AN ANTHROPOLOGICAL STUDY ON HIV/AIDS-RELATED STIGMA AND DISCRIMINATION AMONG THE TANGKHULS OF MANIPUR

ABSTRACT

By

GIDEON JAJO
DEPARTMENT OF ANTHROPOLOGY

NORTH-EASTERN HILL UNIVERSITY
SHILLONG-793022
APRIL, 2015
An Anthropological Study on HIV/AIDS-related Stigma and Discrimination among the Tangkhuls of Manipur

(Abstract)

By

Gideon Jajo

Supervisor: Prof. H. Lamin

Department of Anthropology

North-Eastern Hill University

Shillong – 793022

April, 2015
AN ANTHROPOLOGICAL STUDY ON HIV/AIDS RELATED STIGMA AND DISCRIMINATION AMONG THE TANGKHULS OF MANIPUR

INTRODUCTION

Acquired Immune Deficiency Syndrome (AIDS) is a disease of the human immune system caused by the human immunodeficiency virus (HIV). The condition progressively reduces the effectiveness of the immune system and leaves the individual susceptible to opportunistic infection and tumour. HIV is transmitted through direct contact of a mucous membrane or the bloodstream with a bodily fluid containing the HIV, such as blood, semen, vaginal fluid, pre-seminal fluid and breast milk (Sepkowitz 2001). This transmission can involve anal, vaginal, or oral sex, blood transmission, contaminated hypodermic needles, exchange between mother and baby otherwise called vertical transmission during pregnancy, childbirth, breastfeeding or other exposure to one of the above bodily fluids. However, sexual intercourse accounts for most of the transmission of HIV/AIDS.

Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS) epidemic came to the attention to the world during the early 1980s and debates as to its origin continues to this day. The HIV found mainly in West Africa is the HIV-2 strain, and the HIV-1 strain is prevalent in Europe, Asia, America and the rest of Africa (Peeters et al. 2003). The first recorded instance of a man who died of AIDS appeared in 1979 in the US and the discovery of the HIV-virus as the cause of AIDS was made in 1983 (Ibid). When it was established that the causative organism of mystical disease was a virus, the name AIDS was first described in the United States of America in the year 1981. Stigmatisation and discrimination of people infected by HIV/AIDS is a common phenomenon all over the world. In India, the first case of HIV/AIDS was reported in the year 1986 in Madras. Since then, HIV and AIDS have become unquestionably the major public health problem in India, and its
prevalence have been on the rise for more than a decade and have reached alarming proportions in recent years. India has the third highest number of people living with HIV/AIDS in the world as much as 2.1 million infected people. In Manipur, about 40,855 persons have been infected with HIV/AIDS (MACS, 2013).

**STATEMENT OF THE PROBLEM**

Tangkhul is one of the major Naga tribes predominantly living in Ukhrul and Senapati districts, Manipur in India and in the North-Western part of Myanmar. The epidemic of HIV/AIDS disease is not new in the Tangkhul society. Since 1993, the year when the first HIV/AIDS case was reported in Ukhrul, the number of infection continues to increase at an alarming rate. Many have died because of this epidemic. The first group of HIV positive cases was reported among drug users. Later, it spreads from IDU to sexual transmission, and then further into the general population. The impact remains devastating and the efforts to control HIV/AIDS are found inadequate, which in fact resulted to spread HIV and AIDS further. Based on the data collected by the District AIDS Prevention Control Unit, Ukhrul in 2014, there are at least 1324 people living with HIV/AIDS in Ukhrul district.

It is learnt that the preventive measures have been undertaken over the last decade to mitigate the growth of this epidemic within the risk groups. Attempt has also being made by many groups for the well-being of the infected people through the execution and implementation of programmes under various HIV/AIDS related projects. Despite the public, institutions and the NGOs’ efforts in various ways in the fight against HIV/AIDS, the infection diffuses; the epidemic continues to affect the infected people and their families, partners, and the caretakers of the infected people. Reports of HIV infected people who are being abandoned by the family members are widely known in the district. Some infected people have been evicted from their home and the community have denied their right to
property and right to ownership. While many other infected people received verbal abuse and rejection from the uninfected people of the community. The community reactions towards the HIV/AIDS infected people have many negative implications on the life of PLWHA. These include traumatisation, economic insecurity and emotional disorder of the infected people. In the absence of in-depth studies on the above-mentioned issues, to study on the issues become a necessity. No individuals, institutions or organisations have done commendable study on the HIV/AIDS in Tangkhul society with an exception of some scanty reports on HIV/AIDS by the NGOs. The present work attempts to study the HIV/AIDS related issues in the identified district, primarily focusing on the HIV/AIDS related stigma and discrimination.

