Chapter 2

CONCEPTUALISATION
AND
METHODOLOGY
When the literature available on HIV/AIDS in the world of work is reviewed, one is most often confronted with the following questions – why is there so much thrust upon sexual behaviour of individuals? Is it not leading us into just one direction, so that we are neglecting the other important factors? Why does the majority of research on sexual behaviour studies in India focus primarily upon the extent of sexual activity outside marriage and the levels of awareness about STDs and HIV/AIDS? The Indian studies conducted in this area are conceptually limited and do not come up with a comprehensive account of the true nature and magnitude of the problem. While these studies are useful they fall short in designing appropriate strategies to combat the problem.

Sexual Behaviour Patterns

Sexual behaviour patterns and their determinants are complex phenomena, which need deeper exploration and understanding. Most of the existing studies in India rely on similar designs and methodologies, which do not allow in-depth probing into the complexities (Deepak, 1998). Typically, for example, data are drawn from surveys with self-administered questionnaires (or) with face-to-face interviews, (Goparaju, 1993; Savara and Sridhar, 1993,1994; Sharma and Sharma, 1995). Research on AIDS touches on some of the intimate issues in human life such as people’s sexual behaviour, an area difficult to research (Schoepf, 1988; Caldwell et al. 1994). Responses on such issues can rarely be cross-checked since they do not lend themselves to observation or some other forms of research strategy. Therefore, ascertaining the reliability and validity of information obtained goes beyond a single cross-sectional study (Dare and Cleland, 1994).

AIDS and the Working Population

A study conducted among unmarried male members of three groups of workers viz. migrants, white collar and blue collar workers aged 20-25 years in Nasik and Thane, Maharashtra, came out with significant results. Among the unmarried male workers; 30 per cent of the blue-collar workers, 26 per cent of white-collar workers, and 25 per
Conceptualisation and Methodology

cent migrant i.e. manual labourers have had a sexually active adolescence. The age of initiation of sexual activity ranged between 17 and 19 years among these workers (Savara and Sridhar, 1994). In a similar study among married women aged 27-32 years found that blue collar workers (9 per cent), migrants (7 per cent) and white collar workers (1 per cent), reported pre-marital sexual activity (Savara and Sridhar, 1993).

The Tamil Nadu Behavioural Sentinel Surveillance survey conducted by APAC among ‘Factory Workers’ had a significant outcome (Table 2.1). While the knowledge among Male Factory Workers (MFWs) on the prevention of AIDS remains the highest at 98 per cent, their knowledge on STDs has reduced from 98 per cent to 87.8 per cent in 2003. Knowledge on HIV/AIDS among Female Factory Workers (FFWs) continued to remain high at 93.6 per cent. Their knowledge on STDs had increased from 59 per cent to 87 per cent in 2003.

Table 2.1 HIV Risk Behaviour Surveillance Survey Year wise data (1996 – 2003) in Tamil Nadu

<table>
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<th>Years</th>
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<td>2003</td>
<td>87.2</td>
<td>26.1</td>
<td>83.3</td>
<td>19</td>
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Note: T&H – Truckers and Helpers; CU – Condom Usage; NRS – Non-Regular Sex; CSW – Commercial Sex Worker; MFW – Male Factory Worker; FFW – Female Factory Worker

Source: APAC-VHS, 2004

The MFWs involvement in non-regular sex continues to remain the same at 11.6 per cent till 2002. However, it had increased from 11.6 per cent in 2002 to 19 per cent in 2003. The involvement of FFWs in non-regular sex continues to remain low at 2 to 3 per cent from 1999 to 2003. Involvement of MFWs in both paid and casual sex increased from 4.2 per cent to 10.2 per cent and 7.9 per cent to 9.8 per cent.
respectively. The condom usage behaviour of the MFW with the non-regular partner increased from 45 per cent to 64 per cent in 2003. APAC has implemented workplace intervention for the past one year. When condom use of MFWs was analysed by type of partners, different trends were obtained. In paid sex, condom use had increased from 28 per cent to 90.2 per cent. In casual sex it remained low at 32.4 per cent.

Among CSWs, knowledge about preventing HIV/AIDS without misconception has increased from 24 per cent in 2002 to 32 per cent in 2003. Whereas in the year 1996 only 56 per cent of the CSWs had reported condom use at last sex. It had increased to a reported high of 91 per cent in 2000 and remained stable at 87 to 88 per cent by 2003. Since 1999, the BSS has also monitored condom use with live-in partners. Compared to only 6.4 per cent in 1999, more than 28 per cent reported using condoms with their live-in partners in 2003.

Among 'Truckers' and 'Helpers', a reduction in the number of involvement in non-regular sex was observed. It has decreased from 48 per cent in 1996 to 26 per cent in 2003. The trend is getting stabilised at 26 to 27 per cent. The trends on condom usage behaviour have significantly increased in the last year from 74 per cent to 83.3 per cent (APAC-VHS, 2004)

AIDS and Workplace
An another study carried out by the Centre for Development Research and Training (CFDRT) in 1995 to access the economic impact of HIV/AIDS on the organised sector covers industrial workers and management of 10 select industries in and around Chennai (TN), sponsored by the Employers Federation of Southern India (EFSI) with the support of ILO, New Delhi. As per the findings of the survey 9221167 work hours have been lost due to sickness in the three years preceding the study. Percentage of turnover was less in the ten selected industries due to sickness all through the three years. There was a low awareness among workers as well as management staff regarding AIDS; there were misconceptions about how
HIV/AIDS is transmitted and how one could avoid HIV/AIDS. 75 per cent of employees were unaware that condoms could prevent STDs and AIDS and only 5 per cent used condoms properly.

UNAIDS and The Prince of Wales Business Leaders Forum (1997) concluded from the study that measurement of various costs incurred due to HIV/AIDS is important, because enterprises need to be convinced that it may be financially meaningful to invest on prevention and control programme. Such concerns of the effect of the spread of infection on business have been well estimated especially where HIV prevalence rates have been relatively high. A study compiling the profiles of 17 leading businesses in the African region and their response to the impact of HIV/AIDS reported that the economic impact of HIV/AIDS on business could be substantial. This impact is primarily felt in disruption of production due to absenteeism and illness, increased production costs associated with the higher labour turnover and the need for giving more employment benefits. The study also estimated that HIV prevention programme costs are usefully lower by about half of the financial impact of HIV/AIDS.

Social Dimensions of AIDS
The impact of AIDS on a micro-economic or household level has been very significant. Barnett and Blaikie provided an example of a micro-economic analysis in 1992. Their study showed that the death or illness of a family member due to AIDS resulted in a deterioration of the producer versus consumer ratio in almost all households examined. In this embroil, there is likely to be increasing discrimination in the workplace, resulting in large numbers of those who are HIV positive losing their jobs. The burden on families, who have to care for people dying of AIDS, and those who lose breadwinners, will be enormous. This will be aggravated by unemployment, by inadequate social support services, by discrimination in access to insurance and housing and by the predicted inability of the health services to offer adequate care to affected individuals and support to their families.
There are studies that explore the perceptions and attitudes of HIV/AIDS patients in sub-Saharan Africa. Using data from a study on the social dimensions of AIDS infection in Ghana, the paper explores the attitudes and behaviour of patients and their perception of the attitudes of their relations and neighbours towards them. The traditional forms of support for sick persons in Ghana are under strain either due to or independent of HIV infection. In spite of changes, infected persons perceive their female relatives to be more sympathetic than their male relatives. Some patients continue to deny their HIV status (Awusabo-Asare, 1995).

