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SOCIAL CONSTRUCTION OF HIV/AIDS: DILEMMA EXISTING IN INDIAN FAMILIES

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Introduction

'Reality and Knowledge' is a relative term and anything may be real for a section of society for not for everybody is observed by Berger and Luckmann (1996). Based upon this observation an attempt has been made in this paper that reality is socially constructed and to acquaint as to how the social construction makes its existence.

People belonging to different sects of society have the ability to perceive the same object in several ways. They may tend to add their perceptions and ideologies in comprehending the given problem and thus create their own version of reality (Berger and Luckmann, 1996). Though a person's conception of reality, fear and danger, abnormality and stigma, health and beauty may vary but to a large extent it is culturally patterned. The events, actions, attitudes and beliefs are all influenced by historical and cultural factors. The personal conceptions are only a reflection of a much larger construction, one that transcends from many individuals from the society. Thus, the relationship between an individual perception and social construction is an integral one in which the dynamic socialization shapes the construction of reality (Huber, 1998).

Man is naturally susceptible to construct and to inhabiting this world with others (Berger and Luckmann, 1996). This world becomes for him the dominant and definite reality. Initially its limits are set by nature but, once constructed, this world acts back upon nature. In this conflict between nature and the socially constructed world, the human beings itself gets transformed. Accordingly, in the field of Psychology and Illness, Crystal and Jackson (1992) notes that diseases are not mere biological entities but rather socially constructed phenomenon.

HIV/AIDS is an epidemic of grave proportions (Goldstein *et. al.,* 2003). A body of knowledge concerning HIV/AIDS exists in the societal construction which reflects the complexities of the malady and the various controversies associated with it (Huber, 1998). This knowledge about the disease gives meaning and clarity as to how it is perceive by the society. The disease and its respective knowledge co-exist within the social reality. Since the inception of diagnosis of HIV/AIDS, the social construction surrounding the issue prevailed as it gathered the attention of people by identifying homosexuality as the major cause of the disease. When the syndrome was identified amongst the haemophiliacs, prostitutes, injecting drug users and homosexuals the stigma got attached to the disease due to fears and negativity which worsened the societal image about the HIV/AIDS (ibid).

HIV/AIDS has created untold anguish and tremendous social tragedy (Brandt, 1998). In the beginning of the pandemic mainstream media avoided discussing about HIV/AIDS openly by asserting that the issues touching homosexuality and prostitute were not appropriate topics for evening news (Rollins, 2001; Huber, 1998). Also the early debates ignored policy concerns relating to blood transfusion, women's health and paediatric infection. Only homosexuals were viewed as real culprits to be targeted with minimum expense. Hence, the political responses were shaped based upon the perception that AIDS affect only small and unpopular groups from the society. But with the passage of time a shift has occurred in the social construction of HIV/AIDS (Huber, 1998).

In the present paper a brief endeavour has been made to study the societal approach towards HIV/AIDS and the struggles faced by the contracted persons. To give authenticity to this research work, an empirical study has been carried out confining to the city of Amritsar, Punjab. The data for this empirical work has been obtained from 300 HIV positives having various occupational backgrounds with the help of interview schedule. This empirical work helped in obtaining the socially constructed perception about contracting HIV/AIDS.

Modes of Transmission of HIV/AIDS

According to UNDP (2006), The AIDS Epidemic is a Global Catastrophe and during last two decades HIV and AIDS has become a pandemic around the globe. This situation is more grim then that indicated through public data. This is due to several factors that contribute to the higher risk of HIV infection among the population and therefore the route of HIV/AIDS transmission is very vital to be rightly comprehended. No doubt, homosexuality played a predominant role in fuelling this pandemic as Gilman (1988) explains the early conceptions of HIV/AIDS came to view it as "Gay disease" but most of the global data reveals the fact that unprotected heterosexual contact is the leading cause of HIV/AIDS worldwide.

Sexuality is our truth and that it endangers as surely as it enables. Like nature itself, which both engenders and destroys, sexuality must be understood. Sexuality, in the person of the sexual subject, must be brought to confess. In short, sexuality is the name of who we are. Simultaneously, it is the name of what most threatens us and what we most need to know (Foucault, 1980).

