CHAPTER II

REVIEW OF LITERATURE

INTRODUCTION: -

Researchers almost never conduct a study in an intellectual vacuum, their studies are undertaken within the context of an existing knowledge base. The term literature review, is used in two ways by the research community. The first refers to the activities involved in identifying and searching for information on a topic and developing a comprehensive picture of the state of knowledge on that topic. The term is also used to designate a written summary of the state of act on a research problem.

Review of literature in this study is focused on the following areas:

- 1. Children
- 2. Families
- 3. Nurse's role

Children: - HIV infection related: -

Children worldwide are affected by HIV and AIDS either because they are infected with the virus themselves or because their father, mother their sibling has HIV infection. At end of the 2000, it is estimated that nearly 3.7million Indians are infected with HIV, of these nearly 1.6 lakh are children.

Lesar, Sharon et al (1997) The author studies the effect of HIV infection on the family system reported by 48 caregivers of HIV exposed children. Respondents completed the impact on family scale (IFS), during their participation in the study. Results showed that the psychological burden on the illness was significantly related to the child's status, financial burden, social / familial impact, and psychological burden of the illness was significantly related to the caregivers' HIV status. And the impact of HIV infection differed as a function of the caregivers relationship.

Barbara J. Turner, et al (2001) This study was conducted to examine the association of clinical complications and age at diagnosis with survival for a cohort of child and adult with AIDS. This study was conducted between 1985-1990 in New York State with 784 children 5,584 adults with AIDS. The results indicated that there were significant difference in the association of clinical complications among children when compared to adults with AIDS.

Rodriquez. B, Steal-Duncan J.C, et al, (2004), This study contributes to the face of continuing pandemic of HIV/AIDS. The burden of the disease is now the highest in the resource- poor developing world. The Joint United Nations Programme on HIV/AIDS (UNAIDS) has tested the prevalence rate for the Caribbean, as second only to Sub-Saharan Africa. The aim of the study is to document the socio-demographic characteristics of pediatric and perinatal HIV/AIDS in Kingston, Jamaica.

A Cohort study design was adopted for this study of HIV-infected women, who were identified in the maternity centers, Kingston. Infants and children identified after delivery, whether HIV-exposed or infected were also enclosed as the retrospective group. 239 children, were included in the study. 78 children were in the prospective group and 161; children were in the retrospective group. Among the retrospective group 68% were classified as infected, for the prospective group the patients were recruited within 24 hours of birth in 98.7% of cases, median age of the mothers was 27 years and that of the fathers was 33 years. There were 7 teen-age mothers, 26% of the children were in institutional care. Family size ranged from 1-9 children with the median of two children. Majority of them had

unskilled and semi-skilled jobs. The conclusion indicates an urgent intervention to stem the epidemic.

Vallor and A.H. Hough. E. et al (2005), The current study explored the impact of HIV diseases on mothers as they face the task of balancing their own physical and psychological needs, with the needs of their families as well as the additional burden of deciding whether to disclose their HIV status to their children. Qualitative interviews were conducted with 35 women and 19 children (10-18 years) of age. The mothers were interviewed regarding their experience as a HIV positive mother and issues regarding disclosure, and the children were also interviewed regarding their experience of having a mother who is HIV- positive and issues regarding disclosure. The decision to disclose was dependent on the child's developmental level. The degree of the mother's illness and sometimes from the mothers, when someone else discloses their HIV status to their children, honest aspects of disclosure from the mother-child dyads included open honest communication, and closed relationship between mother's and their children. Common negative themes emanating from the

data included fear, uncertainty, forced secrecy, for fear being ostracized based on the stigma associated with the disease. Behavioural changes in children and shifting responsibilities between the mother and the child.

Findings includes that disclosure is a vital issue with different perspectives. The process and the effects of disclosure has a great impact on the mothers' HIV status. Implications calls for further research.

Villimor. E. Miscgades, (2005), The aim of this study was to examine the impact of child HIV infection on mortality and to identify nutritional and socio-demographic factors that increases the risk of child mortality, independent of human immuno deficiency virus (HIV) infection. This prospective study was conducted at Dar-es -Salaam, Tanzania, among 687 children, 6-60 months of age who were admitted to the hospital with pneumonia after discharge, children were followed up by every two weeks, during the first year and every 4 months. Thereafter. HIV status and socio-economic characteristics were estimated, nutritional status variables were examined. The results revealed the mean age of enrolment was 18 months. A total of 90 children was studied during, an average of 24 months

of follow-up. HIV-infection was associated with 4-fold higher risk of mortality and is a strong predictor of deaths, among children who have been hospitalized with pneumonia undernutrition, anaemia, contributes significantly to infant and child mortality, independent of HIV infection.