Though various studies on HIV/AIDS have been conducted in India, the analysis of its impact has largely been at the level of individuals and households (Gupta, 1997; Basu, et al. 1994; Satyamoorthy, and Sunithi Solomon, 1997; Singh and Ateeq, 1999; Mukhopadhyay, Swapna, et al. 2000).

**Health care utilisation**

India has a three-tier public health system — comprising PHCs in villages, district hospitals and tertiary care hospitals — but the government expenditure is shrinking. At present, India spends about 0.9 per cent of its gross domestic product (GDP) on health care, which is lower than the average of 2.8 per cent of GDP spent by some less developed countries. While the government is spending less, private health care is expanding. According to a World Bank study, nearly 82 per cent of all health spending in India is private. It also pointed to health inequities such as the poorest 20 per cent getting only 10 per cent of subsidies, while the richest 20 per cent capture 33 per cent. “It is a paradox. On one hand, bed capacities in five-star private hospitals remain under-utilised, forcing the industry and government to promote health tourism. On the other hand, PHCs are suffering due to lack of government patronage”, said Jean Dreze in a public hearing convened by Jan Swasthya Abhiyan in New Delhi on 10th March 2004 (Sharma, 2004)
In India, there are two predominant pathways of healthcare financing. The bulk of the resources (roughly 85 per cent flow from individuals and households directly to healthcare providers—predominantly private—in the form of out-of-pocket payments (WHO, 2000). Public resources, the second most important source of healthcare financing (central, state and local governments contribute 13 per cent), are typically used for the provision of healthcare through the multi-tiered system of public providers.

The Government of India’s social insurance schemes (Central Government Health Schemes and Employees’ State Insurance Scheme) and voluntary insurance schemes (Mediclaim provided through four Government Insurance Company subsidiaries) are geared towards workers in the organised sector, who comprise not more than 10 per cent of all workers (van Ginneken, 1998). Together, these schemes cover approximately 42 million people. The only government initiative to cover the informal sector is in Goa (1991 population of only 1.17 million), where the state government has purchased insurance through the Government Insurance Company (GIC) to cover the hospitalisation needs of all permanent residents with an annual income of less than Rs 50,000 (Wyatt and Bhat 1997).

Healthcare costs, and those for in-patient care in particular, pose a barrier to seeking health care, and can be a major cause of indebtedness and impoverishment, particularly among the poor. An individual with a low income may be unable to afford preventive care, or curative care in the event of illness, which may result in the worsening of his or her state of health (Ranson, 2003).

In India (only in part due to the costs of healthcare), rates of healthcare utilisation, both ambulatory and in-patient, are far higher among the wealthy than the poor, and the poor use care of lesser quality. On an average, the poorest quintile of Indian is 2.6 times more likely than the richest to forego medical treatment when ill (Peters et al. 2001). Aside from cases where people believed that their illness was not serious
(which comprised more than half of all cases), the main reason for not seeking care was cost, particularly for the poor. The richest quintile of the population is 6 times more likely than the poorest quintile to have been hospitalised in either public or private sector. Among those who do opt to seek healthcare, the costs can be catastrophic. According to an analysis by Peters et al. (2001), at least 24 per cent of all people hospitalised in India in a single year slipped below the poverty line because they were hospitalised. In theory, government provision of healthcare should cover the poor, but in practice it often does not. Thus, there is a need to find ways of protecting the poor from the costs of medical care.

The 1978 Alma-Ata declaration for “health care for all by the year 2000”, was perhaps the last time when such an ambitious and rights-based call for access to health care was heard. The rights-based goals of Alma-Ata were modest; 90 per cent of children should have weight for age that corresponds to reference values, every family should be within a 15-minute walk of potable water, and women should have access to medically trained attendants for childbirths. Moreover, there was unanimous agreement that these goals could not be achieved without increased international aid (Hall and Taylor 2003). However, this proposed right to universal basic health care was attacked by international experts as naive and too expensive.

A study of 764 HIV positive people in India, Indonesia, Philippines and Thailand noted that more than half reported discrimination in the health sector. Those who were unprepared for testing or who were coerced were more likely to report discrimination. Breaches of confidentiality were common (Asia Pacific Network of People Living with HIV/AIDS, 2003).

Treatment – Antiretroviral therapy
One of the most crucial problems in tackling HIV-1 in India is the social stigma surrounding it. Treatment can help disseminate information that this illness is treatable. If government hospitals have substantial services to offer, more patients
will come out into the open for treatment. With the spread of news regarding the availability of effective drugs and the sight of patients improving, there will be a shift in the public perception that the disease follows a uniformly inexorable course. The spread of this information, coupled with extensive public education, can eliminate discrimination (Anon, 2002).

The WHO/UNAIDS “3 by 5” initiative aims for 3 million people to be started on antiretroviral treatment by the end of 2005 (WHO. 2004). Although AIDS is now treatable, less than 5 per cent of the 40 million people living with AIDS have access to antiretroviral. The 34 countries targeted by the initiative are home to 94 per cent of people needing treatment in the developing world. An honest assessment of the global situation today shows that it is the market that decides who lives and who dies. The de-facto criterion for receiving antiretroviral treatment is the ability to pay for treatment (Mukherjee, 2004).

Antiretroviral therapy has improved the prognosis of patients with HIV-1 infection (Mocroft, Vella, Benfield et al. 1998). Physicians’ supposed lack of awareness and the ‘weak health system’ is no reason why patients must be denied this treatment. Physicians’ experience with comprehensive care and highly active antiretroviral therapy (HAART) will only evolve once they are provided with an opportunity to access the requisite drugs. Years ago, the arrival of directly observed therapy (DOTS) for tuberculosis was met with much skepticism. However, laying down treatment guidelines and enlisting the support of medical-college faculty has been a huge success in India (Granich and Chauhan, 2003). Education in medical schools and strict guidelines will help physicians to prescribe HAART appropriately, and this must be offered as a part of comprehensive care (Priya, 2003). Similar to DOTS drive in India, training programmes must be initiated to a select group of physicians. The right to prescribe HAART must be restricted to physicians who have undergone specialised training (John and Thomas, 2004)
Of 200 HIV positive patients referred to specialist centres in India because of poor response to antiretroviral treatment, only 10 per cent had adhered to treatment; 50 per cent had stopped taking the drugs on the advice of traditional healers, and 80 per cent had been receiving incorrect doses. In India, 60-85 per cent of primary care provision occurs in the largely unregulated, formal and informal private sector (Saple, Vaidya et al. 2002).

An example of a currently operational comprehensive approach to AIDS care, which includes access to free voluntary tests and counselling, the provision of Zidovudine or Nevirapine for the prevention of mother-to-child transmission, diagnosis and treatment of opportunistic infections, social assistance and directly observed provision of HAART (DOT-HAART) by trained community health workers to the most severely ill patients, has been implemented by Farmer et al. in a poor rural area in Haiti where HIV infection is endemic (Farmer, Leandre et al. 2001 and Farmer et al. 2001).

STD and HIV

The quality and accessibility of services clearly plays a role in attracting people with, or at risk of, STD (Mertens et al. 1994). However, social stigma around issues of sexual activity and STDs will have a major influence on patterns of presentation to health care services. In order to increase the proportion of people with STD who seek effective treatment and counselling, programme planners need to know more about factors that influence health-seeking behaviour in relation to STDs (Ward et al. 1997). Numerous studies have shown that improving care for STIs will diminish the risk of acquiring HIV (Behets, Desormeaux and Joseph, 1995; Smith-Fawzi et al. 2003).

