CHAPTER - III

OPINION OF UNINFECTED PEOPLE

Every society has its own ways of categorising their members into different groups. Similarly, every society has its own norms of what is right or wrong, and what kind of behaviour and attitude is considered normal. Relatively, what is normal in one social group might not be the same in another social sphere. A particular group of people can be subjected to stigmatisation in one society, but be totally exempted in another. The point is, what is considered as stigma in one society may not be so in another society. Considerably, what is reflected as taboo in one culture may be completely acceptable in another. In the light of this, this chapter examines the overall responses of the public regarding HIV/AIDS. It also attempt to understand stigma and discrimination associated with HIV/AIDS in the society including misconceptions about the transmission of HIV/AIDS. The chapter focuses on the uninfected people’s attitudes and reactions towards PLWHA and their family coupled with the perceptions of NGOs, health care providers and HIV/AIDS infected family members in the Tangkhul society.

Laws, Norms and Taboos

Virtually, all societies have formal rules of behaviour called laws, which are defined by the state and enforced by a formal governmental apparatus. Even in democratic societies aiming to maximise individual freedom, laws are enforced independent of whether the individual members of the society believe that the rules reflect extant value systems or not (Maine 2004). Even the most unpopular laws must be enforced to ensure the legitimacy of the entire system (Weber 1978). All societies also have
informal rules of behaviour called norms, which are defined by culture and tradition. While many norms are embodied in and enforced by laws, there are also norms that simply set expectations of behaviours. That is norms are enforced by “general societal pressure or the collective infliction of non-legal sanctions on deviants, those who disobey the norms, subjecting them to stigmatization, criticism, ostracism or even non-state force” (Posner 2002). Taboos, on the other hand, are negative norms that involve actions, practices, or states that carry a strong social stigma. Taboos are social prohibitions created over time. They depend on, and are reinforced by, “community wide complicity” (Douglas 2002).

Irrespective of its simplicity or complexity of their social fabric, the Tangkhuls have its own Yanret (laws) and Shiyan Chikan (norms and behaviours) which are largely defined by their culture and tradition. These laws and norms prescribe behaviours that individuals are required to perform; they defined what people must do and otherwise. These, in short, are considered as set of expected behaviours. Anyone who virtually goes against it or behaves in illegal way is being judged negatively and is subject to social stigma and discrimination. For instances, people with unwanted character like Khamarip (drunkard), Suikhangarui-Phasā Khangasho (promiscuity), Kakapik (liars), Ngarai kacha sem eina sem Semkasā (homosexuality), Rai Kaphung (people who posses evil spirit), Khali Kasha (theft) and wife beaters are stigmatised in the Tangkhul society. Nao Kashum (barren couples), and Lāronga kala Yāronga (aged men and women who are unmarried) are also not seen as normal behaviour and therefore, they too are stigmatised and look upon negatively.

There are social prohibitions or taboos called Sharra, which control the actions of the people in the Tangkhul society. There are certain rigid rules and
regulations. Some actions which are considered as taboos are Preigahar Pāngkahai (divorce), Shokhalā (incest), Shangnao akha wui alungli Khangakum (clan exogamy), Miyum (murderer), Ngalā Khangashir (polygamy), Misā Kashai Mi (cannibalism), and Ngalei Khangapai (land encroachment) among others that carry a strong social stigma. People who fall under such categories are strongly marginalised. Of these, incest marriage, clan exogamy, and murder carry some of the harshest penalties. The stigma attached to these kinds of taboos passes from one generation to another or from parents to offspring. It has been observed that penalties for such taboos are applied equally for both men and women in the society.

There are also taboos relating to HIV/AIDS. In fact, numerous sensitive and highly tabooed topics are associated with the transmission of HIV. For instances, Phophāt (adultery), Ari-arai Kakap kala Shikachin (drug injection and usage), Suikhangashai or Shāmkazat (flesh trade), Ngarai kacha sem eina sem Semkasā (homosexuality), and Rasa Maleirang lakha Phasa Khangaso (premarital sex) among others have the potential of transmitting HIV are strongly condemned and prohibited in the Tangkhul society. As indicated by Allan and Burridge (2006), all these taboos are related to the human body and its transformations like sexuality, disease and death. People generally believe that infection of HIV/AIDS is the result of disobeying the norms and values of the society and of breaking taboos, subjecting to stigmatisation, criticism and ostracism in the community.

Many diseases are also being stigmatised as per people’s perception. Diseases like Maraikapai Kazat (cancer), Phārei Kazak (leprosy), Khāheng Kazat (TB), Zingmeirai (epilepsy), Pharaik (syphilis) and HIV/AIDS are stigmatised in different forms and levels. However, these diseases may not have similar negative connotations as much as HIV/AIDS. The case of HIV/AIDS has been identified as
“dual stigma” – not only is the syndrome itself stigmatised because it is perceived as a threat to health and safety, but, furthermore, it is associated with groups that were already highly stigmatised before the global outbreak (Herek and Glunt 1988; Derlega and Barbee 1998).

In Tangkhul society, HIV/AIDS epidemic is believed to be directly connected with moral issue and is considered as “incurable disease”, “immoral disease”, “sin disease”, or perceived as “divine curse”. It is, therefore, understandable that HIV/AIDS patients are most criticised, ostracised and discriminated in the society. Despite this fact, specifically, there is no such law that prohibits discrimination of HIV/AIDS infected people.

**Meaning of HIV/AIDS in Tangkhul Context**

HIV/AIDS-related stigma and discrimination acts as the greatest barriers of AIDS prevention, care, treatment and support. They prevented the effective working of HIV/AIDS programmes. After interviewing a section of people living in Ukhrul district of Manipur, this study makes an effort to define the meaning of stigma and discrimination relating to HIV/AIDS.

There are some local terms that signify HIV/AIDS-related stigma and discrimination on HIV/AIDS in the Tangkhul society. However, those terminologies may not be the exact meaning and interpretations of this disease. Many respondents gave the meaning of stigma relating to HIV/AIDS by using the local terms such as Maishat, Hammak Neokahai, Chukkahai, and Maishi Khangashak. Literally, Maishat refers to tarnishing dignity. It implies an act of humiliating or abusing somebody through words or action. Similarly, the term Hammak Neokahai means an application of something undesirable on the face. Literally, the word Chukkahai
refers to “mark or imprint”. In simple sense, it means a negative deed or action of a person that cannot be easily forgotten or changed in the social set up. The local term *Maishi Khangashak* means any act that gives a bad name which is considered as shameful. It may also mean to make someone feel ashamed by giving certain comments or behaving in certain ways which is absolutely disgraceful in front of others.