Wieku Rozwo, This study was aimed to describe the process of disclosing HIV/AIDS problems in the family to children and to explore the possible determinants. The investigations were carried in 37 children aged 4-16 years living in families with HIV/AIDS problem. (25 children were HIV positive and 12 HIV negative and their parents) / care-givers and their children were included in the clinical interview. Observation of child's behaviour in different context was monitored. The findings of the study indicates (3 HIV positive, 3 HIV negative) that the children had been informed about the problem and they could freely talk to the subjects. The important reason as felt by the parents were: -

- 1. By disclosure.
- 2. Depriving the child of a happy childhood.
- 3. Largest number of risk behaviour problems were noted in older children,

4. Infected children were aware of their serious medical problems.

The parents of infected children were in the protocol of secrecy of disclosing HIV/AIDS. The investigator concluded the study, for this disclosure by the parents to the child involved many factors e.g. providing professional, psychological services, of importance in many instances

Molly L, Wozyee, Sophia lee, et al, studied regarding Paediatric AIDS Clinical Trial Group (PACTG) which are responsible for developing and executing drug trials for HIV infected children. A regular protocol is for neuro developmental assessment. These assessments consist of evaluations which monitor cognitive, motor and behavioural development of children on drug trials.

This study is focused on the prevalence of behavioural problems in one specific PACT (protocol 338). At entry, each subject was administered a standardized age appropriate cognitive measurement. Bayley, Wise-111, and the Conners Parent Rating Scale. The study included 274 subjects who were perinatally HIV infected and were aged 24 between months- 17 years (Mean age 7.2 years). The results of this study revealed that 20% of the children were identified as having ADHD. These children had lower score.

The outcome of the study suggests that children with HIV infection were at higher risk for behavioural and learning problems. This study did not have a matched control group, further analysis included measurements of immune function and viral load.

* Children: - Psychosocial aspects: -

Khan MA, (1992), had conducted a study on two hundred and three multi-transfused children with thalassemia attending the thalassemia clinic of the charak palika Hospital, New Delhi, were screened for human immuno deficiency virus (HIV) antibodies by ELISA test. All positive children (cases) were confirmed by the Western Blot Test. Of the 20 children screened, 17 (83.7%) were sero positive and the other 3 children referred to the AIIMS were from neighboring states. These children were compared with similar 20 age matched HIV negative thalassemics as controls. Of the 20 HIV positive children, four were diagnosed to have clinical AIDS according to W.H.O. criteria.

The clinical features were similar to those described in paediatric AIDS, from other parts of the world. This study describes the clinical features,

behavioural problems, cognitive function and developmental milestones of children with AIDS.

Gamble et al (1996), This study had focused on three charts and one diagram related to: -

Multiple losses

Isolation and lack of social support

Destructive coping behaviours

Problems identifying and maintaining new custodial placements (1993; Hudis 1995). This accords with studies showing the bereaved adolescents are more likely than their peers to be emotionally distressed to experience behaviour problems and impaired social relationships and to engage in risk taking practices (Weller & Weller 1991); (Harris 1991); (Dane and Miller 1992); (Irwin & Millstein 1991) based on analogous situations such as the impact of parental loss from cancer, it is apparent that "Meeting the children's basic physical and emotional needs is a precondition to their mourning. If these needs are unmet, mourning may be inhibited because anxiety leads them to deny the loss" (Siegel & Gorey 1994). Intervention

is essential to lessen the risk for serious medical, behavioural, developmental and learning problems and to reduce the intergenerational patterns of risk taking that may have lead to the parents contracting HIV. Unless a supportive and stable environment is created to improve short-term, and long-term mental health outcomes in orphaned children, a variable custody plan may not endure.

The family center developed two distinct service models to aid the formation, of permanency plans, project talk, user cognitive-behaviour techniques in group sessions with parents who have HIV disease and their teenage children; aged 12 to 18 years. The second model, project care, employs a psycho-educational approach to counseling infected mothers and their children in their homes. The decision to develop two different service models reflects a dual understanding, first because the challenges posed by children is likely, to be orphaned by the HIV disease of their parents have only recognized in the past few years. Information about how best to serve this population is sparse, and pilot projects that take different approaches must be implemented and evaluated.

Mary-lane, Rotheram-Borus, Barbara Hermie Draimin, et al: -

The objective of the study was to describe the disclosure and custody planning of parents living with AIDS and the impact of these on their adolescent's adjustment. Associating multiple-behaviour problems in children and the disclosure and custody plans of their parents living with AIDS. Results has shown the following: - Both mothers (87%) and fathers were significantly more likely to disclose their HIV sero-status to adolescents (73%) compared with younger children (23%) only 44% disclosed their illness to all their children; whereas (11%) disclosed to none. Most parents (80%) living with AIDS had discussed their custody plans, only 30% initiated legal plans typically for younger children. Adolescents, who were informed of their parent's sero-status, had been engaged in more sexual risk acts, smoked more cigarettes and reported more severe substance use and greater emotional distress than uninformed adolescents. Legal custody arrangements were not associated with adolescents' adjustment at follow-up.

