CHAPTER – II

REVIEW OF LITERATURE

In this chapter, the researcher presents a detailed review of the relevant literature based on information derived from various authentic sources. Through this elaborate effort, the researcher has been able to gain additional and in depth knowledge on various social aspects, relevant to the study. The main thrust of the review is to identify and understand the key sociological domains relevant to the field of HIV/AIDS. In this context, the researcher has adopted the guidelines of the Timeline frame work of NACO and has reviewed the sociologically relevant studies under the following three phases presented by NACO (2011). Phase I studies from 1992 -1999. Phase II – 2000- 2006, Phase III – 2007-2012. Some significant studies related to HIV/ AIDS conducted in India and other countries, have been reviewed in order to understand the local and the global trends in this field, during the three distinct phases mentioned above. This will form the Part I of the review.

Part II of the Review highlights on studies related to significant social concepts used in the study. As the study pertains to Women infected by HIV, the third part of the review focuses on issues concerning HIV/AIDS from a gender perspective.

2.1.1 PART I - Evolutionary Perspective:


Robert S Walker 1992 has integrated the socio political and economic issues in relation to the scientific research focusing on the biology of HIV. The study has analyzed the behavioral changes among individuals who want to avoid AIDS. How the AIDS epidemic impacts the socio political system, has been presented in depth. The author has used a wide range of information from various sources, using an integrated method, to produce a coherent synthesis.
David L. Kirp and Ronald Bayer 1992 have published the first comprehensive volume on responses to AIDS in Industrialized democracies from an international perspective. Sixteen leading experts in the field of social sciences, public health and public policy have shared their expertise there by contributing to this volume which has been considered as an important landmark in the field of HIV/AIDS literature. “Contain and Control” programs adopted by various societies have had their impact on education, co-operation and social inclusion. What is unique about the effort is that the volume provides a chance to learn from each other’s mistakes and success stories.

Miriam E. Cameron 1993 has attempted a qualitative study to assess the day to day issues concerning HIV positive people. The author has conducted in-depth interviews with 30 participants. The findings highlight the realities faced by the participants, right from disclosure of diagnosis, facing the illness, health care, finance, family, social relationships, discrimination, sexuality and fear of death. The study also highlights on ethical problems associated with “the right way to live and die”. The entire study focuses on the human perspective and is therefore very significant and thought provoking.

Ruth R Faden, Nancy E. Kass 1996 have studied 150 HIV positive women and 50 of their health providers. The authors have attempted to analyze the reproductive health rights of women and their moral, legal and policy implications. Difficulties that arise with regard to creating awareness against HIV women have also been presented. The need for community based patient care and support initiatives have been emphasized. The book provides valuable information on child bearing issues of HIV women.

Gangakhedkar et al.1997 have examined 916 women who were attending a STD clinic in Pune. The main focus of this comparative study has been to assess the risk of low risk populations by comparing them with high risk group -female sex workers. The study results have revealed that 50% of female sex workers and 14% of other women were diagnosed as HIV positive. The authors have associated inconsistent condom use and prevalence of genital infection like genital ulcer and warts, as the main cause for HIV among female sex workers. Partner’s risk behavior has been another contributing factor. The study has indicated a high prevalence of HIV among
female sex workers and men who attend STI clinics thereby posing a risk for spread of infection to other populations. The author has concluded that increasing proportion of women and infants in India will become infected with HIV, if awareness regarding HIV is not given.

Sodhi S, Mehta S 1997 has studied the awareness level among school students with regard to HIV/AIDS. The finding indicates that 79.6% of the students sort information from television and radio only 9.5% of children have heard about HIV/AIDS through their respective school programs 86.6% obtained information from print media. 2.3% learnt from friends. The findings suggest that HIV/AIDS education should be strengthened further in schools.

Hirve and Sathe 1999 have observed that majority of the HIV related studies have been focusing on urban areas. Their study exposes the risk of some rural populations getting caught with this deadly disease. Through a qualitative study the authors have identified the mobility of men in search of jobs in urban areas and their unsafe sexual behavior as the major cause for higher vulnerability of HIV infection in rural regions. Women face substantial burden because of their HIV partner, and struggle with inadequate income to face family challenges.

The findings of some of the significant studies of this period presented by the researcher have been relevant to the research study as they have highlighted on certain crucial psycho-socio-economic indicators linked to HIV/AIDS.

2.1.2 II Phase 2000 – 2006: Studies Related to HIV/AIDS:

Digumarti Bhaskara Rao 2000 has stated in his study that the virus not only destroys the immune system but also affects the individual both psychologically and economically. It also affects the psycho-social life of the individual and his social networks. According to the authors, no other disease in recent times has had this much implication on human society as generated by HIV/AIDS. The social consequences of the HIV epidemic have been clearly spelt out in this study and therefore the findings is very valuable to the present study.
D N Kakar 2001 has underscored the need for a strong public health commitment to respond to the challenges of HIV/AIDS. The author examines the social implications of the heterosexual mode of HIV transmission which is predominant in Thailand, India and Myanmar. The author has reinforced the need to concentrate on the prevention and control of HIV/AIDS. As the findings relate to economic, political, cultural issues related to HIV/AIDS, the information gathered is very useful for the current research.

Paul Farmer, Fernet Leandre et al 2001 in their work on community based treatment of advanced HIV disease have revealed that the AIDS mortality rate has decreased largely because of the introduction of antiretroviral medicine. This is not widely used in the poor countries where AIDS is taking away the life of many people. The main reason is the high cost of the medicine and lack of infrastructure necessary to use them wisely. With the collaboration of community health workers, the patients infected with HIV and TB are treated by delivering the medicine at the door steps. The study has revealed that such domiciliary services are required at the community level in order to enhance the quality of health care.

Surendra P. Singh 2002 in his study has given a complete picture about the HIV/AIDS disease. The main objective of the book is to disseminate information regarding HIV and its various related areas mainly to create awareness about the issue. As additional information the author has listed out the safety measures and legislations regarding blood bank and blood products. Zonal surveillance centers and reference centers in India are also listed out in this valuable book. The book is very informative as it provides the complete picture about the disease.

Sud A, Dutta U, et al; 2002; have made an attempt to study the general outlook of the disease in India. In India HIV is spread mainly through heterosexual contact. With lack of access to therapy, women in their childbearing age group, form a major reservoir and often become the innocent victims of their spouse's infidelities. The study is conducted with 252 patients in a special medical clinic. Patients attending the clinic for a year have been included for the study. The aim of the study is to assess the
risk factors for acquiring the infection. The respondents’ educational background, awareness regarding HIV/AIDS, and Spouses’ risk behavior are also studied.

The study results indicated that out of 252 patients 134 (53.6%) were women (mean age 30 yrs). In 70% of them HIV testing was part of partner screening for an HIV positive male. 33.5% had symptomatic disease at presentation. Heterosexual contact was the risk in 89% of patients. An HIV positive spouse was the only risk factor for acquiring HIV in 82.25% women as opposed to 2.55% of men. The next most common risk factor was a blood transfusion (19.35%). Among the men, 87.1% gave history of unprotected sexual contact with commercial sex workers. Only 19.4% of the women had received primary education, 75% had never heard of HIV before being tested. 25% of the women were widows, as a result of spouses having died of AIDS. Of all, 83.8% had children below 10 years of age, 24.2% had HIV positive infants. Thus, Heterosexual contact was the chief mode of transmission of HIV in the study population.

Duraisamy P, et al, 2002 have conducted a study on how people living with HIV in South India cope with the costs of treatment. Treatment of HIV imposes a heavy financial burden on families and society. This study seeks to determine the medical and non medical cost of treatment, financial burden and coping strategies of families. Data were collected from 356 HIV clients of YRG CARE, a leading Chennai based NGO. The clients were stratified by sex and stages of illness. They were asked about treatment-related expenditures including Loss of wages and workdays, sources of finance to meet treatment cost, financial coping strategies, and their quality of life.

The findings showed that the average monthly expenditure per HIV-infected person was Rs.1,872, or about 80% of household income. The treatment cost increased with the progression of illness. The average loss of income due to illness was estimated to be 377 rupees per month or 16% of patient’s monthly wage earnings. The burden of treatment (measured as the ratio of treatment costs to household income) was much higher for low-income families than the high-income families. Patients paid for the treatment costs through borrowing (41%), sale of assets and durable goods (24%), past savings (24%), and mortgage of assets (9%). The cost of treatment, loss of income, and financial burden of treatment increased with the advancing stage of
illness. The findings have revealed that HIV caused depletion of savings and increased indebtedness of households. Tamil Nadu has experienced the impact of HIV/AIDS for nearly two decades and is considered a trailblazer in India in terms of combating the infection.

Kattumari, 200 has studied the knowledge level of HIV among HIV infected group. 292 HIV patients at Government Thoracic Hospital, Chennai, and Christian Medical College, Vellore, were studied. The findings revealed that the awareness level was inadequate. Television and peer contact were the most effective sources of knowledge. Patients who were in contact with health personnel were expected to have more information but they came out with low scores. Education, occupation, income, place of residence, and age were important predictors.

David K. Beine, 2003 has examined the cultural contexts of HIV/AIDS in Nepal. It is an ethnographic study that represents the cultural dimension of HIV. The cultural construct of illness plays a significant role in disease management, spread and awareness. The study emphasizes the depth and diversity of people’s view and social constructions of the emerging illness. The author has suggested that cultural knowledge can be utilized to construct cultural models which can be used for controlling the spread of the disease. The study clearly indicates that disease cannot be defined by biology but by society.

Prasanna Anand and Cheryl Koopman 2003 have investigated the HIV/AIDS knowledge, and belief and behavior among women of child bearing age group in India. 210 women attending six health care centers were interviewed for the purpose. The study investigated the health beliefs, HIV knowledge and condom use among women. The study found that 68% noted rare or no use of condoms during their intercourse. Normative belief was associated with that. 54% of the women knew the vertical transmission of HIV. Most participants approved HIV test before pregnancy. Three fourth accepted abortion for the pregnant HIV women. The study recommends intervention effort to remove misconception about HIV and vertical transmission.
Jai P. Narain 2004 in his study has discussed a wide range of issues related to HIV like prevention, care and treatment, which include health, economics, socio-cultural and security dimensions of the disease. The success stories in both prevention and cure and lessons learned from Asian countries have been narrated as case summaries to be emulated as a model for others. The study gives valuable information for those who are involved in combating HIV and mainly involved in control programs.

Premilla D'Cruz 2004 in her work on Family care in HIV has discussed the role of the family in disease management. Family provides care to chronically ill, disabled and elderly. Most of the time, it is women in the family who nurture and take care of them. In the case of HIV illnesses both the care giver and care receiver become unwell because of HIV. More than health care, the family has to manage the stigma, isolation and long debilitating terminal nature of the disease. This infection has totally changed the family dynamics of care giving which leads to major upheaval in families. The book has presented a holistic perspective about the role of family in health care and issues related to care giving settings.

Sudipta Mondal, 2004 has attempted a qualitative study about migrant population who are engaged in jewellery work in Mumbai. The study has explored the migration pattern, their settlement, way of living, and working conditions of the low skilled migrant worker. It has attempted to narrate the complex relationship between migration and risk behavior and their vulnerability towards STD and HIV/AIDS in metro cities. It is an assimilation of qualitative insights with quantitative findings.

David Wessner 2006 has discussed about the important global issues associated with the HIV/AIDS pandemic. The author has elaborated a brief picture about HIV, the immune system, and the role of modern drug research for effective vaccine. Issues related to affordable healthcare, distribution of condoms and the empowerment of women have been the major thrust areas of the book. This book has given a clear understanding about the HIV disease in a scientific way, and the social issues related to the disease have been highlighted.

