CHAPTER V
DISCUSSION

5.1 MAIN FINDINGS OF THE STUDY

5.1.1 Knowledge of HIV/AIDS

- Knowledge regarding HIV/AIDS is low among rural women identified with HIV/AIDS and undergoing Anti Retro Viral drug therapy was moderate.

- Those with the D4t+3tc+Nvp treatment had higher knowledge than respondents with other types of treatments.

- Other selected secondary factors did not have significant influence over knowledge about HIV/AIDS.

5.1.2 Opinion regarding HIV/AIDS

- Opinion regarding HIV/AIDS was moderately favorable among rural women identified with HIV/AIDS and undergoing Anti Retro Viral drug therapy.

- Those respondents who had general opinion had a better opinion scores on HIV/AIDS.

- Other selected secondary factors did not have significant influence over opinion about HIV/AIDS.

5.1.3 Family environment

- The family environment of rural women identified with HIV/AIDS and undergoing Anti Retro Viral drug therapy was not very much encouraging.

- Age groups had significant influence over only 2 components of FES-expressiveness and organization, scores in both the components increased, as the age increased.

- Occupation-wise, the respondents differed significantly in 3 components: cohesion, organization and control, where professionals had higher scores on
cohesion and in control, where as in organization skilled respondents had higher scores.

- Income had significant influence over few of the factors-cohesion, expressiveness, independence, moral religious emphasis, and in organization, as the income increased scores in these 5 factors also increased.

- Type of treatment had significant influence over FES in almost all components- Respondents with D4t+3tc+Nvp and Stv+Lmv+Efv type of treatments had higher scores.

- As the educational level increased, the scores on control component of FES also increased linearly.

- Family type had significant influence over cohesion, moral religious emphasis, organization and control, where respondents with single parent had higher scores.

- SES had significant influence over moral-religious emphasis and organization, as the SES increased, scores also increased.

- Marital status found to have significant influence over conflict, achievement, and active recreational components of FES, married and separated respondents had high scores.

- Spouse status had significant influence over almost all the components of FES except for organization and control. Most of the time spouse with +ve state had higher scores than any other groups.

5.1.4 Marital adjustment

- The marital adjustment of the rural women identified with HIV/AIDS and undergoing Anti Retro Viral drug therapy was very unsatisfactory.

- Respondents with higher educational qualification had better adjusted well compared to respondents with lower educational levels.

- Other selected secondary factors did not have significant influence over marital adjustment.
5.2 VERIFICATION OF THE HYPOTHESES

**H1: Knowledge regarding HIV/AIDS is low among rural women identified with HIV/AIDS and undergoing Anti Retro Viral drug therapy**

H1 stated as “Knowledge regarding HIV/AIDS is low among rural women identified with HIV/AIDS and undergoing Anti Retro Viral drug therapy’ is partially accepted as the descriptive statistics revealed moderate level of knowledge’ among the respondents of the study.

**H2: Opinion regarding HIV/AIDS is unfavorable among rural women identified with HIV/AIDS and undergoing Anti Retro Viral drug therapy**

H2 stated as ‘Opinion regarding HIV/AIDS is unfavorable among rural women identified with HIV/AIDS and undergoing Anti Retro Viral drug therapy’ is partially accepted as the descriptive statistics revealed a moderate opinion towards HIV/AIDS by the selected sample.

**H3: The family environment of rural women identified with HIV/AIDS and undergoing Anti Retro Viral drug therapy is not encouraging**

H3 stated as ‘The family environment of rural women identified with HIV/AIDS and undergoing Anti Retro Viral drug therapy is not encouraging’ is accepted as from the descriptive statistics we find that in majority of the components the sample had moderate family environment and in 3 components the sample had low family environment.