These two factors viz. homosexuality and unprotected heterosexuality structured the understanding of HIV/AIDS in a negative manner. Consequently, Persons with AIDS (PWA) were stigmatized as carriers of infectious disease as well as located within a very specific category of sexual orientation (Douard, 1990). As a result, Gilman (1988) notes that HIV/AIDS was understood as a subset of sexually transmitted disease (STDs) as well as a disease which afflicted gay individuals as a result of their sexual practices and lifestyle. Intern, HIV/AIDS came to be viewed as an illness afflicting "those who wilfully violated the moral code… a punishment for sexual irresponsibility" (Gilman, 1988). As a result, people who are diagnosed as HIV positive are seen as promiscuous, particularly women were always labelled as immoral and blamed for rapid spread of this illness.

Later on other routes of HIV/AIDS transmission were discovered such as use of virus contaminated syringe, contaminated blood transfusion, injecting drug abuse and transfer from HIV positive mother to child (Gillman, 1988; Douard, 1990).

Table 1: Distribution of respondents according to modes of HIV/AIDS transmission

Responses	Total	Percentage
Unprotected Heterosexual Contact outside marriage	101	33.66
Unprotected Heterosexual Contact with HIV positive spouse	82	27.34
Injecting Drug Abuse	55	18.34
Treatment with virus contaminated needle syringe	40	13.34
Blood Transfusion	17	5.66
Needle Stick Injury	03	1.00
Homosexuality	02	0.66
Total	**300**	**100**

The data from the empirical study reveals that the most common route of transmission of HIV/AIDS is unprotected sex i.e. 33.66 percent respondents. The next common route is through HIV positive mother to the child i.e. 27.34 percent respondents. 18.34 percent were injecting drug users and 13.34 percent respondents were infected from virus contaminated syringe, 5.6 percent from blood transfusions and only 1 percent from needle stick injury. The data also reveals that out of 300 respondents, only 0.66 percent contracted HIV through homosexuality.

A study conducted by National AIDS Control Organization (2003) also made explicit that predominant route of transmission of HIV/AIDS is through unprotected heterosexual contact i.e. 85.29 percent. The other modes were injecting drug users (2.87 percent), blood transmission and blood product infusion (2.99 percent) and 7.25 percent falling in the rest of categories. In the study of NACO, Gender roles were also emphasized i.e. 74.88 percent of AIDS cases were males and 25.12 percent were females making the ratio of 3:1.

Another survey conducted by UNAIDS (2008) also supported the above study by revealing that 87 percent of HIV/AIDS worldwide is transmitted through unprotected sex. Thus, this study demonstrates that it is socially and factually constructed that HIV/AIDS has an associated with sexual lifestyles; it is the people who engage in these lifestyles who are more prone to risk. Therefore, the primary protection strategy is to select partners who are "right and to exercise protection".

Psycho-Social Impact of Contracting HIV/AIDS

HIV infection affects all dimensions of a person's life; physical, psychological, social and spiritual (Ankrah, 1993). People living with HIV positive status or AIDS are at an increased risk of developing a mood, cognitive or anxiety disorder. The word "positive" thrust into them a feeling of anger, dejection and sorrow. They crave for emotional and moral support of near and dear ones. The stigmatization attached to the disease is such that it causes mental stress leading to disruption of personal relationships. The fear and anxiety after learning about the positive status causes great suffering. The question then arises is their readiness to share about their disease with their loved ones for seeking moral and social attention (Cogan and Herek, 2001: 627-629). This negative condition makes psychosocial support necessary for the healthy living of HIV infected individuals, their partners, families and care givers (UNAIDS, 2000).

In relation to the stigmatization attached to the disease, it is crucial to understand the concept of Stigma. 'Stigma' is derived from the work of Goffman who referred to it as '…an attribute that is deeply discrediting' and that reduces the discredited 'from a whole and usual person to a tainted, discounted one' (Goffman, 1963). Parker and Aggleton (2003) maintain that stigma and the resulting discrimination are not individualised processes in which some individuals 'do' something to other individuals in a vacuum. Instead, stigma must be understood in relation to the structural dimensions of 'power' and 'domination' that underlie inequalities, whereby some groups are devalued and excluded in comparison to others who are more valued and more privileged. Thus, stigmatisation is a social process inherently linked to the production and reproduction of structural inequalities (Cogan and Herek, 2001: 627-629).

HIV has found a wealth of opportunities to thrive among tragic human conditions fuelled by poverty, abuse, violence, prejudice and ignorance (Lyons, 2008). Social and economic circumstances contribute towards vulnerability to HIV infection and intensify its impact, while HIV/AIDS generates and amplifies the very conditions that enable the epidemic to thrive. Just as the virus depletes the human body of its natural defences, it can also deplete families and communities of the assets and social structures necessary for successful prevention and provision of care and treatment for persons living with HIV/AIDS (ibid).

