# Journal of Social Sciences Research & Policy (JSSRP)



Social stigmatization towards people living with HIV/AIDS (PLHA), at family, community and workplace, the case of Pakistani Society

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ISSN: 3006-6557 (Online) ISSN: 3006-6549 (Print)

Vol. 3, No. 2 (2025) Pages: 397-405

## **Key Words:**

People living with HIV/AIDS, (PLHA); Stigmatization and Discrimination; Community Misconceptions; Mass Awareness, psycho-social treatment.

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**Abstract:** This research article aims to demonstrate the impacts of social stigmatization on People Living with HIV/AIDS (PLHA) in the context of Pakistani Society. The study has been conducted through secondary data analysis method under the qualitative research paradigm. The method is appropriate due to sensitive nature of the issue in the social setup of the study universe. The available data in articles and reports inferred valuable outcomes as proceeds. The data revealed that, the spread of HIV/AIDs in Pakistan is pandemic with an estimated number of 270,000 PLHAs with a prevalence of 0.4 percent. However, it has been found by researchers that the given number is underreported due to lack of proper checkup and social stigma attached with the disease. The main groups identified active in the spread of disease are commercial sex industry, intravenous drug users (IVDUs), blood transfusion, heavy drivers, deported Pakistani workers and other foreign visitors. Nonetheless, Anti-Retroviral Therapy (ART or ARV), a suppressive therapy is provided by government of Pakistan free of charge but the efficient control of epidemic is restricted by lack of awareness and cultural stereotypes. Similarly, the patient is considered polluted and a dissimilar being. This labeling is started at family or peer group level which is later on blindly followed by the rest of the society in school, college, workplace, and healthcare. PLHA have therefore, fewer opportunities for cure, dignified life and development. Similarly, branded actions against PLHA create the feeling of shame, quilt, stress, depression, anxiety, post-traumatic stress disorder (PTSD) and in some cases results in suicide. On the other hand it has been suggested that psycho social (support) from family and society has positive outcomes for PLHAs. Government and Civil Society needs to initiate mass awareness programs, seminars, and mass media programs regarding HIV/AIDS, its causes, preventive measures and the control mechanism. In addition to the already amassed literature from medical aspect, the social aspect of the disease needs a special attention of researchers in the context of developing countries like Pakistan.

#### Introduction

Human Immunodeficiency Virus (HIV) is a retrovirus which infect, destroy and reduce CD4 cells (T cells), which help the immune system fight off infections. If left untreated this virus therefore causes a disease called AIDS (Merriam Webster Dictionary). Whereas, AIDS or Acquired Immunodeficiency Syndrome is a

fatal diseases caused by the infection of HIV. A disease that badly damage the human immune system and hence the body is unable to fight with infections which ultimately lead to infection related cancers (WHO, 2007). HIV/AIDS is among the most fatal diseases spreading throughout the world surpassing all the geographical boundaries. According to UNICEF (2007), every minute in the 24 hour of the day two people of all ages become HIV positive in the world. According to a research conducted by Sharp (2015), 36.7 million People were living with HIV/AIDS and have also caused 39 million deaths worldwide. The only way to know about this virus is HIV test. Due to its chronic effects AIDS is considered pandemic (Callings, 2008). It has been estimated that every day over 5700 people die because of AIDS mostly due to their inaccessibility to prevention and treatment services (Tavoosi, 2004). The most important factor contributing toward massive increase in the patients infected with HIV is their poor knowledge about cause, effects and prevention process. For example, in a study conducted by Lanouette (2003) in Madgascar showed that 68% participant had no information that use of condom minimizes the risk of HIV/AIDS.

Sharp and Hahn (2011) believed that, HIV has originated from West-central Africa in the late 19th century but was lately recognized in 1981 by US Centre for Disease Control and Prevention (CDC). Researchers are agreed that the common symptoms of AIDS include continuous headache, fever, large tender lymph nodes, throat inflammation, rash, diarrhoea, nausea, vomiting, sores of mouth and genitals. The duration of the symptoms may vary according to age and health but usually the duration of these symptoms is one to two weeks (WHO, 2007). This virus can spread through blood borne pathogens from infected patients to healthy one through blood contact. This contact can be caused through many other ways including dental treatment (Beltrami, Williams, Shapiro, Chamberland, 2000). Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) have turned to become a serious health issue in the current century, where millions of people around the world are infected every year throughout the globe (Tee and Huang, 2009). So far, the medical sciences are not completely successful in discovering curable medicine for this risky disease. Nonetheless, Anti-Retroviral Therapy (ART or ARV), a suppressive therapy is considered the closest therapy against HIV/AIDs (Adebajo, Bamgbala, Oyediran, 2003). ART/ARV is more effective in weakening the virus and also prolonging the life expectancy among the patients. HIV spreads through insecure sex including oral and anal sex, infected blood transfusion, and hypodermic needles, to fetus from infected womb, delivery or breast feeding (Markowitz, 2007). Scholars like Visser, Makin and Lehobye, (2006) believe that other body fluids and liquids e.g. urine, tears, saliva do not transmit HIV. For efficient control of the virus; safe sex, needle exchange, male circumcision and effective treatment of the infected people are some of the common methods (Sharp and Hahn, 2011). So far, there is no vaccine and medication that can completely cure this disease, yet antiretroviral treatment can lead to a near normal life expectancy. The treatment is started when the disease is diagnosed yet the average survival without treatment is 11 years (UNAIDS, 2007).