**H4: The marital adjustment of the rural women identified with HIV/AIDS and undergoing Anti Retro Viral drug therapy is low**

H4 stated as ‘The marital adjustment of the rural women identified with HIV/AIDS and undergoing Anti Retro Viral drug therapy is low’ is accepted as we find that marital adjustment of the entire selected sample was less than 30% which indicated that the marital adjustment of the sample was very unsatisfactory.
H5: Secondary variables (age, education, family type, occupation, income, route of transmission, clinical stage and treatment modalities) significantly influence knowledge regarding HIV/AIDS of the rural women identified with HIV/AIDS and undergoing ART.

H5 stated as ‘Secondary variables significantly influence knowledge regarding HIV/AIDS of the rural women identified with HIV/AIDS and undergoing ART’ was partially accepted as we find that only few of the secondary variables influenced knowledge level of the respondents in the study. Those with the D4t+3tc+Nvp treatment had higher knowledge than respondents with other types of treatments. Other selected secondary factors did not have significant influence over knowledge about HIV/AIDS

H6: Secondary variables (age, education, family type, occupation, income, route of transmission, clinical stage and treatment modalities) significantly influence opinion regarding HIV/AIDS of the rural women identified with HIV/AIDS and undergoing ART

H6 stated as ‘Secondary variables significantly influence opinion regarding HIV/AIDS of the rural women identified with HIV/AIDS and undergoing ART’ is partially accepted as the test statistics revealed influence of few of secondary variables on opinion regarding HIV/AIDS. Those respondents who had general opinion had a better opinion scores on HIV/AIDS. Other selected secondary factors did not have significant influence over opinion about HIV/AIDS

H7: Secondary variables (age, education, family type, occupation, income, route of transmission, clinical stage and treatment modalities) significantly influence family environment of the rural women identified with HIV/AIDS and undergoing ART.

H7 stated as Secondary variables significantly influence family environment of the rural women identified with HIV/AIDS and undergoing ART is partially accepted as few of the components of FES were influenced by secondary factors. It was found that Age groups had significant influence over only 2 components of FES—expressiveness and organization, scores in both the components increased, as the age increased. Occupation-wise, the respondents differed significantly in 3 components—cohesion, organization and control, where professionals had higher scores on cohesion
and in control, where as in organization skilled respondents had higher scores. Income had significant influence over few of the factors-cohesion, expressiveness, independence, moral religious emphasis, and in organization, as the income increased scores in these 5 factors also increased. Type of treatment had significant influence over FES in almost all components- Respondents with D4t+3tc+Nvp and Stv+Lmv+Efv type of treatments had higher scores. As the educational level increased, the scores on control component of FES also increased linearly. Family type had significant influence over cohesion, moral religious emphasis, organization and control, where respondents with single parent had higher scores. SES had significant influence over moral-religious emphasis and organization, as the SES increased, scores also increased. Marital status found to have significant influence over conflict, achievement, and active recreational components of FES, married and separated respondents had high scores. Spouse status had significant influence over almost all the components of FES except for organization and control. Most of the time spouse with +ve state had higher scores than any other groups.

**H8: Secondary variables (age, education, family type, occupation, income, route of transmission, clinical stage and treatment modalities) significantly influence marital adjustment of the rural women identified with HIV/AIDS and undergoing ART.**

H8 stated as ‘Secondary variables significantly influence marital adjustment of the rural women identified with HIV/AIDS and undergoing ART’ is partially accepted, as marital adjustment of the sample influenced by few of the secondary factors. Results revealed that Respondents with higher educational qualification had better adjusted well compared to respondents with lower educational levels. Other secondary factors did not influence the marital adjustment of the respondents in the study.