An anthropological study from a holistic perspective can help and throws a light on such phenomena and propose a number of solutions to overcome these issues through examining more closely on the fields in which stigmatisation occurs, the forms that HIV/AIDS related discrimination takes, individual, social and institutional determinants, and the responses to which stigmatisation gives rise. Only by understanding more about such processes will it be possible to develop the kinds of programmes and interventions that will be successful in preventing HIV/AIDS related stigma and the negative consequences to which it gives rise. Perhaps, this research may also have a positive implication and contribution for the district, state and even for future studies as well.

**REVIEW OF LITERATURE**

In individualistic societies, HIV/AIDS may be seen as the result of personal irresponsibility (Kegeles et al. 1989). In yet other circumstances, HIV/AIDS is seen as bringing shame upon the family and community (Panos 1990). While negative responses to HIV/AIDS are by no means inevitable, they not infrequently feed upon and reinforce dominant ideologies of good and bad with respect to sex and illness, and proper and improper behaviours (Warwick et al.
1998). The real or supposed contagiousness of disease has resulted in the isolation and exclusion of infected people (Volinn 1989; Gilmore and Somerville 1994). Sexually transmitted diseases (STD) in particular are notorious for triggering such socially divisive responses and reactions (Goldin 1994).

From the beginning of the HIV/AIDS epidemic, stigma has been a crucial issue (McGrath 1992; Treichler 1999). AIDS related stigma refers to all unfavourable attitudes, beliefs, behaviours, and policies directed at persons perceived to be infected with HIV, whether or not they actually are infected and regardless of whether or not they manifest symptoms of AIDS. Bruyn (1993) has recently identified five factors as contributing to HIV/AIDS related stigma. Anxiety, anger, and depression, which commonly are experienced by people with HIV disease (Kelly and Lawrence 1988), are likely to be exacerbated by AIDS related stigma. HIV/AIDS related stigma and discrimination take different forms and are manifested at different levels - societal, community and individual and in different contexts (UNAIDS 2000).

Clearly, discrimination toward PLWHA is not simply about HIV/AIDS as a disease. Rather, it intersects with other social prejudices, including homophobia, racism and sexism (Parker and Aggleton 2003). HIV and AIDS have been blamed for reinforcing existing forms of social inequalities including gender inequalities (Barnett 2004; Kakuru 2007). Gender inequality is an important aspect of vulnerability differentiation. Women are more vulnerable to the stigma associated with HIV/AIDS as a sexually transmitted disease (Cullinane 2007; Lawless, Kippax and Crawford 1996; Ndinda et al. 2007).

HIV/AIDS related stigma within the family has also been described as the most subtle and insidious form of stigma and the hardest to address effectively. Malcolm and others (1998) further argued that by inhibiting open communication in the family stigma makes disclosure in the family difficult and without disclosure prevention and care become
impossible. Anthropologists for the most part contributed only irregularly to such early research mobilisation, largely based on their own individual research initiatives and publications rather than as part of a formal or organised research response (Bolognone 1986; Conant 1988; Feldman and Johnson 1986; Lang 1986; Stall 1986). The combined strength of theory and practice in the field of international research on AIDS is a significant contribution to anthropology in the 21st century.

OBJECTIVES OF THE STUDY

The main objectives of the study are:

- To identify HIV/AIDS related stigma and discrimination in the society;
- To understand people’s perception and attitude towards HIV/AIDS;
- To examine whether sero-positive men and women are equally treated; and
- To study the relationships of people living with and without HIV/AIDS within and outside family.

