

**AN EXPLORATION OF VICARIOUS STIGMATIZATION CONFRONTED
BY HIV/AIDS PATIENTS**

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Abstract

HIV/AIDS is one of the growing social problems in Pakistan. The menace of HIV/AIDS has consequences on micro as well as macro level. Social stigma is an important aspect while considering the impact of HIV/AIDS on individual and communal level (micro and macro). Vicarious stigma (as conceptualized by Steward et al., 2008) is a type of social stigma whereby an individual become a subject of discussion and part of stories due to status of being an HIV/AIDS positive person. Framed under qualitative research design, the current study is an exploration of vicarious stigma confronted by HIV/AIDS positive persons. The study has been conducted in District Malakand and Dir Lower, Khyber Pakhtunkhwa, Pakistan. Sampling for the study has been done purposively whereby 7 HIV/AIDS positive individuals were interviewed. The collected information has been transcribed, narrated and linked with literature in order to extract findings. Findings of the study reveal that HIV/AIDS positive individuals are stigmatized frequently. Vicarious stigmatization is also a common event for HIV/AIDS positive individuals. HIV/AIDS positive individuals are subject of stories and discussion within family, friends and public.

Keywords: HIV/AIDS; Stigma; Vicarious stigma; Family

1.1. BACKGROUND OF THE STUDY

Currently, 36.9 million people are infected by HIV/AIDS worldwide. Among these, the most important portion is 2.6 million children who are infected which predicts the future consequences and further spread of the pandemic. Underdeveloped and developing nations are the most affected areas by HIV/AIDS in particular Africa (with 70 per cent of the disease) and Asia. Annually 2 million individuals are freshly infected by HIV/AIDS which is an alarming rate (WHO, 2014). According to UNAIDS, among these 36.9 million infected individuals, 17.1 per cent do not know about their infection which is the main cause of further spread of the deadly disease. WHO in 2014 revealed that 22 million HIV/AIDS infected people do not have access to treatment whereby so 34 million people have died of HIV/AIDS related infections so far.

As a deadly disease, HIV/AIDS is not limited to an individual rather the pandemic confronts community and society with a plethora of developmental issues. For example, HIV/AIDS is associated with decreasing income, intensifies poverty, limits access to food, medical services/and or care, broken families, limiting the ability the states to provide services to masses, the viability of different forms of rural production, and affects the survival strategies of different types of household as well as community. In short, HIV/AIDS hinders socio-economic development (Barnett and Blaikie, 2002).

In many regions of the world, for instance, in Africa and few regions of Asia, HIV/AIDS is showing apparent impact e.g. impact on their families, economies, health etc. Majority of affected regions are socio-economically under developed. Such under development is the cause of the epidemic as well as the consequence of the epidemic (UNESCO, 2004; African Development Bank Group, 2013).

Being discovered in 1980s, the first global response to HIV/AIDS epidemic is also traced back to 1980s. A serious concern was emerged that how to tackle the fast spreading epidemic. There are three phases of HIV epidemic which are:

1. The disease (HIV/AIDS) enters and affects the community silently, it remains hidden and unnoticed often for many years and even a decade. The diseases is often misperceived and misunderstood.
2. It is the epidemic itself, the syndrome of infectious diseases that can occur because of HIV infection but typically after a delay of number of years.
3. The third and last phase is the explosive one, for example, reactions are observed from the community including high level of stigma, discrimination and even denial of basic rights (Mawar, Sahay, Pandit and Mahajan, 2005).

Probably the most significant aspect while considering social stigma and HIV/AIDS together to explain underlying factors that why HIV/AIDS stigmatizes the infected individuals? The answer is individuals with HIV/AIDS infection are stigmatized due to causes which lead to HIV/AIDS. For instance, there are certain taboos and norms associated with sexuality and/or sexual behaviors in culture and society. On the other hand, HIV/AIDS may the outcome of inappropriate sexual behavior such as prostitution, sex work, having multiple sex partners and homosexuality which labializes the diseases. Further, drug use i.e. using inject able drugs is one the sources of HIV/AIDS spread which are illegal. In short, it not the disease which is stigmatized rather it is the cause of diseases which are stigmatized which further leads to stigmatization of the individual and the disease as well (Alonzo and Reynolds, 2015).

a. People living with HIV/AIDS (PLHAs):

It is evident that people suffering from HIV/AIDS are stigmatized even along with the social group they belong (40-43). PLHAs are often isolated and distanced and treated like a strange even by family and friends. They face discrimination at work place, at hospital, and are vulnerable to physical and psychological abuse. Such fears of stigma have discouraged individuals from being tested for HIV and from revealing their seropositive status to sexual partners, family, and friends.

b. Men who have sex with men (MSM):

