CHAPTER - VII

CONCLUSION

This chapter summarises the major findings of the study. Observations and concluding remarks are also made in this chapter. The findings of the study indicate that HIV infected people are affected by the stigma attached to this disease in various ways. It also shows the impact of the disease on the lives of the infected people, their families, the community, and on the society.

Discrimination and stigmatisation against PLWHA is still prevalent in the Tangkhul society. According to the findings of the study, the Tangkhuls have some terms which are in use to signify HIV/AIDS related stigma and discrimination. Local terms such as Maishat (to tarnish dignity), Hammak Neokahai (application of something undesirable on the face), Chuk Kahai (marked or imprinted), Maishi Khangashak (to give a bad name or to make somebody shameful) refer to stigma. Similarly, the Tangkhul terms such as Lumkhamakhei (favouritism or partiality towards a person by the society), Yangkakhei (absence of equal action or judgment), Yangkakateo (an act of manifestation of superiority complex meted to lower strata), Khamahi (outcast or ostracism) and Kakhei (separate) refer to discrimination.

Another finding of the study is that the metaphors such as Morei Kazat (sin disease), Suikhangerui Kazat (immoral or promiscuous disease), Khonkashi Kazat (cursed disease), Marakapai Kazat (incurable disease), Reikashang Kazat (civilised disease), Kahang Makhangana Kazat (disobedient disease), Khamakhaio Kazat (dirty disease), Zakkashi Kazat (ugly or harmful disease) and Maikashi Kazat (disgraceful or shameful disease) are used to signify HIV/AIDS.
According to the findings, unlike other terminal diseases, HIV/AIDS is perceived as a cursed disease, deadly disease, dirty disease, immoral disease, incurable disease, civilised disease, shameful disease, or sin disease. It is found that sexual intercourse and IDUs are the most commonly mentioned modes of transmission in Tangkhul context. It is found that majority of the respondents are of the opinion that the HIV/AIDS infected people should be treated properly, as much as the uninfected people treated of themselves. On the line of what Vuuren (1997) had stated, it is found in the study that AIDS is seen as a disease far more contagious than it really is because it is regarded as a divine retribution for certain aberrant lifestyles. According to the findings, the negative reactions of the uninfected people towards the infected people have resulted to keep the HIV status in secret among the infected people. In other words, the societal stigma and discrimination compel the infected people not to go public.

According to the findings of the study, many respondents have limited knowledge on HIV/AIDS, which made them to have misconceptions against the HIV/AIDS infected people. It is also found that many uninfected people also lack proper knowledge on the modes of transmission of the disease. For instance, many uninfected people continue to believe that casual contact, sharing food, utensils, toilets, clothes, shops and sharing washroom, and mosquito bite among others can transmit HIV/AIDS. Consequently, this misconception has further isolated the HIV/AIDS infected people by the uninfected people.

According to the findings, majority of the HIV infected people are of the opinion that innocent children and spouses should not be victimised by the uninfected people. It is found in the study that most of the innocent children and
spouses were often victimised, stigmatised and discriminated by the uninfected people in Tangkhul context.

Another finding of the study is that there are elements among the uninfected people who wanted the HIV/AIDS patients to be “legally separated and quarantined” from the community in order to protect public health. In other words, the HIV-positive person should be isolated from public places in order to control the spread of HIV/AIDS. Generally, it is perceived that the HIV/AIDS infected people are either sexually immoral people or injecting drug users in Tangkhul context. This is the reason why the uninfected people wanted PLWHA to be isolated.

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. Further, it is found in the study that most of the HIV infected respondents wanted to give up their lives after the confirmation of their sero-positive status. Unlike men, infected women are more sensitive and worried on their HIV-positive status in going public.

Based on the findings of the study, there are various forms of rejection, stigmatisation and discrimination against the HIV/AIDS infected people in the Tangkhul society. For instance, 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 are some of the appropriate examples.

According to the findings of the study, very few families are ready to disclose the HIV status of their infected family members to the community. Family members and relatives often keep the seriousness of the infected person in secrecy.
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.

On the line of what Mbilinyi and Kaihula (2000) have pointed out, familial support is especially common in poorer section of the society and is supplemented with religious based organisations and NGOs. It is found in the study that the primary source of help received by the infected people is social support mainly from family members. Based on the case studies in the study, initially, most of the infected people were scolded and rejected by their family members. However, the family members extended their support and took care of the HIV/AIDS patients.

According to the findings of the study, PLWHA who disclosed their positive status have suffered not only the societal stigma and discrimination, but also from within the family. Based on the data collected from the field, in some families, some of the infected people were provided separate utensils and clothes for their daily use, and were not allowed to cook food or prepare food items for the family consumption for fear of contracting HIV/AIDS. This indicates not only the ignorance of the family members on the transmission of HIV/AIDS, but also the presence of stigma and discrimination even within the family.