Children: - Education related to HIV: -

Attaswell, Kathy et al, (1997), This paper briefs on caring for children aged from birth to 5 years with AIDS. This was intended primarily for health workers in developing countries, who are responsible for the management of young children with HIV and AIDS. It provides practical information on: -

- ❖ How HIV is transmitted to infants and young children?
- How transmission can be prevented?
- ❖ How to diagnose HIV and AIDS in children?
- ❖ How to care for children who are not affected by HIV?
- ❖ HIV and AIDS in children affects health workers and caregivers.
- ❖ Other important issues related to HIV / AIDS among children that health workers need to be aware of: includes community support, orphans, sexual abuse and HIV testing and counseling.

Bachu-Theodore-pomeroy et al, (1999), A study was conducted to find the developments in, psycho- educational group intervention provided for children with HIV/AIDS. Information about HIV/AIDS were combined with play therapy technologies, so that the children would benefit

cognitively and emotionally from the intervention. Data were collected from 5 children between the age 9 and 12 years, who were in 'Hug-me' programme, (a federally funded project that provides medical and psychosocial services to HIV/AIDS children and their families). Findings revealed that caregivers were satisfied with the service provided. It was also noted that the children appeared to have a better understanding of their illness as well as their positions/ dispositions in their daily life, in addition, they liked being in the group and wanted to know when the next one was starting again.

Catherine M. Wilfort et al, (2000), This study is related to the treatment offered for human immuno deficiency virus (HIV) infection. Which has enabled more children and youths to attend school and to participate in other chronic illness. These children and youths with HIV infection should receive the same education, including home instruction as those of other children, to provide continuity of education. Confidentiality about the HIV infection status should be maintained with parental consent required for disclosure of their diagnosis.

Jones. S.G. Silitsky. C, et al, (2004), This qualitative study was conducted among the culturally diverse mothers to know their experience, of communicating to their children about HIV/AIDS. The information was collected when they had participated in a nationally renowned prevention and education programme, which illuminated some of the challenges and surprises these women encountered. This study included qualitative data analysis with implications for the future.

Psychosocial and physiologic correlation of perceived health among HIV- infected women, helps to identify factors related to the perception of physical health in a cohort of HIV- infected women. A descriptive correlation design was used to identify factors influencing perceived physical health, in a sample of 275 HIV -infected women who were predominantly single African-American women with an income of less then \$ 10,000 per year. Using Spearman's rho, statistically significant positive correlations (p<0.03) were found between perceived physical health and T- helper cell count, hope, present life, satisfaction, education and income. Likewise, significant positive correlations (P<. 05) were observed between perceived physical health and HIV- related symptoms,

stage of illness, depression, physical and sexual violence experience. The findings support the need to address the psychosocial as well as physiologic factors associated with HIV/AIDS in developing comprehensive plans of nursing care, which includes positive coping strategies for managing the illness.

Psychosocial aspect of certain fundamental families with a child with HIV infection includes: - the presence of the family of a young child with AIDS, with the exception, of small number of transfusion-infected children, implies the presence of infected adults, usually the mother. The problem in such a situation is not just that of a child with fatal illness, but that of an entire family. The study included a sample of thirty natural caregivers. They were mostly mothers and others responsible for the care of sero positive child, such as fathers, aunts and grandmothers. The aim of this study was to describe perceptions of their own psycho-social needs. The results revealed that these caregivers were economically backward. They did not know how to cope with stress and life situations, they are not ready to confide in others because of social stigma associated with this illness. Moreover, they did not see the need to protect themselves and other

members of the family against both HIV and other infections and to know the course and the treatment associated with these diseases.

Goodwin, Kozlalova. et al, (2004), The objective of this study was to determine high-risk sexual behaviours and drug abuse and knowledge about HIV transmission, among adolescents in countries like Russia, Georgia, and Ukraine. Semi-structured interviews on sexual behaviour and structured inventories assessing their knowledge of HIV transmission, sexual behaviour, drug abuse and social representation of the epidemic were collected. It was found that shelter children were more prone than school children to have sex, and injected drugs. Whereas, Georgian school children were exposed to sex and the injection of drugs. Thus the particular groups (Russian and Ukrainian shelter children, Georgian school children) urgently need education about the risk of HIV/AIDS.

2.Families: - psychosocial aspects: -

Disclosure of either the parents or the children's HIV diagnosis to a child is a controversial and emotionally laden issue. The initial reaction of many adults upon learning their own, or of a family member's HIV diagnosis is that, the diagnosis must be kept as a closely guarded secret.

Elizabeth Ngugi, (1988), This study enlightens on counseling which is an important part of the process of preventing the spread of AIDS and treating those who have been tested positive with the disease. Counselors, who care, recommend behaviour that will help the clients avoid 'getting AIDS' and tell the patients when they are tested positive for AIDS, to help them to cope with their depressing prognosis, AIDS counseling is provided.

