**Bulletin of Environment, Pharmacology and Life Sciences**
Bull. Env. Pharmacol. Life Sci., Vol 3 (1) December 2013: 251-256
©2013 Academy for Environment and Life Sciences, India
Online ISSN 2277-1808
Journal's URL:http://www.bepls.com
CODEN: BEPLAD
Global Impact Factor: 0.533
Universal Impact Factor: 0.9804

**ORIGINAL ARTICLE**

# Exploring Perceptions of HIV/AIDS patients Regarding Social outcomes of Disease

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## ABSTRACT

*HIV disease is not only a health problem, but also is a social and cultural challenge. It significantly makes patients vulnerable and hinders them from sufficient treatment. A better understanding of social outcomes, difficulties, and demands of HIV-infected patients considerably facilitates planning to support them. The aim of this study was to explore perceptions of HIV/AIDS patients about social outcomes of the disease.*

*In this qualitative study, using conventional content analysis approach, participants selected through purposeful sampling method. They were HIV-infected patients who referred to a selected behavioral disorders clinic affiliated to Shahid Beheshti University of Medical Sciences. Maximum variation (e. g age, sex, route of infection, disease duration, and education level) was the criterion for selecting participants, and sampling was continued until data saturation. Semi structured interview, which were designed based on literature review, was employed in this study in order to data generation. Two researchers verified the truth worthiness of data using parallel analysis of data, their sampling method, and steps of investigation.*

*14 patients participated in this study. Analysis of data showed 5 social outcomes including life difficulties, uncertainty, enduring of life with HIV, need for common perception and treatment compliance.*

*According to the findings of this study, it is concluded that informing public activities are less than required rate and individual counseling and sectional information may not be a good solution to the community needs including complete awareness of social outcomes of HIV/AIDS, preventive methods and disease transmission.*

***Key Words:*** *AIDS, Social outcomes, Qualitative Research*
*Received 19/10/2013 Accepted 19/11/2013*

## INTRODUCTION

AIDS is a reality that all people, rich or poor, facing [1-2]. HIV disease is not only a health problem, but also is a social and cultural challenge. It significantly makes patients vulnerable and hinders them from effective treatment [3-4]. Twenty years after the AIDS epidemic started about 33 million people around the world, infected with HIV [5]. This epidemic has a significant worldwide impact on development, causing illness and death in productive ages [6] and large funds spent on the disease [1,7]. AIDS drives families to poverty, banishes people from communities and violates many human rights [1,8] this epidemic has become into a social crisis from a public health challenge [1].

HIV/AIDS has several social outcomes as stigma, discrimination, financial difficulties and restrictions in family planning that are referred in some studies [9, 10], but there are no studies in our country, evaluating AIDS complications from the patient's view point. Knowing social outcomes of the disease in infected patients, maybe helpful for policy makers and caregivers to plan interventions based on their needs. Accurate Understanding of difficulties of HIV infected patients, provide the possibility of better planning for them. This research was to explore perceptions of HIV/AIDS patients about social outcomes of disease.

## MATERIALS AND METHODS

This is a qualitative study, using conventional content analysis approach. Participants include HIV-infected patients who referred to a health center affiliated to Shahid Beheshti University of Medical Sciences with a behavioral disorders clinic and they were selected through purposeful sampling method. Maximum variation (e. g age, sex, infection method, infection lifetime, and education level) was the criterion for selecting participants, and sampling was continued until data saturation. After nine interviews, data saturation reached five more interviews, were also conducted to make 14 total interviews. semi-structured interview, which were designed based on literature review, was employed in this study by six experts in order to data generation (the doctor in behavioral diseases clinic, chief healthcare center, corresponding specialist of AIDS disease in treatment assistant of Shahid Beheshti University of medical Sciences, corresponding physician of AIDS department in health ministry and 2 corresponding physicians of AIDS in Damavand's health network). All interviews were conducted by a researcher and recorded with the permission of participants in the study.

The interviews started with general questions and then followed by main questions. Some of the questions asked during interviews are: have your life been changed after the disease, and which of them are caused by this disease? Please describe living with this disease for me? Do the people around you (family, friends and others) know anything about your disease? How they coped with your disease? Would you define a memory of people's behaviors with you as a HIV infected patients?

Every interview took 3 to 4 minutes and they were continued until data saturation. After interviews finished, records were written word by word as soon as possible after 2-3 times listening and they were analyzed simultaneously with collecting data. Then all data reviewed by listening to records to ensure the accuracy.

After this, participant's sentences in this study extracted as a code, suggesting a unit of meaning. Data collected from semi-structured interviews were classified into relevant categories that reviewed again to reach their important themes as important outcomes of AIDS.

