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Research Article

Social Exclusion of PLWHA: Myth or Reality?

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ABSTRACT

This article explores the dynamics of human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) with special reference to life of people living with HIV/AIDS (PLWHA). It is undertaken within the framework of HIV/AIDS patients coming to the hospital. The findings indicate the diversity found in HIV/AIDS patients regarding their problems, source of infection and their current situation. This was an attempt to understand how personal environment or lifestyle of people puts them at risk of acquiring infection. It is not only the high-risk behaviour which put one at risk, even low-risk groups are getting infected. These relationships involve trust and love so a person naturally tends to go for unprotected behaviour believing that other person in the relationship is also loyal. Many people like to live in a world of denial and knowing their personal behaviour they will never get themselves tested. HIV/AIDS is usually considered to be a disease of others. This unsaid otherness is responsible for social tsunami of stigma existing in imagination of everybody.

Keywords: HIV/AIDS patients, social exclusion, trust, guilt conscious, stigma, discrimination.

INTRODUCTION

There is no other word that instills as much fear, despair and helplessness as AIDS. Why people hide their HIV status? The answer is imagined stigma which got embodied into people's mind through the process of socialisation. We got habitual to this thinking of sex as tabooed subject, which takes up the shape of imagined stigma into our unconscious self. The prime association of HIV to sexuality is largely responsible for this imagined stigma. Both human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) and sex are considered to be an alien thing. As said by famous novelist Chetan Bhagat (2013) that 'the default strategy of living in Indian society is to pretend sex doesn't exist'. Unlike other chronic diseases, HIV comes with the responsibility of concealing it from others. Social troubles add up to physical problems of people living with HIV/AIDS (PLWHA). When a chronic disease possessed a person then that person got dispossessed of his/her identity, that is, identity changes. The deliberate use of the term 'possessed' is to show that disease effect one's body but illness associated with it possessed one's social soul. Chronic diseases altered identity in many different ways, for instance AIDS patient, but this in itself includes array of obligations, stigma, questions like how, when, why it happened and so on. This brings us to the variety and degree involved in the concept of social exclusion of PLWHA. Factors causing HIV can never be excluded from people's life as it intervene into their meaningful existence like mother to child, individual sharing pleasure of sexual encounters, rituals and so on. The risk of HIV transmission coincides with human relationship of love and caring (Week 1985). It is impossible to make these activities prohibited so there is need to find out a solution in between these modes of transmission as these two are intertwined to each other.

According to UNAIDS (2010) report, the major route of HIV transmission is heterosexual sex. But people tend to attach the title of promiscuous sexuality with HIV, thereby making it socially excluded. But PLWHA do not reveal their status to others then how they are socially excluded? In case of HIV/AIDS, social exclusion is more of an abstract concept that resides in people's thinking and they follow it because of fear of social stigma.

What is Stigma?

Stigma is a social term arising from physical, mental and biological deformities when reaction of others spoils normal identity (Goffman 1963). Its implications are very much social because 'all human cognition is social cognition' (Steiner and Stewart 2009). We try to conceal our deformities to escape social eyes. It shows the strong presence of social perception in our embodied self, which we follow unconsciously.

Where Stigma Exists?

It exists in some kind of social vacuum as neither the minor stigmatised section nor the major stigmatiser section talks about stigma directly because it will have implication on their social image but stigma in one form or other exists in people's perception. So it is a misconception that onset of stigma is triggered by HIV diagnosis or disclosure of HIV status. The perception of stigma exists in us through our process of socialisation and growing up from starting. It is through this lens of perception that people judge other and themselves. This is the very reason that people knowing their lifestyle do not get themselves tested because they already have this perception of stigma embodied into their self, which unconsciously act to prevent them from testing and if for any reason they get the test done and results are positive then their embodied self will prevent them from revealing it to others. As Goffman explained, the term stigma and its synonyms conceal a double perspective. By double perspective, he meant that either the stigmatised individual assume his differentness is known already and is evident or he assume that it is neither known about by those present. In the former case, we are dealing with the plight of the discredited, that is, stigmatised individual and in later case with that of discreditable, that is, the attribute that is stigmatised. It is possible that the person experienced both the situations. It is important to mention that first kind of stigma exists in society, that is, external stigma and the other kind of stigma in our thoughts, that is, internal stigma (Goffman 1963). Stigma has direct implication on one's identity, which is of two types – one which we present in front of others, that is, social identity and other which we conceal to ourselves, that is, implicit identity. It is this implicit identity that deals with our unconscious embodied self.