According to a study conducted by the ANA (Paediatrics) Paris on Psychosocial problem posed by families having been infected with the HIV virus and are with AIDS (1989), Since the first case of infantile AIDS, it has been noticed that the status of the severely ill child and his or her family are forced to changes. When faced a situation "to hide their children's disease and to bear the tragic burden of emotional and social, shameful" due to the disease transmitted by the mother to her child during pregnancy. Parents feel compelled isolation. This fatal and untreatable

disease occurring as a result of an unconventional lifestyle, is responsible for progressive neurologic deterioration. And makes the child unrecognizable further, sleep and feeding disorders make life unbearable. Pediatricians, nurses, social workers, psychologists etc. need specialized training to manage some of these problems, evaluate the family needs. Emotional suffering and feelings of guilt result in highly specific behaviour that must be identified and understood to provide parents with appropriate support.

Williams AD, (1989), This study had concluded that children with HIV infection have highly specialized and psychosocial needs, appropriately applied standards and creative nursing interventions can greatly improve their quality of life.

Magdalene A. Matso et al (1991), The author has conducted a study on the various tools and methods used to assess the outcomes of nursing interventions used in research. Although the reasons for using assessment tools in practice or research differs. The goal of obtaining remains the same, the purpose for which the tool or method was designed is congruent with

the concept to be measured or examined. Results must be reliable and valid. Appropriate methods for gathering data for all accurate and useful information in research and practice must be followed.

Levasseur C, et al (1992), The study documents the factors that influenced the decision of 12 women of child -bearing age whether to have a child in 3 years, following an infection by the human immuno deficiency virus (HIV) 3 of the 12 women were intending to a have child, and their intention stems from their beliefs and positive attitudes towards having a child. Their partner's position influence the absence of their children, their denial of the disease and the absence of the symptoms within their family. For the other 9 women, the factors that influenced their decision not to have a child include the socio-political and economical context; the fact the family is complete; the fact they are sero positive or ill; their fear of transmitting the infection and the idea of losing a child to AIDS.

Hopkins KM, et al, The study describes the model program that uses multidisciplinary team to assess the developmental and psychosocial needs of HIV- infected children and their families. The aim of this program is to assess the needs of the children, in order to provide rehabilitative and psychosocial services, and to improve the quality of life by optimizing developmental functioning. The team includes developmental pediatricians social workers, psychologists, a medical ethicist, physiologist psychoeducational therapist, each of whom perform complete evaluations. A weekly conference results in the formation of an individual family. Some plan for each child and family. 40 children have been evaluated and are in the program, family composition were varied and non-traditional. The disabilities and rehabilitative needs differed as well. The most frequently required services were occupational therapy and psychosocial intervention to increase parental coping skills in handling disabled, chronically ill children. Children with HIV-infection are living longer and will have serious deficits, the need to develop services to address the unique developmental and psychosocial needs of children and families is paramount.

Psychosocial intervention in the process, of AIDS care, This paper describes a model program that assesses a multi-disciplinary team and the development to psychosocial needs of HIV-infected children.

Nunes, John A, Raymond, Susan J. June (1995), The purpose of this study was to examine the relationship between social support and quality of life in individuals with HIV. Using a descriptive, correlational design, data were collected from 50 HIV-positive individuals who were (a) participants in support groups at a behavioural medicine unit, (b) in-patient or respite care patients with HIV, or (c) respondents to advertisements at AIDS service organizations. Instruments used for data collection were the personal resource questionnaire 85-part 2 (Weinert, 1987) measuring the sense of wellbeing in life including the satisfaction with and functioning, socioeconomic, psychological /spiritual, and family. The results of the study indicated that social support was significantly correlated with quality of life (r=0.81, p<0.0001). Further, HIV status (asymptomatic HIV, symptomatic HIV, AIDS) was significantly related to quality of life (p<0.01). However, HIV status was not significantly related to social support. No significant relationship was found between CD4 counts and HIV status, CD4 counts and social support, or CD4 counts and perceived health status, however, CD4 counts were significantly correlated with scores on the quality of life. The findings of the study indicate that social support and quality of life are significantly inter

correlated and that higher CD4 counts are related to quality of life, in this sample of persons living with HIV. Further areas for research include evaluation of quality of life over the span of HIV disease and interventions aimed at enhancing or maintaining quality of life in persons across the spectrum of HIV disease.

Fried et al, (1996) recently reported that quality of life among many HIVinfected persons is "not as bad as might be predicted", supporting assertions that researchers tend to view the life quality of persons living with chronic illness, more negatively than to individuals living with HIV (Loccu and Rapin, 1994). These mixed findings suggest that additional studies are needed to identify factors related to life satisfaction among persons living with HIV/AIDS. The investigator sought to examine relationships between life satisfaction among persons living with HIV/AIDS and functional aspects of well-being, health care related barriers, discrimination, and fear of sero-status discovery, loneliness social support, and illness coping styles. The research was intended to identify issues and domains important for interventions to improve the life satisfaction of persons living with HIV/AIDS.

