Chapter 6

TO CONCLUDE: IMPLICATIONS FOR CARE, SUPPORT AND PREVENTION
HIV/AIDS is an issue of great importance to public health. The state of health of any group of people is related to its living conditions, the socio-cultural context in which people are socialised and operate, and the respect for basic rights of the individual (Mann 1992; Mann et al. 1994). Whatever the disease, it has manifold effects not only on the infected individuals but also on their family members; HIV/AIDS is no exception. But, there are certain features that are unique to it. Firstly, the age group of economically productive population (15-59 years) coincides with the population category most affected by HIV/AIDS (15-49 years). Therefore, it primarily affects adults in their economically productive years. 'Work' is defined by the Census as participation in any economically productive activity by anyone in the age group of 15-59 years. It is currently estimated that only 10 per cent of the total labour force is employed in the organised sector which ensures a reasonable quality of life and access to medical care. The remaining 90 per cent is engaged in the unorganised sector, both in the rural and in the urban areas. The Indian labour market scenario has undergone characteristic changes in recent years. The NSSO data revealed the following trends:

(i) Increasing casualisation of labour in the organised sector;
(ii) Increasing proportion of women in the workforce;
(iii) A large number of adult working population which migrates from one region to another in search of employment (VVGNLI. 1999)

Although the workplace is not directly involved in the transmission of the HIV virus, it can create vulnerabilities and also allow for different kinds of interventions targeted at protection, care and support for the workers. Therefore, there is a need to understand and study the issues related to HIV/AIDS emerging due to the recent changes in the Indian labour market scenario in the context of 'work', 'workplace' and 'working population'.

Secondly, there are chances of multiple cases of HIV infection within a household, with serious implications for old as well as young dependants of infected family
members. The ill health of the earning individual implies that other household members have to give more time to care for him or her. This would, in turn, directly reduce the leisure time available to them as well as affect time available for tending to the children. Further, this would impede the possibilities of individual and household development. This is especially true for women who often end up caring for the sick. The impact at the individual and household level is mirrored at the occupational level.

Thirdly, there is a long period of invisibility between acquiring the virus and the appearance of opportunistic infections, and the infected persons have to undergo an extended and expensive treatment. Finally, HIV/AIDS is also associated with high levels of discrimination and stigmatization. However, there is no evidence of casual transmission between people in schools, in the workplace or other such social settings.

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 the workers' households. The risk of contracting HIV infection and the subsequent experiences has been 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.

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. 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. This thesis proposed to study the interplay of issues related to work and workplace, social aspects and experiences of treatment and to analyse their impact on the adult HIV infected persons. In order to meet this objective, Tiruchirapalli district of Tamil Nadu was selected. The study was undertaken at Voluntary Counselling and Testing Centre (VCTC), District Headquarter Hospital also known as Annal Gandhi Memorial Government Hospital (AGMGH), Tiruchirapalli, Tamil Nadu, India.

The significance of VCTC
The VCT (Voluntary Counselling and Testing) services constitute the entry point to care, support and treatment for the patients. 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 STD and ANC (for women), 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. In response to the HIV/AIDS situation in Tamil Nadu, TNSACS was the first AIDS Control Society formed in India; in that sense Tamil Nadu is a model state in AIDS control. The HIV/AIDS epidemic has been a challenge for Tamil Nadu. The National AIDS Control Organisation (NACO) has been providing not only the resources but also technical and other support within the government health system, which is immensely beneficial for the successful implementation of the programme. Apart from the government support, there are other organisations which have been working in the area of HIV/AIDS prevention, care and support. The Government Hospital for Thoracic Medicine, Tambaram, Chennai has been receiving grants from the Centre for Disease Control, Atlanta. VHS - YRG CARE Medical Centre which provides an integrated continuum of care and support for People Living with HIV/AIDS is funded by the National Institute of Health (NIH), USA.
through projects that are in association with Brown University, Providence, USA, and Johns Hopkins University, Baltimore, USA.