Integrating HIV prevention and care

Improving HIV care helps to destigmatise AIDS. Decreased stigma is associated with increased interest in voluntary counselling and testing, which is a cornerstone of
effective HIV prevention and care (Farmer et al. 2001).

Counselling and Testing

Holmes (2004) was of the opinion that many Asian countries are still in the early stages of establishing voluntary counselling and testing services, which can play a vital role in prevention, as well as being an entry point to care. However, the pressure to identify those eligible for antiretroviral threatens to skew counselling and testing towards screening those with symptoms, and to weaken principles of consent and confidentiality. Once these safeguards are diluted, vulnerable sections of the community—such as prisoners, injecting drug users, and sex workers—might be coerced into testing.

Lack of treatment guidelines, but more crucially lack of links between private practitioners and specialists and lack of access to research evidence, was reported in Zimbabwe (Nyazema, Khosa et al. 2000). If guidelines are to contribute to a public health approach, they need to take into account public health realities in resource-limited settings (WHO, 2002). Most poor countries lack two proven essentials for working with dominant and uncontrolled private sectors: financial leverage and effective enforcement of regulatory controls (Smith, Brugha and Zwi, 2001).

In time, it was felt that interventions targeting the infected workers at workplace could not overcome the problems since there were a host of other issues involved. For instance, with the ‘workplace approach’ it would be difficult to study the social impact of the disease from the point of view of a working population. We are aware that not only the worker who is infected by the disease is suffering but also his/ her family members and others in the society are affected by the negative impact of the disease. In this wider sociological context, the social and cultural norms and circumstances also influence the general well being of the infected individual. This therefore, essentially, was the backdrop, for emergence of the concept of ‘world of work’ (ILO, 2000).
There have been studies which have dealt with specific 'risk behaviour' occupational groups or which have focused on specific industrial set-ups to study workers' experiences in the context of HIV/AIDS. There have also been studies, which deal across various strata of workers with their vulnerability to the disease. All these studies have been significant in their own right. Yet research in this area has hitherto been inadequate in the sense that we fall short of studies which comprehensively take into account the worker's perceptions and experiences regarding their disease and its treatment, initiatives taken by their employers, and the social aspects with reference to HIV/AIDS. The nexus of all the three components that include issues related to workplace, social implications and treatment experiences means that each one cannot be considered in isolation. There must be a meshing together of all the components on a holistic basis, which is the missing link in most of the studies. In the light of the above issues, it is imperative to formulate a study, which tries to overcome this missing link.

Another point of concern is that besides the possibilities of acquiring the virus from sexual behaviour, other behaviours (IVDU to invasive medical intervention) also need to be considered and addressed. There could be possibilities that a person is confronted with either one or a combination of these factors but the source of infection in any case is just one of them. This does not necessarily prove or disprove the reasoning that sexual mode of transmission of the virus is the predominant one, but to look into the possibility of other sources of infection is equally important. Therefore, the recognition of all possible sources of infection is slowly gaining momentum; there is a need to document such possibilities through appropriate research.

**Conceptualisation of the Problem**

It is absolutely impossible to draw a discriminating line between the general population and the working population, since it is the general population which is
working, and the rest are members of workers' households. The risk of contracting HIV infection and the subsequent experiences can be analysed in terms of three spheres which are closely interlinked – the occupation and work related issues, the social dimensions and the issues of treatment, care and support. Keeping in mind this information about HIV/AIDS and the working population, the present study has been formulated on the basis of the three essential components of the life of the working population and its experience of HIV/AIDS.

(1) Issues related to Work and Workplace
In most cases, the formal workplace is not directly involved with the transmission of HIV/AIDS, unless the work itself necessitates frequent exposure to the virus in some way or the other. The risk of HIV/AIDS in workplace as with other blood-borne and sexually transmitted diseases is low. Broadly, there are two levels of risk associated with occupation. The first level of risk is that which exposes workers to blood or blood products, particularly in conjunction with the use of sharp instruments. This may present workers with the occupational hazard of exposure to the virus. For instance, in the field of medicine, transmission is an occupational hazard (usually from patients to medical workers rather than vice versa) even though it is a rare occurrence and can be further reduced if standard procedures and precautions are followed. A higher level of risk is associated with occupations that expose persons to risky opportunities. The interaction of commercial sex workers and truck drivers in Africa and India, for example, has played an important role in disease spread (Kroger, and Priscilla Holman, 1994).

Several sociological factors work in unison to predispose the ‘economically productive population’ of the nation to HIV/AIDS. It is generally the economic factors, which lead people to migrate in search of better remunerative options. This applies equally to all the classes of workers. However, the vulnerability is greater for the poorer sections, because of the poor working and living conditions they migrate to. Uncertainty of work and poor working conditions such as sanitation, housing,
health care etc. do not allow the male migrants to bring their families. These lead to disruption of marital life and a break in family ties and community support. As a result, the migrants are likely to indulge in unsafe health practices such as intravenous drug use (IVDU) and multi-partner sexual activity. Because of the cultural disruption, they break away from their original environment and are exposed to a new and aggressive social milieu. Such conditions promote the breaking of social norms and encourage sexual activity outside marriage. They also make the young population susceptible to negative peer pressure. In addition, images and aspirations generated and promoted by the media accelerate the pace of change in social values, and increase vulnerability to negative pressures of alcohol; sex-mafia and mafia involved in trafficking and peddling of drugs, thus promoting IVDU. Commercial sex workers and women workers, especially the poorer ones and those at the lower rungs of employment are often susceptible to sexual abuse either by their employer or by seniors in the workplace hierarchy (Mahesh, 1999).

Once a person is infected with the HIV, the most widely discussed issue of relevance within the workplace has been that of 'prejudice' and 'discrimination' against people with HIV/AIDS, be they employees or customers/clients of an organisation. For people who are infected, discrimination occurs both in their attempts to get jobs and keep them and in their relationship with employers and colleagues. Both the employer and employee have equally vested interests to ensure that the disease has the least possible impact on the workplace. It is widely accepted that employment provides an important component of identity and a source of psychological support for many people, over and above the material benefits that it brings. Although such attachments may be undermined by expressions of prejudice and discrimination for many people with HIV, work is likely to remain an important component of their lives. It is, therefore, important to establish guarantees in the labour market to ensure that infected workers enjoy full rights, including the right to full, freely chosen, and productive employment (N'Daba, 1994; Hodges-Aeberhard and N'Daba, 1998).
There is a widespread misconception that HIV is 'someone else's problem'. It is a disease of selected groups commonly referred to as 'high risk groups' i.e., promiscuous people, intravenous drug users, foreigners and so on. Misconceptions breed fear among those who have their first encounter with a person with AIDS or some one known to have HIV. Fear often leads to discrimination against people who have HIV. Also, mistaken beliefs that casual contacts can spread the virus have led to the isolation and loss of dignity and respect of the people infected with the virus. Disclosure of a person's HIV status can lead to the consequence of his/her being stigmatised and subjected to discrimination to the extent of losing their jobs, houses and families. In addition there are certain pertinent issues that need to be considered with regard to the HIV infected workers: The fitness to work during the so-called incubation period and adjustments in the duties of the workers who turn out to be AIDS patients; implementation of adequate precautions in workplace settings to reduce risk of transmission of HIV during accidental exposure to an AIDS patient as the source; mandatory HIV antibody testing of employees without their informed consent and counselling and so on (Evian, 1991).

