Chapter II

Review of Literature
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HIV infection and its development form acquired immune deficiency syndrome are amongst the most dreadful diseases of the modern era. Till date there is no successful treatment of the disease. The antiretroviral therapy can help affected persons to prolong their life span only if other precautions are taken. As and when the infection is detected the patients and their care givers/ well wishers are in a state of shock and fear of death looms large on their faces. Therefore, there is a possibility that the affected persons and their care givers are bound to have problems like anxiety, depression etc besides the biological/physiological concerns. As the disease progresses the affected person’s health deteriorates and his/her capacity for work declines at the same time expanses on his/ her treatment are increased. The cost of caring is increased and someone has to take care of the affected person and then the care givers also sometimes feel burdened. In this section the studies relating to the psycho social problems of HIV/AIDS cases and their caregivers are reviewed.

Psychosocial Problems and HIV/AIDS

The economic, social, and psychological burden on AIDS patient and their caregivers are immense and therefore treatment should focus on all these issues. A holistic framework encompassing the diverse requirement of HIV positive/ AIDS patient is the need of the day. The aim of present research undertaken was to explore the psychological impact and psychological requirement of patient as well as their caregivers. The main objective is to build programmes to alleviate physiological as well as psychological pain and discomfort of AIDS patient and their caregivers. The route is not easy but investigator has some examples to learn and therefore it warrants a brief mention here. HIV disease is not only a medical issue, but a psychosocial one as well. Infection and the subsequent progression of this disease present the client with a broad range of personal experiences to negotiate. HIV/AIDS has many physical effects, but perhaps
some of its most profound effects are on the psychological, social, and economic health of the HIV-positive person, his or her loved ones, and the community.

Since the beginning of the epidemic, stigma and fear have surrounded many of those who live with and die from HIV/AIDS, as well as those who love and care for them. Rotheram-Borus, (2001) stated even if stigma is minimized, an incurable and often fatal disease requires enormous psychosocial adjustments. People diagnosed with HIV, experience many of the emotional responses identified in people facing a terminal illness. When people discover they have HIV or AIDS, their reactions tend to follow a series of stages, although these are not invariable and some people may skip several stages. The stages are similar to the response of dying (Kouacs, 1978). The first stage is shock; denial, and anger, people may feel guilty about their infection or angry at those they believe have infected them. The second stage is withdrawal; they recognize the stigma associated with HIV/AIDS and may be uncertain or apprehensive about how others will react. Third is a "bargaining" stage; they may tell carefully selected significant others about their HIV. Fourth, people may look for others in the same situation to obtain peer support and discuss problems. In some cases, a fifth stage of seeing themselves as special or different may occur, followed by altruistic behavior or acceptance of their infected status. The issues facing HIV-positive people vary in accordance with the disease process, including whether the disease is symptomatic.

In a study following 80 homosexual men with HIV/AIDS for 15 years, Nokes, (2000) noted common themes that emerged at different points in the disease process. Early in the disease, people often see themselves as being "persecuted" by the virus – an external, alien, bad object. At later stages, physical and psychological anxieties and fears about death are common. Existential issues invariably emerged in response to threats to physical and psychological survival. Existential isolation – a fear of being rejected or abandoned – may lead to anxiety and depression. At the severe symptomatic stage of AIDS, patients experience these issues as much more direct concerns related to physical death. Views of the persecutory nature of HIV change over time. Initial bewilderment turns to fear as the disease becomes more severe. Denial is most typical in the early
stages of infection. Helplessness and hopelessness are most concentrated in the severe symptomatic and terminal phases of AIDS.

They formulated the, HIV disease can be characterized as producing four major psychological concerns: existential and spiritual issues; a perception of HIV as a threat or persecutor; feelings of vulnerability and loss of control; and death-related concerns. A wide spectrum of psychiatric disorders has been associated with HIV: mood, anxiety, cognitive, psychotic, personality, sleep, sexual, and substance use disorders. Estimates of lifetime and past-year prevalence of psychiatric disorders in individuals with HIV/AIDS are as high as 68% to 89%. Some propose that anxiety, depression, and suicidal ideation may be a response to patients learning their seropositive status (Catalan, 1992).

Boyd-Franklin, (1995), have reported that HIV is an illness that affects the whole family, not only the infected individual. When one member of a family has HIV, often there are others who are as yet undiagnosed. When HIV infects one partner in a relationship, both partners are affected. The infection may indicate that sex or other risk behavior has occurred outside the relationship, but even if the infection predated the relationship, both partners will be involved in the emotional trauma of the discovery. HIV and AIDS is a chronic/terminal illness that forces individuals and their families to cope with an uncertain progression of disease, complicated medication regimes, and the grief related to the loss of health and possibly the loss of family members. It is further complicated by the stigma related to the transmission of HIV infection. Further many families isolate themselves from their extended family and communities to protect themselves and their children from maltreatment.

Cruess, (2003) pointed out that psychological, social, economic, political, and environmental factors directly affect HIV risk and vulnerability which has stimulated interest in structural approaches to HIV prevention. Progress in the use of structural approaches has been limited for several reasons e.g. absence of a clear definition; lack of operational guidance; and limited data on the effectiveness of structural approaches to the reduction of HIV incidence.
Anderson, (1995) conducted a study on personality, appraisal and additional outcomes in HIV positive men and women. A cross-sectional exploratory design was used to assess the relationship to personality, SES and appraisal with functional and emotional outcomes in 77 men and 50 women with HIV infection. Multiple regression analysis showed that, among men, SES moderated the negative relationship between self-esteem and disruption in usual activities. Appraisal of HIV threat mediated the negative relationship between self-esteem and mood disturbance for men and women, and the positive relationship between self-esteem and purpose in life. For women appraisal did not mediate between personality variables and disruption in usual activities or life satisfaction for men or women.

Weinrich, (1995) determined whether patterns of depression, coping strategies, personality, unsafe sexual behavior, and sexual identity conflicts among gay men would be related to HIV status. Data were collected from over 500 HIV+ and HIV- gay men. Relationships between Feminine Gender Identity scale scores and depression were found for HIV+ but not HIV negative subjects. A similar pattern emerged in the correlation pertaining to MMPI score and unsafe sex, and in the association between escape-avoidant coping and sexual identity conflict. Analyses correlating MMPI scores with escape-avoidant coping were equally strongly associated when broken down by status.

Johnson, (1996) examined the physical and psychological functioning of 66 HIV+ and 41 HIV- homosexual men (aged 22-59 years) to determine whether personality disorders (PDs) increased risk for onset of Axis I symptoms were impairment, after HIV status and lifetime Axis I symptom were controlled statistically. Baseline assessment of personality disorders, Axis/I symptoms, and Global Assessments of functioning (GAF) were conducted, with follow up assessments of Axis I symptoms and GAF every 6 month during a 3.5 years period. Results revealed that 21 of 107 subjects were diagnosed as having personality disorder and 10 were diagnosed with current Axis I disorders at baseline. Subjects with personality disorder were more likely than those without personality disorder to be diagnosed with subsequent anxiety, mood, and any Axis I disorders during the 3.5 year follow up.
These results suggest personality disorders predict onset of future Axis 1 disorder and serious impairment, whether or not they had prior Axis I disorder.

Kooiman, (1996) in a study investigated whether HIV-infected homosexual male patients (aged 20 + years) with a DSM – III-R personality disorder differ from those without a personality disorder in use of primitive defence mechanisms, impaired ability to form stable and satisfying attachment with other people, and perceived parental neglect in childhood. Subjects completed the personality disorder questionnaire –revised, defence style questionnaire, adult attachment scale, parental bonding instrument, and hospital anxiety and depression scale. Compared with subjects without personality disorders, subjects with a personality disorder made more use of primitive defence mechanisms and had more difficulty forming a secure attachment with other. These conclusions remain valid after controlling for level of anxiety and depression, subjects with personality disorders did not perceive more parental neglect during childhood than did subjects without personality disorders.

