Note

Stigma and Identity Construction of People Living with HIV/AIDS in Manipur

Hoineilhing Sitlhou

Ever since the first patient of HIV/AIDS was detected in Manipur in 1989-1990 among the injecting drug users, the disease has been associated with groups that are marked out as social deviants. Given this association and the fact that the disease has no effective treatment, sufferers faced social rejection and discrimination. The disease was seen as a consequence of life style choices and PLWHAs were denied access to the 'sick role'. HIV/AIDS acts as a metaphor for moral and physical contamination. The infection confers on the individual a spoilt image and identity. This is reflected in the level of stigmatisation and discrimination directly faced by those affected and vulnerable to it; as also the way PLHAs construct their identities in the light of their infection with the virus. It is also relevant to an understanding of the ways in which treatment of people dying of HIV/AIDS are being organised.

Keywords: HIV/AIDS, SHALOM, stigmatisation

Introduction

Both globally and nationally, Acquired Immune Deficiency Syndrome or AIDS currently is an "equal opportunity" disease with regard to gender, class and caste. The virus was detected for the first time in the USA in 1981. In 1986, the first known case of HIV was diagnosed by Dr. Suniti Solomon amongst female sex workers in Chennai.[1] The total number of people living with HIV (PLHIV) in India is estimated at 2.4 million with uncertainty bounds of 1.93 to 3.04 million in 2009. Children under 15 years of age account for 4.4 percent of all infections, whilst people aged 15 to 49 years account for 82.4 percent of all infections. Thirty-nine percent of all HIV infections are estimated to be among women.[1]

India HIV estimates 2008/2009 confirm a clear decline in HIV prevalence among female sex workers at national level and in most states. Contrarily, the estimates bring forth the vulnerability of injecting drug users and men who have sex with men as HIV prevalence is increasing amongst these population groups in many states. At national

Hoineilhing Sitlhou teaches Sociology in Hyderabad Central University.

level, HIV prevalence is highest amongst the injecting drug users (IDU) at 12.22 percent followed by men who have sex with men (MSM) at 6.82 percent and female sex workers (FSW) at 5.92 percent. In comparison, HIV prevalence among the general population is estimated at 0.59 percent in the high prevalence states. HIV prevalence in the low to moderate prevalence states amongst IDU, MSM and FSW is estimated at 0.91 percent, 5.40 percent and 3.01 percent respectively. HIV prevalence among the general population in the low to moderate prevalence states is estimated at 0.19 percent.[2]

National Aids Control Organisation (NACO) categorised the states and Union Territories of India to high, moderate and low epidemic zones according to HIV prevalence estimates generated under each HIV Sentinel Surveillance Round for various population groups. The six states of Andhra Pradesh, Karnataka, Maharashtra, Manipur, Nagaland and Tamil Nadu were classified as high prevalence states in 1998. The criterion for categorising states on this basis was in consideration of whether HIV prevalence exceeded 1 percent among antenatal clinic attendees.[3]

According to Manipur State Aids Control Society, the HIV positive case between the year 1990 (blood sample of 1989) to March 2002 was 11426 male, 1758 female, 1151 full blown HIV/AIDS cases and 203 deaths.[1] The first HIV cases in Manipur were reported from a study of random blood samples of injecting drug users (IDUs) in 1989-90. In 2003, 56.81 percent of the total population of HIV-positive people in Manipur were IDUs, though the figure was as high as 80 percent at one point. The geographical proximity of Manipur to Burma (Myanmar) and consequently the Golden Triangle drug trail has made it a major transit route for drug smuggling, with drugs easily available. However, HIV/AIDS in the state is no longer confined to injecting drug users; it has spread further to the female sexual partners of the IDUs and their children. This is not surprising as women are particularly vulnerable to HIV infection and other sexually transmitted infections/diseases because of biological and socio-cultural factors including economic, educational and legal discrimination and unequal gender relations.[2] The disease, as is evident today, is moving away from the earlier known high risk groups to the general population. However, there is still a tendency to associate the disease with its earlier preoccupation with anti-social behaviour.