METHODOLOGY

Erickson (2004) rightly pointed out that the central activity in anthropological research method is fieldwork. Data were collected from primary and secondary sources. Conventional tools of social research like interview schedules, telephonic interviews, questionnaires and observations were used. In-depth case studies of HIV/AIDS infected people were also done during the study. Stratified Sampling Method was used for the selection of respondents. Primary data were collected through personal interviews conducted with the HIV/AIDS infected people, affected families, health workers, non-infected people and NGOs staffs of various organisations working on the HIV/AIDS related activities. The NGOs interviewed during the fieldwork include UNP+, CARE, ISWAR, Elshadai Resource Centre, RRF,
PASDO, and Women for Health Clinic among others. Appointments for interviewing the infected respondents were arranged with the help of the above-mentioned NGOs. It may be mentioned that it was almost impossible to cover all the sero-positive persons, therefore, a total of 110 samples were taken (Male-40, Female-70). With the consent and knowledge of the respondents, audio recording and photography were also taken during the study. The study maintained the confidentiality of the HIV/AIDS infected respondents. Secondary data were obtained widely from various available sources like books, academic journals, internet, research reports, news reports and publications that involved similar studies.

**AREA OF THE STUDY**

Ukhrul district has seven sub-divisions - Ukhrul Central, Chingai, Jessami, Kamjong, Phungyar, Lungchang Maiphei and Kasom Khullen. For this study, two sub-divisions viz. Ukhrul Central and Kamjong Block were selected for intensive study. The Ukhrul Sub-Division with Ukhrul as the headquarters of both the district and the sub-division occupies the central part of the district. Ukhrul Sub-Division was established in 1919, which was upgraded to a District in 1969. Kamjong is one of the sub-divisions of Ukhrul district, Manipur bordering Myanmar. It was established in 1971. The Sub-Division of Kamjong covers 44 villages having an approximate population of 16303. The difference between the two study areas is that Ukhrul is the district headquarters and it is more urban in nature, and Kamjong is in rural area and it is one of the sub-towns in the district. Many active NGOs like Elshadai, UNP+, ISWAR, PASDO, WHC, ORCHID and others are found stationed in Ukhrul headquarters, primarily working for HIV/AIDS. Whereas, in Kamjong only two NGOs namely CARE and SCCRC exist working for HIV/AIDS infected people and other high risk groups in collaboration with Community Health Centre, Kamjong.
MAJOR FINDINGS

Discrimination and stigmatisation against PLWHA is very much prevalent in the Tangkhul society. It is found that IDU is a major mode of transmission in Tangkhul context. The societal stigma and discrimination against the infected people have made many infected people not to go public. According to the findings of the study, there are Tangkhul terms, such as *Maishat* (to tarnish dignity) and *Khamhei* (outcast or ostracism) among others, used to signify HIV/AIDS related stigma and discrimination.

Another finding of the study is that metaphors such as *Morei Kazat* (sin disease), *Khonkashi Kazat* (cursed disease), *Maraikapai Kazat* (incurable disease), *Reikashang Kazat* (civilised disease), *Kahang Makhangana Kazat* (disobedient disease), *Khamakhao Kazat* (dirty disease), and *Maikashi Kazat* (disgraceful or shameful disease) among others are used to signify HIV/AIDS.

In Ukhrul district, many infected and uninfected people lack proper knowledge on the modes of transmission of the disease. The presence of misconceptions among the people has further isolated the HIV/AIDS infected people from the community by the uninfected people. People who have signs and symptoms viz. skinny body, rashes skin, pale looks and wound in the body are often suspect as HIV/AIDS patients.

Most of the innocent children and spouses were often victimised, stigmatised and discriminated by the people in Tangkhul context. There are elements among the uninfected people who wanted the HIV/AIDS patients to be “legally separated and quarantined” from the community inorder to protect public health.

Another major finding of the study is that when the HIV-positive status is confirmed, it often brings embarrassment, shame, shock, grief and depression to the infected person. Unlike men, infected women are more sensitive and worried on their HIV-positive status in going public.
There are various forms of rejection, stigmatisation and discrimination against the HIV/AIDS infected people in the Tangkhul society. These include unwelcoming gesture against the infected people in any community activities or events, insulting words and humiliation against PLWHA, and harassment and torture against the infected by the uninfected people among others.

PLWHA who disclosed their positive status have suffered not only the societal stigma and discrimination, but also from within the family. The family members and relatives often keep the seriousness of the infected person secret. Based on the data collected from the field, only one-third of the total families have disclosed to the community about their HIV infected patients.

