

## **Chapter 7**

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The history of the worldwide AIDS is mainly an unfortunate story of failure to grasp an early opportunity for halting the further spread of the virus. The epidemic began at about the same time (the early 1980's) in many countries. Often, the first people with HIV/AIDS were injecting drug users, commercial sex workers, or gay men in urban areas, but soon the epidemic spread to other populations by heterosexual or other means of transmission, mother to child transmission (MTCT), etc.

The problem is the world's problem, not just a problem of individual nations. In a globalized world of relatively easy travel and rapid transportation, sexual tourism, and migrant workers and commercial sex workers who move across national borders, no single nation can prevent the epidemic from entering its borders. During the 1980's, AIDS started in one or few countries and then spread fairly rapidly throughout the world, transported by airline personnel, truck drivers, sex tourists and others.

'Living while dying' directs attention to the process of sense-making and accommodation that are at the core of living with a terminal illness (with the introduction of ART, AIDS has been termed as terminal illness). A terminal illness is not about dying, but living in the face of

death. Key to this process is the maintenance of ongoing social relationships, enactment of and adherence to basic cultural values, and fixing one's place for prosperity. In this framework, participants' faces on need as the absence of something requisite are readily apprehensible.

Both health-related needs and non-health related needs are necessary. Failure to appreciate the existential aspect of AIDS-related needs leads to considerable dissatisfaction with the service delivery system. From the perspective of the people with AIDS, the system had failed to address their humanity. Service delivery agencies and the policies that guide them must acknowledge the need of people with AIDS to have their humanity recognized and sustained in the face of stigma. Until they do, they cannot truly help individuals live while dying.

It has been suggested that AIDS-related stigma and discrimination substantially interfere with prevention efforts and discourage people from safe sex practices, care-seeking behavior, or finding a diagnosis; or that stigma comprises the quality of care provided to people living with AIDS, their partners, and communities. Via larger discriminatory processes, AIDS-related stigma results in negative outcomes in the forms of violations of social, economic, and political rights, including access to health care.

The social construction of AIDS-related stigma has been nurtured by historical components including social fear, ignorance,

anxiety, and lack of knowledge, denial, shame, taboo, racism, xenophobia, and moral judgments and by misleading metaphors like death, punishment, crime, war, horror, otherness, and shame.

An individual's experience of a terminal and highly stigmatized illness can no more be reduced to the material conditions it generates, such as loss of income or reduced functional ability, than old age can be understood by an analysis of functional status. Living with uncertainty was salient for most of them. Living with physical impairments, multiple treatments, and seeing others still dying from AIDS acted as continuous reminders that the me could not escape from it: "there are always moments during the day when you don't think of it, but it's not far, it always comes back".

AIDS does not cause death of the person immediately. But it has created a sense of fear in the minds of the people that it might cause sense of shame and social boycott which they consider worse than silent death. The physiological consequences may be painful feelings of severe type, but its psychological consequences are anxiety, depression, nervous tension, obsessive compulsive neurosis, sense of guilt and shame, resorting to excessive alcoholic habits and drug addiction, feelings of insecurity in life.

That HIV health is a complex phenomenon imbued with a variety of meanings and interpretations is widely recognized. Constructions of HIV health emerge and transform within an inter-subjective,

transactional web of life experiences, social discourses and constitutional medicines. As anthropologist Robert Ariss reflects, "Being HIV-positive is a process of self-reconstructions of becoming of realizing oneself in a cultural environment of constantly shifting constructions of illness".

The idea that health is complex and negotiable is far from new. Numerous contemporary theorists have challenged the paradigmatic notion of health and illness as natural discrete categories objective deciphered and managed by medicine science instead arguing for the cultural and historical knowledge, the mediating force of individual's agency and the specificity of subjective lifeworlds. Increasingly, analytical emphasis is placed on the importance of 'illness narrative' 'account' and 'stories' to foreground how patients' understanding of health and illness are infused with social symbolic and contextual meaning that repeatedly contradict and escape the confines of biomedical models. Similarly, in line with Maurice Merleau-Ponty notion of embodiment of the basis of being in the world experience is given priority in phenomenological oriented studied to gain insight into the existential and social processes of illness as lived.