**General Profile of VCTC Attendees**

In our study, the majority of the VCTC attendees come under the age group 15-44, which constitutes more than 80 per cent of all attendees. Male VCTC attendees accounted for 62.7 per cent and females 37.3 per cent in a district where the male-female sex ratio in the general population is 1:1 (Census, 2001). Also, 75.5 per cent of people visiting the VCTC — nearly 70 per cent of the men and about 86 per cent of the women — were married. The average age at marriage in Tiruchirapalli district was 26 years for men and 25 years for women, which was above the state (Male - 27, Female - 22) and national (Male - 23.29, Female - 18.33) average figures (Directorate of Family Welfare Year Book, 1999-2000). As many as 60.5 per cent of the people who visited the VCTC were ‘agricultural and unskilled workers’, while about 30.5 per cent of them were non-agricultural workers, working as ‘rickshaw/auto/truck/taxi drivers and cleaners’, ‘industrial and factory workers’, ‘hotel staff’, ‘service class’, ‘skilled workers’ and those involved in ‘business’. It is also worth mentioning another significant category, that of ‘housewives’, which comprised 3.4 per cent of the total number of VCTC attendees. Apart from this, there are a hidden number of ‘housewives’ in the above-mentioned categories. This is due to the inconsistency in recording the occupation category in the consent forms, where the husband’s occupation and income are used as a ‘proxy’ for the wife’s, in case the wife is not in paid employment. 69.6 per cent of people visiting the VCTC belonged to the low-income group, i.e. earning below Rs.1000 per month. Of the VCTC attendees from Tiruchirapalli district, about 47.2 per cent resided in urban areas, as against 52.8 per cent in rural areas (excluding the attendees from ‘other districts’). Another aspect of concern is that 17.2 per cent of the total VCTC attendees were from neighbouring districts of Tiruchirapalli. This not only had an impact on the actual record of HIV/AIDS cases in the respective districts, but was also highly indicative of the
stigma attached to HIV and attendees’ fear of being identified and labelled as ‘HIV positive’ persons within their own town.

Of the total attendees who visited for Counselling and Testing between April 2001 and December 2002, only 21.2 per cent had visited VCTC voluntarily. Referrals included 32.82 per cent from the Department of Dermatology and 19.4 per cent from the Department of Medicine. The main objective of the VCTC is to make testing services available to those persons who wish to know their HIV status because of perceived risk factors. The increase in referral cases and low percentage of voluntary cases in the first place negates the very raison d’etre of the VCTC. Further, labelling people as ‘having’ and ‘not having’ the virus encourages discrimination rather than dispel it, thus leaving people to cope with their psychological and social trauma on their own. The overall HIV seropositivity rate of VCTC attendees who were either referred by the various departments or had volunteered for the HIV test was 27.3 per cent.

**Seropositivity among VCTC Attendees**

**Risky occupation categories and ‘stigma’**

A significant observation regarding three men in the occupation category ‘rickshaw/auto/taxi/truck drivers and cleaners’ was that they mentioned their occupation in the consent forms as ‘agricultural labourer’. Further interaction during the study revealed that they had concealed their actual occupation because of the stigma attached to it in terms of HIV/AIDS. The stigma attached to HIV/AIDS is associated not only with the disease itself, but also with ‘circumstances (in this case occupations) that are considered to predispose a person to it’. Goffman (1963) defined stigma as ‘an attribute that is significantly discrediting’ in the eyes of the society and serves to reduce the person who possesses it or practices what is perceived to be socially deviant behaviour. It is applied by the society through rules and sanctions, resulting in what he described as a kind of ‘spoiled identity’ for the
person concerned. In our study, it is this very 'spoiled identity' that the individuals were trying to avoid by concealing their so-called 'discrediting attribute'. Three women in the sample were commercial sex workers, out of whom two did not disclose their actual occupations. Further, the seropositivity of women in prostitution is 25.0 per cent while that of housewives attending the VCTC is 27.8 per cent. This indicates not only the risk associated with a particular occupation, but also the fact that women in general are a vulnerable category.

The 'risk factor' for Women
In our study, 80 per cent of the women infected with HIV had only one lifetime sexual partner and the 'risk factor' for such women becoming HIV positive was through their husbands (NACO, 2004). Further information from our study shows that the traditional pressures require women to bear children soon after marriage. As a result, it was found that all the infected females in the sample were young married women. Studies have shown that in a patriarchal society like ours, women are generally dominated by men and have little or no decision making power in most household matters. This subservience of women is carried over to the sexual decision-making between the married partners (Nag, 1994; Kumar et al. 1997; Singh and Ateeq, 1999). Additionally, women's lack of education and employment make it difficult for them to negotiate conditions in their personal relationships, most importantly, control over their own sexuality or negotiating conditions of sexual intercourse such as condom use.

