Experiences of patients with primary HIV diagnosis in Kermanshah-Iran regarding the nature of HIV/AIDS: A qualitative study

Fatemeh Gh.Barkisha, Rostam Jalali, Amir Jalali

Psychiatric Nursing Department, School of Nursing and Midwifery, Kermanshah University of Medical Sciences, Kermanshah, Iran

Nursing Department, Kermanshah University of Medical Sciences, Kermanshah, Iran

ARTICLE INFO

Keywords:
Psychology
Qualitative research
HIV diagnosis
HIV
Lived experience

ABSTRACT

Background: A diagnosis of HIV (human immunodeficiency virus) infection causes a wide range of mental challenges regarding the meaning and understanding of such a diagnosis because of the specific nature of HIV and its social consequences. AIDS patients perceived their disease as multidimensional Stigma and rejection and even discrimination and insult in receiving health services. Therefore, a deep awareness and understanding of an individual's meaning and interpretation of a HIV-positive diagnosis and their relevant experiences are essential for providing better care.

Objective: This study aimed to examine the attitude, understanding, and interpretation of a positive diagnosis of HIV.

Methods: The present qualitative study was based on the descriptive phenomenological method. Participants included 13 HIV-positive patients who had been referred to the Kermanshah Counseling Center for Behavioral Diseases in Iran and diagnosed at most 6 months before being interviewed. The data were collected via semi-structured in-depth interviews.

Results: The continuous analyses of the data and the interview notes resulted in the identification of five main themes: contagious disease with two subthemes Illness and Harm to others, new self with a Crisis of identity subtheme, disappointment with the life ending and impending death subtheme, unmentionable disease with two subthemes secretive and horrifying diseases, and loss with Frustration subtheme.

Conclusion: Because the attitudes and behaviors of other people, such as relatives and people in society had a negative impact on the participants' mental status, as well as on their perceptions and understanding about the positive diagnosis, the focus of care for people with HIV/AIDS should shift from therapeutic issues to socio-cultural ones. These issues play a major role in forming an individual's understanding of HIV and can be a vital factor in improving their activities and adaptations to a positive diagnosis.

1. Introduction

According to the most recent reports, the number of HIV infections reached 36.9 million by 2016 [1]. In Iran, more than three decades has been passed since the advent of HIV. During this period, according to the latest reports, the number of individuals infected with HIV has been estimated to be 66000. During 2010 to 2016, the number of the infected in Iran increased by 21%. Although the main source of HIV transmission was the injection of drugs through using shared injecting equipment by the consumers [2], the recent statistics suggest a marked shift in HIV transmission from the injection of drugs to sexual behaviors [3, 4].

Although HIV/AIDS (human immunodeficiency virus/acquired immune deficiency syndrome) has changed from being a fatal disease to a controllable chronic disease because of the advances in antiretroviral therapy (ART) [5] for patients, a positive diagnosis is still a complicated and stressful event.

A diagnosis of HIV/AIDS is often associated with stigma, discrimination [6] and loss [7] and can result in decreased self-esteem [6] and uncertainty [13, 14, 15]. These reactions may cause serious changes in a person's life so that the periods before and after the diagnosis can be distinguished as “two separate realities” [16]. A positive diagnosis of HIV/AIDS is often accompanied by a sense of loss, purpose, and hope [17]. The diagnosis influences a person's image of the future [18], and is
followed by a set of reactions, such as shock and disbelief [7, 19, 20, 21], fear [19, 21], shame and anger [7], despair and desperation [21], and even suicidal thoughts [10, 20, 21].

These reactions are influenced by the social image of HIV as an incurable disease in a specific sociocultural environment [19]. However, negative reactions of the community and the stigma that is attached to the disease can be affected by cultural context of society [22]. Reduced mental health increases the risk of adverse behaviors, such as the non-disclosure of a positive diagnosis, the non-adherence to treatment, substance abuse, and high-risk sexual behaviors [23]. Therefore, a person's interpretations of disease, health, and help-seeking behaviors are largely influenced by the culture and society in which they live [24].

