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A Survey of the Experience of Living with HIV+/AIDS from the Perspective of Ahvazi Women Focusing on Educational Needs and Empowerment: A Qualitative Study

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Qualitative Study

Abstract

Background: In Iran, there is a significant increase in women living with HIV+/AIDS. In a cultural, social, and political context, educational and empowerment needs are still considered a challenging issue among these women. The purpose of this qualitative study was to examine the experience of living with HIV+/AIDS from the perspective of women in Ahvaz, Iran, focusing on educational needs and empowerment.

Methods: The present qualitative study was a descriptive phenomenology conducted in 2020. The research context included all educational, therapeutic, counseling, and support centers, governmental and non-governmental HIV/AIDS associations and institutions located in Ahvaz. The statistical population of the study included all women with HIV and AIDS. The study participants were selected using purposeful and snowball sampling method. Semi-structured open interviews (individual and face-to-face) were selected as the primary and central approach to data collection.

Results: The findings showed that the 5 identified themes of understanding the experience of focusing on educational needs and empowerment in women were severe suffering (shock, anger, resentment of the family and friends, and feelings of isolation), disapproval (prejudices, stereotypes, and taboos related to HIV in society, and feeling of lack of social support), insecurity in social and economic life (lack of readiness for cultural and social participation, equality or inequality in empowerment, assessing relationships based on economic criteria, and doubts about improving health), disrespect (disrespect for unique characteristics, and insult and slander), and hardship in protection (continuing to control health status information).

Conclusion: It can be concluded that the educational and empowerment needs of patients with AIDS/HIV+ should be taken into consideration. Mobilizing individuals, specialists, and providers of counseling and care services in different sectors to gain a better understanding of the complex nature of the phenomenon of non-compliance with the right to empowerment will be useful.

Keywords: Female; Acquired immunodeficiency syndrome; Qualitative research

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Introduction

Although HIV+/AIDS has been identified and its medical dimension have been discussed, its cultural, social, and economic dimensions are also critical and play a decisive role in its growth and rate of increase, and the context of its various health, social, cultural, and economic consequences. It is transmitted at the community level (Lesch et al., 2007). HIV+/AIDS is not only one of the most devastating and terrifying diseases of the present age, but also a new and unique social phenomenon that affects almost all aspects of social and economic life. HIV+/AIDS has a profound effect on the lives of those infected (Deeks et al., 2016). Health, family life, group and social activities, economic development, and personal development are factors affected by this disease. The belief that people are infected intensifies the adverse effects. "From a social point of view, this disease has become a social construct, and more specifically, social stigma or an issue that targets the social dignity of the sufferer at different levels" (Remien & Rabkin, 2001).

It should be noted that individuals' assessments of and responses to stressors indeed stem from their personalities, histories and life experiences, and personal characteristics. Individuals' coping responses to single stress are different, and therefore, individuals have different interpretations of stress, and each individual's adaptation method is unique (Kohan, Mohammadali Beygi, Fathizadeh, & Malbousizadeh, 2008). For example, Kohan et al. (2008) concluded that the lack of family and social support and support from health care system due to inappropriate labeling and judgments forced patients to make maladaptive responses, including denial and avoidance, and in the long run, this increases the symptoms of helplessness such as depression and anxiety in HIV/AIDS patients (Ndlovu, Ion, & Carvalhal, 2010). Moreover, similar studies conducted in Canada in 2010 and Uganda in 2009 showed that seeking and benefiting from social support has been an active adaptive strategy used by people living with HIV/AIDS (Khani, Bidarmaghzi, Majdi, Azadmarzabadi, Joharinia, Shakeri, 2012). The use of dysfunctional coping strategies in HIV/AIDS patients, such as avoidance and lack of adoption of active and effective coping strategies in the face of stress, increases their mental and psychological problems and physically, psychologically, and socially endangers patients (Razavi et al., 2012). Numerous global studies on chronic diseases such as HIV/AIDS have shown that the use of unhealthy and destructive strategies has a direct relationship with high levels of stress, low quality of life (QOL), and the adoption of high-risk behaviors (MacLachlan et al., 2016).