Seroprevalence at VCTC: Voluntary and Referral attendees
The data for voluntary VCTC attendees confirms high HIV seroprevalence (22.5 per cent), with a higher seropositivity of females as compared to that of males. The male VCTC attendees were larger in number and were either voluntary cases with a history of high-risk behaviour, or referred for testing as a part of treatment. On the other hand, the women, though less in number, had a higher seroprevalence. The female VCTC attendees were either wives of infected men or CSWs. In this sense, for men,
HIV testing was primarily a preventive health measure and a way to confirm their negative health status. For women on the other hand, it was a means to confirm their positive HIV status motivated by the sickness or death of either a child or partner. Maman et al. (2001) have reported similar findings in their study in sub-Saharan Africa. Referral cases are usually patients with clinically suspected AIDS and patients from STD. The prevalence of HIV in clinically suspected AIDS is highest in high-risk groups like CSWs followed by patients with STDs, IVDU and users of blood bank. Hence, the prevalence will increase in the VCTC, which is not actually representative of pure volunteers with high-risk behaviour. In HIV testing the positive predictive value; i.e. the percentage of number-of ‘true positives’ given by the test increases in direct proportion to the prevalence. Hence, the actual prevalence in VCTC attendees has been estimated to be less than the recorded prevalence. To make it accurate, the prevalence may be estimated for the specific denominator population, e.g. the percentage of cases among only volunteers with high risk.

When we look at voluntary/referral categories, we observe a high HIV seroprevalence in the cases referred by TB hospitals and District Tuberculosis Centre (41.3 per cent) during the entire study period. Tuberculosis is the most common opportunistic infection occurring among HIV-positive individuals in India, and it is estimated that 60-70 per cent of HIV-positive patients develop tuberculosis in their lifetime (Swaminathan et al. 2000; Kaur et al. 1992). Studies from different parts of the country have reported both low (0.4-4.7 per cent) (Sharma et al. 2000; Talib et al. 1999) and high seroprevalence rates (10-24 per cent) (Ramachandran et al. 2003; Paranjape et al. 1997; Tripathy et al. 2002; Jain, 1996; Deo, 1995; Solomon et al. 1995; Vasadevaiah, 1997) among tuberculosis patients.

**Vulnerability to Infection**

The HIV epidemic in India is no longer confined to high-risk groups or urban populations, but is gradually spreading into rural areas and the general population. It has been mentioned earlier that 80 per cent of the women in the present study had
only their spouses as their sexual partners. Conversely, none of the men in the sample had sex exclusively with their spouses, i.e. all of them except one (who was unmarried and uninitiated into sex) had multiple sexual partners. 60 per cent of the men had visited sex workers, while 40 per cent revealed their involvement in casual sexual relationships.

In the case of men, the circumstances that made them vulnerable to HIV included occupational as well as social circumstances. Among the conditions related to work, migration due to work, nature of work, peer pressure at workplace and frequent change in occupations were found to increase the probability of exposure to the risks of HIV transmission. The monotonous nature of job, lack of job security, distance from the family and the consequent lack of emotional support, all put them in a situation where indulging in promiscuous sexual activities or drug usage become the means of recreation. Being uprooted from the family in search of better economic options and experiencing an unfamiliar urban environment, an individual is required to cope with not only the pressures of work and working conditions but also the absence of family support. This situation is true of all working categories, whether formal or informal. While he tries to adapt to the changed circumstances, the individual is also influenced by peer pressure in order to gain their ‘acceptance and affiliation’. It was also found in some cases that this need for acceptance and affiliation varies depending on the frequency with which he meets his family.

On the other hand, while, the society expects men to be the breadwinners of the family, it also accords power and freedom to them. It has been reasoned that due to these factors, sex outside marriage is likely to be more common among Indian men than women (Kumar et al. 1997).

Our study corroborates that it is often the male members who introduce their families to HIV infection. It is being increasingly observed by various studies that women, especially younger women are among the most vulnerable to HIV infection.
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The fact that all the women in our sample are young and married or widows, emphasizes this point. NACO figures for the total AIDS cases in the country up to August 2004 show that only about 22 per cent of the cases in the age group of 30 years and above are women, but they make up 37 per cent of the cases in the sexually active age group of 15 to 29 years (NACO 2004). Besides, rural women were particularly vulnerable to being infected as they had less access to health care and information on HIV/AIDS.