Furthermore, local terms such as *Lumkhamakhei, Yangkakhei, Yangkakateo, Khamahi* and *Kakhei* are used for discrimination relating to HIV/AIDS in the Tangkhul society. Literally, *Lumkhamakhei* means an act of favouritism or partiality towards a person or others by the family. For instance, unequal motherly treatment given to sons and daughters out of favouritism or dislikes. *Yangkakhei* may refer to the absence of equal action or judgement. It could also refer to despising somebody’s rights. The term *Yangkakateo* may be used as an act of manifestation of superiority complex meted out towards the people who are socially, politically or economically underprivileged. The word *Khamahi* is a more severe term than any of the above-mentioned Tangkhul terms. It is used when someone does things which are against the social norms, and therefore, he/she is ostracised or isolated by the society. Sharing of individual or social activities with such person is strictly restricted. In other words, they are outcast and isolated. The term *Kakhei* means to separate. It is referred to someone who is devaluated. Most of the respondents commented that these terms are “strong word” used specifically to refer to someone who is looked down and devaluated in the society. All the above-mentioned terms denote the negative interpretations of people affected with HIV/AIDS.

There are no specific terms to describe HIV/AIDS disease in Tangkhul language. *Morei Kazat, Suikhangarui Kazat, Khonkashi Kazat* and *Marai Kapai*
Kazat are some of the common terms used for HIV/AIDS and PLWHA among the Tangkhuls. Morei means sin and Kazat means disease; Suikhangarui means immoral or promiscuous; Khonkashi means curse; and Marai kapai means incurable. All the above-mentioned terms are used in a daily conversation, and they may not necessarily refer to AIDS alone. For instance, some terms like Marai Kapai Kazat and Khonkashi Kazat can also refer to other terminal and chronic diseases like cancer and leprosy. Mostly, HIV/AIDS is perceived as a divine curse to the person for going against social prohibitions, norms and values of the society. The Tangkhuls believe that PLWHA are those who are involved in socially unacceptable activities and therefore, they deserve to be what they are. For them, being immoral and having HIV/AIDS are equated seamlessly with sin.

There are also other metaphors that are used to replace HIV/AIDS in Tangkhul context. Local terms like Reikasang Kazat (civilised disease), Kahang makhangana Kazat (disobedient disease), Khamakhao Kazat (unclean disease), Zakkashi Kazat (ugly or harmful disease) and Maikashi Kazat (disgraceful or shameful disease) are used to represent AIDS disease. Sometimes, these words are also used to mock people who get AIDS. Majority of the respondents regarded HIV/AIDS as promiscuous disease.

PLWHA are represented as unfortunate person who have definitely been done something wrong. They are viewed as an outcast and thus lived a miserable life. They are considered as a source of infection that could spread the virus to others. PLWHA women and men are referred to as ugly people, and deserved to be contempt, looked down and discriminated in the society. To avoid public contempt and to escape from the feeling of shame, humiliation and hopelessness, many PLWHA try to hide themselves from being seen by others.
A study found that most people prefer to use HIV/AIDS as *Morei Kazat* (sin disease). They believed that HIV/AIDS infected people are those who have committed or have done something bad in their past life. As a result, they received *Khonkashi Kazat* or cursed disease which is not curable. It is perceived to be a divine curse to the person and family. In addition, whoever received this curse carry vector of virus in their body, and has the capacity to spread further. Another common indication is that HIV/AIDS is identified with people who live an immoral life, which is said to have suffered from incurable *Shuikhangarui Kazat* or immoral disease. As a result, a person with HIV/AIDS are stigmatised and discriminated.

**People’s Understanding of HIV Infection**

Having heard about HIV/AIDS does not necessarily reflect the individuals’ understanding about the infection or the virus. Most people know that HIV/AIDS can be transmitted from one person to another. However, they lack of proper understanding on how this transmission takes place. Due to the lack of knowledge, “even myth and misunderstanding surrounds the modes of transmission of HIV/AIDS virus” (Ramasubban and Rishyasring 2005). The study found that all the respondents have heard about HIV/AIDS disease. However, an in-depth knowledge about HIV/AIDS among the infected person is observed to be poor. On the contrary, most of the infected respondents identified sexual intercourse and sharing needles among drug users as the main modes of transmission of HIV/AIDS. They also emphasise that other modes of transmission are through transfusion of infected blood and maternal transmission. This exhibits the awareness on the modes of HIV transmission among the respondents.
The study also found some “mistaken beliefs” about the mechanisms of HIV/AIDS transmission. Almost all the uneducated respondents show confusion on about the modes of transmission of HIV/AIDS, which is likely to be associated with the stigmatising attitudes of the lay people. People widely held AIDS virus can be transmitted through sharing of food, utensils, clothes and toilets. Such perception on the modes of transmission is in due course linked with stigma. Some respondents even held that HIV/AIDS could be transmitted through flies and mosquitoes bites. One respondent mentioned, “I heard that if a mosquito that bites the infected person bites an uninfected person, the latter would be infected too.” Another respondent stated, “If flies or mosquitoes land on the food of someone with HIV/AIDS and then perches on the food of someone, the latter can get AIDS.” Due to misperceptions and ignorance, some respondents expressed their inconveniences to touch or shake hands or eat together with someone having AIDS. In the words of one respondent, “Knowingly, I do not like to shake hands or touch the HIV infected person as their disease can be transmitted.” Another respondent also added, “I never like to touch anything that belongs to AIDS patients as I may get infected.” Similarly, another respondent revealed, “I fear to ‘contract’ the virus by touching HIV infected people because they may pass on the infection to me.” “If you eat together and share their food and drink their water, you will get their AIDS disease” expressed another respondent. Some respondents lamented that they do not know much about HIV/AIDS.” Similarly, another respondent reiterated, “Since this disease is new to us, I do not have a proper knowledge. But they say this disease is incurable and it is deadly.” Another added, “I have no knowledge about HIV/AIDS but my friends said that people who lived immoral life will get infected with this disease.”
Most community members exhibited that they will not share clothes and drink from the same cup used by someone with AIDS. The wrong notion about the transmission of AIDS and the fear of being infected can be further understood by analysing some responses. For instance, one mentioned, “As the disease can transmit to other people we should be careful not to use the same clothes or the same drinking glass used by them.” Similarly, another respondent said, “We could get HIV/AIDS by sharing a drinking glass with PLWHA.” Similarly, another respondent remark, “If you sleep on the same bed and share clothes and blankets with AIDS patient, then definitely, you will get infected.” There were also respondents in the study who prefer not to use or touch anything which belongs to HIV/AIDS victims as a primary means of precaution. Many explained, “Since HIV/AIDS can be transmitted to other people, there is a risk of getting the disease. So, the best step we need to do is to take care of ourselves and try not to touch anything that belongs to HIV/AIDS infected people.” From the above responses, it is known that many respondents do not have adequate and proper knowledge about the virus.