Furthermore, empowerment is another structure that should be considered in patients with AIDS/HIV. Empowerment is a practical tool that promotes the growth and elevation of individuals' knowledge and skills. The application of its solutions is an obvious goal for the promotion of the health of communities (van den Berg, Neilands, Johnson, Chen, & Saberi, 2016). Empowerment could significantly improve the awareness, knowledge, self-esteem, and self-efficacy of patients and their home caregivers in caring for patients with chronic diseases (Bhatta & Liabsuetrakul, 2016).

There is a consensus in the social work literature that applying the principles of empowerment to work with women is beneficial (Caetano & Pagliuca, 2006). The results of a meta-analysis also showed that women's and mothers' ability improves their social functioning and psychological health (Fargher et al., 2020). In other words, women's psychological empowerment enhances the quality of their motherly role. It reduces the family's psychological distress, and finally, the resulting active participation of women in society leads to an increase in their interpersonal and political authority (Rosenberg, 2018). Empowerment is defined as involving clients and their families in making decisions for their health and well-being in cases that require the power or ability to make decisions. Empowerment means promoting good faith and positive adaptation, a sense of power control, and helping others achieve goals. In other words, empowering the client helps them understand their needs and how to solve their problems. Another definition of the principles of empowerment is the ability to solve problems, be self-reliant, and build self-confidence; thus, empowerment is recognized as a key element in promoting public health (Parker & Aggleton, 2003).

The present study was necessary because the cultural, social, and political structure that women living with HIV experience. This fact seems to be a significant issue in understanding the educational and empowerment needs of these individuals, which are essential and fundamental. In the past, many women in our society have continued their daily lives without realizing their educational needs and need for empowerment. Still, in the current situation where the possibility of self-awareness has been provided for many of them, the needs for education and empowerment in society have become an issue. Even if the existing literature obscures the general idea of meeting educational needs and empowerment in terms of patterns, recipients, frequency, consequences, causes, reactions, and factors, little is known about the unique experience of Iranian women living with HIV. Therefore, it can be said that enhancing the potential of women living with HIV+/AIDS in communities is essential to achieve educational, social, cultural, and economic development. Therefore, according to what has been said, the purpose of this study was to investigate the experience of living with HIV+/AIDS from the perspective of women in Ahvaz, Iran, with a focus on educational needs and empowerment.

Methods

The present qualitative study was a descriptive phenomenology that was conducted in 2020 in order to explain and analyze the experiences of HIV/AIDS patients in living with this phenomenon. The research context included all educational, therapeutic, counseling, and support centers, government and non-governmental HIV/AIDS associations and institutions located in Ahvaz. The statistical population of the study included all women with HIV and AIDS, and the primary method in selecting participants was the goal-based method. Of course, the snowball method was simultaneously used; some patients were asked to introduce other people who had the same infection as them and had experienced this phenomenon. This method seems appropriate due to the growing prevalence of AIDS in Iran and some patients' decision to hide their diagnosis. Semi-structured open interviews (individual and face-to-face) were selected as the primary and central approach to data collection. The study inclusion criteria were definite HIV diagnosis, no mental health problems such as depression, age of at least 20 years and at most 55 years, and Arab women with a fluent translator, ability, and possibility to establish suitable communication. To collect data and access valid and real information, the 3 approaches of in-depth semi-structured interviews, descriptive notes, and diary or life stories of the participants and field notes were used. The number of sessions and the duration of each interview varied according to the content of the topic and the conditions of each participant. They depended on various factors such as time, willingness, tolerance, and individuals (their physical and mental condition). In this process, according to the initial coordination, the interviews were recorded. The researcher conducted narrative interviews from June to September 2020. The interviews lasted from 35 to 80 minutes and, if allowed, the audio sample was recorded on tape, and then, transcribed verbatim. Rich data from participants' experiences were saturated after the interview was completed.

