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Psychic and psychological experiences of AIDS patients: A phenomenological study

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Abstract

Introduction: Acquired Immunodeficiency Syndrome (AIDS) is one of the most fatal diseases of the present century. Due to its chronic and incurable nature as well as the malign thoughts and the label applied in the society, there would be psychologically dramatic impacts on the patient. The present study aimed to explicate the psychic-psychological experiences of such patients.

Materials & Methods: The approach applied in this qualitative study was Phenomenological. The research community was of 13 AIDS patients who were selected by purpose-based sampling method up to reaching saturation point. The data were collected through in-depth and non-structured interviews. To analyze the data, Colaizzi approach was adopted.

Results: Through the interpretation of the data, four major themes emerged: inconsolable grief, anxiety, fury and bleak future. Such themes were called psychic-psychological experiences of the AIDS patients.

Conclusion: The results of the present study demonstrated the AIDS patients were beset with various psychic-psychological problems. While treating such patients, it seems necessary to care for their psychic-psychological needs other than treating them physically. Therefore, it is undeniable to bring in psychological and religious specialists along with the treatment of the nursing-medical services. Moreover, an attempt in changing the public view toward these patients seems essential.

Keywords: Psychological experiences, Acquired Immunodeficiency Syndrome, Qualitative research

Introduction

Acquired Immune Deficiency Syndrome (AIDS) is the incidence of a series of disorders caused by the malfunction of the cellular and hemorrhage immunity, all caused by HIV (1). It is extremely complex and broad to define AIDS. Just being infected with the disease is insufficient to be treated: it should be cared in a wide range from the initial infection – with or without any symptoms – to the degenerative disease. The effects and consequences of the so-called disease would be followed in the whole aspects of the sufferers' lives (2).

It is more than ten decades since the diagnosis of AIDS. Since AIDS became globalized, more than sixty million people suffered from it. Most of the sufferers live in the third world countries in Africa and Asia. The majority of the infected youth are 15-24 years old (3). According to the latest statistics of the Ministry of Health, Treatment and Medical Education, the number of sufferers from HIV infection in Iran – as in the other developing countries – is increasing so that in 2001 the number of the infected ones was 2269. However, in 2010, 21890 caught the disease. The whole number of patients with HIV virus in Iran are estimated roughly 100,000. Such a phenomenon, due to its specific nature, leaves considerable impression on all the aspects and lives of the patients (4).

AIDS alters the patients' path of life, leading to low self-confidence, extreme vulnerability, appearance of physical symptoms as well as disturbing thoughts in them. Daily tasks, social activities and peace of mind all become untidy.

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Along with all the mentioned problems, visiting the physician recurrently, enormous cure expenses and the side effects from the drugs result in low life quality and bringing psycho-psychological problems (5). Eranda and Naranjo wrote that AIDS in of diseases that because of making great social problems, malicious thoughts dominant in the society as well as the applied labels, not only makes the patients to be afflicted with their physical health but also with their psychological and social one. It also contributes to serious problems in the patients beneficial activities and interests (6).

The HIV sufferers are restricted in their family, economic and social spheres owing to becoming infected with a dangerous, deadly, incurable disease which is found a stressful factor in these patients. In addition, they are exposed to psychic-psychological pressures because of the distinctive characteristics of the disease among the public, the particular way by which the infection is passed on and that it is to some extent still an unknown disease(5). The range of the psychological disturbances in the sufferers vary from the light ones, such as pessimism, the feeling of being guilty, a sense of desperation and being sickly indifferent, to the severe ones as depression, psychosis and getting suicidal at some points(7). It is believed that every schedule seems appropriate in initial positive interference for the AIDS patients, becoming close to them, conducting in-depth interviews, understanding their feelings, attitudes and points of views towards themselves as well as others and, finally, persisting in undergoing medical treatments and taking drugs. The main principles of treating HIV sufferers are keeping confidence, medical care and providing them, their families and friends with psychological support which all are quite vital(8).