In Iran, due to the critical role of the family, which is one of the prominent features of Iranian culture, one cannot distinguish individual issues from the family ones [4], as living with family members has a significant impact on the adherence to ART [25]. On the other hand, the traditional nature of the family's cultural context adds to the difficulties of living with HIV/AIDS through highlighting HIV/AIDS-related problems such as stigma and discrimination. HIV/AIDS-related studies in Iran represent a widespread discrimination against the people living with HIV (PLWH) [4, 26], which impedes the disclosure of illness and non-adherence to treatment [27, 28]. Similarly, according to recent studies, individuals with HIV benefit lower social support and lower quality of life than the other individuals [29].

Culture and society play an important role in how individuals perceive stressful events and living conditions, such as a HIV-positive diagnosis. These perceptions play a vital role in directing a person's thoughts and controlling their psychological responses, which determine the quality of their response to the situation. In fact, different meanings and interpretations associated with a positive diagnosis can determine behavioral patterns and thus affect the quality of a person's adaptation [30] and sociocultural determinants have a key role in the spread of AIDS, and a major step in AIDS prevention in Iran [31].

Previous studies on how the perception of HIV determines the quality of life for people after receiving a positive diagnosis have shown that the diagnosis has a dual function, as well as a serious effect on one's life [32, 33]. Iranian patients perceived AIDS as multidimensional Stigma and rejection and even discrimination and insult in receiving health services [34]. That is, it either improves an individual's quality of life and health status or it destroys their life. Valle and Levy [32] concluded that the different interpretations of a positive HIV status are associated with different behavioral patterns. In a study [35], participants who perceived HIV positively had a lower level of depression and a greater psychological well-being. Accordingly, how people perceive and interpret HIV not only affects their quality of life after their diagnosis, but also can be associated with different psychological outcomes. Assisting patients through appraisal of their illness can have an increasing impact on their psychological recovery [36]. Moreover, it seems that there is a widespread range of issues that a person faces after diagnosis (such as making the decision to start treatment) in addition to the psychological consequences. For example, Wrubel et al (2011) studied 20 people who were HIV-positive and showed that a person's assessment of the disease and ART can affect their decision to initiate therapy and to join a treatment program [37].

These studies found that a person's awareness and the nature of their response to a positive HIV diagnosis played a critical role in predicting their behavior patterns, their acceptance of the new conditions, and their decision to undergo treatment. Hence, studying the meaning and importance of an individual's perceptions of a diagnosis of HIV/AIDS are important. Interrelatedness and impact of socio-cultural components on an individual's perceptions and sense-making during stressful conditions, such as receiving a HIV-positive test, reveal the importance of understanding the cultural contexts in which the individual lives.

However, no study has been conducted on the nature of a diagnosis of HIV with regard to people living in Iran. Thus, the present study was performed to examine the attitude, understanding, and interpretation of a positive diagnosis of HIV.

2. Method

Qualitative research is used by a researcher to conduct a study that is based on the facts and viewpoints of individuals. Qualitative studies are used to achieve a rich understanding of a phenomenon as it exists and is perceived and experienced by individuals [38]. In this study, qualitative research with a descriptive phenomenological approach was carried out to examine an individual's interpretation and understanding of a HIV-positive diagnosis.

In-depth semi-structured interviews, notes, and open-ended questions were used to collect information. There were 13 participants in this study who had been referred to the Kermanshah Counseling Center for Behavioral Diseases in Iran. A purposive sampling approach was used to gather information about the participants' experiences [38]. The inclusion criteria were as follows: the participant was able to volunteer and to express feelings, had an HIV test, had received an HIV-positive diagnosis a maximum of 6 months earlier, was not affected by mental illness according to their file, was at least 18 years old, and was able to communicate appropriately.

All participants were interviewed face to face. The interviews lasted from 60–120 min depending on the participants' abilities. The interviews were conducted in a consulting room with a relaxed and private atmosphere at an appropriate time when the participant felt comfortable. The sampling also continued until the data saturation was reached and it lasted for 6 months. Data collection and analysis procedures were carried out from June to November 2016. Because of cultural issues, the researchers did not have permission to record the participants' voices and, thus, had to record the interviews by hand. The interview guide questions were based on the goals of the study. Topics of the questions included the meaning of positive diagnosis, people's perception of positive diagnosis, thinking about HIV, attitudes, and feelings about themselves as an HIV-positive person.