Svikis, (1998) reported a study to examine personality features and psychopathology in a sample of HIV +, pregnant, drug dependent women (aged 19-34 years). Personality was assessed using the Minnesota Multiphasic Personality Inventory – Revised (MMPI -2). The mean MMPI-2 Code type, (6-8), although relatively rare in standard drug treatment settings, characterized nearly one – fifth of study participants. The 6-8 code type is typically associated with unusual thought processes, feeling of hostility and suspiciousness as well as apathy, which may mask symptoms of nervousness, anxiety and depression treatment.

Steins, (1999) examined the effect of a target’s personality and responsibility for a misdeed on a perceiver’s emotion and behavior by determining the variable impact on the perceiver emotional reactions and willingness to help the targets. A total of 134 German and 171 American university student were given information about the level of responsibility (low, median or high) for a person’s infection with HIV, two variations of information about the target’s personality (positive Vs negative), and the transmission
mode of the virus (needle Vs sex). The results showed that the target’s personality also contributed to the perceiver’s emotional and behavioral reactions.

In a landmark study, Wu and Jacobson, (2002) examined sexually risk behavior of 183 HIV – positive men and women within the framework of social cognitive theory. Condom use was found to be associated with high self – efficacy, positive influences from social models, and specific condom use expectancies. As risky sexual behavior may be the manifestation of a more general pattern of risk taking that emerges from personality dispositions such as impulsiveness or psychotics, this possibility was explored with discriminant analyses, self -reported impulsivity, substance abuse, promiscuity and deception served as markers of the presumed disposition. While these variables did not reliably distinguish between consistent and inconsistent condom users, they did enhance significantly the classification of individuals who, during the past 6 months, had been sexually abstinent, monogamous, or non- monogamous. Those who reported more sex partners scored higher on impulsivity disclosed more involvement with illegal drugs and showed greater willingness to mislead potential partners about their sexual history than monogamous or sexually abstinent persons with HIV.

Rabkin, (2000) determined whether apathy is associated with neurocognitive symptoms and / or depressive symptoms in HIV/AIDS and also whether apathy is associated with neurocognitive symptoms and depressive symptoms expectancies about antiretroviral medication adherence. Seventy five HIV + homosexual men (mean age 44 yrs) were assessed for depressive disorders and symptoms. Neuropsychological test measured attention, concentration, learning memory executive function, and psychomotor speed. Other measures included Marin’s apathy evaluation scale, the adherence determinants questionnaire, CD4 cell count, and HIV RNA viral load. Apathy was consistently related to depression and unrelated to neuropsychological impairment. Patient expectancies regarding medication adherence were unrelated to apathy when the analysis was controlled for depressive symptoms.
In a study, Turrina, (2001) investigated the prevalence of depression in intravenous drug users with HIV infection, including both asymptomatic and symptomatic subjects. Subjects were first screened with the Hospital Anxiety and Depression scale, and then all positive subjects were evaluated with the Composite International Diagnostic Interview. Inpatients were also given the Karolinska psychodynamic profile HIV – positive subjects have a high rate of depression (Major depression 36.2 %). Inpatients had the highest rate of depression, irrespective of HIV clinical staging. A personality disorder was diagnosed in 36% of the sample, but those subjects were no more significantly depressed. It was concluded that physicians treating AIDS patients should be alerted to the high rate of depression in clinical HIV illness, in order to identity and properly treat depression.

Penedo, (2003) in a study investigated dysfunctional attitudes, coping, and depression among HIV seropositive men. The role of coping as a mediator in this relationship was also examined among 115, 19-49 years old HIV+ symptomatic MSM. Higher dysfunctional attitude scale, scores were associated with more reported depressive symptoms. The use of adaptive coping strategies such a active coping was associated with lower depression, whereas use of maladaptive strategies such as denial was related to mediate the relationship between dysfunctional attitudes and distress. Findings suggested that interventions aiming at reducing psychological distress in this population using cognitive restructuring and related techniques may achieve their effects by enhancing adaptive coping strategies on the one hand and reducing maladaptive strategies on the other.

Lagana, (2002) in a study examined the depressive symptomatology in relation to emotional control and chronic pain in person who were HIV positive. It was aimed to examine the relations of emotional control and chronic pain to depressive symptomatology in person with positive human immunodeficiency virus (HIV) status. The study was conducted using a cross-sectional survey of one hundred twenty (51
women, 69 men) individuals with serologically documented HIV cases. Main outcomes measures were measures of depressive symptomatology and chronic pain.

Multiple regression analysis showed that constant pain and emotional control were associated with depression scores. It was concluded that within comprehensive rehabilitation programs with these patients, pain management was a critical issue. Treatment should address patient’s comorbid depressive symptomatology and difficulties with expressing negative emotions.

Tobst, (2002) examined relations between a comprehensive measure of personality, (i.e. Revised NEO personality Inventory), and condom use and other HIV risk behaviors. The study sample consisted by 201 disadvantaged, primarily, African/American Subjects (aged18 to 62 years) of HIV status and were stratified into 3 risk groups. The low risk group (number 43) had 0% engagement between 37 to 52 of the high risk group (number 62) engaged in these practices (e.g., shared needles, sex with partner who shoots drugs, received anal sex). The medium risk group (number 96) had intermediate engagement in these practices. Results indicated that high neuroticism, low conscientiousness and low agreeableness were associated with HIV risk behaviors. Thus, high risk behavior is associated with emotional distress. The high risk group differed from the medium and low risk groups on the neuroticism facet of impulsiveness, indicating an inability to resist craving and urges. The high-risk group also scored lower in competence (i.e. fallings of self-efficacy) self discipline (i.e. motivation to carry tasks through to completion) and achievement striving (i.e. aspiration level).

Kaplan, (1998) examined the prevalence and predictors of depression and use of mental health services among 475 HIV-infected men without AIDS. Participants were drawn from three sites in San Francisco and Denver that did not provide ongoing medical care or mental health services. Depression was measured using the Centre for Epidemiology Studies Depression scale (CES-D). Overall, 176 men (37.1%) were classified as depressed based on having a CES-D score above the standard cut-off of 16. In logistic regression analysis, persons with HIV-related symptoms (OR = 3.4; 95% CI = 2.0-5.6), low social support (OR = 2.5; 95% CI = 1.6-3.9), who were unemployed (OR =
1.9; 95% CI = 1.1-3.3), and with CD4 count 200 cells (OR = 1.9; 95% CI = 1.1-3.3), were significantly more likely to be depressed. Only 40.3% of depressed men had seen a mental health clinician in the previous year and only 6.3% were taking an antidepressant. Among depressed men, in logistic regression analysis, men who were unemployed (OR = 2.4; 95% CI = 1.2-4.7) and those with health insurance (OR = 2.2; 95% CI = 1.1-4.5) were more likely to have received these services. Increased evaluation and treatment of HIV-infected persons for depression was suggested.

Albest and Back (1975) examined the symptoms of depression and anxiety among a sample of South African patients living with HIV. The study was conducted on 85 patients receiving treatment at three HIV clinics in the Western Cape. Participants completed the Hopkins Symptom Checklist (HSCL) and the Beck Depression Inventory (BDI), two self-report instruments designed to measure mood disturbance. The mean score of the sample on the HSCL was 47.54, which was significantly different from the commonly used cut-point of 44 for clinically significant distress; 52.9% of the sample scored in the elevated range on this measure. On the BDI, 37.6% of the sample fell in or above the moderate range for depression. The results suggest that a considerable proportion of the sample may be experiencing psychiatric difficulty, for which they may not be receiving treatment.

**Depression and Suicidal Ideation**

Studies of the mental health status of people infected with HIV have consistently found higher prevalence of mental health (Suicidal Ideation) problems than is found in general community or clinic samples (Catalan, 1992). Reasons for the higher prevalence of mental health problems in HIV infected populations include: premorbid mental conditions which predispose people to infection, the effects of the virus on the central nervous system, the psychological impacts of living with HIV/AIDS, side-effects of medication, and results of social stigma and discrimination (Feldman, 2005). Males were more likely than females to experience a mental disorder. This is a reflection of higher levels of alcohol abuse amongst the male population, as in all other categories of mental disorder there was no significant gender difference. People diagnosed with HIV
experience many of the emotional responses identified in people facing a terminal illness. They commonly go through an initial stage of denial, in which they do not acknowledge having the disease or deny its likely consequences.