As the researcher reviewed a series of texts and a few researches with limited studies on psychic-psychological aspects of the AIDS patients, it was determined to describe such experiences through the patient's own expressions. The survey of such experiences could help the nurses and the health and clinical care services to understand their real concerns and psychological problems in order to be applied in their relieving symptoms, improving the quality of life and educating the patients and their families. Therefore, the present study was undertaken to explicate the psychic-psychological experiences of the AIDS sufferers.

Methods

The method of this study was the qualitative one with a phenomenological approach. This method is suitable to explain the concepts of life experiences (9). The phenomenological researcher believes that the life experiences and phenomena embody essences that are conceivable and palpable (10).

The research community consisted of the AIDS patients whose diseases were confirmed by infectious disease specialist and they had active medical records in the Health Behavioral Diseases Center in Isfahan (Shahid Navab Safavi Clinic). The present study was carried out within 5 months in Isfahan since August 2011. The method of drawing samples was purpose-based. Such method is sometimes considered a selective or judgmental one and the careful selection of the samples are the incidence or emergences considered in the study (11). In this method, the individuals were selected due to their awareness of the subject of the research and the researcher initially adopted the criteria, then the selection of the individuals was made (12).

The established criteria were as follow:

1.The patients who were infected with AIDS and they were diagnosed and confirmed by the infectious disease specialist. They also had active medical records.

2.The patients who were interested in participating in the research and expressing their experiences.

3.The patients who were conscious and alert to be capable of sharing their ideas.

4.The patients who were simply accessible through the research.

In qualitative studies, drawing samples would be lasted so that the amount of data would reach saturation and the acquired data would become repetitive (11). In this research, drawing samples also continued to reaching saturation point : after the interview with 13 AIDS sufferers, the obtained data were saturated and drawing samples ceased. In this survey, the tool for collecting data was the in-depth and non-structured interview. The purpose of such interviews was to elicit replies of the participants from the depths of the so-called phenomenon. Thus, the researcher would take on all its aspects (13). Therefore, after providing the patients with obvious detailed explanation about the nature and purpose of the study as well as about the way it is carried out, they signed approvals for participating in this study. Before each interview, the interviewers were asked for their permission for recording their voices. Furthermore, the participations were as sured of the confidentiality of their information. The interview was conducted in a private place and they were assured that every stage of the interview and the study would be optional and they could cease cooperation whenever they wished. The interview initiated with one essential question "Since you became aware of your disease, what psychic-psychological problems did you encounter?" Then, other questions were posed to explicate their responses. Two participants were interviewed in the Behavioral Diseases Center (Shahid Navvab Safavi) and the other 2 were interviewed in a public place (park). The time of the interviews varied from 60 to 90 minutes according to the conditions of the participants. In order to examine and analyze the data, the 7-stage Colaizzi approach was adopted. This approach is a proper method for denoting the interviews in the phenomenological break it up (14).

Initially, the issues taken from the recorded interviews – which were written down word by word – were studied, reviewed and reexamined to sympathize with the participants. Secondly, the key phrases were extracted. Thirdly, the meaning of each main phrase was explained. The codes from the initial examination and analysis of each interview were noted down sparsely and then organized into categories. Then, various codes were merged into broader categories. Next, the results were combined in complete description of the studied phenomenon and then reviewed to obtain clear concepts so that other than being abstract, they would be quite concrete and meaningful. In this way, the readers would grasp the concepts of the study. Finally, the findings were taken to the participants to confirm their validity. They expressed their ideas about the agreement between the findings and their own experiences. Consequently, the final validity was upheld. Accuracy in qualitative researches (the equivalent for permanence and validity in quantitative researches) was rooted in real values (validity), being practical (transferability) and permanence (Dependability) (10).Validity which means the expression achieved by the experiences would be tangible for the ones who actually shared them. In the present study, by referring to the participants and confirming the expressions, such an achievement was constituted. Transferability means whether the findings in a field could be transferred to similar participants or situations. For achieving such a criterion, the researchers attempted to select the participants according to a various range of age and cultural backgrounds. Dependability was achieved when the participants replied identically and no contradiction was observed in their replies to similar questions in different patterns.