Thus, any sexual relationship is 'risky' from the point of view of HIV/AIDS. However, the degree of risk varies owing to other factors concerned with a sexual relationship. These are 'total abstinence', 'stable relationship' and 'unstable or casual relationship'. While 'total abstinence' means 'no risk' and 'stable relationship' means 'low risk', 'unstable relationship', on the other hand translates into 'high risk'. Even single partner sexual relationships lay open a person to the risk of HIV. Therefore, even within the marriage, the risk lies with the sexual relationship, not with the marriage itself. This problem is often misinterpreted by other studies, which believe that for many women being in a marriage or stable relationship which is perceived to be 'low risk' is actually 'high risk' (Chao et al. 1994; Rao et al. 1996; de Zoysa et al. 1996; MacNeil et al. 1999).

The weak bargaining position of women in the interfamilial power relations and their sexual subordination tend to increase their vulnerability. Apart from this, women's exploitation at workplace further weakens their position in this regard. If the sole breadwinner of the family is lost due to death or disability (either as a result of HIV/AIDS or otherwise), the entire responsibility of earning for the family and taking care of the members falls on the women. For some women, such a situation amounts to an 'existential crisis'. This they try to overcome by taking up any available option, including prostitution, which ensures that the most immediate needs of their families will be met. Circumstances like these that throw the women open to the risks of HIV infection have been observed in our study. This fact also stresses the
significance of the work sphere, which, like the social sphere, offers support to the individuals. This support is in the form of employment, i.e. the means to earn a living. If a person loses access to these means because of disease or disability, he has to fall back on support from the social sphere, so that he/she is taken care of by family members and friends. This also demonstrates that a combination of adequate social support, care and proper treatment enables an individual to improve his/her health and return to work.

Experiences of PLWHAs

For the purpose of this study, the experiences of people living with HIV/AIDS were explored in the three spheres of their lives, on the basis of in-depth case studies. These spheres are the social sphere, work sphere and the medical sphere. It needs to be mentioned here that the good and bad experiences were responses they received in each of these spheres as a result of their HIV status. In this sense, the experiences of PLWHAs depended on their disclosure or non-disclosure of their HIV status.

Social Sphere

It has been found in this study that men received better care and support than women. For men household responses to HIV/AIDS were generally supportive and they were taken care of by their female relatives such as mothers and wives. Sometimes, too, male relatives (usually fathers) have been known to help out. In contrary, women received little care and support, when ill, from other household members. Despite this fact the focus on women's health identified in the present study represents a change from earlier findings showing that women with HIV often neglected their own health (Melvin and Sherr, 1993). Infected parents (especially mothers') descriptions of intense relationships with and concerns for their children have been noted previously (Andrews et al. 1993). Parents' acknowledgement that their illness could become a heavy burden and source of guilt when children were to be taken care of has been documented in the work of Faithful (1997) and Hackl (1997). Parents worried about the financial, emotional and physical burden that the
care and guardianship of their children would place on relatives, especially elderly parents. It was for this reason that infected mothers tried, as much as possible, to remain in good health in order not only to earn a living and take care of their children, but also to secure their future. Bharat, and Aggleton, (1999) recommended gender-sensitive care and support programmes to ensure a gender-just approach by increasing the involvement of other household and community members in caregiving. This would help in addressing women’s needs as caregivers and as infected survivors, since home-based care is often advocated as a means of meeting the support needs of people living with HIV/AIDS.

In terms of social support, the HIV positive people reported three kinds of experiences. Firstly, there were those who had no support prior to infection, but received support after disclosing their HIV status. Secondly, those who had the support of family and friends prior to infection and continued to receive it even after they were tested HIV seropositive. Thirdly, there were people who enjoyed good social support prior to infection, but lost it after their HIV status was known.

We found in the study group that some attendees who had previously severed ties with their families and had no social support prior to HIV infection, received support and reassurance from family and friends at their time of crisis.

The majority of the respondents were able to disclose their HIV status to their immediate family members and most of them received support as well. The higher rate of disclosure to family members in our study indicates the importance of families in Indian society as the primary support system, in contrast to studies from the West, where seropositive individuals usually prefer not to ‘burden’ family members with their illness (Hays et al. 1993). Earlier studies have also reported generally supportive settings for illness management and treatment for HIV in most families and communities from India and Thailand (Bharat et al. 1998; Chandra, Deepthivarma, and Manjula, 2003; MacNeil et al. 1999).
This study revealed findings similar to those found in earlier studies (Simoni et al. 1995; Chandra, Deepthivarma, and Manjula, 2003), with most subjects reporting self-focused reasons for disclosing their HIV status, such as expectations of emotional and material support. It was learnt that fears about social isolation, stigmatisation and rejection resulted in non-disclosure. A few respondents reported being treated with contempt as the consequences of accidental or indiscriminate disclosure. These were similar to the results reported by the earlier studies revealing that 'felt' or perceived stigma and discrimination are at times more powerful than 'enacted' stigma and discrimination in discouraging people from being open about their serostatus and in accessing treatment and support (Bharat, and Aggleton, 1999). However, one person in the study group denied the presence of HIV because he believed that he was in 'good health' and moreover had not experienced any symptoms commonly associated with HIV/AIDS. This is a classic case of the 'denial of reality' – a reaction that something cannot be true, that it is not possible – discussed by Gruson and Dulong (1999).

