Orginal article

Explaining the hindering factors for accepting the disease, a barrier for the HIV/AIDS patients to seek treatment: A qualitative study

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Abstract

Background and Purpose: Not accepting the disease by HIV/AIDS patients causes a lot of side effects for the patients and their treatment process. This study aims00 to explain the hindering factors in accepting the disease by HIV-AIDS patients as a barrier for seeking treatment.

Methods: This research is a part of a grounded theory study. The data were collected through semi- structured interviews. 13 patient participants, 3 family members and 2 health professionals were chosen based on goal-based sample among HIV/AIDS patients in AIDS and Behavioral Disease Consultation Center of Tehran Imam Khomeini Hospital.

Data analysis was performed along with the sampling.

Results: The data and the analysis of the data done with HIV/AID patients' experiences from hindering factors led to emerging two main classifications (personal factors and social factors) and five subdivisions.

Conclusion: The existence of hindering factors in accepting the illness may delay treatment and accessing the health services. Therefore, it is suggested to take some necessary health, medical and advisory actions to identify and remove the hindering barriers.

Keywords: Accepting the disease, Hindering factors, HIV/AIDS patients, Qualitative research

Introduction

AIDS is one of the greatest challenges of humanity and one of the main risky problems for the health (1). Despite the fact that the first HIV/AIDS patient has been identified not long ago, the world is facing an epidemic which has no certain and definite remedy (2, 3). According to the statistics issued by WHO and Joint United Nations Program on HIV/AIDS, out of 35.3 million people with HIV/AIDS all around the world, about 6 millions live in Asia (4). Based on the statistics issued by Iran Ministry of Health, 26125 people with HIV-AIDS have been included in the list (5). transmitted through sexual intercourses and it is accompanied with people with unusual sex intercourses (6-11). HIV-AIDS infection is not accepted socially in most countries and the women with HIV/AIDS are considered as prostitutes (12-13). It raises the idea that people with

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HIV/AIDS seem socially different and threatening to the society (14). The HIV/AIDS patients are usually ostracized from the society and considered as disreputable and stigmatic people (15). Therefore, facing their positive HIV test result, they suffer from anxiety, fear and worry and probably get shocked mentally because of the fear of stigma. At first, the patients may deny and hide their status and try not to accept it and express aggressive reactions, anger, a lot of sadness and grief and they feel discouraged, hopelessness, depressed and anxious. But these conditions make them hesitate in referring to medical centers on time and follow their treatment process and sometimes they become deprived of medical and treatment and health services.

The results of Churher's study (2008) indicated that stigma is one of the most important influencing factors for accepting the illness by the people with HIV-AIDS. He believes that the negative experiences that HIV patients obtain from negative interactions and viewpoints of people and health professionals are the factors influencing the reduced motivation to seek the treatment by HIV patients and consequently, a delayed treatment may follow (16). HIV patients not referring to medical centers leads to serious and risky consequences for them, their families and other people.

Smeltzer et al. (2008) here believe that the way we behave while encountering HIV/AIDS patients and the people suffering from it is an important factor for preventing the illness, success in medical programs and providing welfare and promoting the patient's life styles (17).

Since HIV/AIDS patients are under hard and painful conditions and the illness creates a lot of problems for them, how they accept and face the illness can be the significant factors in their referring to medical centers and seeking health and treatment. Now, regarding the increase of HIV/AIDS patients in Iran and the necessity of accepting the illness by them as a key factor for their easy involvement in medical decisions and the prevention of the illness and the patient's timely reference to medical centers as an urgent priority in health system, it is necessary to perform a study to explain the hindering factors of accepting the illness by the patients.

Streubert et al (2011) assert that investigating one dimension of a concept, making social changes in a specific field, examination of life experience and understanding it perfectly are the issues that qualitative researches contribute to clarify (18).

On the one hand, the importance of the disease diagnosis and the accepting the hindering factors as the influencing elements for the patients' willingness to refer to the medical centers and identifying the nature of the barrier in Iranian cultural and health systems, on the other hand, caused the present study to be conducted on HIV/AIDS patients' experience as one of the best and the most realistic ways for accessing the relevant data.