Pakistan is considered to be comparatively safer than the other neighbouring countries (Khanani, Hafeez, Rab, Rasheed, 1988). Whereas, the first case of HIV virus in Pakistan has been reported in the year 1987 and remain relatively safe for two decades (Abdul and Hashmi, 1988). However, this tempo did not remain the same and the situation changed abruptly with first full fledge outbreak in District Larkana of Sindh Province (Shah, Altaf, Mujeeb, Memon, 2004). Since then, HIV has thought to be spreading throughout the nation (Muhammad, 2007). However, among the developing countries including Pakistan, biological understanding of HIV/AIDS has been based on the sociocultural understanding of the phenomenon (Ayranci, 2005). This incorrect knowledge based on social

misconceptions is often associated with social stigmatization of PLHA in majority of the developing countries and lead toward hindrance in effective treatment and awareness regarding the virus (UNAIDS, 2010). This is why this disease is predominantly concentrated among already stigmatized people like drug addicts, homosexuals, and people involved in sexual promiscuousness (Ghosh, 2002).

It has been commonly noted that in countries like Pakistan, the socio-cultural ties are strong and thus people living with HIV/AIDS (PLHA) has far reaching implications and social misconceptions. To avoid discrimination and social rejection they feel reluctant to seek timely medication and other preventive measures. This attitude put the family and rest of the community at risk to active spread of HIV infection (Visser, Makin and Lehobye, 2006). Therefore, awareness, safe behaviour and positive attitudes remains the only remedies in the absence of immediate medication (Yoder, 1997). Parker, Herdt and Carballo (1991), believes that HIV/AIDS is largely sexually transmitting disease therefore the cultural and religious context must be taken in consideration. This means that in encountering the HIV/AIDS menace values, morality and cultural context must be considered in any preventive measure taken for prevention of disease (Nayar, Bhatnagar, Arora, 2007).

It has further been described by Adebajo, Bamgbala and Oyediran (2003), that the main reason about prejudice regarding PLHA is the circulation of information through local gossip which are always incorrect and exaggerated. These misconceptions are widely found in the developing countries. It is a well-known fact that PLHA are socially stigmatized this lead them to be devalued, out casted and having lesser opportunities for education, housing, treatment, employment and promotion. This phenomenon has been extensively researched in the developed countries however the underdeveloped and developing countries like Pakistan need in depth research in this regard. This is necessary because lack of awareness is one of the main causes of spreading HIV/AIDS in the width and breadth of the country (Bashir, 2011). HIV/AIDS is one of the greatest threats to the human life throughout the globe due to medical complications. However, social stigmatization further deteriorates the situation for the patient and family (UNAIDS, 2010). This negative attitude of stigmatization toward PLHA has begun simultaneously with the spread of the disease and thus they live an uncomfortable life of despair and isolation (Farmer, 1992). This social isolation are said to ultimately lead toward psychological disorders and physical complication of the disease (Lee, Kochman & Sikkema, 2002).

## Methodology

Secondary Data Analysis is a method through which research is conducted by using publicly available data of other social scientists. It is more important in those cases where the data collection is difficult, impractical or some time unnecessary. In this method historical and library information are utilized to generate research hypothesis for further studies (Boslaugh, 2007). Similarly, secondary data analysis of qualitative and quantitative data is considered a valuable method for exploring sensitive issues including HIV AIDS.

Johnston (2014), believes that with the advent of the advances in modern technological and communication technology the information and data that has been collected, archived and compiled can easily be utilized for further researches. Similarly, Andrews, Higgins, Andrews, Lalor, (2012) opined that, secondary data analysis is one of the effective method to find the facts regarding the study but it has remained an under-used research technique in many fields. However, due to increased availability of previously collected data to researchers it is important to redefine the data through secondary data analysis in a systematic way and bring new dimensions to the exiting knowledge.