An observation report revealed that HIV/AIDS prevails in quite higher ratio in India for men engaged in sex with men, for example, the statics shows that 24 per cent of men in Mumbai involved in sex with men are HIV/AIDS positive patients (SERD and USAID, 2001). Research also shows that homosexuality in majority of cultures and religions is stigmatized behavior; and therefore, the cause of the disease is stigmatized and as a result the disease.

c. Intravenous drug users (IDUs):

Situation is worse of person who addicted to drug users and is infected with HIV/AIDS. Such people suffer from double stigma, for example, being labeled as drug addicts as well as having HIV. In Manipur, Kohima and Dimapur districts of India, about 50-54 per cent of intravenous drug users carry HIV virus as well. Research in India reveals that such people are even tattooed for identification (Herek, 1999).

d. HIV/AIDS in Pakistan

HIV/AIDS in Pakistan is an understudied phenomenon. It is evident that HIV/AIDS prevails in Pakistan, however, being a highly stigmatized disease majority of cases remain hidden and people die due to it without being reported. According to UNAIDS estimates, some 70,000 to 80,000 persons, or 0.1 percent of the adult population in Pakistan, are infected with HIV.

Officially reported cases are, however, much lower. There are many reason of not reporting HIV/AIDS cases whereby lack of HIV/AIDS branches in government as well as private hospitals, lack of separate and dignified health services provision to HIV/AIDS infected individuals, and a significantly high social stigma (The World Bank, 2005).

1.2. STATEMENT OF THE PROBLEM

It has been often observed that public reacts negatively to HIV/AIDS (both as a disease and to the individuals infected). Such reactions include minor rejection as well as major rejection from family, community and society. There are bulks of instances where individuals infected with HIV/AIDS are banned from entering to home, family and community, removed from job, forced to drop out from school (infected children), denied from giving admission and socially isolated. In short, persons with HIV/AIDS whether adult male and female or children are socially excluded. Because of such social exclusion, the behavior of infected persons is shaped in particular whereby they suffer from feeling of rejection, neglect, stress and live their remaining life with stigmatization (Mawar et al., 2005). People suffering from HIV/AIDS have limited social support and have very limited social response (Kelly et al., 1996). Also, there is no control over stressors like communal and social ostracization, victimization, and deprivation (AVERT, 2005).

Viewpoint as insider and outsider is important to understand social stigma in context of HIV/AIDS. In this connection, according to Goffman (1963), in context of observer's perspective social stigma includes psychological, interpersonal, sociological, economic and/or political effects on persons who possess certain characteristics. The observer does not have the identity which the stigmatized person has. Further, social stigma can also be explained as a

pattern of interaction based on the language of relationships, stigma viewed as a product of, and inherent in a relationship between ‘normal’ and the ‘other’.

This approach attributes state of mind or describes socio-economic effects of the possessor, the accuser, or the relationship of one or the other. Thus, this approach focuses on two types of persons i.e. those who are stigmatized and those who stigmatize. Phenomenological approach is also important in context of stigma, for example, cultural values acknowledge, define and incorporate social stigma; thus, social stigma is a part of culture. With reference to HIV/AIDS, social stigma defines and acknowledges the infected persons as an excluded and isolated group which is supported by cultural values such social stigma in context of HIV/AIDS is linked with opportunistic infections, moral transgressions of both homosexual and heterosexual relationships and afflictions transmitted. Thus, social stigma in context of HIV/AIDS defines two types of people which are “us” (the non-infected persons) and “they” (the infected persons). Therefore, social stigma includes social components such as values, attitude, perception and response towards infected person which defines the infected persons as socially excluded (Goffman, 1963; De Bruyn , 1992; Parker and Aggleton 2003).

Vicarious stigma refers to an event or a situation whereby an individual due to some reason is a subject of discussion among family members, friends or public. Steward et al (2008) the perception about HIV/AIDS persons are often shaped by stories of discrimination against other HIV-infected individuals, termed as vicarious stigma. In this connection, the current study aims explore vicarious stigma confronted by HIV/AIDS positive persons and its impact on them.

1.3. OBJECTIVES OF THE STUDY

HIV/AIDS related stigma is one of the core concerns for social scientists while studying HIV/AIDS in socio-cultural context. In this regard, this study aims to explore specific type of stigma (e.g. vicarious stigma) confronted by HIV/AIDS patients. The study also aims to know about social groups within which HIV/AIDS positive persons confronts the stigma such as the family, friends and public. In addition to it, the study aims to know about the impact of vicarious stigma on HIV/AIDS positive persons.

1. To explore the vicarious stigma confronted by HIV/AIDS positive individual within family
2. To explore the vicarious stigma confronted by HIV/AIDS positive individual from friends
3. To explore the vicarious stigma faced by HIV/AIDS positive individual from community
4. To investigate into the impact of vicarious stigma on HIV/AIDS positive individuals

1.4. METHODOLOGY

Nature of the Study

This study is framed under qualitative research design.