Work Sphere

The respondents in our study were largely employed in the informal sector, with a small percentage of them working in the formal sector. The experiences of people employed in the informal sector are different from those in the formal sector as are the experiences of those who disclosed their HIV status at workplace and those who did not. In fact, the two are more or less overlapping, in the sense that in the present study, disclosure has taken place only in the formal sector largely with the purpose of gaining the medical benefits. Non-disclosure in the informal employment means that there are neither any motives, nor any binding to do the same. It was found in our study that the impending stigma and the consequent fear of the loss of job prevented people from disclosing their HIV status in both formal and informal sectors.
Some HIV positive individuals in the study had been undergoing treatment for opportunistic infections and had not gone to work since they tested for HIV. For them, the greatest issue was to get well soon and enough to be able to return to work. Another important experience was that of the women who were earlier housewives, but after their husbands were either taken ill or died, they were forced to start earning a living in the absence of any support. These women found it very difficult to adjust to the demands of the workplace as well as manage the household chores.

In most formal workplace settings, there are social protections, including health care coverage for specific illnesses and the ceiling to claim such benefits varies according to the hierarchy of the workforce. Although HIV/AIDS epidemic in India can be traced back to 1986 when the first AIDS case was detected in a CSW, now there is enough evidence to support that it has spread from the high-risk groups to the general population. Yet, the needs of the general population regarding HIV/AIDS are not being addressed effectively. Commitment for interventions regarding HIV/AIDS in various workplace settings has been missing despite proper guidelines to this effect by WHO/ILO (1988). In the present study, some of the reasons for this lack of commitment have been noted.

(i) Denial of the epidemic has led to inaction. The main challenge at workplace is to break down the barrier of denial: Unfortunately, for most people — employers, workers' unions and workers — AIDS still is the disease that affects 'other people'.

(ii) It has been observed that the health and safety of workers is neither an issue of concern nor a priority in many organisational policies. Very few problems related to HIV/AIDS have emerged in the workplace in India till date. Therefore, the initiatives taken at workplace for the prevention of HIV/AIDS are still at a preliminary stage. Although task forces have been set up for working out workplace policies at the official level, yet much more needs to be done in this direction.
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(iii) Workers' unions do not see HIV/AIDS as a cause in their struggle for labour rights and are unaware of its impact at the workplace. The important concerns for them are wages, working hours and working conditions. It was seen in our study that when HIV posed a threat to the job of an employee, only then did workers' unions start realising that this issue needed to be addressed. Even then they were uncertain of their course of action, trying to ensure the anonymity of the person as well as fighting for his cause.

The above issues have larger ramifications for building employer-employee relationship and inter-employee relationship, which in turn affects the work environment.

Medical sphere

In the present study, it was the individuals' prerogative to disclose or not disclose their HIV status in the social and work spheres. Conversely, in the medical sphere, most of the respondents visited the VCTC for HIV testing as a part of the treatment they had been undergoing. Therefore, in order to continue their treatment, they had to disclose their HIV test result to their doctors, who had referred them for the HIV test. On the other hand, those who visited VCTC voluntarily chose to decide about their disclosure to the health care providers on their own.

Health seeking behaviour: Most people in our study have sought public health facilities for non-hospitalised care as well as in-patient care. Only a few could afford to seek treatment at private clinics. 'Anonymity' and the apprehension that 'others would come to know of their HIV status' were the two prime concerns, which were the factors that motivated them to seek treatment. Moreover, 'affordability' was another factor that played a decisive role in this regard.

Those people who could afford ARV treatment consulted private doctors. Such facilities lacking in the government hospitals. Therefore, in the District Head Quarter
Hospital or AGMGH and other government hospitals, people continued to seek treatment for their opportunistic infections and were further referred to TB Sanatorium, Tambaram for specialised HIV care and treatment. Periods of illness strengthened peoples' beliefs that the infection was real. However, when symptoms improved they pushed thoughts of their HIV status aside and even began to believe that they had been cured of HIV. This shows the failure of health care providers in clarifying the basic connection between opportunistic infections and HIV/AIDS.