Theoretical Concept
The term "stigma" as given by the Greeks refers to bodily signs designed to expose something unusual and bad about the moral status of the signifier. Goffman (1963) identifies three types of stigma: physical deformities; blemishes of individual character; and tribal stigma of race, nation and religion. The end result of stigma being the demotion from "a whole and usual person to a tainted, discounted one." Conceptually, then, stigmatisation is a process through which persons are characterised as unworthy of full social status. The central feature of the stigmatised individual's situation in life is a question of "acceptance." Society fails to accord him the respect and regard which uncontaminated aspects of his social identity have led them to anticipate. Goffman (1963) brings out two kinds of social identity: actual social identity and virtual social identity. The individuals are obliged to share some of the discredit of the stigmatised person to

whom they are related.

Another theory which has close affinity with the, "stigma theory" is the "labelling theory" by Howard S. Becker. Becker (1963) argues that "social groups create deviance by making the rules whose infraction constitutes deviance, and by applying those rules to particular people and labelling them as outsiders." He continues that deviance is not a quality that lies in behaviour itself, but in the interaction between the person who commits an act and those who respond to it.

Identity is the sense of the self, of personhood, of what kind of person one is (Abercrombie et. al, 2000). Among the classical sociological theorists one finds detailed references to the question of identity only in the writings of George H. Mead and Charles Horton Cooley. Charles Horton Cooley developed his concept of "the looking glass-self", in his book *Human Nature and the Social Order*. He formed the idea of "self" through the process of introspection (Cooley, 1922). The kind of self-feeling a person has is determined by the attitude toward this attributed to that other mind (ibid, 184-185). A social self of this type is called the reflected or looking-glass self (ibid, 184). The self-idea has three principal elements: "the imagination of our appearance to the other person; the imagination of his judgement of that appearance, and some sort of self-feeling, such as pride or mortification" (ibid, 184). Thus, for Cooley when the individual develops a sense of, "I" he also develops a sense of "others". For him self consciousness and social consciousness are inseparable.

The concept of "self" and "I" also takes a central place in the work of George H. Mead. Mead (1972) asserted that the self is something which develops through the process of social experience and activity, that is, develops in the given individual as a result of his relations to that process as a whole and to other individuals within that process. "The self has a character, which is different from that of the physiological organism proper. The self is something, which has a development; it is not initially there, at birth, but arises in the process of social experience and activity, that is, develops in the given individual as a result of his relations to that process as a whole and to other individuals within that process" (Mead 1972: 135). The individual communicates with others around him through significant symbols called languages, which is directed not only to others but also to the individual self. So, during the course of social interaction, by coming to see themselves as "others" see them, individuals ultimately develops a sense of self or self-consciousness.

A defining assumption of the symbolic-interactionist theoretical framework is that human beings are actors not merely reactor. Identity theory shares this assumption, which recognises the possibility of choice as a ubiquitous feature of human existence. At the same time however, identity theory recognises the possibility of choice as ubiquitous in constraining—not in the strict sense determining (MacMillan, 1992).

Literature Review

The research to date have mostly focused on the stereotype or labelling on HIV/AIDS as a product of deviant behaviour; the culture of silence around the disease due to the stigma attached to it; and as an issue of human rights of the individual infected person versus the welfare of the society. William C. Cockerham (Medical Sociology; 2001) has

written that the sociological implication of the AIDS epidemic involved the deeply discrediting stigma attached to the AIDS victims. When people become infected with AIDS that person in many ways becomes a social outcast. The person with AIDS is likely to find that having the disease will negatively influence the attitudes and reactions of others. Family relationship can become strained as families cope with the stigma of AIDS. Since AIDS results from a private consequence that has extreme social consequences, serious moral and legal questions also arise about the rights of the individual versus the welfare of society.

David B. Morris (2000) writes that no contemporary affliction illustrates better than AIDS how the biology of human illness intersects with cultural practices that increasingly reshapes it. He agrees with Jacques Derrida on the fear and suspicion that it introduced into human sexual relations have, "irreversibly affected our experience of desire". Even when the treatment is available AIDS continues to turned parent against child, straight against gay, employer against employee and lover against lover. For him real effort is required to see AIDS patients as merely people who are ill patients rather than helpless victims.