The researcher carefully studied and reviewed the first interview several times in order to understand and be informed of the participants' experiences, and then underlined meaningful words, phrases, and statements which were related to the discussed issue, and extracted important sentences or first codes. Then the meaning of each expression was explained. In other words, from each statement, a concept expressing an individual's meaning and attitude was extracted. After encoding, the concepts were carefully considered and sorted according to similarity. Subsequent interviews were also analyzed. The results were combined to reach a more comprehensive description of the phenomenon under study and more general categories were thus developed. The results were reviewed to obtain clear concepts and they, in addition to being abstract, were completely unambiguous in order for the readers to capture the concepts derived from the study [39]. Finally, to validate the findings, there was one face-to-face interview session with some participants being asked some questions about the results. When results were confirmed by the participants, the findings were verified.

In order to determine the validity of the study, Lincoln and Guba's criteria, which include credibility, dependability, transferability, and confirmability, were considered [38]. To this end, this study focused on long-term engagement, continuous observations, the control of the codes and categories by experts, a diverse sampling in terms of age and cultural background, and the accurate reporting of details and study steps. The codes and interviews were submitted to and confirmed by qualified experts in this field. Furthermore, the participants were used to confirm the accuracy of the interpretation of the data.

2.1. Ethical considerations

This study was approved by the Ethics Committee of Kermanshah University of Medical Sciences (No 95126, KUMS.REC.1395.123). After explaining the research objectives and procedures, informed consent
forms were completed and signed by the participants. Participants were assured of complete confidentiality of all their information. The location and time of the interviews were set by the participants. The principles of “no-harm,” in which the research should not be detrimental to the participant and “confidentiality” were followed.

A summary (150 words) of this study is under review with the form of a research letter.

3. Result

Of the 13 participants in this study, 47% (n = 6) were male and 53% (n = 7) were female. Participants had received their diagnosis 2–6 months before being interviewed; the mean time of the diagnosis was 4.8 months (see Table 1). None of the participants received antiretroviral therapy. The continuous analyses of the data and the interview notes resulted in the extraction of five main themes: contagious disease, new self, disappointment, unmentionable disease, and loss.

3.1. Contagious disease

One of the themes extracted from the participants’ statements is the contagious disease, which encompasses two subthemes Illness and Harm to others.

3.1.1. Illness

I have a problem. HIV has sickened me... I have to visit this center because I am dependent on it... I have to have a test... to check it and if necessary, I should visit my doctor, this continues to the end of my life... (P 12).

Although the participants had received the positive diagnosis test within the past 6 months and were not yet undergoing treatment some described HIV as an illness and said that they felt sick. Referring to the lack of definitive cure, they simply considered the positive test to be an illness: ‘I am no longer a healthy person; I am suffering from a disease that has no cure... no remedy...” (P 2).

3.1.2. Harm to others

When expressing their concerns about HIV infection, the participants, especially women, were afraid of causing harm to others. Therefore, despite being aware of the methods of transmission, they felt obliged to take precautions in their interpersonal relationships to prevent the spread of HIV, especially to their children. As one of the women participants stated: “I took all my daughter’s stuff out of my room... even when showering her, I was wearing gloves so I would not harm her unintentionally...” (P1). Other participants made similar statements: “I wanted to harm no one... I’m cautious at home, outside or wherever I am, especially when I am cooking; I look for my hand not to bleed and harm someone... I am always careful” (P6).

3.2. New self

Participants’ statements represented the development of a new self. They believed that they were no further the ones before the diagnosis and that their feelings and attitudes toward themselves had changed.

3.2.1. Crisis of identity

I feel that I’m not the same guy as I was before. I’m different. Well... you are different because you should be careful, observe and follow the guidelines, visit the counseling center and be involved in this issue (P9).

Being diagnosed with HIV caused a change in the participants’ attitude toward themselves. They referred to HIV as an illness with no cure, to a feeling of being sick, to visiting the counseling center and the doctors, and to being cautious. The participants regarded themselves as being infected with HIV, which made them see themselves as being different from others. For example, one of the participants stated: ‘But now that I am cautious, especially with respect to my daughter, it means that I have changed... I am not the person that I was’ (P1).

