Living in the Blurry World: The Story of HIV-infected Iranian Nurses

Hamid Salehi[1*], Nooredin Mohammadi[1], Mehrdad Eftekhar Ardebili[2], Seyed Ali Dehghan Manshadi[3], Saeed Kalantari[4]

Abstract

Background: Despite progress in reducing HIV-related mortality over the past decade, the prevalence and incidence of HIV infection slightly decreased. Nursing profession as a part of the health care system is most affected by HIV/AIDS. HIV-positive nurses need more support from governments and officials. Little is known about how Iranian HIV-positive nurses experience their life situations.

Aim: This study evaluated the experiences of HIV-positive nurses and their attempts to manage HIV/AIDS in personal and occupational livings.

Method: The hermeneutic phenomenological approach developed by van Manen's methodology (1990) was adopted to explore the experience of daily life for HIV-positive nurses. A purposive sampling of eight HIV-positive nurses was recruited. Face-to-face in-depth interviews were conducted with two female and six male nurses who had infected with HIV via occupational exposure. Data were analyzed using thematic analysis.

Results: The experiences of HIV-infected nurses derived in one major theme and three subthemes. Major theme "living in the blurry world" extracted from three sub-themes: 'being-in-the-risky world', 'being-in-the-shadow of illness', and 'ambiguous being-in-the-world'.

Implications for Practice: HIV positive nurses perceive the world full of fear and ambiguities. They prefer to suffer in silence and reluctant to disclose their seropositive status. The results of this study can be used by professionals to better understand the HIV positive nurses' world and make more efforts to improve their workplace experiences and reduce stigma in the future.

Keywords: Hermeneutics, HIV Infection, Iran, Needle stick Injuries, Nursing Staff, Qualitative Research, Social Stigma

1. Department of Nursing, School of Nursing and Midwifery, Iran University of Medical Science, Tehran, Iran
2. Education Mental Health Research Center, Psychosocial Health Research Institute, Iran;University of Medical Science, Tehran, Iran
3. Department of Infectious Disease, School of Medicine Imam Khomeini Hospital, Tehran University of Medical Sciences, Tehran, Iran
4. Institute of Immunology and Infectious Diseases, Iran University of Medical Sciences, Tehran, Iran

* Corresponding author, Email: salehih@razi.tums.ac.ir

Introduction
Despite progress in reducing HIV-related mortality over the past decade, the prevalence and incidence of HIV infection slightly decreased. Many countries are behind of the 2020-2030 world health organization's goal in reducing the incidence and prevalence of HIV infection mainly due to lack of financial resources. HIV still continues to be a major challenge to the health system in both developing and developed countries with a growing HIV-infected population (1). AIDS is one of the serious public health problems. Receiving an HIV diagnosis can be emotionally devastating and can impose a lot of psychological and social pressure on infected patients (2-5). Studies about the experiences of people with HIV have showed that the most important problems of people living with HIV/AIDS include lack of confidentiality, fear of disclosure, guilt, judgment, labeling, lack of support, insufficient knowledge and negative attitudes toward HIV patients and adaptation problems (4,6,7).

The increasing trend of HIV-infected world population increased the healthcare workers (HCWs) exposures to HIV-infected material during work (8). Among other HCWs, nurses are more vulnerable to HIV infection due to the nature of their services which deliver to HIV-infected patients. Research has shown that the nursing is one of the professions which is most affected by HIV/AIDS (9). HIV-infected nurses often suffer in silence and bear the burden of their illness lonely. When they weighed the benefits of disclosure against its costs, they prefer to keep it as a secret because of the fear of stigma and losing the respect of both patients and doctors (10). Several studies have showed that the fear of stigma from colleagues and supervisors can be a major barrier to disclose their HIV status in workplace (9, 11-13).

According to Iranian Nursing Organization (INO), there is no official statistics in relation to occupational transmission of HIV to Iranian nurses. However, INO reports that nurses are more at risk for occupational transmission of HIV and significant number of nurses suffer from AIDS and hepatitis (14).

