CHAPTER VIII

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CHAPTER VIII

OBSERVATIONS and ANALYSIS.

8.1. Socio demographic profile

During the period from 1996 to 2003, 1585 cases were seen by the researcher. Thirty five cases where the patient died before any concrete response could be elicited. They were not taken into the analysis. Remaining 1550 cases were included in the study.

The incidence of these cases is depicted in Table 1 and Fig.5. It is observed that there is substantial rise in the number of cases. The increase from 50 cases in 1996 to 387 in 2003 is a definitive one.

Fig. 5. Cases by year and status at diagnosis
**Table 1.** Cases by year and status at diagnosis

<table>
<thead>
<tr>
<th>Year</th>
<th>HIV positives</th>
<th>AIDS cases</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>1996</td>
<td>22</td>
<td>28</td>
<td>50</td>
</tr>
<tr>
<td>1997</td>
<td>36</td>
<td>40</td>
<td>76</td>
</tr>
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<td>39</td>
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<td>1999</td>
<td>43</td>
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<td>2000</td>
<td>68</td>
<td>142</td>
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</tr>
<tr>
<td>2001</td>
<td>87</td>
<td>177</td>
<td>264</td>
</tr>
<tr>
<td>2002</td>
<td>88</td>
<td>209</td>
<td>297</td>
</tr>
<tr>
<td>2003</td>
<td>95</td>
<td>292</td>
<td>387</td>
</tr>
<tr>
<td>Total</td>
<td>478</td>
<td>1072</td>
<td>1550</td>
</tr>
</tbody>
</table>

**Table 2.** Cases by age at presentation

<table>
<thead>
<tr>
<th>Age</th>
<th>0-6</th>
<th>6-12 yrs</th>
<th>13-45</th>
<th>45-60</th>
<th>60 +</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number</td>
<td>39</td>
<td>22</td>
<td>918</td>
<td>559</td>
<td>12</td>
</tr>
</tbody>
</table>

**Fig.6.** Cases by age at presentation
From the age pattern of the patients, it is evident that majority are in the prime adulthood, even though the age group between 45 and 60 is also becoming affected. It is probably due to their acquiring the disease in the previous age group and manifesting later. It is interesting to note that 12 patients were above the age of sixty too. The incidence of the disease among children also deserves attention.

![Diagram showing cases by gender]

**Fig. 7. Cases by gender**

As might be expected, 68% were males and the male to female ratio was 7:3 little more than 2:1, which indicates that the ratio will
approach 1:1. The ratio was initially very much in male favour, but as the epidemic advances, more females are getting involved.

It was observed that 997 cases were already married when they were diagnosed. 105 were divorced. Together, it means that in 1102 instances, the infection had created a situation where a spouse is also involved and the family factor comes into play. (see Fig. 8).

Fig. 8. Cases by marital status

Occupation plays a major part in anybody's life. Analysis of the professions practised by the cases are shown in Fig. 9. The distribution is also depicted in Table 3. It is worthwhile noting that the majority were labourers and drivers. Sixty percent of the driver population was constituted by long distance truck drivers who were plying on the national highways outside the state. The involvement of
a large number of housewives denotes the spread of the epidemic to the local households. Others included all categories like engineers, doctors, nurses, teachers, businessmen, priests, local leaders etc.

<table>
<thead>
<tr>
<th>Construction Labourers</th>
<th>Drivers</th>
<th>Office employee</th>
<th>Uniformed forces</th>
<th>Housewives</th>
<th>Others</th>
</tr>
</thead>
<tbody>
<tr>
<td>518</td>
<td>236</td>
<td>124</td>
<td>144</td>
<td>341</td>
<td>126</td>
</tr>
</tbody>
</table>

Table 3. Cases by occupation

Fig. 9. Cases by occupation
8.2. Response patterns

Various response patterns were studied. To find out about the acceptability, the willingness to disclose was taken as a parameter.

8.2.1. Knowing about the serostatus: How does an HIV infected person know about his serostatus? This could help us understand how the situation is handled by people around him. It was interesting to note that 25% (394) did not know about their status even when other persons accompanying the case knew about this. There was a big percentage who knew about this from other HCPs and others, which is not at all an acceptable trend. (see Fig. 10 and Table 3)

![Pie chart showing how the PLWHA came to know about his status](image)

Fig. 10. How the PLWHA came to know about his status
Table 3. From whom the PLWA came to know about the HIV status

8.2.2. Disclosure of the Serostatus to others: It was observed that 780 persons (50.3%) chose not to disclose the result to anybody. 624 only thought they can talk to their spouse. Only 389 (25.1%) considered it satisfactory to inform the family members.

Fig. 11. Disclosure status (To whom the HIV status was disclosed by the PLWA)
186 (12%) deemed it fit information for the family. One interesting observation was that 238 (15.3%) were happy with their friend knowing about the serostatus. (see Fig.11) This was more (68%) in unmarried individuals. They preferred friends to their family or parents. Even though this could be interpreted as a better change in today’s highly individualistic society, the implications it has on the family setup is something to be studied.