We proceed analyzes during data collection to provide data feedback in order to improve the accuracy and quality of data. Other strengthening methods in this study include selection of main knower, detailed and step by step description of research, evaluation of sample characteristics to rise data transmission and peer check by supplemental opinions of colleagues.

## RESULTS

The participants in this study was 14 patients with HIV/AIDS aged between 24-52 years, include 11 males and 3 females, all were single, except two of them. Duration of their infection was 1-14 years. They were plumber, driver, shopkeeper, motorcycle couriers, optician, hair dresser, teacher, sex worker, house wife, wedding services providers and unemployed. Routes of infection were contaminated needle in 4 people, tattooing in 1 and sexually transmission in 9 people.

One thousand and fifty codes were reached after analyzing the manuscripts, which were classified into 13 categories. Then categories merged based on common concepts, and 5 main outcomes were as follows (table 1):

*Life difficulty*: our findings showed that difficult life is one of social outcomes of this disease. This theme includes two categories of unemployment and financial problems.

Most participants (10 out of 14) in this study complained from unemployment and financial problems caused by their illness. Also they said: if they were not infected, they would continue their previous jobs. One of them (a 52 years man) said: if I was healthy, I would continue car body and paint job, but now I am so weak and can't work. Noticeable point of participant's statements was that they had lost they jobs as employers knew their disease, also they complained that employers discriminate between them and other employees. In this regard a 29 year old man stated: people are afraid of AIDS so they do not employ us, if an employer finds out someone is infected with HIV, he/she will exorcise him/her to prevent other's infection and they will discriminate between healthy and ill employees.

Also according to our findings, direct and indirect costs of their disease are causes of life difficulties in these patients, as a patient (a 52 years man) said: access to medical care is difficult for me because of high costs of travelling by taxi.

*Uncertainty*: this theme consisted of hiding disease, marital status and changes in spiritual beliefs.

There was a significant uncertainty in participant's statements, as 14 patients hided their disease, in some cases, they said this is because of unawareness of the others. A 44 year old patient said: I didn't tell about my disease to my friends and the others, because they have little information, and if they find out my disease, they will be separated from me. But some patients hided their disease because of its negative consequences: I won't tell about my illness to my physician, at first when I came to doctor for a cold, I told him/her about my disease, but because of negative consequences I won't tell this future.

Loneliness and lacking partner is another social outcome of the disease, as participants in this study thought it is a kind of uncertainty about future, marriage and family decisions. Only two participants were married. Most participants complained of loneliness and barriers to marriage including financial problems, unemployment, illness and other's opinions. One of patients (a 29 years man) said: my mother believe I have to marry a healthy person who already didn't have a relationship, but I do not.

Changing spiritual beliefs is another category suggesting uncertainty and doubts in patients with HIV/AIDS. Some of participants in this study, told they have lost their faith after the disease. One of them said: I'm not a religious person, and now I believe less, I have prayed before, but not now, I believe in God and prophet, but I don't go to the mosque (a 29 years man).

A 52 year old male patient, stated about believing in God and destiny: I believe in God, whatever God wants, whether keeps me 100 years or not.

*Enduring life with HIV*: there are three categories in this theme including discrimination, stigma and changes in social relationships, discrimination was the most common among all participants.

A 52 years old male participant pointed to discriminatory behaviors of employers as: when they realized I have AIDS, they did not hire me or they discarded me. Another 48 year old male patient told: employers will discriminate between healthy and HIV positive employees surely.

Most participants, mentioned changes in social relationship as loneliness and isolation, changes their feelings about their families and changes in other's opinions about them as a patient with AIDS. A 30 year old female patient said, I am so alone and I feel I have lost my life.

Another patient (a 27 year old woman) told about changes in her feelings and interests as: I hate people including my family.

But in some cases, family relations strengthened and family members supported patient, as a 24 years old male participant said about his sisters: they always console me.

All participants in this study thought AIDS is a stigma that all people consider it as a moral issue. In this regard a participant in this study (a 52 years old man) said: I told AIDS is a moral issue because I know society will not support me.

Another participant (a 44 year old man) told: people should not treat AIDS as a patient with leprosy, AIDS is just like other diseases.

A 32 year old patient mentioned AIDS as a taboo, he said: if I find a job and employer realize to my illness, he/she will discard me, because it is a taboo and people have bad opinions about it.

*Need for common perception*: categories as society perception about AIDS, one sided expectations and social support are in this theme.

All participants noticed common perception as an important need which is neglected in our society. They also talked about moral issues, negative prejudices and people's fears. One participant (a 41 year old man) told: all people afraid of this disease and another one (a 27 year old woman) said: society considers AIDS as a behavioral disease and don't support patients with AIDS.

Another problem caused by AIDS is lack of understanding mutual needs and expectations of patients and society. Most patients in this study, believed about one sided expectations that respectful behaviors and honor are so important. A patient (a 52 year old man) said: mostly I need kindness and respect. A 30 year old female patient, also said: I need sympathy and honor, enduring this stigma is so hard.

