REVIEW OF LITERATURE
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In the third decade of the HIV/AIDS epidemic, the health care system in India still grapples with a disease that may exist for generations or even centuries. HIV/AIDS remains a relevant issue for the fields of social work, health care, and other human service fields. Since the beginning of the HIV/AIDS epidemic, caregivers (defined for this study as parental and non-parental caregivers consisting of family and relatives) have emerged as a critical component of the health delivery system for HIV positive children.

This chapter aims at review of an existing literature. An attempt has been made to review available literature, which helps to understand concepts, issues, problems and developing insights for the study. An attempt has also been made to critically evaluate the studies emphasizing a clear need for the present study. The frame work of review is as follows:

1. Studies on caregivers issues like the caregivers’ burden, psychosocial issues affecting the caregiver like psychological problems of the caregivers, their needs, concerns, quality of life, coping, support, impact of HIV infection on caregiving and disclosure related issues are discussed.
2. The second section focusses on the studies on children living with HIV/AIDS, review more closely examined the academic performance and behavioural problems of the HIV infected children as perceived by the caregivers, given its important role in understanding the psycho social impact of HIV infection on children.
3. Review at a glance on studies related to caregivers and children living with HIV/AIDS.
4. Finally, scope of the study, as informed by the literature, will be stated.

Methodology used to source literature:

The review draws on both published and unpublished material from 1997 to 2010 which was largely identified using keyword searches on electronic databases. Keywords used included HIV/AIDS, parental or non-parental caregiver, HIV infected
child, caring or caregiving, Burden, concerns, psychosocial, mental health, stigma, disclosure, and social support or coping and behaviour of HIV infected children. Databases sourced were: Psych Lit, Psych INFO and Psych ARTICLES; Medline; Family and Society Studies Worldwide; Social work Abstracts; Electronic Journals; Periodicals; e Publications; and PubMed. Further, a limited number of additional papers were identified by scanning the reference lists obtained through the above-mentioned sources.

2.1 Studies on Caregivers: The studies on caregivers have been further sub grouped under various categories for better clarity and understanding.

A. Socio demographic details of the caregivers
B. Caregiving Burden
C. Psycho social issues of the caregivers
   - Caregivers Psychological Problems
   - Caregivers Quality of life
   - HIV and its impact on family
   - Caregiver’s needs and concerns
   - Caregiver’s disclosure related issues
D. Coping and support for the caregiver
E. ART adherence

SOCIO DEMOGRAPHIC DETAILS OF THE CAREGIVERS

The caregivers studies highlighting the profile of caregivers and their socio demographic details and characteristic features of caregivers are described in this section.

Most research related to caregiving for people with HIV/AIDS had focused on defining the population. Friends, family, and volunteer caregivers represent a significant network that struggles to meet the daily needs of the HIV-infected individual. The caregiving network is a heterogeneous group: older parents and grandparents (Gwyther & Allers, 1990); other relatives (Brown & Powell-Cope, 1991; McDonell, Abell & Miller, 1991), HIV-infected caregivers (Cohen &
Durham, 1991), volunteer groups (Jimenez & Jimenez, 1990), and HIV-infected mothers caring for their HIV-infected children (Reidy, Taggart & Asselin, 1991).

Mellins & Ehrhardt (1994) explored stress and coping among families with HIV-infected children. The majority of caregivers were single mothers who were overextended with caregiving responsibilities. Compared with uninfected caregivers, HIV-infected parents reported more isolation and fewer financial and support resources. All children were particularly vulnerable to separations and loss, with uninfected siblings reporting anger and burden from caregiving tasks.

A study by Smith & Rapkin (1996) reported that the category of caregiver differed according to who the person with AIDS was. For instance, women with AIDS relied more on their children than did men.

Engler, Anderson, Herman, Bishop, Miller, Pirraglia, Hayaki & Stein, (2000) examined the role of coping on caregiver burden among a heterogeneous group of caregivers of persons living with HIV during the era of highly active antiretroviral therapy. Results revealed that a total of 58.8% of the caregivers were women. They had a mean age of 42 years; 61.9% cohabited with the persons living with HIV.

Scott Douglas (2001) attempted to bring out the differences between birth mothers and other caregivers on key demographic, stressor and social support variables. Many caregivers were in poor health, with some also caring for additional sick children. However, birth mothers had more health difficulties that place limits on their activities in the home, lower formal education, less support from their family, friends, and church/spirituality than their counterparts. Birth mothers also reported more perceived stress and less arousal than did other caregivers. Yet, it was also found that other caregivers provide care for significantly more HIV positive children, as well as more other ill children. There were no differences between birth mothers and other caregivers on illness management, support from the index child, connections with the community, and formal service support.

Daphne (2001) reported that an understudied aspect of the HIV/AIDS epidemic is the creation of hundreds of thousands of grandparent-headed households that had become
home to children bereft of one or both of their parents. Such "skip-generation parenting" presented a host of challenges to the families involved and the social programs designed to assist them. Despite this unprecedented caregiving responsibility, older surrogate parents remain relatively invisible, hidden in the shadows of HIV care and the demands of raising a child.

Lee, Lester & Rotheram-Borus (2002) described caregivers of adolescents whose parents had died of AIDS and examined how caregivers perceive the impact of raising bereaved adolescents. For adolescents bereaved by AIDS, Most caregivers (89%) were female members of the extended family, 49% were married and 29% were employed. Caregivers were older and more likely to be employed than parents with HIV (PWH), but were similar in ethnicity, partnership and financial status, and religiosity. Caregivers had generally been selected by the parent prior to death (66%) and most caregivers (75%) had at least moderate involvement in the care of the youth prior to parental death. Caregiver-youth relationships were stable (91%) over a 6-month period. Caregivers were significantly less emotionally distressed than PWH had been. The number of positive caregiver-youth relationships decreased significantly over 6 months. Family caregiving is a common, ongoing and stable relationship in families coping with AIDS.

Caregivers of HIV-positive children (43.3) were slightly older than caregivers of children with chronic illnesses (40.3) (Wilson, Moskowitz, Acree, Heyman, Melvin, Ferrando & Folkman, 2005).

Burden and coping (Engler, Anderson, Herman, Bishop, Miller, Pirraglia, Hayaki & Stein, 2006) were examined among 176 caregivers of persons living with HIV. Just over half (52.8%) of the informal caregivers were women; 40.9% were white, 27.3% were black, 23.9% were Hispanic, and 8.0% reported other ethnic origins. Informal caregivers had a mean age of 42.12 (±13.09) years; 61.9% lived with the patient; 22.3% reported being HIV-positive. Nearly half of the informal caregivers were the romantic partners of the PWLH (47.2%). The remainder was divided between family members (33.5%) and friends (19.3%). Approximately 61.9% lived with the PWLH.
Burgous, Hernandez-Reif, Mendoza, Castillo & Shor-Posner (2007) assessed 52 Dominican Caregivers’ perception of HIV-infected Dominican children’s behaviour. The majority of HIV positive Dominican children were infected through vertical transmission, mothers were assumed to be infected as well. This was not confirmed, as there was no regular HIV testing programme in the Dominican Republic. The HIV status of non-mothers was unknown. A similar proportion of mothers (50%) and non-mothers [(50%) – grandmother (61.5%), aunts (11.5%), fathers (11.5%), other family members (11.5%) and non-family (4%)] were caring for the HIV+ children. Mothers and non-mothers were of similar education, socio-economic status and occupation. Mothers were significantly younger than non-mother primary caregivers. A significant proportion of older children (71%) were living with a non-mother, whereas the younger children were cared for equally by mothers (58%) and non-mothers (42%).

