CHAPTER - VII

CONCLUSIONS

&

SUGGESTIONS
CONCLUSIONS AND SUGGESTIONS

This Report concludes with the final chapter on the Conclusions, Discussions and Suggestions based on the researcher’s experiences during the course of the Study. The researcher, before putting forth her conclusions and suggestions on the study, would like to give a brief summary of the study.

INTRODUCTION:

The study on the "Socio-Economic, Health and Family Profile of Mothers living with HIV/AIDS" aims at studying the problems of HIV infected mothers with regard to the upbringing of children. The objectives of the study were:

1. To study the socio-economic status of HIV infected mothers;
2. To study the marital status of HIV infected mothers;
3. To study the HIV status of the children of the HIV infected mothers;
4. To study the ability of the HIV infected mothers to provide basic care and support for the children;
5. To study the health status of the HIV infected mothers;
6. To study the support systems available to HIV infected mothers in the upbringing of the children.

The study was carried out between March and October 2001 at the Government Hospital for Thoracic Medicine at Tambaram Sanatorium, Chennai. The data were collected from all those who satisfied the criteria for sample selection. The sample size worked out to be 120 respondents. The criteria for sample selection were (a) the respondents should be HIV infected mothers with children (one or more) aged less than 14 years (b) the mother's HIV status should be confirmed through Western Blot test and (c) they should be getting in-patient treatment in the Government Hospital of Thoracic medicine, the field of study. The data were collected through an interview schedule prepared by the researcher especially for the said task. The tool was pre-tested and validated. The tool had about 80 questions and sought information on various aspects of the research problem in
tune with the objectives of the study. The data collection was done between March 2001 and October 2001. Reluctance to divulge information and depression on the part of the respondents were the major difficulties encountered during the course of data collection.

The data collected were analysed electronically using SPSS (version 10.0). Statistical test (Chi-Square test) was also applied. Significant data have been represented diagrammatically.

CONCLUSIONS:

I - Socio-Economic and Family Profile of the respondents:

- Majority of the respondents are at the prime productive period of their life. The fact that one-fourth of the respondents belong to the age group of twenty-one years to twenty-five years, and have children emphasises the fact that the mothers are married at their teen age. This is an evidence for early marriages where the women are much ignorant of the facts of Reproductive Tract Infections as well as HIV/AIDS. A great majority of the respondents hail from rural areas, and it is clear that early marriages are inevitable in rural masses.

- HIV patients feel free to avail treatment in Government Hospital of Thoracic Medicine, Tambaram Sanatorium which is far away from their own locality, thus avoiding disclosure of their HIV status to their relatives and neighbours and hence escape from social ostracism. The higher illiteracy rate among the HIV infected mothers makes them involve in risk activities which in turn makes them sick. In such situations, prolonged hospitalization is the remedy as they lack knowledge about living with HIV/AIDS.

Respondents work for their livelihood in spite of their ailment. Economic problem is an added stress to the respondents given their failing health. Though some of the
respondents are employed, their earnings are so meagre that they fall below poverty line. They are forced to work, not only to sustain themselves but also to support their family. Among those respondents who are employed, majority of them work during convenient hours due to their frequent failing health.

➢ Mostly all the respondents receive economic support but only the sources (viz., charity, ancestral property etc) vary. It is appropriate to note that most of the respondents rely on their spouses for economic support. Only when the spouse is deceased or indisposed, are the respondents compelled to rely on other sources.

➢ In a great majority of the cases where the husband is employed, the woman remains unemployed. This might be due to cultural factors or due to their illness. This is reiterated by the fact that the relationship between the two variables - employment status of husband and employment status of the respondent is statistically significant to a very high degree.

➢ The presence or absence of assets in the hands of the respondents does not make much of a difference in their economic life. At the outset, most of the respondents do not possess any significant assets. Further, among those who own assets, it is only meagre and such assets have already been used up for their day-to-day living. Such assets do not make reliable sources of income for the future.

➢ It is heartening to note that in a majority of the cases, the respondents continue to stay with their husbands. Though there might be instances of the respondents' spouses also being infected, the mere sense of living with the spouse will give a better sense of fulfillment and also aid in the better upbringing of children compared to broken families or single-headed families. There are also certain instances, which stands as a proof of early widowhood among certain respondents.
> When the respondents are married and are staying with their husbands, they prefer to be housewives. However, the need to take-up a job increases considerably when the spouse has expired or if he is not gainfully employed or has deserted the respondent.