Many family members of the infected people received positive reactions from the community especially on the dead of the infected person. Some of the common positive gestures given by the community include visitation, presentation both in-cash and in-kind, and their involvement in the funeral related activities.

The notion of self-stigmatisation is found among the HIV/AIDS infected people especially among the female HIV/AIDS patients. The concept of “double stigma” against the HIV infected person is prevalent in concept and in practice especially among the HIV/AIDS patients who also have TB.

Most of the HIV/AIDS women patients lived difficult lives after the dead of their husbands. Many widows are infected with HIV or living with AIDS, and dispossession, harassment and eviction often take place when their economic and health conditions are rapidly deteriorating.

There is an issue of gender inequality in the access to medical care and services between infected men and infected women in the Tangkhul society. Infected women are more stigmatised and discriminated by the community in comparison to infected men. It is
also found in the study that poor infected people are more stigmatised and discriminated than those HIV/AIDS patients belonging to richer section of the society.

One of the major findings of the study is that the National Rural Employment Guarantee Scheme (NREGS) was one of the major sources of income for the HIV/AIDS patients especially for the poorer section of the society. The wages earned by the HIV patients were mostly spent for their medical expenses, children’s education and for other basic needs.

Based on the study, the stigma and discrimination against the HIV infected people are also found in the community health care system. Doctors and nurses often gave medical prescriptions without physical examinations to the HIV/AIDS patients. Some of the most important grievances pointed out by the HIV infected people in relation to heath care system are incompetence and shortage of health care providers, breaches of confidentiality of the HIV/AIDS patients, and lack of facilities like CD-4 count test, ART drugs and other medical facilities in Ukhrul district.

According to the findings of the study, there are many organisations operating in Ukhrul district. Some important NGOs funded by the state and centre government include UNP+, CARE, CHAHA, ISWAR, ORCHID, and Spring of Hope among others. Elshadai Resource Centre and World Vision are functioning through foreign aid in the district. Red Ribbon Forum is the only NGO funded by some Tangkhuls that is in operation in Ukhrul district. The performance the NGOs funded by the Government of Manipur is found to be unsatisfactory for many HIV/AIDS patients. In the study, it is found that PLWHA often acknowledged the supportiveness of the self-help group (SHG) or support groups for the well-being of HIV/AIDS patients.
CONCLUSION

This study claims that societal stigma and discrimination towards PLWHA are very much prevalent within and outside the family. In many ways, such negative reactions against HIV/AIDS patients hindered them from being trying to live positively. HIV/AIDS is often viewed as immoral, curse, disobedient, dirty or sinful disease by the uninfected Tangkhuls. Wrong perception and attitude of the uninfected people towards PLWHA and HIV/AIDS resulted to more self-stigmatisation among the HIV/AIDS patients. The presence of unequal treatment towards sero-positive men and sero-positive women is an example of gender discrimination that is prevailing in the Tangkhul society. In combating against the HIV/AIDS, roles and initiatives of the committed NGOs are very much observable in Tangkhul context. Despite the presence of various stigma and discrimination, it is observed that the AIDS awareness campaign and advances in anti-viral treatment have resulted to a gradual decline of negative reactions among the uninfected people among the Tangkhuls.

The fatal diseases like HIV/AIDS are not an individual issue or problem. The involvement of institutions and social organisations in the fight against societal stigmatisation and discrimination towards PLWHA may be of immense help. It is observed that, apart from the intensive and extensive awareness campaign on HIV/AIDS, the availability of CD-4 count test, ART and other medicines, and sufficient and competent health care providers in Ukhrul district will solve many grievances of PLWHA. However, for this to succeed, political will of the state government of Manipur is required. Similarly, the lack of social cohesion among the people, which often develop stigmatising modes of thought, is vulnerable to the epidemic. Thus, the participation of both the infected and uninfected people in combating the epidemic is of utmost importance. Some of related areas like “Cross Border Drug Trafficking and HIV/AIDS”, “Human Rights Issue of PLWHA”, and “Sex Networking
and HIV/AIDS” among others need to be explored inorder to comprehensively understand HIV/AIDS in the Tangkhul society.

REFERENCES