HIV threatens a person’s life, goals, expectations, and significant relationships; no wonder that many people are reluctant to admit their diagnosis or their risk of infection. It is not uncommon for people who subject themselves to high-risk situations or behaviors to deny that they are at risk of HIV infection. They often avoid testing, and if they are tested, they avoid following up on results, as if avoiding a clinical diagnosis might prevent the disease. In order to battle HIV successfully, people must have some level of acceptance of the disease so that they can seek counselling, social support, and medical care. Cognitive and emotional symptoms may include emotional numbness or hypersensitivity, over identification with patients, grief and sadness, pessimism and hopelessness, cynicism, indecision and inattention, and depression (Bennett, 1995).

In order to examine the relationship between apathy, depression and QOL among individuals infected with HIV, Dybul and Fauci (2002) conducted a study. Apathy was quantified using the marine apathy scale and QOL was measured with the medical outcomes study short -form 36 (SF-36). Results of the study revealed that both apathy and depression were more common among patients with HIV than healthy control subject. 26% of the patients with HIV reported clinically significant apathy while 80% of the patients reported clinically significant depressions. Apathy did not relate to ratings of overall QOL, but it was modestly associated with ratings of mental health and role disruption secondary of mental health. By contrast ratings of depression were strongly related to overall QOL and most indices of medical outcomes (SF-36). Regression equations revealed that depression and apathy independently contributed to mental health and role disruption and apathy independently contributed to mental health and role disruption secondary to mental health. Importantly ratings of depression accounted for the majority of variance for ratings of quality of life.

When people discover they have HIV or AIDS, their reactions tend to follow a series of stages, although these are not invariable and some people may skip several
stages of dying. The first stage is shock, denial, and anger; people may feel guilty about their infection or angry at those they believe infected them. The second stage is withdrawal; they recognize the stigma associated with HIV/AIDS and may be uncertain or apprehensive about how others will react.

Third is a “bargaining” stage; they may tell carefully selected significant others about their HIV. Fourth, people may look for others in the same situation to obtain peer support and discuss problems. In some cases, a fifth stage of seeing themselves as special or different may occur, followed by altruistic behavior or acceptance of their infected status. However, the more stigmatized HIV/AIDS is, the less likely the patient will progress beyond confiding in carefully selected others. When disease symptoms occur, new psychological issues arise.

Presence of HIV/AIDS not only affects the physical health status of the individual but also results in the changes in the emotional and the mental health of the individual. These changes may be the consequence of the psychological reaction to the presence of an intractable practically terminal illness as well as because of the stigma attached with the condition. As the HIV disease progresses it demands constant adaptation and coping with these changes. At the same time, the person's condition may trigger a variety of reactions from others such as family members, significant others, employers, co-workers resulting in constant demand on the individuals coping resources.

Studies of the mental health status of people infected with HIV have consistently found higher prevalence of mental health problems than is found in general community or clinic samples (Catalan, 1999). Reasons for the higher prevalence of mental health problems in HIV infected populations include: premorbid mental conditions which predispose people to infection, the effects of the virus on the central nervous system, the psychological impacts of living with HIV/AIDS, side-effects of medication, and results of social stigma and discrimination reported an overall prevalence of 43.7 % of diagnosable mental disorders in people living with HIV/AIDS. In contrast in a general population stress and health study (Winer, 2001) reported 16.5% as having a diagnosable
mental disorder. Research in Hong Kong shows similar findings as the West that depressed mood is very common among PLWHA.

Evaluation and management of psychiatric, neuropsychiatric, and substance abuse problems is essential in the successful treatment of HIV/AIDS. Recognizing the mental health-related manifestations of HIV is often complicated by the complex interaction of psychosocial and biological factors. A wide spectrum of psychiatric disorders has been associated with HIV: mood, anxiety, cognitive, psychotic, personality, sleep, sexual, and substance use disorders (Bing 2001). HIV infected patients in general reported feelings of guilt, loss, loneliness and hopelessness about future and fear, estimates of lifetime and past-year prevalence of psychiatric disorders in individuals with HIV/AIDS are as high as 68% to 89. It is arguable whether the high prevalence of psychiatric disorders among HIV-positive persons is due to high rates of preexisting illness or increased risk for HIV infection among those with mental illness. Some propose that anxiety, depression, and suicidal ideation may be a response to patients learning their seropositive status or the subsequent symptoms and disability associated with HIV (Catalan, 1995). There is increased risk of suicidal ideation and suicide attempts in people with HIV/AIDS, particularly among women, who are up to 5 times more likely to have ever attempted suicide than HIV-negative women.

The progression of HIV infection to AIDS infection has been associated with central nervous system dysfunction. The signs and symptoms of HIV-related CNS infection include cognitive impairment (i.e., short term memory deficits and confusion), changes in personality (i.e., apathy and erratic behavior), psychotic symptoms (i.e., hallucinations and suspiciousness), and motor symptoms (i.e., ataxia, and weakness). Careful assessment of symptoms is necessary to distinguish central nervous system dysfunction from the effects of mental health illness (i.e., depression and anxiety), as well as other factors that affect neuropsychological functioning. These factors include, but are not limited to, prescribed and recreation drug use, stress of living with a chronic/terminal illness, and nutritional deficiencies. It is important to note that a number of behavioral and psychosocial problems have been noted in HIV and AIDS infected children.
These problems include hyperactivity, attention deficits, social withdrawal, and depression. In addition, cognitive deficits, learning disabilities, and developmental delays have been related to central nervous symptom dysfunction in children. Of course, it is possible that these disorders are related to environmental influences and due to HIV and AIDS infection.

Furthermore, the high rates of HIV infection in ethnic minority men and women, men who have sex with men, and other marginalized groups such as injection drug users and sex workers, means that many HIV-infected individuals, before infection, experienced years of discrimination because of sex, race, sexual orientation, and class that can result in hopelessness, poor coping, loss of personal agency, depression and other mental health problems (Crystal, 1998). Histories of stress, trauma, and discrimination may have contributed to the behavioral risk that led to HIV infection, whereas these same contextual factors can contribute to diminished coping capabilities leading to significant psychological distress and behavioral challenges when living with HIV. In contexts of extreme poverty in which basic living needs such as food, shelter, and clean water are not guaranteed, psychological needs can be seen as secondary to physical health and the other basic physical needs of living. There is increasing awareness on the part of healthcare providers and governing and social service agencies that ignoring psychological factors can contribute to long-term harm to the individual and to the public health.

Mental health, stigma, disclosure and social support are domains that are important in the lives of people living with HIV, and also as factors that are consistently associated with treatment adherence and sexual behavior, two behavioral outcomes that are important to the health and wellbeing of the individual as well as the public health. Coping with the uncertainty of future health and HIV stigma remain the most difficult psychological challenges that permeate many facets of life. Upon learning the diagnosis the individual is likely to experience alternating feelings of shock, disbelief, panic, fear, guilt, shame, anger, despair, hopelessness, and numbness. Supportive counselling and increased access to existing social supports may be sufficient to help individuals cope with these feelings.
Studies have shown that adults and children living with HIV and/or at risk of acquiring HIV are at an elevated risk of psychosocial distress and psychiatric conditions, particularly depression (Bing, 2001).

Although the specific role of HIV is not clear, a number of these studies have found clear and important associations between the prevalence of psychiatric disorders and psychological symptomatology and poor quality of life, elevated sexual risk behavior, poor adherence, and poor health outcomes. For example, chronic and intermittent depressive symptoms in HIV positive women are associated with disease progression, lower CD4 cell counts, and higher baseline viral load levels; and, in general, women with chronic depression have mortality rates twice as high as those with little or no depressive symptoms.

Family burden

Family burden as defined by Goldbort, (1980) is the adverse effect the patients has upon the family. They also categorized burden as subjective and objective. Objective burden had affects on the house hold and subjective burden is the informants on perception of whether the house hold had suffered some degree of burden.