The response to the question as to when are you going to tell your spouse was greeted with different responses. Many wanted long periods to decide about this. There has been some suggestions from patients that they be permitted to take about an year or two, before they can do this. Many wanted the doctor to test their spouses without their knowledge and then only decide about telling them.

8.2.3. Supportive Environments: How good are our supportive environments? Only 1013 adult cases are discussed in this section. (see Fig.12) 484 (48%) depicted the scenario as uncomfortable with negative markings for the environment in society. However 1256 (out of 1550) persons had expressed comfort at the way families take care of them. This means that in many situations, the family in Kerala rises to the occasion, albeit partly to meet with the contingency and
supports the PLWHA. However this is usually not sustained. There had been sixty eight instances where PLWHA came back after a few months and wanted to rewrite this response.

![Pie Chart]

**Fig.12.** Supportive environment

(Negative, Indifferent, Positive)

8.2.4. Emotional care: Emotional care was reported as satisfactory by a large number of patients. 1256 (81%) were satisfied with the emotional attention they received at home from family and relatives. This points to a strength in our family systems and the dependence of our PLWHAs in the conventional family set up. (see Fig. 13)
8.2.5. Household involvement in clinical care: When asked “who would care for you when you are sick?” majority answered in favour of the spouse. And the observations too support this. In 983 instances, it was the spouse who was looking after the PLWHAs, male or female. The instances of spouses deserting the patients were very rare. This happened only in 7 cases and in all of them, there was gross marital disharmony exhibited even prior to the disease.

The close family and relatives were caring in another 365 (24%). Considering the fact that the PLWHAs are promoted to be with their family, this becomes important. As emotional and clinical care improves, survival also will be bettered.
In clinical care too, the spouse and family were the keystones. (See Fig. 14). Together with the family members and relatives as the source of emotional support and clinical care, we can probably look forward to better family care in the future too in Kerala patient care scenario.

Fig. 14. Household involvement in clinical care
8.2.6. Fear of risk of infection for others: However many contacts of PLWHAs happened to be very much afraid of getting infection from the infected, even by casual contact. (see Fig.15). This data seems surprising in a state like Kerala. 1286 persons believed that they will infect the spouses. However the number of PLWHAs who were scared about infecting the other family members, relatives and others are not negligible. This data should focus our attention on many IEC messages and activities aimed at dispelling fear.

![Pie chart showing the distribution of concern among family members.](chart)

**Fig.15.** Fear of the risk of infection

8.2.7. Blame Issues: An interesting component after these discussions about the role of family and spouses in care seems interesting. "Whom do you blame for the whole situation?" was a
question that was asked frequently. The responses are depicted in Fig.16. Majority blamed the friends and bad contacts in their younger days as the culprit and a smaller number put themselves into blame and were in a mood of regret. This is probably a point worth working up in future studies. Only a small percentage considered the spouse (or their behaviour) as a cause for all these.

![Pie chart showing blame distribution](image)

**Fig.16.** Blame Issues (Putting the blame on ---- for the whole course of events.)

**8.2.8. Economic Factors:** How did the disease affect the economic capabilities? The answer was in the affirmative in 70% cases. Probably the rest 30% were people who were poor enough not to think about any of the burdens associated with the disease. The
researcher had across may situations when the death of somebody with AIDS was accepted with a sigh of relief. This happens particularly when the family has spent enormous sums of money and time without any significant benefit.

This has also been noticed when children with HIV disease are offered costly treatment schedules. In many situations where treatments are offered for parents and kids, treating the breadwinner takes priority as he may gain some health to go for a job and thereby improve the financial scenario. Treating any other member may be less productive as far as the money is concerned.

![Pie chart](image)

**Fig. 17.** Impact on Economic functioning

8.3. Community responses The response of the communities to HIV/AIDS is very difficult to assess. Actual exposure situations in
Kerala are not very comfortable. (See the news clippings). (Annexure G).

Fig. 18. Percentage of persons answering correctly on awareness questions

8.3.1. Knowledge about the disease (Awareness): An attempt has been made to assess this through questionnaires amongst different groups. Only few parameters could be judged accurately.

The first parameter was the usual general knowledge type of awareness about HIV epidemic and modes of transmission. The response rate has improved significantly between the two periods compared, i.e. between the first and second half. (see Fig. 18).
8.3.2. Positive attitudes to HIV infected: It is also observed that there is a definite increase in the number of persons adopting a positive attitude to the HIV infected too. The assessment was done by selecting the answers to the specific questions on attitudes, beliefs and perceptions. The increase is dramatic among the academic community and relatives of the patients as well as lay public (see Fig.19). This is probably a very good sign if it translates into better living conditions for the PLWHAs.

![Graph showing positive attitudes to HIV infected over two periods](image)

Fig.19. Adapting a positive attitude to HIV infected (percentage of people compared in two periods)

However, as has been stated in the methodology chapter, a positive bias in answering cannot be ruled out here. People have a tendency to write better answers on paper which may not be
substantiated by their behaviour. Otherwise the fears of PLWHAs must be meaningless by now. This is a contradiction observed here.