No Indian studies on profile of caregivers of Children living with HIV/AIDS were found.

The caregivers group consisted of biological or adopted parents, grandparents and relatives. As stated in the above review most of the caregivers were women. The studies also stated that HIV positive caregivers were slightly older than other caregivers.

CAREGIVERS BURDEN

Parental Caregivers

Studies of caregivers demonstrated that the effects of caregiving can be both negative and positive. Negative effects, such as burdens, were more widely studied than positive effects. Burdens included social isolation and decreased interactions with other family members, depression, and lowered life satisfaction or well-being (Zarit, Reever & Bach-Peterson, 1980; Montgomery, Gonyea & Hooyman, 1985; Gwyther & George, 1986; Kosberg & Cairl, 1986; Morita, Kasl & Berkman, 1989). Theis & Pearson (1991) found that self-reported physical health was better before beginning caregiving, and caregivers attributed the decline in their own health to their caregiving role. Positive responses to caregiving include self-satisfaction, gratification, and increased self-respect (Horowitz, 1985; Motenko, 1989; Archbold,

Some studies have reported negative effects of caregiving for HIV-infected people. Pearlin, Semple & Turner, (1998) identified a higher incidence of chronic fatigue and exhaustion in caregivers. Prior studies concluded that caregiving also contributed to isolation (Cates, Graham, Boeglin & Tielker, 1990), physical morbidity (Trice, 1988), diminished work performance (Pearlin, Semple & Turner, 1998), anger (Phillips & Thomas, 1996), psychological distress (Irving, Bor & Catalan, 1995), and a smaller social support network (Jankowski, Videka-Sherman, & Laquidara-Dickinson, 1996). Brown & Powell-Cope (1991) described issues that were unique to caregivers of HIV-infected individuals such as the stigma of AIDS, fear of contagion, multiple losses, and a high degree of uncertainty in terms of the unpredictable trajectory of the disease. In addition, persons with HIV are living longer, which may increase the length of time and the intensity of caregiver involvement. The latest treatment with protease inhibitors is heralded as having potential to change the continuum of AIDS to a chronic condition, thus either requiring an increase in the length of time spent caregiving or a decrease as persons may remain healthier for a longer period of time.

Mellins & Ehrhardt (1994) explored stress and coping among families with HIV-infected children. The majority of caregivers were single mothers who were overextended with caregiving responsibilities. Compared with uninfected caregivers, HIV-infected parents reported more isolation and fewer financial and support resources. All children were particularly vulnerable to separations and loss, with uninfected siblings reporting anger and burden from caregiving tasks. Although some families had coping resources, many families might benefit from family-focused mental health services.

Pakenham, Dadds & Terry (1995) examined the correlates of carers' burden and adjustment to their caring for a person with HIV. The most common elements of carer's burden reported were distressing emotions, relationship difficulties, somatic symptoms, and grief. Living arrangement was significantly associated with carers' burden, with those carers co-residing experiencing more burden than those living
apart from the patient. Carers' coping strategies were weakly related to carer's adjustment and burden. The patients' emotional and existential concerns were positively related to carers' burden and all domains of adjustment, while patients' instrumental concerns and measures of patients' health status were positively related to carers' burden. Patients had significantly poorer levels of adjustment than carers.

Numerous challenges facing the parents of a child with a chronic illness have been well documented in recent literature, yet little is known about the specific psychosocial factors associated with fathering an ill child (Sterken, 1996). The existing literature on parents of chronically ill children focuses predominantly on the maternal perspective, and literature searches reveal a paucity of information on fathers. Since families of children with chronic illnesses face increased burdens and challenges, fathers in these families play more integral roles with respect to parenting. As such, the father's role as a parent deserves careful attention and consideration. Despite this, very few investigations have focused on the paternal role in families with chronically ill children. HIV/AIDS and cancer have each been found to place severe psychosocial, financial, and practical stressors on the family. Both diseases are potentially life-threatening and require aggressive treatments that affect the day-to-day life of all family members.

Lesar, Gerber & Semmel (1996) studied the relationships of family functioning, parenting stress, and social support of caregivers who are parenting children with HIV infection. A family adaptation model integrated the concepts of stress, coping, and ecological systems for understanding the impact of an HIV-infected child on family adaptation and functioning. A number of factors contributed significantly to the prediction of parenting stress and family functioning. Results showed significant relationships among parenting stress, children's developmental delay status, children and caregivers' HIV status, and caregiving burden.

Lesar & Maldonado (1996), in an investigation reported coping behaviours that focused on strengthening family life and relationships and developing and maintaining a positive outlook on life were most often reported as helpful by parents. The family integration, cooperation and optimistic view of situation coping pattern was significantly related to personal impact, familial and social impact, coping
impact, and caregiver burdens impact. Coping behaviours directed at understanding the medical situation were significantly related to impact on caregiver burdens.

Abenis-Cintron (1996) examined the health-related beliefs, stressors, coping strategies, and help seeking behaviours of inner-city Latino caregivers with HIV infected children, most of whom were the HIV infected birth parent. Results indicated that most caregivers perceived both biological and supernatural etiological agents for their child's illness. Caregivers reported their major stressors as comprised of managing multiple demands including their own and their child's health care needs, emotional demands such as depression and anxiety, diminished sources of support, and recent life events including death of loved ones due to AIDS. Differences in health-related beliefs and expectations between caregivers and health professionals were another source of stress for some caregivers.

Scott Douglas (2001) examined the experiences of individuals caring for children who were infected and/or affected by HIV/AIDS. Many caregivers were in poor health, with some also caring for additional sick children. However, birth mothers had more health difficulties that placed limits on their activities in the home, lower formal education, less support from their family, friends, and church/spirituality than their counterparts. Birth mothers also reported more perceived stress and less arousal than did other caregivers. Yet, it was also found that other caregivers provided care for significantly more HIV positive children, as well as more other ill children. There were no differences between birth mothers and other caregivers on illness management, support from the index child, connections with the community, and formal service support. Support from friends has a main effect, and child support's interaction with illness management had a significant impact.

In an investigation Vasquez, (2003) sought to address a void in the field by considering the unique experiences and coping mechanisms of fathers caring for a child with HIV or cancer. This investigation examined the specific similarities and differences between the two samples of fathers. Results indicated that these fathers had significantly higher levels of psychiatric distress and parenting stress compared to male normative data. Results also revealed that the fathers in this sample were more likely to utilize social support coping resources compared to fathers of children with
other chronic illnesses and compared to male normative data. There were no significant differences between the fathers of children with HIV/AIDS and the fathers of children with cancer on measures of parenting stress, psychiatric distress, or social support coping mechanisms.

Vallerand, Hough, Pittiglio & Marviesin (2005) explored the impact of HIV disease on mothers as they faced 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. The decision to disclose was dependent on the child's developmental level, the degree of the mother's illness, and in some cases this decision was taken from mothers when someone else disclosed their HIV status to their children. Positive aspects of disclosure from the mother child dyads included open, honest communication, and closer relationships between mothers and their children. Common negative themes emanating from the data included fear, uncertainty, forced secrecy for fear of being ostracized based on the stigma associated with the disease, behavioural changes in the children, and shifting responsibilities between the mother and the child. Findings of the study suggested that disclosure, and all it entailed, remained a vital issue for mothers who were HIV-positive. In addition, the findings reflected that children and their mothers had very different perspectives regarding the process and the effects of disclosure of the mother's HIV status.