Another unique finding of the study is that some of the respondents asserted that urinating and defecating in the same place with the AIDS infected patient would result in infecting the uninfected. Some overtly said, “We were told that toilets are places of transmission. If we share common toilet with AIDS infected persons we will get AIDS.” Similarly, another respondent reported, “I have heard that we should not share toilet and bathroom with PLWHA in order not to get infected.” Unwillingness to share same toilets has been elicited by the respondents because of the lack of proper knowledge. It is a fact that AIDS virus does not survive outside the body and therefore, sharing of toilet and bedroom cannot be the medium for
spreading the HIV disease. One respondent also said, “If we touch the saliva and urine of AIDS infected person we can get AIDS.” In a sentence, ignorance of the general population towards HIV/AIDS epidemic aggravates the issue of social stigma and discrimination.

Many uneducated respondents did not have an accurate knowledge of the mode of HIV transmission although they have talked about having correct information of HIV/AIDS. A degree of inconsistency in their perception of modes of infection stipulates that many are not sufficiently informed about HIV/AIDS. One respondent said, “We were told that if we have sexual intercourse with someone having AIDS then we will get AIDS.” Similarly, another respondent reiterated, “AIDS can be transmitted through sex, sharing of contaminated syringes, razor blade and needles used by someone who has AIDS. Also people can be infected by touching saliva and eating the foods which are already touched by PLWHA.” This clearly indicates that even respondents who mentioned correct modes of transmission also reported other incorrect information on how HIV and AIDS are transmitted.

Despite of having a wide and accurate knowledge on the modes of transmission of HIV/AIDS transmission, practically speaking, respondents described their fear of transmission from casual contact. This fear psychosis leads to the social isolation and neglect of PLWHA in the society. There were references in the data where people acknowledged the role of NGOs in educating people about HIV/AIDS transmission and the related unnecessary stigmatisation; however, there are still some fear associated with casual contact. “We are being taught about HIV/AIDS and people are now realising that they should treat PLWHA with respect and consider the sickness like any other normal diseases but in our mind we are scared
of HIV/AIDS and people having this disease,” said one respondent. Another added, “Despite the everyday education on HIV transmission, people are still scared of it. On a similar line, some reiterated, “many times, NGOs have organised HIV/AIDS awareness programmes on prevention and modes of transmission of HIV/AIDS in order to fight this fatal epidemic, but people in our society continue to stigmatise this disease.” The above-mentioned responses reveal that people knew HIV/AIDS could not be transmitted through casual contact and thus they need not fear socialising with people who are HIV-positive. However, in practical reality they still cannot overcome the phobia of getting infected. In a sentence, assumptions about the moral integrity of people infected with HIV/AIDS, like fear of transmission cause stigma towards the infected and affected people (Ogden and Nyblade 2005).

**Respondents’ Concept of HIV/AIDS**

The conceptions of the respondents on HIV/AIDS will affect how they react and behave towards PLWHA in the society. According to Parker and Aggleton (2002), in a rural setting local cultural beliefs and explanations about disease and disease causation can contribute to HIV/AIDS related stigma. In order to explore this phenomenon, respondents were asked to state their understanding of HIV/AIDS disease. Astoundingly, majority of the respondents perceived HIV/AIDS to be a cursed disease, sin disease, sexually immoral disease or incurable disease. A sizeable numbers of respondents in the study perceived that HIV/AIDS is associated with an immoral behaviour like having many sex partners. In relation to this, one respondent stated, “If a person gets AIDS, community will perceive that he or she had lived or has being living a sexually immoral life. People still believe that it comes from breaking social taboos. Such conception is so strong in the community.”
Another respondent mentioned, “HIV/AIDS is a *Shuikhangarui Kazat* (sexually immoral disease), and people who live sexually immoral life got this disease. People do not see HIV/AIDS as like any other disease because other diseases are not transmitted sexually. As a result, people stigmatise and discriminate PLWHA.” Another respondent illustrated, “HIV/AIDS disease is a *Khonkashi Kazat* (cursed disease), because it is believed to be a punishment from God.” In the words of one respondent, “To me, having HIV/AIDS is as good as death. It is a *Morei Kazat* (sin disease) given to those who go against the social norms.”