HIV is an illness that affects the whole family and not only the infected individual. When one member of a family has HIV, often there are others who are as yet undiagnosed but are adversely affected by the disease. When HIV infects one partner in a relationship, both partners are affected. The infection may indicate that sex or other risk behavior has occurred outside the relationship, but even if the infection predated the relationship, both partners will be involved in the emotional trauma of the discovery. HIV and AIDS is a chronic/terminal illness that forces individuals and their families to cope with an uncertain progression of disease, complicated medication regimes, and the grief related to the loss of health and possibly the loss of family members. It is further complicated by the stigma related to the transmission of HIV infection. Further many families isolate themselves from their extended family and communities to protect themselves and their children from maltreatment.
Thus, they are cut off from valuable supports Boyd-Franklin, (1995), reported the findings of his study which clearly support the common perception of the complaints of people, these are in the area of finances, emotional distress, interpersonal difficulties in addition to stigma, and neglect of children, loss of severity, compromised dignity, domestic violence and health risks. HIV/AIDS affects the economic well-being of families, businesses, and societies in many ways. When people become ill and die, society loses not only those people but also their productive potential. They no longer hold jobs, manufacture goods, provide services, or support their families. Families lose their breadwinners; the nation loses people who contribute to the wellbeing of society. Due to illness or death of the parents, primary care responsibilities often fall to extended family members. In fact, grandmothers often become the primary caregiver for multiple children.

Loss of parents and changes in caregivers interfere with mastery of developmental milestones and coping abilities of children and adolescents Boyd-Franklin, (1995). Outline the concerns and apprehension of the family members and caregivers of chronically ill. They reported that whether or not the infected individual is symptomatic, family members often have persistent fears about impending illness, changing roles, dependency and loss of functioning in the ill, and death. These effects can be most pronounced in spouses or partners and children of the individual with chronic illness (Family burden is defined as the emotional, social and financial stresses that an illness imposes on the family. One’s poor social performance in the family has impact on another who has to compensate with the deficiencies experiencing burden. Even when the patient is recovering the burden experienced by the family especially in cases of chronic illness can be tremendous. It is therefore important that whenever a family member is diseased not only the patient but the family should also be supported in order to cope well with the stress of patient care. However, not all caregivers perceive with the same burden of illness because it varies according to their ways of coping and some of the internal traits.

(Cohen 2002) Similar findings have been reported in the report on global HIV/AIDS epidemic (2000-2001). Family burden due to disease in the family impair
family life, productive impotent and may diminish the quality of life. Chronic care giving may challenge the quality of life in caregivers of patients if the care giving role is perceived as a burden. High family burden and poor quality of life has been widely reported by caregivers in context of various neuropsychiatric disorders.

Cohen, (2002) conducted a study as a part of the ‘National Survey of Extent, Pattern and Trends of Drug Abuse in India.’ The study was carried out with 179 women with a male family member currently abusing various substances in 8 centers throughout India were involved in the study, from Bangalore, Chennai Delhi, Haryana, Himachal Pradesh, Manipur, Pune and Thiruvanthapuram. The study was exploratory and qualitative in nature.

There were 56% housewives of all the women caregivers. The study results revealed huge burden in the areas of finances, emotional distress, stigma, interpersonal difficulties, and neglect of children, loss of severity, compromised dignity, domestic violence and health risks (including HIV). It means that there is a greater probability of caregivers of alcohol dependent patients to be emotionally unstable and vulnerable to stressful condition.

A study by Johnson, (1996) on 320 caregivers was conducted to examine the impact of caregiver’s neuroticism on longitudinal change in depression among spouse-caregivers of individuals with Alzheimer’s disease showed similar finding that caregivers with high neuroticism showed a worse longitudinal course of depression compared with those lows in neuroticism was also found similar results showing negative impacts of HIV/AIDS caregivers on their relationship with patient, disruption of social life and finances.

Sherbourne, (2000) in a study of 50 male opiate dependent patients found high burden in spouses in the areas of family interaction and finance. Another study by Shoukidis, (2004) replicated the results showing huge burden on caregivers of HIV/AIDS in the areas of finances, emotional distress, interpersonal difficulties in addition to stigma, and neglect of children, loss of severity, compromised dignity, domestic violence and health risks. Family burden is also associated with stigma and discrimination.
Probably the single most important factor in producing and extending the negative psychosocial impact of HIV and AIDS is stigma. Stigma can be defined as “an act of identifying, labelling, or attributing undesirable qualities targeted towards those who are perceived as being shamefully different and deviant from the social ideal” and as “an attribute that is significantly discrediting (and is) used to set the affected persons or groups apart from the normalized social order. Stigma prevents people from talking about and acknowledging HIV as a major cause of illness and death. Stigma prevents HIV-infected people from seeking counselling, obtaining medical and psychosocial care, and taking preventive measures to avoid infecting others. If one family member exhibits signs and symptoms of HIV, the entire family may face rejection and even violence from the community.

The loss of social support results in isolation for the family, which may also fear loss of employment, denial of school admission, or denial of adequate housing. Even if stigma is minimized, an incurable and often fatal disease requires enormous psychosocial adjustment.

**Health and Quality of Life**

With an alarming increase of Human Immunodeficiency Virus (HIV) Acquired Immunodeficiency Syndrome (AIDS) in developing countries (estimated prevalence in India 0.91%) and inability to afford highly active anti-retroviral therapy, key issues like the quality of life (QOL) have come to the fore. Quality of life is a multi-dimensional concept conceptualized in terms of "an absence of pain or an ability to function in day to day life (Friedland, 1996).

Further as health is generally cited as one of the most important determinants of overall quality of life, it has been suggested that quality of life may be uniquely affected by specific disease process such as AIDS (Weaver, 1995). 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 of current treatments modalities are uncertain. The social stigma attached with the proclamation of HIV seropositivity 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 takes it tolls on the quality of life.

Quality of life is a multi-dimensional concept whose definition and assessment remains controversial (Sharts - Hobco, 1996). 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. Quality of life relates both to adequacy of material circumstances and to personal feelings about these circumstances. It includes overall subjective feelings of well being that are closely related to morale, happiness and satisfaction.

Further as health is generally cited as one of the most important determinants of overall quality of life, it has been suggested that quality of life may be uniquely affected by specific disease process such as AIDS. There is lack of clarity in defining quality of life and concomitant operational difficulties in it. But there is urgency in evaluating the quality of life in HIV infected individual. Since 1989, more than ten health related quality of life (HRQOL) instruments have been used in research with HIV infected individuals. These have documented relationships of HRQOL and HIV status, level of symptoms, use of antiretroviral drugs and use of drugs for prophylaxis of opportunistic infections separately.

In a study conducted by Yen, (2006) reported that quality of life was associated with education, income, occupation, family support and clinical categories of the patients. They included 68 patients in the study and evaluated them on World Health Organization quality of life (WHOQOL) brief instrument. The mean scores in the four domains of QOL was maximum for the social domain followed by the psychological domain, physical domain and the environmental domain in descending order. Physical and psychological domain scores showed significant differences in different clinical categories of HIV patients. However, no significant difference was found between three clinical categories in social and environmental domains. Education, income and clinical
categories of patients were found to significantly affect the psychological domain of QOL. The authors suggested that the higher income and education possibly imparts better coping ability towards illness. They also suggested that treatment improved the quality of life and that the occupation and family support provides better environment to individuals suffering from HIV/AIDS.

Every day, people work, play, eat, sleep, have fun, and just try to live a healthy, normal life. But in some cases or situations, all these things change and living become difficult when a person is affected by a chronic illness. A chronic illness is defined as a long term health problem caused by an irreversible disorder. A chronic illness can alter an individual’s quality of life atomically in all aspect of daily living. Quality of life is something that is intensely personal and particular, including the person’s ability to live independently, age and ability to contribute to society. Some people are able to cope better than other depending on the severity and type of illness, coping strategies, and most important of all, the person's network of supports such as family and friends. Any change experienced in life can be stressful and traumatic. But a downward change in a person's quality of life can be very difficult, especially knowing that life will never be the same again and the illness is life threatening. Having a chronic illness like HIV/AIDS is very overwhelming and often takes over the person's life, making the persons feel powerless and a lot.