Due to structural-functional barriers in the context of HIV/AIDs in case of Pakistani society, this method has been chosen as a safe preliminary investigation for further elaborate studies. The current study has

been conducted on reviewing existing research papers, facts and figures related to knowledge, attitudes and practices regarding HIV/AIDS and PLHA in Pakistani society. This method has been further necessitated by the sensitive nature of the issue in the research area, where HIV/AIDS is still considered new and delicate. In addition, due to cultural issues PLHA are difficult to be found in the researched area.

The study has been carried out under the following objectives:

- 1. To know the impact of social stigmatization on the life and treatment of PLHA
- 2. To see the existing formal and informal knowledge and attitudes regarding HIV/AIDS

#### **Discussions**

Pakistan too is facing the spread of HIV/AIDs as an epidemic (World Bank, 2006). Whereas, the main groups identified active in the spread of this disease are commercial sex industry, intravenous drug users (IVDUs), blood transfusion, professional drivers, deported Pakistani workers and other foreign visitors (WHO, 2008). The estimated number of PLHA in Pakistan in adults (Age 15-49) is 270,000 with a prevalence of 0.4% (NACP, 2022 and UNAIDS, 2023). The ratio is alarming against the findings of Rodrigo & Rajapakse (2009), who believed that by then the estimated number of the people with HIV AIDS in Pakistan is 96000 with a prevalence of 0.1 per cent. However, UNAIDS in its (2007) report suggests that their number is thought to be underreported because of the stigma associated with this disease and lack of surveillance facilities are among the few for least identification of cases.

Conversely, the efficient control of menace is restricted by illiteracy and lack of awareness regarding this disease (Kazi, Ghaffar & Salman, 2000). This situation maximizes its vulnerability toward controlling the biological as well as socio-psychological impacts and also prevail negative perception regarding HIV/AIDS. It has further been recognized by many researchers including Bhattacharya (2004) that in South Asian countries HIV/Aids is considered a dirty disease. Despite utmost necessity, this is one of the least studied areas in South Asia. Some scholars like Aycan (2000) considers Pakistan as an under researched country in context of HIV/AIDS. Hence, with such dearth of awareness social stigmatization in Pakistan is a common practice. To get into further elaboration of the topic we need to make an explanation to the word stigmatization as follows.

Stigma, is basically a Greek word, means a distinctive mark like scars, tattoos, cuts or burns into the skin of the criminals, traitors and slaves in order to visibly identify them as stained and morally corrupted person (Smith, 2009). However, according to scholars like Jacoby, Snape, and Baker (2005), stigma is a label which associates person/persons with some sort of unwanted characteristics which may not be existing in reality and thus become a stereotyping. The most dangerous part of the play is that with in a group such labelling is blindly followed by the rest of the members and this stigmatization becomes a permanent character of an individual which leads to loss of social status and discrimination. Similarly, it has been commonly understood fact that stigmas are differing from society to society and time to time with awareness and educating people (Gallo, 2006). In the current study we refer to stigmatization associated with HIV/AIDS where the patient is considered polluted and different to rest of the society. This feeling of undermining and severe differences leads PLHA toward social seclusion and thus has negative impacts upon his life and family (Health line Network Inc., 2007). This situation is commonly happening in the schools, colleges, workplace, healthcare, justice system and even within the family. For example, the people with HIV/AIDS might not be received as normal in many situations especially in those areas where people are not aware about the disease (Brenda, Laurie, O'Brien, 2005).

The social identity theory suggests that individuals carrying common characteristics are identified in distinct way. Thus, those employees or students carrying HIV/AIDS are recognized and also stigmatized

in institution with fewer opportunities for growth and development. Similarly, this is a common likelihood that such people are engaged in activities and behaviours which are even harmful for them (Tajfel and Turner, 1985). Similarly, it has been commonly noted that mistreatment of a group with common characteristics can result into negative work behaviour and thus create organizational cynicism and create negative attitude characterized by suspensions, hopelessness and disgust (Ensher, Vallone and Donaldson, 2001). These situations lead toward a distrust and make the people think that organization lack integrity (Andersson, 1996). Similarly, it has been commonly noted that stigmatized actions against PLHA such as lesser opportunities and threat of firing from the job constitutes breach of psychological contract (Johnson and O'Leary-Kelly, 2003). However at the personal level HIV/AIDS stigmatization is institutionalized by popular culture and thus internalized by the patient which ultimately leads to feeling of shame, guilt, stress, depression, anxiety and in some cases post-traumatic stress disorder (PTSD) (Lee, Kochman and Sikkema, 2002; Riggs, Vosvick and Stallings, 2007). Some researchers are also of the view that this internalized stigma is strongly associated with feeling of hopelessness and thus lead to suicide (Treisman and Angelino, 2004). On the other hand stigmatization, discrimination and unjust decisions by the organizations and society results in resentment, anger and outrage (Skarlicki, Folger & Tesluk, 1999).