Nilesh Chatterjee and G.M Monawar Hosain 2006 have investigated the HIV/AIDS related knowledge, perception and behavior change among married women in India.
An interview based survey was conducted among 350 married women in Mumbai, of whom, 67% were aware of HIV/AIDS. Fifty nine percent of those who were aware of HIV, expressed that indiscriminate sex activity was the risk for HIV and only 2 in 5 women perceived HIV as a threat to the society. One in eight perceived personal risk for HIV. 7.2% reported behavior change to avoid HIV. The in-depth interviews revealed that the women felt that they were safe and there was no need to change their behavior as they were in monogamous wedlock and not at risk. The study concludes that marriage and motherhood are the important events as far as women are concerned in Indian society. To reduce HIV risk, men should be included in all risk reduction programs.

All these studies, have enabled the researcher to understand the social dynamics of HIV /AIDs

2.1.3 III Phase - 2007 – 2012: Studies Related to HIV/AIDS:

Yadav C.P 2007 in his edited volumes on Encyclopedia of HIV/AIDS has presented the facts pertaining to the disease. The first volume focuses on HIV/AIDS its global trends, and its position in India. Discrimination and denial of the infected groups and their issues have been elaborated in the second volume. In volume three the issues related to health care and hospital services have been discussed. Volume four focuses about the guidance and counseling procedure for HIV infected group. This encyclopedia encompasses all vital information related to HIV/AIDS, its causes, prevention method and control programs. All these facts presented are supported by vital statistics.

Sri Krishnan A K et al 2007 in their qualitative study have obtained information regarding change in sexual behavior of HIV infected individuals across high risk groups. The work was conducted at Y.R.G Care, a nongovernmental organization in Chennai. Thirty HIV infected individuals from various risk groups participated in the study. The in depth interviews revealed that there was a change in risk behavior among the participants after they got information about HIV. The women however were not able to insist and enforce condom use because of subordination. The
medical practitioners were the main motivators for promoting the reduced risk behavior. This varied with each cultural group. Substances abuse and liquor consumption were identified as contributive factors for risk behavior. The study has indicated the role of VCT in the reduction of risk behavior.

N.Kumaraswamy et al 2007 in their study have made an attempt to explore the economic burden incurred due to HIV adherence therapy. The study found that 60% of the family income was spent on ART treatment in the HIV affected family. The heavy cost of the medicine and non availability of medicine in some centers, made the patients to withdraw from their treatment modalities. They also found heavy indebtedness incurred in HIV affected families. Lack of medical care and abstinence from work caused economic difficulties and the family members were forced to sell their assets to provide health care to their near ones. The study identified that inability to purchase food and medication, high cost in travelling to the clinic, family commitment and one or more number of family members infected with the disease as some of the reason for discontinuation of ART medications. The study suggests affordable medical care should be provided and it should be easily available in all places.

Maj-Lis Foller Hakan Thorn; 2008 in their book have examined the nature of HIV as a disease and how it has emerged as a major political challenge to the Nation. It is not only the state but various civil societies and research institutions have been participating in combating AIDS. With empirical evidences, the book addresses important HIV issues. The disease has become transnational, and their control programs extended across the borders.

Negar Akhavi 2008 in her edited volume on AIDS Sutra presents a collection 16 stories written by India’s best known writers. It is an attempt to uncover the country’s AIDS epidemic. The collection of essays ranges from truckers all night journey; how house wives unknowingly contract the disease from their husbands, devadasis, sex workers of Andra, hijras of Bombay, and injecting drug users in the northeast. Sixteen different cases are narrated authentically by famous writers and edited by the authors. In India the epidemic has different modes of spread and it is not uniform. Like its diverse nature the epidemic also spreads in different means in different parts
of the country. It has presented the complex and gripping picture of AIDs in India. The work has elaborated on who HIV can affect and how and why.

Frizelle K.L 2009 in his article on intercultural inquiry and cognitive justice in the Internationalization of HIV/AIDS have made an attempt to review how HIV/AIDS has been globalized and policies and prevention programs are influenced by the international agencies which has influenced the practice of rapid testing with in the South African context. This article has critically reviewed the policies. It argues that information about the pandemic are always produced through an interaction of local and international processes. As far as these interactions are concerned it is characterized by inequalities where the experiences of local people and related factors are not adequately taken care while processing for policy development and implementation. This article concludes by stating that “More intercultural inquiry that prioritizes cognitive justice is required to develop appropriate and effective HIV/AIDS related policies and interventions”.

Ram Shankar Singh and Sunil Kumar (2010) in their classic work on encyclopedia of HIV/AIDS Control and Prevention have discussed about the origin and basic facts about HIV, its symptoms and its mode of spread in the first volume. Subsequent volumes talk about the prevention and treatment method. Global trends about the disease state and role of civil society in disease management have been analyzed. The authors have also discussed the legal issues concerning the disease, and have emphasized the need for living with dignity. The authors have identified the role of education in combating AIDS and have stressed the importance of compulsory education to children. The focus of the book is on giving holistic education to the children. Education alone can solve the twin problem of poverty and ill health. The authors also suggest that the Mass media should be effectively used for combating AIDs.

Jeffray H Samet et al 2010 have studied the use of alcohol and risky sexual behavior. 416 samples both male and female were studied, to find out the role of alcohol in risky sexual behavior among HIV infected group in Mumbai. The findings indicate that alcohol increases the risk of HIV progression and medical complications. The
study suggests the need to address alcohol use both to avoid medical complications and to mitigate inconsistency in condom use that need gender specific approach. The authors have indicated that prohibition of alcohol and substance use will be a significant measure towards secondary prevention of HIV/AIDS.

Saio P Falleriro and Silvia M. Noronha 2011 have elaborated on the economic burden of HIV/AIDS specific to medical expenditure, at individual level, macro/national and sectoral level. The study was a case control study undertaken in Goa. 200 respondents have participated in the study. The study results have revealed that medical expenses of HIV positive respondents alone formed the major portion of total annual household expenditure in spite of many opting for free treatment. The findings indicated increased total annual household consumption and expenditure, decreased saving, increased borrowing, and sale and liquidation of assets. The study has suggested that access to proper and timely treatment with adequate nutritional support is of utmost necessity.

Ram Shankar and Sunil Kumar 2011 have elaborated the current status of AIDs epidemic in their work. Prevalence of AIDS stigma like ostracism, rejection, discrimination and avoidance of HIV infected people prevent people from seeking HIV testing and followed health care. Due to the existence of stigma the manageable chronic illness, has turned into death sentence and has perpetuated the speedy spread of HIV. The authors have viewed this discrimination as violation of human rights and they have elaborated on the legal issues that arise in the context of HIV. The book has been very useful to the researcher as the facts have elaborated on the psycho social and human rights issues pertaining to PLHA. The same authors 2011 have highlighted the importance of education in changing the risk of the individuals in their work on AIDS and Education 2011. They have explained that education leads to higher health literacy and general cognitive ability which will enhance the understanding of the relationship between risky behavior and possible outcome like HIV transmission. The authors have suggested education as the best investment that any society can invest on. It creates choices and opportunities for people and builds a strong society. The authors have concluded that School education should be strengthened and education should be used as a vehicle for combating HIV/AIDS.
UNAIDS report (2011) drafted jointly with UNICEF and WHO indicates that around 48 lakh people have been living with HIV in Asia in 2010 and nearly half of them 49% in India. HIV infection has also risen from 2% to 23% in 2010. India tops the list followed by China, Thailand, Indonesia, Malaysia, Myanman and Vietnam, The prevalence is 18 per cent in South India, says UNAIDS 2011 report The estimated 360,000 people who are newly infected with HIV in Asia in 2010 were considerably fewer than the 450,000 estimated for 2001. The HIV epidemic has been prevalent among female sex workers and traditional risk groups in the six high-prevalence States including Karnataka. But epidemics among men who have sex with men have been growing across the regions, including India. The report also says that 35 per cent of children with HIV infection have been receiving anti-retroviral therapy treatment. There is also evidence that prevention programmes are working in India. One such programme in Karnataka is associated with a drop in HIV prevalence from 25 per cent to 13 per cent among female sex workers in three selected districts between 2004 and 2009. A similar programme has brought down the prevalence from 1.4 per cent to 0.8 per cent among young antenatal clinic attendees between 2004 and 2008 in 18 districts. Yet another intervention programme in Mumbai and Thane has led to a decline from 45 per cent HIV prevalence in 2004 to 13 per cent in 2010 among brothel-based sex workers.

Shalini Suri 2012 has given a brief introduction to the primary understanding of the AIDS epidemic. A detailed review of AIDS pandemic in diverse parts of the world has been discussed. Specific focus is given to India and the role of NACO and NACP. A detailed classification of subtypes and structure of HIV and AIDS infection has been discussed. The author has identified the importance of education and training for AIDS control and related disease. AIDS misconception, discrimination and economic impact have also been thoroughly described.

Muktikesh Dash, et al 2012 has made an attempt to study the HIV prevalence among the antenatal population in Odisha. Blood samples were collected from pregnant women who were attending the tertiary antenatal clinic. The samples were tested for HIV antibodies. Around 18,905 pregnant women were counseled, 15853 accepted for HIV testing. 0.66% of women were found to be HIV seropositive. The mean age of
the HIV positive women was 24.31 years and (S.D 3.9 years). There was a declining HIV Sero prevalence. The HIV sero prevalence rates showed a declining trend from 1.53% in 2006 to 0.34% in 2012. Among sero positive women majority (43.8%) were in the age group of 25-29 years. Declining sero prevalence rate indicated that prevention campaigns were working, as condom usage and preventive sexual behavior had increased.

Kimberly Walters et al 2012 have used a population-based and family structural data from a high HIV-prevalence district of Southern India. This paper explores four areas of HIV risk: (1) infection from and then bereavement of an infected husband; (2) abandonment after husbands learn of their wives' HIV status; (3) economic instability after becoming previously married, leading women to seek financial support through male partners; and (4) the social status of being previously married exposing women to sexual harassment and predation. Analysis was done of household residences patterns (family structure), standard of living, and education. Scenario four emerged as a strong factor in this study. Further, the interdisciplinary literature on the social position of previously married women in India strongly supports the suggestion that, as a population, previously married women are sexually vulnerable in India. Previously married status as an STI risk factor requires further biosocial research and warrants concentrated public health attention.

Reviewing the books related to HIV/AIDS from a evolutionary perspective to the current scenario has given the researcher a thorough understanding about the HIV illness, its immunological origin, mode of spread, myths related to the disease, the psycho-social implication related to the disease, the legal and human rights perspectives of the issue and various public health policies related to HIV. With this basic understanding about the HIV disease the researcher has attempted to further review the books and journals related to some significant social concepts used in the study in the II part of the Review.
PART II

2.2.1 - Awareness Level on HIV/AIDS

Education and awareness have always been regarded as a key concept for prevention and control of disease which has public health importance. Increasing the awareness level will enable people to develop skills that allow them to make decisions and influence community change in key areas. In turn, these programs have a positive impact on some of the most profound issues like HIV and AIDS. So awareness programs have been given wide importance as far as AID prevention is concerned.

The HIV/AIDS epidemic continues to gain momentum in India, destroying innocent lives and imperiling future generations. Controlling the spread of HIV is critical. Ignoring this will lead to millions of Indians trapped in the grip of this pandemic. Despite valiant efforts by government agencies, large cross-sections of Indian society still lack information about the nature of the disease and how individuals can protect themselves against it. As a result, the epidemic is spreading rapidly to the general population.

