

Original Article**HIV positive women's living experiences**

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Abstract

BACKGROUND: Half of the 40 million people living with HIV are women and that the number of infected women is increasing. This study aims to describe the experiences of women living with HIV to get a deeper understanding of meanings and nature of life with HIV to develop general concepts about it.

METHODS: In this qualitative study phenomenological method was used and women living with HIV were interviewed about their living experiences. Sampling was purposive and data saturation occurred after 12 participants. Data were collected by discussion and conversation, making notes, collecting participants' notes and recording in-depth interviews with them in Isfahan Province. Data were analyzed by Colaizzi's seven-stage method.

RESULTS: Most participants were married, had children and were infected by their husbands. From 115 extracted codes, 3 main themes and 9 sub-themes, illustrating the living experiences of these women, were found: vulnerabilities (individual characteristic, family and social factors), challenges with the diagnosis (from unawareness and denial to suspiciousness, referring for test, waiting for the results and finding the seropositivity), patient's interactions in day life (family, HIV, supportive systems).

CONCLUSION: The women provided several experiences including vulnerability to HIV, ignorance about risky situations and how to avoid them, others' reaction to the diagnosis of infection, chaos in family and social relationships, lack of health care services and supporting systems, especially for mothers who had family responsibility. These experiences illustrate various aspects of the problem and show the necessity of planning for counseling, supportive and health care services to HIV positive patients without judging them and their disease.

KEY WORDS: Life experience, women, HIV seropositivity, qualitative study.

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AIDS for the first time was described in the US in 1981 and soon turned to a great epidemic problem of public health care in the world.¹ There are 40 million people in the world living with this disease now.² According to the WHO formula, the real number of infected people in Iran is about 60,000. But there are more than 100,000 HIV carriers in Iran according to Harvard University studies, which mean a rapid and non-controlled widespread.³

Because of their biological and reproductive role, women are vulnerable to HIV infection

and disease development. Also, the different sex role and their social situation make them so.⁴ Half of HIV positive people and patients with AIDS are women and evidences show that their number is growing, so that in Africa, AIDS has become a woman disease. 80% of HIV infections occur in the reproductive age and in 1995 AIDS was the third cause of death for women in 25-44 years of age.²

Studies show that HIV diagnosis for women is accidental by blood transfusion or usual pregnancy tests and most infections occur in heterosexual women and within the family.

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Moreover, due to discriminations and sex inequality, women are more at risk and they are physically more susceptible compared with men.⁵

Most infected women reject seeking medical advice and treatment because of their shame and fear of the social and family outcomes once it is revealed. More than half infected women were rejected by their families and husbands and were banned to see their children once their disease was revealed.⁵

Adjustment and dealing with the disease in the first steps and awareness about infection are the main reasons for seeking health care and preventing transmission. Health advice and support in this period significantly affect the patients' ability to adjust themselves with the situation.¹

Also, with describing life experiences and the patient, her family, friends and the society's reaction to the diagnosis as well as changes in inter-personal and social relationship patterns, health care services and preventing transmission can illustrate the current deficient situations and provide background for necessary plans of medical advice, care and support to decrease the individual and social harms of the disease.

Considering the rapid increase of HIV infection in Iran, women's vulnerability and their role in family and the importance of reproduction health improvement, this study aims to describe the life experiences of HIV infected women. Since the purpose of qualitative studies is to describe life and find meaning and this kind of studies are used in cases about which there is little knowledge available or new outlooks are necessary to be introduced, this study had a qualitative method of phenomenology to find the way to the depth of experiences, meaning and nature of life with HIV infection and provide general major concepts about it.

Methods

This study was a qualitative research which based on descriptive phenomenology. Participants were Iranian women infected with HIV willing to participate in the study. They were

the data source and were able to express their experiences. Navab Safavi health care center was the original place for the study and 6 participants were selected from there. Other samples were selected by snowball method. The interview place was, however, selected based on the participants' convenience. Sampling was purposive and data saturation occurred with 12 participants. Because some participants didn't like their interviews to be completely recorded, discussion and conversation, noting and using participants' notes were used as alternatives. The length of interviews was 25 to 35 minutes. Data were analyzed by Colaizzi's seven-stage method. First, to understand the feelings of the participants, all data (obtained by transcribing interviews or other methods) were carefully read and important statements were identified. In the next stage, the concept of each statement was explained and the concepts were coded. Then, the codes were categorized and to find the validity of categories, they were referred to the original protocols. Next, the results were joined to make a complete description of the study phenomenon and revised to find the clear concepts. Finally, the findings were referred to the participants for the validity approval.

Also after analysis of each interview, it was reviewed referring to the participant to check the validity of data. In addition, the research was carried out by a team guided and supervised by professionals to assure the reliability and non-bias data. Finally, the raw data were given to a third person for validity evaluation of findings.