> Role conflicts in family affect the emotional well-being of the respondents and disrupt the upbringing of the children. The implication is that role-conflict occur in all cases regardless of the type of family in which the respondent lives. In other words, role conflicts seem inescapable as far as our ailing respondents are considered. Even education does not have an impact on the role conflicts occurring in the family. Ageing has no relationship to the extent of role conflicts in the family.

> It is found that a large proportion of widowed / separated women do not consider the husband’s support necessary. Their tendency towards self-reliance is highly significant.

> It is evident that a majority of the respondents come from the confines of a family be it nuclear or joint. However, a small per cent of the respondents lead a single-headed family life.

II - Health Profile of the respondents:

> With the growing awareness about the disease, more number of people are coming forward to get themselves tested for HIV given their vulnerability to this disease. These numbers are likely to grow further. The people prefer to get themselves tested and take medical treatment so as to lead a relatively healthier living and also to prolong their life in the interest of their children.

> The spouse being infected is the most frequent reason for having been tested for HIV and is statistically significant.
➢ Family type does not determine the reason for having oneself tested for HIV.

➢ It is evident that the husband’s own infection is the dominant factor, which forms the reason for testing for HIV among the respondents in the married, and widowed categories.

➢ The respondents suffer mostly from fever, mouth and throat problems followed by genital problems, which are the predominant ailments suffered by HIV/AIDS patients. This also indirectly affects their economic stability.

➢ Though fever is a predominant ailment which HIV infected persons suffer from, they do not give due attention to the ailment and hence do not report to the hospital for treatment.

➢ Diarrhoea is the major ailment which affects the HIV infected / AIDS respondents predominantly. They mostly prefer to seek doctor’s help when they suffer from diarrhoea.

➢ Though only a little more than one-third of the respondents have skin problems, the inconveniences caused by the same is enormous. The itching is unbearable and this often results in sores which aggravate the situation by paving way for more infections. Besides, it also restricts their socialisation which not only has an impact on them directly but also on their family members especially their children.

➢ Mouth and throat problem affects majority of the respondents and because of its severity, most of the respondents prefer the treatment given in the hospital.

➢ The predominant source of HIV / AIDS transmission is the sexual mode. Therefore, genital problems are found to be common among the respondents.
➢ It may be stated that tuberculosis is a common ailment among HIV infected / AIDS patients.

➢ It is clear that affliction with tuberculosis does not necessarily induce the respondents to have frequent check-ups. They mostly come for check-ups when they suffer from other ailments.

➢ Higher the age, greater is the likelihood of the respondents suffering from tuberculosis.

➢ It is evident that the respondents do not avail treatment from their own locality. In other words, they prefer to avail treatment from Government Hospital of Thoracic Medicine, Tambaram Sanatorium which is the India's largest care centre for HIV / AIDS.

➢ Educational qualification has no bearing on the pattern of treatment availed by the respondents.

➢ Each and every respondent of the study have opined that they are in dire need of a social worker for guidance, counselling and referral services.

➢ The amount of money spent by the respondents for the medical expenses is meagre because they avail the services of the Government Hospital.

➢ The respondents are somehow able to manage their survival mostly through debts.

➢ Poverty constitutes the major cause for the inappropriate intake of food by the respondents. This creates a vicious circle. Though a HIV infected / AIDS patient requires good food to boost his immunity, hospitalisation or prolonged illness curtails his financial capabilities resulting in less money being available for food. It is at this juncture, that the food provided by the Government Hospital plays a vital role and is a
thing of value to most of the respondents and above all a great majority of the respondents are not trained on healthy food habits. Here comes again the necessity of social workers who can refer them to NGOs for the above-mentioned training or they themselves can give an orientation to the HIV infected / AIDS patients.

III - Children's Profile and Ability to provide basic care and support needs:

» The increased number of pregnancies have an impact on the number of abortions suffered by the respondents.

» The health status deteriorates with more number of pregnancies. The respondent had been HIV negative during the earlier pregnancies whereas she got infected by HIV during the later stage which could be the reason for abortion.

» The increased number of pregnancies have a negative impact on the status of children born to them. The mortality rate of infants is high when there is an increase in the number of pregnancies.

» Most of the respondents have two children and certain respondents have reported having three and four children. Female children outnumber the male children. Most of the children have not been tested for HIV.

» Fear is a major factor that prevents the mothers from getting their child tested for HIV. This is statistically very significant. Respondents prefer to live in a hope that their children are HIV negative. Proper counselling should be rendered to the mothers to alleviate the fear and make them understand the significance of early diagnosis and treatment.