8.3.3. Perception of risk: The need for one to be careful about a danger or illness in the community is measured using the perception of risk patterns. The number of individuals perceiving the presence of

![Bar Chart]

Fig. 20. Accepting a Perception of risk in the existing environment (percentage of people compared in two periods)

a risk in the society is directly proportional to the number of persons adopting safety attitudes and behaviours and ensuring safe practices.

In the case of HIV epidemic, this will facilitate safe sex behaviour and further protection. Fortunately the number is on the increase in Kerala over the last eight years under study.
8.4. Clinical observations: Even though not one of the major objectives, the study has as one of its objectives, a study of the patterns of clinical illnesses.

The following observations have been made.

1. The following are the ways by which people come to the hospital
   a. 192 had come after accidental detection at employment related medical examinations
   b. 176 had come after blood screening for other reasons, which included blood transfusion, pre-operative testing, voluntary testing and antenatal screening.
   c. 409 women were diagnosed after their spouses had been detected to be HIV positive.
   d. 1072 persons (including children) had come with various illnesses

2. Among the illnesses fever was the commonest in 858 (80%), followed by weight loss in 686(64%), breathlessness in 257 (24%), difficulty in feeding in 482 (45%). 214 (20%) had lymph node swellings. Dermatological illnesses were the major reason for health seeking in 5% cases. Diarrhea, various ulcerations, defective vision, neurological manifestations, memory disturbances were the other manifestations. Many patients had more than one symptom too.
3. Tuberculosis (pulmonary in 418-39% and extra pulmonary in 204-19%) was the commonest opportunistic infection. During follow up another 74 came with reactivations, adding to a total of 697 cases (65%). Almost all of them responded to therapy. Multi drug resistant Tuberculosis was identified in 96 (9%) cases. The other common OI was oro esophageal candidiasis in 386 (36%) cases and they responded very well to Oral antifungal therapy. The other OIs were Pneumocystis Carinii pneumonia in 106 (9.9%) cases, Cryptococcal meningitis, CMV retinitis and CNS Toxoplasmosis.

4. After giving therapy using anti fungal drugs and antibiotics, (along with anti tuberculous drugs, if indicated) 75% improved in less than one month’s time, if they survived that period. Maintenance therapy using the same drugs for specific periods made it possible for 56% to return their original jobs and 42% returned to some productive jobs.

5. The availability of antiretroviral drugs made the survival patterns improve a lot. Zidovudine Lamivudine and Nevirapine is the commonest combination used, followed by Zidovudine, Lamivudine and Efavirenz and Stavudine, Lamivudine, Nevirapine. Forty patients are administered with the typical HAART regimen with a protease
inhibitor. 25% could not tolerate ARV and 26% were not able to take the drugs regularly due to economic reasons. Of the remaining 256 patients, ten patients have completed more than 12 years after diagnosis, 18 more than ten years, 86 more than five years. These persons are apparently normal (with undetectable levels of HIV RNA viral loads). The number of patients who are starting ARV is on the increase every year. Once ARV is started and the person regains apparent health, there are many instances of the family accepting them back into social life.

6. Sixty pregnant women delivered during the course of study. Anti Retro Viral drugs were given for 32 of them. All the babies are reportedly uninfected at followup. Of the 28 in whom this could not be given, eight had been infected and five had died by the end of the study period.

7. Of the 1072 AIDS cases studied, 102(9.5%) had died during the course of study. Five PLWHAs committed suicide. One person died in a road traffic accident and one person died of chronic renal failure which was unrelated.
8.5 Key findings in areas of stigma and discrimination

8.5.1. Forms

Both overt and covert forms of HIV/AIDS-related DSD were reported. The main overt forms of discrimination experienced by respondents are summarized below.

**Hospitals**

- Refusal to provide treatment for HIV/AIDS-related illness
- Refusal to admit for hospital care/treatment
- Refusal to operate or assist in clinical procedures
- Restricted access to facilities like toilets
- Physical isolation in the ward
- Cessation of ongoing treatment
- Early discharge from hospital
- Mandatory testing before surgery and during pregnancy
- Restrictions on movement around the ward or room
- Unnecessary use of protective gear by health care staff
- Refusal to lift or touch dead body of an HIV-positive person
- Use of plastic sheeting to wrap the dead body
- Reluctance to provide transport for the body
Home and community

- Severed relationships, desertion, separation
- Denial of share of property or access to finance
- Blocked access to spouse, children, or other relatives
- Physical isolation at home (e.g. separate sleeping arrangements)
- Blocked entry to common areas or facilities (toilet, etc.)
- Blocked entry to common places like shop, prayer halls, school
- Denial of death rituals
- Labelling and name-calling

Workplace

- Removal from job
- Forced resignation
- Withdrawal of health/insurance benefits
- Poor access to shared facilities
- Social distance
- Labelling and name calling

There were also more covert forms of discrimination.