Philippe Vanthem Emil Tema, et al, (1996), This study has revealed that in the past few years, survival of patients with human immuno-deficiency virus (HIV) has been improved because of the decreased incidence of some opportunistic complications attributable, to prophylactic treatments and anti-retroviral drugs. The impact of these agents should also be reflected in the quality of life. (QOL) of patients. The investigator reviewed the different types of measurements such as Q-TWIST, MOS and the Spitzer score, which seem to be most appropriate for HIV patient's population. Further study can be done for intravenous drug users with HIV, which should be evaluated more often.

III. Sowell R.L. Seals, B.F. Money ham, et al (1997), conducted a study on the Quality of life in patients with immuno deficiency virus infection. Impact of social support, coping style and hopelessness, The Physical and sexual violence scale was used to measure physical and sexual violence, and was taken from the interpersonal violence scale (IVS) an eight-item measuring scale related to verbal, physical and sexual abuse, the IVS was designed to measure (a) verbal abuse, such as being yelled at, humiliated

or made to feel worthless, (b) physical abuse-punched, kicked, tied up, or threatened with a weapon; and (c) sexual abuse, such as being forcel to have sex or perform sexual acts against one's will, higher sexual activities on the PSVS indicated greater physical and sexual violence.

Timothy. G. Heckman, et al, (1997), reports that as AIDS becomes a more chronic but manageable illness, understanding quality of life issues among persons living with this disease has become an important goal of health care researchers. However, most quality of life investigations of persons living with HIV disease have relied heavily on their clinical hospitalized patients, psychiatric samples. e.g. out-patients. The investigator sought to identify psychosocial predictors of general life satisfaction in a community sample of 275 persons living with HIV/AIDS in a large mid-western state. Principal components and multiple regression analysis revealed that improved physical /functional well-being, increased social support, more frequent use of active coping strategies, and fewer incidence of AIDS-related discrimination and stigma, predicted higher levels of general life satisfaction (R2=39). Higher levels of life satisfaction

among persons living with HIV may be produced by implementing intervention strategies.

Chomnad Hanopaibuen et al, (1998), The objective of the study was to assess changes in the family situation of HIV-infected women who had recently given birth. This study was a part of the prospective perinatal HIV transmission. A convenient sample of 129 HIV infected women were enrolled during pregnancy, and were interviewed at 18-24 months of postpartum period. And the answers were compared with baseline information obtained during pregnancy, standardized scale was used to assess the levels of psychological functioning. The findings of the study revealed that women appeared to have high levels of depression and worry. The women's greatest worries were about their children's health and the family's future.

Changes were evident which were manifested by the partner's illness or death, family separation, reduced family income, shifting responsibilities for child care, and signs of depression and isolation providing family support. A major challenge in Thailand is the prenatal HIV epidemic progression.

Diane Franch and Richard P. Wenzel. et al, (1998), This study optimizes heath-related quality of life (HRQL) consideration of HRQL is relevant to the development of new anti-retro viral agents that have significant side-effects. The existing studies had revealed their significance to the scores that do not always align with the disease stage or health index. The study revealed that certain therapies for HIV and opportunistic infections shows significance. The outcome of this study / parameter indicates a major treatment decisions in terms of HRQL, HIV infected patients and in the development and marketing of new pharmaceutical agents in the near future.

Mary Guerita Light Foot et al, (1998), conducted a study on

Human immuno deficiency virus infection among adolescents is a significant and growing problem. It is estimated that of the seventeen million of HIV sero-positive adults in the world, most of them were infected during adolescence. High sero prevalence rates among adolescents in the United States are concentrated geographically in AIDS epicenter e.g LosAngeles, San Francisco and New York City.

III. Money ham, L. Hennessy, M, Sowell, R, Remi et al, (1998),

The effectiveness of coping was measured using HIV coping scale (HCS), a 54-item scale that was developed and tested in a population of HIV-infected women and their families. The HCS was initially tested in 194 and 184 women who completed the scale at two different data points. The findings of the study indicated that the HCS had demonstrated a total scale alpha co-efficient of .90 factor analysis, and revealed seven sub-scales or ways of coping, which included- (1) avoidance coping, (2) using social support, (3) using spiritual activities, (4) managing the illness, (5) focusing on others, (6) information seeking, and, (7) positive thinking.

