

The Life Experiences of the Patients Suffering from AIDS Living in Isfahan (Iran) in 2011

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Abstract: The present research has been done by the purpose of life experiences of patients who suffer from AIDS. Awareness of these patients' life experiences helps us to be better familiar with their personal life and find a general and deep cognition of all the aspects of their life and take step regarding promoting of their life quality in all the dimensions. Qualitative approach (phenomenology) has been used in this research. Sampling has been done by the method based on goal and up to information saturation. The participants were the patients suffering from AIDS whose disease has been confirmed based on diagnostic criterion and they had active records in center of health behavioral disease in Isfahan (Clinic Martyr Navvab Safavi). The extracted interviews were analyzed. Seven main concepts were obtained which include hope, vanishing, supporting, dark future and the fields of catching the disease, remorse and anger. The results of present research indicate that these patients experience a broad range of problems in different dimensions including physically, mentally, socially and economic. These people need watching by family and society in the physical dimension. Economic pressures arisen from treatments' additional costs and inability arisen from disease lead these patients toward dependency and challenge in order to provide health care needs and all of these factors face the patients with many difficulties in the mental area which itself necessitate the need to mental spiritual supports and application of psychological consultations.

Key words: Phenomenology, experience, life experiences, AIDS, the patients suffering from AIDS

INTRODUCTION

AIDS as a new found disease acclaimed its existence so competently that 20th century preferred to deliver powerlessly and pass (Heidary and Jafary, 2009).

AIDS epidemic has been extensively focused in Asia among addicts to injection drug, gays and the centers of prostitution, stree twalkers and their sexual partners. The studies show that about 90% of infected people to AIDS live in third world countries, especially in Africa and Asia and unfortunately this phenomenon spread in these regions is increasing strongly.

The first case of AIDS in the world was found in the blood of an African man in 1959 AD and the first case of AIDS in America was reported in a numbers of gay youth in June 1981 in Los Angeles (Hatami, 2006). This disease expansion in the recent years has been so that AIDS will be considered as the first death factor in 2010 AD according to control disease center of America (Smelters *et al.*, 2008).

While more than two decades have been passed from the time of AIDS disease identification but at least 600 million people over the world have been infected into this virus from the beginning of its globalization (pandemic). The >90% of afflicted persons belong to developing countries. So, AIDS is not only a health problem but also it is a social difficulty (Kapiga *et al.*, 2006).

According to the last statistic of Medical Health, Treatment and Training Ministry, the numbers of infected individuals to AIDS infection in Iran is increasing such as many other worlds' countries. So that, the numbers of afflicted persons have been 2269 in 2001 but the number of 21890 people have been infected to this disease in March 2011. Also according to published statistic the number of 469 person in Isfahan have been infected to this virus up to the first of March 2011 from which 141 number have been dead. The most of the transfer way in men have been from drug injection and it has been from

sexual intercourse in women. According to the estimation of diseases management center of Isfahan, the number of people infected to virus is about 1500 up to 2000.

The total number of infected individuals to virus is estimated something about 100000 number. This is while this phenomenon influences all the existential dimension and life of afflicted persons seriously based on its special nature.

Different reasons are involved in Iranians' vulnerability and especially Iranian women and daughters which include traditional cultures, polygamy cultures, drug frequency and cheapness, owning youth population, low level of literacy, low access to counseling centers and high percentage of injection addiction.

The study of life experiences of patients suffering from AIDS can offer a semantic framework and describe the concepts of life quality, healthy, pollution and preventing its transferring agency from the view point of those who experienced this phenomenon. Evaluating patient's experience in nursing intervention's selection and accomplishing is very more useful than interventions selection based on disease's signs and process.

