

HIV/AIDS Related Stigma in Iran: A Qualitative Study

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Abstract: *HIV/AIDS is considered by many one as the most dangerous disease emerged in the human history. Unlike many diseases, this one is not just a medical situation; but a social problem. Its ways of transmission, generally related to risky behaviors and sexual activities, have pulled the attention of different sectors of society to this disease. It seems that a stigma is formed around HIV/AIDS and people who live with this disease are stigmatized. In this study, by using a qualitative approach, it has attempted that the primary causes of the stigma be discovered. A secondary data analysis was conducted to provide the necessary data for grounded theory. This method provided a theoretical model, in which, the causes, the context, confounders and mediators, consequences and strategies of action and interaction about the phenomenon of HIV/AIDS related stigma are discovered and shown.*

Keywords: *HIV/AIDS, Stigma, Stigmatization, Qualitative Study, Grounded Theory, Sociology of Health and Illness.*

Introduction

AIDS (Acquired Immune Deficiency Syndrome) is a disease caused by infection with the human immunodeficiency virus (HIV). HIV can be transmitted through sexual intercourse, through sharing unclean intravenous needles, through perinatal transmission (from infected mother to fetus or newborn), through blood transfusions or blood products, and, rarely, through breast feeding (Mooney et al, 2014). In 1981, for the first time, AIDS was observed in the United States; among a group of addicted homosexual men; hence some scholars and researchers started to believe in the idea that this disease is related to homosexuality and they named it “Gay-related Immune Deficiency” (Capitanio and Herek, 1999). But a couple of months later, AIDS was observed among male and female Injecting drug users. After observing this disease among addicted women’s babies and some people who hadn’t had the experience of homosexuality, the first idea was critiqued and infection was declared as the main cause of the disease (Zoladl and Shahcheraghi, 2000). Finally, in 1983, the causing virus was discovered and named “human immunodeficiency virus (HIV)” (Fakhar and Niknejad, 2000).

“HIV/AIDS has killed more than 20 million people, and in 2006 nearly 40 million people worldwide were living with HIV infection” (Mooney et al, 2014). In Iran, the first observation of AIDS was recorded in 1986; a six-year child with hemophilia who was infected through using unclean blood products (Tavoosi et al, 2004). The first HIV-positive woman and the first deaths, caused by AIDS were recorded in the years 1989 and 1990 (Ebrahimi Tavani, 2001). The National Committee for HIV / AIDS was formed in 1987 and the Ministry of Health and Medical Education became the main trustee in managing this new problem (Ghazi Tabatabaee et al, 2006). According to the Ministry of Health and Medical Education, until 2011, the number of people with AIDS in Iran was 23125. It has been identified that 91.5% of these patients were men and 8.5 percent of them were women (Public Health Department of the Ministry of Health and Medical Education, 2011). However, According to the studies, conducted by the World Health Organization, the estimated number of people with HIV in

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Iran in 2012 was 80000 (Fallahi et al., 2012). In 27% of cases recorded, the manner of transmission is unknown (Ghazi Tabatabaee et al, 2006). In the past few years, the percentage of sexual transmission remained constant, but its absolute number has increased. The percentage of the cases with unknown manner of transmission has been rising in the past few years (Fallahi et al., 2012). Unknown manner of transmission is probably caused from the refusal of the patients to indicate how they were infected. This indicates that determining how they have been infected could have some bad consequences for them.

AIDS as a Social Problem in Iran

Social problem is “an alleged situation that is incompatible with the values of a significant number of people who agree that action is needed to alter the situation” (Rubington & Weinberg, 2003). According to this definition, one can consider three indicators for distinguishing a social problem from other problems, in this case from a medical problem. These three indicators are:

1. Being an alleged situation
2. Being incompatibility with the values
3. Needing action to alter the situation

Regarding these three indicators for the problem of AIDS in Iran, it can be inferred that this is a social problem.

- First, it is an alleged situation because it has evoked the concern of social, political and cultural elites of the society, there is a considerable amount of media production (interviews, documentaries, etc.) about AIDS and it is hard to find anyone who is not familiar with its name.
- Second, the manners of transmission of the HIV virus are somehow related to ethical and religious values of a traditional society like Iran; in which there are still some strong taboos regarding sexual activities, homosexuality and addiction.
- Third, one can consider the great amounts of budget invested in international (like UNAIDS) and local (like National Centre for AIDS Prevention) organizations, Seminars and conferences, the establishment of NGOs, etc. as signs can show that there is a general determination to find a solution for this problem.