Although, illness representations are the central cognitive constructs that guide coping and appraisal of outcomes, a patient's theory of illness is based on many factors including bodily experience, previous illness and external information.

As understanding of health ground in the concreteness and conceptuality of life worlds, exploring how matter of health and illness become embodied in particular life histories, absorbing personal and social significance from the circumstances in which they transpire is important. The experience of feeling ill or feeling well as broader notions of well being or quality of life is based on degree of emotional, social, sexual or spiritual happiness and fulfillment.

Reflections on the past experiences reveal many milestones which were responsible for their present condition. The women under study had many childhood memories with friends or siblings or with many others but those were not much remembered. They tend to focus more on those areas which shaped their today, that of living with AIDS. These women, while seeking the cause of their sufferings realized that marriage was the channel of their miseries. They reflected on those glorious youthful days when they had the bliss of romance and courtship. Those not-so-serious relationships and those dating and courtships for the sake of fun and pleasure blossomed into marriage and ultimately into AIDS. When they started out, little did they realize that that romance would have such a serious consequence. Most of them were simply flirting, having fun. Some were too lost in love that they failed to think practically of the reality of life. Some failed to take time to know and learn about each other before marriage. Their marriage was filled with fights and beatings.

No wonder, they considered their marriage a big mistake because marriage was responsible for becoming HIV infected. Most of the women became infected with HIV from their husbands. Not only they but their children also became HIV infected and this was taken as a lethal blow to their motherhood. While some women changed their feelings for their husbands after being infected, there were some others who still remained loyal till the end. They even considered AIDS as a 'gift of love' from their husbands. Those women did not have bitter feelings towards their husbands and cling on to those memories of their togetherness.

When the question came on remarriage, some of them wanted to but due to their HIV status, they put a halt to their feelings and desires. They claimed that this was possible because of the awareness that they received from many experts of the field. In spite of that there were still few women who went ahead with the second marriage and they were living a life of guilt and remorse for infecting their husbands. While most of the women of all the communities under study were not ready to marry again, some Muslim women had the desire to marry again. One woman even suggested that if the marriage was between two HIV positive persons, it was alright with her.

Moving on to their feelings and emotions on the time of their husbands' detection, there were varied forms of emotions surfaced. There was shock, anger, sadness and indifference. Though it was seen

that no particular group of women belonging to a particular community expressed the same emotion, the Kuki women were found to be cool towards the handling of the situation.

During the time of their husbands' illness and death, some of the women were sad, some were angry and some felt relieved. Sadness at such a time of husbands' illness and death was understandable. But feeling relieved was hard to digest. It was learnt that those women who were treated very badly by their husbands felt liberated from the torture and bondage of marriage. Two Rongmei women experienced such a feeling. One Meitei woman longed for her husband to die soon because she could no longer bear the brunt of her husband's inhuman nature. Those women who felt angry were those who expected so much from their husbands and their marriage. They felt angry because their husbands did not give their side till the end, instead they left them infected and sick.

After their husbands' detection, illness and death, the time came to learn about their HIV status. There was lots of emotional drama. The worst phase was the time in between the test and the result. Some of them said that though they were sad and cried on being revealed of their HIV status, confirmation of their status gave them a particular stand and released them from their doubts of 'maybe' and 'maybe not'. And this confirmation gave them certain direction to follow.

Analysis of their past experiences offers many lessons to learn and lots of things to avoid. The overall picture that they presented was that of mistakes which transformed their lives and regrets which challenged them to repent and make amends. Their present situation is a story of struggle and battles that they were fighting as persons with AIDS.

Living with AIDS was a difficult life. They were living a life of anger and frustration. Their inability to do their own work frustrated them. Even household chores like washing, cleaning or looking after the children seemed like a mammoth task for them. They felt like burdens to their families and near ones. Not being able to earn and contribute to the family but instead being sick and unwell created financial problems for the family. With this 'diseased' body, they saw that their hopes and aspirations for their children and for themselves were crushed.

