CHAPTER VII
CASE STUDIES

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CHAPTER VII

CASE STUDIES

7.1 Introduction

HIV infection is not just another illness. The effect it has on human mind and thought processes is beyond the scope of any interpretation. As each person has one’s own life styles, the way in which this infection alters one’s own, one’s family’s and community’s future is also different. When otherwise normal and healthy individuals develop this infection, they meet with unexpected and unimaginable alterations in the remaining days. The reactions from dear and near changes a lot towards the better or worse and the ‘sick role’ becomes unacceptable to many. It is worthwhile to discuss a few life stories in any analysis of this pattern. These stories have been chosen since they give us an idea about how individuals are trying to cope up with the situation.

While every human being is different, there are certain common situations that repeat very often. As the researcher comes across similar stories every day, a few representative ones are documented here. (As has been noted earlier, names of persons and their identity has been withheld to protect the confidentiality)
7.2 – Couple & all children

Mr. R. was a barber hailing from a small village in Idukki district. His wife who was handicapped from childhood polio was an unskilled worker in a private factory producing finished food products. Mr. R. had tried to find a job in the Gulf in the 1980s when he had wandered through the streets of Mumbai with a person of the same profession. A person with lot of ideal thinking and religiosity, he had never thought of having sex before marriage. His friend, almost a veteran in the field of multi partner sex had great difficulty in pushing him to the house where he had sex with a woman working part time in a shop. This had happened at time when he was desperate in not finding a way to go abroad. He came back after a few weeks and was running a shop in the village. All villagers had looked forward to him as an ideal hardworking boy too. His wife was found to be HIV positive in 1997 when she went for the delivery of their third child. Things unfurled fast and the whole family was detected to be HIV positive. Everything was in shatters but the couple were educated and they decided to cope with the illness.

The couple were under regular follow up, but started developing ailments like tuberculosis, candidiasis and herpes zoster one by one. The second child was confirmed infected when the child failed to grow after six months, had a bout of vomiting and succumbed to fatal meningitis (pyogenic) at eight months of age. In
1999, Mrs. R. developed severe respiratory discomfort and was diagnosed as having disseminated tuberculosis. While being treated for that she became better but subsequently developed liver damage. The treatment had to be discontinued and during this interval, she developed severe pneumonia, which claimed her life. She died while she was being examined in a local hospital. The hospital authorities did not get the time to do the detailed investigations and hence her death was not labeled as an AIDS death. The elder children four and six years are totally asymptomatic till now.

After the death of his wife, Mr. R. is in shambles, as he lost a regular source of support, psychological and economic. He could manage to keep the HIV status a closely guarded secret and hence there is not much discrimination. But the crisis he is now put through is very complex. Since he has two surviving children, both of them girls, he is being persuaded by the wife’s family for a second marriage for the welfare of his daughters. He is the only person who knows that the children are infected too. The situation is made worse as his in laws are insisting that he marry the young unmarried sister of Mrs. R.

The stress and strain that this person is experiencing is unimaginable, but the solutions.....
7.3 - Couple affected – children uninfected

Mr. T. is a fabrication worker hailing from a village in Alappuzha district. He had worked in many places in Maharashtra, Andhra Pradesh, Karnataka, Goa etc., where he used to change places of work every three or six months. As he had two children studying in schools, he did not want to take the family with him. His wife is a typist working in a state government office. He was planning to go to Gulf to find a better job, when he was found to be HIV positive on routine medical check up. He had lot of difficulty in telling his wife about this. He was convinced of the need to use condoms in every sexual act, but it was a tough act to tell his wife about this, as she had been subjected to a permanent method of sterilization, the post partum laparotomy. After a lot of hue and cry she was informed about the HIV status and was convinced of the need to have her blood tested. Getting her blood tested without anybody else knowing was so difficult. When her blood was found to contain HIV antibodies, the couple had a detailed discussion about suicide in a few days, there was no silverline seen anywhere. But the whole scenario changed when they found that both their children were not infected. The possibility of living for their children made them change their decisions and they are leading a happy life thereafter. It is possible that the wife got infected after the two children were born or that luckily both children were saved.
from the infection. Now the couple is convinced that there is a purpose in their life, even when they know that they may not live to see their children grow up as adults.

7.4 – Husband positive, wife negative.

Mr. J from Ponkunnam is a well established businessman from a high socioeconomic group. He had a job in UAE, and his wife is a school teacher. Mr. J has reported with a report of HIV positivity detected during his routine medical examination and has been hiding this fact from everybody including his wife. He somehow managed to get his wife’s blood tested and the result was a negative serology. He is aware of all the precautions he must take during sexual intercourse and other activities, but does not dare to tell his wife about this. However he had been managing to shun away from having sexual intercourse for a long time afterwards. Now he is being pressurized by his wife to have another kid. When he refuses to accede to her request, she insists and forced the result out of him and their family life is getting shattered. But as soon as the wife could come to a counselor to seek help regarding artificial insemination for pregnancy, she was properly counseled. As insemination in a non sexual setting can also lead to infection, her request cannot be granted. She also agrees with her husband now for protected sex using condoms. The couple are now living a comfortable life. Mr. J has a small guilt feeling in his mind that he did something wrong; not in having
high risk behaviour in the past, but in hiding and delaying the result from her for long.

