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# "STIGMA AND DISEASES: ANALYZING THE IMPACT OF STIGMATIZATION ON TREATMENT AND PREVENTION OF HIV/AIDS IN DISTRICT DIR LOWER, KHYBER PAKHTUNKHWA"

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**Sana Ullah, Prof. Dr. Arab Naz, STIGMA AND DISEASES: ANALYZING THE IMPACT OF STIGMATIZATION ON TREATMENT AND PREVENTION OF HIV/AIDS IN DISTRICT DIR LOWER, KHYBER PAKHTUNKHWA, -- Palarch's Journal Of Archaeology Of Egypt/Egyptology 18(4). ISSN 1567-214x**
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## ABSTRACT
Social stigma has been described as a dynamic process of devaluation that significantly discredits an individual in the eyes of others. Historically, stigma has been applied to different diseases including leprosy, cancer, mental illness and particularly to HIV/AIDS. From the very beginning, HIV/AIDS related stigmas have fuelled the transmission of the disease and have increased the negative impact associated with the epidemic. This study was conducted in District Dir Lower, with the objectives to find out the existence of HIV/AIDS related social stigma, and its impact on HIV/AIDS treatment and prevention efforts. The research was qualitative in nature, while the selection of sample was made through purposive sampling techniques. Primary data was collected from a sample of 12 respondents through in-depth interview using interview guide. The collected information was passed through different phases and was analyzed qualitatively under various themes. The study concluded that HIV/AIDS related social stigma exists in the community from personal to collective level. The persistence of negative attitudes towards HIV infected people creates a sense of fear, isolation and deprivation and they avoid seeking treatment. The study also suggests that community level interventions must be developed and applied to reduce stigma and fear about HIV/AIDS, and to promote HIV/AIDS treatment and prevention.

## Introduction

The origin of the concept of stigma dates back to ancient times and was

referred to as a mark pricked in or branded upon the body of criminals or slaves. Alternately, it was also viewed as a scar of service or a mark of devotion, while stigma also referred to one's place within the social order, bearing the name of or stamp of owner or commander (Howard & Judith, 2000; Falk, 2001). Social stigma has been an entirely reliant process on social, economic, political and religious power, prevalent across societies and mostly related to ethnicity, class, identity, deviance and various diseases including HIV/AIDS (Anderson & Bresnahan, 2013; Cast, Stets, & Burke, 19-99; Crocker, 1999). In modern explanation, stigma has been described as a social construction, a mark of social disgrace and devaluation attached to those who are stigmatized (Stuart & Arboleda-Florez, 2001, Goffman, 2009). Social stigma decreases the honor of people who possess it (Goffman, 2009), reinforces existing inferiority and superiority through which others are judged and measured in a stereotype way (Campbell, & Deacon, 2006).

In past history, Leprosy was considered as divine punishment for moral misconduct and persons infected with Mycobacterium were forcibly excluded from both social and religious societies (Valdiserri, 2002). In early years of the American republic those who became ill with cholera were publicly declared as intemperate, lazy, and vice ridden (Link, & Phelan, 2006). While during the wide acceptance of the germ theory, there was acceptance and discredition and often, physicians were reluctant to treat patients in the latter category, considering the ill person immoral and hence unworthy of care (Lyons, & Ziviani, 1995; Keusch, Wilentz, & Kleinman, 2006). HIV/AIDS is also a highly stigmatized disease, and such stigmatization is prevalent across societies and regions of the world (UNAIDS, 2000).

HIV/AIDS related stigmatization identify differences, construct stereotypes, categorize the stigmatize persons and fully execute discrimination, disapproval, rejection, and exclusion, against the stigmatized (HIV/AIDS patients) in society ( Adamczyk & Pitt, 2009; Link & Phelan, 2001). In this way, social stigma produces a 'spoiled identity' and reduces the social value of the stigmatized individual/s and they are tainted and discounted in society (Crocker, Major, Steele, Fiske, & Lindzey, 1998; Scambler, 2006). Since the beginning of HIV epidemic, social stigma has fuelled the transmission of the disease and has also increased the negative attitudes associated with the epidemic (Goffman, 2009). HIV/AIDS related stigma is most closely related to sexual stigma because HIV was mainly considered as a sexually transmitted disease (Kim, 2008; Weeks, 1981). Regardless of the epidemiological reality of the diseases HIV/AIDS related stigma has reinforced pre-existing stigma associated with sexually transmitted diseases, sexuality, homosexuality, promiscuity and prostitution (Parker & Galvao, 1996). HIV related social stigma is so alarming that Mann (1987), in his study stated about three phases of the HIV/AIDS epidemic, including the epidemic of HIV, the epidemic of AIDS and the epidemic of stigma. The available literature about social stigma has cited its complexity and diversity in different cultural settings as the primary reasons for the limited response to this pervasive phenomenon of HIV/AIDS (Parker & Aggelton, 2003). Thus, social stigma also is a complex phenomenon that has led to many difficulties in accessing to HIV treatment, care, testing and prevention.