Malleshappan et al 2012 have assessed the awareness and attitude of rural young men and women towards HIV/AIDS. A Community-based cross sectional study was conducted. The research included 850 young men and women in the age group of 18-30 years, belonging to Kuppam district, Andhra Pradesh. A semi structured tool consisting of 60 questions, 40 on awareness level regarding the cause and modes of transmission and 20 questions to assess the attitude of people towards people living with HIV was used to collect the data.

The study results revealed that 18% of the women and 7% of the men had not heard about HIV/AIDS at all. The rural women’s knowledge was very poor when compared to the men. Levels of literacy of men & women were significantly associated with their knowledge of HIV/AIDS showing, that literates had better knowledge than illiterates. There were several misconceptions and false beliefs about cause & spread of the infection which were found to be more prevalent among illiterates. Only 12%
of the respondents were willing to undergo the HIV test. The respondents who had less than secondary school education, practiced a discriminatory attitude toward HIV positive people, 46% of the youth responded that it could be prevented and 20% knew that HIV could be present in apparently healthy looking persons. This study suggests a need for innovative, comprehensive scientific information particularly targeting the rural youth in order to impart better knowledge and understanding on HIV/AIDS.

Stigma and discrimination is the main barrier to effectively fight against the HIV/AIDS epidemic. There are several reasons for the stigma towards people living with HIV/AIDS (PLWHA) among the general population, and one of the reasons identified is inaccurate information about the spread of HIV infection creating misconceptions. To understand that, a study on the awareness and attitude of the general public towards people living with HIV/AIDS (PLWHA) in Mangalore city in Coastal Karnataka South India - a community based cross sectional study was done by Reshmi et al 2012. The study surveyed 630 population aged 18 years and above. Semi structured pre-tested questionnaire was used to collect the information. The findings revealed that around one-third of the study population were not aware of the HIV mode of spread, Approximately 45% stated that they would dismiss their maid on finding out her HIV positive status. About 54% were willing to undergo the HIV test. Illiterate people had a discriminatory attitude toward HIV positive people. They wanted to exclude them and felt they deserved that punishment. Dismissing a HIV positive maid, hesitating to sit next to a HIV positive person in the bus, divorcing the infected spouse, and willingness to get tested for HIV, were found to be statistically significant.

Stigma among the general public was mostly due to fear of contracting the illness. Stigma existed to a significant degree among the educated people also. The study showed that poor awareness and stigma were social factors that promoted the spread of HIV.

Adolescents form considerable risk group due to circumstances, peer pressure, curiosity, haphazard knowledge, and risk-prone behavior. Pankaj Kumar et al 2012 have presented an interventional study, in an attempt to assess the knowledge, and
attitude about HIV/AIDS in adolescents, among high-school students of a Municipal Corporation School in Pune. A pre-designed, pre-tested anonymous, self administered questionnaire was filled by 9th standard students. The students were screened a film on HIV/AIDS. The same questionnaire was again filled by the students. Sixty three percent of the students were aware about HIV/AIDS. TV was the main source of information. A significant decrease in knowledge about misconceptions and significant increase in knowledge occurred about various modes of transmission of the disease. The study has revealed that intervention in the form of a film can make a significant change in the knowledge and attitude of adolescent students with regard to HIV/AIDS.

Dulumoni Das Rupak Gupta 2011 has conducted a study in the Seven States of North East India, in order to examine the importance of awareness, prevention and accepting attitude strategies for HIV/AIDS among women and men in the age group 15-49. Data had been taken from the records of the National Family Health Survey (NFHS-3; 2005-06) (www.nfhsindia.org) conducted under the stewardship of the Ministry of Health and Family Welfare, Government of India, with the International Institute for Population Sciences, Mumbai.

The different categories for comparison were Knowledge of HIV/AIDS among women and men, Prevention and accepting attitude towards people living with HIV/AIDS among women and men. A meta analytic model, introduced by Bhattacharjee and Gupta (2008), were followed by assigning weight as mean of the sub-category scores. Analysis of data revealed that Manipur (95%) was associated with the highest level of awareness, prevention and accepting attitude of HIV/AIDS while Meghalaya having the lowest score (17%) was not still fully aware of HIV/AIDS. The findings have highlighted the need for integrated awareness and prevention programmes that emphasize on attitudinal and behavioral changes towards people living with HIV/AIDS this has serious implications for both individual and society as a whole. Further investigations have been suggested to understand the reasons for the low level of awareness in most of the North Eastern states of India.
Anurag Srivastava et al 2011 have conducted a study ‘on adolescence awareness: a better tool to combat HIV/AIDS’ Adolescents are exposed to the risk of being victims of HIV/AIDS, mostly because of a low level of awareness of HIV/AIDS and inadequate access to HIV prevention and treatment services. The cross-sectional study involved 341 students, aged 11-19 years. The objective includes level of awareness regarding modes of transmission, preventive and curative measures of HIV/AIDS and the attitude towards PLWHA. The results revealed that the awareness regarding modes of transmission, methods of prevention and treatment, were found to be significantly higher among boys as compared to girls. There was a low level of awareness of HIV/AIDS amongst adolescents of District Bareilly. The challenge lies in developing programmes to spread awareness and to induce behavioral changes among them.

Various research studies have revealed that one third of reported cases of HIV/AIDS in India are among youth and 60 percent of these reside in rural areas. Assessment of the awareness of HIV/AIDS among youth is an important area for investigation to determine the impact of previous and current awareness programs as well as the need for interventions. To investigate the level of knowledge regarding HIV/AIDS among rural youth a community-based cross-sectional study was conducted among youths aged 15-24 years in rural areas of the Saurashtra region of Gujarat by Sudha B. Yadav et.al 2011. Through cluster sample subjects from 30 clusters were drawn. A total of 1,237 subjects participated in the survey; out of that 60% of the sample knew something about HIV. Of those who had heard of HIV, more than 90% subjects knew the modes of transmission and more than 80% were aware of modes of prevention of HIV/AIDS. One fifth of the subjects had misconceptions in relation to HIV/AIDS. On applying multiple logistic regression, age, education, occupation, and mass media exposure were found to be the major determinants of their knowledge with regard to HIV/AIDS. Basic knowledge of HIV/AIDS was still lacking in two fifths of the rural youth. Literacy and media exposure were factors that determined awareness of HIV among students.

Health care professional like doctors & nurses are expected to have adequate clinical and counseling skills to deal with HIV & its implications. To know the awareness
level of students who have joined the medical profession, a study was conducted by Rekha Udgiri et al, 2011 at Bijapur Karnataka. The study results revealed that all the students who had joined the medical profession were aware of AIDS in terms of its definition and modes of transmission. About prevention and cure no significant differences were found between boys & girls. The study found incomplete knowledge about sign & symptoms of HIV/AIDS among the medical students. There was no statistical association between boys and girls about knowledge of prevention and cure. A similar finding has been observed by G.S.Basavayya et al [2005]. All the respondents were aware about preventive measures like condoms use, blood test before transfusion, avoiding multiple sex partners and sterilization of instruments. 42(91%) of girls and 82(86%) of boys were willing to care for HIV/AIDS patients.

Similar findings have been observed by S.Deb (2004) among nursing students of Kolkata towards caring for HIV/AID patients. It was found that 100% of them were aware of HIV/AIDS in terms of definition & causation. Male students were found to have better knowledge regarding, transmission of AIDS than the female students. Unfortunately 10% of the respondents were of the misconception that AIDS may be transmitted to health Care personnel while examining the patients.

Today School children are exposed to the danger of being victims of HIV/AIDS - The epidemic of HIV/AIDS is now progressing at a rapid pace among young people. Studies have reported that young people form a significant segment of those attending sexually transmitted infection (STI) clinics and those infected by HIV. It is felt that schools can play a vital role in disseminating information and education on HIV/AIDS. Hence school education has been described as a 'social vaccine', and it could serve as a powerful preventive tool. In India, there is a wide gap between the inputs in the HIV/AIDS curriculum for schools and the actual education that is imparted. (IJCM 2008) Since children are an important resource for the future of a country, it is essential that they should be equipped with sufficient amount of information so as to protect themselves and their counterparts from falling a prey to this incurable killer disease.
Tarujyoti Buragohain 2008 has made an attempt to demonstrate the level of awareness of Reproductive tract infection, sexually transmitted infection and HIV and the extent of discrimination in health and treatment seeking behavior among men and women who have got symptoms of RTI and STI. Data were taken from National health survey sample and analyzed; the study results reveal that awareness regarding RTI was greater 8% higher among women than men. As far as STI and HIV were concerned, men knew better than women. The level of education, occupation and working status were related to the awareness level. Regarding treatment only 38% of women opted for treatment. Limited financial resources, lack of awareness, and lack of service providers in rural areas were some of the reasons identified for not having treatment.

Lal P, Nath et al., 2008 have investigated the knowledge level of HIV/AIDS among school children in south Delhi. A total of 2592 students belonging to Classes IX to XI participated in the study. The study revealed that all the students had heard about HIV/AIDS, only 51.4% were able to write the full form of AIDS and 20% were able to write the full form of HIV. Similar observations were made in a study carried out amongst the secondary school students in Haryana and Jamnagar. (Aggarwal AK, Kumar R1996) (Bhalla S, Chandwani H et al 2008, Regarding modes of transmission only 31% and 23% had mentioned blood transfusion and mother to baby transmission as routes of transmission.

A baseline evaluation on HIV/AIDS awareness among 250 Nigerian school students revealed that only 5% were able to expand HIV and AIDS. (Okonta JM, etal. 2007) 48% of the students could name the sexual route while 44% named sharing of syringes and needles as a mode of transmission. Similar findings were observed in a research study done among 2400 secondary school students from Mumbai, in which 50% of students knew about the sexual route of transmission. Low levels of knowledge about general aspects and transmission of HIV/AIDS had also been observed amongst secondary school students in Kolkata. (Chatterjee C, 2001) Studies conducted in other countries have reported higher levels of knowledge regarding transmission routes. (Yazdi CA, Aschbacher K, 2006), (Wagbatsoma VA, 2006). The differences in knowledge were attributed to early appearance of disease in these
countries. 72% of the students were aware of HIV/AIDS as preventable disease. Awareness about the different methods of prevention was low. Only 15% had knowledge about condoms as a means of protection. Higher levels of awareness have been observed amongst school children of Haryana (Sodhi S, Mehta S 1997) Studies conducted in other countries have also reported high awareness levels regarding condom for HIV/AIDS prevention. (Toure B, Koffi K et al,2005, Egger M, Ferrie J et al, 1993) Only 28.6% knew about the availability of drugs for HIV/AIDS. This is similar to the observation made amongst a group of secondary school students belonging to Udupi district in Karnataka. Only 24% were aware about the existence of drugs while a slightly higher number of school students (34%) in Mumbai knew about the availability of antiretroviral drugs.(Agarwal HK, Rao RS et al, 1996,) (Sankaranarayan S,1996) With regard to the sources of information about HIV/AIDS, 79.6% of the students mentioned that television and radio were the main sources of information to them. Likewise, a majority (62.7%) of senior secondary students belonging to a government school in Chandigarh reported that they derived most of the information from TV and radio. (Sodhi S, Mehta S. 1997) Only 9.5% of children had heard about HIV/AIDS through their respective school programmes. This finding suggests that school AIDS education should be strengthened further in schools. As much as 8.6% had obtained information from print media, whereas for 2.3%, friends remained the source of information. These findings imply promoting television as a significant source of information. A greater involvement of print media could also be a cost-effective measure. Friends can also be made instrumental in spreading information through frequent motivation. Published literature indicates that peer education has had a significant impact on reducing risk behavior.