Providing home care for a child with a chronic illness can be stressful for the family. Moskowitz, Butensky, Harmatz, Vichinsky, Heyman, Acree, Wrubel, Wilson & Folkman (2006) tried to highlight the patterns of caregiving and the associated psychological impact on maternal caregivers of children with sickle cell disease (SCD). Results indicated that Children with SCD had significantly lower functional status and significantly more hospitalizations in the previous 3 months than children with HIV. Caregivers of children with SCD were more likely to work full-time and had higher incomes than caregivers of children with HIV. The three caregiving groups did not differ significantly on amount of total care, although caregivers of children with SCD and caregivers of children with HIV both reported significantly more time spent in technical care than caregivers of healthy children. Despite lower functional status of the children in the SCD group, when group comparisons on caregiving time
variables were adjusted for child's functional status, the differences between groups increased. This appeared to be due to the fact that caregivers in the HIV group spent more time in all caregiving categories except skin, crisis, and other care. In terms of caregiver mental health, caregivers of children with HIV and SCD had significantly higher depressive mood scores than caregivers of healthy children but the groups did not differ on caregiving burden.

Kipp, Tindyebwa, Karamagi & Rubaale (2007) conducted a study to measure the burden of care for family caregivers of AIDS patients. A cross-sectional exploratory design was used to describe the care experiences of family caregivers of AIDS care recipients. A questionnaire was used to interview 120 family caregivers of AIDS patients from four rural areas in western Uganda. The questions asked were related to 12 domains of family caregiving. Care burden scores of caregivers were calculated. It was found that care burden scores were high in all domains except those regarding relationships within the families and substance abuse. Serious work overload and low health status were reported. The high burden of caregiving put family caregivers at risk for decreased health status and increased social isolation and depression.

No published Indian studies on parental caregivers of CLHA were found in the review.

Numerous challenges facing the parents of a child with a chronic illness have been well documented in recent literature. They have shown significant relationships among parenting stress, children's developmental delay status, children and caregivers' HIV status, and caregiving burden. HIV/AIDS have each been found to place severe psychosocial, financial, and practical stressors on the family. Many caregivers have more health difficulties that place limits on their activities in the home, lower formal education, less support from their family, friends, with some also caring for additional sick children. Birth mothers also reported more perceived stress and less arousal. HIV-infected parents reported more isolation and fewer financial and support resources. Living arrangement was significantly associated with carers' burden, with those carers co-residing experiencing more burden than those living
apart from the patient. The high burden of caregiving puts family caregivers at risk for decreased health status and increased social isolation and depression.

Non-parental Caregivers

**Brouwer, Lok, Wolffers & Sebagalls (2000)** explored the problems, worries, and needs of the caretakers of HIV-infected children in Uganda and explored ways to improve the support given to them. A combined methods approach for qualitative information gathering was used. It consisted of focus group discussions with caretakers and with counsellors, and a review of counselling reports. The authors examined caretaker psychological stress, health of the child, economic pressures, and preparation for the future. Results indicated that counselling of parents and other caretakers could and should be an important element in the care for HIV-infected children. It could be provided during individual counselling at the health centre. Although little attention was paid so far to the psychological problems of the caretakers, it appeared to be a prerequisite for compliance and further counselling. It would relieve the burden of the caretakers and consequently lead to a better follow-up and compliance, but also to improved care provided by the caretaker.

Family caregiving is a common, ongoing and stable relationship in families coping with AIDS. **Lee, Lester & Rotheram-Borus (2002)** described caregivers of adolescents whose parents died of AIDS and examined how caregivers perceived the impact of raising bereaved adolescents. Caregivers were older and more likely to be employed than parents with HIV (PWH), but were similar in ethnicity, partnership and financial status, and religiosity. Caregivers had generally been selected by the parent prior to death and most caregivers had at least moderate involvement in the care of the youth prior to parental death. Caregiver-youth relationships were stable over a 6-month period. Caregivers were significantly less emotionally distressed than PWH had been. Caregiver burden was rated as moderate; the number of positive caregiver-youth relationships had decreased significantly over 6 months.

**Mwinituo & Mill (2006)** explored the experiences of informal caregivers of AIDS patients in Accra, the capital city of Ghana. Fifteen interviews were completed in 2002 with 11 informal caregivers, including wives, mothers, boyfriends, daughters,
sons and brothers of AIDS patients. Three major themes emerged in the analysis of the interviews with caregivers: stigma, caregiver burden, and caregiver commitment. The authors focused on the theme of stigma by documenting its presence and highlighting its impact on caregiving activities. Caregivers go to great effort to not only “hide” their patients but also their caregiving activities, resulting in the social isolation of both patients and their caregivers. Many caregivers lived in secrecy, not sharing their family member's diagnosis with extended family members. As a result, they received limited support from the extended family. Stigma resulted in negative attitudes of neighbours, relatives, and health care workers toward caregivers and their patients.

Thampanichawat, (2008) in his grounded theory study, explored how primary caregivers dealt with problems in caring for children with HIV infection in Thailand. A total of 27 family caregivers of HIV-infected children participated in open-ended interviews. Maintaining love and hope represented a condition for the continuing process of caregiving. Caregivers had to deal with the stigma of AIDS while providing care for children with HIV. They had high anxiety and fear of loss, bore much burden of care, and faced many difficulties because of limited resources. The results suggested that psychosocial care and informational support are needed to enable these caregivers to provide better care for children with HIV infection.

Non parental caregivers had generally been selected by the parent prior to death and had at least moderate involvement in the care of the youth prior to parental death. Caregivers were significantly less emotionally distressed and caregiver burden was rated as moderate. Many caregivers live in secrecy, not sharing their family member's diagnosis with extended family members. Caregivers have to deal with the stigma of AIDS while providing care for children with HIV. Stigma results in negative attitudes of neighbours, relatives, and health care workers.

No published Indian studies on non –parental caregivers of CLHA were found.
Economic Burden

Knodel, Saengtienchai, Im-em & VanLandingham, (2001) studied the impact of the AIDS epidemic on aged parents of adult children with AIDS and other family members in Thailand. Results showed that, in most cases, parents provided care for their infected adult children, often assisted with expenses, and frequently played a main role in paying for treatment. For one third of the cases, a family member reduced or stopped working to provide care. For approximately one fifth of parents, the infected adult child was their main income earner. Nevertheless, in most cases, the child's death was not judged to have a devastating economic impact for the parents, although poorer families were far more likely to be adversely affected than others.

An examination of the economic consequences for older-age parents of losing an adult child to AIDS in Thailand based on quantitative data derived from a key informant study (Knodel & Im-Em, 2004) and a direct interview survey with parents yielded the following main findings: (1) parents frequently paid for their children's care and treatment, but government health insurance and to a lesser extent welfare measures helped alleviate these expenses; (2) parental caregiving often disrupted economic activity, although the resulting opportunity costs were limited by the typically short duration of caregiving; (3) parents commonly paid for funeral costs but benefited from funeral society memberships and customary contributions from those attending; (4) only a minority of parents supported AIDS orphans although orphaned grandchildren often ended up with their grandparents; (5) most deceased children had contributed financially to the parental household but only a minority were main providers. Poorer parents, however, were most likely to lose a main provider and experience severe financial hardship; and (6) although poorer parents spent much less on expenses related to the illness and death of their children, they were much more likely than better-off parents to be seriously burdened by these expenses. Programs are needed to address the plight of AIDS parents but should target those who are most susceptible to resulting economic hardship.