## Rationale of the Study

Social stigma is a complex phenomenon that has led to many difficulties in

accessing HIV treatment, care, and prevention. The prevalence of stigma has been a great challenge and primary contributor to the global AIDS disease as the disease itself (Pettit, 2008). In several countries including Pakistan huge stigma has been associated to HIV infected individuals, their children and families (Galvao, 2000). HIV/AIDS related social stigma also persists in employment and work place, where co-worker refuses to work near HIV infected individuals. In this sense, social stigma is highly isolating in nature, which further increase the vulnerabilities of the infected population (Gostin & Lazzarini, 1997 & Panos, 1990). In order to avoid termination of employment contract many HIV infected people avoid disclosing their disease to other, which results in rapid transmission of the disease (Williams & Whiteside, 1993). The presence of social stigma in health care settings results in refusal of providing treatment to HIV/AIDS patients and thus contributes to the barriers in HIV treatment and prevention (Virodhi, Carvalho & Andolan, 1993, Panebianco, 1994; Bhaarat et al, 2001). Besides, social stigma transmits negativity and has also silenced open discussion on response towards this deadly disease. This study was carried out in District Dir Lower, in order to identify the impact of stigmatization on HIV/AIDS treatment. The current study was conducted with the objective to find out the existence of social stigmatization and to know that how it influence HIV/AIDS treatment and prevention. HIV/AIDS related stigma transmit negativity, inhibits open debate on the causes, consequences, transmission, treatment of the disease and has been regarded as the largest barrier in HIV/ AIDS treatment and prevention efforts (Brown, Macintyre, & Trujillo, 2003; Parker, Easton, & Klein, 2000). It further promotes risky behavior in the infected population and increases their vulnerabilities. Besides, social stigma transmits negativity and has also silenced open discussion on response towards this deadly disease. Social stigma has been the most important and poorly understood aspect of the disease. This study was carried out in District Dir Lower, in order to identify the impact of stigmatization on HIV/AIDS treatment and prevention.

## Theoretical Framework of the Study

This study utilizes different theories including stigma theory, the labeling theory, and social identity theory. *The stigma theory* explains stigmas related to different situation, behaviors, and diseases including HIV/AIDS, and states that stigma is deeply discrediting attribute which decreases the value of the stigmatized (Goffman, 2009; Link & Phelan, 2001). This theory asserts that stigma is social and relational in nature (Stuber, Meyer, & Link, 2008), and emerges in micro-level interaction as well as in broader social structures (Pescosolido et al., 2008; Phelan, Link, & Dovidio, 2008), produce a spoiled social identity, and the stigmatized person/s has been considered as less desirable, bad, dangerous, or weak" (Goffman, 1963). In the present context, HIV/AIDS patients are stigmatized which hinders their access to HIV/AIDS prevention, and treatment services and thus promote further transmission of the disease. Besides, *the labeling theory* emphasized social and cultural aspects of stigma in society, and argues that stigma or labeling is not an inborn characteristic rather the powerful people in society label the less powerful and consider them as deviant from the existing norms of society (Link, 1987). The labeled person/s are considered as deviant that carry an undesirable mark or produce devalued social position (Edward E Jones et al., 1984). In this way, labeling creates feeling of isolation, poor self-esteem, and makes the stigmatized people vulnerable

to other social problems, and their label becomes a cultural reality of society (Link & Phelan, 2001). At large, stigmatizing attitudes mostly led to discrimination, isolation, rejection and denial in society (Gates, Badgett, Macomber, & Chambers, 2007; Herek et al., 2002), and the labeled persons develop consciousness and belief that social interaction will be a stigmatizing experience from them threatening their honor, respect and dignity (Major, Quinton, & McCoy, 2002). *The social identity theories* states that intergroup biases have been socially created. It is the result of the perception of individuals that they belong to a particular social category (Tajfel 1959, 1978, 1981; Fife & Wright, 2000), and such perceived social categorization defines one's place in society. Tajfel (1959), Bruner (1957) and Wilder (1981) argue that social categorization has been a fundamental cognitive process known as categorical differentiation, and state that because we cannot process the infinite collection of information present in our surrounding, people develop short cuts by categorizing objects and people into groups. The different groups such as HIV-negative and positive people are categorized differently, after an evaluative and emotional process. This categorization determine the comparison between various groups (Foster and Potgieter, 1995), thus making the perceived superior and inferior identities. The social identity theory emphasize that individuals shall be motivated towards and strive for a positive self-concept, and asserts that if a social outcome carries a negative social identity within society, individuals shall try a change for achieving a positive social identity (Fife & Wright, 2000). In this way, social identity is linked to social inequality and is critical in producing and reproducing relations of power and control, and thus causes some groups to be feeling devalued while others feel that they are superior in many ways (Parker and Aggleton, 2003). The social identities, acceptance and rejection are constructed in social interactions and the broader societal forces reinforce it.