The existing challenges and shortage of knowledge about these people's life experiences pursued researcher to evaluate and study these vulnerable group's life based on their real experiences. Therefore, it seems that more extensive study in order to more detailed recognition of all the aspects of their life and consequently increase life quality of these patients is necessary. In this regard, in present research, the below questions will be answered:

- What are the sub-concepts of life experiences of patients suffering from AIDS
- What are the main concepts of life experiences of patients suffering from AIDS

Research history: Research results by Hast (2011) showed that they have a satisfied life and they have some plans for futures. In spite of this disease, they have has a sense of happiness and have accepted this disease, because these people are supported by friends and family. This issue makes them satisfied. Of course, obtained information showed that some also feel exclusion, sense of being stigmatized, depression, shame and sense of guilt.

The research results by Peterson showed that those who have more relationship and stronger faith have a less sense of depression and this affair causes sense of security and peace in them. Some of them consider role of worship to direct themselves toward direct and peace way. The relationship with God in these individuals was able to create a fundamental change in their life and be as a biggest supportive system in these individuals.

The results of the study which has been done by Holzmer showed that Hispanicizes can be a separate race group which experienced stigmatization more than Africans, Americans and white skinned and they may need to some interventions to decrease it in their culture. Generally, while depression signs are remarkably a predictor for life quality, perceived stigmatization due to AIDS show a difference of 5.3% in life quality after signs controlling. The interventions decreasing stigmatization can have this success that they not only lead to better access to supervision and drug consumption but also they increase individuals' life quality. In other part, the research results by Najarkolayi *et al.* (2009) showed that most of the participants did not have a lot of information regarding AIDS.

The results of a research by officer showed that the most important reason of lack of condom application in relation with fixed sexual partner and sexual intercourse in exchange for receiving money or drug and sexual relationship with other man was declared lack of interest in condom and it was stated sexual partner's disagreement regarding sexual intercourse with one other than spouse and without receiving money or drug.

In other part, the research results by Tabrizi *et al.* (2009) showed that catching AIDS can be the cause of characteristic disorder in one hand; this is while those suffering from AIDS experience some mental emotional disorders after catching.

In other study, research results by Heidari and Jafari (2009) showed that totally respecting the averages which were respectively 43.85 and 20.80%, the individuals infected to AIDS virus have a lower level of general health compared with ordinary ones.

MATERIALS AND METHODS

Respecting the topic under study that is life experiences of patients suffering from AIDS and it has a qualitative concept, research kind is proportional to it and it has been selected qualitative. Research method in this study is phenomenology. Phenomenology is originated in research tradition which has been expanded by Hosrel and Hidger and it is a method for thinking about individuals' life experiences. Research environment in this research has been behavioral diseases section (Clinic: Martyr Navvab Safavi) and dependent to Isfahan' health Center. Population under study in this research were patients suffering from AIDS whose disease has been confirmed by infection experts according to diagnostic criterion and t disease constituted sample in this research and sampling method based on goal has been used. Sampling method which is based on awareness goal is named as judgmental or selective

sampling and author’s intentional selection of certain samples and events are considered in study. Sample size in this research was obtained following interview with 13 numbers of patients suffering from AIDS and information filling was obtained. In the other words, sample size in this study is 13 numbers of people and field method has been used to collect data. This observation occurred when the phenomenon are studied in their natural status. A detailed and without structure and field note and recording statements was used. The interview was started with a broad and general question and the next questions were asked regarding daily life events and the way of life in the past and now. It was aimed during interview with open questions and non-verbal in order to confirm and show interest in their statements, the participants state the problem in detail. Data analysis in present research has been done based on seven-stage method called “Colaizzi”.

RESULTS

Descriptive findings: The 13 numbers of patients suffering from AIDS interviewed in order to receive research objectives. Age-range of participants in research was 25-57 and their average age was 34.92. Three numbers of participants were woman and 10 other numbers were man and average time of their catching was 4.07 years (Table 1).

Inferential findings: The Colaizzi phenomenology analysis method is researcher’s activities director in data analysis of present study.

According to first stage from seven-stages of Colaizzi analysis: Participants recorded statements was studied several times and it wrote down on the paper word by word and the product was reviewed several times and it was compared with recorded sound studied and

researcher aim to better understand and have the same feeling with participants through accurate and repeated reading the interviews and describing participants.