Stigma of AIDS

The difference between the estimated number of patients and the identified, mentioned above, could indicate that people who have had high-risk behaviors, have less desire to test and determine the conditions of their infection. This may have been caused by public attitudes toward the disease. In different societies, people's attitudes towards the disease is different and in many cases, negative and with discrimination. People's attitude could be related to the social acceptability of the manner of transmission in the community and can cause the health service centers refusing to deal with patients (Akala and Semini, 2010). Fear of stigma, feelings of anxiety, frustration, depression, stress, low perceived quality of life are the problems generally seen in people after getting infected with this disease (Maman et al, 2009). Negative attitudes toward patients can be observed even in the health service centers and it has had negative impacts on patients' access to health services, social interaction and social support. Stigma leads to discriminatory behavior toward HIV patients and this will have some consequences for them, including social exclusion, isolation, losing jobs and difficulties in access to health services. Stigma can affect mental health of the patients. People are generally reluctant to talk and eat with HIV patients. In many cases, patients have lost their jobs after the revelation of their disease or lost their chances for education. Perhaps, one of the main causes of the negative attitude is lack of knowledge about HIV virus and its ways of transmission (Li et al, 2009) Nowadays, scholars consider these attitudes as the most important obstacle for successful implementation of the programs which are designed for prevention, control and treatment of this phenomenon (Mahajan et al, 2008). From the perspective of labeling theory, the emergence of a social

problem is caused by the reaction of the people in violation of norms and rules (Rubington & Weinberg, 2003). As it is mentioned above, people have a negative attitude towards AIDS; they consider this disease as the consequence of patients' actions. Since it is observed that AIDS, in many cases, is related to some kind of assumed immoral acts, like drug abuse or unprotected sexual activity, patients have a greater chance of being stigmatized; especially in traditional societies. Stigma can have bad effects on the patients' quality of life and can lead to social exclusion or perhaps secondary deviance.

Research Method

The main aim of this paper is to analyze HIV/AIDS patients' experiences in order to achieve a valid knowledge about the causes and consequences of the HIV related stigma. The approach of this research can be classified in the paradigm of social definition. Based on the assumptions of this paradigm, social reality and its meanings are made through action and interaction of people. Grounded theory (GT) method seems to be the most appropriate method for this study. GT is based on the data obtained from individuals involved with the issue. The goal of the GT is achieving a theory, based on the process of data analysis; the data which are related to the nature of the phenomenon. For this reason, in GT, it is vital to go to those who are somehow involved with the issue and try to achieve a theory which can reflect the internal structure of values, attitudes and experiences (Strauss and Corbin, 1998). In this method, rather than proving or testing the existing theories about an issue, the researchers try to create and address a new theory. In fact, researcher tries to distinguish new concepts and understand the relationships between them. The researcher does not use pre-prepared variable and concepts; but tries to discover key indicators and concepts related to the phenomenon within the process of data collection, and to formulate these concepts in form of a new theory (Bell et al, 2004).

Data Collecting

In this study, a secondary analysis was used to collect the data. In a secondary analysis, data that have already been collected in another study, can be analyzed and reinterpreted for the present study's goals. For this research, the data, collected in the study of Mohammadpour and his colleagues (2010), "The experience of people with HIV / AIDS from interacting with others: a phenomenological study" was used. These data were collected from interviews with 19 HIV patients. In order to validate the output theory, other data were considered; including interviews with HIV patients revealed in the media and two documentaries produced by the Islamic Republic of Iran Broadcasting (IRIB). Finally, after open, axial and selective coding, by the means of a qualitative data analysis application (Atlas-ti), the conducted result was a theoretical model which can provide a testable theory to explain the phenomenon of stigma in patients with AIDS. In the following section, the findings of this study will be presented and discussed.

Findings and Discussion

The findings of this study can be classified into five categories: causes, contexts, confounders and mediators, consequences and strategies of action and interaction. In this section, these five categories and the concepts classified into them, will be discussed and the final theoretical model will be presented.

➤ Causes

According to the words of the patients, three major causes of stigma were identified. These three reasons are:

1. Negative perceptions: patients have stated that people have a very negative view about the disease and consider it as a seriously affected and irreversible issue. People consider this disease as the worst thing that can happen to a person in his life.
2. Hatred: people hate the HIV patients. They even refuse to communicate with them.
3. Fear of transmission: People are too afraid of this disease and they do not turn away from anything they think can help them prevent the transmission of HIV virus.

These causes are significant in a context which will be introduced in the next section.