Results

This study was carried out by interviewing with 12 women infected with HIV, aged between 18-48 years. Four participants were pregnant during the study. Eight participants were infected through their husbands, 1 was infected via intravenous drug addiction and 3 were infected through extramarital sexual affairs. 115 extracted concepts were coded, which were all put together into a complete description of all details and 9 sub-themes under 3 main themes were recognized:

Theme I. **Vulnerabilities:** each participant in some ways tried to explain the reasons of their infections and the main factors in their explanations included individual, family related and social factors.

a: Their experiences about individual predisposing factors to HIV infection included limited education, ignorance about transmission of diseases through sexual relations, financial dependency on men (having no independent income). For example, the participant number 012 said: *"I knew nothing about this disease and that it can be transmitted from men to women."*

b: Family factors also were significant in their evaluation, including insecurity in the family, poverty, addiction and patriarchal family relations which neglect women's decisions and independence. Participant number 01 said: *"there were always argument and violation in our family; my dad tortured us a lot, imprisoned us in the basement. At last I escaped one day and never returned home and this caused my misfortune and illness."*

c: Since most women got infected through their husbands, the main social factors for men's infection and in some way for women's too include denial due to stigma, unemployment, poverty, abroad business trips, addiction and jail. Participant number 06 said: *"my husband was addicted to opium and was selling drugs too, until he went to jail. When he was out, his addiction was intravenous; nobody gave him a job, so to get drugs he had to go to drug dealer again ..."*

Theme II. **Challenges With the diagnosis:** how the healthy looking people got suspicious to go for test and seek medical advice and treatment. The participants described this process as follows:

a. from unawareness to denial and suspicion: although all participants, themselves or their husbands, had risky behavior regarding HIV infection transmission, none of them thought of this disease, which shows the public ignorance of the society. In most cases, the patients got suspicious from medical file during pregnancy or when some health care personnel fol-

lowed their risky behavior. Some even tried to deny their infection in spite of obvious evidence and their surrounding people's suspicion, while some cases just got suspicious after the permanent sickness of their husband or his death. Participant number 08 said: *"my husband was involved with drugs, I got divorce. There was a rumor that he died in jail from hepatitis, even though I was completely healthy, I got suspicious if I have the disease too."*

b. Referring for test and waiting for the results: during the time from taking a blood test until the results are ready, the participants had experienced from ease due to ignorance to psychological distress of anxiety, fear, agitation and seeking help. Participant number 07 said: *"when the doctor told me to take a blood test for AIDS I became crazy, my body got hot, I got very anxious. The doctor said that he advised me for the test because I was health care personnel. I was devastated by anxiety."*

c. Finding the Seropositivity: participants had a devastating difficult life from finding the Seropositivity to adjustment with the situation. They were shocked and angry and tried or planned to suicide. Then after a while and when they got some information about the disease, they accepted that and finally dealt with it in a long term process of depression, seeking treatments, fighting the disease, personal and social isolation. Participant number 02 said: *"I didn't expect to be positive, when I found, I couldn't believe, I told them to repeat the test again. I was crying, I imprisoned myself for several days and didn't eat anything, I was angry, I took a lot of pills to kill myself but they saved me. I thought a lot, decided to stay alive and fight my disease ..."*

Theme III. Patients' interaction in daily life: this is one of the main themes of the research, implied from the basic experiences of participants in their daily life after they were infected with HIV.

a. interaction with family: participants description of changes in family life included chaos in emotional relationship with husband, frustration in sexual relation and intention to take care of their children. A kind of

frustration and obvious change in sexual relation pattern was observed. For example, participant number 03 said: *"every time we have sexual intercourse, I feel that I got sicker and these viruses entered my body again. I just hate it, it should be stopped..."* Although most participants could not financially support their children, believed that they were their reason for seeking treatments and their hope for continuing to live and they had positive attitude toward pregnancy. Participant number 05 said: *"Since my baby was born, I have been taking better care of myself and take my medication regularly and I want to stay healthy and alive until my baby is grown up ..."*

b. Interaction with the disease: The disease is a concept beyond the physical symptoms for most participants and in their description; they used terms such as torture and misfortune, destruction and unknown future. Participant number 07 said: *"disease (AIDS) means that all your life in upside down with a test, you lose everything and be destroyed, there is no pain worse than this..."* Most participants did not have any special prediction about process of the disease, symptoms, physical and emotional changes and thought themselves to be healthy and they had complain about frequent referring to health care centers, using a lot of medications, transportation problems and unexpected recurrence of the disease symptoms.