**5.3 GENERAL DISCUSSION**

The individual HIV illness, even if it is subjectively experienced as unique and isolating, always happens in the context of the HIV epidemic. The face of the HIV epidemic may look different from country to country or even between rural and urban areas. However, the epidemic of HIV is more deeply seated than the person’s body.
Barnett (2002) notes that “an epidemic reveals many of the fractures, stresses, and strains in a society”; among these, one can enumerate long-term historical and societal structural inequalities and inequities (poverty, inequities in distribution of income and wealth, polarization by social class, levels of social justice, education, ethnicity) or other aspects such as social order and social cohesion, which may be affected by war or migration or similar social and physical dislocations. “The HIV/AIDS epidemic did not just happen. There are social, economic, and cultural reasons why such events occur” (Vignette 4). When assisting and working with an HIV infected patient, health care providers must consider the preceding aspects. The HIV infection may, depending on context, be seen to a greater or lesser extent as a “lifestyle disease,” depending on the perceived mode of transmission. But becoming HIV infected and coping with the disease is not totally the individual’s responsibility, because everyone’s life is unfolding in a society and a social context that generates circumstances for risk environments, thus making the individual more or less susceptible to acquiring HIV and remaining at risk for higher morbidity and mortality. Stigma and discrimination are channels that funnel the epidemic, raising obstacles to prevention and treatment.

Stigma and discrimination also occur in the health care setting. Sometimes HIV-infected patients are denied appropriate care or are segregated from the general hospital population. Health care workers may selectively use universal precautions only with HIV-infected patients. Reasons may include a lack of medical resources, but health care workers’ ignorance and stigmatization of HIV can also be factors. A survey of 1000 physicians and nurses in West Africa in 2002 found that 20% of them felt that HIV-infected patients had behaved immorally and deserved their fate. Oftentimes health care workers who help patients with HIV may also be stigmatized because of their association with the virus.

Statistics indicate that close to 75% of the global HIV/AIDS caseload occurs in Africa. As in other places, stigma associated with HIV/AIDS in Africa involves attributions of other stigmatized behavior, such as homosexual acts among young men. Homosexuality is highly stigmatized and is even illegal in many parts of Africa and Asia. People often blame outside forces, such as foreigners or the devil, for HIV/AIDS. Stigma may even lead to violence against those blamed for introducing
the disease. In 2003, schoolchildren in Ghana staged a demonstration to demand that all tourists be required to get HIV tests. Most societies stigmatize sex workers (prostitutes), who are an integral part of the spread of HIV. Stigma and discrimination prevent sex workers from playing a larger role in the fight against HIV/AIDS. Anal sex is also widely stigmatized, independent of its association with HIV infection. Anal sex is a more common practice in Africa than previously thought, in a 2004 survey in South Africa, male-male sex (MSM) accounted for 7% of sexual practices, and heterosexual anal intercourse is a common form of birth control. Stigma may cause people not to talk about risk behaviors and risk reduction. By association with HIV, stigma may also attach to HIV prevention methods, such as the use of condoms, and thus prevent HIV risk reduction among the uninfected. Social dislocation carries with it not only additional risks of infection but also the stigma associated with being a foreigner or outsider. Many refugees may have contracted HIV in their own countries before seeking refugee elsewhere. Warring groups in Sudan, Congo, Uganda, and Rwanda have raped thousands of women and girls, putting them at high risk of contracting HIV. Among an estimated 250,000 rape survivors, up to 67% might be living with HIV.

Sex education may also be stigmatized, perhaps in the belief that it can contribute to sexual activity. As a result, young people may lack information to prevent the spread of HIV. Research shows that many girls in Africa contract HIV during their first sexual encounter. Remarkably, 8% of women surveyed reported having sex before the age of 13 years, and 15% said that they had sex before their first menstrual period. Only 27% reported using a condom during their first sexual experience. In areas of high HIV prevalence, infection during early sexual encounters is likely. Most routes of HIV transmission are not exclusively associated with “immoral” behaviors. But such behaviors are attributed to those infected, thus doubly stigmatizing them-through infection and through attribution. Prevention efforts are also stigmatized through their association with HIV; the attribution is that those trying to protect themselves must be infected. Stigma is thus associated not only with psychosocial distress but also with a reduction in prevention efforts and practices. We must minimize the effects of stigmatization to improve prevention and treatment efforts. Because HIV/AIDS stigma is a social and cultural phenomenon of the entire community and not simply the result of individual actions, attempts to reduce stigma
must address the community rather than focus on individuals. Health care professionals must be aware of the stigma faced by their HIV-positive patients and must be scrupulous in protecting their patients’ confidentiality. At the same time, providers can take steps to reduce the effects of stigma on their patients. By promoting disclosure of a positive HIV test result to the patient’s family or spouse, health care providers can help build a support system for the patient and educate family members about HIV. They should provide supportive counseling to patients, caregivers, and fellow health care providers to reduce the stressful effects of stigma. Finally, all providers should regularly examine their personal values as they relate to caring for people with HIV/AIDS.