Heideggerian phenomenology represents a pursuit of an understanding of the nature of human existence and experience – of being-in-the-world – against the background of an understanding of the nature of "the logos of other, the whole, the communal, or the social" (15). Interpretive phenomenology is, therefore, the approach used to address the lived experience and meanings of living with HIV/AIDS for nurses. The experience of living with HIV as a nurse in Iran could be somewhat different from other social and cultural societies (16).

Although many research have been performed on the experience of HIV-infected people (16-20), little is known about the experience of HIV-positive HCWs in general and nurses in particular(9, 21, 22) This study was performed aimed to evaluate the lived experiences of Iranian nurses who had been diagnosed with HIV infection.

Methods
This qualitative study was performed using a phenomenological approach. Van Manen's existential framework was used as a methodical guide and participants were asked to express their personal stories and perspectives based on their lived experiences. Van Manen's six research activities provide a framework for conducting hermeneutic phenomenological research and interpreting the experience were used in this study (15).

A purposive sample of eight HIV-infected nurses (two female and six male nurses) were recruited and interviewed. Participants were selected through a purposeful sampling method from Tehran West Health Center, Imam Khomeini Hospital HIV/AIDS Counseling Center, and a non-governmental organization for HIV in Tehran. The inclusion criteria were: age> 26 years, nurses with minimum degree of bachelor in nursing, at least two years of work experience in nursing, HIV-infected according to medical report, ability to communicate verbally and willingness to participate in the study.

Van Manen's (1990) existential framework was used as a guide that consists of six activities. The first activity in van Manen's phenomenological method (1990) is turning to the nature of the lived experience. The initial step – orienting to the phenomenon – began with involvement with this issue as a nurse who is potentially at risk of occupationally infection with HIV and have several needle stick injuries experience, then I began to search information about HIV positive nurses in the literatures. I also became purposefully engaged in the process of increasing my knowledge and awareness about occupationally infected HIV. The second activity focuses on investigating the lived experience that can be achieved by researching lived experiences in the life world. This means that instead of researcher's conceptualizing what it would be like, she or he can seek to understand this

experience from someone who lived it. In this regard, the researcher performs in-depth interviews with HIV/AIDS-infected nurses to extract the meaning of the phenomenon of living with HIV. The third activity is reflecting on essential themes and can be achieved by the researcher's reflection on what made the experience significant. In this regard, Van Manen has proposed three approaches for thematic analysis including holistic, selective, and detailed approaches (15). Credibility of results and interpretations were assured through continuous engagement with the data throughout all steps of the study (23, 24).

The fourth activity is writing and rewriting to "bring into words" something thoughtful about the experience. Thus, the transcribed interview becomes the texts that the hermeneutical analysis will be conducted upon. The significant themes are detected during this stage. The fifth activity is about maintaining a strong relation to the phenomenon. The investigator should not permit false data to compromise the research. This step draws upon the concept of the hermeneutic circle that in order to obtain the essence, the researcher has to understand the interrelation of themes to the individual interview and that of the whole and determine if the interpretation fits the context of a specific section, in addition to the overall data collected. The sixth activity involves putting it altogether. The identified themes will lead to the essence, which according to van Manen (1990), "makes a thing what it is". The data, analysis, interpretations, and conclusions were continuously peer reviewed by members of the dissertation committee who are experts in this field. The audio-taped interviews were not destroyed until member check and transcription verification. Lincoln and Guba (1985) described the member check as the "… most crucial technique for establishing credibility" (25,26).