Not only that, they were also living with a guilty conscience. Their bodies, being weak with AIDS, could not give themselves a chance to give back to their parents. There was the pang of guilt in seeing their old parents working and earning to meet their demands. On top of that they felt that they have spoilt their families' good name with HIV/AIDS. There were even cases of suicide attempts due to guilt. They were burdened in every manner. Like one of the Rongmei women said, she was burdened physically, mentally, emotionally, financially and spiritually. Those Christian women irrespective of their cultural

background felt that being infected with HIV was the punishment for their sins. They had sinned against God and wronged their families by disobeying their parents. These women were found to be more spiritually burdened.

There are other realities that these women had to live with. They are the physical changes like their degrading bodies, their fading looks, the change in their complexion, excessive hair fall, loss of body weight. All these added in their loss of confidence and loss of interest in mixing with the society. When others failed to recognize them, they felt hurt. Sometimes they avoided even their friends. Women, irrespective of their ethnic background went through this torture. They avoided social functions and other public gatherings. They did not even feel like looking at mirrors lest their reflections sadden them.

One major thorn is the pain of stigma and discrimination. They experienced stigma at the hands of their own families, their relatives, church (for the Christians), hospitals and other care-centres. This made them self-alienated from the society. They also experienced self-stigmatization.

Motherhood was also one reality which put them in a paradox. If it brought her joy on one hand, it also reminded her of her failed responsibility. If there was the bliss of completeness by being a mother, there was also this guilt of infecting their children with HIV. As mothers, they had failed; they could not provide for their children but instead

were living on the mercies of their families. The insecurity felt over their children's well-being stung them.

Their encounters with ART, awareness programmes and NGOs provided mixed responses. Some of them got hope from ART but others felt that taking ART drugs was a constant reminder of their reality. The side effects of the drugs like nausea, stomach ulcer, weight loss, deafness, etc. are also some of the additional burdens they had to deal with. While some felt that awareness programmes reminded them of their status, others felt that such programmes were useful and should be availed to everyone – both infected and non-infected. Their perceptions on NGOs started with negative shades like – “they were used”, “cheated”, “unavailability of clarity in the administration”, etc. Though they were disappointed with the workings of the NGOs, they agreed that atleast it gave them exposure and provided them an opportunity to meet other women like them who were also HIV positive. This expanded their horizon and their circle of friends.

But the other side of AIDS is death because being infected with HIV is taken as a death sentence. And this fear of death lingered in their psyche. Study of their perceptions on death reveals that there was constant fear in their mind. There was fear of death in general, they were afraid of being dead. But the most terrifying of all fear is the fear of dying in suffering. Though they were afraid of death in general, it was acceptable so long as death remained a reality for everyone. Their fear

was soothed by the realization that everyone was going to die. Since death was the most personal and intimate of possibilities, there was no escape from it. They could not bargain with anything in place of that. There was fear in being dead because of the uncertainty of death. There was also anger on being reminded of death because they did not want to leave their loved ones behind. There were some women who were very insecure about their children's future. They were angry because death was taking them away from their children.

The process of dying was feared the most because dying of AIDS was not a pleasant one. They were afraid to look terrible and felt disgusted by everyone, and on top of that their death was considered as bad death. They did not want to die in pain and in shame.

When things got too hard and when their bodies could no longer meet the demands of life, they gave in to the flow of the reality situation. So, some of them started making preparation to meet their end. They looked out for their children's security after their death. One Meitei woman suggested for orphanage for the orphans of HIV positive parents. Not only that, they tried to make amends to clear their conscience and died guilt-free. They always felt that their present condition was the punishment for their sin of disobedience. So, they prayed more and tried to live a pious life.

Though they were afraid to die, they longed for death at the same time because the life was too difficult. They thought that all their

sufferings would end after death. If there was something to lose by being dead, it is their sufferings for which they would happily exchange with anything. So, death was seen as an escape route.

These women adapted strategies to carry on with living. From the analysis of their narratives, altogether eight coping strategies were come across. Though their living was difficult, putting all their problems to God lightened their burden. Their present state of sorrows and miseries were replaced with hope of eternal happiness after death. Through repentance of their sins, they felt relieved of their guilty conscience. One Kuki woman who had been treated badly by her husband and his second wife lived in the hope that God would avenge her.