At the second stage of Colaizzi analysis: Researcher posed some questions for pursuing subjects during listening and transferring topics and reviewing them. He did not focus on written explanations in determining important sentences and he also consider next and previous phrases, the questions which were led to say these sentences and phrases and even face status and the accent by which participant uttered mentioned phrases.

At the third stage of Colaizzi analysis: Researcher aimed to conceptualize and formulate extracted meaning to perform this stage based on Colaizzi comment. In this stage (primary codes) main sentences related to event under discussion which have been specified by underline method were extracted.

At the fourth stage of Colaizzi analysis: According to Colaizzi theory, formulated concepts have been placed into thematic clusters and categories after codes’ repeated readout and repeating third stage and so second level conceptual codes were obtained (Table 2).

In present research, 17 sub-concepts (second level code) which were obtained in the field of life experiences of patients suffering from AIDS combined together and seven main themes which have been shown in Table 2 were extracted according to researcher’s logical deduction from mentioned experiences by patients. As an example, unawareness is one of the extracted concepts.

At the sixth stage of Colaizzi analysis: It was tried that a comprehensive explanation of phenomenon under study is offered in a statement without ambiguous. At the seventh stage of Colaizzi analysis, researcher has went to each ones of participants in research and ask

Table 1: Participants’ demographic features in research

Participant	Gender	Age	Marriage status	Job	Catching time	Education level	Way of catching
1	Man	38	Married	Unemployed	6	Cycle	Drug injection
2	Woman	36	Married	Householder	2	Secondary education	Sexual intercourse (spouse)
3	Man	28	Married	Unemployed	1	Diploma	Dental surgery
4	Man	41	Married	Unemployed	5	Secondary education	surgery
5	Man	35	Single	Unemployed	3	Diploma	Drug injection
6	Man	40	Divorced	Unemployed	13	Associate degree	Drug injection
7	Man	36	Single	Free	7	Cycle	Drug injection
8	Woman	57	Married	Householder	5	Illiterate	Sexual intercourse (spouse)
9	Man	41	Divorced	Free	4	Cycle	Unknown
10	Man	26	Single	Unemployed	1	Diploma	Tattoos
11	Man	33	Single	Free	3	Secondary education	Drug injection
12	Man	31	Married	Free	2	Secondary education	Drug injection
13	Woman	25	Married	Householder	1	Secondary education	Sexual intercourse (spouse)

Table 2: Extracting main theme from sub-concepts based on fifth stages of Colaizzi analysis

Sub-concepts	Main concepts (themes)
Unawareness	Hope
Recourse	
Acceptance	
Disability	Vanishing
Progressive signs	
Accompanying	Support
Helpless	
Financial difficulties	
Annoying behaviors	
Grief	Dark future
Concern	
Inability	
Stigmatization	
Reservation	
Remorse	Remorse
The areas of catching	The areas of catching
Anger	Anger

some questions regarding research's finding validity and he studied their confirmation regarding extracted subjects and final reliability was acquired in this way.

DISCUSSION

We aimed in this research to be close to the life of these patients and study these patients' problems and difficulties from their own opinion. The present research's findings showed that these patients have experienced many physical problems. In other hand, they have experienced many spiritual mental difficulties such as anxiety and depression. Unfortunately, other than spiritual mental difficulties which were seen in these patients because of this disease, this disease is considered as a social stigmatization and taboo according to its special nature which it was transferred from the sexual or drug injection ways and this by itself multiplies these patients' problems. Stigmatization and the consequences arisen from it put most of these patients under intense psychological pressure that it can have a main role in occurring psychological diseases. Social stigma makes people to resort to hide this disease from the others' vision which this can be effective in decreasing these patients' level of adherence to drug regimens and in the other hand, the fear from spouse, child, family and friends' judgment and consequently taking action to secrecy lead to infection expansion. The AIDS issue and the rights of patients suffering it are considered as one of the main issues of present century. The first right which has been imagined for these patients is the right to enjoy health without discrimination and difference. Today the rights of people who transfer AIDS virus have been promoted. In the field of researches question including what are the sub-concepts and main concepts of patients suffering from AIDS, finally we

reached to 17 numbers of sub-concepts and 7 numbers of main concepts which they have been described in detailed in following.