Sarah Nettleton (1995) has made a distinction between, "guilty-group," and "innocent group" among those inflicted. Guilty group are those who partake in "unsafe" practice like the prostitutes, gay or bisexual man and IVDUs (Intra Venous Drug Users). The innocent group comprised of the homophiliacs, the recipients of blood transfusion and babies infected in the mother's womb. She highlights the lay health belief that everyday situations such as the use of a carrier's razor, transmission via public toilets and being in hospital close to people with HIV, are still identified as, "risk situations" by a significant majority of people. She termed these beliefs as "risk-over estimation".

The book, *Living under a shadow-gender and HIV/AIDS in Delhi* (2001), by Mukhopadhyay and others is about the study of gender dimension of HIV/AIDS in Delhi carried out in 1999-2000 by the Institute of Social Science Trust. The study examines two aspects of the epidemic: first, the societal norms that influence "risk behaviour" of men and the resultant increase in women's vulnerability; and second, the gender differentiated impact of the illness within the family. Stigmatisation for people of both sexes may vary across economic classes or social strata.

The research findings of Alan Clarke (2001) suggest that individuals with HIV/ AIDS are stigmatised because their illness is; seen as both a product and producer of deviant behaviour; viewed as the responsibility of the individuals; considered to be contracted as a result of engaging in what is morally sanction able behaviour; thought to represent a character blemish; perceived as contiguous and a threat to the community associated with an undesirable and anaesthetic form of death; not very well understood by the lay community, and viewed in a negative light by professional health care workers. According to Clarke, individual patients who are continually exposed to this stereotype in their encounter with health workers can internalise the stigma associated with being HIV positive in a process of self-stigmatisation.

Ritu Priya (2003) has written about the problem of accessibility and affordability of Anti retroviral (ARV) treatment for poorer victims. The epidemic according to her is a development issue, as it deals with issues of human rights related to health. The af-

fected person's voice and diverse identities ought to be allowed a valid place in health institutions.

Kent L. Sandstrom (1998) uses the symbolic interactionist perspective to construct a framework for examining how people with AIDS define themselves and their illness as it accentuates the processual, interactive and interpretative dimensions of human experience and selfhood. In the earlier phases of their illness, people with HIV/ AIDS struggle most centrally with issues of stigma and uncertainty. Gradually AIDS taken on the "master-status", in that it becomes the single most important social characteristics of an infected person. They experience the loss of the sense of autonomy, masculinity and self as they become independent on others around them.

A Case Study of SHALOM

The universe of study is an NGO based in Churachandpur district of Manipur called Society for HIV/AIDS and Lifeline Operation in Manipur Universe of Study (SHALOM). It was jointly designed in 1995 by Deutschman, Tamara Aboagye Kwarteng from the Macfarlene Burnet Centre for Medical Research in Melbourne who had extensive experience designing HIV/AIDS projects in developing countries; and two doctors from the project town itself who were already key figures in the indigenous response to HIV/ AIDS, Dr. B. Langhkam and Dr. V. Muana.[1] This NGO has been chosen for its record of spearheading the needle-exchange programme in 1995 as part of harm-reduction campaign.[1] "But SHALOM is more than a needle and syringe exchange program. It is an integrated approach to the twin problems of drug addiction and HIV which endorses abstinence from drugs as well as rehabilitation and harm minimisation. It has established a home based detoxification service, a confidential HIV testing and counselling service, a home based care program including jail visits for people with AIDS and an innovative community education program. Commercial sex workers are also starting to be reached with safe sex messages and condom distribution."[2]

Methodology

Given the stigma and secrecy that surrounds the ailment, locating the infected individuals or affected families will be difficult; finding those that are willing to talk will obviously be even more difficult. Therefore, qualitative method rather than quantitative method is preferable and the individual informant has to be assured strict confidentiality in the matter of protecting his identity. The methodology adopted for data collection would be the following:

• Individual interviews with PLHAs
• Case Studies
• Key informants: doctors, nurses and social workers working with HIV/ AIDS
• Non-participant observation
• Primary and Secondary materials.

The case study method would provide us with personal experiences, attitudes and problems of the infected persons. Non-participant observation is conducted on the PLHAs

interaction with his immediate surrounding (family members and key informants) and the treatment and care given by members of the family and friends. The key informants' gives information on their impressions, experience of individual cases, problems they face and their views regarding the fear associated with the disease.