Most (2004) examined the relationsips among purpose in life, death anxiety, and HIV-related life changes for gay and bisexual men living with the human immunodeficiency virus (HIV). It was hypothesized that purpose in life significantly and inversely correlated with death anxiety and significantly and positively correlated with HIV-related life changes. It was also hypothesized that health status would demonstrate an effect on the main variables. Additionally, the study is the first known to utilize HIV-related life changes, including improvement, as a main variable. Study was conducted on 72 gay or bisexual men with HIV (48 with AIDS, 24 without AIDS). The majority of the men were white, well educated, and in their 40s. Participants voluntarily selected research materials from one of five private medical clinics. Measures included a demographic questionnaire, the Purpose in Life Test, the Templer/McMordie Death
Anxiety Scale, the Marlowe-Crowne Social Desirability Scale, and a measure assessing HIV-related life changes constructed for the purposes of this study. Results of this study were not consistent with the hypotheses of a significant inverse association between purpose in life and death anxiety or of a significant inverse association between death anxiety and HIV-related life changes. Additionally, results failed to show significant differences along the main measures as an effect of health status. Results were consistent, however, with prediction of a positive and significant correlation between purpose in life and HIV-related life changes. Importantly, results did demonstrate notable reliability for the HIV-Related Life Changes Questionnaire and participants indicated significant degrees of improvement in the majority of life areas surveyed. The results of the study were not consistent with the negative relationship predicted between purpose in life and death anxiety as proposed by Viktor Frankl.

However, this study demonstrates a significant and intriguing relationship between purpose in life and HIV-related life changes. Furthermore, the study empirically demonstrates that, although not necessarily causal, many men report life improvement even after HIV-infection.

A study conducted by Saitoh, (2005) evaluated the relative importance of social (Social support, material resources, disclosure and family functioning) and psychological factors (stigma, emotional distress, intrusion, avoidance and fatalism) as predictors of the quality of life of women infected with HIV. The cross-sectional data were drawn from interviews with a sample of 264 women recruited from 8 HIV/AIDS treatment sites variance in quality of life variables including limited daily functioning, general anxiety and HIV symptoms was analyzed using ANOVA, correlations and hierarchical multiple regression analysis. Limited daily functioning was predicted by stigma, fatalism employment status and stage of disease. General anxiety was predicted by emotional distress, intrusion and marital status. Reported HIV symptoms were predicted by material resources, disclosure, intrusion age, employment status and race. Results support the idea that social and psychological factors are important in their influence on quality of life in women with HIV – infection and suggest the need for interventions which address such factors.
In an interesting study, Burch, (1998) developed an ethnically sensitive instrument to assess quality of life. Interpretive data generated from interviews with 10 men and 3 significant others, a total of 19 interviews, shows that they learn to live with the virus but that after crossing over (the time when AIDS was diagnosed) they became aware that there was no turning around useful strategies for maintaining quality of life were controlling hoping, talking and reminiscing. Reminiscing was like a sentimental journey into the past, not looking to the future, letting go while planning and preparing to die.

The study conducted by Sherburne, (2000) estimated the burden on health related quality of life associated with co morbid psychiatric conditions in a nationally representative sample of urban and rural areas to produce a national probability sample of persons with HIV receiving medical care in the US were screened for psychiatric conditions with the short form of the composite international diagnostic interview.

Health related quality of life was rated with a 28 - item instrument adopted from similar measures used. Subject with a probable mood disorder diagnosis had significantly lower scores on health – related quality of life measures than did those without such symptoms. Diminished health – related quality of life was not associated with heavy drinking and in drug users. It was accounted for by presence of a co morbid mood disorder. It is concluded that optimization of health related quality of life is particularly important now that. HIV is a chronic disease with the prospect of long term survival. Co morbid psychiatric conditions may serve as markers for impaired functioning and well being in persons with HIV.

To explore whether there were differences on health – related quality of life variables between 73 person aged above 50 and 640 persons below 50 years old in a national sample reported that older participants reported significantly more medical conditions such as diabetes or hypertension, more limitations in physical functioning and self- disclosure of HIV- infection to fewer people. There were no significant differences on any of the other variables. There were relatively few differences in older as compared
to younger persons living with HIV/AIDS, yet mortality rates were higher in older samples.

A study conducted by Benedict, (2000) examined the impact of neuropsychological (NP) impairment on activities of daily living (ADLs) and quality of life in human immunodeficiency virus Type-1 (HIV-1) infected persons of low socioeconomic status (SES). Thirty nine out patients (mean age 39 years) were stratified into three impaired groups thirteen who were cognitively normal, 15 with mild of three cognitive impairment and 11 with moderate/severe impairment. Quality of life was assessed with the sickness impact profile and ADLs were evaluated via structured interview performed at the patient's residence, while there were no significant differences across groups on disease stage, drug use, depression or estimated premorbid IQ. cognitively impaired patients were more likely to be unemployed and failed in social planning and medication management tasks.

The study confirmed a previously reported association between neuropsychological impairment and unemployment among HIV-1 infected patients. The data also extends this relationship to a low SES sample with a high base rate of unemployment and to instrumental activities of daily living other than work.

Flannelly, (2001) tested three hypotheses about the quality of life of individuals who are HIV positive. It was hypothesized that quality of life among HIV+ individuals would be directly related to their (1) health status (2) religious affiliation and (3) religious faith. A co relational design was used with a non-random sample of 40 subjects 32 males and 8 females, (aged 25-54 years) who were HIV+. Bivariate analysis was done to obtain intercorrelations among several independent variables, including two measures of religion (religious affiliation and a composite measure of religious faith) number of symptoms, level of physical functioning and various demographic measures, including SES. Stepwise regression was done and it was found that 4 independent variables made significant, positive contributions to subject scores on the quality of life index (QLI). These were SES, religious affiliation (affiliation vs no affiliation) religious faith and a combined measure of health status based on the subjects number of symptoms and
Karnofsky performance status. The other independent variables (age, ethnicity and gender) did not make significant contributions to the regression model accounted for 2.3% of the variance in the QOL.

Erlin, (2001) assessed quality of life (QOL), coping styles, mood and uncertainty in illness in non-random sample of 46 symptomatic HIV patients (aged 20 to 22 yrs) living in Hong-Kong. QOL was moderate and the main concerns were related to the environmental effects of QOL, spirituality and social relationships. Considerable mood disturbance was demonstrated, especially with regard to depression, fatigue and tension/anxiety. High level of uncertainty in illness was also reported. A median split of the uncertainty was related to lower levels of overall QOL, higher psychological dysfunction, worse adjustment with the environment and higher mood disturbances. Subjects predominantly used internal coping, which also correlated well with higher QOL scores. Through regression analysis, it was shown that QOL could be predicted with the combined effects of uncertainty in illness and fatigue.

Burgoyne, (2001) conducted a study which examined health related quality of life (QOL) of 113 adult people (aged 18-61 years) living with HIV/AIDS (People Living with HIV/AIDS) attending an outpatient hospital clinic. They were assessed upon initial registration using the medical outreach study SF-36. QOL ratings on both physical functioning and psychological well being aspects of the SF-36 were lower than for the general population, especially among PLHA in the sample who were symptomatic or from whom AIDS has developed. Although not compromised in terms of physical functioning, asymptomatic PHA had well being QOL scores comparable to other chronic medical conditions. In general demographic, social and many of the health and immune status variables examined were not significantly related to QOL. PHA in the symptomatic AIDS patients on few QOL dimensions. Mean QOL ratings did not significantly differ between AIDS patients and those with symptomatic (Non-AIDS) infection. These findings suggest that becoming symptomatic has a significant impact on a majority of dimension.
Eller, (2001) investigated the effects of selected variables on quality of life (QOL) in persons living with HIV. A sample of 81 HIV positive adults (aged 20-76 years) completed a demographic questionnaire, the sickness impact profile, the centre for epidemiologic studies depression scale and a fatigue visual analogy scale. Blood samples were collected for CD4+ and CD8+ Lymphocyte numbers. Based on an expanded psychoneurotic immunology model, hierarchical multiple regression analysis was used to determine the extent to which 4 blocks of variables predicted variance in QOL. These included sociodemographics, depression, immune status and fatigue. Findings revealed that work status, depression and fatigue predicted 58% of the variance in QOL in person with HIV. Findings support the need for routine assessment and management of depression and fatigue in person living with HIV.