In this regard, the study by Etemad (2009) matches with current studies because the results of their studies showed that the participants' awareness level in study has been tangibly low regarding AIDS disease signs and the ways of no transferring such as dinnerware set, mosquito bite, cooker suffering from AIDS and total only 28.4% of participants have has good awareness and 36.6% have had average awareness and 35.1% have had weak awareness.

It was specified in the research by Najjarkolayi *et al.* (2009) that most patients have incomplete information regarding transfer or prediction ways of AIDS.

Kalkhoran and Hale (2008) showed in their studies that some ones of those catching AIDS virus did not have the main way of their disease transferring and in any way they did not refer to infection through sexual intercourse that it seems that mentioning transferring uncommon ways is risky because of sexual intercourse stigma and shame.

In the study by Ramazami which was done on the Iranian groups at risk such as: truck drivers, passengers of border, the women with illegal sexual intercourse and youth, showed that the awareness level of infection HIV and AIDS disease is medium low and even it is lower regarding those who commit more risky behaviors. This is while the research of Sigarlaki with the purpose of the awareness level of prisoners regarding AIDS showed that only 12.08% of prisoners enjoyed good awareness of AIDS disease and 52% have had medium percent of awareness and 35.84% have had weak awareness regarding the nature of AIDS or in the same study by Zafar in 2003 which has been done on Pakistani and Afghani addicts in Kate City, it was specified that only 8.3% of Pakistani addicts were listened about AIDS while this number in Afghan addicts in only 4.3%. In this regard, the research results by Mohammad poor have been in this regard. Ironson *et al.* (2006) showed in their study that 45% of samples who infected to this disease showed spirituality increase after disease identification.

In this regard, Allahbakhshian *et al.* (2010) and Qolami and Beshlide (2011) showed in their research that spiritual healing have had very much effect on mental health of divorced women and it has led to decrease occurring physical signs and anxiety and sleep disorder in them.

Accepting disease was one of the problems that patients suffering from AIDS referred it according their experiences.

In the field of acceptance' the results of Hast' study in 2011 in research of Vizeh and Moradi showed that many participants have a satisfied life and they have some plans for future. They have a sense of happiness in spite of AIDS disease because they have accepted this disease.

Also, most participants in present research following immunity system weakened and incident of disease symptoms and side-effect of consumption of anti-virus drugs suffered from inability in daily work doing, inability in putting on clothes, inability in supervision of themselves or disability in doing personal duties. The study findings by Moses *et al.* (2005) showed that 94% of participants in research had at least one unsatisfied need and the highest level of unsatisfied needs was related to tiredness (81%), pain (72%), inability to doing work (72%), fear from disease intensification (72%), sleep problem (70%) stress and anxiety (69%). Since, participants in present study were selected from the patients in the AIDS stage, so the maximum of them have experienced very symptoms due to the effect of virus on body's different organs and in the other hand, they were got these symptoms following drug prescription and also mental pressure due to disease nature. The study by Javadi (2010) regarding more prevalence of parasites in those suffering AIDS have shown these people's more Immunity system weakness and high sensibility at first toward gastrointestinal parasites. Rad performed another study in Sanandaj regarding the skin appearance of positive HIV patients which showed a broad range of skin disorders in 74 samples under study.

"Accompanying" was one of other main extracted concepts of life experiences of patients with AIDS disease who participated in this study.

In this regard, the below authors' researches such as Murphy *et al.* (2002), Ichikawa and Natpratan (2006) and Mosavi and Mostafayi (2011) are consistent with these results. Many participants in present research had experienced following others' informing of their disease something such as helplessness, having none, lack of receiving support from others, social isolation, being disregarded by others that these reactions by themselves has led to create several spiritual problems and increase the stress in these patients. The study of below researchers in this regard is consistent with obtained results of the experiences of some participants. For example, these results are consistent with the research results by Murphy *et al.* (2002), Heidary and Jafari (2009) and Jia *et al.* (2004).

