Chapter 4

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Individuals who identify as a Person with AIDS (PWA) have developed a guiding, dominant (i.e. master) status in which their health status is centralized in their sense of self, in how others are perceived to interact with them, and in their managed social identities. The distinguishing features in the lives of PWAs are that they embrace an AIDS identity. This means that the individual accepts the impact disease has on personal and social identities and interactions, as well as finding worth in their identity as a Person with AIDS. An identity as a Person with AIDS is representative of full internalization consequences (physical, emotional and social) and as indication that while the biographical disruptions introduced by disease are recognized, such are not perceived as catastrophic or minimally significant. To identify as a Person with AIDS is to go beyond selective disclosures, and to proclaim the identity publicly and widely.

In addition to physical or cognitive challenges, people living with AIDS may face significant emotional, psychological and social obstacles to full involvement in daily activities. Stigmatized because of their health status, such individuals experience decreasing societal legitimate social arenas (Tewksbury and Mc Gaughey, 1998: 215)
For persons with HIV disease, the incorporation of HIV into a
definition of self serve as guides to the perceptions and experiences of
numerous social actions and interactions. Therefore, HIV becomes an
important determinant of how persons conduct, manage and proclaim
personal and social influences, how individuals see themselves and act,
disease becomes a part of self identification both personally and socially
for those individuals who are aware of their infection.

Living with AIDS is an experience of a lifetime. If they face
physical challenges on one hand, they also have to face emotional battle
on the other. The women under study went through varied forms of
experiences, the experience of living with AIDS. Their stories and
narrations were analyzed and presented in the following manner.

4.1. Anger and Frustration

Living with AIDS is such a torture. If it takes away the wealth of
their physical health, it also burdens them with worries and problems
mentally, adds financial crunch and shakes their emotional and spiritual
stand. No wonders, people living with AIDS end up getting frustrated
and angry.

I am too weak to work. I can't even look after my
children properly... There are many trainings given by
NGOs but I don't join. Even if I go for it, I won't be able
to work (make use of it). What's the use? I can do
nothing. I cannot see properly.

That was how a 42-year-old Tangkhul woman showed her
frustration. Not being able to do daily house-hold chores and inability to
look after the children was such a burden to this woman. Taking other’s help for everything hurt their ego and degrades their self-esteem and also made them helpless, as in the case of a Muslim woman, 30 years of age. She explained,

Not being able to do everything irritates me. I can’t wash clothes. I’m always taking other’s help. My right hand is not functioning well, I feel pain and numb. I feel so helpless. How I wish I could do many things for my children - their studies, their well-beings. I feel so useless.

Being a burden to one’s family was also a matter of great concern. Here, burden did not mean just the physical one but also others. A Rongmei woman, a mother of seven children was a worried person. Her physical health did not allow her to do heavy work or the opportunity to earn for her family. She often got angry and irritated when the cruel hands of poverty struck hard and often. She shared that not being able to earn and contribute to the family’s income frustrated her. Since hers was a big family, they had to spend a lot for family maintenance and on top of that they had to spend extra for their medicine and diet.

Like that, frustration and anger surfaced at the face of financial problems. This was also true in the case of one Muslim widow. After her husband’s death, it had become difficult for her to remain at the house of her in-laws. The relationship between them turned sour because she had become more of a burden. So, when things had really become out of control, she went back to her parents’ house with her two children. But
her problem was not yet over even at her parents' house. Though they treated her and her children with love and care, family's poor economic condition often destroyed the peaceful atmosphere at home. She shared,

When I have financial problem, I feel very angry. I can't ask help from others also. When I can't handle things by myself, I have tension and I get angry. I become much dishearten. I feel like crying also.

But for some women, there were other things more pinching than financial matter. Like for instance, their weak health and the disease that they were suffering from made them helpless and this helplessness gave them frustrations. Two Kuki women shared the same emotions of frustration. One of them complained that she had tuberculosis and she never seemed to get well. She was fed up because of this. The other woman was worse. She complained,

Nothing gives me relief. I have been ill for more than a year now. Staying together with my mother-in-law and sister-in-law is also very uncomfortable. But I can't do anything. I have to bring up my two children also. I am not feeling well.

Anger and frustrations were also seen to be around when hopes and aspirations were crushed. When such thing happened, life took a twist. A Meitei woman of 37 years of age had high hope for her children. But she felt dejected when she came to know that one of her children was HIV positive and she was also living with AIDS. Her husband also died of AIDS and now she was also suffering the same ailment. She poured out her anger with these words:
I am very angry, frustrated because I can’t get my desires fulfilled. I don’t have anyone to turn to. So, I pour out my anger to God and sometimes to myself.

Some of them even cursed their birth. One Tangkhul woman scolded her mother for giving birth to her. She felt that she should never have been born.

It is seen that anger and frustrations surface at the face of many instances. Their inability to do things by themselves made them frustrated. Taking others help to do simple household chores like washing clothes or cooking or looking after their children hurt their self respect and devalue their worth. Such a situation is found among the women of all the communities under study.