➤ **Context**

The context, in which the causes of stigma to HIV patients are significant, includes the following elements:

1. People's lack of knowledge about the disease, its origin and its ways of transmission: Most of the people do not have sufficient knowledge about the disease. They think that AIDS, like other contagious diseases, can be transmitted through everyday contacts. Many people are not aware of the origin of the disease and they have no knowledge about its nature as well as the effects and consequences.
2. False beliefs about the disease: general belief is that the disease is only the consequence of patients' behavior. People consider the disease as Allah's punishment for patients' sins. Most people also believe that this disease is only related to sexual promiscuity, homosexuality and other forms of unconventional sexual relationship. This belief usually ignores other possible ways of transmission and can lead to negative attitudes and hatred toward patients.
3. Healthcare workers' behaviors: while it is expected that doctors and other healthcare workers have the most information about the disease, it is observed, in some cases, that doctors and nurses involved with HIV patients, treat them very badly; with insult, humiliation, neglect and lack of response.

➤ **Confounders and mediators**

Factors that mediate the relationship between cause and effect and the stigma are:

1. Family support: In cases where patients' families have supported them, it has been observed that stigma and its consequences had been much less. On the contrary, where the family members were the first people who have stigmatized the patients, the experience of rejection and stigmatization of patients were higher and serious physical and psychological consequences were observed.
2. Health care sector's support: It has been seen that if patients receive support from health care workers (doctors, nurses, etc.), like appropriate and non-discriminatory behavior toward them, they would have less experience of stigma and its consequences would be less harmful for them.

➤ **Consequences**

Stigma has had the following consequences for the patients who have been studied here:

1. Mistrust: Stigmatized patients can barely trust others, even those who are close to them, like their families and their friends.
2. Homelessness: In some cases, patients have been forced to leave their homes because of the behavior of landlords, neighbors or families.
3. Anxiety: stigmatized patient experience anxiety in their daily communications. They are always afraid of their diseases being revealed.
4. Hopelessness: Most of the stigmatized patients have lost their hope in life and future.
5. Desire to die: Some of them wish to die sooner.
6. Inability in Marriage: Most of the stigmatized patients have lost their chances of marriage. While it is medically proven that they can marry and even have children under especial medical supervision, they cannot do that because the others' attitudes toward them.
7. Fear of death: Some patients have declared that they live in fear of death. They are waiting for a painful death in entire their lives.

➤ **Strategies of action and interaction**

Regarding the consequences mentioned above, stigmatized patients have pursued the following strategies of action and interaction:

1. Refusing to visit doctors: because of inappropriate behavior of doctors and because of fear of reality and fear of death, patients refuse to see doctors insofar as they can.

2. Suicide: Hopelessness, desire to die and depression, in some cases, have let the patients to commit suicide.
3. Internalizing the stigma: Most of the stigmatized patients shape their identity around the stigma itself. They accept that this has been their destiny. They start to believe that they are guilty and they blame themselves.
4. Solidarity with other stigmatized patients: In some cases, patients have declared that only the other stigmatized patient can understand their pain and problems.
5. Hatred in return: In reaction to hatred of people, patients start to hate them too. Some patients declared that they wish that other people become infected and experience their situation.

The final theoretical model is shown in Figure 1.