Results

The mean ± SD age of the participants was 80.7 ± 11.42 years. The minimum and maximum age of participants was 33 and 56 years, respectively.

Theme 1: Severe suffering

Shock, anger, and resentment of family and friends: One source of suffering, shared by all participants collectively, was the reactions of those around them and the secrets of the disease, which seemed to them to be more of an unexpected and accidental event. These reactions included shock, anger, rage, and disgust. "Now, my mother has completely separated my toilet; my food is also completely separated."

Feelings of isolation: Without exception, all the women interviewed experienced loneliness, which meant being separated from the world. Some were entirely cut off from their society. Some reported the danger of isolation that threatened them. "The teacher, realizing that I was ill, took me to a classroom to sit alone ... She did not let me go out ...She said I should be alone."

Theme 2: Disapproval

Prejudices, stereotypes, and taboos related to HIV in society: The women in this study mentioned prejudices, stereotypes, and taboos associated with HIV. Participants indicated that they had experienced disapproval, opposition, and rejection in their daily lives. "Everywhere I went to work, they heard that I had this disease and they told me no. I am looking for a job. Even when I worked, I was told that I was no longer insured because I have this disease and I was fired."

Feeling of lack of social support: Feeling of lack of social support was a sub-theme that most of the women in our study mentioned and was essential to demonstrating educational and empowerment needs. This sub-theme was described in different ways, depending on each woman's experience. Support was interpreted as a desire or expectation and a reason for empowerment. The positive effects of support helped the participants adjust to their reality and to end disrespect: "Yeah, I had much support in my life and ... now I think this is very important and necessary."

Theme 3: Insecurity in social and economic life

Lack of readiness for cultural and social participation: Not all women living with HIV/AIDS were equally prepared to report and to be asked tough questions about their social and economic life insecurity. This theme included a detailed analysis of aspects related to equality or inequality in empowerment: "I want to say, but I cannot say anything because I know I am alone. "The greatest difficulty in my life is that I am lonely ... I mean, my wife, my marriage."

Assessing relationships based on economic criteria: The lack of empowerment that these women perceived. "Doctors performed the tests with difficulty. The cost of tests and medications was high. I did not have insurance. "Doctor ... when they saw that we had this problem, they donated $10 for the tests."

Doubts about improving health: Most participants persisted in doubting their health. They gave vague explanations for their deteriorating health: "There is no cure for this disease ... they say it is like this here ... it is not like this abroad ... I am not well ...".

Theme 4: Disrespect

Disrespect for unique characteristics: The fourth theme shows the importance of maintaining respect for empowerment and respect for equality among these women. For these women, respect for the right to empowerment is a matter of personal rights. Having the freedom for their unique feminine characteristics and the distinctive features of each lived experience: "We have specific and non-specific facilities in medical centers ... these are not officially stated ... facilities are forbidden and for somebody... what does this mean?"

Insult and slander: Several participants did not describe being HIV positive as a sin, a bad self-image, and a sense of worthlessness and unworthiness. They considered themselves good people who had been infected with the virus: "For a month I just cried and did nothing. I had not committed a sin. Why should I get this disease?"

Theme 5: Effort and difficulty in protection

Continuing to control health status information: Participating women protected themselves and their loved ones from potential threats by limiting the number of people with whom this information was shared. Several participants continued to control their data while maintaining their status. This control was considered an excellent way to protect themselves from risks and other negative consequences, such as exclusion and discrimination. "I did not tell anyone that I had the disease. When I tell someone, I feel that their reaction changes compared to before ... I have a fear in my heart, and I do not tell anyone because of the fear I have ... If my colleagues find out ... I am afraid of losing my job. "

Discussion

The purpose of our qualitative study was to examine the experiences of living with HIV+/AIDS from the perspective of Ahvazi women with a focus on educational needs and empowerment. This study's primary goal in this field was to extract the meaning of educational needs and empowerment from the participants' recorded statements. In our research, the life experience of women living with HIV/AIDS is described as a dynamic and evolving process of meeting educational.