Informal caregiving represents a substantial economic value to the society. The total care burden among chronically ill children is higher than that among children with
HIV. Wilson et al, (2005) compared types, amounts, and costs of home care for children with HIV and chronic illnesses, controlling for the basic care needs of healthy children to determine the economic burden of caring for and home care of chronically ill children. Caregivers of 97 HIV-positive children, 101 children with a chronic illness, and 102 healthy children were surveyed regarding amounts of paid and unpaid care provided. Caregiving value was determined according to national hourly earnings and a market replacement method. Chronically ill children required significantly more care time than HIV-positive children (7.8 v/s 3.9 hours per day). Paid care accounted for 8% to 16% of care time. Annual costs were $9300 per HIV-positive child and $25,900 per chronically ill child. Estimated national annual costs are $86.5 million for HIV-positive children and $155 to $279 billion for chronically ill children.

Sansom, Anderson, Farnham, Dominguez, Soorapanth, Clark, Sukalac, Earp, Jo, Bohannon & Fowler (2006) examined changes in healthcare use among perinatally HIV-infected children and developed new estimates of expected lifetime treatment costs. Results showed that from 1995 to 2001, hospitalization rates fell from 0.67 per child-year to 0.23 per child-year. In 2001, the average cost of healthcare utilization per child was $12,663, including $2164 for hospitalization, $9505 for HIV-related drugs, and $994 for laboratory tests. The discounted lifetime treatment cost, based on those 3 cost categories, was $113,476 for 9 years of survival, $151,849 for 15 years, and $228,155 for 25 years. Hospitalizations among perinatally HIV-infected children decreased significantly from 1995 to 2001. Compared with previously published estimates, lifetime treatment costs for children perinatally infected with HIV had remained relatively stable. However, as years of survival increase for this population, lifetime costs also are likely to increase.

Indian studies

Babu Raj, Kumar, Shetty & Jawalkar (2010) reported on the experiences from Karnataka. 245 children from 104 single mothers (50% on ART) living with HIV. They had poor access to HIV treatment, family support and stigma and discrimination results in poor quality of life and forced migration. Thus children had poor nutrition, education and emotional support; became school dropout and joined trivial jobs.
Women deserted by husbands were not eligible for widow pension; hence forced to offer sexual favours in exchange for emotional and financial support. Linkages with Government schemes and the positive response had an impact on the widows and their children as these were not limited to project period.

**Kinikar, Kulkarni, Valvi, Mave, Adhav & Kadam (2010)** aimed to evaluate the health, social and economic impact of an adult HIV/AIDS – related mortality on their HIV-positive children. HIV-positive orphans (cases) were compared to HIV-negative orphans (controls). The controls had better immunization status (85%) as compared to cases (35 %). 87% cases had severe malnutrition (control-27%); 87% had repeated hospitalizations (control=18%). Educational status of the caretaker was higher in control group (51% vs. 36%). 87% cases had stopped attending school, as compared to 30% of controls. Maternal age at marriage in both the groups was not statistically significant as opposed to the paternal age at marriage (median 19 years in cases vs. 26 years in controls.). The age at marriage in 58% fathers of cases was between 18 and 21 years, i.e. below the legal age of marriage and 84% had indulged in high risk behaviour at an early age compared to 15 % of controls. 36% of the cases group caretakers were below poverty line compared to cases (22%). Their study found that HIV/AIDS related mortality has a negative health and socioeconomic impact on their HIV-positive orphans.

HIV and AIDS contribute to increased vulnerability to poverty and increased burdens on families and children. HIV-affected households incurred proportionately larger expenditures on medical care and funerals. HIV-affected households were more likely to sell off assets, borrow from family members, take out loans, and ration medical care and food for children. Parental caregiving often disrupted economic activity, although the resulting opportunity costs were limited by the typically short duration of caregiving; Some of the findings on economic burden reveal that infected children had poor nutrition, education and emotional support; become school dropouts and joined trivial jobs, children were eating fewer meals in a day, increased frequency of hunger, and increased household and employment responsibilities. AIDS orphans often ended up with their grandparents. The total care burden among chronically ill children was higher than that among children with HIV. Changes in health care use among perinatally HIV infected children indicated that hospitalizations among
infected children decreased significantly, lifetime treatment costs for infected children have remained relatively stable. However, as years of survival increase, lifetime costs also are likely to increase for infected children.

PSYCHO SOCIAL ISSUES AFFECTING THE CAREGIVERS

Psychological Problems of the Caregivers:
Several studies have shown that HIV positive women are at greater risk for depressive symptoms than HIV negative women (Miles et al. 1997; Moneyham et al. 2000; Jones, Beach & Forehand 2001a; Miles, Gillespie & Holditch-Davis 2001; Murphy, Marelich & Hoffman 2002; Morrison et al, 2002). Risk for depression were associated with an accumulation of health-related factors such as number of physical symptoms, having non-HIV-related medical conditions, perceptions of health, an inability to perform usual activities, and difficulty caring for a child due to ill health; social or contextual factors such as lower education and experiencing more negative life events; and psychological factors such as poor self-esteem, inadequate social support, and lack of family cohesion (Miles et al. 1997; Jones, Beach & Forehand 2001b; Silver et al. 2003 Tostes, Chalub & Botega 2004; Orlando et al. 2005). In some instances, risks to emotional well-being were also associated with women’s need to maintain their parental status (Ciambrone 2003; Freeman 2004).

Susser, Miller, Bortner, Spielberg & Richman (1992) studied the psychological problems experienced in caring for children. They also explored the impact caring for a seriously ill child had on caregiver's emotional status. Results indicated that despite severe illness in the family, the caregiver group as a whole was neither especially depressed nor demoralized. However, the HIV positive caregivers were significantly more depressed and demoralized than HIV negative parents.

Anxiety, depression, coping, and anticipatory grief of psychological adaptation of parents (biological, foster, or adoptive) of HIV-infected children had shown that heightened anxiety, depression, and anticipatory grief were associated with child's age at diagnosis, parent's HIV status, and parent's relationship to the child. Biological parents were found to be having higher depression, state anxiety, and anticipatory grief than did foster or adoptive parents (Weiner, Best & Pizzo, 1994).
Depression was positively correlated with death anxiety, and negatively correlated with hope. Death anxiety was higher in HIV+ than in HIV- caregivers. Death anxiety was negatively correlated with hope and denial of gravity of illness. HIV+ and HIV-hope levels were similar. Depression was primarily predicted by hope and caregiver age; death anxiety was predicted by depression and hope; and hope was predicted by depression and death anxiety (Gular, 1995).

Gay (1996) examined psychological distress among HIV infected mothers. As a group, mothers infected with HIV reported significantly higher levels of distress and less satisfaction with their social support, even when compared to a demographically similar control group.

A study (Melvin & Sherr, 1997) reported that 1 in 5 families there was a parent whose depressive episodes triggered referral for psychological support. Over half of the families (57%) experienced a parental or child death within the core family. Although there were no suicides recorded, there were 4 self-harming episodes (all women), and another 3 parents expressed suicidal ideation of a magnitude to trigger referral to a mental health agency.