Regarding attitude towards people living with HIV, Nashik Gangule S K Rekha PP et al 2002 have done a study to assess the attitude of people on PLWHA 52% of the students felt they should be hospitalized 33% were in favor of home care. The findings reinforced the need for AIDS education in school. Significant changes were found between pre-test and post-test knowledge and awareness levels through school education. As teachers play an important role in sensitizing the students regarding the sigma and favorable attitude to accept HIV/AIDS and imparting knowledge and awareness of HIV, their services need to be made use of in this context.
Alexandra McManus and Lipi Dhar, 2007 have done a cross sectional study to find out the perception and attitude of adolescent urban school girls towards Sexually Transmitted Infection, HIV, and Sex Education. 251 students were studied. The study findings revealed that one third of the students were not aware of the HIV and related disease. 30% had an opinion that HIV can be cured. 40% felt that condoms were not available to youth. They had misconceptions about HIV. The study recommends HIV awareness campaigns and sex education at the school level.

Chakrovarty A et al., 2007 have done a study among school students to assess the level of knowledge, mode of spread and prevention about HIV and the history of sexual exposure. The study was conducted in 4 governmental schools in Kolkatta, 258 students were studied. The study results revealed that boys were more aware of the mode of transmission and prevention of HIV than girls. Awareness about HIV/AIDS was poor among girls. History of sexual exposure revealed that 12% of the boys and 2% of girls had premarital penetrative sexual exposure, without using condoms. Awareness on vertical mode of transmission of HIV was very poor among both boys and girls. The study suggests that scientific information on reproductive and sexual health should be included in the school curriculum.

Shelah S. Bloom, Paula L Griffiths (2007) have investigated the relationship between women’s autonomy and four measures of HIV related knowledge and behavior, condom awareness and condom use in three culturally different states. Around 16,221 samples were drawn from the National Sample Survey from three states i.e. Kerala, Karnataka and U.P. Kerala scored high among the health outcome followed by Karnataka. Women with greater autonomy were more knowledgeable in the awareness of HIV and use of condom. The study suggests a gender based approach to HIV prevention programs in India.

Liane M Summerfield and Carl A Grant (2006) have explored the role of educators to serve as HIV/AIDS prevention agents. The educators were identified as effective trainers and good influencers to change the behavior of young people. ‘Humanizing pedagogy’ includes focusing on the social, economic, racial gender and other variables that impact the prevention of HIV. The author concludes that educators can
be a good change agent as practitioners of knowledge and community agents of health and well being.

Meenu Sharma (2006) has in her study on AIDS awareness through Community Participation, deals with a broad objective of creating awareness about HIV/AIDS amongst the most vulnerable sections of the society using community participation approach. The study was done in three districts. The sample of the study group comprised of commercial sex workers, Rickshaw pullers and truck drivers. It was an intervention study. Baseline information and awareness level of the participants were studied. Then Information on HIV/AIDS was given in Audio/Video presentation. Few members from the community were trained as peer educators, to conduct outreach activities within the community. The post intervention study revealed that significant level of change happened among the participants as far awareness level, concept of fatality of the disease and most importantly HIV prevention method. The study concludes with the crucial theme that awareness, care and empowerment of the communities can lead them to a positive beginning, directed towards safe behavior.

Heterosexual transmission being the commonest route of spread, the only way to check its transmission is by increasing the awareness regarding the modes of spreads and methods of prevention of this disease among people, particularly those belonging to the sexually active age groups. In this context, a study by Sarkar et al; (2007) was conducted to study the extent of awareness, its determinants as well as the attitude of married women in reproductive age group towards HIV/AIDS in Pondicherry. 250 married women in the 15 to 50 years age groups, attending various out-patient departments were interviewed. It was observed that 96% of women had heard about HIV/AIDS. The sources of knowledge were television (81.98%) radio (42.79%), newspaper (15.76%) and health care providers (10.8%). Around 30% were aware of the type of people usually affected by this disease and its signs and symptoms. 83% women knew one or more modes of spread of this disease. Half of the sample populations knew that HIV can be detected only through laboratory test. 62% women were aware of condoms but only 30% knew that condoms can prevent STD and HIV/AIDS.
Saseendran Pallikadavath et al., 2005 aimed to identify socio-cultural and reproductive health correlates of knowledge about AIDS among rural women. Data were taken from National Family Health Survey of two Indian states Maharashtra and Tamil Nadu. The study revealed that the urban HIV prevalence rate was relatively high. 47% of all rural women in Maharashtra were aware of AIDS, 28% knew it could be avoided and 16% possessed correct knowledge about its transmission. In Tamil Nadu 82% of rural women were aware of AIDS, 71% knew that it could be avoided, and 31% were aware of the mode of transmission and prevention method. In both states, the women participated in the study group were hailing from socially and economically backward groups. The rapid spread of the disease to rural areas demanded quick prevention action for health protection rather than waiting for knowledge to follow the appearance of the disease in communities. In particular, innovative strategies to disseminate knowledge among disadvantaged groups are desirable, according to the authors.

Knowledge of HIV/AIDS continues to be surprisingly low. The National Family Health Survey, 1998-99 showed that only four out of 10 women of reproductive age had heard of AIDS. Awareness was much lower among rural and less educated women. Only 18% of illiterate women had heard about AIDS, compared with 92% of women who had at least completed high school. Those who had heard about HIV/AIDS awareness to prevent the infection was very low. Nearly, all respondents in four community-based studies on gender and HIV/AIDS sponsored by the United States Development Fund for Women (UNIFEM) 2000 viewed the condom primarily as a contraceptive device. The study conducted in Pune, Assam and Andhra Pradesh, showed that the most common perceptions about condoms as a contraceptive devise and women who were pregnant and who have undergone family planning program felt that there was no need for condoms as it was difficult to persuade their husbands to use condoms.

According to Samuel NM et al., (2007) in his study on the acceptance of HIV-1 education & voluntary counseling among pregnant women in rural south India, found that baseline knowledge of HIV was lower than that reported in other studies in India among adult women. Base line information regarding HIV awareness revealed that
one-third of the sample population had never heard of HIV or AIDs. 30% women were aware of the vertical spread of the disease and 35% of women could describe the transmission routes of HIV. The study found that the knowledge of rural women regarding HIV/AIDS was much lower than that reported by India’s National AIDS Control Organization (NACO, 2006) for Tamil Nadu.

Evaluation studies in Tamil Nadu showed that the general awareness about HIV/AIDS increased from 23% in 1992 to 98% in 2002. The awareness level was 98.2% urban areas and 94.4% in rural areas, due to the constant efforts of the Government.

A Shrotri MD, A V Shankar et al., 2003 have attempted to study the awareness of HIV/AIDS and household environment of pregnant women in Pune. The study was conducted at an urban Antenatal hospital in Maharashtra. Through structured interviews 707 women were randomly selected. Of these, 283 were further interviewed for their experience in social and physical difficulties. The study found that 75% of the women were aware of the primary transmission routes. 70% of the women demonstrated knowledge of maternal to child transmission; however, only 8% of the sample knew about the prevention method. TV and written material were more strongly related to knowledge than access to radio messages or conversations with individuals. Thirty per cent of the women experienced physical or mental abuse. They revealed that spouse’s alcohol addiction was a major problem. The women who were undergoing domestic abuse showed better awareness level than the women reporting no such abuse. The study found no relationship between reported household abuse and educational level of woman, language or religion. No significant relationship between HIV status and knowledge of HIV and HIV status and risk of abuse in the household.

The studies on HIV/AIDS Awareness, reviewed here, have revealed that the knowledge level regarding HIV/AIDS varies from place to place and the awareness on mode of transmission and prevention methods needs to be intensified further. The findings of these studies have enabled the researcher to gain insight into the social dynamics involved in the process of creating Awareness regarding HIV/AIDS among different groups.
After reviewing studies related to HIV/AIDS awareness, the next part of the review will focus on mental health studies related to PLWHA.

PART – III

2.3.1 Studies Related to Mental Health and HIV/AIDS:

The World Health Organization defines health as a positive sense of well being encompassing the physical, mental, social, basic economic, and spiritual aspects of life; not the absence of disease (Anant kumar 2005). Mental health is an indicator of the psychological health and social life of a people and the increasing morbidity and mortality rates are a sign of social as well as individual malaise. The scope of mental health is related to the whole range of health activities.

Mental health refers to the overall well-being of a person, including a person's frame of mind, emotions, and behavior. The incidence of mental illnesses in HIV-infected individuals is considerably higher than in the general population. HIV/AIDS imposes a significant psychological burden. People with HIV often suffer from depression and anxiety because of the diagnosis of HIV and living with chronic life threatening disease. Instance shortened life expectancy; complex therapeutic regimens, stigmatization, and loss of social support, and break in family ties add fuel to the existing issue. HIV infection can be associated with high risk of suicide or attempted suicide. The psychological predictors of suicidal ideation in HIV-infected individuals include depression and presence of hopelessness. The diagnosis of mental health problems in HIV-infected individuals faces several barriers. Patients often do not reveal their psychological state to health-care professionals for fear of being stigmatized further. Also, health-care professionals often tend to ignore psychological symptoms. Integrating mental health into HIV/AIDS initiatives and programmes in countries presents an opportunity to improve the health of people with HIV/AIDS. Despite the fact that developing countries carry more than 90% of the burden of HIV/AIDS, little information about the interaction between HIV/AIDS and mental health is available. (source: WHO series 2008).
A modest attempt is made by the researcher to review the books and articles related to the mental health status of HIV infected persons.

Unnikrishnan B 2012 has made an attempt to study the depression and its associated factors among women living with HIV/AIDS in Coastal South India. This cross sectional study was carried out in Mangalore city at one public and one private hospital. 137 HIV positive women were interviewed for the study purpose. The Beck’s depression Inventory was used to assess depression and the Lubben’s Social Network scale was used to assess the social support. The study has revealed that 51% were depressed, and 16% were having moderate to high isolation. Depression has been statistically significant in rural women, widowed women and lower socio-economic groups. The study concludes that depression was highly prevalent among women living with HIV but they did not receive any treatment for this condition. According to the study, Women with HIV are four times more likely to be depressed than normal people. It is one of the most prevalent psychiatric diagnose seen in HIV positive individuals. The study suggests the need for incorporating mental health services as an integral component of HIV care.

Selvaraj V et al.,2011 have made an attempt to study the major depressive disorder and its association with health related quality of life among people living with HIV in coastal South India.103 patients were interviewed for Psychiatric diagnosis and to rate the severity of depression using depression rating scales. The study found that 46% were mildly depressed, 38% moderately, 14% severely and 1% very severely depressed. There was a negative correlation between depression and quality of life severity of depression was linked with poor quality of life. The study suggests that early diagnosis and referral of depressed patients needs to be incorporated into intervention programs to improve patient outcomes and Quality of Life (QOL). More research is needed to investigate the impact of antidepressant therapy on QOL using this study as a comparison group in a similar population.

Wingood, Gina M et al., 2008 have done a cross sectional study among black women from South Africa. The study attempts to associate HIV stigma and mental health status, around 177 women were screened for this purpose. The main outcome
measures were fear of HIV disclosure, depressive symptoms, stress of HIV discrimination, post traumatic stress, suicidal ideation and quality of life. Through linear regression model, the study found that HIV stigma was related to depressive symptoms and lower quality of life. HIV stigma was associated with adverse mental health among black African women. The study suggests that educational and legal efforts are required to reduce HIV stigma. According to the author a public health infrastructure should integrate mental health services to reduce adverse mental health consequences of HIV stigma.