3.3. Disappointment

Because of the prevalence of HIV and the negative social status of this phenomenon, the participants’ comments reflected a feeling of disappointment following the positive diagnosis since this event represented them the life ending and impending death.

3.3.1. Ending

In this study, all participants felt despair and were depressed after receiving their positive HIV diagnosis. They considered the positive test to be the finish line, and expressed feelings of falling, gradual death, and being at a dead end in life. One of the male participants interpreted the positive HIV test itself as follows: “it’s like falling into a deep well with no way of escape, it’s like a gradual death; you feel that you’re stuck. It is somehow like a dead end and there’s no way to escape...” (P12). One female participant referred to the despair and desperation that she felt following the positive test and claimed: ‘I'm really happy with nothing or no news... Even when my nephew was born, I was not happy. I feel everything is gone; my life is over...’ (P10).

3.3.2. Impending death

Although recent advances in the ART have redefined HIV as a chronic disease, all the participants in the study viewed HIV as a fatal illness. They considered the positive test result to be a premature death sentence.

I thought that I was to die... but then I was told that they are not the same... But I think of it again... you feel as though you’re not permanent. You’re not going to be alive, even though I know nobody knows this issue. For me as a HIV positive patient, I think I am not going to live a long time... you always have the terms death and dying in your mind... (P9).

Not only is the premature death perception a concern for people infected with HIV, but they also worry about post-mortem defamation because of the ethical issues that are associated with HIV. One of the male participants in the study pointed out that HIV could degrade a person’s...
value and take their dignity away even after dying. He said:

The first thing that comes to your mind is death, but not a natural death. A death linked with HIV has no dignity. Later, it would also be said that he died of this disease. Until the end of the world, you are tagged with HIV... (P13).

3.4. Unmentionable disease

Another extracted theme is unmentionable disease, which encompasses two subthemes secretive and horrifying diseases. A negative view to the HIV causes this phenomenon to be distinct from other chronic diseases. The negative attitudes and behaviors of the society impose pressures on these individuals to the extent that this often makes them silent about their condition. Hence HIV can be considered an unmentionable disease since the patients are exposed to negative outcomes after the positive diagnosis.

3.4.1. Secretive

"When a person is positive HIV, he must always keep his secret from others. We have to do everything in secret. Visiting the counseling center, you have to be careful not to inform others..." (P5). Only five participants in this study informed their families, which may have referred to only one or two members, about their positive diagnosis. Participants were incapable of telling their families because of the common perception that the disease deviates from ethical norms and is not accepted in society; in other words, this was their secret and they were trying to hide their condition from others. They described how they lived their life while concealing their condition. Because of the method of transmission of HIV, it is possible to avoid exposure to the disease and, thus, society assumes that people who are infected are responsible for contracting HIV and disrespects them. Patients with HIV are misjudged and face the negative attitude of society. Under these circumstances, disclosure of HIV status can be threatening and can lead to stigma and discrimination, as well as to the loss of family, friends, and jobs.

"This is a secret to you. The HIV positive means that you have a secret of which no one should be informed. If you reveal your secret, you will face many problems..." (P7).

People with HIV face the negative reactions of society, as well as the judgment and blame that is placed on them for having the disease. This makes people with HIV prefer to bear the burden of the disease by themselves. As one of the participants said, "If they know, they will escape, so I prefer to inform no one ... It is better" (P6).

3.4.2. Horrifying disease

The studied population considered HIV to be a horrible disease. The participants appraised their HIV-positive diagnosis as being horrendous due to the attitudes of the society to the HIV and regarded it as scary, horrifying, and horrible. For example, one of the female participants said: "Its name is horrifying. It's scary ... when it's called, everyone is scared ..." (P9). It seemed that the horrifying image of HIV was affected by a lack of awareness and information about the methods of transmission, the progressive nature of the disease process, antiviral treatment, the incorrect beliefs about an early death, the link between ethical issues and HIV, and discrimination and stigma, which are less common in other chronic diseases and conditions.

3.5. Loss

The other theme extracted from the participants’ statements is loss. Participants claimed that HIV deprived them from many benefits such as emotional and supportive relations, respect, and credibility.