Table 2: Readiness to disclose HIV positive status

Responses	Total	Percentage
Those who disclosed their HIV positive status		
Spouse	115	38.33
In Laws	28	9.3
Cousins	22	7.3
Parents	21	7
Children	08	2.6
Friends	03	1
Total	**197**	**65.67**
Those who refused to disclose their HIV positive status		
Total	**103**	**34.33**

It is clear through empirical study that 65.60 percent were ready to share their agony with someone known and 34.33 percent were not ready to do so. The reasons cited for which are their fear of stigma attached to the disease, fear of marital discord, feeling of loneliness, fear of being suspected of moral misconduct, development of suicidal tendencies in spouse etc.

Holt *et. al.* (1998) found that immediately after post diagnosis; individuals typically do not disclose their condition and use avoidance and denial mechanisms to respond to the diagnosis. Asymptomatic individuals who have begun to accept the diagnosis may disclose their HIV status as coping mechanism to regain control over their lives and relieve the stress of not disclosing. When an individual becomes symptomatic or develops AIDS, disclosure in necessary to get medical services and social support. However, disclosing at this point could be a positive experience for some individuals but for others it was an unwelcome indication of the effects of the illness for others (ibid).

Wolitski *et. al.* (1998) found that when individuals do disclose their HIV status, it is most frequently to significant persons such as primary partners and friends, rather than to people considered to be less significant such as employers or co-workers. Green (1996) mentioned that, disclosure of HIV status is a double-edged sword because it creates opportunities for medical and social support which can be crucial in adjusting to the illness but it may lead to extra stress as a result of stigmatization, discrimination and disruption of personal relationship.

Need for Disclosure/Non-Disclosure of HIV Positive Status to Family – a Dilemma

A family in every individual's life plays a very crucial role. It is defined as "a social network of biologically related members and socially (chosen) relationships such as spouse, close friends and even close external family who may support gay men" (Bonuck, 1993; Miller *et. al.*, 1993; Pequegnat *et. al.*, 1997).

Any individual contracting HIV becomes a big challenge for the family. It causes large psychological, physical and social impact on them. However, the impact of HIV on the family depends on which member is infected. Depending on whether the person infected is a heterosexual man, woman, gay man or infant, they may face different challenges. Due to the negative image constructed surrounding the issue of HIV status; the toughest challenge is to fight stigmatization. The fear of

discrimination and isolation due to stigma hinders the prevention and treatment process of HIV and hampers social support and disclosure of HIV status (Klitzman, 2001: 211-213).
Within the family, if any member contracts HIV there are numerous issues involved (Van Empelen, 2005: 9) which are as follows:

1. Physical, Psychological and Social impact.
2. Challenge to meet new medical, personal and social situation.
3. Adverse effect on sex lives and feeling of discomfort.
4. In case of HIV positive parents, psychological stress on children and adolescents to take responsibility for caring and to cope with their loss of foster care.
5. Risk to new born of HIV infection by vertical transmission in-utero and during labour and breast feeding (ibid).

These issues further cause dilemma of disclosure of HIV positive status to family members by the infected person (Van Empelen, 2005: 9). The infected person conceals about his positive status due to the fear of revelation of sexuality, infidelity or drug use, due to fear of social unacceptability and disturbance in the emotional well-being of the children. The major concern is the fear of associated stigma, discrimination and exclusion. However, the disclosure is important as it avoids the enhanced risks of HIV transmission among the spouse/partners due to concealment; it helps gain additional support including access to proper treatment, planning of pregnancy, replacement feeding for infants, future care and custody planning; it improves the notions and existing knowledge about HIV and its transmission (Van Empelen, 2005: 11; Klitzman, 2001: 211-213; Bor, et. al., 1993: 187-204).

Disclosure to family member has its pros and cons (Vallerand et. al., 2005). It may increase closeness, but it may also increase stress (Green et. al. 2004: 5-46). The impact of disclosure on the family is thus mixed. It may increase closeness or may increase stress; it may generate feeling helplessness or fear of losing loved ones, concern about care and may even cause fear of being getting infected (Van Empelen, 2005: 12).

A study conducted by Asian Network of People Living with HIV/AIDS (2004) also showed that after diagnosis few of the infected individuals experienced discrimination from their family. They were excluded from usual household activities life cooking, sharing of food and sleeping in the same room with other family members.