Similarly, another respondent added, “If I have HIV/AIDS my life is finished. It is to face death as HIV/AIDS is an incurable disease (*Marai Kapai Kazat*).” Such pervasive perception of HIV/AIDS has led to an unfounded fear about the disease. One respondent cited, “This disease is conceived as being bad in our society because people who got this disease are considered to have broken social taboo, as a result they acquired this *Maikashi Kazat* (shameful disease) bringing shame and bad name to the family.” In similar line another respondent described, “Individuals having this disease are thought to be living immoral lives which is deemed filthy, thus they get *Khamakhao Kazat* (unclean disease).” Others added, “HIV/AIDS epidemic is a part of God’s plan to get rid of extreme sinners especially those who are sexually immoral, infidel, injecting drug users (*Ari* or *No.4 Kakāpbing*) and others.” One of the respondents reported, “When a person has HIV/AIDS what people have in their mind is that it is someone who sleep with lots of women or men and is considered as living an immoral life. As a result, he or she gets *Shuikhangarui Kazat* (sexually immoral disease).” In the words of one respondent, “HIV/AIDS disease is not socially accepted and whoever has this sickness is thought to be going against the norms and value of society. Someone
who has broken taboo (*Sharra*), and eventually has *Kahang Makhangana Kazat* (disease of disobedience).” Another respondent said, “We perceived HIV/AIDS as *Maikashi Kazat* (shameful disease) because it brings disgrace and shame to the family.” One respondent also said, “Mostly, our society see HIV/AIDS disease as *Reikasang Kazat* (a disease related with modern civilisation) as this disease does not exist in olden days. Only in this present generation this disease came into existence because of an immoral behaviour.” Similarly, another respondent reiterated, “HIV/AIDS is *Zakkashi Kazat* (bad disease) as it is connected with bad behaviour of a person who lives a bad life.” Another respondent also expressed, “People who have HIV/AIDS show that they did not live a good life in the past and they are getting the results for what they did.” This suggests that negative perception of HIV/AIDS as cursed disease, immoral disease, sinful disease, disobedient disease, shameful disease, and incurable disease among others have nurtured fear and negative behaviours. The severity of the disease has made HIV/AIDS more stigmatised than other chronic diseases. The term immoral or promiscuous is negatively value laden and can be questioned, but this term shows how HIV/AIDS are regarded by a significant number of people. The view that HIV virus is mainly transmitted sexually makes this disease more vulnerable for stigmatisation, although there are other ways to catch the virus such as through blood transfusion, mother to child, breast-feeding and sharing of needles.

Several diseases are subjected to stigmatisation. Leprosy, cholera and polio have in the past been subjected to stigma because of deep-rooted social fear, anxieties and prejudices (Aggleton 2002). These feelings are similar to how people feel about HIV/AIDS today. The study found that some opinions of the respondents are highly prejudiced in relation to associating HIV with TB. For instance, “If you
have HIV/AIDS, people would believe that you might have TB too” asserted one respondent. Another added, “A person with TB is associated with HIV/AIDS. Anyone who is HIV-positive may also have TB too.” However, respondents who have such negative existential about HIV/AIDS and TB are only few. The study also reveals some other forms of preconceived ideas or notions about HIV/AIDS. According to one respondent, “People do not see HIV/AIDS disease like any other disease. The ways of infection are viewed from different perspectives. People infected with HIV/AIDS are seen as wrongdoers and they alone should be blamed for getting infected.” Another respondent added, “For patient with cancer, malaria and typhoid, people will obviously take care of them and take them to hospital for treatment, but they do not treat equally with HIV/AIDS patients.” In support of this statement another respondent stated, “Almost everybody would sympathise and pity someone suffering from any other chronic illness but the same cannot be said for HIV infected person.” “Unlike other illness people do not see HIV/AIDS like a normal disease because of the fact that it is a sexual disease,” remarked another respondent. Such opinions connote that HIV/AIDS is look upon differently unlike other diseases, and people having this disease are more prone to be stigmatised and discriminated in the society.

In the study, we found some narrations of PLWHA’s experiences about their physical deterioration and some commonly found symptoms. It is found that physical signs and symptoms enable them to identify with AIDS. Physical appearance of many people changed after they were infected with HIV/AIDS. Based on their narration, if a person has excessive hair loss, weight loss, skin rashes, skinny body, persistent sickness, paleness, high fever, boils, and diarrhea among others, it is a sign and symptom of AIDS infection. One respondent pointed out that
“People who are HIV/AIDS positive are very thin, have excessive hair loss and they are sick all the time. This is a sign that they differ from the rest in the society.” Another respondent mentioned, “I heard that when someone has deep pale looks, wounds on the body and very skinny, then it is a clear sign that he/she is HIV-positive.” “When someone is always sick or sick for a very long time normally people suspect that he or she is HIV-positive,” added another respondent. Further, some commented, “People with HIV/AIDS are easily identifiable because of their physical weakness, thinness and other physical signs” and also remarked that, “HIV infected people usually do not mingle much with other people.” Some of the respondents are of the opinion that “Our society often sees thin people with rashes on their body and pale looks as someone having a bad behaviour or immoral that has led them to contract HIV/AIDS. As a result, they are discriminated for having this disease.” The above statements show that people with tangible physical illness became a victim of stigmatisation because they are assumed as people with HIV/AIDS. Stigmatisation correlates with a person’s social identity as asserted by social anthropologists like Goffman. According to him, social identity is information about our identity that people in our surrounding apprehends. We categorise people in our surrounding when we have created this social identity. That information is mainly based on our physical appearance (Goffman 1963).

However, in today’s generation, characterising someone as HIV/AIDS infected merely based on their physical signs and symptoms can be inaccurate and deceiving as even a HIV/AIDS infected person can appear to be healthy because of the anti-retroviral treatment. Moreover, some signs and symptoms mentioned by the respondents may appear to be consistent with clinical descriptions of AIDS but they
need not necessarily be treated as being positive unless confirmed through HIV tests.

**Attitudes, Feelings and Behaviours towards PLWHA**

Respondent’s attitudes, feelings and behaviours towards PLWHA in the communities can be further understood by examining the opinions of the respondents. Few highly ignorant (nine) respondents said that they would not buy anything from shops owned and manned by PLWHA.” “It is better not to buy anything from the shop own by HIV infected person,” said one respondent. In support of this statement another respondent added, “If I know a person is having HIV/AIDS, I will not buy vegetables or goods from his or her shop.” One respondent also mentioned, “When there are many other shops why go and buy from the shop of HIV infected people.” Similarly, “No matter what HIV/AIDS infected person is selling, even if it is something that I really like, I will not buy or go near to that person.” However, majority of the respondents do not share the same understanding, and revealed that they would not mind purchasing goods from a shop run by HIV infected people. They commented that they would patronise PLWHA, and show them love and compassion as they need every assistance from others. As HIV/AIDS has specific modes of transmission, therefore, buying of goods from their shops is unlikely to infect customers. Moreover, many respondents opined, “being a Christian society it is commendable that we show good examples and impart Christian values to the infected group of people.”