What compel a person to go for unsafe behaviour knowing it could lead to life-threatening disease/illness? Is it as simple as saying use condom every time or use clean syringes. No if it was so simple then the number of HIV/AIDS patients visiting Antiretroviral Therapy (ART) centre would be less. The dominant models of health promotion have reduced the complex psychological issue to a question of instrumental technique 'use a condom every time'. We need to understand how this behaviour is embedded in cultural psyche of the individual of which they may not even be consciously aware (Crossley 2004). Therefore, it is embedded deep in our behaviour of structure that Bourdieu (1977) referred to as habitus. People got habitual of unsafe behaviour, which then becomes part of their behavioural structure. There are certain attributes that are embedded into our embodied self. It could be trust, need for love, etc., which unconsciously act on our cognitive behaviour. There is need to find out more on embodied self and structure of behaviour in context of PLWHA.

The personal environments are also important determinants of acquisition of infection and development, which are in turn molded by powerful macro-environmental forces including socio-economic, geographic and other factors (Wasserheit 1994). This article deals with the personal environment or so-called lifestyle of people, which put or prevent them from risk and how inherent social exclusion creates more troubles for them. Unlike other infectious diseases, HIV/AIDS is treated in isolation particularly because of its mode of transmission (sexual conduct).

It is often believed that the stigma of AIDS is related to ideas of morality and sexual conduct prevalent in society. But this stigma is rooted in powerlessness rather than in any acts of behaviour. If the stigma is associated with AIDS is linked to laxity of sexual norms like homosexuality or having multiple partners, then such behavioural myths are often associated with persons in show-biz but

who certainly not shirked by society (Channa 2005). It is important to note that although this stigma is associated with HIV/AIDS but it is shown against PLWHA, therefore it varies. More stigma is attached to marginalise communities like sex workers, etc., but it is also true that majority of people think that profession of show-biz is bad. At the same time, it is not easy to point a finger on them because they are famous people with lots of power. So power does come as a factor in showing discrimination against people as the term PLWHA is not a uniform category, but contains with in itself many categories based on age, sex, social class and position. It makes a difference whether such a person is male or female, a bread winner or a dependent, a person from elite class or a marginal group, rich or poor (Channa 2005). It is significant to recognise this diversity found in social environment of human beings.

METHODOLOGY

Fieldwork was undertaken for this study, selection of the patients was based on the following criteria: registration of the patients in the out-patient department as HIV patient, patients who were coming for 4 months regularly for their checkups and consented to the study. Hundred patients were interviewed from one of the leading hospital of Delhi (India). All the written obligations were fulfilled, related to the promises of considering all the ethical issues, and the rules of the hospital. Methods used were interview schedule and case study. In addition to this, observation was used to know about people's behaviour in the market place and in certain eventful areas of Delhi usually after 10 PM. So the key method used was observation accompanied with interview method resulting into case studies of patients.

RESULT AND DISCUSSION

PLWHA falls into two categories: first when they acquire infection due to them self and second when they gets the infection from their respective partners, particularly in relations involving trust. In former case the person become guilt conscious, whereas in latter the person feel betrayed and become aggressive. It can be illustrated through following case studies.

The patient is 32 years of age, and knows his HIV-positive status for 1 year when this case study was taken. He got infected due to contaminated blood and blood products used during his surgical operation. He had disclosed his HIV-positive status to his wife and mother. No one else in the society and in the family knew about his seropositive status. Economically he was well-settled and managed a business with two partners, who were also his cousin brother. According to him, his life has changed completely after this.

Now I am HIV positive, and this is a very disturbing event for me. This shows that people after knowing their status, starts treating it as their identity. *For few days after detection, I was not able to face anyone. All the time I thought that I would die.* So these patients have strong tendency to end their life or to think that they will die soon. *Even today I am thinking the same: there is no future for me. My wife who had done nothing also became the victim of fate. I had spoiled her life. These days I do not want to do any work as I have no stamina.* It appears that before the disease could make them physically sick, they had already assumed and accepted those symptoms psychologically. *Whenever I am at home, I want to go the office, but when I am in office, I do not want to be there, as I do not want to face any official problem.* Even if other people in society are not aware of one's HIV-positive status but still one starts isolating him from others. *Whenever anyone asks about my health, I become very worried, and the very first thing that comes to my mind is, what will happen if he knows about my status? Had he seen me in the hospital?* Person not only deals with the disease physically but also socially. It is important to mention here that although he knows others are not aware of his status still he is conscious of society because of his thinking. *Today, I am asymptomatic but one day when my disease will progress everyone will know about my condition. All the time I think about this and it is the biggest hurdle due to which I am unable to focus on my work, on my family and on my children. I know I will die with this thought as other patients have died. Now I do not want to do any work anymore, I just want to lie down on my bed. I do not wish to hear anyone's voice. Although my wife motivates me a lot, but this makes me more conscious about her future. My mother health is deteriorating day by day as all the time she worries about my health. I am responsible for their bad condition.* Such patients have high tendency to become guilt conscious as if they are responsible for putting others through all the miseries.