The feeling of anger and frustration was also revealed vividly during the time of financial problem. Being burdened with disease or diseases, they were weak physically and were unable to contribute to the family in any manner. They felt as burdens to everyone around. And due to these disabilities, their hopes for themselves and their children’s future were crushed. They were found to be in a very helpless situation. This made them very angry. Sometime, they were found pouring their anger to God or to themselves. While the responses of these women were anger and frustrations, the experience of living with AIDS is also responded in other form of emotion – guilt.
4.2. Guilt

A sense of guilt was felt strongly by most of the women under study. This was learnt through the narrations of their experiences. They felt guilty because they had become a burden to their families or because they could not look after their children. For instance, 37-year-old Tangkhul woman was full of guilt and remorse whenever she thought about her parents who had grown very old. She always remembered how her parents sacrificed their comfort to bring her up and to educate her. Instead of repaying them by looking after them in their old age, she had heaped more burdens to them by being infected with HIV and suffering from AIDS. This brought them shame and worries. She could not return to her home in the village because her parents could not take her back because of her HIV status. Besides that, she had married a person of different faith and community against their wishes. Her life was a story of mistake, regret and guilt.

Another woman, a 20-year-old Muslim widow was also a guilty one. She came back to stay at her parents' house after her husband's death. She could have continued staying at her husband's house had it not been for her in-laws. She was terribly sick, bed-ridden and the left side of her face rotted. She was never nursed nor provided any medical treatment from her husband's family. So, her mother came and took her away with her. From there, she never went back. She recovered from her illness but the scar remained – physically and emotionally. Though she was never asked to contribute to the family's income or expected her
share in the house–hold chores, she could not help herself feeling guilty. She confided,

I feel guilty. My mother still has to earn at such an age and I’m taking away all her earnings. She is struggling a lot. My mother is so unlucky... even me (sobs).

On the other hand, there were other category of women who had been disobedient and brought shame and humiliation towards their family with the manner in which they got married. But when problems arose and when things started going bad for them, they turned back to their parent’s home. And instead of being scolded or punished, they were overwhelmed with their response because they were given love and care. One such woman was a 36–year–old Meitei woman. She got married at a very young age much to the annoyance of her family. But after some years, her husband died of AIDS, one of her two children was detected HIV positive and she herself was also infected and ill. While her in–laws could not meet the demands of even her basic needs, she was warmly welcome by her brother and her parents. She felt very guilty for all the shame and pain that she had brought to them. She confessed,

My brother is very loving and caring to me. But the more he shows his love to me, the more I feel guilty because I was disobedient. I got married in that manner but in return, he’s treating me so nicely.

Some felt so guilty that they even thought of committing suicide. After her husband’s death, a Meitei woman, aged 35 years thought that she would be more secured at her parents’ house. She did find security
but due to poor family condition, she could feel the financial crunch of her family. When they used to discuss about the ways to get her medicine and other care, she used to feel very guilty. That was when she thought of committing suicide.

While some thought of committing suicide, some had even attempted. A 33-year-old Rongmei woman had to undergo the trial of guilt and suicide many times. She was hospitalized and she needed blood transfusion. The staff of an NGO, SASO promised her family a 50 percent re-imbursement of the hospital bill. The family took loan and went ahead for the treatment. When the money was never refunded, there were arguments and fights in the family. When she could not take it anymore, she made a firm decision one day. The decision could better be explained in her own words.

I have five elder brothers. The eldest one is well to do but he is very selfish and stingy. The others are not well-off. Nobody wanted to keep me with them. But my third brother is loving and I live with him. After my husband's death, I had cut off all ties with my in-laws. My day always started with them arguing over who will repay the loan. This continued for many weeks. I got fed up. When I could take no longer, I decided to end my life. I drank a bottle of phenyl one night and went to bed. In the middle of the night, I felt as if someone woke me up to go to toilet. I vomited everything out. The next day also I drank a mixture of dettol and kerosene. The same thing happened again. I threw up everything. Later, I realized that it was God who was calling me, stopping me from taking my own life.
Like that, when guilt is driven too far, they are vulnerable to take such extreme steps.

There are also some women who were feeling the pang of guilty conscience. Christian women who got married to non-Christian men were often the victims of spiritual guilt. This pricking of guilty conscience made them very restless and troubled. Their conscience was subdued till they started suffering. One of the Rongmei women became a widow at a young age and when she came to know that she was suffering from AIDS, she became realized that it was all due to her sin—the sin of disobedience. She testified how she came from a religiously sound family as her father was the Pastor of her village Church. But she went astray and got married to a non-Christian family. Thus, she lived a sad and remorseful life. She said that because of such a marriage, she was suffering from AIDS.

Due to such guilt and remorse, they could not do things wholeheartedly. Another Rongmei woman, 27 years of age confessed that she was burdened physically, emotionally, spiritually and financially. She further added,

I’ve spoilt God’s wonderful creation by getting infected with this disease (AIDS). It’s a curse.