Some participants emphasized financial supports, in this regard a 52 year old patient told: government and insurance should support us, it is better for us to get paid from social workers, I mean low pay.

Another important aspect of participant's view was social support, that most patients are suffering from social rejection and lack of family and friends supports, a 27 year old female patient said: my family don't accept me, I am so depressed, I hate them, I do not participate in any family parties.

*Treatment compliance*: this theme include access to medical services and understanding the disease.

Most participants (13 out of 14) reported easy access to medical services, also most of them (11 out of 14) complained from unawareness of people and even health care providers that is effective in the quality of health services.

Although there are easy access to medical services, free drugs and laboratory tests, some patients noticed negative view of health care providers, as a 44 year old man said: when I was admitted in a hospital for surgery of my leg after an accident, one of nurses left when she realized I am HIV positive, she was nurse, so what about the others?

He also said: I have no problem in getting into medical services, if you have money, access to medical services won't be a problem.

One of participants noticed good behaviors in some medical centers as: they treated me well, even when I was depressed, they talked to me to make me better.

Some participants emphasized awareness of routes of infection in prevention of disease, as he told: I am ill now, but all people should know routes of infection.

Another patient (a 52 year old man) stated about important roles of media in awareness of people about prevention of disease that: media should talk about routes of infection and prevention to support me.

All participants in this study considered difficult life as a common result of the disease, all patients were uncertain in their life, they thought, living with AIDS is so difficult and they need common perception. Also they told they have good access to medical services, but people don't know enough about the disease.

Table1. Categories and themes founded in interviews.

| Main theme | Category |
|---|---|
| difficult life | Unemployment, financial problems |
| uncertainty | Hiding the disease, marital status, changes in religious beliefs |
| enduring life with AIDS | Discrimination, stigma, changes in social relationships |
| need for common perception | Society's view of the disease, one sided expectations, social support |
| treatment compliance | Access to medical services and knowing about the disease |

## DISCUSSION

The aim of this study was to explore conceptions of patients with HIV/AIDS from social consequences of the disease. After interviewing with 14 patients with AIDS, and analyzing the results with conventional content analysis, 13 categories in 5 themes reached.

One of the most important themes was difficult life for most participants. This is consistent with most studies in this field. In a study by Bahadori et al [11] on 120 patients with HIV/AIDS it is concluded that this disease causes high indirect costs. As most patients are unemployed or have low salaries, providing health insurance for patients and their families is needed.

A study by Ezy [12] et al on patients with HIV/AIDS in Australia showed that the disease results in severe physical, financial and social problems . The most important cause of life difficulty in these patients is unemployment caused by their physical disabilities, discarding and lack of job assignment. In a study by Sing et al [13] on 100 patients with HIV/AIDS in India, unemployment raised significantly after infection .

So, financial problems can also make life difficulties. These financial problems are caused by unemployment, high costs of treatment and lack of medical insurances. In n study by Ergas [14] about patients with HIV/AIDS in USA, it was shown that patients diagnosed with AIDS will lose their medical insurance and suffer from financial problems and unemployment .

Uncertainty was another theme concluded from this study, it means doubtful future appeared as hiding the disease, doubtful beliefs and lack of planning for life. The disease will hide from family, friends and health care providers. In most studies, it was shown that this approach is so common among patients with HIV/AIDS, for example in a study by Mawar et al [15] in patients with HIV/AIDS In India, fears from unsuitable behaviors caused patients to hide their disease, interfering in their treatment procedures.

For participants in this study, one cause of disease hiding was teachings of health care providers, as they tell: there is no need to talk about your disease, if you practice good personal hygiene, and hiding is a protective mechanism against some inappropriate social behaviors, but it can be greatly dangerous for people in contact with these patients.

Another study by Sadr et al [16] concluded that patients with HIV/AIDS hide their disease because of personal problems, so many of them won't be treated and their health is endangered. They will spread virus in different ways and challenge public health , as one of participants in this study, hided the disease from his partner and dentist. Disease concealment can become to an important social challenge that is spreading the virus in society.

Change in spiritual beliefs is another category involved in uncertainty. Despite participants believes in God, they are not willing to participate in religious rituals. It is consistent with the study by Cotton et al [17] on 405 patients with HIV/AIDS conducted in three cities in America. They found that unwillingness to participate in religious rituals is caused by inappropriate attitudes of religious bases as they think patients with AIDS are guilty . Another study by Nije et al [18] on American-African pregnant women with AIDS, showed that patients trusted in God to be helped, but also they did not inform church and people about their illness as they are not supportive .