The patient is 31-year old-female, acquired HIV infection heterosexually from her husband. Her two children are seronegative. She had disclosed her HIV status to mother-in-law, father-in-law and sister-in-law. No one else in society and in the family knew about this. *When my in laws came to know about it, they scolded my husband and supported me as they know their son has spoilt my life. All family members motivate me but whenever they do so, I became very aggressive. I do not wish to listen to them. Sometimes I think I am worthless I know everybody is sympathetic towards me because I am dying. My children ask me about my health for which I have no answer. How can I tell about their father's wrong doing and my infection? He has breached my faith.* Such patients got disturbed due to unfaithfulness of their partner and lost love and faith in other family member also. They see others changed behaviour as manifestation of their anxiety about losing her to death. As a result, patients isolate them self from their primary support group and enter into depression.

As observed through the lens of fieldwork especially case studies, it was realised that most of the patients disclose their positive status only to their parents, sometimes to their parents in law and to their wife. So society never came to know about them being HIV positive, this raises a prominent question – where and how stigma and discrimination exists without society knowing about it. But no doubt that these two evils – stigma and discrimination – exist against people from marginalised communities who are considered by society people as high-risk group irrespective of their own promiscuous behaviour as society people or so-called low-risk group visits sex workers and become a bridge between the two ends. Next case study will make it clearer:

The patient is 31-year-old male who acquired HIV infection heterosexually during his relationships with commercial sex workers. He got married at the age of 27, for more than 18 months he has deserted his wife. She is unaware of his seropositive status and resides with her parents thinking that his husband has left her because he is a patient of tuberculosis. He has disclosed his status only to his parents. He said "*I am worried, had I infected her? I have made her a victim. She had done nothing but because of my wrongdoing she has to suffer. I had pre-marital relation with sex workers but I did not tell her about this. I had never thought that I will contact this disease. These days I like to live alone*". Such cases provoked to ask a question – Does HIV/AIDS has taken away our sexual freedom? It is true that people are scared of HIV/AIDS and also know how it occur but at the same time they hold a strong belief that it will not happen to them. As observed in above case study that the husband in spite of his risky lifestyle did not get him tested and got married because he strongly believed it could never happen to him. Later he left his wife without disclosing his status to her knowing the chances of her being HIV positive. Now, if she marries again then she will be affecting her future husband. It becomes a chain where some people knowingly and some unknowingly transmit their infection to others.

People enjoy their sexual freedom and even knowing their lifestyle they will never get them tested. It is all about living in a world of denial. It is only after appearance of symptoms and after long procedure of believing that it is because of some black magic done by neighbour, some deficiency in the body or simple tiredness. After all possible assumptions, one might think of getting tested for HIV. But it is quite likely that till then he/she has passed the infection to others (if one is HIV positive). Upcoming case study will put more light on this: 25-year-old female got herself tested after 6 years of her relationship with her boyfriend. When she started felling tired after little exertion, pain in body, headache, drowsiness, etc. At first she thought her neighbour or somebody has done black magic on her, so she tried to counter it by visiting temples. It does not make her situation any better. Next assumption of her was 'I might be suffering from some deficiency' so she got herself tested but everything was normal. At last, she thought of getting herself tested to eliminate her fear of being HIV positive. This fear was in her from starting as she used to engage in unprotected sex with her partner. But the reason she got involved because she trusted his partner. Her test report was negative and it helped her to overcome that fear also. It points towards rising of new type of high-risk group, that is, love and trustful relations that can be the biggest reason for unsafe sex. In sex worker–client relation, use of condom is comparatively easy to love relationships where trust is involved. Even nuptial couple use condom only for the purpose of preventing unwanted pregnancy and when other method are available for this purpose then use of condom is very less in

love and trustful relations. The problem here is mutual fidelity is not always maintain by couples and it is quite possible that they do not go on to marry the same person with whom they had first sex.