(2) Social Aspects
The workplace is not directly involved in HIV transmission. It creates conditions, which accentuate behaviours leading to HIV transmission viz. 'the recreational activities of sex and drug use'. More often than not, it would be the monotonous nature of the work that might lead the workers to seek such recreational activities, which put them to the risk of getting infected. In the context of HIV/AIDS, 'risk' is defined as the probability that a group or sub-population may acquire HIV infection. There is documented evidence to elucidate that in a working environment, the working and living conditions shape the perceptions of 'risk' (Singh et al. 1999). Certain types of behaviour create, enhance and perpetuate this risk. High-risk behaviour includes for example, unprotected sex with a partner whose HIV status is unknown, multiple-unprotected sexual partnerships, lack of adherence to infection-control guidelines by health care personnel, repeated blood transfusions, especially
using untested blood, and injecting drug use with shared needles (ILO, 2000). It is not necessary that every person who stays away from home without the social support and family would get involved in risky behaviour as it is usually made out to be. But we cannot rule out the possibility that under conditions of migration combined with the stress of work, such a risk increases. Mobile workers, including migrants tend to be more vulnerable to infection than local populations for reasons, which may include lack of hygiene, poverty, powerlessness and the precarious family situations, which accompany their status. A number of gender related risk factors increase women’s exposure to HIV and sexually transmitted infections, and impair their ability to protect themselves from infection. These include:

(i) Behavioural factors, such as inability to participate in sexual decision-making;
(ii) Gender-related cultural factors, such as different expectations regarding sexual roles, fidelity and marriage;
(iii) Socio-economic factors, such as inadequate access to health care and unequal educational and economic opportunities which may promote dependency on a male partner, or even lead to commercial sex (ILO, 2000).

The above-mentioned working conditions and just about any other kind of work, all need to be taken into account when studying the problem of HIV/AIDS in relation to workplace.

Moreover, certain features are unique to HIV/AIDS, which complicate the issues. There are chances of multiple cases of HIV/AIDS occurring within a household. Another significant and inevitable fact is that when a person is infected, it is not only the individual who is suffering, but also people who depend on him/her in all means, who undergo the trauma. Therefore, it is essential to focus not only on the people infected with HIV/AIDS but also on those affected by the dreaded disease. There is a long period of invisibility between infection and appearance of opportunistic diseases during which an HIV positive person can remain disease free for years.
Following this, multiple illnesses invariably lead to death. The early detection of HIV infection differs from similar detection of most other diseases for which a test is available because of the following reasons:

(i) HIV infection is believed to be invariably fatal irrespective of best possible treatment.

(ii) HIV infection and AIDS are still associated with high degree of discrimination and stigmatisation. The implications of a positive test go well beyond those related to physical and mental health and may involve the loss of employment, medical and social benefits; friends, family and freedom of movement.

(iii) HIV infected persons may lead a completely normal healthy life for several years before they manifest physical effects and become ‘AIDS cases’. Overlooking this unnecessarily increases social suffering of the HIV infected (NACO, 1999-2000).

(3) Treatment Experiences
Issues of accessibility and quality of health care have an added significance in the context of vulnerability to HIV/AIDS. In health care services the practice on safety precaution needs improvement, both in the process of blood transfusion and in other common procedures; for example, use of injections. This as an important issue holds for all levels of workforce, but even more so for the poorer section or the lowest rung of workers who usually go for untrained medical practitioners.

‘Health for all’ remains a distant dream yet to be achieved in its true sense as conceptualised in Alma-Ata declaration in 1978; it is defined as “attainment of a level of health that will enable every individual to lead a socially and economically productive life” (Park, 1995). Health is a fundamental human right. This implies that the state has a responsibility for the health of its people. Similarly, in an employer-employee relationship in any workplace situation, individual employers are under an obligation to protect the well being of workers and to secure to them their due shares
Conceptualisation and Methodology

in the gains of economic development. There are various social welfare legislations to protect the worker’s health and well being; like Employees’ State Insurance Act, 1948; The Workmen’s Compensation Act, 1923; The Maternity Benefit Act, 1961, etc. But worker’s health is not given appropriate priority in workplace policies. Therefore, the problem of general health at workplace is not considered an issue of concern by the employers in both organised and unorganised sectors. They escape from their responsibilities and disregard any such provisions made by the state for the employees. Though there is a very small, rather insignificant percentage of workforce that is covered by formal social security arrangements which take care of aspects like medical care, and ensure a reasonable level of quality of life.

Among the workers those who are infected by HIV, stigma and fear make knowing that one is HIV positive a great trauma. If one tries to hide ones HIV status for fear of losing one’s job and for fear of being stigmatised, seeking social security and other benefits is impossible. On the other hand if one reveals one’s HIV status, there is no guarantee of gaining access to social benefits. Conversely, it proves self-depreciatory to the extent that one might even lose one’s job. Under these circumstances, then, those who have contracted the virus face tremendous stress from all quarters of life. To make the situation worse, there are very few who are willing to treat these patients. This, despite the fact there are provisions for the treatment and care, counselling services and follow-up measures among the guidelines set up meticulously by NACO in its components for ‘Clinical Management of HIV/AIDS patients’. But, the steps taken in the development of treatment mechanisms remain far from satisfactory. Apart from the curative aspects, both the infected as well as the affected population needs to be provided with basic preventive knowledge.

A policy on AIDS at workplace is a sound economic investment for the community (Nangia, 1998). The workplace management also fulfils its social responsibility, which results in positive image for the organisation. There is an urgent need to evolve a system where the employer, the employee and the community share responsibility to
address the treatment mechanism of people infected with HIV/AIDS. One step in this process has been to establish new support services for care for persons with AIDS in partnership with NGOs and CBOs by establishing small community based hospitals, hospice programmes, drop-in-centres and home based care (NACO, 1999-2000).

Regarding the three essential components that have been discussed above, it is important to point out that there are certain factors of significance, which link up these components. They remain conspicuous in one form or another either in the workplace setting, or in other social settings or even during treatment. One such factor is the source of infection; AIDS has become an issue of morality primarily because of this factor. In most cases the HIV positive person is ostracised and socially reprimanded, owing to the lack of awareness about the sources of infection other than sexual behaviour. Further, there is need to realise the vulnerability to infection; for instance the vulnerability of women, intravenous drug users, etc. with regard to HIV/AIDS. The absence or presence of support by family, friends and other members of the community depends on proper knowledge and awareness regarding these issues. This in turn determines the attitude of the patient as well as the society towards the disease and shapes the psycho-social support provided. Moreover, individuals who suffer such discrimination are less able to cope with the burden of HIV/AIDS. For people exposed to HIV, it will be difficult to seek testing, counselling, treatment or support if this means facing discrimination, lack of confidentiality, and loss of employment or other negative consequences. Thus, access to treatment is another important factor. The socio-economic conditions of workers vary according to respective positions at the workplace. Therefore, primarily due to economic reasons, the access to treatment becomes a distant possibility. Besides, the General Health Services have an important role to play in the testing and treatment of HIV/AIDS patients. Effective medical services with quality care and credibility are therefore, essential for AIDS action as for other medical problems (Priya, 1998).
It has already been pointed out that it is not possible to draw a distinction between the working population and adults in the general population. The study not only considers issues related to workplace but also social aspects and issues related to treatment experiences. Therefore, considering the working population with regard to HIV/AIDS does not necessarily require that we limit ourselves to a workplace setting. Since this study involves contacting the HIV positive persons, access to HIV positive persons is methodologically easier at the hospital end than in a workplace setting. Also, in a workplace setting it is practically and ethically inappropriate to screen the workforce in order to gain access to HIV positive persons.