It has been pointed out that undesirable behaviours that have led to HIV/AIDS were often described as *Shuikhangarui Kazat* (sexually immoral disease), *Morei Kazat* (Sinful disease), *Khonkashi Kazat* (cursed disease), *Marai*
Kapai Kazat (incurable disease), Reikashang Kazat (civilised disease), Kahang makhangana Kazat (disease of disobedience), Khamakhao Kazat (unclean disease) and others. Many uninfected respondents felt that HIV patient got what they deserve. They are being punished for breaking social taboos. However, a sizeable numbers of respondents hold a more tolerant viewpoint making little or no difference between them and HIV infected people. They opined that HIV/AIDS people must be treated as they would want themselves to be treated. One respondent explained, “They are human too, it is better we treat them like one of us. Who knows we might be the next one. I would not treat them as somebody who deserves to be blamed or judged all the time in our society.” Another responded added, “We all are human beings, we have our own mistakes and no one is perfect. One may have done something wrong today, but we may find ourselves in that same situation tomorrow.” One respondent mentioned, “HIV/AIDS is highly stigmatised in our society as people are afraid of this dreaded disease and the way it is infected. But for sake of goodness and humanity, it is better to respect and treat the infected victims well.” Another respondent also expressed, “There is no point of stigmatising and discriminating HIV infected people in our society, after all, they are our own villagers and family members.” “Of course there is no curable medicine for HIV/AIDS disease, but I would prefer to help the infected and try to take necessary steps to prevent further spreading of the disease,” commented another respondent. The above-mentioned statements indicated that many uninfected respondent have sympathy for PLWHA.

In the study, majority of the respondents firmly commented that an innocent children and spouse should not be victimised just because their parents. This stipulates that instead of discriminating them, they need to be treated with equal
respect and sympathy. One respondent said, “I pitied those innocent children. They do not deserve to get HIV/AIDS. They are not responsible for their illness.” “Children are the epidemic’s innocent victims. We should not victimise innocent children and spouse who got the disease from their parents or partners. They are innocent and ignorant for their illness.” Some respondents stated, “Blame the other HIV infected person who are injecting drug users (IDUs) but not the innocent children and wife.” “We cannot blame the entire HIV/AIDS person for having the disease because some were not their making. Of course, some of them have to be blamed, for transmitting this virus to their younger ones.” It is found that most respondents expressed their sympathies towards children and spouse who are not responsible for getting HIV/AIDS. However, they are intolerant with those who continue to engage in harmful behaviours that put other people at risk.

It can be stated that uninfected respondent’s feelings towards the HIV-positive are related to the perceived life style of the infected individual behaviours. As one respondent demonstrated, “If I knew that the person is someone who has never been promiscuous or drug user but have lived a careful life, I would definitely feel pity for them but if it is someone that is known to be immoral and injecting drug users, why should I feel pity for those infected people.” Another respondent also reiterated, “There should be zero tolerance against individuals who become infected through injecting drug users (IDUs) and yet continue using drugs even after diagnosis.”

In the words of one respondent, “I will care for those HIV/AIDS patients who have acquired the disease through blood transfusion but not those who have acquired through IDUs and other modes of transmission.” In fact, “IDUs and people who got infected through sexually immoral activities should not be given any
compassion.” Another respondent stated, “I pitied to those people who are good, but
get this disease accidentally. I knew a person who had this disease through blood
transfusion. He died some years back after prolonged illness. I really feel pity for
such people.” This confirms that those HIV-positive, perceived to be promiscuous or
sexually immoral and injecting drug users, are more vulnerable to social stigma and
discrimination than others PLWHA infected through some other means.

The above findings suggest that respondents categorise HIV patient into two
groups: those unfortunate innocent HIV-positive victims who are infected
accidently, and those groups who are infected because of their immoral lifestyle and
who deserve to be blamed and judged in the society. If a community believes that
their moral traditions are being broken because of people’s sexual behaviour, they
are not likely to show empathy towards the infected person. This results in stigma
towards the ‘offender’.

People largely held that the above-mentioned second category of people
deserve to be blamed or judged. This is mainly because people consider HIV/AIDS
as a venereal disease. It carries a “moralistic judgement of blame, supposedly due to
the indecent or promiscuous behaviour of the infected person” (Zhou 2007). As a
result, the infected person is held responsible for contracting the illness and
therefore stigmatised (Madru 2003). Twenty one percent of the total respondents in
the study elicited that HIV-positive people deserve to be marginalised and blamed
for what they have become. It is regarded as a just reward for their behaviour. One
respondent revealed, “I would definitely blame a person living with HIV/AIDS for
their illness because they are reaping what they have sown. They have no moral
values. They sleep around with many people and use heroin or inject drugs. So they
have to face the consequences.” Another respondent said, “They got this illness
because of their careless behaviour and deserve to be blamed and judged. They have gone against the norms of the society. They have no moral conduct, and, society must decide how to judge them accordingly. Life is not about taking drugs and sleeping around with many partners. Therefore, people who fall under this category deserve to be marginalised in our society.” In support of this statement another respondent stated, “Those people who after being confirmed as HIV-positive and who try to keep spreading the disease consciously have to be strongly blamed and condemned. This act of behaviours needs to be pointed out and be severely marginalised.” One other respondent added, “Men who acquire HIV/AIDS through IDUs should be blamed for giving virus to their wives. Women and children should not be marginalised.” According to the above responses, feelings and attitudes of the community towards PLWHA are related to the perceived life style of the individual. The perception that HIV infection is the product of personal choice, which makes a person choose to engage in bad behaviours, or may impacts the community’s assumption that such the person ought to carry the blame. In essence, it creates stigma from the community towards PLWHA if “longstanding cultural traditions are broken in the process of making a personal choice that caused HIV infection; this stigma is latter extended to affected kin” (Odden and Nyblade 2005).