Inability of patients in making family decisions is another finding of this study in the theme uncertainty. Families prefer not to enter another patient to their family or the patients do not want to marry another patient. In the study by Fallahi et al [10]) on 34 patients with HIV/AIDS in Tehran, about social consequences of the disease, it was shown that there are social, economic, psychiatric and physical consequences that inability in marriage and having child are the most important ones.

Living with AIDS is a big challenge in all communities. In this study, enduring life with AIDS is one of important themes suggesting negative conditions imposed by this disease. One of the most harmful social consequences of AIDS which makes life difficulties is discrimination, a worldwide challenge, that some researcher pointed out in their studies [15].

Based on the findings of this study, discrimination has different aspects in family, friends and colleagues. Changizi and Bitaraf [9] showed that stigma and discrimination have destructive effects on patients with AIDS resulting in unemployment, however, social service providers may also discriminate.

Stigma is another negative result of the disease, noted by participants in this study, the study by Bluthenthal et al [19] over 14 religious groups in America, showed that stigma is a basic barrier in prevention and treatment of AIDS, and religious structures believe that homosexuality and drug abuse (as the most common causes of the disease) are sin and patients with AIDS are sinful. In other studies, stigma made so many problems to patients with HIV/AIDS and finally interfered with their treatment [15].

Change in social relationship is another category of life difficulties in AIDS patients. These changes may be caused by changes in perceptions about families and friends appeared as hating, loneliness and rejection from society in the study by Nije et al over African American pregnant women AIDS, patients felt fear, loneliness, resentment as their families and friends realized their disease [18].

Need for common perception is another theme, nor society neither patients don’t know needs, interests and expectations of each other so in the absence of no common perception, there would be activities to provide needs and expectations.

For example society, has a vision of fear, resentment, hatred and bias for this patients. In a study by Cotton et al [17] over 405 patients with AIDS in three cities of America, religious societies, regardless of route of infection, look at patients as guilty persons.

Expectations of AIDS patients from society is a category in this theme, consisted of human dignity, respect for social rights. Rahabar [20] concluded in a study in Iran that preventing the spread of AIDS, require respect for individual rights. Patients have similar rights as healthy people, should be respected. These rights include right to work, eliminating discrimination against them, right to work, education, health, equality, marry, safety, social helps and welfare and legal freedom. Undermining rights of AIDS patients not only support society, but also raise spreading of the disease eliminate discrimination, equality, and participation are basic principles in every strategy against AIDS.

In a study by Singh et al [13] over 100 people with AIDS, patients expected jobs and social acceptance. Another expectation of patients with AIDS, is social support including financial and emotional support in family and having relationships with friends and families. According to a study by Foruzan et al [21] in Tehran, over the patients with HIV/AIDS, social supports are so important and often families will provide it . Most participants in this study emphasized financial supports of society and family.

Another theme extracted from interviews, was treatment compliance, that is an important challenge in these patients management. Access to medical services is a helpful agent in treatment, that all participants said it is good and enough, however it seems that this sufficiency caused by selecting participants from a particular referral AIDS center. In a meta analysis study by Neuman et al [13] over patients with AIDS in four sub-Saharran African countries, it was shown that access to medical services is enough and just 10% of patients had restricted access because of discrimination . Also Singh et al [13] concluded a study on 100 patients with AIDS in India, founded that most patients are satisfied with the access to medical services.

Another category of treatment compliance is recognizing the disease. The prominent point in interviews in this study is awareness and knowledge of patients on the various aspects of diagnosis, treatment and management of the disease. Most patients were aware of their disease and treatment and emphasized on teaching the routes of infection in schools and by media, also they believed that they were infected because of unawareness, and as awareness raise, disease spread will decrease.

In a study by Attaei et al (2010-2011) over female hairdressers in Isfahan, it was showed that their information about routes of infection and preventive actions was moderate. Oyeyemi et al (2012) conducted a study over medical students in Nigeria concluded that inadequate knowledge in these students after graduation, is a cause of doubtful or insufficient treatments.

There are no enough informing activities and individual counseling and temporary advertisements as Worlds AIDS day can’t meet the needs of awareness of prevention from the disease. Regular and public educations, for example in colleges, high schools and educational programs in media, are probably helpful.

The most important limit of present study, is interviewing patients in a referral center of AIDS, so untreated and uncontrolled patients may have different opinions about social consequences, however, access to these patients isn’t possible because of special circumstances in our society.

## ACKNOWLEDGMENT

This study has been a part of thesis of social medicine assistance so researchers appreciate all who have assisted in this study.

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## Citation of this article

Ameneh M. R., Kambiz A.,M., Ali H., Hourieh S. M, Maryam R.. Exploring Perceptions of HIV/AIDS patients Regarding Social outcomes of Disease.Bull. Env. Pharmacol. Life Sci., Vol 3 (1) December 2013: 251-256