c. Interaction with supportive systems: The participants described their interaction with supportive systems from different aspects including: **trusting to health systems** (satisfied by advising manner of skillful personnel as well as the physical characteristic of the center). Participant number 02 said: *"I come from a small town and here is like a home for me. The day I came here, I stayed for several hours and asked questions frequently, sometimes even repeated questions, but everybody replied me with patience..."* However, they were avoiding from systems. participant's experiences showed that personnel of hospital were judgmental, not trustworthy to keep the patients' secret, indisposed to help patients with AIDS, fear of transmission and also the patients were afraid of the expensive hospital costs. Participant

number 05 said: *"They left me in a room alone, I was in labor pain and nobody came to see what happened to me, they were afraid, to check my pulse, they wore gloves and mask. I asked them why they were acting like that, my disease transmission is through blood ..., in the maternity room, and one person came and did everything herself. I even heard they asked the hospital why admitted a patient with AIDS ..."* Women participated in this study were disappointed by social systems and described experiences of rejection and being hurt because of personal and social attitude to the disease, while most of these women had HIV infected drug addict or imprisoned husbands and had problem with basic life expenses, at the same time were under public pressure to deny the disease and were limited to ask help from their relatives. Participant number 011 said: *"Just like drug addiction which were rejected by the society and now is everywhere, I am sure AIDS would be the same, they hide it so much and we are exposed to a disaster. Therefore, the society should be informed, the criminal view to this disease should be revised and we should think of control and prevention rather than asking why somebody is infected ..."*

Discussion

All themes are related and illustrate a life pattern helping to understand the reality of living with HIV. In qualitative studies, generalization of results is not an issue, but the important issue is the correct description of an experience to develop knowledge and insight. The findings of the present study develop the following concepts about the experiences of women living with HIV infection.

The first theme is vulnerabilities. Subedi et al in a study in Nepal introduced the individual and social factors as the major cause of women HIV infection. This study reported that illiteracy, ignorance and lack of social abilities make women vulnerable to this disease.⁷ Also, studies by population Bureau showed that women have little information about AIDS and just 30% of women who were at risk knew their situation.⁸ Financial, social and sex inequality as well as women's financial dependency on men and being inferior to their men, are the major family

causes of increasing AIDS among women in Tanzania.⁹

The main factor in our study was individual and public ignorance, especially women's ignorance about sexual transmitted diseases, AIDS and its modes of transmission and keeping safe. Therefore, it seems that educating the society about HIV transmission and keeping safe as well as sexual diseases and safe sexual relations are significantly necessary and it is better to be started from the schools.

Facing the diagnosis of HIV seropositivity was another theme of this study. In fact, the critical period of being informed of the results until dealing with the disease needs counseling and continuous support to systematically pass the patients through this period.

Most women in Nepal, also, experienced fear, disappointment, denial and shock at the time they were informed to be HIV positive.⁷ Jarman et al in a qualitative study found that social supports and primary counseling opportunities at the time of informing a patient about the results of their HIV test are the vital factors for the adjustment process.¹⁰

Patients' general interaction in daily life is one of the main themes of this study, and it affects the health condition and the disease transmission. The first problem of infected women at the reveal of the disease is rejection from the family and society, and some even lose their job. But Subedi et al believe that with family and social supports, patients can keep their job and income and have a longer life.⁷

In a study by Doyal et al on HIV positive African women living in London, 30% of them were rejected by their husbands, thrown out of their houses and were banned to see their children when their disease was diagnosed.⁵ In Pierret et al study also, patients described experiences of disorder in their usual life activities, so that their relation with family and relatives was totally changed.¹¹

HIV positive women's experiences of inappropriate and illogical reactions of their family, friends and the society toward their disease which lead to break down their family and social relations suggest the necessity of some ef-

forts to correct the society's attitude towards AIDS. The society can be prepared to accept these patients by improving the public awareness about modes of transmission, public health and keeping safe as well as emphasis on women's vulnerability.

Moreover, Bell et al in a study of experiences of HIV positive women found that in the next steps of adjustment with the disease in daily life, there should be some supporting groups to help infected men and women to overcome the problems created by the disease, to decide for their sexual relations and seek treatments and health care. There should be a connection between these groups and diagnosis and treatment systems to offer support to the patients since the beginning of diagnosis.¹²

The participants' experiences of medical system that was avoiding these institutes especially hospitals suggest that the authorities of medical sciences education should consider this in the curriculum of medical sciences students as well as in-service educations for the health care personnel in order to prepare them with communication skills and giving advices to these patients, offering them care without judging them and act in accordance with medical ethics. Likewise, the insurance national policies help these patients with medical expenses.

Pierret et al believe that considering the special condition of these patients and the anxiety of health care personnel's about transmission of infection, some special health care policies should be prepared for these patients.¹¹

Another concept is the patients' disappointment with social systems especially in financial helps for these patients. It seems necessary to provide a systematic financial support for these women. Especial attention to the children of these women and follow ups of their infection with HIV virus, their health and education are important and need total support from all parts of the society.

Gunnel et al believe that medical and support systems should provide effective support for HIV positive women, especially those who have children and their families are broken up because of the disease or their husbands have

no job. Special support should be offered to the children regarding the possibility of infection transmission and their educational needs.¹³

It seems that planning about counseling services, support and care for these patients; away from judgmental attitudes, we can minimize the individual and social problems of this disease and prevent its widespread.

The researchers declare that they had no conflict of interest in this study and it was done under the research ethics.

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