A total of twelve in-depth semi-structured interviews were conducted to collect data ranged from 45 to 70 minutes. Interviews were audio taped and transcribed verbatim. Single face-to-face and semi-structured interviews were conducted from February 2019 to May 2021 with participants in Tehran West Health Center and Imam Khomeini Hospital HIV/AIDS Counseling Center. During the interviews, the participants answered open-ended questions like: a) Tell me about living with HIV / AIDS? b) What was life like for you after you became positive, how did you feel? c) Tell me about your experiences when caring for patients. Interview transcriptions were used to analyze collected data through thematic data analysis method (15). Data were analyzed in MAXQDA software version 10. This study was reviewed and approved by the Ethics Committee of Iran University of Medical Sciences and was performed in accordance with the ethical standards of Declaration of Helsinki and all subsequent revisions in 1964. The participants were reassured that their actual identities were kept strictly confidential. In this study first author as the interviewer tried to address all questions and concerns of participants to sign the informed consent. All participants were advised of their right to withdraw from the study at any time.

Results

Nurse participants in the study aged 31 to 57 years. All participants had bachelor's degree in nursing. Time since being diagnosed with HIV was ranged 3 to 15 years. Two out of eight participants were married and six were single. Length of their work experience ranged 5 to 25 years. Places of work included general hospitals and psychiatric hospital.

One main theme and three subthemes were emerged. 'Living in the blurry world' was the main theme of this phenomenological study which emerged across analysis of the lived experience of participants. This theme refers to the participants' Being-in-the-world and shows that how their Being-in-the-world was influenced by HIV infection. In fact, living in the blurry world reflects the participants' perceived Being-in-the-world. For the study's participants, their whole existence was surrounded by a threatening atmosphere and unsafe environment. The theme of living in the blurry world was extracted from three sub-themes including 'Being-in-the-risky world', 'Being-in-the-shadow of illness', and 'ambiguous Being-in-the-World' (Table 1).

Being-in-the-Risky World

Being-in-the-risky world reflects the participants' fragile living world that leads participants in a risky situation due to physical and psychological challenges. The participants stated that due to AIDS and HIV infection they physically and psychologically become more vulnerable to occupational stressful issues and they experience daily events differently after the symptoms and complications of AIDS initiated. Participants stated that they have lost their physical strength compared to the past and could

Table 1. Sub-themes of Living in the Blurry World

Themes	Sub-Themes	category
Living in the Blurry World	Being-in-the-Risky World	Progressive physical weakness Progressive psychological weakness
	Being-in-the-Shadow of Illness	Fear of disclosure Fear of rejection Fear of discrimination
	Ambiguous Being-in-the-World	Duality of Existence Duality of Professional Identity Duality of Professional Affiliation

not work as before and therefore worked in shorted work shifts. They felt weaker in the workplace than their peers. The first participant said: "I feel exhausted and can't do anything as before. I can't bear the workload, especially night shifts are annoying me." (Participant no.1). Another participant also expressed feelings of physical weakness and diminished physical ability to work. "Since the onset symptoms of AIDS, I could no longer work as before. I get ill and tired easily in the normal shift, and I had no longer the stamina to work full-time" (Participant no.2).

Most of the participants insisted that they feel their immune system is vulnerable. One of the participants said in this regard: "when the flu spread to the staff, and like everyone, I got it, but it was significantly worse for me, which means maybe my symptoms were ten times worse than others. I took a leave from work" (Participants no.8). Another participant describes "I am always afraid of getting sick because it disrupts my life thoroughly" (Participants no.5). The other participant added: "Sometime ago, I disputed with a colleague about the TB patient allocation. Clearly, I didn't want to care for those patients, and I am afraid of caring TB patient. I asked my colleague to change allocation, but she didn't accept. It was very stressful and upsetting, but what can I do? I was much stressed" (Participants no.7).

The majority participants described the experience of living with HIV as very stressful and frustrating. They indicated the experience of high ongoing stress level that the HIV/AIDS imposed on them in their work and personal life. One of the participants described this perceived ongoing stressful situation as follows: "For me, starting any work shift is always accompanied by stress" (Participants no.2).