Hospitals

- Delays in treatment; slow service (e.g. made to wait in queues, asked to come again)
- Excuses or explanations given for non-admission (but admission not directly refused)
- Shunting patient between wards/ doctors/ hospitals
- Keeping patient under observation without any treatment plan
- Postponed treatment or operations
- Unnecessarily repeated HIV tests

Home and community

- Disparaging remarks about the HIV-positive family member
  (e.g. "he is paying for past sins")
- "Guilt tripping" for burdening the family economy and for lowering family prestige

A wide range of different forms of HIV/AIDS-related stigmatization, discrimination and denial were identified in the study conducted. The focus was on stigmatization and its consequences within the health care and employment settings, stigmatization, discrimination and denial in intimate relationships at home, in the community and even after death (in relation to the disposal of bodies and funeral arrangements). In each of these settings, felt and enacted stigma were discerned, as well as HIV/AIDS-related stigmatization, discrimination and denial in both overt and covert forms. The
majority of people living with HIV/AIDS who were interviewed had learned about their serostatus either during an illness, surgery, pregnancy or during a routine check during job entry or blood donation. Differential treatment was reported as occurring immediately after (and sometimes even before) disclosure was made.

8.5.2. Quotable experiences

Health care context

Saroja, the 38-year-old HIV-positive wife of a man diagnosed in hospital in Eranakulam, said:

"The staff were looking after my husband well, but after they tested his blood for HIV their behaviour changed and they separated our vessels, pushed him to a corner of the room and talked about us in hushed tones. I couldn’t understand why their behaviour had become so cold."

The experience of the following HIV-positive person receiving treatment for tuberculosis was typical of many others in many hospitals in Kerala:

"My blood was tested and from that day they stopped giving me injections. They didn’t tell me why."

A majority of key informants in the medical and NGO fields acknowledged that health care settings were a major source of
discrimination and stigma, but these informants nearly always placed the greatest blame elsewhere. For example, a majority of the staff in all hospital types stated that, while they provided “proper and adequate” care to HIV-positive patients, the patients’ families did not. The “family discriminates the most” was a common refrain from health care respondents. Family members, it was alleged, usually abandoned the patient with HIV infection to the health care system or kept a “safe” distance.

Doctors in government hospitals tended to blame those in local private hospitals, claiming that they frequently transferred patients rather than treating them. Staff in private hospitals, on the other hand, argued that government hospitals provided substandard treatment and care and that this led to a rise in the number of inpatients in the private sector.

“In private hospitals, the news of HIV-positive patients once detected is closely guarded and the patient is conveniently transferred to [a government hospital].” (Surgeon in a government hospital)

“The conditions in government hospitals are bad.” (Doctor in a private hospital)
Government hospitals were reportedly “under orders” to provide suitable health care facilities to HIV-positive patients, although, in general, the perception was that care in government hospitals was of poor quality. In Trivandrum, one hospital was said to be “specially designated” for AIDS care. Staff at this hospital were of the view that because of this designation, all the city’s hospitals “dumped” their AIDS patients on them.

In Cochin, individuals diagnosed with HIV/AIDS in private hospitals were frequently transferred to government hospitals where conditions and the quality of care are often far worse.

As a surgeon in a government hospital explained: “In private hospitals the news of HIV-positive patients once detected is closely guarded and the patient is conveniently transferred to a government hospital.”

A nephrologist attached to a private hospital said: “We are not bound by any rule to give treatment to infected patients. Let the government hospitals take that responsibility. There is a great risk of infection to my staff in the nephrology department, and I’m responsible for my staff’s welfare and health.”

Elsewhere in Mumbai, Bangalore, Pune and Chennai, a few private hospitals were reported as accepting people living with HIV/AIDS as patients – although this acceptance came with a price.
The costs of fumigating operating theatres and labour rooms, or liberally providing double and even triple hand gloves to staff, and an HIV/AIDS kit to all staff assisting in surgery, amounted in some medical professionals’ eyes to an indirect form of discrimination against people living with HIV/AIDS.

The practice of identifying HIV-positive patients in the wards by using boards proclaiming their status was reported as having been discontinued in most hospitals. In both private and public hospitals, however, medical files of patients were being marked “HIV-positive” in red ink. Although these files were in the safe-keeping of the ward nurse, staff in one private hospital reported that the identity of HIV-positive patients in the general ward (mainly for poorer patients) was public knowledge. ‘I can see the patient file. When the patient comes to our ward, it’s written on the file ‘HIV’ in big letters. Anybody can see it. It’s kept next to the patient. Even relatives can see it’”

The status of HIV-positive hospital staff also becomes common knowledge very easily. During group discussion in a hospital, staff members freely referred to the ward and bed numbers of HIV-positive colleagues admitted for treatment. Although it is probably difficult to avoid such identification in a closely knit hospital
setting, the lack of a culture of patient confidentiality among hospital staff was very noticeable. Within any one hospital, departments differed in terms of how they identified people with HIV. The crowded labour ward of the same hospital used a symbol (a cross within a circle) to identify the HIV patient’s bed because “in a crowded gynaecology ward where patients are put on the floor [for lack of space], staff have to quickly identify the positive patient in order to take precautions”. In other departments of the same hospital, the use of any symbols or boards was forbidden. However, in yet another department of this same hospital, a separate, small room inside the ward was used to isolate HIV-positive patients. The staff pointed out that the room had been meant for patients with infections like gangrene, but it was now being used for HIV.