» It was found that none of the respondents had disclosed the HIV status of the infected child to the other "healthy" child / children in the family. They opined that the
children were too young to understand the implications of the same and hence preferred to avoid any complications.

- It is clear that the mother is unable to provide equal care and concern to all her children.

- The level of awareness among the children about the HIV status of their mothers seems to be very low.

- Due to prolonged sickness and hospitalisation of the mothers, majority of the children are not provided opportunities for physical and mental development.

- Respondents affected by Tuberculosis are unable to take care of their children and are consequently unable to provide opportunities for physical and mental development of their children. This is statistically significant.

- Due to frustration and sickness, the mothers are not in a position to ensure spiritual solace for a large majority of the children. It is understood that HIV / AIDS has an adverse effect on child development.

- Socialisation is absent among the children of HIV infected persons due to their HIV status and this affects the children irrespective of their (the children's) HIV status.

- The occurrence of Tuberculosis has an effect on the respondents' child-rearing patterns as they are unable to make the child socialise with neighbours and relatives.

- Majority of the respondents are not utilising the medical care provided by Government establishments.

- In only less than half the cases, the mothers are sure that adequate nutrition is provided to their children. The acute level of poverty they suffer from has already
been referred to in the socio-economic profile of the respondents. Children's deprivations spring directly from the poverty conditions.

- Marital status has no relationship with the respondents' ability to provide nutrition to the children.

- Family type has no relationship with the respondents' ability to provide nutrition to their children.

- Despite their poor economic strata, majority of the respondents have reported that they are satisfied with the housing facility that they provide for their children.

- There is no statistically significant relationship between marital status of respondents and their ability to provide for housing for their children.

- Mothers in nuclear families are significantly more often able to provide for housing to their children probably due to fewer family members and relative economic self-sufficiency.

- In over half the cases the mothers are not sure whether their children enjoy adequate recreational facilities.

- The relation between the two variables - marital status and ability to provide for recreation for children is statistically significant.

- Family type has an impact on the ability to provide recreation facilities.

- Only in a few cases the mother is not happy with her role in terms of ensuring care and responsibility for the child.
Marital status has a positive influence on the respondents' ability to help their children grow up under their care and responsibility.

- There is no significant relationship between the two variables studied viz., family type and the respondents' ability to provide care and responsibility for the children.

- In only less than half the cases the mother is able to ensure good education for the children.

- Marital status does not have an impact on the ability of the respondents to provide education to the children.

- At least in a fourth of all the cases, the mothers are not sure that their children are protected against exploitation.

- There is a statistically significant relationship between the two variables viz. Marital Status and Ability to protect child from exploitation

- The respondents from both nuclear family set-up and joint family set-up are able to protect their children from exploitation.

- Mostly the children are HIV negative, so there is no need for medical expenses. A few respondents have HIV positive children; mostly the treatment is given free of cost to them in the hospital.

IV - Support systems:

- Similar to the case of any other diseases, marital status did not make any variation in the availability of help to the respondents.
Family support is available to a majority of the respondents to a considerable extent. This family support is predominantly from the kith and kin of maternal side. The advantages of being a member of a Joint family are amply borne out by the results of the statistical procedure (Chi-Square Test) which confirms that these benefits are indeed significant. It is pitiable to notice that there are respondents who receive no help and suffer the pangs of stigmatisation.

Increase in the number of ailments suffered by the respondents does not increase the amount of help received. The quantum of help received remains the same irrespective of ailments. There is no statistically significant association existing between the number of ailments and the help received by them.

Only a negligible amount of respondents receive economical and physical help from their neighbours. Almost all the respondents (98.3%) have reported that they do not receive any help from their neighbours. The major reason behind this is that the respondents have not disclosed their HIV positive status to their neighbours. There are also a few cases who suffered ostracism after disclosing their HIV status.

Majority of the respondents do not avail the help provided by health care professionals and social workers. It is found that there is no social work intervention provided for HIV infected / AIDS patients in Government Hospital of Thoracic Medicine, Tambaram Sanatorium.

The respondents do not seem to make the best use of the Governmental and Non-Governmental Organisations working in the field of HIV/AIDS.

**Suggestions:**

1. Actually self-employment may suit these ladies better, from the point of view of health. They could remain at home, avoid the strain and expenses involved in
commuting. They can be close to their children and other relatives. Medical emergencies to which they may be prone, could be quickly attended to. Above all they can work when they feel energetic.