Our study results demonstrate the complexity of the experience of meeting educational needs and empowerment in terms of stratifications. These results confirm the concept of the status position defined in Max Weber's theory of social stratification, which, according to his definition, is any component of a kind of human life that is determined based on a social assessment, negative or positive, specific to respect (Caetano & Pagliuca, 2006). Dignity groups are based on similar lifestyles and can have both negative and positive points (MacLachlan et al., 2016). According to Weber, different degrees of social status are the source of the emergence of social strata composed of holders of similar social bases (22). Weber believes that social status with its interdependence is the primary basis for the distribution of facilities and resources among individuals (van den Berg et al., 2016).

The experience of educational and empowerment needs in these women showed the intense suffering from non-compliance, the first theme, revealing their HIV-positive status to others and the reactions of relatives and confidants toward their illness, and isolation. All of these aspects define the suffering experienced by Iranian women living with HIV/AIDS, which confirms the literature on the "burden of secrecy" that can itself lead to severe isolation (Bhatta & Liabsuetrakul, 2016).

The second theme is described as power relations in educational and empowerment needs. We agree with Parker and Aggleton (2003) in that conceptualization of stigmatization as an "external process" reinforces social inequalities and existing power relations. Based on our results and those of Parker and Aggleton (2003), it seems reasonable to think of stigma as entirely beyond the individual level and as a social process; a process in which interventions can change the social, cultural, and political context. It is a painful and uncontrollable reality that increases the complexity of educational and empowerment needs.

The third theme is described as persistent insecurity. In the community of women living with HIV/AIDS, the constant feeling of insecurity is an unpleasant, painful, and humiliating feeling that not only testifies to, but also supports and reinforces inequality in educational needs and empowerment among these women.

The fourth theme, disrespect for education and empowerment needs, extends to understanding the experience of inequality in terms of respect for education and empowerment needs. Social conditions can contribute to an imbalance in respect for the educational needs and empowerment of women living with HIV. Interpersonal relationships play a significant role in these circumstances.

The difficulty in protecting the right to empowerment (theme 5) is confirmed by what some authors have written about the reasons for inequality in education and empowerment needs (Fargher et al., 2020; Rosenberg, 2018); writings that are primarily intended to prevent harmful effects, such as fear of rejection, disregard, social isolation, and discrimination, on the individual, although they also avoid the prevention of some worrying adverse effects (Parker & Aggleton, 2003).

The concepts and points of view that the authors have described in detail provide a fundamental understanding that is the basis for the sociology of women's empowerment. However, it can never be claimed that the theories of educational needs and empowerment are inextricably linked to the experience of women living with HIV/AIDS. Women's social groupings are essential in studying HIV/AIDS patients, but they are not the only determinants of their life experience. A valid group is also an interpretive phenomenon. The adventures of facing the lack of educational needs and empowerment cannot be recognized only through the objective analysis of social groupings. Still, this study is also virtually a mental and interpretive process. Furthermore, it is not the gender of the patients that determines their empowerment in society, but the disease itself that determines their empowerment in society. The main limitation of this study was that the use of narrative interviews to access the details of individuals' biographies raised questions about research ethics.

Conclusion

It can be concluded that the educational and empowerment needs of patients with AIDS/HIV+ should be taken into consideration. Mobilizing individuals, specialists, and providers of counseling and care services in different sectors to gain a better understanding of the complex nature of the phenomenon of non-compliance with the right to empowerment will be useful. This, in turn, can facilitate the implementation of appropriate, necessary, and enforceable interventions.

Conflict of Interests

Authors have no conflict of interests.

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