Materials and Methods

The present study is part of a grounded theory research which aims to explain the illness acceptance hindering factors as a barrier for seeking treatment by HIV/AIDS patients. Since in qualitative research cases, the integrity of human phenomena is significant, this method can be one of the best ways to study people's experience based on the social phenomena (19-20).

Data analysis has been done as the data were collected. The Strauss & Corbin Method (1998) was used to analyze the data (21). In this study, the including criteria include having HIV/AIDS, ability to speak and listen Farsi, having physical, mental health and intention to take part in the study. The research was conducted in the Clinics and AIDS and Behavioral Disease Research center of Tehran University of Medical Sciences. The sampling first started purposefully and then went on quickly. The key participants of this study were HIV/AIDS patients but after the primary analysis of the data and consulting with the research team to abstract the concepts and categories, the sampling included the patients' families and medical staff.

First, the study objectives were explained to the participants and they declared their satisfaction to take part in the interviews. The semi-structured interviews were done face to face. The interviews started with general questions like "what happened when you first found out you had AIDS", "What obstacles did you face while accepting the illness", and based on the participants' answer, the probing questions were set and asked.

All interviews were in Persian language and performed by the first writer. Each interview lasted 45 to 90 minutes, and performed where the participants felt comfortable. 18 individual interviews were performed with 13 patients, 3 patients' family members and 2 medical staff. Data collection lasted until data saturation. Streubert believes that no new data will be obtained from the interviews when reaching to a saturation point (18). The interviews were recorded by the participants' permission and based on the current contents; data analysis was done as the data collected. The contents of the interviews were typed after each interview word by word excluding verbal signals like crying, laughter and silence and then were put in Max QDA 2007 software to be organized. The interviews were read and reviewed for several times and finally were broken into meaningful units. After frequent review of each meaningful unit, the suitable codes for each unit were assigned. Then, the primary codes were categorized based on the conceptual and semantic similarities and finally, they were put in main categories being more general and conceptual. Finally, after continuous integration of the categories, the main and hidden themes of the data were extracted (22) (Table 1). For the purpose of confirming the collected data credibility, Lincoln and Goba criteria were used, so prolonged engagement and member check were used, too. For doing this, a short summary of the interviews was given to the participants so that they confirm the correctness of the researcher's understanding. For the data being confirmed, peer check method was applied. All encoded data and

categories were studied and reviewed by the coworker consultants and supervisors. Audit trail was employed to check the data dependability (23).

In this study, the researcher keeps the primary data, categories and themes until the end of the research process. Also in this study, sampling was performed with maximum variance (age, sex, education level and suffering background) which helps the transferability and stability of the findings.

Ethical Consideration: In the present study, some consideration was followed such as getting the certificate of research implementation from the research ethical committee of Tarbiat Modares university, obtaining the written and intentional willingness from the participants after explaining the research objectives, the role of the researchers and participants and the methods of collecting and recording the data, providing comfort and privacy during the interviews, the participants' right to leave the study anytime they like, the anonymity of the participants and keeping the data confidential and availability of the results for the participants.

Results

Interviews with 13 patients (9 Male, 4 Female; Average age 26.15; 3 Married, 8 Single, 2 Widow; 2 Higher Education; Infection Duration of 5 Months to 12 Years), 3 family member (A mother 42 years old and Two fathers 46 and 48 years old) and 2 health professional (A female, Infectious Disease Specialist and A men, Bachelor of Health) caused to obtain rich information and data saturation and repetition. Of the research data, 287 primary codes were extracted. The main contents extracted from this study included two main themes (personal factors and social factors) and 5 secondary categories, like mental reactions, negative feelings emerging, lack of knowledge, misunderstanding of the illness, stigma and inadequate support (table 2).

Personal factors: Personal factors explain a persons' understanding of his or her mental and

emotional conditions as a unique person and different from others while facing HIV/AIDS diagnosis that were introduced as mental reactions of fear and phobia, shock and denying. Alsonegative feelings like the early death feeling, lack of knowledge, misconception and misunderstanding of the illness by the participants.

Mental Reaction: Facing HIV/AIDS infection puts

Table 1. The process of extracting the personal factors

the participants against a chronic disease and an inevitable reality. Fear and phobia, grief, shock and denying the illness were the common reactions that all patients experienced. When diagnosed with HIV, the sadness and distress of HIV diagnosis lasting from a few days to several months, they frequently asked themselves "why me?"