Ethical considerations

The researcher introduced herself to the participants. The purpose of the study and the practical results were also explained to them. Special full permissions were obtained from the participants for taking part in the interviews and recording their voices. In addition, they were

assured of the absolute confidentiality of their personal information.

The interviews were conducted in private places and the questionnaires were filled in with no name and just with the codes. Moreover, they were assured they were free to cease cooperation in every stage of the interview or the research.

Results

After analyzing and interpreting the interviews with 13 AIDS patients (3 women and 10 men), within the age range of 25-57, with the average infection of 4.7 years, 4 main themes emerged: grief, anxiety, fury and helplessness.

Finally, these themes, as a whole, were called the psychic-psychological experiences of the AIDS sufferers. Since describing and developing the major themes, these experiences were brought about separately.

A) The Feeling of Inconsolable Grief

Because of the particular and chronic nature of the disease, the label and its high death rates, many of the participants in this study, since becoming aware of their infection, had gone through such experiences as depression, constant cries, sadness, being indifferent to the physical appearance, letting themselves go and disturbed sleep.

…since I got to know I'm infected, I'm depressed so far. I didn't like to talk to anybody. I just wanted to sit silently aside. I didn't tolerate anyone. I had very little sleep and food. I was the one who had daily shower and shaving but then it was a week I hadn't done them …" (participants 1)

"… since the moment I took the test result and gave cries, I had non stop cries for days, ate nothing, lost weight, wished for death as if it had come to end. I couldn't sleep at all during the night or had bad dreams all the time. I was too much depressed…"(Participant 2)

"… I'm always sad. Crying is my job. I'm worried about everything. I did a lot for my life. Why did this misfortune happen to me? Why I should get the disease from my husband? I wasn't sinful …"(Participant 9)

B) Anxiety

The feelings of anguish, constant stress, obsession with the future, the fear from incapability and death, the dread of losing honor and social reputation, the worry about being banished by the people and the society, the anxiety for transferring the disease to the spouse and the children and so on were the problems mentioned by the participants.

"… I' m always stressful and worried. I'm afraid if people and the neighbors get to know I have AIDS, how do they behave toward me? You know I live in a biased neighborhood and if they know some body has the disease, they expel him …" (Participant 5)

" … The moment they gave me the test result and said you have AIDS, I trembled inside. I had my heart in my mouth .My body had frozen. I thought about hundreds of matters. My social position in the city, and that I die very soon. That what would happen to my wife and children after my death and that I'm the cause of their dishonor. How to get the money for the cure. Since then the stress and these thoughts don't let me free …" (Participant 4)

"… It's a long time I take tranquilizers. If these drugs weren't, I didn't know what to do with my stress. If such a disease wouldn't kill me, its stress would …" (Participant 11)

C) Fury

Most of the participants in this study, especially those who were infected with this incurable disease in youth or without committing sin or any wrong behavior, had become totally sensitive, impatient and quarrelsome since they became aware of their infection. In some of the expressions, it was clarified that many physical and verbal aggression were displayed by them. "… Among the relatives I was a cool person but not anymore. I quarrel over everything, sometimes get in

to brawl, remember once I hit my child so harshly that all his body was black & blue …" (participant 13)

"… The word of the disease itself makes everyone sick, what if the disease would be AIDS that's not just a physical disease and it affects all your life. Since the day I saw the test result and got I have AIDS, I' m very nervous and flare up with the smallest matters…"(participant 10)

D) Bleak Future

Of the other experiences referred to by most of the research units were the feeling of desperation, no hope toward future, committing suicide, the tendency for divorce and the desire for death.