And in this time of difficulty, they found courage and solace in the love of their families and in the companionship of friends who were also HIV infected. In this group, they found no division amongst themselves. They opined that if they had the love and support of their families, people could not say anything against them. Families stood as pillars of strength for them. Though the reality says that there is no cure for HIV/AIDS, still, they presumed that there was no harm in hoping for the drugs that may cure them one day. They felt that ART was one way to prolong their lives while hoping for the right drugs.

Ignoring the reality (that they were suffering from AIDS) was one way of diverting their attention from their miseries, a way of getting

relief. The other ways are listening to music, watching movies, playing cards, etc. and some women resorted to intoxicants like chewing betel, smoking, taking tobacco, etc. The high that they got from them gave them certain relief though temporary it may be. Some women comforted themselves by thinking that AIDS was just another disease. They felt that they were better than cancer patients or diabetic patients. Unlike the cancer patients, they said that they did not bear the pain and unlike the diabetic patients, they did not have to go on strict diet. Considering this, they felt that they were *luckier*. These were the strategies they adopted to keep themselves going on.

The thesis depicts a sorry picture of mistakes and regrets of the women under study. Reflections on their past experiences, living through the present condition and glimpsing on their future aspirations make them realize their mistakes. Though they had their own share of sunny moments and sweet memories, one wrong decision (mostly by themselves and sometimes by their parents) took away all the beauty of life. Most of them experienced that their romance blossomed into marriages which killed them in many ways. They felt to have died in many ways. Their physical bodies were wasting away, their social life had been blocked due to stigma and discrimination, their spiritual faith was shaken, their emotional life was in turmoil and their economic condition was in a critical state. At the peak of their romance they failed to realize that there was life after the wedding.

They could not work and earn anymore. Even if they were qualified for the job, they did not have the stamina to be employed anywhere. It is seen that most of the women were living with a guilty conscience. They were guilty for getting infected with HIV and in the process brought shame and humiliation to their families. They also felt that they had spoilt God's wonderful creation by the 'disease'. They felt responsible for getting their children infected. So, as mothers, they considered themselves as failures because they could not give the protection needed to be given to their children but infecting them instead which left them in a helpless situation. Their emotional life was seen to be disturbed in this manner. In addition to that, HIV/AIDS brought about many disturbances in the family – between the spouses and between them and in-laws. As already seen in the preceding chapters, it was described how the romance flew away out of their lives as they or their husbands were detected as HIV positive. The love and bonding between them were found to be replaced by anger and frustration. The woman who abandoned her family for the love of her husband cursed him as she found herself to be HIV infected. Such is the reality of HIV/AIDS... even today!

People with AIDS are categorized as those people who are open about their conditions. But in this regard, an imbalance was come across. Though the women were ready to come out and mingle with the people and enter the society, the people were found not ready to accept them. It is seen that though they have accepted themselves, the people

still do not accept them. This situation gave them a tough time. So, they found joy in each others' company and away from the world of 'normal' people.

These people who failed to understand their worth are those from whom they expected the most. They experienced ill-treatments from medical personnel, other health service providers – government and non-government, people from the religious place of worship, their immediate families and relatives as well. So, it would not be wrong to consider the suggestion from one of the women under study who suggested that awareness should be provided to other people and not to them. She felt that people like her were all aware of the gravity of the situation and knew how to take care of themselves. What was urgently needed, according to her was that awareness should be given to those normal people, people who stigmatized and therefore lived in constant fear. Coming back to the issue of stigma, these women were surely the victims of this. The then UN Secretary General Kofi Anan once said that if AIDS did not kill them, stigma would definitely kill them. Because of this fear of being hated and looked down upon by the people, many people who are HIV positive are afraid to come out for treatment and timely medical check-up. There are also people who are suspected of being HIV positive but are afraid to get themselves tested because they are afraid of the reality, afraid of being alienated, afraid of being ostracized. They also feel that the reality may shatter their families. And if these people

happen to get married and infected their spouses and their children, who is to be blamed? So, the situation is much tensed.