Given that the respondents do not prefer to disclose their HIV status at their work place for fear of discrimination or loss of job and their frail health, alternate forms of employment may be thought of. For example, small-scale income generation programmes like tailoring, paper-making, sale of flowers, art-work may be considered. NGOs may initiate such activities and engage the HIV victims when they feel relatively healthy so that they can have an income and feel relatively secure. The researcher, however, feels that these business venues should be carefully identified; they should not be detrimental or should not aggravate their condition. For example, certain NGOs promote chemical based activities like phenyl making, soap making etc. But the respondents expressed that such activities complicated their health problems. Thus more viable measures should be thought of to support them economically.

2. The researcher came across cases where the women who have been deserted by their families, prefer to stay back in the hospital citing frivolous health complaints. It is at this juncture that the researcher feels that effective rehabilitative measures need to be evolved to support them.

3. Crisis intervention techniques should be employed to relieve the mothers with HIV from stress. Young widows in order to earn their livelihood should not resort to indulging in high-risk behaviour for the sake of their children. In this regard, ego-supportive and moral counselling should be given. During these counselling sessions, it should be clarified to the respondents that high-risk behaviour would gravely affect them. Alternatively, they should be taught to lead a life of abstinence, concentrating more on bringing up their children well; they should be given inputs on taking care of their health life viz., nutritious food, positive outlook on life, meditation, religious orientation etc.
4. Family support is very essential to enable the respondents cope effectively with the rigours of the disease. Family counselling by social workers or NGO personnel should be rendered to every member of the family as regards the role of the family in sustaining the affected. They need to clarify certain aspects of the disease that AIDS does not spread through social contact, family members can play a main role in the psychological well-being of the patients. This provides tremendous support to the affected and boosts their morale. It further reassures the patients that there is someone to take care of their children after they are gone.

5. Given that the HIV affected are susceptible to Tuberculosis (TB), they can be counselled during the pre-screening sessions for healthy living. In the venue of data collection, both the HIV affected patients with and without TB were lodged together in the same ward. This, the researcher feels should not be the case. Lodging TB and non-TB cases in the same ward will affect the relatively healthy ones to a large extent. Hence action in this regard needs to be taken.

6. A routine health check pattern can be given by the social worker or physician with due emphasis to adhere to the pattern. The health status of the HIV infected will be fluctuating. In order to prolong healthy life style, they have to visit hospitals on a periodical basis instead of coming whenever it becomes necessary i.e., after aggravation of symptoms.

7. Despite being the largest care centre for HIV / AIDS in India, the hospital does not have sufficient number of social workers at the time of Study. This adequately highlights that the role of social workers has not been accorded its due place in the medical field.

The Government has to ensure the availability of the services of social workers in each ward because the role of a social worker in this field is important - they play a vital role right from registration of the patient till the discharge and even follow-up. Since there is a flooding of patients in the hospitals, the doctors are unable to
concentrate on the social and psychological requirements of each patient, which can be catered to by the social workers. Pre-test and post-test counselling, crisis intervention, case work, group work are the other means by which the social workers can contribute. For instance, some of the respondents stated that they found it delicate to disclose their personal problems as well as their genital problems to the male physicians. So it is a pre-requisite to appoint a social worker or a female physician while dealing with such sensitive issues.

8. The HIV infected / AIDS patients need a balanced diet for the maintenance of their health but the associated ailments of the disease restricts them from taking food and also from taking medicines. In some cases, this loss is required to be supplemented by IV fluids.

HIV affected should be given adequate inputs on cost-effective nutrition like greens, pulses, dates, broken gram etc. Further, their morale should be boosted and they should be given a purpose for living. They should not be made to neglect themselves on account of depression.

9. India has a majority of rural and illiterate masses. Hence, the AIDS prevention programmes, to be effective, should begin from the level of understanding of the masses. Majority of the respondents of this study are illiterates. They are totally unaware of the implications of the disease and also the interventions and facilities available for them. High level planning and high budget allocations are prone to go waste if the needs of the respondents are not taken into account. Intervention strategies have to be planned so that it reaches this mass of people who desperately need awareness.

10. In the interest of the mothers’ health and also to restrict the mother-to-child transmission of HIV, the HIV infected mothers-to-be should be trained on the family planning techniques and should be encouraged to embrace the family welfare schemes.
11. Most of the children are not tested for HIV which is to be taken into consideration by the hospital authorities. More counselling should be rendered to the mothers to make them come forward to get their children tested for HIV. This ultimately is good for the child also. Thus, NGOs / social workers should motivate the parents to give their voluntary consent to test their children for HIV by explaining to them the importance of timely screening.

12. Fear is a major factor that prevents the mothers from getting their child tested for HIV. The finding is statistically very significant. Respondents prefer to live in a hope that their children are HIV negative. Proper counselling should be rendered to the mothers to alleviate the fear and make them understand the significance of early diagnosis and treatment.