Sampling

Purposive sampling technique has been adopted for selection of the respondents. A total of seven respondents were sampled based on the following sampling criteria fulfilling the purpose of the study:

- a. The sampled individual must be HIV/AIDS positive person
- b. The status of the person (status of being HIV/AIDS positive) must be exposed to family, friends and the nearby community e.g. neighborhood.

Tool for Data Collection

An interview guide designed specifically for the current study has been utilized to collect the information from the sampled respondents.

Data Analysis

The collected information has been analyzed in thematic form which is a type of qualitative analysis.

Ethical Issues

HIV/AIDS is one of the highly stigmatized illnesses. Therefore, the researchers faced many problems while collecting information such contacting the patients, discussing the issue with them and persuading them for sharing information. To tackle this problem a key informant was utilized to contact HIV/AIDS positive individual and persuade them for interview. Further, the respondents have been kept anonymous.

1.5. RESULTS OF THE STUDY

HIV/AIDS patients are often considered as sinners, disgust and menace for society. They are called with different names, ignored in familial gatherings, discriminated at work place, hospitals and educational institutions. With reference to the current study, HIV/AIDS positive persons are also subjects of discussions in familial gatherings, friends and public gossips.

Family is important to the life of every individual. Family (e.g. family members) is the source of interaction, socio-economic and psychological support. However, for HIV/AIDS positive individuals' family is a place where they are stigmatized, neglected and ignored. In this connection, field information reveals that HIV/AIDS persons are stigmatized by their family members. They become the subject of discussions among the family members and relatives. A respondent told that:

“...my son told me that my brother and his wife were talking to each other and I was the subject of discussion. They were thanking the god that they are now living in a separate house....”

Another respondent stated that:

“... I observed many times that my brothers' talks about me in whispers. When I came close to them they start talking loudly or stop talking....”

A respondent (with tears in his eyes) said that:

“... I came to home from work. My wife and her sister were talking about me while they were unaware of my entrance to the home. My sister in law was telling my wife to not let the children in close contact with me, to eat with me and sleep with me. She also said that if I try to remain close with her and my children than she (his wife) must insist for divorce....”

A respondent told that:

“...my wife and daughter had discussion about me. They were discussing about my immoral acts which made me HIV/AIDS positive....”

Friendship is an important dimension of social life. Friendship is a source of socio-economic and psychological support. However, for HIV/AIDS positive persons maintaining friendship is a difficult task. Field information obtained through interviews reveals that after disclosure of an individual as HIV/AIDS positive, friends are no keener in maintaining friendship. They start to remain absent at gossip time as they were before the discloser of the status. Further, friends do not invite them to ceremonies and even starts to ignore HIV/AIDS positive persons in ceremonies. Most importantly, with reference to the current study, HIV/AIDS positive person become subject of discussion among friends. Respondents said that their friends talk about them but get silent when they observe them coming. One respondent shared an interesting example:

“.... We (friends and him) regularly go to hotel for eating fish, Chicken etc. I disclosed my status to friends as I was expecting support from them. However, once we were in a hotel, my friends were discussing about me as they were not aware of me that I was near to the room. They thought that I was with the cook and were discussing that how I got the disease, and were planning that how they can tell that they are not interested any more to be friends of mine”

Another respondent stated that:

“.... I have four close friends. Two of them know that I am HIV/AIDS positive. I noted many times that they talk in whispers which made me curious about their discussion. I decided to listen to them secretly, and I heard that they were talking about me. They were discussing that I have

been involved in sexual activity with a prostitute which made me HIV/AIDS positive....”

Upon the disclosure of status, HIV/AIDS positive individuals become subject of discussion in community. In this regard, a respondent argued that:

“... people looks to me in odd manner and I feel weird because of it. Further, I have felt many times that when I pass near a gathering of people, they start talking in whispers”

Another respondent replied in a similar manner, and stated that:

“... few of the neighbors know about my illness. It’s really annoying for me when I observe people looking to me in odd manner. They talk about me in whispers which make me frustrated....”

A respondent argued that:

“...I had few disagreements with my brother on familial matters. I had few heated arguments with him. Once he told me that neighbors talk about me as an evil for the village, and that my acts will ruin them....”

There are many adverse consequences of vicarious stigma on HIV/AIDS positive individuals as well as their families, friends and social life. Field information reveals that HIV/AIDS positive individuals get frustrated and tensed as they observe themselves as subject of discussion.

“... after realizing that friends discuss negative things about me I started to keep distance with them, and after two or three months the relationship ended....”

“... I do not want to maintain relations with my brother and his family....”