The unstated intention behind all such practices was to inform staff about the need to take special precautions with patients with HIV/AIDS. While this information was meant to be displayed unobtrusively so that other patients did not know, in congested public hospitals some staff members revealed the information by their words or actions.
"Earlier in the wards a board used to be hanged from the bed, now it is not put. Still, in the ward nurses shout out at times 'Take this HIV patient for X-ray.'... All heads turn and everybody comes to know who the HIV patient is.”

“There is an almost hysterical kind of fear ... at all levels, starting from the humblest, the sweeper or the ward boy, up to the heads of departments, which make them pathologically scared of having to deal with an HIV-positive patient. Wherever they have an HIV patient, the responses are shameful.”

Certain kinds of discrimination were also reported in care settings managed by NGOs. Some NGO staff assumed that all their HIV-positive women clients worked in the sex trade; as a result, staff had a casual attitude towards their rights and needs. People with HIV who had once been offered care by an NGO in one city said that their care was provided with “attitude.” One HIV-positive woman, for example, was photographed for an AIDS programme without her knowledge and was later rebuked for questioning the staff about this. “Look you are eating here without any payment, so don’t make any fuss” (HIV-positive woman, age unknown).

Testing and related issues

In all hospitals, HIV testing was reported as being carried out on patients who did not respond to treatment for “marker diseases”
such as tuberculosis, diarrhoea, and persistently swollen lymph nodes. Blood tests were also administered on the “suspicion” that a patient had HIV. Such suspicion could arise because of a patient’s thin physique, weight loss, or skin problems, or because he or she belonged to a perceived “risk group” such as truck drivers and sex workers. As a rule, pregnant women and patients for surgery were also subjected to mandatory testing in private hospitals.

Hospitals in general did not ask for consent prior to testing. Instead, doctors acted on the assumption that patients would comply with their instructions. In one hospital, one doctor explained that patient consent is implied when the HIV test and its likely outcomes are explained during “counselling.” “There is no written consent taken [for the HIV test] but we explain the test to the patients. Only verbal consent is taken.” Verbal consent here meant a “yes” from the patient when asked if he or she understood what the HIV test meant. However, pre-test counselling was not uniformly practised, and patients were frequently asked to get an HIV test from the microbiology laboratory of the hospital or an outside laboratory before further action would be taken.
“We never keep them in the middle of other patients because they may also contract the infection. But we do not tell other patients about positive patients.”

In the course of the study, numerous accounts were elicited of medical and nursing staff breaking the confidentiality of an HIV-positive diagnosis and telling family members and relatives before the patient him/herself.

Positive test results were also often shared with the family member accompanying the patient. If the patient had come to the hospital alone, relatives were often called in, sometimes from the village, to receive the results. In one hospital, parents, wives, and siblings were called in to receive test results. In the case of married, male patients, doctors had a tendency to share the diagnosis with the man’s wife. Unmarried young men were better able to control disclosure of their HIV status. However, when the patient was accompanied by a friend or a relative, the results were often shared with them too. In most Mumbai hospitals, close relatives were given the results ostensibly “to protect the patient from shock and possible self harm”: 

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"The patient, as it were, is half-dead. If he is told of the test results, he might commit suicide, so the family members are told".

Several patients reported that their results were revealed to their parent(s), sibling, spouse, or other close relatives.

"My wife was very curious about my sickness, as I had not told her. She showed my case papers to the company's medical doctor and the doctor told her everything about my problem without my knowledge. She was very angry with me and within two days she deserted me." (HIV-positive man, aged 30)

"They [doctors] called my mother from village. She was informed about my disease." (HIV-positive man, aged 23)

"The doctor told my parents first about this disease. We came to know about it later. Only after we came here we knew about it. My parents sent us here." (Couple, both HIV-positive)

Health care staff clearly believed that the principle of confidentiality extended to sharing test results with particular groups of people, including other health care staff and family members. However, the principle of confidentiality was often disregarded altogether in the case of women, the less educated, and the poor. In the case of pregnant women, confidentiality did not even appear to be an issue. Women were sometimes not told of their own HIV
status. Their husbands, though, were often informed, based on the assumption that it was they who would decide the future course of action – that is, whether or not to continue with the pregnancy and whether or not to get tested for HIV themselves. Yet, the husband was not always the doctor’s first contact.

In the case of less-educated or economically poor patients, other family members might be informed first so they could help explain the situation to their relatives.

“When a young woman who is first-time pregnant is found to be HIV positive we call her mother-in-law. We explain the report to the mother-in-law and ask her to get the son also tested. These patients who come in here are from low-income groups, and if the girls are newly married they are really dumb and don’t understand anything, so mother-in-law is called.” (Gynaecologist, private hospital, Kozhikode)

Sometimes doctors and nurses argued that this was done so as to protect the patient from shock and possible self-destructive behaviour.