In any cultural context, a prerequisite of most instances of health seeking is recognition of symptoms. Of key significance, therefore, is the way in which symptoms are interpreted by the individuals affected and by those around them - the meaning the 'symptoms' have, the attribution of cause, and the beliefs held about appropriate and effective treatments (Mechanic and Volkart 1961; Scambler et al. 1981; Morrell and Wade 1976; Wadsworth et al. 1971; Ingham and Millar 1979; Calnan 1987).

Studies have demonstrated that HIV/AIDS-related stigma has adverse affects on the health seeking behaviours of PLWHAs (Muyinda et al. 1997). Moreover, in some cases fear of rejection and stigma (the social consequences of the disease) may be of greater concern to those getting tested for HIV than the actual technical and scientific details concerning HIV/AIDS (Lie and Biswalo, 1994). This fear of social rejection could play a role in preventing individuals from going for HIV testing. For these reasons, in the present study, some persons suffering from STIs refrained from seeking treatment.

Apart from the impending stigma, another reason among the respondents for not seeking treatment was that they could not afford to miss out on a day's work, and therefore, wages. Unless any illness hampered their remunerative and other daily activities, it was not considered 'serious enough' to initiate health-seeking action. However, in our study, it was seen that unlike previous studies, women were keen to
address their own health issues keeping in mind the fact that they needed to take care of their children and other dependants.

Counselling Services: For those who are HIV positive, counselling and testing services can be the entry point into HIV/AIDS care. While, it is beyond the scope of this study to know when individuals became infected, early treatment of infections has a significant role to play in improving the quality of life and in preventing other infections in partners, as observed in the present study. These findings support the premise that early entry into care is the key to improving the quality of life and enhancing prevention activities (Osbourne, 1996; MacNeil et al. 1999). The role of counselling services in providing psychological support to face the situation is of extreme importance. The first step in this direction is to help the patients ‘accept the situation’, dispel negative feelings and refocus their efforts to minimise stress. It also means preparing them to lead an optimistic life, in spite of the existing circumstances.

Patients were tested for HIV without informed consent, their test results were revealed to others resulting in breach of confidentiality and in extreme cases the health care providers refused to treat an HIV infected individual. These negative experiences found in our study related to HIV testing and treatment has also been observed in previous studies (Tharyan et al. 1999 and 2003). The testing policy of the National AIDS Control Organisation proscribes mandatory or routine testing of patients, but the majority of hospitals in the private sector within the country routinely screen patients before surgical procedures in the interests of hospital infection control and due to fears of the risk of occupational exposure to HIV infection (NACO, 1995).

Patient-Provider Relationship: Patients felt that the doctor-patient relationship in the private hospitals was conducive for continuing treatment as against the public hospital due to non-availability of the same doctor during their follow-up visits. Behaviour of health care providers has an impact on the patients seeking treatment,
which in turn effect doctor-patient relationship, therefore, a mechanism needs to be developed where, the interests of the patients have to be safeguarded by the health care providers. The patients felt that in order to receive appropriate medical attention, ‘there is a binding to reveal one’s HIV status to one’s doctor’. In this sense, the support in the medical sphere can be in the form of proper treatment of opportunistic infections, without any discrimination and stigma.

Indian culture highly respects a prescriptive role and hierarchical authorities. Health care professionals are generally viewed as authority figures with expertise. In fact, one of the respondents in the present study mentioned that she thought of her doctor as a ‘deity image’ or ‘God’. Participants may be habituated to assuming a subordinate role in health care encounters, which is in contrast to Western society’s emphasis on individual autonomy (Ting-Toomey, 1985). Participants in the present study were unable to voice concerns about their negative health care experiences to the doctors. But, they felt free to share their experiences with their counsellors. Only a few participants who had the support of positive people’s network were able to voice their concerns. For those positive health care experiences, participants were grateful to their health care professionals and were satisfied by the quality of health care (Hsiung, 1998)

**Emerging Issues**

It was found in the present study that maximum number of HIV positive VCTC attendees were lost to follow-up. Only a few came for follow-up visits, in addition to those who had been undergoing treatment either at District Headquarter Hospital (AGMGH) or TB hospital as long as they stayed in the hospital. Protecting their anonymity was the main concern even when they were seeking treatment. Going to a government hospital meant that there were chances of having to consult a different doctor every time. Moreover, patients complained that as soon as their HIV status was known, the doctors did not take the responsibility of treating them. Instead, they were referred to TB Sanatorium, Tambaram. As a result, those who could afford
preferred to consult a private doctor because this helped them maintain their anonymity. Others who were already hospitalised in the government hospitals at the time of being tested for HIV continued their treatment.