## Methodology

Qualitative study design was used for conducting this study. Study sample was taken from HIV/AIDS patients from District Dir Lower. In this regard, the primary field information was collected from twelve (12) respondents through in-depth interview using interview guide. Further, the selection of the samples was made through non-probability sampling, using purposive and snowball sampling technique. For maintaining anonymity and confidentiality of the respondent's, a three character i.e. (1-H-2) codes were developed and used. Furthermore, data was collected from married and unmarried respondents between the ages of 20-50 years. As the study was qualitative in nature therefore the collected information was elaborated, interpreted and thematically discussed using secondary information as a base, and conclusion was drawn on its basis.

## Results and Discussion

Considering nature and objectives of the study the data was analyzed qualitatively under various themes. The data was passed from various stages such as transcription of data, coding interesting features, producing potential themes within data, checking these themes, defining or naming these themes, and producing research report in line with study statement and objectives ((Braun & Clarke, 2006).

## Social Stigma and HIV Treatment and Prevention

Throughout history stigma has negatively impacted public health, and a form of prejudice, discrediting, discounting, devaluation, and discrimination has been directed toward a person who is ill (Herek, Mitnick & Burris, 1998). From the very beginning, the concept of social stigma has been applied to a wide range of different diseases in general and to HIV/AIDS in particular (Parker & Aggleton, 2003). Social stigma is the main barriers in access to HIV/AIDS treatment, care, prevention, and people living with HIV are often stigmatized by health care providers, family members, employers, coworkers and friends. HIV/AIDS related stigma has silenced open discussion about the associated causes and appropriate responses towards HIV treatment, and it thus delays treatment and prevention efforts (Singh, 2014, Parker, Easton & Klein, 2000). It was found during analysis of the field information that HIV infected people were stigmatized and disliked by their family members and colleagues. During field interview a respondent explained that:

*"I kept my HIV in secret because of the fear of community negative reaction that when people know that he is an HIV infected person they will start disliking him…"(1-T-4).*

HIV/AIDS related social stigma is considered as a barrier to effective HIV prevention and treatment programs. In many societies HIV/AIDS has been perceived as a result of personal irresponsibility, and thus individuals are blamed for contracting the infection (Corno & De Walque, 2013).). Social stigma is partly responsible for low uptake of and poor adherence to prevention and treatment services. In this regard a respondent explained that:

*"...I my opinion there are many HIV infected people in our society, but because of the fear of community negative reaction and associated stigma, they did not disclose their HIV positive status...."* (5-*Z-11).*

HIV/AIDS related stigmatization is because of several factors that includes lack of knowledge and information, perception, moral attitudes, and that caring HIV infected person is useless because HIV is an incurable disease (Danniel & Parker, et al., 1993). In this context, local explanation about disease and cultural beliefs about disease may also create hurdles in HIV prevention, care and treatment. HIV was regarded as a shame and a bad disease in the target area and the community associated the disease with many irresponsible and bad behaviors on the part of the infected individuals.

## Social Stigma and access to HIV Tests

A broad range of studies has shown that because of the fear of receiving a positive test result many people avoid seeking HIV testing. HIV/AIDS related social stigmas have contributed to the number of untested thousands of people (Valdiserri & Holtgrave, 1999). Recent research studies show that young men and women aged (15–19) as well as teenagers are highly frustrated by health care workers' negative attitudes toward them, and they hesitate to seek HIV testing in such environments where they perceive workers to be judgmental about their sexual behavior (Lee & Paxman, 1997). Primary data indicates that the infected individuals were reluctant

to seek HIV testing and treatment because of the fear that they will be further stigmatized. In similar context, an extract from field interview indicate:

*"...I personally was badly treated by my family members, relatives and health workers in hospital. My family consider me as a shame and black spot on the honor of my family, while health care workers blame us to be involved in unfair sexual relations…"(6-B-10).*