"… When one knows he has so many misfortunes and now he has AIDS too, becomes exhausted and hopeless. Remember when I got I have AIDS, I cut my vein with razor blade and committed suicide…." (Participant 7)

"… It's very difficult to say I have AIDS since I have son-in-law and daughter –in-law. I'm 57 and got it from my husband. Hundreds of times a day, I pray for death before being dishonored, ask God to let me free of this life, no hope to future any more …" (Participant 8)

"…Since I got to know I have AIDS & then found my wife hasn't got the disease yet, made her separate from me. You know living with this disease is torturing for you and the family. I've lost my hope to future. All my wishes are unfulfilled …" (Participant 12)

Discussion

One of the fundamental concepts framed from the interviews with the participants was the constant feeling of grief. After becoming aware of their infection all the participants in this study had undertaken different stages of depression. Most of them took antidepressant pills. According to them, the fear of having a fatal and killer disease, on the one hand, and the bleak future of this disease and the social label applied by it, the long-lasting process of the treatment and such matters, on the other, all lead to developing depression in these patients. As Mohraz and Moatamedi Haravi mentioned all the HIV sufferers experienced depression in a period of their disease, metabolic disorders and the disorders in endocrine glands such as hypothyroidism, especially in the advanced stages of the disease, the psychologically stressful factors like being fired from the job and the applied label all are also involved in the onset of depression (15). Depression is the commonest HIV/AIDS indirect effect and the commonest psychotic disorder. The outbreak of depression in positive HIV and AIDS patients was 57.3 percent and the reported statistics is 5 times more than the general population. The depressed positive HIV sufferers may undergo more traumatic experiences of their disease though they might not have any physical symptoms (16). Infected with the AIDS disease which is fatal and terminal and also incurable, the sufferers deviate from the daily routines to the disease itself. The patient may lose the financial security, routine functions and roles, self-confidence, the ability to interact with the surroundings as well as the sexual intercourse. Moreover, they may be banished by the partner, the family and the friends. On the other hand, the attempts for controlling the patient infection would lead him/her to more solitude. Each stress would contribute to more social isolation and developing depression in the patients (17). It was determined in Durvasula and Myers research –which studied the psychological disturbances in African-American men and women infected with HIV and AIDS in 234 men and 135 women –that the depression outbreak in men was 23 percent and, that, in women was 20 percent (18). However, in Shakeri and colleagues study, the psychological status of the male and female HIV patients in Kermanshah demonstrated that 93.18 percent of the samples contained the diagnostic criterion for psychotic disturbances. For instance, temper tantrum was 41.32 percent in men and 63.63 in women (that the manic depression disturbance and the severe depression disturbance were of highest outbreaks in both sexes) (7). Mobayyen and

Farhadi Nasab also proved, in their study on 270 injector addicts – 90 of whom had positive HIV and the other 180 had negative HIV – that 79 percent of the positive HIV addicts suffer from depression; whereas, the percentage of depression in negative HIV addicts was 60 (19).

Anxiety was another basic concept grasped in this study. The fear of becoming dishonored, constant anguish for their position and their future, the fear of being banished by others, the obsession with incapability and death would lead to inconsolable stress and the weakening symptoms caused by it emerged in all the participants. Therefore, most of the participants in this study took anti-depressant drugs. The HIV/AIDS patients suffer from various ranges of psychotic disturbances such as: agitation disorders and post-event stress disturbances (15). The symptoms as agitation, anguish and anxiety, the feeling of being guilty, sleep disorders and sometimes hallucination are observed (20). The label of the disease and the amount of unfortunate events in life are of considering factors for post-event disturbances in HIV patients (21). The outbreak of agitation disturbances in HIV sufferers vary from 2 to 28 percent (22). Galvao and colleagues indicated – in a research entitling evaluating the quality of life in HIV women sufferers – that AIDS causes financial and health concerns, fear of revealing the disease for the friends and the anguish for their sexual intercourse so that most of the studied units in this research underwent some degrees of such anxiety (23). Myers and Durvasula also – in another part of their study on 369 HIV and AIDS patients (234 men and 135 woman) – showed that the range of anxiety disturbances were 38 percent in men and 50 percent in women (18). In Carroll and colleagues study, in which 457 AIDS teenagers and their parents were studied, was also indicated that there was a reasonable harmony between the anxiety and stress of the research units and being ridden and banished by their parents (24).