Piot (2000) states that shame and fear are causing stigma. The shame comes from the taboos and moral judgments that are associated with both sexual transmission and drug injections. People fear HIV/AIDS because it is a new and deadly disease with no curable vaccine developed till date. Two-third of the respondents, considers HIV-positive as a shame for the family and community. Some of the respondents’ opinions that confirmed on the above-mentioned lines are mentioned in the following lines. One respondent mentioned, “HIV/AIDS people
certainly need to be blamed for their illness because they bring bad name to the family. Having HIV-positive is a shame to the family as well as the community. Since it is a disgraceful act, we cannot abstain from judging them for bringing in immoral disease to the society.” Similarly, one respondent said, “To me, it is necessary and good that we blame HIV-positive people for bringing shame to the family and community. They should be stigmatised so that the younger generations would know that this disease is not accepted in our society in order that they will be more careful and aware of what they will do in their life. I am sure this kind of steps or actions will definitely control the spread of HIV/AIDS to some extent.” One respondent strongly reacted, “Life is not about taking No.4 (heroin) or having sex with others whenever or wherever you like. Why acquire this type of habits which is very much immoral. You do that and get HIV/AIDS. HIV-positive people are pinpointed because of this reason. The result is that you brought immoral and dirty disease into the family and community as a whole.” One respondent pointed out that, “Having HIV/AIDS in the family means having immoral disease, sinful disease and cursed disease which is a shame to the family.” This strong existential people’s negative perception reveals that HIV-positive people are hardly spared in the society. They are being judged negatively in one way or the other. Often, people considered having HIV/AIDS infected member as a shame to the family and community because they mostly believe that HIV is the reward of immoral activities. Therefore, public are likely to discriminate against HIV-positive people.

**Quarantine and PLWHA**

Quarantining of PLWHA is not found in the Tangkhul society and therefore it can be considered as unique. Though there are no process of keeping the infected people
away from others in order to prevent the disease from spreading, yet, few respondents revealed that since HIV/AIDS threatened the very survival of people in the community; therefore, PLWHA might be legally separated or quarantined.

One respondent said, “Indeed it would be better if our society could legally enforce this kind of measure strictly in order to control further spread of HIV/AIDS to protect the public. Because some people are really wicked and can do anything, therefore, quarantined is required.” Another respondent also stated, “Certainly people with HIV/AIDS should be legally separated if possible. Such legal enforcement will have great impact as this epidemic is spreading rampantly everywhere in our society.” One of the respondents mentioned, “People who were infected through injecting drugs, and yet continue using drugs even after diagnosis are the ones who put the lives of others at risk; therefore, these people need to be quarantined. Such people should not be allowed in the public space. They need to be separated from the public in order to protect the innocent people. Our society or government should prepare a place or accommodate a safety place for them.” Some even desired that movement of HIV/AIDS infected people should be restricted to certain areas. In support of this view some respondents added, “Government should have a place for HIV-positive people or hospitals, wherein, they would remain until they are cured.”

One of the respondents mentioned, “HIV/AIDS issues have become a great problem and it is unstoppable now in our society. Seeing the happening of many death and infected cases, I would encourage such type of actions especially to wayward people, who despite public sympathy and support keeps on doing their old habits. In the meantime, HIV/AIDS education should effectively be given in order to stop further spread of the disease.” Such explanations suggest that because of the un-
repenting nature of some of the infected person, some respondents views are resolutely against HIV-positive people. They strongly asserted that HIV infected people should be isolated from other members of the communities mainly to curb their fear of contagion or infection. Due to the misconceptions of HIV/AIDS or modes of transmission or ways of infection, infected people are even more stigmatised. While some suggested that quarantining of PLWHA, yet many respondents are opposed to the idea of legal separation of HIV infected people in the society. They surmise that this kind of legal enforcement would prove to be more destructive rather than yielding any constructive results.

Despite the existence of many negative perceptions, many respondents talked about HIV infected person from positive perspective too. Many respondents did not want infected people to be blamed for their illness or give any negative judgemental opinion about them. They argued, “There is no point of discriminating them. Instead, they should be encouraged to joint hand with the NGO’s campaign for HIV prevention.” Rather than judging an infected person, another respondent exhibited that “the society in which he/she lives should be blamed for their unreasonable fear and indifferent attitude towards HIV infected people.” Some suggested, “Instead of blaming or judging HIV/AIDS infected people for their illness, the society must try its best to make their paths right, and make them feel safe. Instead of blaming them for their illness, one should look after HIV/AIDS person by integrating them into the family and in the society.” Similarly, one respondent added, “If we continue to blame HIV-positive people and keep on judging them, other infected ones will keep their sero-positive status reserved and will never be exposed to the society. Therefore, we should take initiative for their health and spiritual healing.” One respondent also asserted, “It is not good to set apart someone with AIDS. We should
comfort them, eat and drink together as these practices do not transmit the disease.”

Another respondent also gave the statement positively, he said, “Do not blame HIV/AIDS victims for their illness instead we should encourage them to live and have normal life in the society. They should be treated in a manner we treated the other patients suffering from other diseases.” The above findings demonstrate that there are positive changes occurring with people’s perceptions towards HIV/AIDS victims. It also demonstrates that there is a decline in the level of discrimination against the infected people although the ways of infection are continued viewing with strong reservation.

**Community reaction to PLWHA and their Families: NGOs Perspective**

The assessment of the NGOs regarding the degree to which the community treats AIDS families either positively or negatively is remarkable. Staffs of different NGOs gave different opinion about community reactions to persons living with HIV/AIDS and their families. An assessment of how open the family was to the fact that their member had HIV/AIDS; how they were treated by the community during the illness; and how they were treated by the community after the death of infected person were asked during the interview. The study found that sources from the NGO workers revealed that majority of the families were generally not open to the community about the fact that they have members suffering from HIV or AIDS. Sixty percent of the workers informed that family members were open only to some members in the community, and some family were not open at all. The reason for this, as stated by one UNP+ staff, is that “the infected families fear the negative reactions of the community.” In the words of C. Phaoreigam (President, RRF), “Still many infected people are hesitant to openly reveal their sero-positive status. And
there is stigma and discrimination against anyone working with the HIV/AIDS infected people as well.” He further stressed that people are afraid of learning their HIV-positive status because of the hostile presence of stigma and discrimination against the infected person. The study also found that opening up of the infected family to the community largely depends on the socio-economic condition of the infected family. For instance, in the words of Wungpam Kasar (President, UDNAH), “There exist differences in degree of openness among PLWHA and their family, and it is determined by socio-economic status they occupy in the society.”

NGO’s staff workers reported that at least two-third of the families who were open to the community experiences both positive and negative reactions. According to PASDO staff reports, “a HIV-positive person who openly reveals his or her status obviously receives negative reactions in the society.” As a result, most HIV infected people prefer to keep their ‘positive’ status in secrecy. NGOs often encourage all HIV infected people to come out openly and fight against various prevailing social stigma and discrimination. However, practically, it proves an impossible task because many are more concerned and worried about how society would look at them.