She admitted the mistake she had committed in life. The situation was such that she could not think of anything else about her illness than that it was the consequence of the sin that she had committed. Guilt is
observed to be a subdued form of anger. This feeling is come across women of all the cultural groups under study. Sense of being a burden to their families made them very angry. This is more prevalent among those women whose old parents had to struggle to earn and look after them. On the other hand, they were filled with guilt for bringing shame and humiliation to their families (paternal) by becoming HIV positive. This also explains the degree of stigmatization of HIV/AIDS. They also felt guilty on failing in their part to look after their children. They felt that their duty of motherhood could not be fulfilled due to their helpless condition. Due to this, they felt that their children were not done enough justice. Some women had to live separately from their children, while some women had to separate their children – between her and the in-laws. This pang of separation also contributed to their amount of guilt felt. When the feeling overtook them, some resorted to extreme steps like suicide. Spiritual guilt was mostly seen among the Christian women irrespective of their cultural background. These are those women who got married to non-Christian men. They felt that they suffered because of their sins – their sins of marrying with non-Christians.

In addition to their emotional and mental trauma and also their ill health, these women were also ‘gifted’ with many physical changes which are for the worse. The hardships that they faced and the battles that they encountered are discussed in the following section.
4.3. Physical changes

Good looks are indeed a special gift from God. When women are blessed with such a gift, most of them try hard to maintain it or make themselves even more attractive. While other women who are not towards the beautiful side make an effort to look presentable and pleasing. It is not a new thing that majority of the women do not mind spending hours before the mirror in the process of pleasing themselves and making others appreciate them. But when their looks are distorted with a disease or an illness, they feel robbed of their important asset. And AIDS does not add beauty to their looks or their body but more problems to deal with. When it comes to the women under study, the words they often used to describe their present looks are ‘dark complexion’, ‘thin’, ‘hair-loss’, ‘pigmentation’, etc. There are many feelings and thoughts that they went through. The new looks were responded in the form of complaints. Some of the typical ones from all the different groups were as under.

A Tangkhul woman —
I have become very thin, skinny, dark. Due to excessive hair fall, my hair is cut short. I look terrible.

A Kuki Woman —
I was very healthy, fat and fair before. But now I’ve become so thin and dark.

A Rongmei Woman —
Everything has changed - my face, my hair, excessive hair fall, pigmentation on the face...
A Muslim woman —
My face looks squeezed in. My complexion has changed for worse. My entire fats portion has dried up.

A Meitei woman —
My complexion has changed. I see lots of pigmentation. When I see my photographs in the album and compare them with my present look I feel very sad.

It is seen that their complaints were more or less same. Some women have the additional bonus of the scars as the remnants of their illness, like the scars from herpes. So, what did these women do with their physical changes? Some try hard to fight with their altered looks by putting make-up or changing their hair-style. Some have agreed to live with it.

These changes in their looks made them look older than they actually were and that did not add much to their self-esteem. Some women avoided their old friends or people from their previous locality. A 36-year-old Meitei woman was one who did that. She said,

I had a very nice complexion before. Now, it's all gone. Whenever my friends come to my place to meet me, I hide from them. I used to run inside. I don't want them to see me in this condition. I look terrible. I don't want them to feel pity for me.

Though she was in a bad shape, she was too proud to be pitied by her friends. She was beaten but her self-respect was still alive.

All the physical changes in their bodies, specially their looks discouraged them to look at the mirror. They avoided it because they did
not enjoy it. The worse part of these changes was when people failed to recognize them.

A 42-year-old Tangkhul woman was the apple of everyone’s eye in the village. The village elders, Church Pastor, mission workers were very pleased with her. Any Church meetings or social gathering was incomplete without her presence. After marriage, she settled in Imphal. She got infected with HIV and due to AIDS, her looks changed, her physical body deteriorated. When she visited her village, this was what she encountered.

Nobody in the village can recognize me now. When I gave my greetings to Pastor, mission workers, and others; they just stared at me and asked who I was. When they asked ‘who are you?’, I felt like covering my face with cloth and run away.

Not being recognized really hurt. A 45-year-old Kuki woman spoke on this behalf.

When people fail to recognize me, I feel very hurt.
I turn away and avoid them. I don’t want to explain things to them or give my introduction. I feel ashamed.

Like her, there were many women who did not put up any effort to persuade others to recollect their memories about them. The best way they opted to avoid such an embarrassing situation was to avoid people.

It is found from their narrations that they faced lots of physical changes, especially their faces. The changes in their complexion, extreme weight loss, etc were found to lower their self esteem. In the
initial phase of these changes, they tried to cover up with make-up or new hair styles but finally, they let things be as they were. Not being recognized was very hurtful. And to be singled out from others was a matter of shame. They avoided the company of other normal people and tried to find solace in the company of each other.

These physical changes that they were going through affected them. However hard they tried to ignore the changes, the reality of these changes hurt them. If AIDS made them guilty and frustrated and gave them ‘new looks’, they also had to cross another hurdle – stigma.

4.4. Stigma

Inspite of many awareness programmes and propaganda on HIV/AIDS, there are many people who do not erase their minds off with stigma. Stigma is one harsh reality that the HIV positive people are living with. It has become a part of the baggage of HIV/AIDS.

Stigma not always comes from people who are not related to them. Sometimes it starts from their own family, from their kinsmen. Three Tangkhul women experienced the woe of being stigmatized by their own families. One of the women narrated,

My own family stigmatized me. After the death of my husband, I went to my village along with my daughter who is also HIV positive. It was a sad experience. They did not have any knowledge of HIV/AIDS. My village people think that HIV means death. They think that it’s the worst form of disease. So, they avoid people with HIV/AIDS. My family treated us very badly. They separately kept all the things used by
me and my daughter. That's why I don't want to stay at my parents’ house. Besides that, my three sisters-in-law were also not happy with me and did not treat me well. I have this feeling that I'd die sooner than I am destined if I remain at my parents’ house.