Demmer, (2001) examined quality of life concerns among HIV-infected individuals and assessed their perception of AIDS and the need for safer sex. A sample of 196 HIV-infected individuals (aged 26-70 years) completed questionnaire concerning demographic characteristics, quality of life, AIDS severity and the importance of safer sex practices, 75% of subject were receiving protease inhibitor combination therapies. Results revealed that subjects reported a high level of life satisfaction and trust in their medical service providers. Primary concerns included health and financial worries. A significant minority of subjects indicated reduced concern about AIDS and the need for continued safer sex practices. Subjects with greater quality of life concerns were more likely to believe that AIDS was less severe now and that safer sex was of less importance.

Zaidi, (2002) explained that the 10 item HIV treatment satisfaction questionnaire (HIVTSQ) was validated amongst 150 HIV-1 seropositive individuals (134 men and 16 women aged 21 to 62 years), receiving 1 of 2 protease inhibitors as part of combined therapy in an open-label randomized trial. It was hypothesized that satisfaction with control would be greater than with the control treatment. The HIVTSQ showed construct validity; viral load correlated negatively with satisfaction with side effects. The HIVTSQ was sensitive to differences between groups. Compared with subjects in the control group, those receiving the new treatment had significantly, higher perceived flexibility.
and life style /ease scores at week 8. Patient perceptions did not simply mirror clinical measures, highlighting the importance of measuring patient views.

To estimate the associations between measures of oral and generic health related quality of life in persons receiving medical care for HIV planned a study in which physical and mental health were assessed using 28 items in 2,864 HIV infected patients (70% males and 30% females aged 18-77 yrs) oral health was assessed using 7 items on oral – related pain and discomfort, worry appearance and function clinical measures included CD4 count, oral symptoms, physical symptoms and stage of HIV. Physical functioning and emotional well being were measured on a 0-100 scale with higher scores indicating better health. In multivariate analyses, oral symptoms had the strongest association with oral health related quality of life.

Each additional oral symptom was associated with both physical and mental health. It was found that one point increase in oral health was associated with .05 point increase in mental health and .02 point increases in physical health. It was concluded that oral health is strongly associated with physical and mental health but provides noteworthy unique information in person with HIV infection. Thus physical and mental health measures of HIV patients should incorporate indicators of oral functioning and well being.

Lanfer, (1998) examined the reliability and validity of the Euro QOL (EQ – 5D) and MOS-HIV and their responsiveness to HIV- related clinical events. A sample of 990 subjects (931 males and 59 females mean age 38.5 years) with advanced HIV disease were enrolled in a randomized trial. The EQ-5D includes a weighted sum of five domains (EQ-5D index) and a visual analogy scale (EQ -VAS). The MOS- HIV has 10 subscales and physical (PHS) and mental health summary scores (MHS). Construct validity of the EQ -5D was tested based on hypothesized relationships to subscales of the MOS- HIV. Relative precision and responsiveness to adverse experiences was highest for MOS –HIV. In these patients with advanced HIV disease, EQ – 5D showed good construct validity but there may be a ceiling effect for its EQ -5D index component. EQ -5D was less responsive to adverse events than the MOS –HIV; however, the EQ -5D was most
sensitive to developing an opportunistic infection and is likely to be a useful measure of HRQOL for generating QALXS in cost–utility studies involving patients with advanced HIV disease.

The study conducted by Blalock, (2002) explained the need to address the role of employment in the psychosocial adjustment of person with HIV/AIDS. 200 volunteer HIV/AIDS patients (75% male aged 22-63 yrs) completed questionnaire assessing medical and vocational histories and quality of life scales and unemployed participants did not significantly differ in terms of gender, education level, ethnicity, prevalence of diagnosed psychiatric functioning. However when HIV illness severity statistically controlled, employed participants reported significantly higher quality of life.

A study conducted by Vosvick, (2003) examined factors associated with four dimensions of functional quality of life (physical functioning, energy, fatigue, social functioning and role functioning) in 142 men and women (aged 21 – 59 years) living with HIV/AIDS. Participants completed the brief cope inventory and the medical outcomes measure. Finding revealed that greater use of maladaptive coping strategies was associated with lower levels of energy and social functioning. Pain severe enough to interfere with daily living tasks was associated with a lower functional quality of life on all four quality of life dimensions. It was concluded that interventions aimed at developing adaptive coping strategies and improving pain management may improve functional aspects of quality of life in person living with HIV/AIDS.

In order to explore the factors affecting quality of life among HIV patients; Heckman, (2003) conducted a study. The theories suggested that satisfaction in persons living with a chronic illness such as HIV disease is a function of illness-related discrimination, barriers to health care and social services, physical well being, social support and coping. The CTQOL model was evaluated using data from 275 persons living with HIV disease. Women reported less life satisfaction and confronted more barriers to health care and social services than men and white participants reported higher perceptions of AIDS related discrimination than non-white participants. The CTQOL model provided an excellent fit to study data and accounted for almost a third of the
variance in life satisfaction scores. Barriers to health care and social services played a particularly prominent role in the model.

Chandra, (2003) examined the relationship between HIV related disclosure and quality of life (QOL) anxiety and depression among HIV – infected subjects in South India. 68 subjects (35 men and 33 women) were assessed for QOL and psychological morbidity using WHO QOL – BREF and the hospital anxiety and depression scale (HADS). Details of disclosure were collected using a semi structured interview. Certain disclosure related variables appear to be related significantly with QOL among HIV-infected persons. A positive outcome related to disclosure and extent to which a subject felt the need to disclose were significantly associated with higher scores on the total QOL measure and in the social and environmental domains of the WHOQOL-BREF.

No relationship was found between disclosure related variables and psychological morbidity of other domain of QOL. The type of disclosure (voluntary / without consent) did not appear to influence QOL in this sample. Disclosure related variables may have an important influence on QOL in the context of HIV infection in India.

A study conducted by Lecher, (2003) examined treatment effects on total QOL and 11QOL domains from baseline to post intervention follow up. Subject were assessed at baseline randomized to a treatment condition for ten weeks, (IP, number 180, CBSM +, number 150) and assessed with 4 weeks. Post intervention quality of life was measured using the medical outcomes study HIV-30 QOL scores increased over the course of both interventions for the total QOL score and 3QOL domains: cognitive functioning, health QOL, women in the IP condition did not change. No changes were observed for energy/fatigue, health transition single item overall QOL, pain, physical well being role functioning or social functioning in either condition. Results suggested that group based CBSM+ and CBSM + may be particularly effective at increasing QOL related to mental health in women with AIDS.

Weaver, (2004) examined the relationship between three HIV specific coping strategies (cognitive coping strategies, denial and religious coping) and quality of life (QOL) in 90 HIV+ predominately minority women on highly active antiretroviral
therapy. Religious coping was unrelated to QOL; however, use of cognitive coping strategies was related to greater QOL and denial was related to poorer QOL. Results suggested that utilization of certain coping strategies may lessen or increase perceptions of life stressfulness thereby including QOL in this understudied population.

The studies cited above in various section/heading clearly reveal that over the years the researchers at global level have taken up the issue of HIV/AIDS and associated problems. These will definitely help in research, policy planners, the health professionals, the HIV/AIDS patients and the public at large in understanding the problems and the associated consequences. It is clear from the review that one of the major problems faced by these patients and their family is the ‘Stigma’. Studies also revealed that depression and anxiety are also major problems of these cases and their caregivers.