The significance of VCTC
The VCT (Voluntary Counselling and Testing) services constitute the entry point to care, support and treatment. They have an added importance in the official programme in identifying and dealing with HIV positive people. In this context, counselling along with diagnosis is of crucial significance. The VCTC is one of the three contact points apart from ANC and STD, which address specific kinds of cases, as opposed to the VCTC, which has a broader spectrum to address the adult working population. Therefore, it acts as a fulcrum for further intervention.

It is in the light of the above understanding that the objectives and the design of the study have been formulated.

Objectives of the Study
On the basis of the above knowledge, the objectives of the study have been formulated. The main objective is to study the interplay of issues related to work, workplace, social aspects and experiences of treatment and to analyse their impact on the HIV infected persons.

The main objective has been broken up into the following specific objectives:
1. To study the occupational and demographic characteristics of the VCTC attendees.
2. To develop an understanding of the social aspects related to vulnerability to HIV infection and its subsequent consequences on the infected persons.

3. To study the workplace policies and other workplace related issues with regard to HIV/AIDS and their implications for HIV infected persons.

4. To identify the barriers faced by the VCTC attendees for testing for HIV.

5. To look at the complexities of the decision to disclose their HIV status to family members and at the workplace.

6. To understand and analyse their treatment seeking behaviour and their problems and perceptions in this regard.

7. To identify the VCTC attendees’ perceptions and experiences with regard to different systems of medicine.

8. To explore the positive and negative experiences of the VCTC attendees after being tested HIV positive.

9. To examine the strategies adopted by the infected persons on these issues and to develop them as inputs into the design of intervention programmes for the infected persons.

Design of the Study

The Study Area and Study Population

According to NACO data, Tamil Nadu reported the maximum number of AIDS cases in India. From the sentinel surveillance data, it has been observed that Tiruchirapalli district has experienced an increasing trend in the HIV prevalence over the last few years in the STD sites, and is also listed as a ‘high-risk district’. In keeping with the objectives of the study, therefore, Tiruchirapalli district of Tamil Nadu was selected (Map 1 and Map 2). The study was undertaken at Voluntary Counselling and Testing Centre (VCTC), District Headquarter Hospital also known as Annal Gandhi Memorial Government Hospital, Tiruchirapalli, Tamil Nadu, India. Tamil Nadu reported a maximum of 37,087 AIDS cases i.e. 44.7 per cent of the total AIDS cases (87,596) reported in India, till September 2004. The VCTC in Tiruchirapalli was
INDIA
POSITION OF TAMIL NADU IN INDIA 2001

Boundary, International
Boundary, State/UT's

KILOMETRES
100 200 300 400 500

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Selection: Survey of India map with the permission of the Surveyor General of India.
The territorial waters of India extend into the sea to a distance of twelve nautical miles.
The lateral boundaries between Arunachal Pradesh, Assam and Meghalaya shown on this map are as
drawn from the North-Eastern Agreements between Governments Act, 1971 but have yet to be worked.
TAMIL NADU
TIRUCHIRAPPALLI DISTRICT

URBAN AREA WITH POPULATION SIZE

CLASS I
CLASS II
CLASS III
CLASS IV
CLASS V
CLASS VI

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BASED UPON SURVEY OF INDIA MAP WITH THE PERMISSION OF THE SGI

Boundary, District
- Taluk
Headquarters: District
- Taluk
National Highway
- SH 3
State Highway
- SH 45
Important Distressed Road
- Metro Gauge
Railway line with stations, Broad Gauge
- River and Stream
Village having 5000 and above Population with name
Urban Area
Post and Telegraph Office
Degree College and Technical Institution
Rest House, Travellers' Bungalow
established in April 2001. HIV seropositivity rate reported at the VCTC during April 2001 to December 2002 was 27.3 per cent (total cumulative individuals detected with HIV were 722 out of 2645 persons screened) with a male:female ratio of 3:2. People from other neighbouring districts namely Namakkal, Perambalur, Thanjavur, Pudukkottai, Karaikkudi, Madurai, Dindigul and Karur come for treatment to AGMGH.

Voluntary Counselling and Testing Centre (VCTC) is attached with Microbiology Department, established in medical colleges and district hospitals in the high HIV prevalence states. As an entry point to care-and support services for HIV/AIDS, the VCTCs are well equipped with diagnostic facilities for HIV infection and provide counselling service through trained counsellors. HIV Voluntary Counselling and Testing (VCT) is the process by which an individual undergoes counselling enabling him or her to make an informed choice about being tested for HIV. This decision must be entirely the choice of the individual and he or she must be assured that the process will be confidential. The VCT process consists of pre-test, post-test and follow-up counselling.

**Pre-test Counselling:** The counsellor prepares the person for the test by explaining – what an HIV test is, how HIV is transmitted, as well as by correcting myths and misinformation about HIV/AIDS. The counsellor may also discuss the personal risk profile of the individual, including discussions of sexuality, relationships, possible sex and/or drug-related behaviour that increase the risk of infection, and HIV prevention methods. The counsellor discusses the implications of knowing one’s sero-status, and ways to cope with that new information. Informed consent both oral and written from the person being tested is usually a minimum ethical requirement before an HIV test. The person duly signs the consent form. An identity slip is given consisting of personal details and identity number and the same person is asked to collect the HIV test report on producing the identity slip.
Post-test Counselling: The main goal of post-test counselling session is to help the VCTC attendees understand their test results and initiate adaptation to their seropositive or negative status. When the test is seropositive, the counsellor tells the person the result clearly and sensitively, providing emotional support and discussing how he/she will cope. During this session the counsellor ensures that the person has immediate emotional support from a partner, relative or friend. When the person is ready, the counsellor offers information on referral services that may help the person to accept their HIV status and adopt a positive outlook. Sharing a seropositive result with a partner or trusted family member or friend is often beneficial and some persons may wish someone to be with them and participate in the counselling. The counsellor also discusses prevention of HIV transmission to uninfected or untested sexual partner/s. Sharing one’s HIV status with a sexual partner is important to enable the use of safe sex practices, and should be encouraged. However, it may not always be possible, for fear of abuse or abandonment if known to be seropositive.

Counselling is also important when the test result is negative. While the person is likely to feel relief, the counsellor emphasises several points. The counsellor discusses changes in behaviour that can help the person stay HIV negative, such as safer sex practices including condom use and other methods of risk reduction. The counsellor motivates the person to adopt and sustain new, safer practices and provide encouragement for these behaviour changes. This may mean referring the person to ongoing counselling, support groups or specialised care services. During the “window period” (approximately 4-6 weeks immediately after a person is infected), antibodies to HIV are not always detectable. Thus, a negative result received during this time may not mean the person is definitely uninfected, and the person is encouraged to consider taking the test again in 1-3 months.

Follow-up Counselling: VCT services offer the opportunity for continued counselling to persons whether they are seropositive or seronegative. For seropositive persons, counselling is an integral part of ongoing care and support services. Counselling, care
and support is also offered to persons who may not be infected, but whom HIV affects, such as the family and friends of those living with HIV.

**Study Group**

From the inception of VCTC in April 2001 to December 2002, 2645 cases were registered at the VCTC, which form the study group for the research. Occupation and demographic characteristics of the total VCTC attendees for the study period (April 2001 to December 2002) were analysed from the records. These also included the 722 HIV positive people tested during the same period.

**Time Schedule of the Field Work**

The fieldwork for the study was initiated in October 2001 and lasted till March 2003. The research work during this period can be divided into three phases.