Non-governmental organisation staffs also reported that women with HIV/AIDS are significantly more open comparing to the men folks. According to the UNP+ staff, “Most of the people who disclose their ‘positive’ status are women.” Counsellor of ISWAR-Drop in Centre said, “Women are more open about their sero-positive status and seek assistance more than men.” Women are more likely to respond to the sympathy, support and help extended by the NGOs and are in turn more helpful to other infected friends in comparison to men. One of the reasons could be that majority of the women respondents are widows, and are
apparently seeking more help from the NGOs. Apart from the gender issue, the level
of openness of the infected person is also bracketed by the economic and literacy
status of the individual. In short, HIV-positive people who are knowledgeable and
educated and who have better economical status are more open unlike the illiterate
ones.

Despite the various negative reactions from the community, the study found
that over one-third of the infected families received either visitation or expressions
of sympathy from neighbours and friends during the illness. The coordinator of
ISWAR explained that infected family received “visitation, food, medicines, money
and moral support from the community.” However, it is found in the study that not
all families receive such positive reaction from the community. As mentioned
earlier, attention from the community depends largely on certain status of the victim.
It may be added that positive reaction toward the family became more pronounced
after the demise of the infected patients. According to the findings of the study, at
least 90 percent of the infected households revealed that they experienced positive
reaction from the community only after the dead of the infected person. The staff of
CARE pointed out, “Usually after the dead of infected person, people tend to show
more positive reactions towards the affected family. At least sympathy was offered,
and assistance was extended for funeral arrangement.” In relation to this
development, Raihao Horam (Project Manager, WHC, Ukhrul), stated, “Unlike in
the past years, our society’s reactions towards HIV infected victims have become
much better. Even at the funeral, we see positive reactions from the people. Many
people attended the funeral of our infected friends who died of AIDS.”

The study also found that an infected person or affected family with bad
class is less likely to be treated positively and more likely to be given negative
treatment by the community during their time of illness. However, after the dead of
the victim, his or her family discontinued to carry the burden of poor reputation in
the community. According to some NGOs, an important factor that contributed to
stigmatisation and discrimination is related to the burden of caring the HIV/AIDS
infected people. There are limited resources to take care of the infected person. For
instance, it is found that often the families with HIV-positive are very poor and their
illness further strained the family’s limited income and resources hindering them to
get even proper food and medication. Many infected individuals directly depends on
their immediate family for their survival. This is because the Tangkhul society does
not consider AIDS patients as “normal human beings” and therefore, the society has
huge reservation to employ someone with AIDS. Since they have no stable income,
therefore, person with HIV/AIDS are regarded as burden for many families and
society as a whole.

The study also found that the initiative of the non-governmental
organisations working on AIDS has a positive impact in the Tangkhul society.
Today, because of the efforts of various NGOs like Red Ribbon Forum, ISWAR,
CARE, El Shaddai and UNP+, the infected group of people has become more open
towards their society. Provision of financial aid, social grants, care programmes and
other community-based initiatives by such NGOs has prompted the infected people
to be more optimistic. Yet, NGOs pointed out that despite their assistance, family
and community remain an important source in providing care, and moral and
financial support to the HIV/AIDS infected person.
Community reaction to PLWHA and their Families: Health Care Providers’ Perspective

Community reaction as assessed by public health providers who serve as professionals working in the communities is also observed and studied. In the interview, majority of the health care providers reported that community reactions towards PLWHA are largely positive. However, negative reactions towards people having HIV/AIDS and their families are also not absent. A common problem encountered by community health providers is that, since there is already a taboo associated with HIV/AIDS people, people avoid contact with the infected person for fear of contagion. Even after acquiring the knowledge of treatment and prevention of HIV/AIDS, the community at large continues to criticise PLWHA and their family knowingly or unknowingly.

The health care providers often asserted, “Someone with HIV/AIDS should be treated and given equal treatment like any other sickness. But such mentality is mostly absent at the community level because it is believed that people who go against the societal norms often succumb to this dreaded disease.” Therefore, people in the Tangkhul society look at HIV/AIDS infected people differently. However, women are the worst victim. They are given unequal treatment unlike men folks. Most of the health care providers observed that women living with HIV/AIDS face more stigmas as compared to men. This reveals that one cannot deny the existence of negative community reaction against the AIDS patient even in today’s highly developed century.

Apart from the above negative connotation, a more positive community reaction has been observed. The study found that, of late, people have become more aware of the disease and therefore has become more tolerant with PLWHA. Health
workers pointed out the discrepancy in the level of community treatment against the AIDS patient. In the past, HIV-positive people were socially isolated and their participation in the community activities was restricted. However, today the phenomenon is changing. The Tangkhul community is becoming more tolerant to PLWHA and the affected families. This view is strongly substantiated by some of the abstract of the interviews.

One health official commented, “Most people are now educated about HIV/AIDS. During illness, we see reaction that is more positive in the community. Someone with AIDS has to be treated in a manner equal to all other sick people. Positive community reactions are seen in the forms of help, visitation and financial support during illness and during funeral.” Another official reiterated, “Earlier, people would stay away from the AIDS infected patients because they were afraid of contagion. They did not want to be near them. But now we see that people sympathised and pitied the HIV infected people and their families especially during the time of illness and the dead of PLWHA.”

One respondent said, “When HIV/AIDS disease first came into our society everyone was afraid. Now it is better. In the past, HIV/AIDS infected persons were looked upon negatively. People do not dare to eat or sit with them because they were afraid.” Similarly, another respondent added, “Now people’s attitude and reaction towards HIV/AIDS disease have changed. The strong stigmatisation of the past is not seen today. Primarily, education campaign and awareness programme has played a big role.”

Further, in the words of another health worker, “No doubt our society continues to stigmatise and discriminate PLWHA, but the level of negativity has come down substantially. Due to the initiative taken by NGOs and other agencies
dealing with HIV/AIDS, it is moving towards positive trend.” The above statement reveals and reflects the changing attitude of people towards HIV/AIDS disease. The earnest assessment of the health care providers concerning community reaction towards families affected by HIV/AIDS has also found to positively impact the attitude of the society. Such development can be attributed mainly to the role of education.

Another overwhelming response provided by the local health workers is that their attitude towards the infected people is not influenced by the knowledge of their infection. The issue of infection does not concern the health workers. Majority of the public health providers also reported that people today voluntarily sympathise and offer help to the AIDS patient. However, it may be noted that such positive assessment does not necessarily deny the existence of negative community reaction in the society.

