminatory treatment in medical centers, as well as unequal access to health care. These people have been discriminated against due to the stigma of the disease and the lack of proper admission in health care centers, so they hid their illness or refused to follow their treatment, while these women need optimal treatment to have a better life to be accepted for the medical services without any discrimination. This finding is consistent with the results of studies by Brown et al. (2003), and Rueda, et al. (2016). According to these studies, HIV-infected women experienced discriminatory behavior in healthcare centers; therefore, their willingness to go to these centers to receive their needed services was significantly reduced. Access to therapy is a virtuous social cycle that the symptoms of the disease are reduced with the treatment of people. It enables them to return to society.

The findings show that HIV-infected women suffer from shunning and discriminatory behavior due to HIV stigma and lose social support, so they face several psychological problems, including stress, depression, anxiety, suicidal thoughts, suspicion and pessimism towards others, fear of the disclosure of their disease, loss of social status, fear of death, frustration with life, and so on. Participants have been questioned by the community on the accusation of unchastity, and this extreme and unfair generalization exacerbates their psychological harassment. This finding is consistent with the result of numerous studies including Berger et al. (2001), Audet et al. (2013), Rueda, et al. (2016), and Sadati et al. (2019). According to these studies, HIV stigma had severely affected the mental health of infected women. They

felt ashamed, guilty, and had several mental health problems, including depression, anxiety, and negative self-image. They suffered and worried about the disclosure of the disease and the negative reaction of the members of the community.

According to the findings of the study, HIV-infected women suffer social phobia due to the stigma of the disease and the negative attitude and humiliating behavior of people in the community because this disease is associated with the illicit sex label. Women's Fear of stigma contributed to a lack of HIV disclosure and reduced social support for seeking HIV care. The findings are consistent with the results of studies carried out by Berger et al. (2001), Ingersoll (2004), Sadati et al. (2019), Arias-Colmenero et al. (2020), and Kisigo et al. (2020), who showed that HIV-infected people are highly worried about disclosure of the disease and the fear of others' reaction. HIV-related stigma is associated with shame and disgrace and has negative social reactions. HIV-infected people face both individual and structural discrimination. Social forces such as poverty, gender, etc. facilitate stigma conditions, limiting and restricting access to diagnostic and treatment services. Such stressful pressures create structural violence. Victims of such violence, including HIV-infected people, are more at risk of stigma (Castro & Farmer, 2005).

According to the findings of the present study, HIV-infected women reacted to the problems caused by the disease in two ways: active (optimism about the future and appealing to religion) and passive (secrecy and avoidance). Some of them attempt to solve or cope with their problems through active strategies. But others resort to passive, covert, and self-imposed leadership because of the stigma of the disease and the fear of violent and repulsive treatment. Because of the disclosure of the disease, their problems were added. Several studies have also shown the effect of stigma on the adjustment of infected individuals (Heckman, 2003; Schmitz and Crystal, 2000). A sick person has a lower quality of life and mental well-being compared to healthy people (Rasoolzadegan, et al., 2020) and people use indifferent adaptive mechanisms in dealing with the disease (Abdekhodaie1 et al., 2018). Access to social support is an adaptive mechanism in HIV-infected women (Taylor & Stanton, 2007). Affected women who use avoidant coping mechanisms, such as self-isolation, are less likely to refer to social and health services (Audet, et al., 2013).

Conclusion

The final findings of the study show that HIV-infected women suffer from several problems, including stigma and social discrimination, social exclusion, psychological problems, job loss, job discrimination, rejectionist, and discriminatory behaviors in medical and health centers. They are trying to adapt to the problems with two active and passive strategies. Due to the consequences and the social stigma of disclosing HIV, talking in this area in many cases is unpleasant, and searching and researching about it is considered as spying in the private sphere of individuals. This made it difficult to reach the target individuals, so the researchers were forced to select samples from clients of centers.

To reduce the problems of HIV-infected women, interventions should be used to promote well-being and social networks, increase social support and health-promoting behaviors, self-care behaviors, and stress management of infected women. Besides, structural and social interventions are also necessary to reduce the effects of AIDS stigmas. These interventions can be implemented through community-based actions such as public education, advocacy, and social change, public health policy, and mass media. Implementing these interventions will contribute to the infected people by removing barriers to the disclosure of the disease and promotion of health and quality of life.

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