1. First Phase (October 2001 to February 2002) – permission was sought from TNSACS for conducting the fieldwork at VCTC, AGM GH, Tiruchirapalli. Also, background information was collected from VCTC.

2. Second Phase (March 2002 to June 2002) – time was taken to articulate the information collected during the first phase and to finalise the research tools.

3. Third Phase (July 2002 to March 2003) – Sufficient time was spent during initial months of the fieldwork in getting absorbed in the system of VCTC as a counsellor and establishing a rapport with the patients, the counsellor and other staff of VCTC, so that they gradually started to open up with the researcher. In the last two months, no new cases were taken up for the study, but an effort was made to strengthen the existing cases.

**Sampling**

During the period of data collection (from July 2002 to March 2003), the seropositive people who attended VCTC, including the old cases that came for follow up, formed the sample of the study. The researcher was dealing with them in capacity of a counsellor, and was therefore, aware of their HIV status. 60 of these people who
consented to give their time and share their experiences were selected for in-depth case studies and intensive non-participant observation to gain insights into their experiences and perceptions, related to their economic, social and psychological conditions as well as to their physical health.

Out of 60 HIV positive persons who consented for the study:

1. In-depth case studies of 15 seropositive VCTC attendees were prepared with an average of 6 sessions each, exclusive of pre- and post-test counselling.
2. Apart from these, 32 case studies were prepared with an average of 2 sessions each, exclusive of pre- and post-test counselling.
3. The remaining 13 respondents visited the VCTC either for only the pre-test and did not come for post-test counselling, or only pre- and post-test counselling. They were therefore, lost to follow up.

Data Collection

Type of Data Required

(i) Information collected from various Institutions and Organisations

- VCTC, Tiruchirpalli: Occupational and demographic characteristics taken from consent forms of VCTC attendees for the study period – April 2001 to December 2002. Seropositivity status of VCTC attendees taken from the VCTC registers. Functioning of VCTC obtained from various official documents.

- AGMGH and KAPV_Medical College, Tiruchirapalli: Organisational structure, staff pattern, infrastructural facilities, functioning and health care utilisation from the Medical Record Office.

- Deputy Director, Health Services, Tiruchirapalli: Various Health Programmes including HIV/AIDS initiatives at the district level. An account of NGOs activities in the district.

- TNSACS: Organizational structure, activities and programmes and
achievements of TNSACS since its inception in Tamil Nadu.

- TB Sanatorium, Tambaram: Care, support and treatment of HIV positive persons. Research on alternative systems of medicine to strengthen the immune system.
- APAC/ VHS, Chennai: Targeted Intervention for behaviour change and public communication campaigns along with State AIDS Control Society.
- NACO, New Delhi: Country update, new initiatives undertaken during second phase of national AIDS control programme.

(ii) Issues explored from patients

- **Socio-economic Background**: Age, education, caste/community, religion, marital status, total number of family members; occupation, place of residence (rural/urban), total family income, assets (movable and immovable property), any savings, loans, indebtedness, social practices (marriage, rituals, customs etc.).

- **Work/ Working Conditions/ Response to HIV Status or Illness**: Workplace (organised/unorganised), nature of work, mobility, occupational risk (personal/occupational hazard), response to HIV status – mandatory testing, informed consent, confidentiality, pre-test and post-test counselling, fitness to work (work adjustments) to explore three possibilities: (1) Can’t work (2) Can work but don’t want to work (3) Can work and the problems they face, discrimination against people with HIV/AIDS, discrimination at work, workplace policies (any interventions), employer-employee relationships, role of trade unions, occupational health and safety measures, social security benefits.

- **Family Structure/ relationships/ Response to HIV Status**: Nuclear/ joint/ extended
family, familial relationships – interaction/ communication, monetary support, social gathering, affinity towards kith and kin, response to HIV status, stigmatisation, care and support given by family members.

- **Community/ Relationships/ Response to HIV Status:** Relationships – interaction/ communication, monetary support, social gathering, response to HIV status, stigmatisation, care and support given by friends, relatives and community.

- **Personal History:** Past history of sexual diseases, sexual history, drug use, blood or blood product transfusion, any surgery in the past, use of injections, obstetric history, clinical symptoms.

- **Process and Experience of Treatment:** HIV status (how did one come to know about his/her HIV status for the first time), In this process – confidentiality, pre-test and post-test counselling, testing, treatment facilities, follow-up services, referral, the health problems experienced, different types of treatment (Ayurveda, allopathy, other systems of medicine), history of medical intervention (for past 5-10 years), place of treatment (private clinics, govt. hospital), role of workplace in treatment process (cost/benefits), social welfare legislation’s like ESIC, CGHS etc, attitude and behaviour of doctors and para-medical staffs, employers towards HIV/AIDS patients and in their treatment process.

- **Any other perceptions/feelings mentioned by the HIV status persons:** Sources of moral and emotional support, opinions about society/ social change/ support systems/ workplace, socio-cultural beliefs (rumours, religious beliefs)

(iii) Issues explored from significant others

- **Family members / Spouse/ Friends/ Relatives/ Community leaders/ Religious leaders:** Relationship, interaction/communication, psycho-social support, monetary
support, social gathering, response to HIV status, history of the individual
(conditions of long illness, drug use, blood or blood product transfusion, any
surgery, use of injections, history of medical interventions known for past 5-
10 years). General safe practices, sexual life and associated safe behaviour
practices with spouse. Role played in the ongoing process of treatment, care
and support, opinions about society/social change/support systems/workplace
issues, socio-cultural beliefs (rumours, religious beliefs), problems
and good practices experienced during care and support.

➢ Doctors/Counsellor: Doctor-Patient relationship/Counsellor-Patient relationship,
rapport establishment, confidentiality, pre-test and post-test counselling,
informed consent, HIV testing, response to HIV status, the problems and
good practices experienced during treatment, follow-up and referral services,
adherence, different types of treatment (Ayurveda, Allopathy, other systems of
medicine), history of medical intervention (for past 5-10 years), place of
treatment (private clinics, government hospital), attitude and behaviour of
doctors, counsellors, paramedical staffs, and significant others towards
HIV/AIDS patients in the process of treatment.

➢ Employers/Co-Workers/Trade union: Response to HIV status – mandatory
testing, informed consent, confidentiality, pre-test and post-test counselling,
fitness to work (work adjustments) to explore three possibilities: (1) Can’t
work (2) Can work but don’t want to work (3) Can work and the problems
they face, discrimination against people with HIV/AIDS, discrimination at
work, workplace policies (any interventions), employer-employee
relationships, role of trade unions, occupational health and safety measures,
social security benefits, problems and good practices to support treatment,
referral and counselling services.
Tools of Data Collection

(i) Bibliographical Studies: Published and unpublished data from government and non-government agencies. Articles collected from local, regional, national and international journals and periodicals.

(ii) The case studies of the patients were prepared on the basis of information obtained from clinical reports, the patients and their significant others, through:

- Interviews which were free flowing and conversational but purposive: A person’s own narrative formed the main core of the case history.
- Counselling sessions: Counselling helped to give insights about some of the inner feelings of patients and their relatives, issues which are not well documented and are difficult to obtain in interviewing sessions.
- Observation methods: Detailed information was collected about the activities, relationships and perceptions of patients.
- Group discussions were organised in order to give feedback to the participants of the study and to get further insights into specific themes that emerged as inconclusive issues from the case studies.