The third formulated concept from the interviews with the participants was fury. In this study many of the participants confessed that they were not capable of controlling their anger anymore while confronting problems and that would lead to causing problems for themselves as well as for others. Heidari and Jafari said that although the major characteristic of HIV infection would be the gradual annihilation of the physical ability, the psychological psychotic phenomena would emerge. After becoming aware of their disease, the patients who become sufferers of depression and anxiety would have low level tolerance and are not able to be flexible confronting problems and mostly lack self-confidence. Such individuals are not able to control their emotions and stressful interactions and they are weekly skilled in managing their anxiety and fury. They are not capable of controlling their negative emotions and reactions so that they would rage inwardly against the slightest disagreement or disapproval (5). The study by Sharifi and colleagues in Tehran, which was carried out on 50 healthy people as the control group and 50 AIDS sufferers as the test group, also indicated that the AIDS patients group were highly marked in their furious, self-destructing, sadistic, quarrelsome inactive behavior(25).

Bleak future was the last concept framed by the analysis and interpretation of the interviews texts. The majority of the participants had lost their hope to the future, for getting married, having child, educating and as a whole for the whole life. Some of them expressed that they felt blank and wished their life would come to an end. Even 3 participants had the experience of committing suicide. Awareness of the disease –particularly the ones that are fatal, life-threatening and that they bring out symptoms or those that are known as social taboos – arouses considerable anxiety. The patients react differently to their infection according to their cultural, social and supporting conditions as well as their marital status and soon. Their reactions consist of depression, committing suicide, etc. (15). In the study of Heckman and colleagues on 201 AIDS sufferers in 8 American

States, it was determined that 38 percent of them were obsessed with suicide and such increase in the level of suicidal obsessions was related to the depression symptoms, the feeling of not being so much able to overcome the problems, the concern about transferring the disease to others and most important of all was the anxiety about becoming disreputable by the disease (26). Farzadi and colleagues also conducted their research aimed at surveying the social aspects and coping with the diseases in two groups of sufferers from Acquired Immune Deficiency Syndrome. One group had much psychological consolation (satisfaction with life in all its aspects) and the other group had little psychological consolation (no satisfaction with life). These researchers revealed that positive HIV patients with psychological consolation attempted to cope with life in significantly appropriate ways. In contrast, those patients who didn't have psychological consolation used refusal compatibility to manage their life. Thus, they were less self-confident, more depressed and hopeless and the rate of committing suicide was also higher in them (27).

Finally, it is worth to mention that AIDS diagnosis probably would make the patient to go through a crisis. The question raised in the sufferer's mind would be how s/he could continue to live with such a serious problem and what its entity would be. How long they have to live their life in such ambiguous conditions (28). Resolving the crisis depends on such factors as: the rate of family, social and financial support, the accurate record of taking proper adapting mechanisms, sometimes the patient age and the educational status (21). Besides treating and medical interferences, attempts for providing comprehensive services, psychological services, improving the patient status and self-conception, reinforcing religious and spiritual aspects in the patients by encouraging them to pray and think deeply and group behavior therapy are all determining in affecting the patients spiritual and psychological aspects (29). The researches revealed that understanding a positive concept of the disease could leave psychologically beneficial impacts on the patients and even that would bring out advantageous health and supporting impacts. Moreover, it was demonstrated that the patients who grasp a positive concept of their disease would be psychologically healthier than the other patients (30).

Conclusion

Regarding the presented results of this research, the AIDS patients participating in this study underwent a variety of psychic-psychological problems since becoming aware of their infection. Knowledge of such experiences and understanding the psychic-psychological problems of these patients would enable the medical team to examine the problems from the patients own point of view and that they would take steps to aid them. Therefore, the application of psychologists consults, taking part in training courses –such as the psychology of the crisis, anger management, improving life-style and consultation with religious experts (to reinforce the spiritual and religious aspects) as well as the attempt to alter the social view in treating these patients would seem essential. Individual characteristics and mental obsessions of the participants were limitations to the present study and that influenced the way they relied the questions.

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