Objectives
All the methods and techniques would be directed towards answering certain questions or objectives as given under:
· To assess the level of knowledge and awareness about the virus within the universe of study.
· To study how the PLHA construct their identities in the light of their infection with the virus.
· To understand the specific aspects of discrimination and stigmatisation directly faced by those affected and vulnerable to it.
· To explore the kinds of existing lay beliefs, attitudes and perceptions about risk behaviour in the community.
· To study the socio-economic factors making the people vulnerable to HIV/AIDS.
· To find out the impact of the epidemic at the level of community, house hold or indi vidual level.

Hypotheses
· People tend to stigmatise those with HIV/AIDS.
· The stigma surrounding HIV/AIDS is due to "risk over-estimation" of its modes of transmission.
· The stigma meted out by HIV/AIDS is due to its earlier exclusive association with immoral and anti-social behaviour.

IDUs and HIV/AIDS in Manipur
In Manipur the first case of HIV/AIDS detection happens among the Intravenous drug users (IDUs) community. The high-risk groups i.e. those persons who are liable to get this disease were those groups who were heterosexually promiscuous, homosexuals, injecting drug users (IDUs), blood donors, blood recipients, ante-natal mothers, patient on dialysis, relatives of AIDS patients, peri natal transmission, etc. From this above listed categories, the group topping the chart were the injecting drug users (IDUs) who constitute about 43.48 percent and the heterosexually promiscuous constituting 29.04 percent.

Examination of blood samples drawn from a group of confined intravenous drug users inside the state jail of Imphal leads to detection of HIV/AIDS in 1989. When the news of the epidemic reaches the general public, there was fear and commotion all around.

The general population, government and state law enforcing agencies, pressure groups, CBOs (community based organisations) and armed groups tried to curtail illegal drugs (especially heroin) and on people who use drugs (IDUs). Drug dealers were hunted and prosecuted and many were shot dead by armed groups and IDUs were harassed,

abused and humiliated in public. A sizeable number of IDUs were also shot dead or crippled for life by shooting at their legs or arms as a warning not to use drugs by armed groups. IDUs who got caught were beaten, harass, humiliated, heads tonsured and were paraded in public. Worst still their names and address were flashed in local newspapers and private TV news channels.

The entire society, including women activists (Meira Paibis), police and insurgents swing into action to get rid of the IDUs. While the police put the detected drug users behind bars, women activists and insurgents operated through midnight knocks of the houses of suspected drug addicts, and warning the parents to hand over their addicted children to the police or the insurgents. The insurgent group, People Liberation Army demanded the names of the HIV positive and claimed their ability to control AIDS by killing them.

Nowadays, there is a shift of the HIV/AIDS epidemic from high risk groups such as IDUs to the general populace especially women and children.[2] The injecting drug users also have affected partners in the form of spouse or sexual partners. Moreover, during the early 1990s, there was a belief that if drug users were made to marry early, they would mend their ways. This encourages parents to marry off their wards at a very young age. Most of the men died at a young age due to HIV/AIDS, leaving behind acutely vulnerable wives and children.[3] There is also a growing number of children and cases of patients having been infected as a result of receiving contaminated blood products or through promiscuous spouse, hence sufferers are more likely to be seen as innocent victims and worthy of sympathy. However, this is often not the case in which the disease due to its prior association with deviant groups in the society is labelled as a deviant disease. Given this association and the fact that the disease is fatal and that there is no effective treatment, sufferers faced social rejection and discrimination.

Life and death of PLHA

Various initiatives of the community and the state have changes the face of HIV/AIDS to a certain extent. According to the Annual Report 2010-2011 of the National Aids Control Organisation (Department of AIDS control), Ministry of Health & Family Welfare, addressing the issue of stigma and discrimination against people living with HIV/AIDS has been envisaged as a major step to mitigate the impact of HIV/AIDS.[1] Various channels of communication such as mass media i.e. radio, T.V. and newspaper, mid-media and out-door communication, including folk theatre, exhibitions, hoardings, information displays and inter-personal communication are used to address this issue**.**