Psychosocial Effects of HIV on the Individual

Even if stigma is minimized, an incurable and often fatal disease requires enormous psychosocial adjustments. People diagnosed with HIV experience many of the emotional responses identified in people facing a terminal illness. They commonly go through an initial stage of denial, in which they do not acknowledge having the disease or deny its likely consequences. HIV threatens a person’s life, goals, expectations, and significant relationships, no wonder that many people are reluctant to admit their diagnosis or their risk of infection. People who subject themselves to high-risk situations or behaviors commonly deny that they are at risk of HIV infection. They often avoid testing, and if they are tested, they avoid following up on results, as if avoiding a clinical diagnosis might prevent the disease. To battle HIV successfully, people must have some level of acceptance of the disease so that they can seek counseling, social support, and medical care.

Finding Meaning and Mediating Successful Adaptation to a Life with HIV

Professionals need to be able to recognize the aforementioned processes and help patients overcome denial and splitting, improve self-esteem, and restore the symbolic function of mind. The final goal is to assist the person to recognize the unpleasant reality of the disease while keeping hope and goals in life, to offer a safe mode of expressing fury and fear while keeping the love and support of significant ones, and finally integrating the disease into the self-concept. However, Ross et al. and Nilsson Schönnesson and Ross note that with successive health crises, people may regress briefly to earlier stages as they adapt to new health circumstances. Professional counselors, social workers, health care workers, clergy, trained volunteers, friends, and family play crucial roles in providing psychosocial support. One of the first steps
in providing adequate assistance for people with HIV is to ensure that the helper is thoroughly aware of and comfortable with the facts about HIV transmission. If helpers feel personally at risk from HIV-infected patients, they will convey those feelings to the patients, who will then feel even more isolated than before. Counselors need to educate themselves about HIV to adequately counsel people with HIV. Individual and supportive counseling can help patients come to terms with their HIV diagnosis and with how it will affect all aspects of their lives. Patient education should include information about how HIV is transmitted and should give the patient some idea of common physical and emotional responses to HIV. This type of education can help patients anticipate and plan for these experiences. Professionals can also help patients assess controllability of HIV-related stressors and to design adaptive coping mechanisms. For example, the therapeutic focus can be on developing a problem-focused coping response when the stressor is controllable, whereas an uncontrollable stressor should focus interventions on finding, defining, and redefining meaning (Vignette 5).

One useful tool to use is the self-report scale “Meaning of illness questionnaire” that helps evaluate illness-related meaning appraisals in five domains:

- Impact (Has this illness negatively affected how you live your day-to-day life?)
- Type of stress (Would you describe this illness as a loss?)
- Degree of stress (Are you pleased with the way you are handling stress?)
- Challenge, positive attitude, motivation, hope (Would you describe this illness as a challenge?)
- Non-anticipated vulnerability (Was this illness expected before the doctor told you?)