Being-in-the-Shadow of Illness

The theme of being in-the-shadow of illness reflects the participant's life world surrounded by fear. The participants perceived fear in every moment of their life everywhere. Therefore, they constantly experience the fears encountered in their lives after becoming HIV seropositive. Participants explained situations that they experienced fear. They believed almost fear was speared like an umbrella throughout their life. Some of the participants believed that the shadow of fear covered their entire life. In this regard, one of the participants says: *"I always fear that people who know me to be informed about it (HIV). Although as a nurse who works in hospital, only the staff of this HIV care center already knew my seropositive status"* (Participant No.6). Most participants expressed that they fear from being rejected, discriminated against, and socially isolated if their HIV/AIDS status is disclosed. One of the participant's states: *"I fear my colleagues do not accept to work with me as a team if they know I am infected with HIV"* (Participant no.3). Rejection due to disclosure of HIV status was not always from others' side. But some participants uttered they avoid participating in teamwork or social activities as they fear disclosure of their HIV status. For instance, the following excerpt has been taken from one of the participants. He points out: *"I was reluctant to participate in this study when you asked me for this interview. The only reason was fear of disclosure. However, I was sure about confidentiality if I participated in the study"* (Participant no.5).

Almost all participants stated they were concerned about losing their relationship with family members and relatives if they disclosed their HIV status. Participants believed that they were endlessly surrounded with a fear of rejection by relatives and family members. For this reason, some of the participants had hidden their HIV status from their family members and relatives. In this regard, one of the participants said: *"No one knows about my problem.… I take a lot of drugs, but I hide this issue from my family. My mother always asks what medication I am taking. I answer her that the*

medication is supplementary drug like vitamins" (Participant no.7). Another participant added: "*...I had lied over and over about my HIV status. I was afraid that if he* [brother]*found out about my illness, I would be disgraced to the whole family*" (Participant no.5). Some of the study participants expressed their reflection about fear of mistreatment and discrimination. The other participant said: "*I saw how some of my colleagues behave when they look after seropositive patients. These patients could be mistreated and discriminated. I am afraid if my colleagues know that I am a seropositive one, they will discriminate me*" (Participant no.3).

Participants stated that their fear and concerns about disclosing their HIV status increased with the society's attitude toward healthcare workers; people always expect that health care workers, especially nurses and doctors, to be healthy. For example, a participant stated: "*Once I told someone who was also HIV-positive, about my job that I work as a nurse in a hospital, he was very surprised, he said surprisingly, whether doctors or nurses even get sick, too.*" (Participant no.8). Another participant stated: "*It's happened to me a few times that when I trusted someone and said that I am HIV-positive, they didn't have acceptable reactions, they said if you are a nurse why should you be HIV-positive.*" (Participant no.3).

Ambiguous Being-in-the-World

Ambiguous being-in-the-world refers to the duality of participants' existence, professional identity, and professional affiliation. Participants declared that they had a duality in their existence as healthy or unhealthy person. One of the participants expressed: "*You know, I can't say how HIV impacts my life. Sometimes I think, HIV doesn't influence on my life, and I have no problem. But sometimes I feel all my life is impacted by HIV, and there is no escape to be survived*" (Participant no.3). Another participant regarding duality in his existence said: "*…I don't know whether I am survived from HIV or not?*" (Participant no.5).

Participants stated that they need to play two roles simultaneously or occasionally struggle to shift completely between patient and nurse roles. Nurses acknowledged that they did not know how to live this dual role. Participants stated they wanted to fulfill their responsibilities, but sometimes they faced with a dilemma between choosing self-care and patients-care. Asking for any help from others needed to disclose their positive status, they prefer to keep their HIV status secret; hence they have to play two roles simultaneously without any help. In this regard, one of the participants stated: "*When you feel sick and you're not feeling well, it's hard to take care of someone else, sometimes at work I need myself that someone care for or help me, but I don't know how to ask for help, I can't say that I'm positive, these moments I confused that who am I, nurse or patient!!!*" (Participant no.6).