Bernatsky, S, Souza. R and De Jong K 2011 have done a comparative study of mental health status of HIV pregnant women and other pregnant women. 134 women were studied. To assess the mental health status, general health questionnaire 12 (GHQ12) was used. Those scoring three and above were considered as having emotional distress. Multivariate regression analysis revealed that HIV positive women had more than twice the mean score of the control group, indicating the poor mental health status among positive group. Two third of the positive women had emotional stress compared to the control group. HIV status and marital status were strong independent predictors of mental health status. Married women experienced less emotional stress. The study has suggested efforts to be taken to minimize the stigma and discrimination of HIV positive women.

Kowalczyk, R, et al 2009 made a study to assess the psychosexual problems in HIV infected patients in Poland. To assess the mental health status GHQ28 scale was used. To assess the sexual problems Mell-Krat scale and BSP questionnaire were used. The study results have revealed that the HIV patients had general health problems and sex played an important role in their life.

Shankar Das and George S. Leibowitzb 2010 attempted to study the mental health needs of people living with HIV/AIDS in India. Through content analysis method, the study endeavors to identify the mental health issues, which has been reported in three domains. Prevalence of Mental health problems among HIV patients, Mental health needs of PLHA and gaps in policies and program in HIV. The authors have also attempted to study about HIV stigma and discrimination. The study found that there
was a higher rate of mental health problems among HIV patients compared to others. Co morbidity as mental depression occurred among HIV positive persons. Social stigma, discrimination, and lack of social support caused more mental depression among them. Untreated mental illness induced many other health issues. The study has brought out the need for incorporating suitable health level policy changes so that PLHA can be assessed and treated for mental health disorders. This requires training of medical and para medical staff and support from the community.

Ahuja, Parkar and Yeolekar, (1998). have made an attempt to investigate the psychiatric morbidity among HIV patients. A cross sectional study was carried out in a General Medical ward at Mumbai. The study found the prevalence of psychiatric disorder as co morbidity among HIV patients 33.3% with major depressive disorders; 27.8% with adjustment disorder; 5% with psychotic disorder; 44.4% with alcohol dependence. The authors have also identified various demographic and socio-economic factors of HIV associated with high risk behavior.

Chandra et al. 1998 conducted a cross sectional studies to assess the mental health status of HIV infected person. 51 prospective samples were drawn from HIV clinics. Both men and women were included for the study. Clinical interviews were conducted based on ICD 10 diagnosis. The findings indicated that 40% had depression; 36% showed severe anxiety, 35% shows signs of anxiety and Depressive disorders; 14% had persistent suicidal intent or attempt.

Chandra et al., 2003 has done a study in South India on psychiatric morbidity of HIV patients in HIV counseling clinics and Respite Care Centers. A cross sectional study comprising a sample size of 68 men and women showed that 47% had depressive disorders; and 25% had anxiety disorders.

Kermode et al., 2008 have done a study in North east India i.e. Manipur and Nagaland. The sample was drawn from 74 HIV affected widows. Quantitative and qualitative data were collected to assess the impact of interventions on the lives of these women. GHQ 12 scale was used to assess the mental health status. The study
revealed that 70% of the sample experienced a common mental disorder such as depression or anxiety.

Abiodun O. et al., 2012 have studied the post traumatic stress disorders after stigma related events in HIV infected individuals in Nigeria. One of the most pertinent issues related with HIV was stigma. Intense stigma caused trauma. This study investigated 190 HIV infected adults in an HIV care centre. The study used GHQ 12 scale and the Rosenberg’s self Esteem scale to assess the self esteem among the sample. The findings indicated that 2/3 of the sample experienced an intense HIV related stigma. Past history of traumatic events, low self esteem, poor social support and presence of poor general health condition were the strong predictors variable for HIV stigma. The study suggests that stigma should be considered while planning for rehabilitation for HIV individuals.

All the above studies have confirmed the need to integrate mental health assessment and interventions for HIV/AIDS patients. Reviews of these studies related to mental health have enabled the researcher to gain a deeper understanding of the problem under study.

PART – III

2.3.2 Studies Related to Social Support in the context of HIV/AIDS:

Social support is the physical and emotional comfort given to an individual by their family members, friends, co-workers and others. It is regarded as resources provided by others. Support can be instrumental (e.g., assist with a problem), tangible (e.g., donate goods), informational (e.g., give advice), and emotional (e.g., give reassurance), among others. Health and well-being are not merely the result of actual support provision, but are also a consequence of participation in a meaningful social context.

Receiving support gives meaning to individuals’ lives by virtue of motivating them to give in return, to feel obligated, and to be attached to their ties. There are perceived and actual supports. The perceived may pertain to anticipating help in time of need, and the actual support is help provided within a given time period.
As the rate of HIV infection among women increases, understanding the impact of HIV/AIDS has on women has become important. Seeking social support is one strategy that helps to cope with HIV-related stress. Social support has been associated with positive emotional and health outcomes for people living with HIV. Many women are able to counteract these outcomes by surrounding themselves with those who can provide various forms of support. Social support is considered as a very important criterion for women’s empowerment. It is ranged next to economic empowerment. Social support is considered as one of the most important sociological parameters which will influence the quality of life of women suffering with deadly disease like HIV/AIDS. These measures show consistent and strong relations to mental health, and are often related to many indices of physical health. Studies related to social support and coping with HIV are reviewed here.

Kalichman, Seth C. 1995 focus on the structural and functional aspects of social support for people living with HIV-AIDS. There are structural and functional dimensions of support which are important dimensions of psychological adjustment to HIV-AIDS. Four sources of social support have been described: relationship partners, friends and peers, family, and professional caregivers. The influence of self-disclosure of HIV-status, reciprocity, and loss on social support has been discussed. Three functional dimensions of social support are described: emotional support, informational support, and instrumental support. Four types of social support interventions have been analyzed: support groups, volunteer programs, and hospice services. The author gives a broad spectrum of the concept of social support and how it should be viewed from varied perspective.

Kallichman SC et al., 2003 have investigated the social support, and HIV-status disclosure to family and friends among HIV-positive men and women. The pattern of HIV-status disclosure and social support were examined among 331 HIV-positive men and women. Structured interviews were conducted to assess the HIV-status disclosure to family and friends, perceived stress of disclosure, social support, and depression. Results showed that the participants had disclosed selectively. They preferred to disclose to their friends and maternal relatives. Disclosure was associated with social support. The study group experienced perceived social support from
friends than family members. Mother and sisters were perceived to be more supportive than father and brothers. Further statistical tests revealed that perceived stress of disclosing HIV was associated with disclosure, and disclosures were related to social support. Disclosure and its association to social support and depression varied for different relationships and these differences had implications for mental health and coping interventions.

Majumdar B. 2004 has done a qualitative study among 10 HIV positive women aged 18 to 70 years to explore the socioeconomic, spiritual, and family support among HIV-positive women in Kolkata. The study has revealed that heterosexual contact is the main source of infection; poverty and sexual violence are indirect social factors. The women experienced less socio-economic, spiritual, and family support after contracting the disease. Worsening physical symptoms, emotional and mental agony forced them into isolation, harmfully affecting their mental health. Social isolation penetrated their spiritual lives, producing feelings of helplessness about the future of their children. The identification of this process is very important for nursing practice, as it highlights the key areas of concern in the implementation of prevention programs and for future research.

Since HIV is a terminal illness and patients are expected to follow strict medical adherence, frequent illness may cause withdrawal from regular medication, which may complicate the issue. Various research studies have proved that social support and treatment adherence were positively correlated which enhanced their quality of life. Some of the pertinent studies have been reviewed here.

Gonzalez, Jeffrey S et al., 2004 have examined the relationship between social support, depression, Positive State of Mind (PSOM) and medication adherence among HIV positive men and women. Ninety samples were drawn, i.e 29 women and 61 men, with HIV positive status. Depression and Positive State of Mind were evaluated. The study result revealed that greater social support and PSOM related to better drug adherence. Higher depression score was related to non adherence. PSOM was an important predictor variable for mediating social support and medication adherence among the positive patients.
Lorece V Edwards 2006 has made an attempt to investigate women’s perception of social support and how it affects their medication adherence. HIV infected African American women, from an outpatient clinic, were studied for the purpose. The study found that supportive family and presence of young children were positively promoting medical adherence. Barriers to adherence included perceived stigma, feeling of isolation, problem in relationships, and having a HIV positive spouse. Though participants were moderately satisfied with the quality of social support, they expected better emotional and instrumental support from their near ones.

BM Gaede, et al., 2006 have explored the relationship between social support and health behavior of rural and urban HIV women in South Africa. 262 women were studied descriptively. 165 patients from urban area and 97 patients from rural areas were selected for the study purpose. The study found that 71% of the urban women had disclosed their HIV status to someone while only 49% of rural women had disclosed. Receiving counseling as well as membership of a support group showed stronger association with positive health behavior than social support on its own. The higher social support was not associated with increased disclosure.

Pranita Taraphdar, Aparajita Dasgupta, B Saha 2007 have done a cross sectional study among HIV positive patients in Kolkatta. 46 patients were studied out of that 6 were females. The study found that all the female patients had disclosed their status compared to the male patients. The disclosure status was 69.5%. Majority of them expressed that they had positive impact after disclosure. They got good social support, kindness, acceptance, attention and help in seeking treatment etc. The important finding was that disclosure need not be associated with breakup of marriage. Only one in six had experience negative impact including blame, abandonment, violence, anger, stigma and depression. Older people were more likely to disclose than younger people. Disclosure of HIV status to one’s sexual partner was associated with less anxiety and increased social support. In addition, it resulted in better access to HIV prevention, and treatment. Moreover, risk behaviors changed most dramatically among couples where both partners were aware of their HIV sero status. It also
enabled couples to make informed reproductive health choices, which ultimately lowered the number of unintended pregnancies among HIV/AIDS positive women.

Phebe k Lam et al., 2007, have investigated 66 HIV positive youth in the age group of 16 to 25 years. The study aimed to evaluate social support, disclosure status and physical status as predictors of symptoms. The study has found that 50% of the sample had clinically significant mental health symptoms. Limited social support, higher viral load, HIV status disclosure is significantly correlated with more mental health symptoms. But disclosure to family and close friends and service providers are not correlated to mental health symptoms. The study suggests mental health intervention and potential social support interventions to improve mental health. Further research work is necessitated to address the role of HIV related stigma and homophobia in social support and coping mechanism.

Vyavaharkar, C. et al., 2007 have examined the relationships among perceived social support, coping strategies and antiretroviral medication adherence in a sample of 224 rural women with HIV disease, recruited from community-based HIV/AIDS organizations, serving rural areas of three states in Southeastern United States. The findings indicate that social support and coping strategies influenced adherence to antiretroviral drug regimens among rural women with HIV disease. It was not mere availability of social support, but the satisfaction of the available support which was important for better adherence. Coping by spiritual activities and focusing on the present, mediated the effect of social support on medication adherence. Satisfaction with available support and coping by managing HIV disease were the best positive predictors of medication adherence, whereas the number of children was a negative predictor of medication adherence.

McDowell, Tiffany Lynee; 2008 have done a study on the relationship between social network characteristic and mental health for women living with HIV. The study investigated the characteristic of social networks which influence the mental health of positive women. The important predictor variables identified by the study were Network size, dissatisfaction with their relationships and quality of relationship with the network. All these factors affected the mental health status of HIV positive women.
The HIV women needed more psycho-social support and counseling than just information sharing, from the net work organization.