As a nurse in Malappuram explained: “The patient, as it is, is half-dead. If he is told of the test results, he might commit suicide.”
Family context

That said, there was considerable evidence that once the news had reached relatives the outcomes were far from supportive. Young women in particular reported being blamed and rejected by in-laws and other family members. Men were dealt with far more supportively and positively.

As Mary, a 25-year-old HIV-positive woman in Ranni, explained: ‘My in-laws blame me for their son’s death. They have severed all relationships with me. They never discriminated with their son but to me they say, ‘You also have AIDS. Stay happily wherever you are.’ I took great care of their son – never felt dirty cleaning him up. But they always say ‘You married him and our son got bedridden’. I have lost faith in everybody.’

And as Chellamma, a 40-year-old HIV-positive widow in Idukki, narrated: ‘My in-laws do not have a good opinion about me. They say that my husband got this disease from me. I sometimes feel why should I live with the insult. It is better to die. But I am living for the sake of my children.’

In another focus group discussion conducted in Kottayam, respondents suggested that: “People would wish that a widow living with AIDS died sooner rather than later so that she does not spread AIDS after she has got treatment and looks healthy.”
Legal professionals interviewed in Pune and Chennai reported that: “Widows have told us many times that, after the death of their husbands, among the consequences faced is ostracism, the children are taken away from them, property is grabbed by the in-laws, and people mock them that much…”

“One father-in-law sold land that belonged to his deceased son, including the plot where the widowed daughter-in-law lived. She was told to go where she got AIDS from!”

Perhaps in fear of punitive actions, some women were reported as deserting their sick husbands before the death as a means of avoiding reprisal afterwards. Men participating in a focus group conducted with people living with HIV/AIDS said: “Kinship/relatives always blame their widowed in-law for having ‘killed’ their son in case he dies of AIDS. Other reasons (for running away) are that the widow fears the likely reprisal but also running away is a demonstration of a kind of denial, not wanting to face the truth there and then.”

Occasionally, more extreme responses were noted, as in the following story, told by another woman infected with HIV in Pathanamthitta: “A 20-year-old woman had got results that she was HIV positive. She had vowed to kill her children as she had never gone with anybody else apart from her husband.”
Workplace Issues

Despite the fact that legal measures have been taken against companies that have attempted to discriminate against people living with HIV/AIDS within their workforce, seropositive workers reported being fearful of revealing their serostatus in the workplace. “Finger-pointing” was a frequently cited workplace response to people living with HIV/AIDS who were open about their condition at work.

“Even if your boss has not shown any sign of dismissing you, the fellow workmates talk behind your back. In this case, the boss may sack you.”

HIV-positive interviewees reported experiencing strong pressures to keep their serostatus secret within the workplace. The shame of admitting to colleagues and friends that you have HIV, coupled with the perceived likelihood of being dismissed on discovery, combined to silence the majority of respondents.

As one HIV-positive 23-year-old auto-rickshaw driver put it:

“You know how the society is. They want your reputation to be sullied. I know if my HIV status comes to be known to them, they will call me names, laugh at me, jeer at me, and I’ll have no other option than to commit suicide. I shudder at the very thought.”
Another HIV-positive respondent explained: "And who will give me a job? My health will not be good. I will not be able to work so they will think. What will I do for my living? So it is better not to tell anybody."

One of the army personnel was offered the choice to inform his superior officer about his sick status, so that he will get exemption from heavy duty. But he shuddered at the thought of being put in the sick list, for fear of the whole company knowing about it.

The experience of those few respondents who had revealed their serostatus at work was far from reassuring:

"Those staff members who know about me talk about it. They point at me and say, 'Look, he is the HIV fellow.' They... keep their distance from me and remain aloof. I don't share my tiffin box with them any more. I don't feel like coming to work. I remain absent for 10-15 days and then lose wages."

"My colleagues didn't openly say anything to me, but the environment was no longer the same. They avoided me. If I entered the room they would leave abruptly. Then they asked me to keep a separate glass for water. I decided to quit the job."

Beyond the enacted stigma and discrimination evident in the instances described above was the felt or perceived stigma that led
individuals to police their own behaviour to prevent their serostatus becoming known to others.

As one interviewee stated: "It is not good to reveal one's serostatus because once one's friends know, they start spreading rumours which may even reach schools where one's children study, and obviously such children get affected."

In some cases, this self-stigmatization resulted in an individual's avoidance of particular social settings and/or places of work. These included bars and clubs as well as other environments in which individuals felt they might be subjected to stigmatization and discrimination. We had encountered clients who have not been dismissed from their work but who have sort of dismissed themselves due to self-stigma. Others also saw felt stigma as triggering an uncooperative attitude as individuals refused to accept the help and support offered to them.

"One lady who had AIDS had earlier been rejected by the relatives and the community, but after she went public and declared her serostatus, those who had deserted her now come for assistance and guidance on how to cope with AIDS."