As a group, caregivers (Miller, 1997) reported a significantly greater level of psychological distress than the general population while the level of well-being reported by caregivers was similar to that of the general population. Illness and demographic parameters failed to significantly predict aspects of caregiver adjustment. Specifically, higher levels of caregiver psychological distress were associated with poorer caregiver health status, greater number of coping strategies reported, and higher levels of family conflict. Higher levels of caregiver well-being were associated with perceptions of less impact of negative life events, lower levels of family conflict, and greater perceptions of emotional support.

Bachanas, Kullgren, Schwartz, Lanier Blake, McDaniel, Smith & Nesheim (2001) found a significant differences in psychological functioning between caregivers of HIV-infected children and caregivers of healthy children and found that Caregiver psychological distress scores did not significantly differ between the HIV and control groups, and clinically significant rates of psychological distress were
reported by more than a third of caregivers in both groups. In addition, caregiver psychological distress was a significant predictor of children's maladjustment.

Lee, Lester & Rotheram-Borus (2002) examined the emotional distress, self-esteem and problem behaviours of adolescent daughters aged 11-18 years (n = 121) and their mothers with HIV were examined and related to reports of parental disclosure of sero status and adolescents' perceived bonds with their parents. Most mothers with HIV reported emotional distress in the clinical range (70%). The levels of emotional distress, self-esteem and drug use were significantly correlated between mothers and daughters. Adolescent's emotional distress was significantly related to maternal disclosure of HIV status. Daughters who perceived their mothers as highly caring also perceived them as low in overprotection. Daughters who perceived their mothers as low in caring were more emotionally distressed and reported more conduct problems and lower self-esteem.

With respect to the impact on child outcome, mothers’ poor psychological functioning has been shown to predict poor monitoring of children, as well as other more general adverse impacts on children’s emotional and intellectual development (Jones, Forehand, Brody & Armistead, 2002). Child behaviour problems were marginally associated with the mother having illness-related activity restrictions but no association was found to other measures of maternal physical health, stigma or disclosure of HIV status to the child (Bauman, Camacho, Silver, Hudis & Draimin, 2002). The association to child behaviour problems was most marked in older children since this group was more likely to observe and understand the mother’s ill health (ibid).

Vasquez, (2003) sought to address a void in the field by considering the unique experiences and coping mechanisms of fathers caring for a child with HIV or cancer. Results indicated that these fathers had significantly higher levels of psychiatric distress and parenting stress compared to male normative data. Results also revealed that the fathers in this sample were more likely to utilize social support coping resources compared to fathers of children with other chronic illnesses and compared to male normative data. Contrary to hypotheses, there were no significant differences between the fathers of children with HIV/AIDS and the fathers of children with
cancer on measures of parenting stress, psychiatric distress, or social support coping mechanisms.

Providing home care for a child with a chronic illness can be stressful for the family (Moskowitz et al., 2006). They examined patterns of caregiving and the associated psychological impact on maternal caregivers of children with sickle cell disease (SCD). Fourteen maternal caregivers of children with SCD were interviewed as part of a study of maternal caregivers of children with chronic illness. Forty-four caregivers of children with HIV and 36 caregivers of healthy children were included as comparison groups. Interviews included questions regarding amount of time spent providing care for the child (technical care, non-technical care, and health care management), hospitalization, emergency room visits, illness stigma, and mental health of the caregiver. Results indicated that children with SCD had significantly lower functional status and significantly more hospitalizations in the previous 3 months than children with HIV. Caregivers of children with SCD were more likely to work full-time and had higher incomes than caregivers of children with HIV. The three caregiving groups did not differ significantly on amount of total care, although caregivers of children with SCD and caregivers of children with HIV both reported significantly more time spent in technical care than caregivers of healthy children. This appeared to be due to the fact that caregivers in the HIV group spent more time in all caregiving categories except skin, crisis, and other care. In terms of caregiver mental health, caregivers of children with HIV and SCD had significantly higher depressive mood scores than caregivers of healthy children but the groups did not differ on caregiving burden.

Overall, mothers with HIV (Brackis-Cott, Mellins, Dolezal & Spiegel, 2007) exhibited more depressive symptomatology than uninfected mothers. There were no significant differences, however, in depressive symptomatology between children of mothers who were HIV-positive and children of mothers who were HIV-negative. Among families directly affected by HIV, mothers who disclosed their status to their children endorsed greater depressive symptomatology than those who did not disclose and children who had been disclosed to were more likely to score in the clinically depressed range on the Child Depression Inventory than those who did not know.
Latina mothers and their children were at increased risk for both depression and anxiety symptoms.

No Indian studies on psychological problems of the caregivers of Children living with HIV/AIDS were found.

Several studies have compared HIV positive caregivers with HIV negative caregivers, general population. The main findings are most parents who are HIV positive are emotional distressed, exhibited more depressive symptomatology, state anxiety and anticipatory grief than uninfected caregivers. The HIV positive maternal caregivers are at greater risk for depressive symptoms than HIV negative caregivers.

Caregivers’ Quality of life:

Research examining the potential impact of gender on quality of life in HIV/AIDS is limited (Smith et al., 1997; Mrus et al. 2005). Among Persons Living with HIV/AIDS, there were gender differences in access to treatment, care, economic income, and social and personal power. Among women’s barriers to care were the lack of knowledge about HIV/AIDS, family responsibilities and the burden and fear of disclosure. A US based study showed that women and HIV-infected individuals reported the poorest QOL scores (Wisniewski et al, 2005). Women had more HIV symptoms, poorer functioning, and greater disruptions in physical and psychosocial well-being (van Servellan et al. 2002). Women scored significantly less positive well-being than the men despite less advanced disease.

Indian studies

Gender differences in QOL examined by the WHOQOL HIV group (2004), which included two centres in India, showed that men reported poorer physical well-being and level of independence, while women reported poorer environment, social support and spirituality. Subsequent studies in India, using the WHOQOL HIV BREF showed that women had significantly lower QOL scores than men despite having less advanced disease (Casado, 2005; Kohli et al, 2005a, b). However, one study done in India, did not find a significant association between gender and QOL (Wig et al.
A few Indian studies on QOL among HIV infected patients had not examined gender differences (Chandra et al. 2003; 2006).

The findings in the above studies from the West and India suggest that women have lower scores on several areas of Quality of Life compared to men (Shor-Posner, 2000; Kohli et al. 2005a, b; Wisniewski, 2005). Gender differences emerged significant on four domains of quality of life. Men reported significantly higher scores on the physical, psychological, social and the environmental domain.

HIV and its impact on family

Miller, Goldman, Bor & Kernoff (1989) examined how acquired immune deficiency syndrome (AIDS)/human immunodeficiency virus (HIV) had affected children with haemophilia, their siblings, those who had remained antibody negative, and those with HIV infected fathers. The impact of haemophilia and AIDS on the family was considered and the ripple effect of AIDS on health care staff was addressed. Themes that emerged in families in which the child had HIV included anxiety about becoming stigmatized, contaminating others, talking about sex and sexuality, and issues surrounding death.

Hollander (1995) examined the impact of HIV from a professional perspective. The study revealed a wide range of issues and a variety of opinions. In terms of mental health assistance, HIV/AIDS affected family members were presenting professionals with problems involving the health of the HIV infected adult in the family, concerns about death and dying, and need for advocacy for services. Issues less widespread and more specific to this population included worries over the child(ren)'s health, child rearing concerns, and questions about disclosure, particularly to children. In seeking assistance, professionals felt family members most wanted emotional support and building of their self-esteem. Information and referrals was seen as the second most important type of assistance. Findings were also indicative of dissatisfaction with the nature and extent of services for families and need for more home-based assistance.