Youth Susan Abramowitz, et al., 2009, have made an attempt to examine the nature, type, and source of social support available to a diverse group of HIV-infected adolescents and the relationship between social support and depression. Data were obtained from 166 HIV-infected youth, ages 13-21, in care at four urban medical centers. The youth completed the Medical Outcomes Study Social Support Survey, Beck Depression Inventory, and questions about HIV-specific social support. Linear regression analysis revealed the relation between HIV-specific and general perceived social support, and between social support and depression. Participants were predominately minority (72% black and 20% Hispanic); prenatally infected. Most of them had someone to either remind them to attend or to bring them to the clinic. In majority of the cases it was family and fewer friends (4%). More youth reported being satisfied with family (64%) social support than that from friends (51%). Behaviorally infected youth (BIY) had significantly more friends who knew their serostatus than prematurely infected youth but received significantly less help from the family in accessing care. Satisfaction with family social support was the best predictor of general perceived social support and behavioral mode of transmission the best predictor of depression. The study suggests regular screening of HIV-positive youth for social support needs, especially BIY, and identification of sources for social support should be a regular part of care.

Mahalakshmy T, Premarajan K C, Hamide A 2010, have identified the factors associated with high level of stigma and perceived social support. Two hundred samples were drawn from patients living with HIV having treatment from tertiary care hospital and three Non-governmental organizations from Pondicherry. The study findings revealed that a high level of stigma was associated with non-disclosure, poor social support, younger age group and males. PLHIV with lesser stigma and PLHIV, whose income was maintained, perceived better social support.

The next part of this chapter reviews studies related to quality of Life which is discussed in detail.
PART – III

2.3.3 Studies Related to Quality Of Life:

There is no cure for HIV infection or AIDS nor is there a vaccine to prevent HIV infection. However, the introduction of new antiretroviral therapies in the mid 1990s has allowed many persons with HIV infection to live longer before progressing to AIDS, and to have longer survival following an AIDS diagnosis. The new medications not only can slow the progression of the infection, but can also markedly suppress the virus, thereby restoring the body’s immune function and permitting many HIV-infected individuals to lead a normal, disease-free life. In this situation it is very important to know and assess the quality of life of people living with HIV/AIDS.

Quality of life is defined as “individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.” (WHOQOL-BREF – INSTRUCTIONS 1996: 6) This definition reflects the view that quality of life refers to a subjective evaluation which is embedded in a cultural, social and environmental context. Because this definition of quality of life focuses upon respondents' "perceived" quality of life, it is not expected to provide a means of measuring in any detailed fashion symptoms, diseases or conditions, but rather the effects of disease and health interventions on quality of life. As such, quality of life cannot be equated simply with the terms "health status", "life style", "life satisfaction", "mental state" or "well-being".

With an alarming increase of HIV / AIDS in developing countries and inability to afford highly active anti-retroviral therapy, key issues like the quality of life (QOL) has come to the fore. Determining the impact on the quality of life in HIV/AIDS patients is important for estimating the burden of the disease. This is true because AIDS has a chronic debilitating course and the long-term adverse side effects and current treatments modalities are uncertain. The social stigma attached with the proclamation of HIV sero-positivity may at times force the individual to change the job or the place of living,
putting further stress on the already weak economic situation. This further leads to progressive deterioration of health, low morale, repeated consultation, abstinence from work and low productivity. The vicious cycle thus goes on; economic deprivation and social isolation take their toll on the quality of life.

Quality of life is a multi-dimensional concept whose definition and assessment remains controversial. Quality of life is conceptualized in terms of "an absence of pain or an ability to function in day to day life". Several researchers described Quality of life as a "fighting spirit" associated with longer survival time for individuals. HIV is not simply a virus that causes disease, but also a social and historical event that impacts how others react towards positive status. Issues including personal safety and human rights as well as other aspects of the political and social infrastructure can radically affect the quality of life.

M. Y. Smith J. Feldman et al., (1996) conducted a study in New York, U.S.A., The purpose of the study was to assess the reliability, validity and responsiveness of a health-related quality of life (HRQOL) instrument, 202 HIV infected women without AIDS who were under hospital care were studied to check the internal consistency. The study results showed acceptable reliability for the four multi-item scales on role function, physical function, general health and mental health. Patients who were older, unemployed or who had a history of injection drug use also reported lower quality of life, than those who were younger employed or who had no drug use history. The MOS SF-20 is a reliable and valid instrument of HRQOL for women with HIV infection. Its sensitivity to differences in clinical status over time suggested that it might be useful as an HRQOL indicator for HIV/AIDS clinical trials.

Rose, Molly A. Clark-Alexander, Barbara et al; 1996 conducted a study on the quality of life and coping styles of HIV positive women and children. This descriptive study had taken 52 samples of women with HIV/AIDS who answered an adapted Padilla Quality of Life Index and the Jalowiec Coping Scale explored the quality of life and coping methods of HIV positive women with children. The results revealed that social quality of life was rated highest and the psychological scale was rated the lowest among the psychological, physical, and social quality of life subscales. The three styles of
coping, included confrontive, passive and emotive. There were significant relationships between coping and quality of life. The study concluded that health care workers working with HIV women should be aware of their common concerns and provide effective strategies to improve the quality of life through enhancing decision making and coping skills within the context of the family unit.

The Chronic diseases like HIV/AIDS affect every dimension of quality of life. Gender has a powerful influence on the stresses in life, the availability of personal and social resources, and the impact of stress on both physical and psychological health outcomes (Baum & Greenberg, 1991). In a study of quality of life in persons with HIV infection, Wachtel et al. (1992) found that women scored worse than men in areas of role and social functioning and in mental health. When individuals were faced with distress, coping mechanisms became important in managing HIV progression over time. However, when unable to deal effectively with the stresses of their own HIV infection or that of their children, maladaptive coping--such as anxiety, denial, depression, and anger were manifested.

Swindle Susan et.al. 1999 have attempted to study the influence of Social support, coping style and hopelessness on the measures of quality of life among HIV women. 138 HIV infected patients were prospectively studied. Measures include Medical outcome, Social Support questionnaire, the Beck hopelessness scale, and the Moos coping inventory were used. Coping was related to quality of life. Lesser satisfaction with social support was associated with decline in quality of life. Problem-focused coping was associated with better QOL, while emotion-focused coping, avoidant coping, hopelessness and AIDS were predictors of poorer QOL. Physical functioning correlated positively with employment, and inversely with AIDS, hopelessness, avoidant coping, and age, while adherence with antiretroviral therapy was associated with an increase in QOL score.

A. C. Gielen, K. A. et al., 2001, conducted a study on HIV women in Baltimore, U.S.A to assess the Quality of life among women living with HIV which described the relationship between psychosocial factors and health related quality of life among
287 HIV-positive women Standard measures were used to assess the physical functioning, mental health and overall quality of life. The average age of the respondents was 33 yrs and knew their HIV status, 39% had been hospitalized at least once due to HIV, 19% had sex partners who were also having HIV 83% had children.63% reported physical and sexual abuse. There was a history of childhood abuse among 41% of the sample. Women with larger social support had better mental health and over all better quality of life. Women with good self care behavior like health diet, vitamins, adequate sleep, exercise and stress management had better physical, mental health and overall quality of life. . Multivariate analysis revealed that history of child sexual abuse and adult abuse, social support and health promoting self-care behaviors were the factors affecting quality of life. The high incidence of physical abuse and child sexual abuse reported by this data emphasized the importance of screening for domestic violence while providing health services to HIV-positive women. Social support and self care behaviors were strongly associated with health-related quality of life.

Lucia Yasuko Izumi Nichiata, et al., 2002, have made an attempt to study the quality of life of patients living with HIV/AIDS in Brazil. The study was to determine the relationship of quality of life and social demographic and clinical aspects of HIV positive women. 344 prospective women attending HIV clinics were interviewed using WHOQOL 100. The study found quality of life was good for 45% of the sample. HIV status and seriousness of the illness had negative correlation with quality of life. The economic status and employment status positively correlated with QOL.

Fang C T et. al., 2002 - Studied the reliability and validity of the World Health Organization quality of life (WHOQOL) assessment instrument in patients with human immunodeficiency virus (HIV) infection. WHOQOL-BREF was used to assess 136 HIV-infected outpatients. The results were analyzed and compared with data from 213 healthy persons. The Cronbach's $\alpha$ for internal consistency ranged from 0.74 to 0.85 across domains in HIV-infected patients. The test-retest reliability ranged from 0.64 to 0.79 across domains at average 4-week retest interval. Factor analysis identified four major factors: social, psychological, environment, and physical, consistent with the four domains of the instrument. The scores of all four domains
correlated positively with self-evaluated health status and happiness, and correlated negatively with the number and severity of symptoms. The scores of physical, psychological and social domains, but not the environment domain, showed difference between healthy persons and HIV-infected patients. The study concludes that the WHOQOL-BREF can be a useful quality-of-life instrument in patients with HIV infection.

Sigma Research 2003 found that African people living with HIV in the UK had a significantly reduced quality of life than reported by white British HIV-positive gay men a year earlier. Good economic condition and good housing were the most common concern for HIV-positive Africans in the UK. Immigration status was also cited as a problem by at least half of African respondents. However, mental health and relationship issues were found to have an equally serious impact on quality of life for both HIV-positive Africans in the UK and white British HIV-positive gay men.

Angela Hudson et al., 2003, have attempted a cross sectional descriptive study to find out the influence of symptoms on the quality of life among HIV infected women. 118 women who had self reported gynecological and cognitive symptoms were included in the study. The study reported that common symptoms were depression 83%, muscle aches 84%, weakness 80% and painful joints 71%. Symptoms with the highest mean intensity, however, were headaches, rash, insomnia, vaginal itching, and shortness of breath at rest. Symptoms also significantly predicted role functioning. This study contributes to the understanding of the nature of symptoms and the influence of symptoms on the role and physical functioning of HIV-infected women.

WHOQOL HIV group 2004, Assessment of quality of life in persons living with HIV/AIDS (PLWHA) is becoming crucial to research. This paper describes the analysis of the WHOQOL HIV field test instrument. The study was conducted among 1334 PLWHA from seven culturally diverse centers (Australia, Brazil, Italy, Thailand, Ukraine and two centers in India: Bangalore and New Delhi). The instrument demonstrated good psychometric properties (alpha values for domains between 0.70 and 0.90) and good discriminant validity, with poorest QOL found for those who reported that they were least well. Men reported poorer physical well-being and level of independence, while women reported poorer environment, social support
and spirituality. Older people demonstrated poorer QOL on physical and levels of independence while younger people showed poorer environmental and spiritual domains of well-being. The instrument provides a promising means for QOL assessment for HIV/AIDS in diverse cultural settings.

S.B. Mannheimer, 2005 has made an attempt to study the Quality of Life of HIV-infected individuals receiving antiretroviral therapy. 1050 Prospective, longitudinal data were examined in two large, randomized, multi-centre antiretroviral clinical trials. QOL was assessed based on a self report. Participants included 20% women, 53% African Americans, 16% Latinos; the mean age was 39 years; mean baseline CD4+ cell count 230 cells/mm; 89% were ART-naïve at entry. Baseline physical and mental health summary QOL scores were 45.4 and 42.9, comparable to scores reported in other advanced HIV populations. Significant improvements in mean QOL scores were seen for the group as a whole after 1 to 4 months on new ART regimens, and persisted for 12 months. Participants reporting 100% ART adherence achieved significantly higher QOL scores at 12 months compared to those with poorer adherence. Those with 80% ART adherence had smaller gains in QOL at 12 months when compared to baseline, while those with less than 80% adherence had worsening of QOL. In this analysis, ART adherence was associated with improved QOL, particularly if drug adherence was sustained.