Table 3: Factors behind disclosure/non-disclosure about positive status to spouse

Responses	Total	Percentage
NO		
For being suspected of sexual immorality	68	22.67
Will effect sex life negatively	50	16.67
Development of suicidal tendencies in spouse	67	22.33
TOTAL	**185***	**61.67**
YES		
Due to procedural requirement of HIV testing for spouse	48	16
To cross check the HIV status of spouse	46	15.3
Both are HIV positive	16	5.3
Under emotional circumstances	05	1.6
TOTAL	**115**	**38.33**

*Refer table 2, 103 totally disagreed and 82 had agreed to disclose to family members other than spouse

As per table 2, 38.33 percent of the total respondents had agreed to disclose their positive status to the spouse, the reasons for which have been laid down in table 3 such as procedural requirement to extract their reports from HIV testing centre, to cross check their spousal status, if both are HIV positive and the fact is already revealed to them or under emotional circumstances. The data in table 3 also clarifies 61.67 percent did not feel the need to disclose about HIV positive status to their spouse due to the reason such as being suspected of infidelity, negative impact on their sex lives or development of suicidal tendencies in their spouse.

The present study supports the fact that although stigma attached to the disease may have adverse effect on individual's and the family life but the overall safety of the health of the spouse is the need of the hour. Thus the disclosure to the spouse must be encouraged.

Table 3.1: Factors behind disclosure/non-disclosure about positive status to other family members

Responses	Total	Percentage
NO		
Indirect and circumstantial disclosure by medical officer	83	27.67
Fear of being discriminated	47	15.67
Considering the old age factor of parents	21	7.00
Fear of being denied of property rights	26	8.67
Fear of mockery	22	7.33
Fear of being misunderstood by children	19	6.33
TOTAL	**218***	**72.67**
YES		
Death of spouse due to AIDS	27	9.00
For seeking financial assistance	21	7.00
With the belief that disease is curable	20	6.67
Already being treated by family for drug addiction	14	4.67
TOTAL	**82**	**27.33**

*Refer table 2, out of 218 respondents, 103 totally disagreed and 115 disagreed to disclose to other family members

As per the data in table 2, 27.33 percent had agreed to disclose their positive status to other family members. In table 3.1, reasons have been laid down such as circumstantial disclosure by the medical officer and not directly through the respondent, death of spouse due to AIDS, to seek financial assistance from the family, under the belief that the disease is curable or if the family already knows about the problem of drug addiction of the respondent.

72.67 percent of the respondents did not feel the need to disclose their positive status to other family members due to the fear of discrimination, to avoid giving mental agony to their old parents, fear of being denied of property rights, fear of mockery by others or fear of becoming a cause of distress to their children.

A Study conducted by Paxton *et. al.* (2005) reported discrimination in their family. Most common forms of discrimination reported were separating eating utensils, preventing positive people from cooking or sharing food and denying them the use of common spaces and toilets. Diagnosis of HIV infection among women has been shown to result in attribution of blame and labelling in diverse contexts (Bharat *et. al.*, 2001). She explains that in the case of married women, member of the husband's household tend to blame them for the disease and for the misery brought on the entire family. The infected women were significantly excluded from usual household activities than men and more often by their in-laws, as stated by Asian Network of People Living with HIV/AIDS (2004).

Another study conducted by Bharat (1996) found that, although a majority of those who had shared their HIV status with their families received care and support, it was largely men rather than women who qualified for such care. Forms of discrimination against women with HIV included being refused shelter; being denied a share of household property; being denied access to treatment and care; and being blamed for a husband's HIV diagnosis, especially when the diagnosis was made soon after marriage.

Repercussions of Contracting HIV/AIDS on Family Members

HIV/AIDS-related stigma is recognised as a major barrier to HIV prevention efforts and an impediment to mitigating its impact on individuals and communities (Bharat, 1999). The social stigma that surrounds HIV may have adverse repercussions not only for the individual, but also for their family. It may cause the following kind of changes:

1. Overt and covert change in behaviour – The person suffering from HIV/AIDS may face overt and covert change in behaviour of people living nearby such as rejection which may be blunt or subtle through gesture like reduced visits from friends and neighbours, children/family members not been invited to functions and social gatherings. Such kind of social denial may impact the psychological health of family members in long run (Van Empelen, 2005).
2. Financial impact – HIV/AIDS can cause enormous financial strain on the family. The patient often loses his job after being diagnosed. The combination of decreasing income and increasing health care cost may make even the most basic survival difficult (Van Empelen, 2005).
3. Discrimination – Due to irrational fears attached to HIV/AIDS, the infected person faces discrimination not only from the outside world but also by the family members especially in the form of isolation (Blumenfeld, 2001: 215).