Reverend Daniel Beatrice, a Consultant for Peace of American Baptist Association, in one of his visits to North East India said that we should accept HIV positive people into our midst and give them a second chance to live. He said that giving them a place in our midst would give them the courage and the confidence to open up and reveal their identity. Rejecting them would put many of our loved ones at risk and the epidemic would never end, he further said. This is true because there are many cases in many young widows of IDUs got physically involved with some other men or got married again and this poses as a serious threat to the prevention and control of the virus. These women, during their early stages, are difficult to be differentiated from the normal people. They look as beautiful or fresh or young as any other normal women of their age. And until they advance to the final stage of AIDS, they look very normal and this can be very deceptive. Thus, accepting people with HIV/AIDS and tolerating their condition will not only improve their quality of lives but also will create a healthy and risk-free environment.

One counselor at Calvary Counselling Centre at Chingmeirong, Imphal narrated a story of how one Tangkhul woman became a commercial sex worker. Rose (a fictitious name) became a widow very young. She was only 25 years old when her husband, who used to be an

IDU passed away leaving her alone to fend for herself and their two children. She summed up all courage to continue living and look after her children. So, in order to survive, she had to earn. She went from door to door to sell the vegetables which she grew in her garden. But nobody wanted to buy anything from her. It so happened that at one particular house, the mistress of the house spat on her and her vegetable basket and scolded her for entering her compound. She asked her never to come again and even told her that people like her should not mix with the society. The incident left a deep impact on her. This happened at one of the villages in Ukhrul District of Manipur. Since people in the village knew each other, there was nothing hidden from anyone. And it came as no surprise that everyone in the village knew that her husband was an IDU and he died of AIDS. AIDS for them was the epitome of fear and disgust. No one was ready to help her, not even her relatives.

She realized that she did not have a place in the village and in the hearts of the people. So, she decided to leave her village and go to Imphal where she could easily get lost amongst the crowd and nobody would know her or recognize her. But in the city she did not have any means of livelihood. So, through one woman, she got into flesh trade. She ignored her silent tears and all the moralities she had accumulated in the past because she had to survive and bring up her two children. The mother in her got the better of her 'moral being'.

Then, after sometime, she began to feel unwell on and off. She knew what she was suffering from or at least suspected the worst. But she continued to fight her inner voice to go for a medical check-up or at least meet a counselor. When she could bear it no longer, she went and met Wonchung (the narrator of her story) and poured out her story in between sobs. She was sad; she was full of remorse and was also filled with anger. She was sad because she knew what her HIV status might be. She was remorseful because she felt that she had infected her clients directly and their spouses indirectly. Her conscience pricked her. But on the other hand, she felt that it was the society who was to blame for making her do what she was doing now. She wanted to lead a normal life and even put an effort to live normally but she was not allowed to do so. She said that she became a sinner because the society made her sin. She was in a state of dilemma because she was feeling guilty for what she had contributed and also at the same time, seemed to be at bliss by taking revenge on the society that rejected her. But she did not fail to put the question, 'who is responsible?'

There are many voices that aspire for a second chance, a little love and tolerance to help them carry forward. Though many of the women accepted that they were responsible for their present condition, and also that they were carrying the virus that could not be killed and suffering from such 'disease' that can never be cured, they at least long to be treated well and allowed to live with dignity. They were sick but their self-respect was alive and thirsted for recognition. They longed to be treated

well and not with contempt. They expected the medical personnel, caregivers at home and outside not to stigmatize and pass any judgment on their condition. They felt that they were already ill-fated and requested the people not to heap more burdens to their overloaded shoulders.

It is seen that an individual's experience of AIDS can no more be reduced to the material conditions it generates, such as loss of income or reduced functional ability. This is not to say that interpretation alone explains the illness experience, but rather that there is a dynamic relationship between the underlying physical condition, the material circumstances produced by the illness, and the interpretation of the illness and the patient's experience of that illness.

Needs of people living with AIDS cannot be understood if solely limited to a narrow functional definition of need as the existence of a necessity or want. Rather need, in the case of people with AIDS must be understood as a condition marked by the lack of something requisite, namely treatment as a human being. The women under study wanted the restoration of self-esteem. There is the commonality: the overwhelming need to cope with the experience of stigma.

A terminal illness is not about dying, but about living in the face of death. Service delivery agencies and the policies that guide them must acknowledge the need of people with HIV/AIDS to have their humanity recognized and sustained in the face of stigma. Until they do, they cannot truly help individuals live while dying.