Zimpel RR and Feleck MP 2007 made an attempt to study the Quality of Life in HIV-positive Brazilians and application and validation of the WHOQOL-HIV. The study aims to test the psychometric properties of the Brazilian version of the WHOQOL-HIV. The QOL of 308 HIV-infected men and women were assessed in the different HIV disease severity stages. Women, below 35 years and married patients were associated with a lower QOL. The reliability, construct validity, discriminant and concurrent validity were assessed. Cronbach alpha was above 0.70 in 27 of the 31 facets of the WHOQOL-HIV and ranged between 0.32 and 0.65 in the remaining four facets. The study results revealed that better QOL in the early stages of the infection was found in asymptomatic and symptomatic groups while the AIDS group showed poorer scores in all domains of WHOQOL-HIV. Thus it was a useful tool to assess the subjective QOL in people living with HIV and AIDS.
B O Ollelly and A J Bolajoko 2008 conducted a study on Psychosocial determinants of HIV-related quality of life among HIV-positive military in Nigeria. 125 air force personnel, 56 seropositive and 69 seronegative were interviewed for quality of life and psychosocial measures. The study found the overall quality of life was less among sero positive compared to sero negative individuals. A greater number of negative life events and trauma symptoms, traumatic disorders were reported by sero positive group. Seronegative military personnel reported more sexual risk behaviors compared with seropositive personnel. Multivariate analysis showed that trauma symptoms were a significant contributor to QOL. Other variables that predicted quality of life, includes age, number of negative life events and increased symptomatology. These findings highlight the importance of evaluation of quality of life in HIV-infected military personnel.

Rena Patel; Seble Kassaye; Cheryl Gore-Felton et al; 2009, conducted a study on Quality of life, psychosocial health, and antiretroviral therapy among HIV-positive women in Zimbabwe. A cross-sectional study was conducted to assess the impact of ART on HIV-positive women's health-related quality of life, using the HIV Quality of Life (QOL) questionnaire. In addition, socio-demographics, reproductive and sexual health, HIV-related history, disclosure, social stigma, self-esteem, and depression were also assessed. Structured interviews were conducted with 200 HIV-positive women and categorized into three groups by treatment: Little was known about the psychosocial impact of antiretroviral therapy (ART) among women in sub-Saharan Africa. The study found women on ART reported higher mean scores in quality of life scale, fewer AIDS related symptoms, less depression compared to women not on ART. The research findings suggest that ART delivery in resource-poor communities can enhance overall QOL as well as psychosocial functioning, which have wide-range public health implications.

Ferial Ahmed Hayajneh, Mahmoud Al Hussami et al., 2009 has investigated the relationship among quality of life, coping skills and social support in a sample of women in the United States infected with HIV/AIDS using quality of life as a measure of disease status. 162 samples were drawn for the study. Each participant had CD4 count less than 200/UL and an opportunistic infection. Stepwise regression analysis revealed that a positive correlation existed between quality of life and coping
skills, and greater use of maladaptive coping skills resulted in a lower quality of life. However, there was a weak relationship between quality of life and satisfaction with social support. Among women living with HIV/AIDS, those who endorsed greater levels of positive coping techniques had higher perceived quality of life.

Imam MH, et al., 2011 have done a cross sectional study to determine the level and factors associated with HIV and quality of life. Through convenient sample 82 HIV infected people were interviewed for the study purpose. “WHOQOL-HIV BREF instrument” was used to assess the quality of life. The study found that majority of the respondents was having low quality of life in all domains. The lowest score was obtained in social relationship domain then followed by psychological domain. People living in urban areas and who were employed and a HIV asymptomatic stage were having better quality of life than others. The perception of overall health was higher in females. All the respondents were less than 35 years of age, asymptomatic of the CDC stage of disease and were with a current CD4 count greater than 200 cell/mm3. These findings highlight the need for enhanced psychosocial support and a better environment for improving the health related quality of life among people living with HIV.

Pedram Razavi et al 2011 have done a cross sectional study on 191 HIV/AIDS patient to check the Quality of Life among Persons with HIV/AIDS in Iran and to assess the Internal Reliability and Validity of an International Instrument and Associated Factors. WHOQOL-HIV instrument was used to study quality of life. Student's t-test was used to compare quality of life between groups. Mean Cronbach’s α of facets in all six domains of instrument was more than 0.6 indicating good reliability. Item/total corrected correlations coefficients had a lower limit of more than 0.5 in all facets except for association between energy and fatigue facet and physical domain. Compared to younger participants, patients older than 35 years had significantly lower scores in overall quality of life, social relationships and spirituality/religion/personal beliefs Unemployed patients had significantly lower scores in overall quality of life, level of independence and environment, compared to employed participants. This study demonstrated that the standard, complete WHOQOL-HIV 120 instrument
translated and evaluated among Iranian participants provided a reliable and valid basis for future research on quality of life for HIV.

Rueda S et al., 2012 have studied the Labor Force Participation and Health-Related Quality of Life in HIV-Positive Men Who Have Sex with Men. Large number of people with HIV had left the job market permanently and those with reduced work capacity were unable to keep their jobs. The present longitudinal study collected data from 1,415 HIV-positive men who have sex with men taking part in the Multicenter AIDS Cohort Study. Generalized Estimating Equations showed that employment was associated with better physical and mental health quality of life and suggested that the employee should be trained to adapt to the process of unemployment. Post hoc analyses also suggest that people who were more physically vulnerable may undergo steeper health declines due to job loss than those who were generally healthier. However, this might be the result of a selection effect whereby poor physical health contributed to unemployment. The study suggests policies that promote labor force participation need to be strengthened in order to increase employment rates and also improve the health of people living with HIV.

Ml Grijzen, Koster GT et al., 2012 have done a comparative study to assess the quality of life of people living with HIV who were under treatment and those not taking treatment. It was a multicentre prospective cohort study of primary HIV patients embedded randomized trial was carried out. HRQL was assessed with the Medical Outcomes Study Health Survey for HIV (MOS-HIV) and a symptom checklist administered at weeks 0, 8, 24, 36, 48, 60, 72, 84 and 96. A total of 112 patients were included in the study: 28 received no treatment, 45 received 24 weeks of ART and 39 received 60 weeks of ART. Over 96 weeks of follow-up, the groups receiving 24 and 60 weeks of ART had better cognitive functioning than the no-treatment group. Patients receiving 60 weeks of ART has less pain better role functioning better physical functioning and a better physical health summary score than the groups receiving no treatment or 24 weeks of ART. Mental health is better in patients receiving 24 weeks of ART than in patients in the no-treatment group or the group receiving 60 weeks of ART. At week 8, patients in the groups receiving 24 and 60 weeks of ART reported more nausea, diarrhea, abdominal pain, stomach pain and dizziness than those in the no-treatment group. These differences had disappeared by
week 24. Temporary ART during PHI had a significant positive impact on patients’ HRQL as compared with no treatment, despite the initial, short-term occurrence of more physical symptoms, probably related to drug toxicity.

Reis R K et al., 2012 the present study has attempted to assess the quality of life in Brazilian women living with HIV/AIDS; a quantititative, cross-sectional, analytical study was carried out in healthcare centers specialized in assisting people living with HIV/AIDS, located in a municipality of the state of São Paulo, Brazil. One hundred and six women of age 18 years or more, users of the public healthcare system, participated in the study. Socio-demographic and clinical variables were collected using a specific questionnaire. Quality of life related variables are collected by means of the WHOQOL-HIV-BREF instrument. As per the QOL domains, study results showed that the Spirituality domain reached a standardized mean score of 65.7, followed by the Physical (64.7), Psychological (60.6), Social Relationships (59.5), Independence (58.6), and Environment (54.5) domains. Results of the multiple regression analysis indicated that the women's employment or retirement, income greater than the minimum wage, and higher educational level were associated with a higher standardized mean score of quality of life. However, recent HIV/AIDS diagnosis and exposure to antiretroviral agents for a period shorter than two years were negatively associated with quality of life. It is critical that public policies favor an all-embracing social inclusion of these women, thus promoting better social conditions. Counseling, clinical follow-up immediately after the infection diagnosis, and initiation of antiretroviral treatment were the crucial moments in the lives of these individuals.

Tran BX, Ohinmaa A et al., 2012 has assessed the Health related quality of life and its predictors among men and women with HIV/AIDS. A cross sectional study was conducted among 155 patients 37% women and 73% men who were under ART at Vietnam General Hospital. WHOQOL – BREF instrument was used for assessing quality of life. The results showed that men had higher scores in overall quality life indicators while the women had lower scores in overall quality of life. The study highlights the need for support and gender specific interventions in HIV treatment.
2.3.4 Relevant Indian Studies on Quality of life:

Antoine Douaihy, MD and Nina Singh, 2001 have conducted a study on Factors Affecting Quality of Life in patients with HIV infection. This review highlights current knowledge about the relevance and complexity of physical, psychological, and social factors as determinants of health related quality of life (HRQOL) in HIV-infected persons. Existing data have revealed that physical manifestations of antiretroviral therapy, psychological well being, social support systems, coping strategy, spiritual well being, and psychiatric co morbidities are important predictors of QOL in this population. Health care professionals were encouraged to become familiar with the full spectrum of predictors of HRQOL, so that they could eventually contribute to the development of multiple entry points for interventions in promoting QOL in these patients. Identifying variables influencing and designing effective interventions specific to the social and psychological well being of patient living with HIV-infected were areas for research.

Kabiraj S, 2004, has conducted a study on Strategic models for enhancing the quality of life for people with HIV/AIDS: A holistic perspective in the Indian context. A growing number of people in India affected with AIDS often find it difficult to adjust to the main stream of life. A number of Indian organizations have been restructuring their corporate policies so as to offer employment opportunities to people living with AIDS rather than quarantine them. But no strategic models are available so far to guide them in the manner in which the dissemination of information, change management, humanistic involvement, enhancement, monitoring and roll out of the plan should take place.

Naveet Wig et al., 2006, have made an attempt to study the quality of life of HIV patients in North India by using WHOQOL. The study results have revealed that social domain had the highest scores which had questions related to personal relationships, social support and sexual activity. Education, income and clinical categories of patients were found to be significantly influencing the psychological domain of QOL. Higher income and education had better coping mechanism. Disease morbidity resulted in higher deterioration of psychological domain of QOL. Hence decreasing morbidity through easy access to antiretroviral helped in improving the
psychological domain of QOL. Factors like Clinical categories and occupation of an individual had significant effects on the physical health domain. The study reflects the impact of HIV/AIDS on physical health of the patient as the disease progresses. Skilled workers and businesspersons had better physical health domain compared to others, signifying that people with better occupations had better physical health. Higher levels of symptoms were associated with lower quality of life. There was a need for access to anti-retroviral drugs for all symptomatic patients because lower the morbidity in an individual better was his physical domain score.

Environment played a major role in determining health states. Family support and occupation significantly affected the environmental domain of QOL. In addition, skilled workers and business persons had better scores in environment domain scores. Hence improving the all round environment surrounding of HIV infected individuals will lead to better quality of life.