Ambiguous Being-in-the-World also refers to the duality of participants' professional affiliation. Professional affiliations were disadvantaged by HIV infection for some of the participants. This extract from one of the participants reveals how his professional affiliation was impacted by HIV infection. "*You know well, nursing is a teamwork profession. However, I don't know whether or not I could be a team member due to HIV infection*" (Participant no.5). Another participant revealed: "*After I understood that I am HIV positive, I do not think that I would be a nurse*" (Participant no.3). The other participant added: "*I feel I get emotionally away from my colleagues. I am doubtful what happens if my colleagues know about my seropositive status. Formerly I felt my workplace was a friendly environment, we were like friends, but now I feel I am alone; no one understands me* (Participant no.7).

Discussion

The findings of this study presented unique and new understanding on daily living of HIV positive nurses in Iran. According to the results of the present study, the "blurry world" of HIV positive nurses is full of risks, fears, and sense of duality in their existence, professional identity, and professional affiliation.

Being-in-the-risky world indicated that HIV/AIDS made nurses physically and psychologically more vulnerable to occupational stressful issues. They find their immune system weakened so they were always watchful of catching nosocomial infections. In this study, HIV positive nurses tried to be more careful during patients' care. They tried to fulfill their duties while avoiding nosocomial infections but there constantly is sense of susceptibility. Knowing their fragile health status after becoming HIV positive, they considered health risks posed by the work of nursing more seriously. In Daley's study,

participants also felt that their health was very fragile after being infected with HIV. They also described how challenging it is to tolerate the side effects of antiretroviral drugs and how the treatment affects their daily activities (27). Findings of other studies showed fear of acquiring secondary infections and the side effects of antiretroviral treatments can negatively affect a person's ability to work (28,29). Some studies also reported that after becoming HIV-positive or having a needle stick experience with HIV patients, nurses paid more attention to self-care. They have also become more cautious in providing care for patients because of the perceived risk of acquiring nosocomial infections (27,30).

Being-in-the-Shadow of Illness is the other subtheme of living in the blurry world. This subtheme showed that how participant's life world is surrounded by fear. HIV/AIDS imposed fear in every moment and everywhere in participants' life. The results of the present study revealed that participants were fearful of engaging thoroughly with colleagues in the workplace, and the anxiety of disclosure was so intense that two participants described an unwillingness to develop new relationships. Also, in the Audet's study, the participants experienced similar reactions. They reported perceived or actual discrimination by families, friends, medical staff, and within the workplace; thus, they chose self-isolation as a coping mechanism to limit their exposure to damaging reactions (31).

 Participants in the present study stated that they were reluctant to seek emotional or psychological help from family or colleagues because they were more likely to be stigmatized. Rintamaki's study found that people who used antiretroviral drugs were unwilling to take their medication in public and conceal their medications that directly led to delayed or missed doses (32). As in this study, HIV-positive nurses prefer to suffer in silence and isolated for disclosing their illness and seek help from family and friends. They are trying to maintain the status quo, and the slightest change generates more anxiety and tension (33, 34).

Nurses are always considered as reliable and trusted people (35). Becoming HIV-positive as a nurse displays their own vulnerability and alleged lack of self-control in their personal lives(9). It is challenging for people to accept that an HIV-positive person may take care of them. In this study, participants stated that they fear unwanted disclosing their HIV in the workplace. In the study by Kiakuwa et al., nurses were worried that patients would become aware of their HIV-positive status. They feared losing the respect of both patients and doctors when their HIV status to be made public (10).