An alternative to Voluntary Counselling and Testing Centre: Why is it needed?
The VCTC is an institution, which can act as a hub for primary prevention, treatment and care. At present, the HIV positive individuals find it difficult to get treatment for at least the ‘Opportunistic Infections’ from the clinicians. They need special attention regarding regular treatment and prophylaxis of opportunistic infections and ARV. Though there will be breach of confidentiality as the special attention may itself lead to identification of the particular HIV positive individual, considering the patients’ welfare and the fact that the regular treatment will increase the quality of life and longevity, it may be justified.

It is probably more beneficial to HIV negative individuals i.e. for ‘Primary prevention’. Therefore, there is a need to address these people who are lost immediately after post-test counselling once they are tested to be HIV non-reactive. Utilizing their services constructively is itself a strategy to be worked out.

Although VCTC plays an important role in primary prevention, it may not be a cost effective approach for countries like India where there is an increasing burden of AIDS patients. According to the Medical Officer In-charge, VCTC, he felt that if there is a centre where counselling is given top priority, testing simplified, and care provided by the same centre, it may really make an impact in HIV prevention in the following ways:

(i) Primary prevention through counselling
(ii) Treatment of Opportunistic Infections and prophylaxis thus delaying the progress to AIDS, which in turn will reduce the transmission of HIV (HIV virus titre increases many times during AIDS).
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(iii) ARV therapy in the same centre may also significantly reduce the transmission of HIV.

(iv) On the whole the programme may look vertical, it may be integrated with regular healthcare when there is a decreasing prevalence of HIV.

(v) The very fact that there is some treatment will definitely enhance the attendance of the volunteers approaching the centre and get tested.

(vi) Initially it was thought testing was a complicated procedure requiring the help of a Microbiologist who is just bothered about testing. Now it is proved convincingly that simple and rapid tests are as accurate as Elisa.

These suggestions of the Medical Officer In-charge, VCTC reflect what he felt strongly about in the existing circumstances, which he had to deal with on a daily basis.

The concept of VCTC has been found to be of immense value as a tool of HIV prevention in sub-Saharan Africa (Painter, 2001). The potential for increasing access to VCT by embedding it with the health services is particularly important as it is likely to gain increased acceptability and effectiveness by broadening the scope of diagnostic, counselling, treatment, care and referral options. In the Indian context, though, we need to analyse the merits and demerits of introducing the VCTC into the Health Service System. Voluntary counselling and testing requires that the person opting for the test should be somewhat informed about HIV in order to be able to understand what risk behaviour, in relation to HIV/AIDS, means. Hence, realising their past risk behaviour, people can utilize the VCT services as a preventive tool. It has been found in the present study that more referral rather than voluntary cases are coming in at the VCTC. This means that the voluntary nature of the Counselling and Testing Centre has been negated and it has been functioning more as a ‘Referral Counselling and Testing Centre’. The VCTC, instead of being used as a preventive tool, has become a diagnostic procedure as part of seeking treatment. The reason for this could be the ignorance or lack of information regarding HIV/AIDS among the
To Conclude: Implications for Care, Support and Prevention

general public. During the treatment seeking procedure, it is through the health care provider that they can be informed about HIV/AIDS. But, often doctors, due to excess patient load do not take it upon themselves to inform the patients about HIV and the HIV test, expecting the counsellors to do the same. The counsellors for their part, also due to excess patient load do not get the opportunity to ensure whether the information provided by them has been understood and absorbed by the patients effectively. Hence, it is perceived that there is a gap, which needs to be overcome in order to achieve what VCTC should actually achieve.

Here, it is important to mention that the VCTC as an entry point for care, support and treatment can be strengthened by taking some of the following actions:

(i) Mechanisms to adopt and sustain ‘safe behaviours’ among those who are engaging in ‘risk behaviour’ or are vulnerable need to be instituted among those found ‘negative’. These individuals can be instrumental in facilitating other people’s access to the VCTC.

(ii) Mediatory role between positive persons and treating doctors is required, thereby, facilitating treatment and ensuring adherence.

(iii) Persuading and clarifying issues with health care providers (doctors and paramedics) who do not want to treat HIV positive individuals.