These women came across rejection and avoidance from their own family. Some of them were even asked never to return to their village again.

Though most of the women got infected from their husbands, their in-laws did not miss a chance to stigmatize them. A 28-year-old Rongmei woman’s case is one such. When she was detected HIV positive, everyone left her. Her mother-in-law asked her to live separately. By that time, her husband was already dead. And since her native village was very far from her husband’s, she had no one to run to. She was forced to live alone with her young son who was also HIV positive with no income and no means to meet even their basic needs.

It was found that AIDS was also a means to lose friends, as learnt from the case of a 33-year-old Rongmei woman. She recalled,

When my HIV status was still not yet confirmed, many of my friends used to visit me. But after I tested positive for HIV, people said so many things against me, including my friends. Many of my friends left me except for few faithful ones.

Stigma and discrimination does not happen only at the village where there is supposed to be lack of awareness about HIV/AIDS. It also happens in the heart of Imphal city, among the so-called educated
people. One of the Meitei women said that she could not share a conversation with normal people. It was because they talked such things which hurt her. That was the reason why she did not mix with them. She remembered an incident.

One woman narrated how she spent a sleepless night on learning that she shared a plate with an HIV positive woman. We were sitting together in one house when she said that. I was so hurt to hear that. Imphal is an area where it is supposed to be aware of such thing but it’s not so.

If this woman felt so hurt on hearing about words of avoidance, one can imagine the quantum of pain that a Kuki woman went through. Her family lived at Langol Housing Complex, Imphal. The living quarters there were mostly occupied by government employees who were educated and qualified. This woman and her family could get no respite from them when it came to stigmatization because her husband and his brothers had AIDS. She narrated,

The neighbours and people of our locality and even relatives - they don’t want to come to our house. Right from the days my husband and his brothers were unwell (they had AIDS) people did not want to visit us. Even if they came, they used to sit far from them (the sick persons). They did not take tea or even water from our house.

Like those neighbours, educated medical personnel also stigmatize. It happens in the hospitals where it is supposed to be the haven for such people with HIV/AIDS. A 33-year-old Rongmei woman who had been a victim of such an attitude shared her experience.
I was hospitalized at JNH (Jawaharlal Nehru Hospital). The junior doctor treated me very badly. He didn’t even check my pulse because he didn’t want to touch me. He simply looked at my papers and gave me the discharge orders while I was still unwell. The nurse was also very rude. She shouted from far that I should vacate the bed immediately. She knew my name but she addressed me according to my bed number, as if my bed number was my identity. I was very hurt.

It is observed from this incident that even educated people like a doctor were not free from such irrational belief that a mere touch of an infected person could infect him. She was found to be not treated as a human but as a numbered animal or thing. Though she had reached the bottom of the pit of life, she still longed to be treated well and still held on tight to her self-respect.

Another woman, a Tangkhul also shared a similar experience. She narrated,

I once suffered from excessive bleeding. I was taken to RIMS Hospital. The nurse who gave me dressing shouted at me when I groaned in pain. She shouted, “Keep quiet! We are nursing you not because we care, we don’t want to touch you even”. I felt so ashamed of my HIV status that time. I wasn’t provided even a bed. I was made to sleep near a toilet. I was treated so badly. I was ill-treated because of the ‘disease’ which everyone looks down with contempt.

If the hospitals do not give them shelter, then they hope that church, being a religious place, a house of God would give them refuge. Even there also they were disappointed. Many Christian women shared how they were stigmatized in the church.
One Rongmei woman revealed,

Stigma and discrimination happens in the church. I was made to baptize last out of all the candidates. They were afraid that the germs might come out in the water and spread to others.

A Kuki woman also joined her. She said,

At the church, I can always feel that people are staring at me. They look upon me with contempt. People don’t want to sit near me or talk to me.

The above two cases happened in Imphal city. Such things happen in the village church also. A 29-year-old Tangkhul woman said that even if she went home to visit her mother, she never went to church. Her mother was often upset with her because of this. But she told her mother that she did not want to sit alone on a bench because others avoided her. And she found that very embarrassing.

But another form of stigma was also seen among some of these women. It was self-stigmatization.

Others don’t stigmatize me. It’s me who stigmatize me. Since I’m already infected, I feel bad about me. I always feel that I’m so different from them. Sometimes, I doubt that their (husband’s family) love and concern for me is only superficial.

This is the condition of one Rongmei woman, 27 years of age. She did not want to mix with others because she was afraid to be treated badly or looked down upon by other normal people. It also shows her perception about her in-laws love for her. She felt that her in-laws cared for her because they felt pity for her condition. She was living in
constant dilemma. If people ignored her, she felt stigmatized and if they treated her well, she felt as if they were taking pity on her and her condition.

Many other women also shared such incidents of social cut-off. They avoided any social gatherings, meetings, functions and other occasions where there would be a gathering of many people. Some even avoid going to church. A 45-year-old Kuki woman said that she did not want to go to church out of shame.