7.5 – Wife positive, Husband negative

Mrs E was found to be HIV positive when she was submitted for a medical screening for visa to go to UAE as a housemaid. She was in the same country earlier, about three years back. She admitted to having been lured into commercial sex work, during her previous stay in UAE and during the transit points at Mumbai. She was a victim of organized cheating that was taking place in Mumbai airport and surroundings and could not escape from the misdeeds of people of Kerala origin trying to exploit her lack of knowledge of any language other than her mother tongue.

She was so distressed that she thought of continuing the sex work in one of the cities in Kerala to make a living. However her husband, who was a manual labourer was not ready to permit her to leave house for any reason. He was tested negative and agreed to look after her illness with dedication. They are practicing protected sex and are in the process of getting their grown up children married before the society has a chance to interfere with their family.

7.6 – Wife infected from blood transfusion, husband negative

The stories are not all that good too. Mrs. M got married to Mr. M when he was working in Mumbai. They lived in Mumbai for about three years. She got
pregnant and was being cared in a private hospital in Mumbai. When she
developed bleeding, as per medical management, she was given three units of blood
from his friends and contacts. Even though the she lost the first child, she
recovered.

After sometime, he got a job in US and the wife and kid shifted to his
house in Kerala. After about five years, she became pregnant again and this time,
the hospital authorities did the HIV antibody test and she was told to be positive.
She discussed the issue with relatives, as she was aware that blood transfusion was
the culprit. However the response of the family members was beyond what she
could anticipate. They immediately rang up Mr.M and he was asked not to call
her or talk to her. She went through the agony alone during the pregnancy. After
the delivery, she was shocked to find out that she was shown the way out by the in
laws and she took refuge in her own house. To her dismay, the second child was
infected too.

It was all without her knowledge that the husband became addicted to
alcohol. He refused to meet her and has filed a divorce suit. Even though the
families are rich, they are not ready to spend money for her now. She is jobless and
does not know how to take care of her treatment and is worried what might
happen to the child after her death.
7.7 – Child only infected

One hemophiliac boy was brought with history of weightloss, diarrhoea and fungal infections. He is the only son of the family and is studying in high school now. The parents are manual labourers and they have been somehow managing the expenses for his treatment of hemophilia, also with some help from various NGOs.

On testing he was found to be HIV positive and was in an advanced stage requiring antiretroviral drugs. He was becoming weaker too. He had an intense desire to attend his classes. As he was not having much bleeding these days, he could not understand why he was becoming weaker. It was very difficult for the family to understand the consequences of his present illness. It was next to impossible for them to come to terms with the reality that their son would need treatment with drugs costing twice their earnings every month to sustain his life.

The couple were not prepared to leave everything to mercy too.

With some support from a local leader they managed to raise some money for his treatment. But after about three months, when they knew that he was buying drugs for HIV disease and not hemophilia, they stopped the act. The story took a bad turn as the couple are realizing now that they are also being denied jobs nowadays, quoting the son’s illness, even though many efforts are on to educate the community.
7.8- Remarriages & infected discordant partner

Mrs A from Thodupuzha was found to be positive when she came for a routine antenatal visit to her gynaecologist & Obstetrician. She was immediately referred to a higher centre for further followup. Her first husband had died in suspicious surroundings in Mumbai about two years after marriage. After that she was leading a very depressed life as a widow, when her husband’s cousin, a soldier offered to marry her. She recovered from her loneliness and was leading a very happy second married life. She understood the details about the illness and was fast in realizing that she must have been infected by her first husband. Her first apprehension was whether she might have infected the present husband.

It was her moment of joy in life, when it was verified that he is not infected, even though they had many sexual exposures. She thanked God for that and asked the boy to disappear from her life and asked him to follow a route of escape. This young man refused to do so and insisted that he wants the child from her and was ready to look after her, without the slightest regret. In spite of warnings and threats from the family, he came home to help her pass through the stages of pregnancy. He paid for her drugs afterwards too. The child born was not infected. The couple now leads a happy married life, but without sexual exposures. She is all in praise for this divine act of his, which he calls an act of human love only.
7.9 Summary

These case studies tell us about the vagaries of human life. An apparently normal family gets disrupted after their knowing about the disease. It is to be noted that HIV infection has been existing in these individuals for many years. It does not produce any change in their life at all, because of ill health. The consequences described are because of the revelation of the affliction and is thereby directly linked to the mental status, rather than physical situation. Regarding the social reactions too, it is worth noticing that most responses are arising out of apprehensions. It is in this context that we have to focus the attention on social apprehensions.

Regarding the interactions inside the family, many of them have been closer to the expected, if not the desired. The type of relation with one's partner and how he/she behaves afterwards is perhaps the most deciding factor in survival, in the case of married persons.

These case studies are highly representative and have influenced the researcher in identifying the diversity and variety of human life and thoughts.