Lesar, Gerber & Semmel (1996), examined the relationships of family functioning, parenting stress, and social support of caregivers who were parenting children with HIV infection. A family adaptational model integrated the concepts of stress, coping,
and ecological systems for understanding the impact of an HIV-infected child on family adaptation and functioning. Hierarchical multiple-regression analysis showed that a number of factors contributed significantly to the prediction of parenting stress and family functioning. Results showed significant relationships among parenting stress, children's developmental delay status, children and caregivers’ HIV status, and caregiving burden.

**White, Melvin, Moore & Crowley (1997)** described the incidence of discordance in a heterosexual population in London. The children had been exposed to HIV infection because they were born to HIV positive women. There was HIV discordance in more than one-fifth of the parents' relationships. In over 46% of the relationships, the HIV status of the natural or birth father was not known because he was either untested or unavailable. It was likely that not all of these men were infected and the number of discordant couples was greater. There were more discordant couples where the man and woman came from different ethnic groups. The disruptive effects of HIV infection on family life were immense, and discordance represented an additional pressure which required support and family-based care.

**Mawn (1999),** explored the phenomenon of raising a child with HIV from the perspective of parents of long-term paediatric HIV survivors. The findings from the longitudinal study revealed that initial reactions to the diagnosis included confusion, anger, denial, and despair. A process of adaptation emerged from the stories which included a tendency toward normalization, a strong sense of spirituality, a focus on a positive attitude, and strength from family support.

The impact of HIV/AIDS on children and families (**Foster & Williamson, 2000**) was compounded by the fact that many families live in communities that were disadvantaged by poverty, poor infrastructure and had limited access to basic services.

**John & Kumar (2001)** examined HIV-infected children to evaluate factors affecting care and found that commonly majority of HIV infected children were born to young, unmarried, and economically deprived HIV infected mothers. A significant percentage of care for these HIV positive children involved grandparents.
Yang, Wu, Duan, Li, Shen, Mathur & Stanton (2006) conducted a survey to study the lives of children with HIV-infected parents. Results showed that most of the children resided in a household with low economic status and a high dependency ratio. Many children experienced discordant family relations, family anxiety and shame. Compared to orphans, non-orphans and their families were less likely to receive social support from the community. Orphans and older children were less likely to attend school and more likely to be truant if enrolled in school. Findings suggested that many children whose parents were infected with HIV or had died from HIV were living in stressful environments with minimal support from the community.

Li, Jiang, Lord & Rotheram-Borus (2007) explored the discrepancies in perceiving family conflict between HIV-infected parents and their adolescent children. A significant gap in perceiving family conflict was reported between parents and young adolescents aged 12. A higher level of discrepancy was associated with poor economic status, lower parental education, parental hard drug use, and negative parental coping style.

Among families (Murphy, Marelich, Herbeck & Payne, 2009) with more frequent family routines, over time adolescents showed lower rates of aggression, anxiety, worry, depression, conduct disorder, binge drinking, and increased self-concept. Among families with higher levels of parental monitoring, adolescents showed significant declines in anxiety and depression, conduct disorder, and binge drinking, along with increased self-concept. Mothers' level of illness was associated with parenting. Greater variability in parental monitoring resulted in higher levels of problem behaviours.

Palloni & lee (2010) studied on the effects of the HIV/AIDS on women and children in African countries. Unless massive social remedies mitigated the growing orphanhood, the rates of school dropout, child-labour participation and outright abandonment would increase. Increased adult mortality would raise the incidence of widow(er)hood. Increased adult mortality could induce and overhaul of family arrangements where female children, mothers, and grandmothers were likely to bear the bulk of the personal, social, and economic burden in the absence of social interventions.
Indian study

Sandipan, Kumkar & Gupta (2010) conducted a cross sectional to study the impact of HIV/AIDS on the psychosocial status of Adolescent children. In their study, indicated that HIV implied significant psychological impact in the form of frequent sicknesses, anger, isolation tendencies, fearfulness, loss of confidence, and suicidal tendencies.

The disruptive effects of HIV infection on family life are immense, and discordance represents an additional pressure which requires support and family-based care. Significant relationships were been found among parenting stress, children's developmental delay status, children and caregivers' HIV status, and caregiving burden. Increased adult mortality could induce and overhaul of family arrangements where female children, mothers, and grandmothers are likely to bear the bulk of the personal, social, and economic burden in the absence of social interventions.

HIV and its impact on mothers

A sample of mothers (Peterson, 1995), who were symptomatic for AIDS were examined to determine whether they differed from HIV-positive but asymptomatic mothers. Mothers with AIDS were significantly less able to care for themselves adaptively, were significantly more depressed, expressed significantly less positive affect, and were significantly less able to interact positively with their infants than mothers without AIDS. Infants of mothers with AIDS were significantly less securely attached than infants of mothers without AIDS.

Miles, Burchinal, Holditch-Davis, Wasilewski & Christian (1997) examined longitudinally, depressive symptoms in HIV-infected mothers with infants. Most of the women were single and African American, and most were on public assistance. About a third of the mothers were at risk for depression, the best predictors of depressive symptoms were found to be feelings of stigma, self-perceptions of health, and physical symptoms, all factors associated with HIV.

Manopaiboon et al (1998) in their prospective study assessing the changes in the family situation of HIV infected women who had recently given birth found that
Mothers worried extensively about their child's health and their family's future. Only one third believed they could find someone to talk to about their feelings related to HIV. More than half of them were interested in joining a support group for women with HIV. These findings of family disruption, reduced family income, shifting responsibilities for child care, depression, and isolation indicated an urgent need for increased social support for HIV-infected mothers.

**Murphy, Greenwell, Resell, Brecht & Schuster (2008)** This longitudinal study examined the impact of maternal HIV/AIDS on children's care taking responsibilities during the early years (ages 6-11) and their development of autonomy during adolescence (ages 11-14.5). Findings evidence those adolescents who assumed a high level of responsibility had mothers with poorer health compared with the mothers in the 2 other groups. The authors indicated that it is vital that mothers with HIV/AIDS develop a strong attachment relationship with their children when they are young. They emphasized the importance of this relationship, specifically among mothers who must rely on their children to complete tasks not typical of other children their age.

**Indian study**

**Babu Raj, et al (2010)**, reported on the experiences from Karnataka, India. 245 children from 104 single mothers (50% on ART) living with HIV. They had poor access to HIV treatment, family support and stigma and discrimination results in poor quality of life and forced migration. 69% were daily wage labourers and 11% were not able to work. Average income was Rs.1350/-. Thus children had poor nutrition, education and emotional support; become school dropout and joined trivial jobs. Women deserted by husbands were not eligible for widow pension; hence forced to offer sexual favours in exchange for emotional and financial support.

Mothers worried extensively about their child's health and their family's future. These findings of family disruption, reduced family income, shifting responsibilities for child care, depression, and isolation indicate an urgent need for increased social support for HIV-infected mothers.
Most of the children resided in a household with low economic status and a high dependency ratio. Many families lived in communities that were disadvantaged by poverty, poor infrastructure and limited access to basic services. Many children experienced discordant family relations, family anxiety and shame. Compared to orphans, non-orphans and their families were less likely to receive social support from the community. Many children whose parents were infected with HIV or had died from HIV were living in stressful environments with minimal support from the community. HIV implies significant psychological impact in the form of frequent sicknesses, anger, isolation tendencies, fearfulness, loss of confidence, and suicidal tendencies in adolescents.