The state government in Manipur have open centres for free ART treatment. The Prevention of Parent to Child Transmission Counsellor, Margaret Lalmalsawmi said that in terms of 12 months trend, the official figures of people who had come for HIV/AIDS related case was twenty one and there were more patients from the general population and not from the "high risk group". They belong to the age-group of 18-28 years. According to the Director of SHALOM, Lalruatpui Pachuau community wise responses to the epidemic have changed. Religious groups are also trying to incorporate a more sympathetic approach towards the sickness. In Churachandpur District (Manipur), there are many churches like Reform Presbyterian Church and the Salvation Army which have various projects in order to spread awareness and change attitudes of the people about

the epidemic. Though attitudes have changed at the community level, things does not change much when one levels it down to issues of choice at the personal level. For marriage partnership, the people who belong to the high risk group like IDUs, female sex-workers or someone who have tested HIV positive are shunned. Moreover, they are not considered to be the "ideal" or preferred groups even for friendship or any forms of social relationships or partnerships. There are pastors who preached it as a sign of wrath upon the PLHAs for sin or sins committed by the later. Therefore, there is a paradox in societal attitude towards the epidemic; accepted at the formal point and rejected or ab-horred at the informal or primary group settings.

With regard to the treatment of people dying from HIV/AIDS, there is usually a differential treatment meted out to their dead bodies. SHALOM director Lalruatpuii Pachuau narrated how in the past the bodies were covered in plastics. In many instances informants narrate how they witnessed the stigma that shrouded PLHAs did not end with their dying. The image and identity is projected into life beyond physical death. Gossips surround the death of the person. Folks who come for the funeral often question the life-style of the dead person in order to know how the disease was contacted. Some even assume that the family of the deceased might have committed some sin at some point of time for such a calamity to befall them.

Conclusion

The disease was seen as a consequence of life-style choices and AIDS victims were denied access to the "sick role". The assumption was that they could have avoided the disease if they had not chosen a deviant way of life. The metaphors of AIDS contributed to the stigmatisation of the disease and the consequent construction of a putative social division between those who are seen to be "at risk" and the general community, which is not. Being labelled as a deviant identity has a profound impact on the individual's self-image and their social relationships with others. HIV/AIDS patients still experience so-cial difficulties in dealing with the social and physical consequences of their condition. A strong negative societal reaction can dominate an individual's self concept to the ex-tent that they come to see themselves as others see them and behave in such a way as to confirm the deviant status ascribed to them. The social stigma surrounding AIDS makes it difficult for them to maintain a normal social identity.

There is a need for the AIDS patients to be seen as merely people who are ill rather than helpless victims. There ought to be dissociation of AIDS from its earlier image of a "morally repugnant disease" to an "equal opportunity" disease. Risk over-estimation and lay health belief about the virus should be replaced by knowledge and awareness, for it is only in knowing the enemy, that we can combat it.

List of Interviewees

1. Lalruatpuii Pachuau, Director, SHALOM, telephonic interview on 11 August 2012.
2. Margaret Lalmalsawmi, Prevention of Parent to Child Transmission Counsellor, SHALOM, telephonic interview on 11 August 2012.
3. Discussion based interviews with PLHAs.

Notes

[1] HIV/AIDS in India, WIKIPEDIA the free Encyclopedia, http://en.wikipedia.org/wiki/HIV/AIDS_in_India

[2] Technical Report on India HIV Estimates by Ministry of Health & Family Welfare, Government of India,
p.xi, accessed from http://www.nacoonline.org/upload/Publication/M&Epercent20Surveillance,percent20Research/Technicalpercent20Reportpercent20onpercent20HIVpercent20Estimatespercent202010.PDF (accessed on 07 August 2012).

[3] Ibid

[4] Technical Report on India HIV Estimates by Ministry of Health & Family Welfare, Government of India,
p.16, accessed from http://www.nacoonline.org/upload/Publication/M&Epercent20Surveillance,percent20Research/Technicalpercent20Reportpercent20onpercent20HIVpercent20Estimatespercent202010.PDF (accessed on 07 August 2012).

[5] National Aids Control Programme, 'Manipur State Aids Control Society', accessed from http://www.cicmanipur.nic.in/HTML/Aids.asp#MANIPUR (accessed on 07 August 2012).