Moreover, they must tolerate treatment with adverse side-effects, deal with rejection and social discrimination (Green, 2000).

4. Fear of losing HIV infected parent – the children, adolescents have to depend upon foster care as there is higher chance of losing HIV infected parent. The parent who is infected has to confront issues of disclosure of their HIV status to their children or adolescents. They also need to plan for proper foster care for their children after their incapacity to function as a parent or after their death (Havens and Claude, 2001: 261-262).
5. Challenges of foster care – with the death of the infected parent, children or adolescents often feel orphan. Their adaptation in foster environment becomes very difficult. They are highly neglected, abused by society and this situation leads then the conditions of poverty. These factors also cause stress, anger, ambivalence towards parents, self esteem deficits and feeling of hopelessness among the orphaned children or adolescents (Havens and Claude, 2001: 261-262).
6. Faces discrimination due to myths surrounding HIV transmission – the family members of the infected person faces discrimination from the society due to socially constructed myths surrounding HIV transmission such as disease is incurable; leads to premature death especially if the anti-retro viral is beyond the prices range of the person; lack of information regarding transmission of HIV such as contacting HIV through casual contacts such as sneezing, touching, kissing, sharing food or drinks with infected persons; fear of blame as HIV or AIDS is associated with sex, gay-men, sex workers, IDUs, having sex with multiple partners. The victim, even if innocent is eyed guilty and society describes his problem as "part of Gods plan to rid the world of sinners" (Usdin, 2005).

Table 4: Change in behaviour of family members due to the repercussions faced by them

Responses	Total	Percentage
The infected person faced discrimination	43	21.82
Suspected for immoral activities	42	21.32
Constant nagging by the family members	39	19.80
Boycottism by the family members from all basic facility like sharing of food and kitchen	38	19.29
Their behaviour generates feeling of dependency on them	25	12.70
Family members have become more concerned than earlier	10	5.07
Total	**197**	**100**

*115 respondents have shared their status to their spouse and 82 have shared to other family members

Due to the above factors, the infected person finds alteration in the behaviour of family members. Table 4 depicts that out of 197 respondents who agreed to share their sero-status to their family members, 43 faced discrimination from their family members, 42 were suspected for indulging into immoral activities, 39 were constantly nagged for getting infected, 38 were boycotted by their family members, 25 were made to feel dependent on their family members for treatment and only 10 respondents felt that the family members have become more concerned than earlier for the purpose of care and protection.
In 2004, a study conducted by Asia Network of People living with HIV/AIDS also revealed the following facts that 18 percent of the respondents experienced discrimination from their family, 14 percent was excluded from usual household activities like cooking, sharing food or sleeping together. The study also revealed the influence of the disease on the gender as women were significantly more likely to be found to be excluded from usual household activities than men and more often by their in-laws.

Conclusion

Fear and discrimination are the offspring of stigma and have their base in ignorance and lack of information. A stigma itself is attached to HIV/AIDS as a result of both fears surrounding contagion and pre-existing prejudice against the social groups most seriously affected by the epidemic (Cogan and Herek, 2001). Much of the hysteria stem from the erroneous belief about the disease such as contracting through casual contact, sneezing, kissing, sharing food and drinks with infected person, through mosquito bite etc. This mistaken belief about the mechanism of HIV transmission is widespread which socially constructs the concept of HIV/AIDS (Usdin, 2005: 59).

In Indian family structure, the myths surrounding HIV/AIDS is highly prevalent due to lack of adequate knowledge, hesitation to discuss the modes of transmission openly, mental block to permit sex education at school level, orthodoxism in discussing issues related to sex and sexuality etc. These factors become the major reason behind concealing the positive status by the infected from their family members. The once who decide to boldly disclose their status faces discrimination, suspicion and in extreme cases boycottism.

The concern is to eradicate the myths and dilemmas existing in the Indian families concerning HIV/AIDS by educating the masses that it is not communicable like common cold but can be contracted only through specific modes of transmission. Masses should be educated to treat persons with HIV/AIDS with care and not with discrimination, that HIV can be prevented by proper measures. This will help in understanding HIV/AIDS in right perspective and will attach dignity to the infected survivors.

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