PS Chandra et al., 2008 has made an attempt to examine the gender differences in quality of life among people living with HIV/AIDS in South India using WHOQOL. 120 HIV patients were taken for the study out of that 109 were males. There was no gender difference in CD4 count or use of antiretroviral therapy. As far as quality of life was concerned, men had reported higher quality score in positive feeling, sexual activity, financial resources and transport while women had better score in forgiveness and blame facets. Of the six domains of QOL, men reported better quality of life in the environmental domain while women had higher scores on the spirituality/religion and personal beliefs domain. Accepting gender differences may provide useful information for designing interventions to enhance QOL among people infected with HIV/AIDS.

Manoj Kumar Tiwari, Saroj Verma et al., 2009 have done a study on Quality of Life of Patients with HIV Infection. The research aimed at comparing the quality of life of people living with HIV/AIDS. WHOQOL – 26 BREF the Hindi version was used to collect information on quality of life with 60 samples. There were twenty HIV positive patients newly identified, twenty HIV positive patients registered in Pre-ART, and twenty HIV positive patients taking HAART. Twenty non infected persons were taken as normal control group matched on the basis of age and socioeconomic
condition. The results indicated that ART and Pre-ART patients significantly differed regarding their quality of life in the physical domain. A significant difference in quality of life scores in the psychological domain was observed between each group of this study except Pre-ART and newly infected positive patients. Results of the study have revealed that the patients belonging to urban areas had better QOL as compared to the rural HIV infected patients.

Basavaraj KH, Navya MA, Rashmi R. (2010) have highlighted the relevance and complexity of physical, psychological, and social factors as determinants of health-related quality of life in HIV-infected persons. The study data has indicated that physical symptoms, adherence to antiretroviral therapy, psychological well-being, social support, coping strategies, spiritual well-being, and psychiatric co-morbidities have been important predictors of QOL. As HIV/AIDS patients adjust to live with a chronic illness, a lot of new challenges emerge; among them were issues of occupation and employment. For working individuals, employment provided not only financial benefits but also a source of, social support, role identity and gave them the strength to face HIV challenges. The study suggests that effective symptom management and adherence to ART will enhance the quality of life of patients. Stress management intervention for HIV patients will facilitate positive adjustment.

Talukdar A et al., (2012) have attempted to study the health related quality of life among HIV infected patients who were receiving ART at Government hospital at Kolkata. Measures like Eysenck personality questionnaire, WHOQOL – BREF, and Beck Depression Inventory were used to get information regarding personality traits, QOL and depression. 175 patients were interviewed i.e. 128 were men and 47 were women. 56% had depression, presence of depression and high neuroticism were significantly associated with poor quality of life. The study suggests HIV infected patients need intervention to manage psychological issues.

The review of studies on quality of life, have enabled the researcher to develop greater clarity in understanding the Research subject.
PART – IV

2.4.1 Understanding HIV from Gender Perspective;

Gender dynamics can be understood as character, role, behavior, identities, opportunity, obstacles that society imposes on men and women based on sex. Though boys and girls, men and women have same potential, rights, caliber, they are still discriminated by social norms and are often relegate women to lower social positions. Because of this discrimination, in the name of gender and cultural norms women are pushed to disadvantageous status. They are denied equal opportunities, access to resources, and have no decision making power. They are denied rights and opportunities in all walks of life.

Gender relations are an important component of the socio-cultural fabric of any society. Boys and girls socialized to adapt to their gender specific roles right from their early childhood. They are encouraged to have specific ideals of femininity and masculinity. These socio cultural norms and values have a significant influence on the sexual behavior of men and women, on their sexual education and on their ability to access information about sex and resources. These gender roles are ascribed by society and it has direct bearing on sexual decision making relevant to the context of HIV epidemic.

In the early stages of the HIV/AIDS epidemic, infection was largely among men. This scenario gradually started changing over a period of time. Now more women are contracting the disease. More alarmingly, young women are becoming infected at younger ages than men, and are estimated to comprise 67% of all newly infected 15-24 year old in developing countries. This trend supports the strategic need to address the gender dimensions of the epidemic – especially in relation to the greater vulnerability of women and girls.

Marginalization of Women due to poverty and gender inequality has been largely responsible for this dilemma. Some of the significant studies that highlight this issue have been reviewed in this context. Jane Mugambi (2006) has studied the impact of HIV/AIDS in rural women in Kenya. HIV prevalence in Kenya is comparatively more
among women than men. According to the author 7, 20,000 Kenyan women aged between 15 to 49 years are HIV positive, compared with 3, 80,000 of male affected by HIV. Besides this there are many who have not been diagnosed due to lack of awareness. According the author there are several socio-cultural factors that make African men and women vulnerable to HIV infection. The findings reveal that besides marginalization and poverty the subordinate status of women has increased the rate of HIV in rural Kenya. Lack of awareness and inadequate services to cope with the diseases have all contributed to the crisis. The women respondents were sending their children to school. Most of them did not have resources for nutritious food and usually survived on simple food like corn. Land shortages added to their woes. Men were the decision makers in the family. Women had no control over sexual decision. In the case of the death of the spouse, the woman’s property went to her in laws. Therefore HIV positive women were left with no financial and family support. Stigma and discrimination both in the community and in the work place were so strong leading to ostracism and social exclusion. Feelings of self blame; shame and guilt were experienced by the positive women. According to human rights watch 2003 domestic violence has been the other problem faced by these women. There has been very little support from the government through some local NGO have initiated community based projects that provide counseling and rehabilitation work for the women. The findings of the study have helped; the researcher to identify the harsh realities faced by HIV infected women.

Barbara Dane 2002., has studied the issues concerning Thai women living with HIV. The AIDS epidemic in Thailand is a heterosexual one. The ratio of infected women vs. men is 60:40. The rate of infection among pregnant women is more than 10%. Records from Thai hospitals indicate that 42% of pregnant women who are infected with HIV have transmitted the disease to their wards. Thai women affected with HIV particularly fear the problem of rejection, and loss of family ties. 25 HIV women participated in the study. The women were in the age group of 23-47 years. Majority of them were having low level education and income. Their husbands died of AIDS. Majority of them had not disclosed their HIV status due to fear of stigma and rejection. All of them had small children, and reported having economic burden. The
author concludes by stating the need to have programs that will empower such women.

Hilary Anderson, Karen Marcovici and Kathleen Taylor 2002 have discussed the effect of female and male gender roles, power relations and sexual behavior in their report on Gender and Women’s vulnerability in HIV/AIDS in Latin America and Caribbean Region. The study explores the issues related to women’s vulnerability. The unequal social status of women, lack of accessing information about HIV/AIDS prevention and treatment, not able to negotiate safer sex and gender violence were some of the factors identified by the study to stop the spread of the disease and give equal treatment. The study highlights the importance of addressing gender-related expectations and attitudes. Due to the high prevalence and emergency of the HIV/AIDS pandemic, the public health sector has been gradually forced to discuss issues of sexuality and power in sexual relationships. Prior to the HIV/AIDS, the general attitude was that sexual relationships are private matters to be discussed between sexual partners, however HIV has put women's sexual and reproductive health and rights on international and national agendas. The International Conference on Population and Development 1994 (Cairo) and the Fourth World Conference on Women (Beijing) 1995 discussed and gave due attention to the impact of gender on sexual relations, reproductive health decision-making and the transmission of HIV/AIDS. Issues are recognized, but are yet to be fully operationalized in health policies and programs. The study concludes by suggesting the changes in gendered power relations, couple communication and access to health information and services in order to impact the pandemic before it claims millions more lives.

Sonam Rana, 2004, views the HIV/AIDS pandemic in India as inextricably attached to the social and cultural standards and economic associations between men and women and in communities. While social inequalities facilitate its spread in the country, the virus, in turn, reflects and reinforces these inequalities. Women have very less say in the society because Indian society admires and values patriarchy and male sexuality and mourns the births of daughters. In addition, there is an absence of choice at the individual and systemic levels, whether it is the choice to use a condom or even
to have sex. In the last few years, in India the people working on the prevention program have started shifting from looking at the HIV/AIDS epidemic as a health issue to focusing on other factors that increase vulnerability to infection. For women, low economic and social status, abuse and violence, as well as limited legal and social protection increase their vulnerability to HIV/AIDS.

The New Indian Express 2012 states that incidence of violence of all forms are significantly higher among HIV-positive women than among HIV-negative women. A study was conducted by doctors at the Armed Forces Medical College at a tertiary care hospital in Pune. On a randomly selected 150 married women (75 HIV-positive and 75 HIV-negative) who were seeking treatment there. The study revealed that 56 per cent of HIV-positive women reported of domestic violence. Violence and the fear of violence emerged as important risk factors contributing to the vulnerability to HIV infection among women. There was a strong association between violence and women's HIV status HIV-positive status, rural residence, number of children, and alcohol consumption by husband were significant factors that put the women at higher risk of domestic violence.

Arivanantham 2012 expressed how a HIV positive woman was refused a Green House under the free government scheme because she was a HIV affected widow from Jedukothur near Nochikupppam village. Her appeals to the Veppanahalli Panchayat Union chairman, the Project Director of DRDA (the implementing agency) and also the District Collector did not yield any result. She was advised to avail the benefit under the Indira Awaz Yojana Scheme instead of the state sponsored Green House scheme. This case study reflects the plight of HIV infected women in our society.

Sudhir Varma 2012 has discussed elaborately on the various types of issues faced by women under gender context. In spite of law, women even today do not have property and inheritance rights. Women are discriminated right from her childhood. Good food, quality education, good health and health care behavior have been denied to her. The main reason for this discrimination is lack of awareness, illiteracy and gender socialization. The author has given number of reasons for women to be highly
susceptible to HIV/AIDS- higher incidence of STD, frequency of intercourse, sexual practices and the male female age difference in sexual relationships. Biological causes like presence of lesions, inflammation and scarification in the genital tract have been cited as important reasons for high HIV rate among women.

The author says that HIV/AIDS develops in the crack and crevice of the reproductive organs of men and women. It spreads because of cracks and crevices of the society which is full of inequality, contradiction and conflicts. It is because of this reason that HIV/AIDS epidemic has had a disproportionate impact on the weaker sections of the society. Weaker sections in India include scheduled castes and scheduled tribes and women and they have not been able to protect themselves from assault made by the dominating patriarchy. Women are the weakest, irrespective of their caste and are therefore regularly raped and exploited. The article highlights on the low nutritional status and the poor socio-economic conditions of HIV infected women in India.

The extensive reviews have given the researcher a clear picture about the origin and nature of the disease and it impacts on various walks of life. Through the review of literature it is visible that HIV/AIDS is not merely a public health issue. It is more than that. It is intrinsically associated with gender dynamics. Its demographic, economic and social implications are alarming. This socially constructed illness need better understanding from various perspectives. Though the researcher has made a humble attempt to review all the areas taken for the research purpose, these revelations and expositions are inadequate to understand comprehensively the various psycho social issues of HIV infected women. Accordingly a comprehensive attempt focusing on the HIV positive women’s socio-economic status, awareness about the disease, general health condition with reference to mental health, quality of life and social support with sociological overtone was felt and found as research gaps with special reference to HIV women in the larger cities. Accordingly to fulfill this research gap the present study is formulated to conduct the same in Chennai region capital of Tamil Nadu with strong methodological support and also with specific research questions.
The Review of literature has enabled the researcher to gain greater clarity over the social issues underlying the prevention, detection and management of HIV/AIDS. The studies reviewed in this chapter, have enabled the researcher to develop the appropriate research areas and to identify the variables for the study. The inputs gained from the Review of Literature have facilitated the development of the research design and hypothesis, which will be presented in a systematic and sequential order in the next chapter on Research Methodology.