Other important dimension in the spread of HIV/AIDS is the alarming number of rape cases including gang rapes. Such behaviour is rarely protected that makes them a high-risk group who can transmit infection to rape victims. The number of cases of sexual harassment of children is also increasing day by day. There are cases where males both heterosexual and homosexual seek paid sex not from sex workers but from children (beggars, poor children in need of money). Following case studies will make this point more lucid. In a very posh area of Delhi, around 9 PM, a male in his twenties dressed up in formals was standing and a beggar girl of around 8 years came to him. But he asked her for paid sex and she ran away then he went after her. Another case in a busy market, male in his twenties dressed up in red trousers and pink shirt. He saw two boys of around 10 years and pulls them to the corner and asked for having anal sex for money. As these children do not know much about HIV/AIDS and other such infections so they got ready easily just to have some money. As such activities takes place in a hidden manner, therefore, not much can be done to prevent such things.

Moreover, it was also observed that most of the people hardly know about any HIV patient so practically discrimination does not exist but in their mind fear exists that if they meet any HIV patient, there are chances of getting infected. Even educated people knowing very well how it spreads holds such thinking. Due to this collective thinking people do not disclose their seropositive status. Like our biological immune system, people develop social immune system to protect them from social eyes. This system is based on fear in our mind, which guides our behaviour, for example: it prevent people from disclosing their status. If this fear is channelised properly, then it could prevent people from putting themselves at risk. In HIV/AIDS, fear of social stigma acts as poison but this fear itself is an antidote.

CONCLUSION

This study reflects risk behaviour and practices, which not only set adult population on the threshold of HIV but also reflects the increasing trend of infection in housewives. Those who were infected by commercial sex workers initially become carriers of HIV. Later due to their unsafe sexual practices, non-discloser and sometimes ignorance of their own HIV status, infect their spouse with HIV. This makes the condition of women more vulnerable and they become innocent victims of HIV/AIDS.

Another noticeable change has been in the sleeping arrangement in the family. The percentage of spouses sleeping with their HIV-positive partner decreases considerably after infection, before it was 80% while after infection it decreased to 41%. The relationship between married couples changed drastically after HIV infection. It was characterised by high tension and non-enjoyment of each other's companionship. However, lack of affection and total abstinence from sexual relation were the main and prominent effects of the HIV-positive status on the marital relationship. A total of 34% of the patients have reported total abstinence of sexual activity, while 31% said that they did not use a condom during sexual intercourse even after testing HIV positive. This makes women more susceptible to HIV infection. Some patients were not living with their spouse, due to the fear of transmitting the virus. These results poignantly demonstrate the loss of companionship for infected spouse. It raises a significant point about sexual needs of HIV/AIDS patients, which is largely ignored (Paliwal 2006). It is very important to understand the importance sexuality plays in life of virtually all people. By keeping them isolated or generating fear in our mind against them due to misconceptions, will make them not only hide their seropositive status but also provoked them to live without getting tested (knowing their lifestyles).

The most prominent feature of HIV infection is the onset of guilt consciousness, which is interlinked with mode of infection and source, family values and patient's role in society, 47% of the respondents suffered from guilt consciousness. A higher intensity of this felling is noticed among those who were exposed to commercial sex workers, had multiple sexual relations and felt they had betrayed their family values.

This entire discussion leads us to ask a simple question why people go for unprotected sex, when they know the result. If we know by putting hand into fire, we are surely going to get burns. In the same way, knowing the

consequences of unprotected sex, what compel a person to go for it? It could be love which involve trust or as in the sex work (for the sex worker a way of earning money and for client it is pure lust). Love and lust are important factor here because may be the consequences of unprotected sex (compared to fire) is HIV/AIDS (compared to burns), but the process of sex involve pain and pleasure. Therefore, in both cases of love and lust, sex cannot be made prohibitive but the need is to promote safe and healthy sex. It is a three way process that involve having knowledge of safe sex first than enjoying it in the present time to have safe and healthy future. This is not an easy task but in front of loosing immune system, and living on treatment forever with unpleasant side effects, it is surely the easiest thing to do. It is necessary to come out from the social imagination of stigma, which exists much more into people's fear thereby taking shape of reality. If people are so scared of stigma, then it should prevent them from risky behaviour rather than hiding it. It can only be possible when people are going to realise that HIV/AIDS is a disease among us and not a disease of others.

It was observed that most of the HIV/AIDS patients coming to hospitals are from economically lower section of society, which hints towards the association of HIV with subalterns. HIV/AIDS association with people from marginalised community or people at bottom of society does not exclude the possibility of its existence into other section of society provided we ever able to know about it.

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