Mcneil, Kevin,F et al, (1999), The investigator had conducted a study among 596 adults from a moderately sized community in central California and they were divided into four groups, i.e. person with HIV or AIDS; friend or relative; care givers or service providers such persons or members of the general public. They completed a schedule which assessed their perceptions of the importance of 36 items related to potential services for persons with HIV or AIDS. Factor analysis of these items yielded in 6 constructs. e.g. counseling, medical, assistance, home care adjunct, auxiliary and non-

traditional, accounting for 65% of the variance, regardless of group membership, medical services were perceived as of highest importance, but differences were found in all groups regarding assistance services and non-traditional services for persons with AIDS.

E G Bing, et al, (2000), This study examines the effect of HIV status, symptomatology and CD4 + lymphocyte level, health- related quality of life. The medical outcomes of the study reveals, short-form health survey (SF-36) was administered to 2,295 gay men who were enrolled in the multi center AIDS co-hort study (MACS) in 1994. Distinct physical and mental health factors of the SF-36 were found. Sero-positive asymptomatic individuals and sero-positive individuals with CD4+ lymphocyte above 500/mm3 scored well as sero-negative participants, lower scores were obtained on the general health perceptions and physical health. In conclusion HIV positive men who are asymptmatic or have CD4+ lymphocyte above 500/mm3 have similar perceived mental health but worse perceived physical than sero-negative men. HIV positive men who are symptomatic or have CD4+lymphocytes below 200/mm3 have worse perceived mental and physical health than sero-negative men.

Nathan. L. Linsk, et al, (2000), The researcher has conducted a qualitative study, which explored the experiences of 19 older women from minority communities, who provided care to their children or adult relatives infected with human immuno deficiency virus (HIV). These caregivers felt that providing the care contributes significantly to their sense of identity. These caregivers provided care to such individuals in need of care because they were the best available source of care, or had a personal commitment in caring for the individual. The findings of the study revealed a previously, hidden group ageing family members, who provide extensive support for people with HIV and AIDS, while paying minimal attention to their own needs.

Peter Tsasis, et al, (2000), This study argues that the enhancing efficacious social network are developing new adaptive social ties for HIV infected individuals, without adequate social resources which may enhance their adaptive response to the disease and treatment. Further suggestion of this study adds that the success of an adaptive response to the disease may

depend on the relationship between the patients and the health care providers.

Gouveta-Andrade. LZ (2003), This study deals with the concerns of women and children infected with HIV. Clinical investigation related to ethical issues are both unavoidable and controversial, different arguments are presented by different partners. This study is concerned with ethical controversial dilemmas, philosophical principles, epidemiological context and different perspectives concerning this as painful in times of evidence based medicine. The same medicine which, wants to protect them offers wide-open opportunities to these two special populations who are treated in an empirical situation, because of the most terrible infection that mankind has ever faced.

Frod Sham. L.C. et. al, (2004), This study is concerned with the demand for assisted conception among HIV-infected couples, in parallel with increased efficacy of anti-retroviral medication, which has improved life expectancy and reduced vertical transmission with n= 13 HIV positive couples, where one or both partners were affected with HIV and referred to

infertility hospital at Chelsea, during 1999. 59 couples received sperm-washing treatment (male partner infected) resulting in 17 healthy babies, and 14 couples were treated in the female positive preparation. (5 concordant an 9 discordant for HIV), resulting in 3 healthy babies. The results indicated the issues were existing and were significant enough to withhold treatment in 5 cases. Many were of relationship issues, and surrounding acquisition of infection, fear of infection in the negative partner or child (n=1) poor prognoses due to multiple drug resistance (n=3). Or disability related to infection (n=1). Counseling was provided by the specialist in regard to the welfare of the child and couple had required close liaison with HIV specialist and involvement of the couples was a must.

Joseph. E.B, Bhalti R.S. (2004), The aim of the study is related to the psychosocial problem encountered in living past HIV-infection and the coping patterns adopted by HIV sero positive wives of men with HIV/AIDS. An exploratory research design was used with thirty (n=30) HIV positive women, attending counseling clinic in Bangalore (South India). The subjects were selected by purposive sampling technique by an

interview method and with a standardized coping scale. It concluded that majority of the respondents were the primary care-givers for their infected spouse / children. The findings of the study is inducted that with content analysis of increased financial (burden). Difficulties (problems) in child care and support, compromised help seeking behaviour, was due to stigma. Problems in sexual interaction and communication in their marital relationship, role strain in care giving, gender discrimination and inadequate care, increased concerns about parents, efficacy past HIV infection, escape and avoidance was the most common mode of coping. The study was conduced in a social-familial situation. Wherein social and mental health practices are significant findings of the study.