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If there was a margin of security for hospital and some factory workers who were open about their serostatus, the same was certainly not true for those employed in more marginal occupations.

Raju, for example, used to run a tea shop in an upper-middle-class residential neighbourhood in Ambalapuzha. He used to consult his local doctor about his medical condition and when he came down with an STD was advised to take an HIV-antibody test as well. He showed the positive result to his doctor who explained it to him but also alerted the local police inspector. The next day the police asked him to “move out from the locality of the rich and influential people since he was said to pose a risk to their health.”

Then there is the story of an elite club in Kochi refusing to grant their hall for a meeting on counselling for the commercial sex workers, saying “this is where our children have to play later”

In the majority of businesses with whom contact was made, denial was the order of the day. Personnel managers and welfare officers refused to acknowledge either that HIV infection was a problem or that it might be so in the future. An estate in Idukki was reported as not having a policy on HIV/AIDS because “there is not a single case of HIV reported in the staff so far”.

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The human resource development officer in a software company in Bangalore said in interview that: “Our staff is very highly paid. They are drawn from the most reputed institutes and we are quite sure they do not have behaviour which makes them suspect for HIV. They are very well educated and have easy access to sources of information, so cannot easily fall for such things.”

8.5.3. Determinants

Clearly, many factors underpin the forms of stigmatization and discrimination described above. Many of these relate to the very real fear of HIV/AIDS that exists among both the general public and professionally qualified health care workers. The sources of these fears are complex and include lack of knowledge and understanding, as well as the manner in which AIDS has been reported in the national and local media (e.g. as being highly “contagious” when in fact it is not). Other causes of stigma and discrimination have their origins deep within Indian culture and the manner in which “sexual wrongdoing” is popularly understood. Others – particularly those within the health care setting – appear to relate both to lack of knowledge about HIV/AIDS, its routes of transmission and means
of protection, as well as to local beliefs about infection through
closeness and proximity.

Long-standing ideologies of gender that result in women being
blamed for the transmission of sexually transmitted infections –
either directly as the supposed “vectors” of transmission or indirectly
through failing to “satisfy” their husbands – influence the ways in
which families and communities react to the seropositivity of their
members. While seropositive men may be offered support and care,
the same is unlikely to be true for women – many of whom are
blamed for the illnesses from which they and their husbands may
suffer.

Processes of stigmatization, whereby people living with
HIV/AIDS are rendered outsiders and “others”, are also reinforced
by the tendency for people living with HIV/AIDS to make
themselves invisible and to disavow their condition. This enables
employers and others to deny that there is a problem.
8.6. Summary of Observations

Clearly, HIV/AIDS has evoked a variety of responses in the Indian context, some of them positive, others considerably less so. At the positive end of the spectrum are the reactions of households and families who agreed to provide care and support for affected members. These responses, it has to be said, were relatively frequent, but were more likely to occur when male household members rather than women were affected.

Much more common were responses of ostracism and rejection. The predominant effects at the individual level were fear and withdrawal leading to secrecy about HIV status and self-imposed social isolation. In a few cases, suicidal tendencies were noted, and in a few other instances people living with HIV/AIDS sought to avoid stigmatization by denying their serostatus, thereby risking transmission of infection to others. Negative responses in the health care setting (or the belief that there will be negative responses) lead people to conceal their HIV status in treatment facilities for fear of being denied care. Individuals who are sick may also delay seeking treatment until the last moment, harming their own health in the process.
Within the workplace, widespread denial that HIV/AIDS is a problem means the majority of companies and employers have no policies and procedures with which to respond to seropositive employees. The belief that HIV only affects promiscuous people, and that “such types” are unlikely to work in a given location further contributes to institutional denial. Because of the social stigma associated with HIV/AIDS and in the absence of legislation and procedures stipulating how people living with HIV/AIDS should be treated at work, many prefer to keep their serostatus secret. This contributes to the invisibility of the epidemic and makes life more difficult for those individuals affected.

Occasionally, however, HIV/AIDS-related stigma may trigger more positive responses such as the altruistic actions of those who carve roles for themselves as educators, counsellors and HIV/AIDS activists. Through their work, such individuals may develop a collective identity and mobilize group support that results in a greater awareness of the epidemic and more positive responses towards those affected.
8.7. Barriers to Control

Even though HIV infection is easy to prevent and rather easier to manage there are many barriers. These can be summarized into two main types, personal barriers and system barriers.

8.7.1 Personal barriers:

Denial of HIV status: Denial is the strongest argument of asymptomatic patients. The community perception that, without symptoms, there is no infection and therefore no risk of transmission to others. Denial was quite common and was often the reason for resistance to continuing contact, to attending clinics, or to disclosing HIV status to family and partners. The rational approach would be not to argue with the patient but to try to explain HIV by calling it "the hidden disease". This is usually explained by comparing to situations in agriculture or environments where calamities take time to manifest and even harvest failures occur in spite of an apparently pleasant appearance.