[6] HIV/AIDS in Manipur: The need to focus on women, Chitra Ahanthem, http://infochangeindia.org/public-health/analysis/hivaids-in-manipur-the-need-to-focus-on-women.html, August, 2003

[7] HIV/AIDS control in Manipur, Andrea Mc Laughlin, http://www.ausaid.gov.au/publications/focus/focuspdfs/29635-36.pdf, (accessed on 11th august, 2012)

[8] Harm reduction accepts the realities of drug use. It says that along with attempts to stop the supply of drugs and the demand for drugs, some people will continue to use drugs and that measure must be taken to minimise the harm they do to themselves and society. It's a controversial approach, rejected by many, especially law enforcement agencies, as giving in to the evils of drug abuse.

[9] HIV/AIDS control in Manipur, Andrea Mc Laughlin, http://www.ausaid.gov.au/publications/focus/focuspdfs/29635-36.pdf, (accessed on 11th august, 2012)

[10] Epidemiological analysis of HIV/AIDS in Manipur, Sarlima Laishram, http://siroy.info/articlepage.aspx?article=LhAoidHs+3uqQEe1M5vHRQ==, (accessed on 11 august, 2012)

[11] Menace of HIV/AIDS in Manipur, Harjeet Sinam, http://www.gomanipur.com/your-story/item/680-menace-of-hiv-and-aids-in-manipur, (accessed on 11th august, 2012)

[12] ibid

[13] Children living with HIV/AIDS in Manipur has reached 2578 as of January, http://manipurhub.com/children-living-with-hivaids-in-manipur-has-reached-2578-as-of-january/, (accessed on 11 august, 2012)

[14] HIV/AIDS in Manipur: The need to focus on women, Chitra Ahanthem, http://infochangeindia.org/public-health/analysis/hivaids-in-manipur-the-need-to-focus-on-women.html, (accessed on 11th august, 2012)

[15] National AIDS control organisation, Department of AIDS control, Annual Report 2010-11, http://www.nacoonline.org/upload/REPORTS/ NACOpercent20Annualpercent20Reportpercent202010-11.pdf, (accessed on 11th august, 2012)

[16] Ibid

References

Clarke, Alan (2001) *The Sociology of Health Care* (Harlow: Pearson Education Limited).

Cooley, Charles Horton (1902): *Human Nature and the Social Order* (New York: C. Scribner's sons).

Cockerham, William C (2001): *Medical Sociology* 8th Edition (Malaysia: Prentice Hall, Pearson Education Limited).

Goffman, Erving (1963): *Stigma: Notes on the Management of Spoiled Identity* (Touchstones edition, New York).

Mead, George Herbert (1972): *Mind, Self and Society* (Chicago: Chicago University Press).

Morris, David B (1998/2000): *Illness and Culture in the Postmodern Age* (Los Angeles: University of California Press, Berkeley).

Mukhopadhyay, Swapna et al. (2001): *Living under a shadow: Gender and HIV/AIDS in Delhi,* (New Delhi: Institute of Social Studies Trust).

Nettleton, Sarah (1995): *The Sociology of health and Illness* (Cambridge: Polity and Press).

Priya, Ritu (2003): "Health Services and HIV treatment: Complex issues and options", *Economic and Political Weekly,* Vol. 38, No. 50, (13-19 Dec), 5227-32.

Ramasubban, Radhika (1998): "HIV/AIDS in India: Gulf between rhetoric and reality", *Economic and Political Weekly*, Vol. 33, No. 45, Nov. 7-13, 2865-72.

Raj, N. Gopal (2004): "A ticking time bomb?", *The Hindu*, December 5, 2004.

Sandstrom, Kent L (1998): "Preserving a vital and valued self in the face of AIDS", *Sociological Inquiry*, Vol. 68, No. 3, Summer, 354-71.

Sjoberg, Gideon et al (1968): *A Methodology of Social Research,* (New York: Harper & Row Publishers).

Young, Pauline V (2009). *Scientific Social Surveys and Research,* Prentice Hall of India, Private Limited, New Delhi.

MacMillan (1992): *Encyclopaedia of Sociology* (New York: MacMillan Publishing Company).

Nzioka, Charles (2000): "The Social Meanings of death from HIV/AIDS: An African interpretative view"*, Culture, Health and Sexuality*, Vol.2. No. 1, 1-14.