13. Child rearing is the major responsibility of the mother. In this study, child rearing is a source of worry for most infected mothers. The study analysed the various aspects of child-rearing like ability to provide adequate nutrition, housing, medical care, recreation, education, socialisation, protection from exploitation etc. Nearly half the respondents were unable to provide the above-mentioned necessities satisfactorily. Even the other half of the respondents rely on others' support to satisfy their child's needs. Lack of child care will have tremendous drawbacks like the child may turn out to be a delinquent or may undergo exploitation by others (ex: child labour) etc. Hence this is an important issue that needs to be taken care of. Most of the mothers have not disclosed their HIV status of their children, even to the grown-up children. It is always better to disclose the HIV status of self or of the children to the children at a certain point of time to keep them psychologically prepared for any drastic change in the family.

14. Towards better child-care, cost-effective nutrition plans can be provided to the mothers; regarding the education of children, NGOs / social workers can place them in a school where free education may be provided. Even the children can be counselled on HIV & AIDS, the role of the child in the family etc. The elder child
should be groomed to take care of the younger siblings. As regards education of the children, they may be provided trade-based education or vocational education so that they can start their own establishments and become economically independent on an earlier date. In this regard, NGOs can evolve special intervention programmes for the HIV affected children.

15. Spirituality heals hurts and wounds. It is desirable for the children to be given religious care by the respondents, which in turn is good for both. If the respondents do not feel inclined or competent to provide religious care for their children they should keep the children under the care and supervision of some guardian or well-wisher so that the wholesome development of the child is ensured.

16. It is always better to teach the children to socialise in the community as it is an important requisite to live in today's world. Further, if they are not taught they may fall prey to misleading hands thereby resulting in change in perspectives.

17. Some children enter work force in a young age due to compelling family situations. They are much ignorant about the happenings of society. The working children should be oriented on the possible risks of sexual exploitation in order to reduce their vulnerability to contract HIV / AIDS.

18. Because of prolonged hospitalisation of the mothers, they are not in a position to take care of their children. Besides, the children are forced by circumstances to stay with their mothers in the hospitals. This is not good for the children not only from the health point of view but also psychologically. Hospitals may provide separate creches or child-care units wherein the children of HIV infected mothers may stay during the prolonged hospitalisation of the mothers. Else, NGOs may arrange for foster care set-ups wherein the children of the HIV infected mothers may be lodged during the prolonged hospitalisation of the mothers.
19. Family counselling can be rendered to all the family members so that the affected may get better support and understanding. If the uncles or grand-parents take care of the children, the child gets an opportunity to stay in a family atmosphere in stead of staying in hospitals and hostels. Social awareness on HIV / AIDS and on the rights of HIV infected persons should be given to the general public. Stigma and discrimination should be eliminated in the field of HIV / AIDS. The HIV infected can also lead a healthy life for more than a decade provided they are extended the necessary support and guidance required for the same.

20. The researcher feels that it is better for those respondents having slightly grown-up children to keep them informed about the HIV status of self and thereby keep them mentally prepared for the inevitable consequences of HIV / AIDS. For instance, as in Case Study - IV presented in the Appendices, the children should be prepared to face the eventual loss of their mother.

21. Though many NGOs work in the field of HIV / AIDS, not many NGOs cater to the needs of the children of those affected by the disease. This is a lacunae that needs to be attended to. Else, the lives of such children may be wasted away or they may be left at the mercy of destiny for no fault of theirs. Thus a more organised approach to the care of the children of HIV infected has to be drawn up and followed.

CONCLUDING REMARKS:

HIV / AIDS has been the talk of the entire world since the past two decades. Since then volumes of resources have been earmarked and spent on research, action work to curb the menace. Strategies and focus areas for tackling the problem have been revised according to the times. However, not many researches have been undertaken to study the problems of mothers affected by HIV / AIDS in the upbringing of their children. Even the affected mothers themselves are not conscious of the problems they face consequent to them being infected with HIV / AIDS. This lack of awareness by itself is an unhealthy sign.
The findings of the study have revealed that the HIV infected mothers face a plethora of problems when it comes to the caring for their children. There is a lot that the society can do to mitigate the losses faced by the HIV infected mothers. The society should abstain from condemning them and need accept them as they are and extend a helping hand so that they can lead a healthier life during the rest of their life. It is at this juncture that the UN's declaration of the theme of the year 2003 - 'Live and Let live' gains relevance and prominence.