Fear of stigma: The level of stigmatization in the community presents a very high barrier to care and support. Patients resist contact with health systems for fear of being “found out” by others in the community. Fear of stigma by family members or regular
partners could be overcome by offering help in disclosure, but the barrier is greater for the unmarried young adult. In few cases the partner broke off the relationship after learning about the status of the patient. The patients had a feeling that the health care managers (doctors and the like) were the only people respecting confidentiality (if at all).

**Resistance to condom use:**

Lack of basic knowledge about HIV/AIDS or the use of condoms and reactions to condom use often depended on the marital status of the HIV positive person or the type of relationship that this person had. There were several reasons for this resistance.

- Most of the people in the community are religious, and many not favour small or no kid families.
- Many believed that suggesting usage of condoms was equivalent to divulging infidelity.
- Some patients did not believe in the ability of condoms to prevent infection.
- Some patients indicated the belief that condoms decrease sexual pleasure.
- Persons who denied their HIV status consciously or subconsciously had great difficulty in accepting the need for condoms.

**Fatalistic beliefs:**

This barrier included the belief that the disease is ordained or is a stroke of fate. There is nothing that a person can do to change this situation. Most saw it as an act of God or of a bad spirit, as a punishment or curse. This belief was more when the whole family of husband, wife and all kids were affected. Few could think that they need to change their behaviour and show that they were responsible for others: then God would make things better for them.

**Lack of empowerment of woman in sexual matters:**

Many wives of infected men said that they could not refuse sex because of their dependency on their partner. The need to empower women was widespread and has to be accomplished in very sensitive ways. One of the very important argument was the importance of preserving the health of one’s wife, so that she could take care of the children and support the husband when needed. In some cases the fear of being abandoned by the wife prompts men to adopt safer sex.
8.6.2 System barriers:

System barriers were not related to the difficulties of the people with HIV but were imposed by the system or case managers.

Reporting pressures:

Many health staff and volunteers experience great pressure to let the result be shared by many. They feel that it is a great offence if they do not let others know about the result. They sometimes made revelations very dramatic that caught the attention of the society quickly. The official channel of reporting also could not escape from this malady when statistics without any data were being released. The same pressure sometimes forced the providers to shout about the serostatus to relatives and neighbours too.

Disbelief:

Some personnel, usually working in a protected environment with very little understanding of grass root realities did not believe in the scientific truth. They even questioned the theories, and made their own interpretations that ran in a direction comfortable for the people at large. When there were suggestions that HIV may not be the cause of AIDS (a very wrong notion), people were very eager to hold on to it, not because of any reasoning, but because that might give them
a chance to avoid any behaviour change, which is uncomfortable for many (if not all).

All the providers do not believe that behavioural interventions can change the situation. They find different reasons to say that these persons who might have adopted a risk behaviour for reasons well known to them are never going to change. These people sometimes adopt the all or none criteria to prove their point. Such disbeliefs tend to be self-fulfilling, as there is general lack of cooperation from these type of individuals. Calls for sensitizing and training staff had come at a very early stage and these are still continuing.

8.7. Inferences

The analysis places people and their communities at the centre of the exploration of repercussions of the spread of the virus. We are still struggling to understand all the factors that determine the nature and parameters determining the virus spread. An improved understanding of these will enable us to better understand how the virus moves from place to place, person to person and generation to generation so that we can more effectively control the spread and anticipate the repercussions.
Inequalities of Wealth, Power and Autonomy is a major factor. The greater the disparity, the more stratified a society is, the faster and further the virus spreads. Both the rich and the poor suffer. The rich, like the powerful are more mobile, less constrained by community norms and can afford lifestyles they choose, which often place them at risk of infection. The poor and the powerless alike are less able to make choices about their life circumstances, more often forced to work away from home and family. They may even be forced to seek pleasure or earning from sex work or engage in sex for extra earning related to or unrelated to regular work or even study. Their health and nutritional levels are low and often they cannot afford to use the regular health services. A lack of autonomy is captured by concepts such as subordination, oppression, and exploitation. These may be psychological, physical, emotional, cultural or social.

Community norms and values: Societies where the social construction of gender leads to quite different paradigms of masculinity and femininity have higher infection rates. Communities which place sexual satisfaction of male above responsibility to others and where passivity and self effacement in women are valued have
higher infection rates. The indicators of these attitudes are increase in the levels of domestic violence, physical abuse of women, Where women are denied dignity the virus spreads faster.

The genital health is also related to the levels of sanitation, hygiene practices, nutritional status, access to sensitive health services, cultural practices etc.

Mobility of the average population has a direct bearing. Majority of infections in Kerala has occurred in labourers working and changing places. The transport routes, commercially vigorous trading centres, the exit and entry areas to other job markets are all linked to higher infection rates.

Stories and Correct news have a major role to play. The stereotyped stories of having got the infection from a CSW or from casual sex, having been lured into sex in guise of employment, romance, security etc. must be publicised. Conditions must exist where stories of being infected and how behaviour change helped prevent infection are known to the society at large. For this to happen, there must be a strong legal and ethical framework which will lessen the almost inevitable discrimination and stigma.