Reactions of the Local Community to PLWHA: Parents’ Perspective

The types of community reactions to people living with HIV/AIDS can be comprehended better by exploring some of the reactions at the family level. The study found that some parents are hesitant in disclosing to the community about the serious illness in their household; and the kind of illness that resulted to HIV/AIDS related death. Families with lower social status restraint from disclosing their problem to the community for fear of being discriminated. However, for the same reason, family with higher status also hide their problem. Yet, based on the mark of socio-economic status, richer families are less stigmatised in comparison to the poorer ones.
In this study, nine families indicated that their concerns on how they would be treated by the community, once their HIV status is made public, questioned them either to disclose or not about their status. However, it is found that the apprehension of the infected family about the community’s reaction may not be the same as much as the actual societal reaction. Some families restrict their infected children from going out and mingling with others for fear of being ridiculed by the community. However, it is found that society may not actually react in the way as apprehended by the family. In the words of one respondent, “I told health care providers and NGOs that my son is a HIV/AIDS infected patient. However, I insisted that the information is to be kept confidential.” Another family explained, “I do not want people to visit my daughter. I only want family members to be around her. We cannot trust other people because they can act as an agent of spreading the news of my daughter.” Such statements confirm that infected family members were not only concerned about the community’s reaction, but they are also protective of their HIV infected members to prevent them from being stigmatised and discriminated by others.

A remarkable 90% of the affected families mentioned that they have no difficulty in sharing their problem with the community, and further illustrated that they have received positive reaction from the community. These include visitations from family, friends and community during the time of illness, and financial and material assistances from others. It is said that visitors brought food, medicines, money and even offer advice. Many who came to visit also offer prayers as well. The friendliness and support of the community can be grasped by examining some responses from the affected family. One family narrated, “We are five of us in the family. When I am (infected person) sick, friends and neighbours offer foods,
medical assistances and other help.” Another family also mentioned, “Everyone in the locality knows about our suffering from HIV/AIDS and the consumption of ART. They did not discriminate us. Instead, they brought food, medicines and also help us financially. They always gave us moral support.” Among the informants, one family stated, “Some neighbours are helpful after knowing the condition of my son. They say they do not want us to carry the burden alone. So, they help us in whatever ways they can, through cash or kind especially during the time of illness.”

Another unique finding is that infected parents with bad characters or reputations are less likely to receive assistance from the community as compared to parents of PLWHA with good social conduct. The following statements given by one respondent substantiate such view: “People’s sympathy and help would always be there if parents of PLWHA are good in character and sociable.” Another respondent added, “people who had done good things for the society would receive more sympathy and tolerance even after being diagnosed as infected.”

A sizeable numbers of interviewed families reported that they received some forms of negative reactions. For instance, a woman respondent stated, “It is not fair the way our society viewed at women. We are not given equal treatment. If HIV/AIDS infected person is a woman, it is obvious that she would receive more negative reactions during her illness.” This indicates the presence of gender biasness in the society.

As has already been indicated elsewhere, community is prone to react more amicably during the death of the AIDS patient. Many affected families narrated that people, who would otherwise have avoided the affected family, show courtesy by attending the funeral service of the deceased, showing sympathy and offer assistance to the deceased family. The following statements given by parents of a deceased
victim support such views, it says, “I am happy that at least friends and neighbours are supportive during the funeral service of my son. Every one of them helps us in funeral arrangement.” Another respondent also reported, “Different people have different negative judgments about people living with HIV/AIDS. Most of the time, while the person was alive, negative reaction exists, but at the time of death, nobody refuses to help or visit.” Another family also cited, “We saw positive reactions from the villagers and neighbours during the funeral service of my son. We did not receive negative reaction, but rather we have received love and sympathy from them. Everyone offers help and many people attended the funeral.” One widow said, “After the dead of my husband, I received positive reaction from neighbours, friends and villagers. They did not abandon us during our hard times, and help us during my husband’s funeral. We received help in-cash and in-kind as well.” After understanding the above–mentioned statements, it is important to note that in the Tangkhul society, families with deceased AIDS member usually receive positive or neutral reaction from the community.

In Tangkhul society, it has been observed that family with infected children with unruly and immoral characters experience discrimination even during the dead of their infected child. It is found that fewer people attended their children’s funeral, lesser help or assistance, and fewer visitations from neighbours and other members of the community. Some even revealed that they would not eat or drink at the funeral of an infected individual who had lived an immoral life. For instance, one respondent expressed, “Many people would not attend the funeral and would not take tea or food offered by the unsociable affected family.” Another finding in relation to this is that parents of male infected person are likely to endure shorter durations of negative reactions from the community, unlike the parents of female
infected patient. However, the sample size concerning this issue is quite small due to
the small number of households who showed willingness to report such type of
negative community reaction. Nevertheless, the manifestation is that women are
subjected to a more negative community reaction as compared to men.

Another revealing statement found in the study is that the issue of “double
stigmatisation”. It means AIDS infected person who also has TB experience a
double stigma and discrimination as compared to the one who has only HIV/AIDS.
Four respondents stated that in the case of illness and funeral of PLWHA, who also
had TB, only few people have would attended the funeral services. People usually
abstain from attending such kind of programme because of fear of getting
HIV/AIDS and TB. A woman respondent mentioned that she had to request her
relatives and neighbours to attend her daughter-in-law’s funeral because the latter
has a “double stigma”. Based on the findings of the study, many such similar
incidents were reported. One family narrated, “People were scared to get close to
our son as he was suffering from HIV and got TB at the end. Initially, people’s
judgement was not so critical. However, they became very critical when they
learned of his TB. As a result, people stopped visiting him.” This implies that those
infected people who have both HIV/AIDS and TB experienced double stigma and
discrimination. TB remains a main cause of death among people living with HIV.
Many people infected with HIV develop TB as the first sign of AIDS. Herek and
Glunt (1988) argue that the stigma attached to AIDS as an illness is layered upon
pre-existing stigmas. This stigma is most common with diseases which are seen as
incurable. In addition, people responded negatively to PLWHA because of the life
threatening nature of the disease. As noted earlier, this negative perception is more
severe when any PLWHA suffers from TB.