After few month or years the immunity gives in and general problems/illnesses started setting in and the general health and quality of life gets deteriorated. The problems of perceived burden of caregivers is also a major problem and it also affect the psychosocial state of the patient and the caregivers. Through, studies relating to the anxiety, depression and quality of life of HIV/AIDS patients have been conducted in almost all parts of the world, yet there is a dearth of comprehensive studies taking the psychosocial and their caregivers.

**Counselling and HIV/AIDS**

HIV/AIDS is often associated with a range of psychosocial squeal that must be addressed throughout all stages of the infection. Psychological support is therefore critical for helping individuals, couples, and families affected by HIV to cope with their emotions and psychosocial needs. Very often the counselling component of counselling and testing interventions is minimized and greater emphasis is given to the need for an HIV test and the provision of test results. These are often difficult to measure objectively. The long term psychological needs of persons with HIV/AIDS are often overshadowed by physical and social needs in a setting with limited resources and are often ignored. Development of counselling in relation to HIV/AIDS has occurred in hospital settings in communities as a response to psychosocial needs generated by individuals with
HIV/AIDS and their families. Several authors have noted cultural issues that may have impact on counselling in relation to HIV/AIDS, including the importance of the economic and emotional aspects of sexual relationships, the strong cultural links between women’s status and childbearing and fatalistic acceptance of misfortune (NACO, 2006) described a counselling approach with a strong education component where complex issues were simplified to content that could be understood; this is an important factor in encouraging persons with HIV and communities to take a proactive approach in decreasing the spread of HIV/AIDS. Empirical data support the need for client-centered counselling in the African setting.

Provision of factual information needs to be balanced with a person-centered approach; exploring the clients conception of the problem and helping the client identify persons in their network who can give further psychosocial support (Leplegec, 1997).

Evidence indicates that a comprehensive community-based and culturally sensitive approach towards care of persons with HIV can increase community acceptance of these individuals and improve disclosure, with a large proportion of persons with HIV being able to move beyond sero-positivity to planning for the future. The initial counselling and assessment given to newly diagnosed patients is of paramount importance. The objective of the intake assessment is to understand the needs and current functioning in each aspect of life, such as occupational functioning, social functioning, and source of supports. On the basis of his study reported that eighty seven percent of interviewees had received some pre-test counselling and 78% post-test counselling. The vast majority found the pre-test counselling to be either very helpful (71.7%) or somewhat helpful (13.4%), while 78.1% found the post-test counselling to be very helpful and 10.7% found it to be somewhat helpful in coping with their positive diagnosis.

Patton and Coffey, (2006) administered Beck depression inventory and anxiety rating scale to 50 AIDS patients (34 males and 16 females) selected through purposive sampling from ART centre of, PMCH, Patna. The measure of anxiety and depression were administered twice i.e. before the counselling and after the counselling. It was found
that there was a significant reduction in depression and anxiety after counselling. It was suggested that in the area of crises, counselling is the only solution to prevent and reduce psychological and psychosocial stress of AIDS patients. Counselling also helps to cope with the trauma of the disease and also on able them to lead a normal life through better communication with family members and society.

In one study by Rotherman, (2001) examined the effects of a cognitive behavioral intervention aimed at improving quality of life (QOL) in young people living with HIV who completed the being together modular of a three part intervention. Subjects completed interviews and were assessed prior to and following completion of the module regarding QOL and coping styles. Results revealed that subjects receiving immediate intervention training were significantly less emotionally distressed than were control subjects.

Subjects who attended the intervention showed decreasing emotional distress even when controlling for HIV symptomatology. It was concluded that the being together module reduces emotional distress for these patients.

Elen, (2001) explored the use of life review in a sample of 20 people living with AIDS (PLHA) through a randomized controlled trial of its effectiveness in decreasing depressive symptoms and in increasing self esteem, quality of life and purpose in life. Compared to the control group the treatment group (80 % male, mean age 43.7 years.) had an improved overall quality of life and self esteem over 12 months, less depressive symptoms over twelve months, and a greater purpose in life at three months. Mainly small to medium effects were observed. The findings from this feasibility study suggest the potential value of life review to enhance quality of life, purpose in life and self esteem and to decrease depressive symptoms in PLWA.

In order to find the effects of a 16 week exercise intervention on several aspects of psychological and physical well being in a sample of HIV I positive individuals, Rajas, (2003) conducted a well thought study. An exercise group (N-19) was compared with a control group (N-14) prior to and following the intervention on several outcome variables, including health related quality of life, psychological well being (depression,
anxiety, global symptoms) immune parameters and cardiopulmonary parameters, the exercise group experienced a significant improvement in cardiopulmonary fitness and health related quality of life improved significantly in that group relative to control group. However, while immune indices did not change in either group consistent with earlier studies. It was suggested that a moderate exercise intervention enhanced the health related quality of life in HIV I positive individuals.

The study of Malassiotis, (2001) examined the impact of counselling provided for HIV-infected women in Zimbabwe. Qualitative research was used for data collection. In total 44 women were included most of them were members of an HIV support group. Doctors and nurses play an important role in the first counselling session, because tests to diagnose HIV-infection are done in the hospital. Interviewed women mention slow disclosure of status as the most comforting way to hear the news.

The HIV-infected women experience strong emotions directly after diagnosis. Counselling at this moment is of major importance to reduce fear and can prevent suicide. Women should be prevented from discovering their status on their own. Counselling given once is found not to be effective. First, if only one counselling session is given, the women may not hear or remember all that is said. Second, in case of depression, access to counselling is important and it appears that periods of depression return frequently. Support groups play an important role in providing this continuous counselling.

UNAIDS, (2006) investigated the HIV counselling and care programmes at the district level in Ghana. Patients require not only medical care, but often economic support and counselling for themselves and their families it was recommended that psychosocial support should be provided at the hospital and in the home, the latter often being the preferred option. A team approach to HIV disease care and counselling, with careful selection and support of staff, and appropriate training in counselling skills is essential. A primary health care approach at the district level, mobilizing community participation and moral support is necessary.
UNAIDS, (2006) investigated the voluntary counselling and testing for couples which included a high-leverage intervention for HIV/AIDS prevention in sub-Saharan Africa. Most HIV infections in sub-Saharan Africa occurred during heterosexual intercourse between persons in couple relationships. Women who are infected by HIV seropositive partners risk infecting their infants in turn. Despite their salience as social contexts for sexual activity and HIV infection, couple relationships have not been given adequate attention by social/behavioral research in sub-Saharan Africa.

Increasingly studies point to the value of voluntary HIV counselling and testing (VCT) as a HIV prevention tool. Studies in Africa frequently report that VCT is associated with reduced risk behaviors and lower rates of seroconversion among HIV serodiscordant couples. Many of these studies point out that VCT has considerable potential for HIV prevention among other heterosexual couples, and recommend that VCT for couples be practiced more widely in Africa. However, follow-up in the area of VCT for couples has been extremely limited.

Thus, current understandings from social/behavioral research on how couples in sub-Saharan Africa manage HIV risks as well as HIV prevention interventions to support couples’ HIV prevention efforts have remained underdeveloped. It appears that important opportunities are being missed for preventing HIV infection, be it by heterosexual transmission or mother-to-child HIV transmission by mothers who have been infected by their partners. Based on an overview of documentation on VCT in sub-Saharan Africa, this study proposed that increased attention to couples-focused VCT provides a high-leverage HIV prevention intervention for African countries. The second half of the study indicated areas where VCT needs to be strengthened, particularly with respect to couples. It also identified areas where applied social/behavioral research is needed to improve knowledge about how couples in sub-Saharan Africa deal with the risks of HIV infection.

NACO, (2006) examined the impact of counselling on management of tuberculosis in HIV/AIDS patients in Mumbai. The study was conducted on 50 patients with tuberculosis and HIV. They prospectively counselled for treatment compliance (Group A) is compared retrospectively with a comparable group where there was no such
emphasis on counselling (Group B). In both the groups wherein the patients were asked to bring the empty packs in the follow-up visit. As an added incentive the patients in both groups were informed that the first visit charges would be reimbursed at the successful completion therapy. Treatment was advised for 1 year. The regimens consist of 4 drugs AAT (HREZ) initially for 2-3 months followed by 2 drug ATT (HR) for 9-10 months. In patients with dissemination 5 drug ATT (HREZ+ SM or Ofloxacin or Ciprofloxacin) initially for 2-3 months, then 4 drug ATT (HREZ) for 1-2 month, then 2 drugs (HR) for 7-9 months.