Process of Data Collection

The process of data collection involves various stages, which include:

(i) Establishing rapport with the patients.
(ii) Assisting in some pre-test and post-test counselling.
(iii) Interaction with the doctors and building upon the case studies on the basis of the clinical reports.
(iv) Home visits/meetings outside the hospital, at a place convenient to the patients.
(v) Interviews with all other relevant persons in the patient’s narrative to triangulate the data, cross-check versions and develop a holistic understanding of the case.
Entry into VCTC: The Dean of the hospital gave permission to undertake the research study at Annal Gandhi Memorial Government Hospital (AGMGH), Trichy and directed the researcher to meet the Head of the Dermatology Department. The HOD denied permission, following which the researcher discussed his requirements with the Medical Officer (MO) in charge of Voluntary Counselling and Testing Centre (VCTC), who was extremely helpful and encouraged the researcher to carry out the study. The purpose of entry into VCTC was to gain access to the data and to do detailed case studies on patients. The initial understanding was to sit in the pre-test counselling sessions with the patients’ consent and to interact at a place and time convenient to them and their family members. But, what the researcher had not foreseen was to work virtually in capacity of a counsellor in the VCTC. By approaching in this manner, the researcher got an opportunity to be a part of the system, which provided him with access to primary sources of information.

Rapport with the Counsellor: The counsellor was under the supervision of MO in charge of VCTC and was responsible to handle VCTC data, files and reports. The counsellor facilitated the entry point for the researcher to meet the patients and interact with them. The researcher’s concern was that his presence in the counsellor’s domain should not be a hindrance in the functioning of the VCTC. In the beginning, the researcher was made to sit in the pre-test counselling sessions with the consent of the patients. Throughout this period he maintained the status of an observer and discussed the case and the counselling techniques with the counsellor in the later part of the day. Occasionally, the patients had their misgivings about his presence during the counselling session (according to the patients, the researcher was an outsider and not part of the system). The same criteria were followed for post-test counselling and follow up counselling sessions.

Rapport with the patient: Initially, the researcher had interacted with a few patients who had a good rapport with the counsellor, but the interaction could not be sustained for various reasons. Most of them felt that the system could not be trusted.
Some were not interested to share their life experience and a few others had no time to spare. In order to overcome this problem, a decision was taken in consultation with the MO that the researcher was expected to interact with the patients in the capacity of a counsellor. This was how he gradually developed a comfortable rapport with the patients.

**Daily routine at VCTC:** Initially, the day in VCTC began at 9 am and continued till 1 pm at AGMGH and shifted to KAPV Govt. Medical College from 2 to 4 pm. But this was not always the case. Sometimes the morning session would stretch beyond 2 – 2.30 pm if there were patients who needed extra sessions or sometimes sessions involving couples' counselling. After the morning session at AGMGH, the counsellor and the researcher had to travel back to VCTC, KAPV Govt. Medical College for the afternoon session. Apart from the others who visit VCTC, patients from TB hospital, which is located within the campus, were also referred. At the end of the day, the counsellor and laboratory technicians would discuss their problems with the medical officer in charge of VCTC. After the working hours at VCTC, the researcher met the in-patients at wards or at a place convenient to them within the hospital premises. Likewise, the researcher had the opportunity to meet other patients at a place and time of their choice. This explains the daily routine at VCTC in which the researcher saw himself as a counsellor as well as a researcher. When the researcher was visiting VCTC in the beginning, he noticed on an average about 10 VCTC attendees present during the day for pre-test and post-test counselling. The task of the counsellor was really hectic. Apart from counselling, he was supposed to fill up a rather lengthy pre-test assessment proforma for each VCTC attendee and at times he was called to counsel ward patients who were not in a condition to walk down to the VCTC. The researcher felt that his presence was as much beneficial for the counsellor as it was for him. Since the number of attendees was also increasing during this period, at the administrative level the need was felt to appoint an additional counsellor. Monthly reports were sent to TNSACS on the basis of which creation of a new post was being thought upon. Meanwhile, the Joint Director of TNSACS, Dr.M.Sentamizhan also
recognised the fact that an additional counsellor was required, as the VCTC team had been performing well. The researcher had the opportunity to tour along with the Joint Director (TNSACS) during his supervisory visit to the VCTCs of four districts. Thus the researcher had ample opportunity to interact and discuss with him the related issues. The JD summarised the following observations based on his visits:

(i) Visit to District Tiruchirappalli VCTC on 24.01.2003: The VCTC was partially located in K.A.P.V. Govt. Medical College in the Microbiology department and in the A.G.M. Govt. Hospital campus in Trichy town proper. Lab. technician and counsellor were available in the VCTC. Registers are maintained well. The performance of this centre in the year 2002 was 1811 (tested) and 442 were positive for HIV. The walk-in percentage needed to be improved. Majority of attendees tested belong to the referral group. Testing was carried out in KAPV Government Medical College, Trichy. Dr.S.Dhanapaul, Microbiologist evinces very keen interest in improving the performance, improving walk-in percentage and in providing care to the positive people by better coordination with doctors of the other departments and the administration of the Head Quarters Hospital.

(ii) Visit to District Karur VCTC on 25.01.2003: Medical officer, Lab. Technician and counsellor were all available. Medical officer STD was in charge of this centre. During 2002, 1273 were tested for HIV in this centre and 202 persons were found to be positive. The number of voluntary individuals attending VCTC for testing has to be improved.

(iii) Visit to District Pudukkottai VCTC on 27.01.2003: Medical officer STD was in charge of this VCTC. Discussed with Joint Director Health Services (JDHS) and requested for printing the registers and formats for this VCTC. The room was not situated that was conducive to carry out counselling. JDHS had promised to make necessary arrangements to create a better atmosphere for carrying out effective counselling. In 2002, 800 persons had been tested in
this centre and 171 were found to be HIV positive.

(iv) Visit to District Thanjavur VCTC on 28.01.2003: The VCTC was partly located in the campus of Thanjavur Medical College in the Microbiology department and in the R.M. Hospital campus in Thanjavur town proper. The M.O. STD was in charge of this VCTC. He had requested to shift the lab. to RMH so that it will benefit larger number of people. In 2002, 2998 were tested and 234 were found to be positive for HIV. Here also, speciality doctors referred most cases. Voluntary persons were low in percentage of attendance.

**Researcher’s observations during VCTC visits:** VCTC as a unit within the hospital was in the evolving stage and functioning effectively from 2000-2001 in Thanjavur and Trichy, and from 2001-2002 in Karur and Pudukottai. It was observed during the visits that though VCTC had been initiated and functioning for some time, the efforts were inadequate in realisation of care and support services for HIV/AIDS through VCTC as an entry point. Another significant observation that was outstanding during the visits were absorption of VCTC in the existing system and its overall performance in terms of VCT services, including providing care to positive people and effective documentation. This depends mostly upon the interest and commitment of the VCTC team in particular and through better coordination with doctors of the other departments and the administration of the Head Quarters Hospital. It was also evident that a large number of persons attending VCTC was from referral group. The main objective of the VCTC was to make testing services available to those persons who wish to know their HIV status because of their indulgence in some high-risk behaviour. The VCT process has been extended to a majority of persons falling under referred category as against its conception on voluntary nature. This spill-over, though unavoidable, has caused overcrowding at VCTC and therefore the need to expand the services by appointing more counsellors and laboratory technicians was felt acutely. This is true in the case of Trichy VCTC. The implication of increase in referral cases and decreased voluntary cases in the first
place negates the very concept of setting up of the VCTC. Further, it has long lasting
effects on the patients. Using VCTC for screening of patients before surgery or
delivery and referred by private practitioners would be counter-productive and not
serve the purpose for which they had been established. Action must be taken to
improve voluntary screening by establishing adequate publicity in required places
(within hospital premises as well as in the district). District AIDS Advisory
Committee (DAAC) has immense potential to play a vital role to make VCTC
popular to serve larger number of people. This role of the DAAC is yet to be
explored. This becomes increasingly important because the existence of VCTC and
the role it plays is not known to people at large.