**Familial substance abuse**

For children with alcohol/drug abusing parents (Wiener, Harens & Yiu Kee, 2003) risk factor for mental health problems clustered in two areas. They were broadly conceptualized as sequale of parenting deficiencies such as neglect, abuse, discontinuity of attachments and disruption of placement and treatment etc. The biologic risks associated with parental alcohol/drug addiction were prenatal drug exposure, heritable psychiatric disorder like affective and anxiety disorders and childhood histories of attention deficit hyperactivity disorders.

Caregiver drug and alcohol use and HIV+ status (Naar-King, Arfken, Frey, Harris, Secord & Ellis, 2006) were associated with non-adherence and elevated viral load. Negative outcome expectancy was associated with lower adherence. Extra-familial factors such as dissatisfaction with medical specialty care and more stressful life events were not directly associated with adherence but were related to increased caregiver substance use.

No Indian studies on the impact of familial substance use in caregivers of Children living with HIV/AIDS were found.
HIV/AIDS and Stigma

Associative stigma may affect caregivers who step in and help care for infected or affected children whose parents have died. Children may be affected by associative stigma if their parents are publicly known to be infected with HIV (Poindexter & Linsk, 1999).

Stigma management (Poindexter & Linsk, 1999) is a way of coping with HIV/AIDS stigma by being aware of possible negative reactions and finding ways to minimize them. Children who know their diagnosis may practice stigma management by choosing and limiting whom they disclose to in order to minimize the chance of negative reactions or rejection.

To safeguard a child from experiencing stigma, caregivers may delay disclosing the child’s diagnosis to the child; if children are unaware of their diagnosis, they are less likely to tell the “wrong” people. Data show that between 25 percent and 90 percent of school-aged HIV-positive children were unaware of their own HIV status (American Academy of Pediatrics, 1999).

Many caregivers felt that if children knew their diagnosis, they will internalize the stigma and give up. Through this, stigma lead to an atmosphere of secrecy within the family that the child often sensed. Labelling the diagnosis a secret that must not be discussed only served to increase the stigma. Many parents also were afraid to disclose the child’s HIV-positive status because of deep feelings of guilt or shame, especially when the route of transmission was from mother to child. The parents would feel guilty about their role in infecting the child and feared that the child would become angry or blame them (Close & Rigamonti, 2006).

Mwinituo & Mill (2006) explored the experiences of informal caregivers of AIDS patients of Ghana. In their article, the authors focused on the theme of stigma by documenting its presence and highlighting its impact on caregiving activities. Caregivers would go to great effort to not only “hide” their patients but also their caregiving activities, resulting in the social isolation of both patients and their caregivers. Many caregivers lived in secrecy, not sharing their family member’s
diagnosis with extended family members. As a result, they received limited support from the extended family. Stigma resulted in negative attitudes of neighbours, relatives, and health care workers toward caregivers and their patients.

**Bogart, Cowgill, Kennedy, Ryan, Murphy, Elijah & Schuster (2008)** examined the interconnectedness of stigma experiences in families living with HIV, from the perspective of multiple family members. All of the families recounted experiences with stigma, including 100% of mothers, 88% of fathers, 52% of children, 79% of adult children, and 60% of caregivers. About 97% of families described discrimination fears, 79% of families experienced actual discrimination, and 10% of uninfected family members experienced stigma from association with the parent with HIV. Interpersonal discrimination seemed to stem from fears of contagion. Findings indicated a need for interventions to reduce HIV stigma in the general public and to help families cope with stigma.

**No Indian studies on HIV/AIDS and stigma affecting caregivers and children living with HIV/AIDS were found.**

A major factor that distinguishes HIV/AIDS from other chronic or terminal illnesses is the stigma associated with the disease. This stigma comes from a lack of knowledge about HIV and how it is transmitted. Stigma can adversely affect children and their caregivers in ways that have long-term negative psychological and social effects. Several studies and interventions have shown how caregivers and people living with HIV/AIDS have managed the negative effects of stigma, by not disclosing to many people.

**Death due to HIV/AIDS**

**Death of parents**

The study (Melvin & Sherr, 1997) reported that over half of the families (57%) experienced a parental or child death within the core family. The prevalence of parental death in South Africa.
Family caregiving is a common, ongoing and stable relationship in families coping with AIDS (Lee et al, 2002). While over 50% of all adult deaths were due to AIDS, households continue to face other causes of illness and death. HIV-related illness and AIDS deaths of household members were only part of the households' cumulative experience of HIV and AIDS.

Patients (Grant et al, 2003) often describe how the support of close family relationships, and the care shown by their community and religious fellowships helped meet many of their emotional, social, and spiritual needs. But physical needs often went unmet. Patients died in pain. Some suffered in poverty; others were troubled by the guilt of using all available family resources to pay for treatment and care. Accessible pain relief, affordable clinic or inpatient care when required and help to cope with the burden of care were among the key needs of patients.

Illness and death of non-household members, for example, former partners who were parents of children within the households or relatives who provided financial support, also impacted negatively on households (Hosegood et al, 2007).

Operario, Pettifor, Cluver, MacPhail & Rees (2007) reported death 27.3% overall: 22.4% reported a father deceased, 7.9% reported a mother deceased, and 3.0% reported both parents deceased. Parental death was disproportionately associated with black ethnicity, impoverished household living conditions, lack of an adult guardian in the home, and not completing compulsory education levels.

No published Indian studies on Death of parents/ caregivers due to HIV/AIDS were found.

Infected children’s death

Research (Dubik-Unruh, 1989) showed that children dying of perinatally-acquired human immunodeficiency virus (HIV)-infection moved from one chaotic system to another as medical and social services scrambled to meet the growing need. Incarceration, addiction, illness, abandonment or court removal of children, hospitalization, sibling separation, or homelessness would all contribute to family
death, even before the physical death of family members. Another important finding was that the death of HIV positive mothers, but not of HIV negative mothers or of fathers, was strongly associated with increased child mortality (Crampin et al. 2003).

The increased risk of death among children was shown up to the age of three (Sewankambo et al. 2000 in USAID 2004; Urassa et al. 2001 in USAID 2004) or five years (Crampin et al. 2003). Further, mortality rates were four times greater among infants and nearly three times greater among children (Nakiyingi et al. 2003 in USAID 2004). Boys and children born to teenage mothers were at higher risk (ibid).

Indian study

Shivakumara (2010) in his study had found that 3% of children had died during the follow up period on ART. 10% of children were orphans and 36% were with single parents.

Unfortunately, death and grief are harsh realities in this pandemic. Children’s experience of losing parents and loved ones is often compounded by their own illness and by other factors surrounding the loss, such as secrecy and stigma. These families need additional support and care from their health care providers during their time of mourning.

AIDS-related deaths are decreasing

The number of annual AIDS-related deaths (Global Report 2010) worldwide is steadily decreasing, the decline reflects the increased availability of antiretroviral therapy, as well as care and support, to people living with HIV, particularly in middle- and low-income countries; it is also a result of decreasing incidence starting in the late 1990s. Globally, deaths among children younger than 15 years of age are also declining. The estimated children who died from AIDS-related illnesses in 2009 were 19% fewer than the estimated who died in 2004. This trend reflects the steady expansion of services to prevent transmission of HIV to infants and an increase (albeit slow) in access to treatment for children (Global Report 2010).
Review of literature

Siblings of the infected child

**Bettoli-Vaughan** (1995) examined the psychosocial functioning of siblings of HIV infected children. The mothers' level of psychopathology was the only significant predictor of the siblings' internalizing and externalizing behaviour. The siblings' adaptive behaviour, in terms of daily living skills, was best be predicted by knowledge of the siblings' age only. The siblings' academic performance was not affected by having a brother or sister infected or exposed to HIV. Exposure to violence was a significant predictor of the siblings' externalizing behaviour problems. In contrast, knowledge of their brothers' or sisters' diagnoses did not adversely affect sibling functioning.