One of the major findings of the study is that all the HIV-positive women respondents are found to have infected by their husbands. On the other hand, almost all the HIV-positive male respondents were infected through IDUs with an exception of two cases - (a) one was infected through blood transfusion, and (b) the other from his wife. Based on the finding of the study, it can be surmised that sharing of syringes among the IDUs is the main mode of transmission in Tangkhul context. The availability of drugs like opium and heroin in abundance in India-Myanmar border areas could be one of the main reasons for the rise of HIV/AIDS
patients in Ukhrul district. It is found in the study that people who have signs and symptoms viz. skinny body, rashes skin, pale looks and wound in the body are often suspected as HIV/AIDS patients.

The concept of “double stigma” against the HIV infected person is prevalent in concept and in practice in the Tangkhul society. As found in the study, family members of the infected person received positive reaction from the community especially on the dead of the infected person. People show sympathy, make visitation, and offer service to the relatives during the funeral service. On the contrary, according to the findings of the study, people hardly show sympathy or make visitation to those AIDS patients who have both HIV-positive and TB. In other words, family members of the AIDS patients with TB receive no positive reaction from the community even on the day of his/her dead. In short, no positive reaction or gesture was given to the AIDS victim because the victim also had TB.

One of the major findings of the study is that most of the HIV/AIDS women patients lived difficult lives after the dead of their husbands. FAO (1999) mentioned that 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. Consequently, such widows are left without shelter and means of livelihood. In the study, it is found that some infected widows were victimised even to the point of eviction from the homestead by their in-laws. In many cases, they were denied to have access to the family resources or wealth, and the care and support from the in-laws are seldom available for the infected widows. One of the most common accusations of the in-laws against the infected widows is that the latter were held responsible for the dead of their sons or siblings. In other
words, the infected widows infected their husbands, which resulted to the dead of their husbands.

According to the findings, 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. If both the spouses were HIV/AIDS patients, the family members, especially among the poorer section of the society, often gave priority to infected men for medical treatment and regarded infected women’s health as secondary one. Infected women are more stigmatised and discriminated by the community in comparison to infected men. For instance, most infected women experienced unwelcoming gesture from the uninfected people in public events and occasions, which was not much observable in the case of infected menfolk. 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.

The notion of self-stigmatisation is found among the HIV/AIDS infected people. According to the findings of the study, majority of the infected female respondents experienced self-stigmatisation. Contrariwise, very few infected male respondents experienced self-stigmatisation. In other words, unlike the infected women respondents, many HIV infected male respondents did not experience self-stigmatisation in Tangkhul context. Further, HIV infected women were more expressive and approachable than HIV infected men during the field study.

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. It is also found in the study that even
the richer section of the society also availed this scheme. It is observed that there were manipulation in the allotment and distribution of ‘job cards’ of the scheme. In other words, in the name of ‘quota’, the richer and influential section of the society were given more ‘job cards’ of the scheme; whereas, some of the poor HIV infected people were not given even a single ‘job card’ of the scheme.

Based on the study, the stigma and discrimination against the HIV infected people are also found in the community health care system. According to the findings of the study, 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 health 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. Further, unlike most of the uninfected people, almost all the HIV/AIDS infected respondents wish the community to treat HIV/AIDS as like any other chronic diseases.

According to the findings of the study, there are many organisations operating in Ukhrul district. Some of them are funded by local and international NGOs, and some others are funded by the government under the supervision of MACS and NACO. 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. It is observed in the study that most of the assistance for the HIV/AIDS infected people in the district came from those NGOs funded by foreign sponsors and local individuals; whereas, the
contribution of the NGOs funded by the central and state governments were not much observable apart from the scanty distribution of ART to the infected people. In the study, it is found that PLWHA often acknowledge the supportiveness of the self-help group (SHG) or support groups for the well-being of HIV/AIDS patients.

Based on the findings of the study, most of the HIV infected people especially the poorer section of the society experience stigma and discrimination from the members of the community. It is found that very few infected people, primarily the richer and educated section of the society, did not receive such negative reactions from the community. Linked to societal stigma and discrimination, children of the HIV/AIDS infected parents receive similar negative reactions from the society. It is also found in the study that all the HIV/AIDS infected parents have concerned for their children’s future in the face of social stigma and discrimination.

According to the findings of the study, 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. Based on the observation of the study, prayer supports were often given to the HIV/AIDS infected people by the Church leaders and elders. It is also found that the parents of PLWHA with bad reputation or unsociable ones received less number of visitors and assistance from the community in comparison to those parents of PLWHA with good reputation and sociable ones.

It is evident from the findings of the study that PLWHA are subjected to stigma and discrimination in the Tangkhul society. This study claims that societal stigma and discrimination against 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. As UNAIDS (2001) rightly pointed out that “no population group is completely safe from the epidemic and that only a global approach based on mechanisms that strengthen social cohesion in which people are respected regardless on their background and lifestyle and of the group or social category to which they belong, can reduce the spread and impact of the disease.” 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 machine, 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.