This tool can provide insight to both the patient and the professional that offers assistance on how the person subjectively experiences the illness, and it can be the starting point in designing a successful intervention plan. Improved quality of life and successful adaptation to life challenges are the main goals of psychosocial intervention plans. These are developed by multidisciplinary teams, taking into
consideration the many factors presented in the beginning of this chapter and their dynamics. The general goal is then elaborated into more concrete objectives connected with designed interventions and anticipated outcomes. The interventions of the multidisciplinary team might focus on the following areas:

- Improved physical well-being
- Reduction or control of stigma and discrimination
- Improved access to health care
- Improved access to social support

Activation of internal resources Heckman (2003) presents the logic model of the preceding factors (Figure 1) that should be the goals of psychosocial interventions to ensure a good quality of life and the best possible successful adaptation to the HIV diagnosis and life with HIV for affected adults. The process depends on how each individual activates, combines, and uses different resources available, both internal and external.

5.4: PSYCHO-SOCIAL INTERVENTIONS FOR HIV/AIDS AFFECTED

5.4.1 Types of Psychosocial Interventions for Adults

All the preceding issues presented have stressed the complexity and variability of unique constellations of psychosocial factors that come together in the life of each patient. Good care can be provided through structured psychosocial services that involve a multidisciplinary team. One key principle before designing any intervention that will address a specific need of our patient is to always involve the client in the design of his intervention plan and prioritize issues together. The multidisciplinary team should have clear standards of care and intervention that will guide their actions (Figure 1). Clients might have different needs, starting with the need for information or legal support with respect to rights and responsibilities, continuing with need for know-how on accessing services available.

Counseling can be linked with many aspects, such as HIV testing and support for adaptation to the new status, promoting a healthy lifestyle (e.g., adherence to
antiretroviral therapy, behavioral changes), decisions regarding current conflicting emotional situations, and confidentiality and its limits. It can be an individual process, but involving the couple or working with family members or in a group format might also be required. Education includes several components, such as sexual education, education about HIV infection and opportunistic infections, and education about the legal framework that the patient should be aware of. It can also focus on, for example, developing parenting and nutritional skills for those caring for HIV-infected newborns and teaching nursing skills for caregivers of the terminally ill. Educational approaches can take a variety of forms, starting with professional guided education and ending with self-education based on printed materials or mediated by a peer educator. However, situations often require practical support and assistance. Such interventions include providing free condoms, temporarily helping with transportation fares or medication, helping the patient to represent himself at different institutions to access his legal rights, or simply paying home visits for follow-up. Because HIV infection is a chronic condition, the follow-up and monitoring of a patient does not end, even if he or she might not need intensive support at one time. Health care workers should have ongoing evaluations and keep track of changes that might negatively affect the person.

Supporting the spiritual needs of HIV-infected people and their families is a critical component of good care and support. Patients with AIDS report significantly lower levels of spiritual well-being than do patients with cancer and other terminal illnesses. They also report greater feelings of loneliness, fewer support systems, and less satisfaction with the support systems that they have. Support from spiritual leaders who are significant to the patient helps the patient and family cope with the existential and intrapersonal questions raised by a life threatening illness and with regrets that the person may feel about past actions, relationships, or experiences. Traditional healers, often the first care providers sought to establish needs and level of support required out by patients, can also be a source of support. When traditional healers and other medical providers work together, and have a shared understanding of goals of care, patients with HIV benefit. One can engender hope in terminally ill patients by controlling symptoms, encouraging relationships, assisting patients with practical needs, affirming their value, and helping them review their life experiences and personal worth positively.