Participatory action techniques can be used by a social worker or a counsellor at VCTC to help individuals and groups analyse their social vulnerability to HIV, recognize specific barriers, and assist programme staff to incorporate measures that address social vulnerability into care and support programmes as observed in previous studies (Gupta and Weiss, 1993; De Guzman, 2001). A participatory approach can ensure that the voices and needs of many different people are heard, including groups who are socially vulnerable to HIV/AIDS. They seek to strengthen and support local efforts rather than impose external solutions that are likely to meet with failure (Foster et al. 1997; Mann and Tarantola, 1996).
Is the VCTC functioning in the medical college (microbiology dept.) giving care to HIV positive individuals?

Though the VCTC at present is trying to manage the HIV positive individuals through counselling as a preventive measure regarding opportunistic infections, the expectation of the HIV positive persons are increasing particularly in terms of treatment of their health problems.

Microbiologists are competent in maintaining the quality control in HIV testing, laboratory diagnosis of opportunistic infections, helping the health care workers practicing universal precautions and guiding the hospital in the biomedical waste management.

Counselling alone cannot fulfill the needs of the VCTC attendees. Though the VCTC attendees can be helped to seek the advice of the physicians, surgeons it may be difficult for them to go to various departments without getting themselves identified. At present, the scenario is not conducive for the VCTC attendees due to discrimination by doctors and health care workers.

As HIV testing has been simplified since the introduction of Rapid tests, the VCTC is now capable of providing the test results on the same day. While on one hand this will lead to a marked increase in the number of VCTC attendees, on the other, it will ensure that more people come to collect their test results and attend post-test counselling. Though the specificity and accuracy of the Rapid test is equivalent to that of Elisa test, it is not being used in the VCTC due to its high cost. Here, we need to question as to whether it is appropriate to provide the test results on the same day or to continue with the current practice of the VCTC — giving the test results biweekly — which will give some time to the patients to prepare themselves for the result after the pre-test counselling. The real role of the microbiologist i.e. HIV testing is minimised to the extent that any health care worker preferably a trained doctor or a laboratory technician can do HIV testing.
In this regard, the district VCTCs may be in a better position than the VCTCs in medical colleges. If the doctor in charge of VCTC, preferably a general physician can perform both functions testing and care of the VCTC attendees. The existing practice of having VCTC under the control of STD medical officer in the District Head Quarters may decrease the number of volunteers due to the stigma attached to the STD. However, due to the manpower shortage, the Joint Director Health Services may find it convenient to hand over the VCTC to the STD medical officer who is not entrusted with 24 hours call duty service.

It is essential that the various departments in an institution have a proper coordination with the VCTC in order to take care of the referred cases effectively. Since maximum number of cases are referred to the VCTC from Skin and STD departments, such coordination is even more vital for proper delivery of services. There is some misunderstanding between the Microbiology and STD departments regarding the running of VCT services. The STD departments which were having a separate counsellor appointed by the State AIDS Control Society (which was subsequently removed) feel deprived of the counselling services. Though the SACS (guidelines from NACO) has clearly stated that there is no need for a separate counsellor after the VCT service, the STD departments are not convinced. As the ARV is going to be introduced shortly, the physician's role is going to gain momentum and it may automatically reorganise the existing VCT concept.

As the follow-up of the clients is one of the responsibilities of the VCTC, the burden of detecting opportunistic infections, particularly tuberculosis, at the earliest, and referral to the doctors for the management of the disease is increasing day by day. Since counselling is the main responsibility of the counsellor, the early detection of opportunistic infections lies with the medical officer. In the case of VCTC, Trichy, the medical officer in charge is a Clinical Microbiologist and the HOD of the Microbiology Department in the KAPV Government Medical College, Tiruchirapalli. His first priority, therefore, lies in teaching because of which he cannot be present in
the VCTC during the 'peak hours'. The HIV positive individuals coming with a lot of hope despite knowing their HIV status feel desperate when they are not in a position to get treatment from a doctor in the same centre where their privacy can be maintained.

The needs of PLWHAs go beyond clinical care and treatment. They include, for the most part, basic needs for food, shelter, treatment for opportunistic infections, right to protection in employment, right to confidentiality, right to medical care, access to new treatments, counselling and emotional, social and psychological support, protection against discrimination and stigma, and social support for their orphans left behind after the patients die (Van Praag, 1998). In order to address all these needs of PLWHAs, we need to move beyond the continuum of care. A good and well-equipped infrastructure for Primary Health Care, which can educate and help people, is essential. Furthermore, the Primary Health Care should be linked to community-based AIDS services and to the workplaces with the purpose of providing a strong network of welfare and support.