In the present study, nurses stated that they did not receive enough support from the work environment and therefore felt that it had relatively decreased their sense of professional belonging. The literature review results on the studies of HIV-positive nurses 'experiences did not directly address any change in nurses' professional belonging (9, 21, 22, 36). A culture of discrimination and exclusion in the workplace and fear of nosocomial infections cause HIV-positive nurses to lose some of their professional attachment. Trying to be more careful while avoiding nosocomial infections and constantly worrying about their health reduced their motivation to work (30, 37). In the study of Kyakuwa et al., participants expressed that fear of stigmatization was worsened by the notion that nurses usually are expected to be healthy. These concerns cause a culture of silence and psychological detriment (9). HCWs providing HIV care in South Africa refused to get tested for HIV because of perceived stigma and fears of breach of confidentiality. The identity of HIV-positive people in the position of health care workers has more complexities. These concerns and complexity led to more secrecy and silence among HCWs (38). Similarly, in the Audet's study, participants stated they didn't want to add extreme tension to the family; or they assumed that the parent would not be supportive (31).

The experience of the participants in the present study revealed that they were reluctant to disclose their health issue. As they feel that disclosing HIV/AIDS have unfortunate consequences like blaming or rejection by family, friends, and colleagues. Participants expressed that they try to hide their disease from others in various ways. Taking medicine secretly, fabricating stories to hide the truth, lying, receiving care from health centers other than their workplace, avoiding periodic occupational health examinations were done to cover the HIV-positive identity from others. In this regard, literature review showed that in most studies patients experience social stigma, behavioral challenges, negative emotions, and psychological distress as the results of disclosing their illness (39-41). However, Stutterheim's study showed that HIV-positive health workers disclosed their HIV status in the workplace because of the need to share their secrets (emotional release) and anticipate it to be positively acknowledged. In some cases, they obtained supportive feedback from their colleagues and

managers (36).

Ambiguous Being-in-the-World reflects the participants' ambiguity in their existence as healthy or unhealthy person. Ambiguity in the role of the nurse and the patient sometimes manifests itself in such a way that sometimes fear and worry about stigma cause people to avoid receiving help or treatment or to seek treatment late. In this study, the participants' identity is like a spectrum that on one side was nursing's identity and the other side was patient's identity.

Most participants in the present study felt they are on the patient's side instead of being on the care provider's side and lose somewhat their sense of professional belonging. Sense of belonging generally refer to "an individual's sense of identification or positioning in relation to a group or to the college community, which may yield an effective response" (42). Similarly, the sense of vulnerability and feeling ill in nurses experiencing skin injuries during work caused them more careful of themselves in clinical settings. The nurses feel a need to be more vigilant and less accepting of potential risks in workplace. Also, lack of adequate support for nurses made their experience more distressing and heightened sense of loneliness and abandonment. The author concluded that colleagues' absence of support or respect caused participants to lose some of their attachment to the profession and even rethink about their careers (27). In the study on HIV-positive nurses in Uganda, the participants struggled to cope with the dual role of being HIV-positive, they opted for secrecy about their HIV status in their workplace (10).

Nurses in the present study felt that HIV/AIDS made them mentally and physically vulnerable, and therefore they found their career environment full of danger and stress. Although nursing gives them a personal identity and financial independence, HIV/AIDS makes a dilemma between working in a stressful environment and quitting their job. The dichotomy between patients' care and self-care added more ambiguities to their world and affected their occupational belonging. Although HIV-positive nurses are expected as professional and knowledgeable people to better manage their illness, the results of this study showed that they needed more adaptation skills and support, to better adapt in their workplace.

Implications for practice

HIV positive nurses perceive their world full of fear and ambiguities. They prefer to suffer in silence and are reluctant to disclose their seropositive status. The results of this study can be used by professionals to better understand the HIV positive nurses' world and make more efforts to improve their workplace experiences and reduce stigma in the future. Findings in this study also support the need for more explicit national guidelines to encourage HIV positive nurse to initiate counseling and treatment follow-up. Also, it is necessary to develop the specific facilitating policies which address positive nurses' physiological and psychological needs in work place.

Acknowledgments

Conflicts of interest

The authors declared no conflict of interest.

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