*VCTC – Another blood testing centre:* Patients who are referred by doctors to
VCTC substitute the terminology ‘HIV testing’ with ‘blood test’. This is not to argue
that testing is not part of VCT process, but the doctors often do not mention
counselling as part of it. Most of the doctors prescribe HIV test by either mentioning
VCTC or Elisa test and the room number where the test is performed in the case
sheet or in the registration OP sheet. Patients referred by doctors for HIV testing
have no idea about VCT process and doctors have no time to explain what it means
to them about counselling, followed by informed decision-making and finally testing.
This means that often the waiting time is high because of the time taken for
counselling and many patients get impatient and leave. The implication is that the
doctor prescribing an HIV blood test must inform the patient of the process to be
followed at the VCTC. It is the counsellor who enlightens the patients about the
VCT process during pre-test counselling and most of them feel relaxed after their
interaction with the counsellor. A patient feels for the first time that he is being
accepted as an individual and therefore, carries with him the feeling that there is
somebody to listen to his/her problems without being judgmental. Patients’ initial
interaction with the health care providers plays an important role in determining the
extent of utilisation of services.
**Issue on informed consent:** In the context of HIV testing done at VCTC, patients were informed in brief about 'HIV/AIDS', 'testing' and the outcome of the test if tested positive or negative. The counsellor provides necessary information during pre-test counselling and the decision to go ahead with the test or to opt out of it lies with the patient. A patient's informed decision-making or the absence of it during the short span of time following pre-test counselling is a matter of concern. The decision, for instance, of not opting for the test, may be vetoed by the patient's doctor, because 'the doctor knows the treatment better than the patient', and 'the test should be done for proper treatment'. Secondly, being forced to decide within a few minutes whether to go ahead with the test or not, after acquiring all the dreaded information about the disease is not an easy task. It might evince various kinds of responses; some might be willing to test irrespective of the test results and take all the necessary precautions in future. Some others might not want to put themselves through the trauma for several social, if not personal, reasons. This is evident in the case of women, who come to the health centre for treatment, not because they seek HIV testing. Because many women do not know about Voluntary Counselling and Testing opportunities before arriving at hospital settings, being referred for an HIV test does not make any sense. They come to know about the test only during pre-test counselling. They find themselves unable to decide within a short time whether to refuse or to consent for the test. They postpone their decisions, usually to consult their husbands often amounting to deferred refusal. They often confront the everyday realities of communicating, much less negotiating, protective actions in sexual relationships with their partners who are absent from the VCT session. After the VCT session is over or sometimes in the middle of the session, however many women return to partners in couple relationships. Despite their non-involvement in pre-test decision making, these absent partners can importantly affect the decisions that VCT attendees make: to accept or refuse HIV testing, to return or not for test results and post-test counselling and to disclose test decisions and test results.
**Issue on confidentiality:** An important issue in AIDS research is ensuring confidentiality. The medical history of any patient is between the patient and the medical officer. If a patient decides to share that with another person, whatever transpires is expected to be only between the persons involved. This is important under the circumstances where people are stigmatised and isolated. It has an ethical dimension as well, especially if the respondents confide in the researcher that they are putting other people at risk through their activities. The researcher was denied permission by a few doctors to access information on treatment for the reason of breach of confidentiality. Whereas, patients who were aware about the researcher's intention to undertake research involving them had given their consent. In this situation, the patients were willing to share their experience, but the medical officer in charge of Dermatology had denied access. Since most of the referred cases were from STD and Skin Department and were treated in STD wards as in-patients, their experiences and perceptions about treatment provided a fruitful insight. However, providers' perspective on treatment was missing which would have thrown more light on the issue of treatment in a comprehensive manner.

**NGO referred patients:** There are few NGOs who are interested to know the HIV status of patient's who shall add up to their magic numbers for the record to please the funding agencies. This was true with many NGOs who kept adding to their list of people living with HIV/AIDS without addressing issues of their concern. Also, by saying this, one can't deny the fact that there are a few NGOs who are working for the cause of PLWHAs by effectively implementing intervention programmes. Proper monitoring and evaluation by donor organisations done on a regular basis would help to motivate NGOs to be focused in their work rather than to forget once funding is disbursed.

**Data Analysis**

(i) SPSS version 10 (Computer Software Programme for Social Science Research) was used for tabulation and cross-tabulation of the quantitative data.
(ii) Occupation and demographic characteristics of the total (2645) VCTC attendees for the study period (April 2001 to December 2002). A similar analysis for the break-up study period from April 2001 to March 2002 and April 2002 to December 2002.

(iii) Occupation and demographic characteristics of total persons (722) diagnosed as HIV seropositive at VCTC by gender.

(iv) Socio-demographic characteristics, history of risk behaviour and knowledge about HIV/AIDS and disease-related symptoms of the sample (60) of seropositive VCTC attendees by gender.

(v) Qualitative data was analysed by putting together all the field notes, sorting them into domains, identifying linkages and deriving the significant issues for discussion. This was done by relating the qualitative information with the quantitative data at each step of the data analysis.

Limitations of the Study

(i) Given the highly selective nature of our sample, it is nearly impossible to make pronouncements on 'Caste' as a causal factor although caste might be a statistically significant variable in social science research. Also, it was observed that the respondents were not only more keen, but also more comfortable in discussing issues and circumstances related to their present health condition than about their personal and caste-based information.

(ii) The complexity of VCTC attendees' lives and problems eludes documentation in strictly empirical ways. In order to build a detailed case-study, apart from a person's own perceptions in relation to social, occupational as well as treatment experiences, the perceptions and experiences of 'significant others' (family members, friends, relatives, community members, colleagues at work, doctor) are required. In that sense, the information obtained is, more often than not, one-dimensional. The patients, in most cases, had not disclosed their HIV status to their family members, friends and employers. Therefore, the case-studies are based on their own, and, in some cases their spouses'
accounts. In order to gain more information or to authenticate the existing information, the norms of confidentiality could not be broken.

(iii) It is realised that in a setting like VCTC, patients appear for a short time during pre-test and post-test counselling. VCTC is an entry point for care and treatment. A regular and continuous access to patients in a residential care home or hospice centre would have helped the researcher to interact with them more openly and frequently, thus building an easy rapport and enriching the study further.

(iv) Only those individuals were included in the study who had tested for HIV. In this sense, they had overcome the barriers they may have faced prior to testing. To gain a better perspective of the range of factors that individuals face when deciding whether or not to test for HIV, it would have been important to sample individuals who never came for HIV testing, probably because they were unable to overcome the barriers. In such a sample, the environmental barriers to HIV testing and disclosure may be more evident.

(v) The researcher was not able to mingle with the seropositive VCTC attendees in their natural setting because of the nature of the problem. Therefore, intensive interviews and observations could not be conducted.

Ethical Considerations

(i) Informed consent of all participants was taken which was vouched for by the researcher (see Annexure 2.1 for 'Consent Form')

(ii) Confidentiality of the persons has been strictly maintained.

(iii) Probing only as far as the rapport allows and that does not cause emotional upheaval/ upset the patient.

(iv) To give information to the participants on the findings of the study and to incorporate their feedback on it in the interpretation of data.