Theall, K.P. et al. (2004), The goal of this study was to determine the period of prevalence of mother-child separation (e.g. living apart from mother) and factors associated with separation between women infected with HIV type 1 and their children (17 years old and younger). A retrospective cohort study was conducted, based on routinely collected data by the family advocacy, care and education (FACE) of children's hospital (New Orleans, Louisinea, on 586 children and 231 HIV-infected

mothers were followed from July 1st, 2001- March 2003. The three-month period of prevalence of separation from mothers ranged between 12.7% and 21.2% over the course of follow-up at baseline, 14% of the children were separated from their mothers over the course of follow-up of (older children about 6-17 years). Those with mothers, suffered from illegal drugs / alcohol had a permanent residence, CD4 count was below 200cells /ml were most likely to be separated from their mothers. No significant differences was seen in women lost to follow-up and those in care. If additional research could be enhanced for substance abuse and mental health treatment. Many prevent or reduce maternal-child separation among similar populations.

Kennel D. Phillips, et al, conducted a study to identify factors related to perception of physical health in a co-hort of HIV-infected women. A descriptive correlation design was used to identify factors influencing perceived physical health in 275 HIV-infected women in Georgia, South Carolina and North Carolina. Participants were predominantly single African-American women with household incomes of less than \$ 10,000 per year. Using spearman's rho, statistically significant positive

correlations (p<. 05) were found between perceived physical health and 'T' helper cell count, hope, present life satisfaction, education and income. These findings support the need to address the psychosocial as well as physiological factors, which associate with HIV/AIDS in developing comprehensive plans of nursing care.

Lois J. et al, conducted a study on the neuro development outcome in HIV and described its advances in the treatment of perinatally acquired HIV which has increased children's life expectancies and decreased the incidence of severe neurological sequelae. A retrospective study was conducted potentially pertinent variables were considered in the analysis, which included severity of the disease, age of initiation of anti-retroviral therapy; maternal substance abuse and guardianship. The study cohort included 29 children (20 male/9 female) age range between 3-10 years. Severity of the disease was classified upto the degree of immune suppression. (1994, Revised Classified Systems for HIV Infection in Children less than 13 years) with 16 (55%) of the children were mild, 6 (21%) were moderate and 7 (24%) were severely immune suppressed. 4 children (14%) received anti-retroviral therapy prior to 5 months of age.

Members of multidisciplinary team determined neuro developmental status (cognitive, motor and sensory) via neurological examinations and psychometric tests including Bayley and McCarty and Wechsler scales. The findings indicated that majority of the children had less deficits, most commonly a pattern of language delays or disorders. Special educational interventions should be initiated during the children's preschool years with particular focus on language development; continuing surveillance is required.

IV. Margaret S Miles, et al, reports that there is a growing awareness that depressive symptoms in mothers has an impact on there parenting, ultimately, in the development of the children. Infants born to mothers with HIV are at a particular risk of having a depressed caregiver. Many mothers with HIV are highly stressed by poverty and are upset by their diagnosis of HIV. As a result of maternal and social problems, some seropositive infants are not cared. CES was used to assess the depressive symptoms of infants on medical examination.

The other depressive behaviours are: -

(1) Positive attention during naturalistic observation

- (2) Attention should be placed in helping others.
- (3) Attention should be placed in helping others with HIV and personal distress.

Vaenstra. N, Whiteside A, This study unfolds the economic impact of HIV/AIDS on human beings. And emphasizes the concept of human capital with much higher costs associated with the epidemic, impact studies are most important for planning which includes the household impacts, which are more important and devastating on household HIV/AIDS. The economic impact of HIV/AIDS will be modified through prevention and treatment interventions. The potential savings to the government is through the implementation of mother-to -child prevention programmes. The investigator feels that the health services are suffering under a dual burden of the increased demand and reduced capacity to deliver, which contributes to the cycle of poor health and economic decline.

4. Nurse's Role: -

Nurses' were found to express the most worry and discomfort with HIV patient care. Nurses' are the care-givers who are considered to be at the forefront of AIDS patient care.

Sandra Anderson et al, (1984), The researcher has conducted a study on the challenges of AIDS, which will be managed at home. This challenge can only be met if strategy exists to develop comprehensive care across the continuum from hospital to home. Destignatizing AIDS home care relies on two strengths that exists around the world, the family and the community. Concerning carers, AIDS home care has to be developed and supported in the midst of poverty, inequality and discrimination.

Thebisa Hamu koma chaava (1996), the study revealed that the Communities and families are sharing responsibility with local hospitals caring for people with HIV and AIDS. In several areas of Africa, home based care and community counseling are the keys to both care and prevention. Community counseling is a process that focuses on groups or communities. It uses principle of one to one counseling and promotes a

sense of ownership and responsibility within the community with regard to preventive and curative care. The team of counselors attending community itself decides how it can best minimize the spread and impact of AIDS. "Shared confidentiality" is a traditional practice in many cultures and is consistent with the family's understanding of the responsibility towards members who are sick. Community counseling has also helped them to deal with fears and get on with the much-needed work of care and prevention and income-generating project can support HIV/AIDS patients financially.

The community counseling process includes the following steps: -

- Community selection. Relationship Building.
- ***** Exploration of the problem. Strategy formation.
- ❖ Decision making Implementation. Evaluation.