“... I had a heated argument with my sister in law when I heard that she was persuading my wife to be not in close contact with me and for divorce. Besides, my wife's behavior also changed after she was persuaded by her sister. I think that it is difficult for me to keep up with my familial life, and I am afraid that soon my wife will demand for divorce....”

“... before the disclosure of my status I had good relationships and gossip with relatives and neighbors. However, after disclosure I avoid sitting with them especially when I observe them talking about me and looking at me in odd manner....”

“... I am stressed, I had fight with neighbor whom I observed whispering about me. I don't want to face people and the community. I am also taking sleeping pills to get some relaxed sleep...”

“... stress and anger is the outcome when somebody had a discussion about me as an immoral person....”

“... I prefer to not interact face to face with neighbors as I fear of being cursed or abused by them....”

“... I want to spend most of the time in home. I don't want to gossip with people in shop, mosque and have a walk with neighbors and friends....”

1.6. DISCUSSION

Social stigma is one of the considerable socio-cultural impacts of HIV/AIDS. HIV/AIDS positive individual are confronted with social stigma. Vicarious stigma is one of the core issues related with HIV/AIDS positive individuals (see steward *et al.*, 2008 as well). Findings of the current study reveals that for HIV/AIDS positive individuals' family is a place where they are stigmatized, neglected and ignored. Family members and relatives discuss them as sinners and say many negative things about them in their discussions. These findings are in line with studies of UNAIDS Report on the Global HIV/AIDS Epidemic (2004) which revealed that in India and Ghana, family is the social sphere where HIV/AIDS positive individuals are stigmatized, neglected and ignored. Further, the study of Mawar, Sahay, Pandit, and Mahajan (2005) explains that HIV/AIDS positive individuals are confronted with severe social stigma within familial sphere.

Besides, findings reveal that HIV/AIDS positive individuals are stigmatized by friends. Friends discuss their status of being HIV/AIDS positive, and talks about the causes of getting HIV virus. After the disclosure of the status of an individual as HIV/AIDS positive, friends are no keener in maintaining friendship. In this context, Chandra , Deepthivarma and Manjula (2003) and Mawar, Sahay, Pandit, and Mahajan, (2005) stated that HIV/AIDS positive individuals are stigmatized by friends and friendship often ends with the discloser of status.

Friends often do not invite HIV/AIDS positive individuals to gatherings, and even starts to ignore HIV/AIDS positive persons in ceremonies. In terms of communal response towards HIV/AIDS positive individuals, this study reveals that HIV/AIDS positive individual become

a subject of discussion among neighbors and public. People talk about them in shops and gatherings, and labels them as sinners and disgust for society. People look at them in odd manner and start talking in slow tone about HIV/AIDS positive individuals.

About the impact of social stigma on HIV/AIDS positive individuals the current indicates that there are multifaceted consequences of social stigma on HIV/AIDS positive individuals. For instance, HIV/AIDS positive individuals get involved in heated arguments and fighting with family members. HIV/AIDS positive individual starts to keep distance with family members, friends, and community members and maintaining relationships with family, friends' public become a challenge for them. In this regard, Alonzo (2015) affirms that maintain marital and familial relationships become difficult for HIV/AIDS positive individuals. In addition to it, stress, anger and depression is another consequence of vicarious stigma among HIV/AIDS positive individuals. Ann (2003) also argues that one of the major impacts of HIV/AIDS is anger, stress and depression primarily due to neglect, labeling and abuse.

1.7. CONCLUSION

Social stigma is one of the considerable socio-cultural impacts of HIV/AIDS. HIV/AIDS positive individuals are confronted with social stigma. Vicarious stigma is one of the core issues related with HIV/AIDS positive individuals. HIV/AIDS positive individuals' family is a place where they are stigmatized, neglected and ignored. Family members and relatives discuss them as sinners and say many negative things about them in their discussions. That HIV/AIDS positive individuals are stigmatized by friends. Friends discuss their status of being HIV/AIDS positive, and talk about the causes of getting HIV virus. After the disclosure of the status of an individual as HIV/AIDS positive, friends are no keener in maintaining friendship. Friends often do not invite HIV/AIDS positive individuals to gatherings, and even start to ignore

HIV/AIDS positive persons in ceremonies. In terms of communal response towards HIV/AIDS positive individuals, this study reveals that HIV/AIDS positive individual become a subject of discussion among neighbors and public. People talks about them in shops and gatherings, and labels them as sinners and disgust for society. People look at them in odd manner and starts talking in slow tone about HIV/AIDS positive individuals. , HIV/AIDS positive individuals get involve in heated arguments and fighting with family members. HIV/AIDS positive individual starts to keep distance with family members, friends, and community members and maintaining relationships with family, friends' public become a challenge for them.

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