Similarly many reports from health care settings show that there has been incidence of HIV testing without consent, breaches of confidentiality, and denial of treatment and care (Tirelli, 1991, Virodhi, Andolan & Carvalho, 1993). The field information further show that social stigma attached to HIV/AIDS prevent treatment of the disease in many direct and indirect ways, and majority of the respondents hesitated to have HIV follow up tests and to continue treatment. A respondent in his interview argues:

"*....Yes, I have kept my disease in secret and I fear that my disease will be exposed to my family, friends and community members. I thus hesitated to have HIV follow up tests and treatment, and left my treatment incomplete...." (02-W-07).*

Although treatment of HIV starts with diagnosis of the disease, but many people around the world who are at considerable risk of HIV infection were not receiving tests in time because they fear negative treatment and attitudes from health care providers. In a study, related to HIV testing and stigma in South Africa, individuals who were not tested for HIV experienced bitter stigmatizing attitudes against people living with HIV/AIDS (Kalichman, Simbayi, 2003), while another study indicate that 68% of patients did not disclosed their HIV status to their family members and majority of those who reported delaying HIV testing, due to fear of HIV/AIDS related stigma (Bangsberg, et al., 2006). In this regard, a field respondent was of the opinion:

"*...In believe that the associated bad name and social stigma is a barrier to HIV testing, prevention, treatment and care. After knowing my HIV status, the attitude of my family, friends and colleagues towards me was very embarrassing…" (A-09).*

The social stigma and discrimination also frightens away HIV patients, from getting tested and disclosing their HIV positive status and thus results in poor quality of care or no care (Blendon & Donelan, 1988). HIV/AIDS related social stigma central to the global AIDS challenge as the disease itself (Mann, 1987). Thus, secondary literature and field information validate that many HIV infected people avoid testing because of the fear of social stigma.

**Social Stigma and HIV Risk Behavior**

Social stigma is widely recognized as a major facilitator of the HIV epidemic. Various research studies have also demonstrated a close association between stigma and has increased risky behavior. According to the CDC estimates there are approximately 300,000 HIV infected people in America those are unaware of their infection status (Holtgrave, et al., 2001). Due to stigmatization HIV-positive individuals were more likely to be engaged in high risk behavior (Chen, Choe & Zhang, 2005). In South Africa, those who experienced stigma were not disclosing their HIV status to their sexual partner, and non-disclosure was associated with further HIV transmission and risk behavior (Cluver, Orkin, Yakubovich, & Sherr,

2016). Relevant to the context of the study HIV related stigma and fear reinforced HIV risk behavior in the infected individuals. In this regard, an extract from an interview is:

*"….As HIV/AIDS is a bad name so, I feared of the stigma and reaction of my wife, family members and community. I did not expose my HIV status even to wife and children for two long years…" (8-S-02).*

Similarly, in a study sample of over two thousand sexually active HIV infected people in France, who experienced the social stigma resulted in their increased unsafe sex (Watel, Spire & Obadia, 2007). In order to develop HIV prevention and treatment strategy and to effectively reduce risk behavior, the relationship between HIV risk behavior and stigmatizing attitude must be explored and explained more rigorously.

**Conclusion**

This study concludes that enormous stigma has been associated to HIV/AIDS. HIV/AIDS related stigmatization create constrains to treatment and prevention efforts. The stigma interacts and reinforces the pre-existing stigma associated with sexuality and sexually transmitted diseases, and the infected people are looked with disgust and they are treated as subhuman being. The stigma has been found in the social network, and most of the people have little or no understanding of the social causes of the infection rather it is considered as an individual act. The study also found that HIV/AIDS patients are considered as immoral, irresponsible and the disease is recognized as a curse of God, and a punishment for their promiscuous behavior. It was also found during the study that the social stigma associated with the disease slows down the treatment and prevention of the disease, rather it is the main contributor to the disease. In addition, the study also revealed that HIV/AIDS treatment and prevention programs are not tackling the stigma, and most of the patients avoid treatment in order to avoid stigma from family members, relatives and health care providers.

**Recommendations**

On the basis of findings the study recommends an awareness raising campaign for improving people's knowledge and information on the causes, consequences and control measures of HIV/AIDS. There is also a need of awareness and advocacy against the associated stigmatization, in order to reduce stigma and promote the fight against the disease. For, combating the menace of HIV/AIDS, there is also a need for specifying the role and place of the various institutions to help country's HIV response program, provide counseling to individuals living with HIV/AIDS and convince them on treatment and prevention. Further, the fight against HIV/AIDS is not possible without behavioral and attitudinal change and thus it is a necessary to tackle those socio-cultural behaviors and values that promote stigma against HIV/AIDS patients. There is also a need of developing a new way of thinking about stigma and in order to accelerate HIV/AIDS treatment and prevention efforts.

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