One of the most common raised complaints by participants in this research was a financial "problems" which was created following incident of consequences due to physical or spiritual signs for these individuals. The research by Mills *et al.* (2006) and Abedi *et al.* (2012) are consistent with these results.

Most participants in this research have been suffered somehow from behaviors and the ways of impact of wife, family, friends and sometimes the health team members. The study by Myers and Durvasula (1999) are consistent with these results.

The many participants referred to some difficulties such as sense of anxiety, stress, concern about future, fear of inability and death, fear of losing honor and social status, fear of being rejected by society and concern about transferring disease to wife/husband and children and some other concerns like this. In this regard, the bellows researches are consistent with current research: Galvao *et al.* (2004).

One of the other experiences that the units under study referred it was the sense of inability, lack of hope to future, commit suicide, tendency to divorce and its occurrence and having hope to be dead. In this regard, the researches by Cazalo and Farzadi are consistent with present research.

Due to AIDS disease nature and special ways of its transfer and society's view on these patients, many participants in this research feared continuously of judgment of others, wife/husband and children or they have received some stigma from them following their informing of their infection to this disease based on this that they have been guilty people or they have not been adhered to ethical principles in their martial relationships. In this regard, the studies by Santos *et al.* (2007), Duffy (2005) and Joseph and Bhatti (2005) and finally Skinner and Mfecane are consistent with our research.

Many participants in this research expressed that they have hidden their disease from their wife/husband, family and friends. Mohammad Poor wrote quoted by Calin that: Amaking AIDS recognition hidden from others occurs as a reaction to some experienced encounters which it by self makes the condition worse and also it leads to disease expansion and it will be cause of incident of physical and psychological signs because of lack of "ersuasion" Page 32.

In this regard, the studies by Murphy, Sorlise and Hid and Rahmati Najjar Kelayi are consistent with the findings of present research.

"Remorse" is main theme which was extracted from the experiences that participants in this research referred to it, so that most samples experienced some senses such as sense of guilt, shame and embarrassment or they were blamed by themselves or others following informing from their infection to AIDS disease. Those who were affected by this disease because of committing social undesirable behaviors, they considered it as divine torment and the punishment for their sins and they were regretful because of their past. Respecting the factors which make the fields for catching AIDS, the researches by Najarkalayi *et al.*

(2009), Javadi (2007), the study by DiClemente *et al.* (2001), Huebner and Howell (2003) and Li *et al.* (2009) are consistent with the results of present study.

In the other hand, it seems that absence of religious beliefs and adherence to religion are ones of the fields of catching this disease, because most participants in this research which had risky behaviors did not have strong religious beliefs and the level of their adherence to religious formalities have been few. It was specified in this research by Agadjanian (2005) in this regard in Mozambique that religion is a variable which influences risky behaviors and being religious is a barrier for some risky behaviors such as illegal sexual intercourse and it is considered as a barrier in catching HIV infection and AIDS.

It was specified in some samples' statements that oral and physical violence has been occurred following that their wife/husband informed of their disease. Research results by Doering *et al.* (2004).

Therefore, this research results can be used to better supervision and with higher quality, training these patients and their families by Health Team Members whether nurses, doctors, psychologists, social works and all the people that are connected to these patients in any way. Respecting mental-spiritual difficulties arisen from virus's direct effect on some organs such as Brain or mental-spiritual difficulties due to existence of parasites and discriminations, the necessity of psychology and psychological counseling in order to effective accepting and using adjusting mechanisms in these people will be important.

CONCLUSION

The existence of social supporting systems such as assurance, supporting assembly of these patients is sensed and statesmen's attention in this regard is important. It seems that the most fundamental step to settle existing vacuums is giving required training and awareness to them and their families. Nursing team must play more active role in this regard.

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