5.5 SPIRITUALITY, RELIGION, AND HIV/AIDS

Existential issues, including spirituality and religious belief, may take on increasing importance to people who get a diagnosis of what is still, despite advances in treatment and health care, a frequently fatal disease. Unfortunately, despite the importance of the spiritual and religious dimensions of life, some officials of some established religions seek to stigmatize, rather than help, people with HIV, even though all the major religions emphasize the importance of caring for the sick and suffering and clearly recognize the obligation to support personally and charitably those suffering from disease. The health care worker also has a special obligation to help the sick live and die with respect and dignity. Regardless of whether the health care worker personally has a spiritual or religious belief, the patient has an absolute right to be cared for and respected. Stigma, which is a problem in the mind of judgmental others, not inherent in the disease, can be significantly lessened if the patient’s spiritual and religious beliefs are supported. One can do so by recognizing that the spiritual and religious needs of patients may be as important for their mental health and comfort as more widely recognized psychological adjustment and mental health. Health professionals should not overlook such existential issues in caring for
the total needs of the person with HIV disease. And social supports. Particularly when medical interventions are of limited effectiveness, the health worker may sometimes, if requested by the patient, support or facilitate (but never impose) ways of meeting the patient’s religious or spiritual needs. Sometimes the consolations of traditional spirituality or religion may make a significant difference to psychosocial Symptoms of AIDS-related burnout may be physical (e.g., exhaustion, headaches, back pain, sleeplessness, malaise, and gastrointestinal disturbances) as well as behavioral (e.g., becoming easily irritated and angry, increased alcohol/drug use, marital/relationship problems, inflexibility in problem solving, impulsivity and acting out, and withdrawal from non-colleagues). Cognitive and emotional symptoms may include emotional numbness or hypersensitivity, over identification with patients, grief and sadness, pessimism and hopelessness, cynicism, indecision and inattention, and depression.

Group counseling can also play an important role by allowing individuals with HIV to share experiences with one another. However, this approach is usually not a good idea until the person has been able to accept the diagnosis enough to come to the group and communicate honestly. Group support can help patients cope with their emotional responses to HIV on the basis of accurate information, shared experiences, empathetic listening, and assistance with problem solving. Counseling and support can help people with HIV share their feelings about secrecy and stigma and consider how these influence their emotional and physical health. Counseling and support can also help people consider how their own behaviors can promote health and well-being, such as seeking resources for adequate nutrition, shelter, proper medical follow-up, adequate sleep, and management of stress and anxiety.

5.6 IMPLICATIONS OF THE STUDY

- It can help identify the reasons for non-compliance to Anti Retro Viral Drug Therapy;
- The identification can help foster information for promoting better drug compliance by bettering guidance and counseling for rural women identified with HIV/AIDS and undergoing Anti Retro Viral Drug Therapy.
• It can help understand the personal, familial and social dynamics involved in populations of rural women identified with HIV/AIDS and undergoing Anti Retro Viral Drug Therapy.

5.7 LIMITATIONS OF THE STUDY

• The main limitation in the present study was self-rating which is a concern when individuals are given self-appraisals. According to Bradbery and Graves (2003), individuals have difficulty rating their behavior with accuracy. People often overrate themselves, some underestimate themselves, and a few accurately rate themselves. Self-report tests can be developed to minimize self-rating bias, but not eliminate it.

• The study covered only rural women under AVRT in and around Mysore, Bangalore, Chamarajanagar and Mandya.

• Only family environment as a psycho-social factor studied in this investigation.

• The study has not included male HIV/AIDS affected population on ART

• The study has not covered the sample on patients with non-ART therapy.

5.8 SUGGESTIONS FOR FURTHER RESEARCH

• The study can be extended to male sample affected by HIV/AIDS both on ART and non-ART

• Other variables like subjective/psychological wellbeing associated with HIV/AIDS can be studied

• Impact programme on improving family environment of the HIV/AIDS is need of the hour
CONCLUSION

Even at very low prevailing prices for generic antiretroviral therapy medications in India, Government funding antiretroviral therapy is very expensive and reduces the burden of the AIDS epidemic only marginally. While more cost-effective than ever before, antiretroviral therapy still costs more than Rs. 5000 per life-year saved and thus would not rank high in comparison to many other life-saving interventions. In view of the relatively high costs and potentially dangerous spillover effects of funding antiretroviral therapy one has to monitor the behavioral effects of awareness of improved access to antiretroviral treatment on risk behavior of people not under treatment, especially high-risk groups. In consultation with all state and national stakeholders, the policy makers should design and implement an institutional arrangement that rewards effective prevention programs, thereby ensuring that the availability of treatment has useful spillover effects.