Category	Subcategory	Code	Semantic unit
Personal factors	Mental reactions	Shocked when I realized I was suffering	When I was told that my HIV test result was positive, I felt terribl and shocked. I was worried about myself. I felt that I committed crime. (Woman, 52, married).
	Negative feelings	Feeling early death	In army hospital, when I was told I had HIV, I became angry an scared. I felt I was dying. I thought I would die soon.
	Lack of knowledge & misunderstanding	Lack of enough information about AIDS	First, I didn't know AIDS and I had no information about it. I ha heard that it was common in homosexual people and drug injectin abusers and it was a fatal disease that destroys body immunit system and all infected people die soon.(Male, 26, single)

Table 2. The subthemes associated with the HIV/AIDS patients' experiences from hindering factors for accepting the disease

Theme	Subtheme	
	Mental reaction Forming negative feeling	
Personal factors		
	Lack of knowledge and misconception of the illness	
Social factors	Stigma	
	Inadequate support	

Since HIV-AIDS has been horrible to the patients and influenced their mentality, the feelings of shock and fright and illness denial have increased.

The patients' unwelcome feelings have always accompanied with the early death feeling. Increase of these reactions often caused the acceptance of their illness with delay.

They believed the longer and later they accepted the illness, the less they had the motivation to start treatment and receive health and medical services.

A 32-year old female participant, a sex worker, stated: "When I found that my HIV test result was positive, I was devastated and shocked. I couldn't believe it. I couldn't accept it. I was frightened and I thought that I would die soon due to AIDS. I wasted a long time to persuade myself to start and follow medical treatment."

A 30-year old single man said: "When I heard I had AIDS, I was ashamed of myself. I was scared. I felt I was close to death. It was too difficult for me to accept the illness. It took me about a year to start the treatment process and look for medicals srvices."

A 32-year old male participant stated: "When I realized my test result was positive, I felt terrible. I couldn't believe it. I always thought the test result was mistaken. I couldn't accept it. This is a horrible and incurable disease. At that time. I didn't think about treatment."

Some patients stated that they were so depressed and sad that they decided to suicide.

First, they treated the depression then started medical treatment.

Another 32-year old single male participant revealed: "AIDS leads to death. I mean the future is

dark .There is no certain cure for that. You don't know how long you are alive. I don't know which effect of the illness threatens your health. At first, these negative thoughts were annoying and they didn't let me see the reality. I was strongly depressed. A few months later, after I was mentally recovered, I went to a medical center for treatment."

A 35-year old married male participant said: "When I discovered I had AIDS, I felt awful. I thought that any effort would be useless to survive. I felt I was a piece of garbage, I saw no way to escape except suicide and getting rid of my life."

Negative Feeling Formation: With the diagnosis of AIDS, the patients imagined a dark future with negative feelings about future. They thought they would run into early death.

A 30-year old single male participant stated: "A few years ago, I lost one of my close friends suffering from AIDS. It took 6 months for him from the time he realized he had AIDS to his death. I imagined such a future for myself. I always thought I would never be treated and I would die soon. I felt awful. It took me one year and a half to find myself again and start medical treatment." A 52-year old widow woman said: "When I realized I am a positive HIV person, I was so confused and bewildered that I couldn't think and decide clearly and wisely. I felt terrible. I got angry and upset easily. I always remembered my husband's moods and situations and reactions and I thought and imagined that soon I would be like him and die. I told myself that I will die soon, so what's the use of medical treatment."

Lack of Knowledge about & Misconception of the Illness: Since most HIV patients didn't have sufficient information about HIV and AIDS, they came up with negative attitudes towards the illness. This negative feeling and attitude affected accepting their illness and reduced their motivation for medical treatment.

A 32-year old divorced male participant asserted: "First, I didn't know AIDS. I had heard that AIDS was like cancer. The patients had large infectious wounds and herpes simplex throughout their body. I was too uncomfortable and sad because I thought AIDS wouldn't be cured and many people will die soon. I thought I was at the end of my way. It was like a nightmare for me."