Researchers like Pearson, Micek, Pfeiffer & Gloyd, (2009) believe that the process of stigmatization cannot be understood without understanding of cultural specific beliefs and values system. Similarly the intensity of stigmatization and discrimination depends upon the attitudes associated with this disease (Keusch, Wilentz, & Kleinman, 2006). Due to this variation in the moral and value structures across the cultures, the spread of HIV/AIDS and associated stigmas must need to be studied within the cultural context of every society and country. Similarly, the available literature mainly focused on the developed countries, while there is a dearth of knowledge and awareness regarding HIV/AIDS in the developing countries. Researchers have identified that little attempt has been made in the context of stigmatization and thus through this research an attempt has been made to fill the gap specifically by analyzing secondary data in the context of Pakistan. This study therefore provides a background for a detail research in the context of developing countries generally and Pakistan in particular.

#### **Results**

Based on the above discussion this study lead us to the following findings:

The study discovered that Pakistan too is facing the spread of HIV/AIDs as an epidemic disease. The groups active in the spread of this disease are commercial sex industry, intravenous drug users (IVDUs), blood transfusion, professional drivers, deported Pakistani workers and other foreign visitors.

It was revealed that this virus can spread through blood borne pathogens from infected patients to healthy one through blood contact. This contact can be caused through many other ways including infected blades, tools, syringes, commercial sex industry, blood transfusion and dental treatment.

The most important factor contributing toward massive increase in the patients infected with HIV is their poor knowledge about causes, effects and prevention process. Lack of knowledge and unavailability of the testing services at rural setup further complicate timely diagnosis.

The incorrect community knowledge based on social misconceptions is often associated with social stigmatization of PLHA in majority of the developing countries and lead toward hindrance in effective treatment and awareness regarding the virus. This is why this disease is predominantly concentrated among already stigmatized people like drug addicts, homosexuals, and people involved in sexual promiscuousness.

Largely, HIV/AIDS is considered sexually transmitting disease and therefore both the cultural and religious context gives tough time to the patients. This means that in encountering the HIV/AIDS menace values, morality and cultural context must be considered in any preventive measure taken for prevention of disease. To avoid discrimination and social rejection they feel reluctant to seek timely medication and other preventive measures. The social gossip and social labelling lead them to be devalued, out casted and having lesser opportunities for education, housing, treatment, employment and promotion. These attitudes further degrade their psycho-social and medical condition.

The negative attitudes of stigmatization toward PLHA have begun simultaneously with the spread of the disease and thus the patients are believed to be living in an uncomfortable life of despair and isolation. This stigmatization becomes a permanent character of an individual which leads to loss of the social status and discrimination. Some researchers are also of the view that this internalized stigma is strongly associated with feeling of hopelessness and thus lead to suicide

#### **Conclusions**

In a nutshell it can be concluded that like many other countries, Pakistan too is facing spread of this epidemic with many cases unreported due to social stigma. Lack of awareness regarding preventive measures and unhygienic practices are the main causes of its spread. In general masses, the disease is considered a sexually transmitting disease and thus false socio-cultural beliefs and religious notions regarding PLHA have taken precedence over the disease and its treatment. The social gossip and discrimination is commonly practiced in Pakistani society against PLHA with in the family, community and work place. Patients with HIV/AIDs therefore face acute stereotyping in the society whereas the shame and guilt associated with the disease convince the patient to conceal the reality and this lead to delayed treatment and pandemic spread. Similarly, this social labelling marginalized the PLHAs with having fewer opportunities in education, housing and employment. This situation further burdened them on the family and community. Likewise, the loss of status and life of despair lead to depression, anxiety and suicide. On the other hand psychological and social support has positive impacts on the patients' recovery and wellbeing.

This study recommends awareness and education of the masses regarding HIV/AIDS in the context of social misconception prevailed in the community. The role of mass media, involvement of religious and other community leaders' in the awareness program would lead to a positive change. The academia, developmental organizations and independent researchers are also suggested to shed light on the HIV/AIDS especially in the context of Pakistan and developing countries from the socio-cultural and psychological aspects.

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