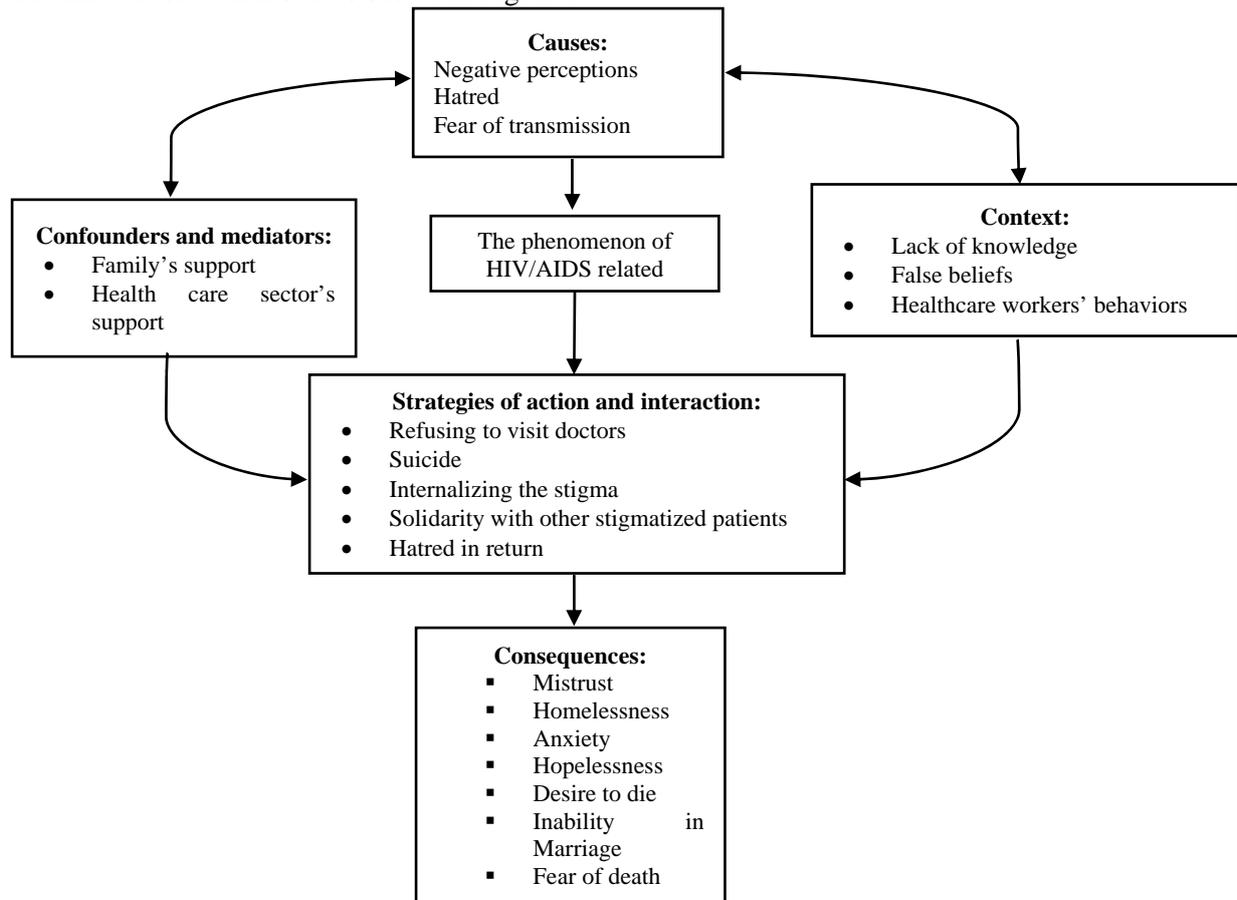


Fig (1): Final theoretical model

Conclusion

According to the theoretical model (presented in Figure 1) and by considering the limitation of qualitative method and the small sample of this study, however, it can be said that this study has reached to a level of explanation for the phenomenon of HIV/AIDS related stigma in Iran. In this study and based on the assumption of the social definition paradigm, causes are extracted from HIV patients' words. These causes are evaluated and validated, through the process of data collecting, by other materials. As it is shown in the model, causes of the phenomenon are declared. But this causes are significant in explaining the HIV/AIDS related stigma only when they are in a social context, consist of lack of knowledge, false beliefs and Healthcare workers inappropriate behaviors. The relation between the causes and the phenomenon is mediated by two mediators; family's support and healthcare sector's support. It means that if a patient receives appropriate support, in first place from his or her family and in the second place from the healthcare sector (doctors, nurses, hospital workers, etc.), the chance of being stigmatized could be less. The path from mediators to consequences shows

that these mediators can also mediate the relationship between the stigma and its consequences. In the case of receiving appropriate support from families and healthcare sector, the consequences of stigma could be less harmful and drastic for the patients.

Now, according to the theoretical model, it seems logical that to reduce the intensity of this phenomenon, HIV/AIDS related stigma, the causes should be weakened. If the social context changes then maybe the causes of the phenomenon would be weakened. Lack of knowledge is one of the most important components of the context. One can assume that if people learn more about this disease, its origins and ways of transmission, then their negative attitudes toward the patients would be ameliorated. Informing people about the truth of this disease can take place through national media, which plays a powerful role in the society of Iran. Also, teaching children in schools about HIV/AIDS can help in growing up a new generation who has a more logical view about these kinds of disease.

Doctors and other health care workers can play a significant role in reducing the intensity of stigma to HIV/AIDS patients. If they have professional behavior with these patients and do not behave them with discrimination, the intensity of stigma would be much less. It should be the task of universities and medical professional organizations to teach doctors how to behave with HIV/AIDS patients.

False beliefs, is the most difficult component of social context to change because it is related to many other cultural religious characteristics of the Islamic society of Iran.

Maybe religious elites, clergymen and powerful religious institutions can play a role in changing these beliefs and attitudes. But it would not be such easy to conclude and there should be more researches, studying the relationship between religious ideas and attitudes and HIV/AIDS stigma. This point seems the most important issue to be investigated in a society like Iran where religion still plays a powerful role in all social problems. At the end, it must be mentioned that although HIV/AIDS may be a very dangerous disease, but life is the right of all human beings and no one can deprive anyone of this right. The HIV/AIDS patient, by receiving regular medical treatment, can live for many years, can get married and have children and can continue their social activities. Besides, the society should not deprive itself from part of its human resource. HIV/AIDS patients experience a tough situation because of their disease, but without stigma and discrimination, their situation could be more tolerable for them. It's the duty of all society to help them back to life and benefit themselves and the society as well.

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