3.5.1. Frustration

Because of the emergence of psychosocial problems and extreme socio-familial deprivation, a positive HIV diagnosis for some participants meant nothing but loss: “It is like a big dam that deprives me from a lot of things I want ... things like marriage and marital life ...” (P10). Another participant interpreted being HIV-positive as follows: “One loses everything: value and respect... dignity ... family ... health ...” (P12). Others described being rejected and losing their loved ones and family:

When you are positive, you lose many privileges, including your family and your siblings... you have to restrain yourself ... you should put everything and those you love away ... because if they know about this disease, they will put you out of their life (P7). Some participants considered the positive test results to be a limitation and isolation. One of the female participants said, “There are a bunch of thoughts attacking your mind. For example, how long do I stay alive and live with my children? I’m not always supposed to be with my children...” (P4). Referring to the specific conditions of HIV in the community, participants stated that their HIV-positive status led to isolation and seclusion. A 35-year-old man who did not disclose his secret to anyone asserted, “You should give up a normal life, you have to pack your stuff and have a tent in a desert...” (P3). Another participant emphasized isolation and noted, “Isolation and loneliness! I have to take a certain path alone...” (P2).

4. Discussion

The aim of this study was to evaluate the understanding and meaning of an HIV-positive diagnosis. Each participant in the study, based on their mental imagery and content, had different interpretations of their diagnosis, which were influenced by many factors, such as the disease's incurability and the nature and specific status of HIV in the community. Participants referred to their diagnosis as a challenge that affected all aspects of their personal and social life. From the participants' interpretations and statements regarding the meaning of their HIV-positive diagnosis, we extracted five main themes: contagious disease, new self, disappointment, unmentionable disease, and loss. The patients' perception and understanding of HIV is such that they have concerns about the psychosocial and social reactions such as contagious disease, disappointment, loss, new self, unmentionable disease, stigma, and social rejection.

Although the participants had recently received their positive diagnosis and showed no signs or symptoms of opportunistic infection, they assumed that the HIV-positive diagnosis was a disease and that they themselves were patients. This contradicts the results of previous studies, such as the study by Wouters and De Wet (2016) [12], which concluded that the participants considered themselves to be sick only when they were physically ill or had signs of opportunistic infections. Our findings emphasized the importance of providing psychosocial counseling services based on the attitudes and perceptions of the patients. However, a person who equates an HIV-positive diagnosis with a disease would be in a psychologically difficult condition and would be more vulnerable to future problems and consequences. Previous studies showed that having positive attitudes to an HIV-positive person can promote an individual's mental health [35, 40].

One of the differences between women and men participating in this study was their sensitivity to HIV transmission. Because of the contagious nature of HIV, the women felt more responsibility, sensitivity, and concern regarding the transmission of the disease to others especially their children. They had adopted prudent and self-control measures, had strict discipline in their daily interactions, and were cautious in their interpersonal relationships to prevent transmitting the disease to others; however, men were less concerned in this regard. These results agreed with previous studies that showed that fears of HIV transmission to one's child or partner made some patients avoid becoming pregnant and having children [9, 41], as well as made them cautious and restricted in their interpersonal and social relationships [42].

The findings of the study also indicated that a positive diagnosis had
caused the participants to feel differently and to change their attitudes about themselves. In this study; contagiousness, incurability, visits to medical centers and doctors, ethical issues regarding HIV, and the interruption of daily living activities were factors that influenced the participants’ feelings about themselves and challenged their identity. These findings are in line with previous studies [12, 43]. However, given that the integration of HIV into one’s identity integration of HIV into one’s identity takes time and is influenced by one’s beliefs about HIV [44], the participants’ negative attitudes and understandings can affect the duration of this process. This further identifies the increased need for targeted and effective intervention by healthcare providers.

The findings of this study suggested that for participants, an HIV-positive diagnosis was synonymous with falling and despair. In fact, if a person was aware that HIV was incurable and was a taboo in society, that individual could find themselves in a vague, threatening, and difficult condition, which could result in despair and disappointment by distorting the prospects of their life.

Morse and Penrod (1999) illustrated despair as an absolute black, dark tunnel with no end in which people were unable to find a way out of the pain and suffering [45]. However, hope is of great importance when tackling the prospect of being diagnosed with a chronic disease, such as HIV/AIDS, because it is a stimulus for seeking care, adhering to treatment, facilitating adjustment, and reducing emotional distress in response to stressful events [46].