These women often practice self-alienation from the society. Even if they were invited for any function or ceremonies, they seldom go, but this is what they usually do.

Even if I'm invited for marriage or other functions, I go before the day of the function to give the gifts. I don't want to mix with others. I don't want others to feel pity on me.

— said a 30-year-old Meitei woman. The feeling of not being wanted to be pitied was an indication that her self-respect was still alive.

Stigma was found to be of two types—stigmatization by others and self stigmatization. Women were stigmatized at home, their relatives, and people from their village or locality. They were stigmatized at the hospitals and other health care centres by health personnel like doctors and nurses. They were also found to be stigmatized in a religious place of worship like church. The one reason why such complaint was heard from Christian women was because of the nature of worship of the
Christians where there is community worship. People come together in one place and worship together in one particular time. There is ample opportunity to interact with people. This is not so in the case of the Hindus. Muslim women on the other hand, do not go to the Masjid or mosque. So, the Hindu and Muslim women did not come across such a situation. Being stigmatized by their own families or kinsmen was found more among the Tangkhul women.

While battling through all these hardships, most of the women under study who were also mothers had another battle to fight, that of motherhood. This is studied in the following section.

4.5. Being a Mother

Out of all the women, three were childless. A Rongmei woman lost her daughter who died of sudden illness. The other woman, a Tangkhul suffered miscarriage and the third woman, a Kuki woman was barren. The rest of them were mothers. Being a mother for women with AIDS was a dilemma. Motherhood brought them joy and a sense of completeness. It also gave them guilt and a burden of responsibility to them. Motherhood for them can be discussed in two manners – being a mother with AIDS and being a mother of HIV positive child/children.

4.5.1 Being a mother with AIDS

Motherhood means responsibility towards her children. But being a mother with AIDS makes a woman very helpless and burdensome. However strong her desire may be to render her right and
duty as a mother, her physical body and weaknesses does not allow her to do so. There is always a shade of frustration and anxiousness and also uncertainty in their minds. A Meitei woman, 36 years of age was a mother of two sons. She was often very ill and was heavily burdened with the future of her two sons. She could not expect anything from her husband who was a drunkard and also HIV positive himself. Her in-laws were very cruel people, as she said. Being sickly, she could neither earn nor look after her two children.

Worries and anxiety over the security of the children were always there in the mind of the mothers. Another Meitei woman, a mother of two said,

I feel that I can die peacefully if I know that my children’s future is secured.

She also suggested,

The government should provide certain provisions for bringing up such orphans of HIV positive parents.

If AIDS gave them these worries and diseases, it also brings about division in a family. Due to constant need of money due to her poor health, a 35-year-old Meitei woman had to go back to her parents’ home. Since she was not allowed to take both her sons with her, she had to leave her elder son behind with her in-laws. Her husband, the only son of their parents was also dead and her parents-in-law needed someone to live with them. And besides that, bringing home two children would be too much of a burden for her family. This pang of
separation always pricked her conscience. She felt that there was less attachment from the side of her elder son. She felt very guilty about that. She said, "I feel that my elder son doesn’t love me much. I can sense that lack of affection". She felt bad because she could not stay with both of them. She explained, "Since I myself am living at the mercy of my family, I cannot afford to ask for more help".

Some of them were very sad because they would not be able to see their children grow. One such mother was a 27-year-old Rongmei mother woman. She said,

My daughter is very young. I don’t know how long I am going to live. I wonder how she’d look like when she grows up. I wonder whether my in-laws will bring her up properly after I die.

Being a mother was a very big burden for a 28-year-old Rongmei woman. After her husband’s death, she was given the choice to go back to her house or to remain at her in-laws. If she went back to her parents, she could not take her son along as laid down by the custom of her tribe. So, she chose to stay with her son however cruel her in-laws were. Being a mother, she did not have the heart to leave her son behind. Her son was also HIV positive. She knew that it was her responsibility to look after him.

AIDS has made them physically weak, financially unsound and psychologically disturbed. Due to this, they could not render the responsibility of motherhood smoothly or in a normal manner. AIDS had
made them disabled. There were piles of worries and anxiety about their children's future. The burden of not being able to provide care and support to their children and their knowledge of not seeing their children grow up were very torturous. But the worst parts of being a mother with AIDS was the guilt of infecting their children with HIV and see their children live with AIDS or rather dying with AIDS.

So, the following discussion is the turmoil that the mothers of HIV positive children were going through.

4.5.2. Being a mother of HIV positive child

When a Meitei woman, aged 30 years, saw her daughter taking ART at such a young age, she was shattered. She cried out,

My daughter has started taking ART. I felt very bad when her status was revealed. Bad because she is so young and she has to carry such a big burden. I feel angry with my husband (though he is dead) for infecting not only me but also my young innocent daughter. I decided that I'd never perform the rite of din (annual rite for deceased soul in Meitei custom) for him. I feel cheated.