Social Factors: Ostracism and rejection are the significant consequences of AIDS for the patients. All the participants have experienced stigma from other people. They often said that after getting HIV-AIDS, they were ostracized by their family members and everybody gave up supporting them. They also mentioned that not only were they suffering from AIDS but also they were sad and uncomfortable because they were left out and were ostracized from social relationships. This situation was so hard and tragic that they had no motivation to go on living and took them too much time to accept the illness and start to follow medical treatment.

Stigma: After realizing their positive HIV test, some patients were scared of notoriety and the peoples' negative reaction frightened them.

It was very annoying and heart rending for HIV patients to be notorious for debauchery and sexual intercourses. They were convinced that people know AIDS equals sexual intercourses and ethical and sexual perversion. They tried to stay away from stigma and wasted much time to accept their illness and receive medical treatment.

A 25-year old widow female participant stated: "Most people think you are a prostitute as soon as they found out you are a positive HIV. Their humiliating look makes you feel awful. At the beginning of my illness, I was scared of going to doctor and receiving treatment because of staying away from peoples' look and notoriety."

A 24-year old married female participant said: "Most of the time, people look at you strangely even medical staff members. This is very painful. At first, I tried to take it easy and not to care them but it was very annoying."

A 32-year old single male participant stated: "When someone understands that I suffer from AIDS, he or she thinks that I am a homosexual or I have been a drug abuser. At first, I tried not to pay attention to these behaviors, but it was very tormenting. Even most of the medical team members thought of me like that."

Inadequate Support: The patients' family's inadequate support also plays a significant role in accepting the illness and seeking medical treatment. The patients who lost their supporters or were rejected by them got to seek the treatment late.

A 30-year old single male participant said: "I had very difficult days. I was still in the shock of accepting my illness when my father realized that, he threw me out of his house. I lost everything as I became ill. I lost my father, my health, my job and everything. I didn't want to be alive. How could I think about treatment?"

I addition, when they were informed of their HIV positive test result the first time, they were in a grave condition and expected the medical staff members to support them mentally and spiritually to make them accept and believe the situation. They expected the medical team members to understand their mental and spiritual condition and to give them enough knowledge about the illness to cope with the stress and fear of negative attitudes due to the malady. Lack of mental and spiritual support from the medical staff led to late acceptance of the illness by the patients.

A 25-year old married female participant stated: "In blood transfusion center, when they told me that my HIV test result was positive, I cried loudly. I shouted, I yelled of tragedy. No body or no medical team member tried to make me calm and just gave me a letter of introduction to refer to Imam Khomeini hospital.

A lady as the infectious disease specialist, and also the head of AIDS research center believes that weakness and lack of consultation in medical centers for AIDS patients affects the illness' acceptance. Experienced consultants are very useful and helpful when the patients encounter their positive HIV results and they are very effective in accepting the disease. The consultants can give them necessary information to accept and live with HIV and follow their medical programs. It's a weakness that we don't have enough consultants in our medical centers.

Discussion

This research was done in order to explain the illness hindering factors acceptance in HIV-AIDS patients as a barrier to seek treatment. As mentioned, the main themes obtained from this study included two main categories of personal and social factors with five subdivisions. Based on the findings, HIV patients experienced mental reactions such as fear, phobia, shock, denial, grief, depression and suicide commitment when they encountered their positive HIV status. They stated the more the negative reactions, the longer to accept the illness and search for medical treatment.

The results of the qualitative study of Zhou (2009) in China on 21 HIV patients whose data were collected through deep interviews with the patients showed that the participants could safely control a wide range of the negative psychological xperiences like lack of faith and incredulity, shock, anger, depression, fear, pessimism and the thought of suicide. The patients who were tested and diagnosed with positive HIV in special hospital for HIV patients experienced less psychological and mental pressure and adapted to their illness sooner (14).

The results of some studies have suggested that the ways the patients react to their illness and the way they pay attention to their health are the important factors for hindering the disease spread, being successful in their medical treatment and increasing their quality of life (16,17). The results of Mohammad Pours' study (2010) on 19 HIV/AIDS accomplished patients through deep and semi-structured interviews denoted that fear. uncertainty, obscurity, instability, mental and physical injuries and treatment paradox were the main themes achieved from the study done with HIV/AIDS patients. The results suggested that living with AIDS for the patients from different personal, family and social life status was accompanied with pain and numerous troubles and challenges. Mohammad Pour believes that promoting patients' knowledge and awareness, correcting the negative attitudes of the society and developing supporting actions can help the patients accept their illness and also can be an introduction to get medical treatment, health education and consultation services (24).