Nevertheless, the participants in our study interpreted the positive diagnosis in various ways: as being a dilemma, being at a dead end, having the feeling of falling, and having a shift in life. They considered it to be a factor that caused demotivation, contributed to the meaninglessness of life, and caused them to seek seclusion from society. In contrast to the findings of this study, a number of studies reported that the participants perceived HIV as a positive achievement that presented a new set of opportunities and goals [32, 47]. These differences in findings indicated that more attention is needed to develop effective and innovative attitude-based interventions in order that people with HIV can continue to live and be accepted in their community.

Based on the findings of this study, the participants indicated that an HIV-positive diagnosis meant an imminent death sentence. Although recent advances in the ART can prolong life by suppressing viral activities and HIV is now identified as a controllable chronic illness, there is still no known HIV/AIDS cure and the life expectancy of PLWH is low [48]. Accordingly, the disease is perceived as a “social and physical death” [11] in society. Therefore, an HIV-positive diagnosis contributed to a life filled with the fear of stigma [18], and also made death a key concern. In other words, people experienced disappointment and a fear of imminent death after a positive diagnosis [7, 32, 42]. However, in some studies, HIV/AIDS was considered to be a chronic disease and it was not equivalent to death [33, 47].

One factor that should be considered while assessing people with HIV is the time interval after diagnosis [33]. For example, Flowers et al. (2011) [43] interviewed 14 HIV-positive gay Scottish men 4 years after their HIV diagnoses and showed that, although they still considered HIV to be a death sentence, their perception had diminished over time. However, psychosocial factors associated with the diagnosis, such as identity, remained sources of distress. As the diagnosis interval for the participants in this study was limited to a maximum of 6 months, the concept of “imminent death,” which was also emphasized in other studies, was highlighted more than other concepts. Evidently, this concept was more evident with an increased time interval [43, 49].

However, it should be noted that other factors, such as the cultural context of the community, access to appropriate health services, and the existence of supportive systems, can also influence this assessment. This study found that the participants still perceived HIV to be more frightening than other chronic diseases. This may be due to its incurability and its close connection with prostitution and drug use, which are considered to be contrary to the moral values in the studied society. This interpretation was also apparent in other studies that were carried out in a variety of other cultures [42, 50].

For this reason, the disclosure of a positive diagnosis was one of the most challenging issues facing the participants in this study. Because of society’s attitude toward this disease, which is related to its deviation from ethical norms, most of the participants were incapable of telling their families about their positive diagnosis because of stigma, discrimination, and rejection. Their diagnosis was their secret. They described living with HIV while concealing their condition and feared disclosing their circumstances to others because, in their view, a positive diagnosis meant the loss of loved ones, the removal of their circle of friends, and perturbation in social relations. This negative attitude is rooted in the contagious nature of HIV, which can be transmitted through sexual intercourse. Hence, unlike other chronic diseases, HIV is not regarded as a normal chronic disease by society. However, living in silence without disclosure put a patient in the condition of “having two faces” and “living a double life” [42] and “living in two worlds,” [12] which constantly caused them to feel broken inside and to be cautious with others.

Constant concerns about disclosing that they were HIV positive to others imposed more stress and psychological burdens on the patients; however, disclosure led to better disease management, protected the individual from discrimination and stigma [51], created a sense of control, and maintained a social identity to ensure the continuation of a normal life [52]. While disclosure can expose a person to a difficult situation that can be associated with suffering, loss and its link with suffering is one of the most important concerns people have when living with HIV/AIDS [50].

Participants in this study interpreted a positive HIV diagnosis as a loss because of its psychosocial aspects and the possibility of being excluded from one’s family and from society. They considered their positive diagnosis to be a threat to their individual and social lives because it led to the loss of their family and social status and to the deprivation of equal socioeconomic opportunities, such as a job, marriage, and housing. In other words, an HIV-positive test meant trouble because the patient was in a vague and difficult situation that involved an incurable disease and resulted in psychosocial problems.

Although HIV/AIDS is less prevalent in Muslim countries than in other countries, the HIV-related stigma is more and more perceived in these societies [4, 53]. This might be due to religious and ethical norms governing these communities and Islam’s teachings regarding the prohibition of high-risk behaviors as the main source of HIV transmission since Islam emphasizes on moral values and self-cultivation and prohibits high-risk behaviors.