And when it comes to children, mothers can be so selfless. They think beyond themselves. A Tangkhul woman was very worried for her daughter. She said that she did not care even if there was no medicine that could cure her. She felt sad that her daughter had to survive all her life on medicines
The sorrow of being HIV positive was nothing compared to the 
pain on knowing about their children being affected. When their children 
felt sick or suffer from any ailments, they felt very guilty and put all the 
blame to themselves for infecting their children. Many of these women 
shared their grief over their children being infected. A Rongmei woman 
cried whenever she talked about her HIV positive son. She said,

I was hurt. It is okay upto some extent when I was 
tested HIV positive. But when my son was confirmed as 
HIV positive, I was shattered.

Another woman, a 37-year-old Meitei widow and also a mother 
of two boys was often tortured by the thought of her first son who was 
HIV positive. Though her younger son was not, she wished for both her 
sons to be normal and healthy.

But one Muslim woman was too scared to know the HIV status of 
her daughter. So, she never got her tested. She confessed,

I’m very suspicious about my daughter’s HIV status. 
But still then I didn’t get her tested because if she 
happens to be HIV positive, it will be unbearable for me. 
So, if my daughter suffers from mild cold or even a 
slight headache, I get very worried. I’m so sad.

Motherhood brings about many shades. While some were afraid 
to know even the status of their children, one Meitei woman came out 
stronger. She got both her children tested. And unfortunately, her 
daughter was found to be HIV positive. But she did not lose heart. She 
posed questions about the present situation, had hope for their children 
and also shared suggestions for the NGOs. In her own words,
My daughter has started ART. She asked me about the medicine that she is taking everyday, I can’t give her a frank answer. I can accept the fact for myself but I can’t do it when it comes to her.

As the children are growing, so also their questions are getting tougher. I think we need to be given proper counseling from the NGOs’ side so that we can prepare ourselves to open up, tell the truth about HIV/AIDS before our children.

I have this aspiration that my HIV positive daughter will get married one day with an HIV positive son of one of my friends. She should get married. I want her to become somebody in life (get settled).

She did not trust a normal man to treat her daughter nicely. She did not want her daughter to be discriminated because of her HIV status. She did not want her daughter to get hurt.

There were some mothers whose happiness knew no bounds on learning that the test result of their children came out as negative. A 29-year-old Rongmei woman was HIV positive. She was unwell most of the time. Her husband also died of AIDS. Whenever she thought about her children, she became sweaty and her heart pounded faster. She was very worried about her children more than she cared for herself. But when the result of the test of her children came, she could breathe again. She exclaimed that she forgot about all her sufferings when both her sons were tested HIV negative. She said that she did not care for herself.

And for this 30-year-old Muslim woman, the day her daughter was tested negative for HIV was the happiest day of her life. She said, “Her result had covered up all my worries of being HIV positive. I’d have
died if she were tested positive”. Some went to the extent of giving treats to their friends and the staff of the hospital.

Mothers think the entire world for their children. They forget all their sufferings at the well-being of their children. Though they may not live to see their children grow up or may not be able to provide for their future, they were happy with the feeling that they were going to live and not live to suffer like them, but going to live a normal life.

The plight of being HIV positive and the sufferings of AIDS were experienced by them. The knowledge of the children being HIV positive shattered them. Even though they themselves were living with AIDS, they wanted their children to be clean. The sight of their young children taking ART drugs was unbearable to them. There were also women who were not bold enough to know the HIV status of their children. They still did not have the courage to get them tested. Though this was found to be a rare case, it was not far from truth. On the other hand, those women whose children were tested negative for HIV were the happiest lot.

4.6. ART (Anti-Retroviral Therapy)

When death seemed to be the other name for AIDS, consolation came in the form of ART – not a cure but to prolong their lives. Women across the cultures have reacted in different manner. Inspite of the assurance of the therapy, there was anxiousness and doubt about it.
The first time I took ART (medicine), I was scared because I had heard a lot that some people had allergy. But nothing happened to me.

That was the experience of one Meitei woman. A Rongmei woman, 42-years of age had different perception of her first dose of ART. She recalled,

I really hated to take ART. When I was about to take it for the first time, I did not want to take it because I thought that I had to take it till I die.

Taking the ART drugs seemed like a reminder of her HIV/AIDS status instead of a therapy. In contrast, some others were more optimistic and hopeful. A Muslim woman recollected her first day of ART. She said that she knew from the first dose that it was going to help her because she could feel a certain heat inside her. Inspite of her optimism, her knowledge about the nature of AIDS pulled her down. She added,

But then ART is not a cure for AIDS.

While everybody grasped the opportunity to prolong their lives and control the virus, a lone Kuki woman did not feel excited about the drugs nor the zeal to continue with life. She debated,

My life is a torture. I don’t want to prolong this torture by taking ART drugs.

For her, ART did not prolong her life but it prolonged her sufferings. She had become very bitter because life had treated her very severely. She had no one to turn to. Her husband and his second wife had thrown her out of the house after infecting her. She did not have the
face to return to her parental house because she had eloped and lived with her husband without her parents’ blessings. Even when she was given a chance to come back home, she chose her husband over her family. Her self-respect forbade her from seeking help from her family. She neither had anyone to lean on nor anybody to live for. She had no children and stayed alone in a rented house. Thus, with such harsh reality, she refused to go for ART.