Results of the study revealed that in Group A, 37 patients completed 1 year of treatment, 5 patients completed 8-9 months of treatment, 2 patients completed up to 6-7 months only of treatment, 3 patients after 1-2 months stopped due to drugs side-effects, 1 patient died in first month and 2 patients had relapse. In Group B, 20 patients completed 1 year of treatment, 10 patients completed 8-9 months of treatment, 5 patients completed 6 months only of treatment, 7 patients 1-2 months only stopped due to side-effects of drugs, 3 patients died in first month and 5 patients had relapse.

The study showed that counselling plays an important role in management of opportunistic infections especially tuberculosis, improves compliance of the treatment regimens and can therefore decrease rate of morbidity, mortality and relapse.

The effect of brief safer-sex counselling by medical providers to HIV-1 seropositive patients: a multi-clinic assessment by Richardson. This study was conducted on 585 HIV-positive persons, sexually active prior to enrolment. It was found that participants who had two or more sex partners at baseline, UAV was reduced 38% (P < 0.001) among those who received the loss-frame intervention. UAV at follow-up was significantly lower in the loss-frame arm [odds ratio (OR), 0.42; 95% confidence interval (CI), 0.19-0.91; P = 0.03] compared with the control arm. Using generalized estimating equations (GEE) to adjust for clustering did not change the conclusions (OR, 0.34; 95% CI, 0.24-0.49; P = 0.0001). Similar results were obtained in participants with casual partners at baseline. No effects were seen in participants with only one partner or only a main partner at baseline. No significant changes were seen in the gain-frame arm. Brief
provider counselling emphasizing the negative consequences of unsafe sex can reduce HIV transmission behaviors in HIV-positive patients presenting with risky behavioral profiles.

NACO, (2006) examined the couple-centred testing and counselling for HIV serodiscordant heterosexual couples in sub-Saharan Africa, in a large proportion of HIV infections occur within stable relationships, either because of prior infection of one of the partners or because of infidelity. In five African countries at least two-thirds of couples with at least one HIV-positive partner were HIV serodiscordant; in half of them, the woman was the HIV-positive partner.

Hence, there is an urgent need to define strategies to prevent HIV transmission within couple relationships. HIV counselling and testing have largely been organised on an individual and sex-specific basis, for pregnant women in programmes for prevention of mother-to-child transmission of HIV and in STI consultations and recently male circumcision for men. A couple-centred approach to HIV counselling and testing would facilitate communication about HIV status and adoption of preventive behaviors within couples despite positive outcomes, couple-oriented programmes have not been implemented on a large scale. In order to stimulate and strengthen HIV prevention efforts, increased attention is required to promote prevention and testing and counselling for couples in stable relationships.

WHO, (2006) examined the prevalence and predictors of failure to return for HIV post-test counselling (PTC) among adults in rural Kilimanjaro, Tanzania. Following a cross-sectional survey, people aged 15-44 years living in Oria village were interviewed and offered individual HIV-1 pre-test counselling. They were asked to return for PTC two weeks after blood sample collection. HIV-1 testing was accepted by 1491 (97.6%) of participants with 98.9% expressing desire to know their results. The proportion of individuals who did not return for PTC was 50.9%. These proportions did not differ by sex. Seropositive HIV result (AOR: 2.2; 95%CI: 1.3-4.3 for women and AOR: 2.1, 95%CI: 1.2-5.7 for men), low HIV/AIDS-transmission and ART availability knowledge, perceived low risk of HIV infection, not accepting to share results (men only) and
inability to self-prevent HIV infection (women only) predicted failure to return for PTC. Additionally, participants were more likely not to return for PTC if they had no-formal education or reported recent sexual-risk behaviors, for both sexes. Age, prior HIV testing or AIDS-related clinical symptoms were not associated with return for PTC in this population. These findings suggest that low returns for PTC, especially for HIV-seropositive individuals, result in a substantial missed opportunity for prevention and care. Knowledge of ART accessibility is necessary but not sufficient to promote adequate return for PTC.

The high attendance for pre-test counselling should be utilized to identify potential individuals who may not return for PTC and to promote risk reduction and care. Diana, (2010) addressed the factors that played a role in the limited but effective implementation of provider-initiated HIV counselling in tuberculosis (TB) clinics in the Eastern Cape Province, South Africa, as part of a clinical trial.

The Eastern Cape is a region with some of the highest TB and HIV rates in the world. The parent study was a pragmatic, cluster-randomized trial designed to measure the impact of provider-initiated (“opt-out”) counselling on the uptake of HIV counselling and testing in newly registered TB patients. Key informants were interviewed and clinic nurses who participated in the study were invited to participate in focus group discussions (FGDs). Thematic content analysis of transcriptions was conducted on data collected during interviews and FGDs. Three major themes regarding nurse experiences were derived from analysis, indicating that multiple structural and personal factors influence the success of provider-initiated HIV counselling of TB patients in primary care settings: (1) chronic frustration with knowing what TB tasks need to be accomplished but not having the resources, including staff, to accomplish them; (2) conflict between the appreciation of the need and importance of HIV counselling and testing and the health system’s recognition of their difficulties implementing it; and (3) ambivalence in their roles as care providers and educators in the context of HIV counselling and testing. Innovative and coordinated strategies are needed in this environment to facilitate greater number of patients receiving HIV counselling and testing services.
PROBLEM, OBJECTIVES AND HYPOTHESES

Review of the literature and the conceptual framework clearly highlight that in general there are very few studies relating to the psychosocial effects of HIV/AIDS. Further, there was a relative paucity of studies relating to the impact of the counselling on HIV positive and AIDS patients and their care givers. Present study, was designed to assess the psychosocial problems of HIV/AIDS patients and their caregivers. Further it was also intended to examine the effect of counselling on psychosocial problems of HIV/AIDS patients and their caregivers. The problem of study is "IMPACT OF COUNSELLING ON PSYCHOSOCIAL PROBLEMS OF HIV/AIDS PATIENTS AND THEIR CAREGIVERS". The specific objectives of the study were as follows:

OBJECTIVES

1. To assess and compare depression and suicidal ideation among HIV negative, positive and AIDS cases.

2. To assess and compare depression and suicidal ideation amongst caregivers of HIV negative, HIV positive and AIDS cases.

3. To assess and compare the perceived family burden in HIV negative, HIV positive and AIDS cases.

4. To assess and compare the perceived family burden in the caregivers of HIV negative, HIV positive and AIDS cases.

5. To assess and compare the health and quality of life of HIV negative, HIV positive and AIDS cases.

6. To assess and compare the health and quality of life of caregivers of HIV negative, HIV positive and AIDS cases.

7. To assess and compare the impact of counselling on depression, suicidal ideation, family burden, health and quality of life in HIV positive and AIDS cases.
8. To assess and compare the impact of counselling on depression, suicidal ideation, family burden, health and quality of life in caregivers of HIV positive and AIDS cases.

HYPOTHESES

To achieve the objective of the study the following hypothesis were formulated.

1. HIV negative, positive and AIDS cases would differ in terms of depression and suicidal ideation.

2. Caregivers of HIV negative, positive and AIDS cases would differ in terms of depression and suicidal ideation.

3. HIV negative, positive and AIDS cases would differ in terms of perceived family burden.

4. Caregivers of HIV negative, positive and AIDS cases would differ in terms of perceived family burden.

5. HIV negative, positive and AIDS cases would differ in terms of health and quality of life.

6. Caregivers of HIV negative, positive and AIDS cases would differ in terms of health and quality of life.

7. Counselling would have significant impact on the criterion variables in HIV positive and AIDS cases.

8. Counselling would have significant impact on the criterion variables in caregivers of HIV positive and AIDS cases.