In Iran, traditional religious individuals form a large proportion of the population; therefore, behaviors that are inconsistent with the ethical norms of the community are not accepted by the general public, resulting in negative attitudes towards patients with more severe symptoms. This would have a deeper negative impact on individuals’ perception and understanding of the meaning of HIV and would lead to a more painful positive diagnosis and more complicated conditions for the PLWH.

Another study in Iran indicated that a positive diagnosis extended beyond physical problems for the participants who referred to it using such concepts as annihilation, suffering, mortality, and a vague future [54].

Considering the significant impact of religious cultural components on the meaningfulness of the positive situation, the role of religious leaders in shaping the beliefs of the community is of high importance; therefore, the religious leaders’ teachings in this field seems to be of use in reducing the negative attitude towards HIV/AIDS and PLWH [4, 26].

4.1. Limitation of this study

The participants were selected from individuals who were referred to the Kermanshah Counseling Center for Behavioral Diseases. Thus, the findings may be different from the results for other patients who do not visit these types of centers. Sampling was limited to those participants who met the inclusion criteria, which did not include investigating the
meaning of an HIV diagnosis from the viewpoint of children, adolescents, or those with mental disorders. In addition, the participants were generally from a middle-class and low-income background, which could have influenced society’s attitude toward HIV. To further understand the results, a more diverse and larger sample size is recommended. Furthermore, the researchers had to rely on handwritten sentences and statements because they were not able to record the participants’ voices, which might have resulted in the loss of certain non-verbal observations and behaviors.

5. Conclusion

Despite the remarkable advances in the field of HIV/AIDS in recent years and the fact that it is now a controllable and chronic condition, the participants in this study described a positive diagnosis in terms of loss, despair, and death. The use of these terms was related to its incurability and to the negative reactions of society. These interpretations showed that despite the advances in ART, there has not been a parallel change in the attitudes toward HIV; thus, the progress made in the field of antiviral therapy has not been successful in changing people’s attitudes and perceptions toward HIV. The incurability of the disease and the sociocultural context of the community dominated the participants’ understanding and interpretations, which indicated that HIV cannot be separated from the sociocultural reality.

In general, it can be concluded that the perceptions of individuals with HIV and attention to their individual characteristics is essential for counselors and healthcare providers in order to provide better services to these patients due to the paramount importance of understanding the meaning of HIV in individual coping. While the findings highlighted that society’s attitude has a significant impact on the interpretation of an HIV diagnosis, a positive diagnosis is a major challenge to all aspects of a patient’s personal and social life. Therefore, raising society’s awareness about HIV should be considered by policymakers.

Because of the significant role of religious leaders in Iran, they are of influence in society. Various dimensions of HIV can be taught to them so that they can develop a positive attitude towards the individuals with HIV and bring them social respect at the community level, thus making an important step in improving individuals’ perception and understanding of positive diagnosis and its acceptance.

In addition, macro-level training programs can be used to modify misconceptions and misinterpretations about the disease. The development of educational programs for the public can largely increase the community’s awareness about HIV, change the community’s attitudes and beliefs towards HIV, and improve the behaviors of others in dealing with PLWH. Such an attitudinal change also creates empathy and social support and facilitates the acceptance of a positive situation by PLWH. More emphasis should be placed on the need to increase social support, education, and counseling for people affected by HIV.

Declarations

Author contribution statement

Fatemeh Gh.Barkish: Performed the experiments; Wrote the paper.
Rostam Jalali: Conceived and designed the experiments; Analyzed and interpreted the data; Contributed reagents, materials, analysis tools or data; Wrote the paper.
Amir Jalali: Analyzed and interpreted the data; Contributed reagents, materials, analysis tools or data; Wrote the paper.

Funding statement

This work was supported by Kermanshah University of Medical Sciences, number 95126.

Competing interest statement

The authors declare no conflict of interest.

Additional information

No additional information is available for this paper.

Acknowledgements

The researchers express their gratitude and appreciation for the great contributions by the authorities and staff at the Kermanshah Counseling Center for Behavioral Diseases, as well as to Mrs. Karami, an advisor, and all the participants in this study.

References