The ART drugs gave hope to many but it came with a price. There are many side-effects as experienced by these women and they shared these experiences which were more or less same. A 32 year-old Meitei woman complained,

Though the medicine is good for one thing, it’s bad in other ways. It affects my eyesight, my hearing... there’s hair-loss. Even my liver is affected. There is stomach ulcer. Taking ART (drugs) has such side effects on one’s complexion. The cheeks become hollow. And when people mention about the change, I feel all the more hurt... I feel that I have been a total loss.

Such side effects as deafness, change of complexion were a common one among them. All the women complained of stomach ulcer, nausea, weight loss, etc. One Rongmei woman said that she found difficulty in brushing her teeth in the morning because she always felt like vomiting. And for one Kuki woman, taking ART drugs had made her very short-tempered.
Inspite of its side effects, the therapy continues because life has to continue if not for them, then it was for their children or their families. Though ART has been provided free of cost, availing the drugs is one mammoth task for many. One Meitei woman complained that due to frequent bandhs and blockades in Manipur, there was always tension among people thriving on ART.

A 33-year-old Rongmei woman found her hidden courage in her battle to procure the ART drugs. Presenting the incident in her own narration will do more justice:

Those days, we had to buy the ART drugs unlike nowadays. The manager of World Vision India, Mr. Dimpu helped me with money to buy the ART drugs. I went to RIMS (Hospital) to buy them. There, we had to register ourselves. My registration number was 86. But the Meitei people working there manipulated things and gave the medicine to their friends and relatives only. I really quarreled and had a heated fight with them. When I was shouting, the Director came in. He asked what was going on there. I told him, "Doctor, I've been coming here daily for my medicines. I don't have money to buy medicines. The one that I'm taking now is also brought by somebody". Then, the Director got angry and scolded everyone there who was working in MACS. He asked me to bring two passport-size photographs. After that only I began to get free medicines.

By nature, she was very shy, timid and a person of very few words. But the eagerness to live gave her the courage to fight for her right. She said,

"I was very thin and weak, almost dying but out of anger and frustrations, I broke the steel chair (laughs)."
When I recollect that incident, I am even surprised at myself. After that, there is no looking back. I realized that I have to snatch (or) fight if I have to survive.

Thus, she discovered her strength at the face of death.

Though ART gave them hope to live longer, the drugs are ridiculed on the accusation that it was a reminder of their HIV status and also that it prolonged their sufferings. This was mainly due to its severe side effects like ulcer of stomach and mouth, nausea, deafness, poor vision and weight loss among others. These side effects have made them look like a ‘breathing lump of meat’.

In spite of all these negative attitudes towards it, they continued to take the drugs. Some were taking it for the sake of their children, some continued with the hope that new drugs may come out in the process that can really cure them and not just postpone their deaths. Living with AIDS is a life-long struggle – a struggle to sustain their life, a big effort to maintain their health, a spiritual war and emotional struggle. Amidst all them, it seems necessary to learn how they were making use of the awareness programmes which are presented in the following discussion.

4.7. Awareness Programmes

With the uncontrollable cases of HIV/AIDS, the government, NGOs and other agencies also speed up its prevention and control measures. As a part of the program, awareness programmes are
conducted which include propaganda on Radio, T.V., documentary films, billboards, postures, etc. But from the stories and narratives of the women under study, one cannot help but put up the question. "Do these really serve the purpose?"

This is how one Tangkhul woman opened up,

When I see billboards on HIV/AIDS or listen to programmes on radio, I think that it's about me. Sometimes, when they put up terrible pictures, I'm put off. That's why I avoid it most of the time. When I see pictures of people becoming very thin and scary due to AIDS, I feel scared. That makes me very sad and it narrows my thinking sometimes. Life is smooth and cool but such propaganda and people's talk remind me about my HIV status. It disturbs my life.

And a Rongmei woman added that all these programmes seemed like targeting her. She felt as if she was a part of the programme. Though she knew that she was, she did not want to be a part of it.

A Meitei of 37 years of age also felt scared when she saw posters and billboards on AIDS. She felt that whatever was mentioned was about her only.

Some mothers were more concerned about their children than about themselves. A 34-year-old Muslim woman was one such. She said,

The posters of HIV/AIDS used to look so bad before, very terrible to look at, especially of the affected children. Whenever I see those posters, I place my children in their place and it really upsets me. I don't think much about me.
The worst form of fear these posters and billboards give was before their status was confirmed. A 28-year-old Kuki woman always knew that she was HIV positive since she began to feel and see the symptoms. And on top of that her husband had died of AIDS. The only thing that made her status not confirmed was because she had not gone for the test. During those days, her fear for such billboards was very high. She felt as if they were writing about her. She hated it because it reminded her about her possibility of being HIV positive. She said that she still hated it. But the tremendous amount of fear generated by such awareness programmes motivated her to go for the test finally.

But for some others, it was a different story. However bitter the reality sounded, if they take it with a pinch of courage, these awareness programmes serve their purpose as reported by a 37-year-old Meitei woman. She said that she learnt a lot from it and suggested that everybody should listen to it or watch it on T.V., because she also got to learn so many things from it. And according to her, there were some who never listen to such programmes and therefore were not aware at all. Those were dangerous people, she said.