The critical point is that, three decades after epidemic and outbreak of AIDS, AIDS stigma is still the main element of the patients' experience (21). This way of thinking can be the result of the belief that an HIV patient is infected due to unusual and unconventional sexual behaviors. Delay in accepting the illness has been known as the biggest challenge of AIDS and also one of the consequences of stigma causing delayed medical and health services (26).

Regarding these conditions and the UN AIDS Center emphasizing to organize stigma reduction programs in order to contribute on time treatment, control and prevent HIV/AIDS in the field of general health, no specific and particular actions have been taken yet(27).

Loneliness, inadequate support and rejection of the HIV/AIDS patients are the most important problems for the people with AIDS which are obvious in all of their life dimensions. The patients stated that these factors cause delayed illness acceptance and late medical treatment programs.

Social support is an important factor that plays a significant role in making the HIV patients adapt with their illness. Social support means to understand other people in dilemmas and try to help them (28). Social support is the strongest and greatest factor to cope with chronic diseases and stressful conditions that makes it easy for the patients to overcome the disease (29).

The results of Madiba's study on 50 positive male HIV patients showed that social support has been an important factor for HIV patients to get antiretroviral treatment. Fear of being rejected and losing money or fear of HIV condition disclosure and losing social reputation are the barriers for HIV patients to take part in supportive groups and consequently, not to receive medical treatment and services (30).

Inadequate support of medical staff was another factor that participants mentioned in the present study. Jefferys believes that multiple social prejudice and fanaticism and stigma toward AIDS patients cause the health professionals' social support to get low and judgmental attitudes and their rejection to interact with the patients and present health care services and treatment (31).

Yurkovich et al (2012) in a qualitative study using semi-structured interviews and group discussion concentrating on HIV/AIDS patients obtained the results that show the interaction of the doctors and patients can influence the correct understanding of the patients about their illness and its treatment. Understanding the malady and its acceptance have positive effects on making medical and treatment decisions and health seeking behaviors (32). As it was noticed, suffering from HIV/AIDS changes the patients' normal life style and increases the feeling of vulnerability and lowers self-confidence and causes abnormality in social activities, mental and spiritual peace and reduced quality of life (33). HIV patients are often limited in most social, economic and family activities. AIDS is either a tension making factor for these patients or puts them in critical thoughts like lack of a definite cure, obscure future, and social attitude towards them as sexually deviated These conditions leads people. to mental abnormalities like indifference, feeling guilty, helplessness and hopelessness, anxiety, depression and sometimes thinking of suicide.

Since delay in accepting the illness is a big obstacle to get and reach the medical treatment services for HIV/AIDS patients, the results of this study can give beneficial information to the patients, their families, and health professionals about the illness acceptance hindering factors and help them reduce the consequences and effects of this phenomenon with supportive intervention programs.

Conclusion

Regarding the growing and increasing process of HIV/AIDS in our country, it is necessary to find, recognize and explore the hindering factors of the disease acceptance and design and perform suitable strategies and procedures to remove the acceptance related barriers in order to accelerate the start of HIV/AIDS patients' treatment programs. Seeking on time health services is essential to prevent and treat AIDS. Diagnosis and treatment of the patients in early stages through destroying virus transition risk leads to the primary prevention in the total population, the secondary prevention for the patients and quick management of HIV infection effects and consequences.

According to the results of the study, inadequate knowledge and misunderstandings about the ways AIDS gets epidemic and fear of infection and stigma can create improper social behavior towards HIV patients.

We can create a positive attitude or viewpoint to take care of HIV patients and reduce their social problems by showing sympathy to them, understanding their conditions and encouraging people to agree with them and promoting the public general knowledge about HIV/AIDS.

Conflict of interest

The author declares his lack of conflict with interest through his article.

Author's contributions

M. Saki was in charge of the study interviews, extracting and encoding the data, data analysis and drafting the article. S. Kermanshahi & E. Mohammadi did revising the codes and data analysis, reviewing the content critically and M. Mohraz did the final revisions and critical reading.

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