The major goal of community counseling is movement towards sustained behaviour change. The process of discussion is recorded by agreement; this helps in the implementation and consistency of measurement.

Sandes Gracia Jones. **(1998)**, the findings of the study revealed that Fever is a common symptom in hospitalized HIV/AIDS patients (Holtellan, 1998,

Jones,) Nurses caring for patients with AIDS used antipyretic medications plus physical cooling methods for fever management (100.5 degree F to 104 degree f in hospitalized patients with HIV/AIDS Jones, 1998.) the purpose of this study was to determine which intervention was the most effective in decreasing body temperature while, increasing patient comfort. The theoretical frame-work for the study was derived from koleatia's (1995) theory of comfort care in which the outcomes of nursing practice are measured by patients perceptions of their own comforts. The study was conducted at South Florida among 200 patients with HIV/AIDS, these patients were admitted to the in-patient block of the medical center with fever and were randomly selected for the study. The interventions were

- 4. Oral administration of Acetaminophen (Tylenol 650 mg).
- 2. Antipyretics with physical cooling method Tylenol plus the application of cold compresses on the forehead.
- 5. Evaluations were based on self reports of patient's perception of comfort. A paired t-test was done for pre and post interventions. No statistical significance was found concerning pulse, respiration, blood

pressure or oxygen saturation rate, the greatest decrease in temperature was noted with Tylenol plus cooling scarf.

Nancy f. Berto Witz et al, The author intended to conduct this study in order to examine health-related attitudes, including willingness to provide care by health care professionals towards HIV infected patients. To control the attitudes towards people who may have engaged through high-risk behaviour for HIV infection e.g. Intravenous drug use or homosexual behaviour. The attitudes of paediatric nurses were studied, since children with HIV almost never acquired the infection through these behaviours. The research population included 517 paediatric nurses from twenty states, of the district of Colombia and Puerto Rico. The major findings were that those paediatric nurses with more experience in caring for people infected with HIV, were willing to care for such patients. Very few nurses could refuse care for these children, although most of them acknowledged moderate fear of acquiring HIV from their patients. Greater occupational risk was associated with less positive attitudes and less willingness to provide care.

NURSING THEORETICAL FRAMEWORK: -

Rosenstoch's (1974) and Becker and Maiman's (1975) Health -belief model addres ses the relationship between a person's belief and behaviours. It provides a way of understanding and predicting how children suffering from AIDS and their principal care-givers will behave in relation to their health and how they will comply with health care therapies.

The first component in this model involves the individual's perception of susceptibility to an illness. eg. children suffering from AIDS and their principal care-givers needs to recognize the familial link for HIV/AIDS disease. After the link is recognized, particularly when one parent or sibling would have died in their first to fourth decade from HIV / AIDS. The children suffering from AIDS and their principal care-givers may perceive the personal risk of HIV/AIDS disease.

The second component is the individual's perception of the seriousness or severity of the illness eg. HIV/AIDS disease. This perception is influenced and modified by socio-demographic variables eg. age, sex,

race, ethnicity, etc.), and Psycho-social variables eg. (personality, social class, peer and reference group pressure, etc) and Perceived threats of the illness / disease HIV/ AIDS and Cues to action, includes eg. Mass media campaigns and advice from family, friends and medical/ nursing professionals.

The third component- the likelihood that the children suffering from AIDS and their principal care-givers would take preventive action, which includes the person's perception of the benefits of taking action. Preventive action may include lifestyle changes, increased adherence to medical therapies, or a search for medical / nursing advice or treatment.

The health belief model helps nurses to understand factors influencing clients perception, beliefs and behaviour and plan of care that will most effectively assist clients in maintaining or regaining health & preventing illness. A research study by Prewitt (1989) investigated the correlation between the health beliefs and preventive health behaviours and educational materials dealing with acquired immuno deficiency syndrome(AIDS).

MODIFIED CONCEPTUAL FRAMEWORK BASED ON HEALTH -BELIEF MODEL

Individual perceptions

Modifying factors

Likelihood of action

Socio-Demographic variables of (age, sex, race, ethnicity etc.), Psycho-social variables (personality, social class, peer and reference group pressure, etc.)

Perceived benefits of preventive action to HIV/AIDS in children /principal caregivers

Health promotion

Minus
Perceived barriers to preventive action
eg. stigma effect, discrimination

Perceived susceptibility to the disease HIV/ AIDS perceived seriousness (severity) of HIV/ AIDS

Perceived threat of disease HIV/ AIDS

Cues to action

- Mass media campaigns
- **❖** Advice from others
- Reminder post card from physician or dentist
- Illness of family member or friend
- Newspaper or magazine article

Likelihood of taking recommended preventive health action. eg. health education community based action program eg. role play

SOURCE: - Health belief model. from Becker MH, Maiman LA: Med care 13 (1): 12, 1975