Another Rongmei woman also joined her in saying that it took a bit of courage to face reality but such programmes were helpful. Like them, there were others who share the same view. Those programmes were specially made for the preventive measures and they do not usually suit their status or present condition as they were already affected and
have reached a high advanced stage. What they actually longed for was care and support, a soothing word to ease their tension, a helping hand to lessen their pain.

Their perception on all these awareness programmes were fear, anger, motivation, useful, etc. Some were scared because it reminded them of their reality and this made them angry because it disturbed their normal course of life. Though it gave them fear, it also gave them the motivation to face reality and accept life in a more rational way. Some felt that it was useful and opined that they helped in giving awareness to people. The attitude on such a programme was found to be very subjective. To take care of such people there are many related NGOs. The NGOs were set up for the benefits of these people. The relationship between the clients and the staff of the NGOs has always been a love – hate one. This is further discussed in the following segment.

4.8. NGO (Non–Governmental Organization)

The perception of the women with AIDS regarding NGOs can be broadly divided into two. Some are all praise for it while some experienced a bad taste about it. A 33–year–old Kuki woman was one such person who was not happy with her experience with NGOs. She complained,

They (the NGOs staff) took us for meeting and other programmes. They take advantage of our conditions before their sponsors and government agencies while we get nothing from them. I feel cheated. Before, it used to be beneficial. These days, it’s not anymore. It has
already been two years since I went (for such programmes). I don’t get any help and support now.

Another Kuki woman also did not find any consolation with the NGOs because they did not talk to her about God. As for her, she lived only for God now. She said that NGOs were all about politics.

A Meitei woman of 36 years of age had more to add with the bitter experience of NGOs. According to her,

This testing of hemoglobin or LFT (Liver Function Test)... they say that it is done for free. But we can’t say how far it is for free. I don’t think I get any benefit out of it. Whenever I approach them, I always find that their booking is already full.

I think the NGOs should not do such things. I think that they have a big role to play in making us reach the benefits. They take our documents and keep those papers with them. They can see from our papers that this person needs CD4 count or Hemoglobin or Liver Function Test. These are the things that they ought to know. Their way of saying that it’s too late... I think it’s much unrelated. Even for medicine support...how can we guarantee ourselves to fall sick after 10th of a month? They’d say that there are no more medicines. Do we fall sick looking at the dates of the calendar? If we happen to fall sick after the 10th of a month, we have to buy the medicines on our own. This is what’s going on at present. I think there should be some clarity in the management and working of NGOs.

While some could not find any good words for NGOs, some women had love-hate relationship with NGOs. A 30-year-old Meitei woman was one of them. She put forward this opinion,

The NGOs are earning in our names. They took down our names, our stories and in return, we get nothing. When we approach them for any help, they’d keep
making excuses after excuses. I'm fed up with them. I'm never happy with their manner of working.

But she was also grateful to some NGOs for this reason:

This scheme of Don Bosco in which they refund 50 percent of admission fee for HIV positive children brings relief to our betrayed life (smiles).

A 33-year-old Rongmei woman also experienced such twin relationship with NGOs. When she was denied of re-imbursement of her hospital bill by the NGOs, she felt betrayed and cheated. The hospital bill was Rs. 13,000/- and she was promised to be refunded 50 percent by them. When the promise was broken, she felt so hurt that she even attempted suicide twice. But her experience with World Vision India gave her a new leash of life. She gradually began to accept her condition and assistance to many women living with HIV/AIDS.

Another woman, a Tangkhul widow narrated her experience:

Once I suffered from severe diarrhoea and I was informed that NGOs help people like us. So, I informed the NGO. But nobody came and no help came from them. That's why I don't believe in NGOs. In meeting and public gatherings they'll talk big things but when I approach them, they'll say that there's no fund or the time period is over and other things, I usually waste my time in going to their office for 2 - 3 days but I'll get only one medicine.

If she had seen the dark side of NGOs, she had also seen the other side. She said,

Some NGOs like Hope Care Centre (of World Vision India) are good. I've become broad-minded after joining here. When I'm sick, the NGO people come to visit me.
For many women, NGOs gave them a second chance to live. A Muslim widow of 37 years of age was a broken woman. She did not earn and had to look after her two children all by herself. Her in-laws did not want them to stay at their place anymore as she had become a burden after her husband’s death. She went back home but she was still disturbed. She recalled,

Before I joined an NGO, I was all messed up. But after I joined, I had certain peace of mind. I began to mix with others, became friends with many. I realized that I was not alone. There were many people, many friends like me. When we meet, we broaden our outlook.

A Tangkhul woman also agreed with her. She said,

I attend every workshop or camp conducted by NGOs. These going-outs change my outlook. Before, life was so miserable for me. I could not think beyond my sickness. I was very weak at heart. Now things are different.

Personal experience with NGOs was found to be responsible for their perception of it irrespective of their cultural background. Some felt cheated and used by them. They complained that NGOs were earning in their names. Some opined that NGOs were all about politics. On the other hand some women agreed that the care and helps given by them gave them a new leash of life. The NGOs not only gave them material help but also the motivation and the zeal to serve others. All these women under study agreed that whatever their experiences may be, NGOs gave them exposure and a chance to meet many women who were also HIV positive. Such exposure made their network and friends circle bigger.