**Melvin & Sherr** (1995) examined data from children living in families where HIV infection was present. Results indicated that there were no significant differences among the siblings in the three diagnostic groups (HIV infected, HIV exposed, and controls) on any of the dependent variables. The mothers' level of psychopathology, as measured, was the only significant predictor of the siblings' internalizing and externalizing behaviour.

**Fair, Spencer, Weiner & Riekert** (1995) discussed the epidemiological and psychosocial issues related to non infected children within families with HIV/AIDS and suggested that they were at significant risk for poor developmental outcomes as a consequence of the skewing of familial resources and were also impacted by issues such as stigma, isolation, and death.

**Young** (1998) assessed the psychological functioning and adjustment of uninfected children of parent(s) living with HIV/AIDS. Projective test results revealed significantly elevated levels of depression and difficulty coping among this population of children. Additionally, greater behavioural disturbance among HIV-affected children was indicated. The findings suggest that this group of children was at-risk for developing depressive and affective disorders.

Siblings are severely emotionally affected (**Weiner, Heliman & Battles**, 1998). Family life is strengthened when individuals can communicate openly. But many
parents chose not to share their HIV diagnosis, blocking healthy expression of feelings. When the diagnosis was known, many reported resentment of the special medical care and parental attention given to the sick child and a sense of guilt for escaping the infection. Many feared abandonment, worried about who will take care of them once their parents die and wish to be part of that decision making process. Family support and counselling are vital in helping families negotiate the siblings’ roles in terms of age, maturity and competence.

Dolezal et al (2003) reported that early adolescents were most concerned about sexual activity, pregnancy, safety and violence, and drugs. Early adolescents whose mothers were HIV-positive were concerned additionally with their mothers' sickness and death, adult responsibilities, stigma and ostracism, and an even greater uncertainty about their futures.

Research (DeVane Fair, 2006) results had indicated that HIV-uninfected children, 6-15 years of age, whose mothers were HIV-infected and used substances had poorer emotional functioning when their mother experienced HIV-related symptoms compared to the comparison group. Results also indicated that HIV uninfected children were significantly less likely to be rated as disruptive during the interviews.

Mellins et al, (2008) examined the effect of maternal HIV infection, as well as other individual, family and contextual factors on the mental health of the adolescents. Results indicated that although the HIV status of mothers alone did not predict youth mental health, youth knowledge of mother's HIV infection and mother's overall health were associated with poor youth mental health outcomes.

No Indian studies on siblings of children living with HIV/AIDS were found.

The siblings' academic performance was not affected by having a brother or sister infected or exposed to HIV. Research has indicated that HIV-uninfected children whose mothers are HIV-infected and use substances have poorer emotional functioning. The findings suggest that HIV-affected children are at-risk for developing depressive and affective disorders. The studies revealed significantly
elevated levels of depression, greater behavioural disturbance and difficulty in coping among HIV-affected children.

**Uninfected Children’s Concerns**

Witte & de Ridder (1999) children expressed concerns regarding their parent's HIV status, improving communication skills, identifying and expanding coping strategies, and facilitating peer support for normalization and validation of fears and concerns.

A significant number of children Murphy, Roberts & Hoffman (2002) expressed concerns about their friends finding out, fearing that they would be ostracized or that it would be assumed they were also infected. In addition, the children did not want others to find out because they wanted to protect their mothers. The burden of keeping the secret of their mothers' serostatus did seem to be a stressor for some of the children.

A significant number of children expressed concerns about their friends finding out their parent's HIV status, improving communication skills, identifying and expanding coping strategies, and facilitating peer support or that it would be assumed they were also infected. The burden of keeping the secret of their mothers' serostatus does seem to be a stressor for some of the children. They were concerned additionally with their mothers' sickness and death, adult responsibilities, stigma and ostracism, and an even greater uncertainty about their futures.

**Orphan and Vulnerable Children**

Children who had experienced an HIV/AIDS related death (Collins-Jones, 1997) in their family, had their parent's or sibling's diagnosis disclosed to them, had a lack of available social supports and/or lack a stable living environment were at greater risk for developing behavioural and/or emotional problems.

Most of the children left orphaned by AIDS (Safman, 2004), were being cared for by members of their extended family, especially grandparents or maternal aunts, and that many caregiving households were experiencing significant financial hardship which
might have implications for the children's long-term well-being and stability and for their opportunities for educational advancement. Concern were also expressed about the unavailability or inaccessibility of childcare for AIDS-affected children and the perceived instability of fostering arrangements which placed young children in the care of elderly relatives.

Arnab & Serumaga-Zake (2006) investigated the plight of AIDS orphans and reflected that the African tradition of the extended family which should be encouraged because most of the orphans were raised by their relatives (grandparents and uncles). Many of the orphaned children were household heads. Orphaned children were, in most cases, not well educated and trained, they ended up performing menial work or odd jobs, which were the lowest on the earnings ladder. The findings also indicated that very few young people, especially those in the 10-14-year age group (less than 28%) knew how HIV transmission can be prevented.

Potential risk and protective factors in a range of dimensions (Cluver & Gardner, 2007) including bereavement, family functioning, social support, poverty, access to education and perceived stigma. Many factors reflected international literature on children experiencing similar stressors (e.g. non HIV/AIDS-related bereavement). However, this study also identified factors which may be specific to this group, notably stigma, abuse and peer factors.

Child-headed households and lone-elderly carers (Jones, 2006) were not the most common; maternal kin played a more important role in orphan care than did paternal kin, indicating both stresses due to AIDS and the dynamic nature of the family. Women of all ages were bearing the brunt of the extra care responsibilities caused by the epidemic. There was limited involvement in children's well-being by agencies of any kind and orphan care remained largely situated within kin structures. The AIDS epidemic was impacting on families in a variety of ways, with a corresponding increase in poverty and vulnerability. Carers did not perceive orphans as a separate category of children requiring assistance over and above any other vulnerable child. Families require assistance at the household, community and national level.
Indian studies

Jain & Bhargava (2010) investigated the influence of gender, age, HIV status, state of orphanhood and the type of institution on the self-concept of children living with HIV/AIDS in residential institutions of Delhi. Results revealed that older children living with HIV/AIDS had better self-concept than younger children. Self-concept of affected children was better than the infected children. Children of the institutions providing opportunities for unfolding the talents of the children and meant for affected children of older age group had overall better self-concept. Girls performed better in physical appearance, global self-worth and behavioral conduct. Single orphans had better self-concept than double orphans. Self-evaluation of children is affected by age, gender, HIV status, orphanhood and by the physical and psychosocial environment of the residential institutions.

Jebaseelan & Jayalakshmi (2010) focused on the psychological trauma experienced by the HIV/AIDS children who were under the institutional care. The study included children with one or both parents who were HIV-positive, and children who had lost one or both parents to AIDS. The areas of enquiry were related to where that child lived, how s/he was raised, attending school, getting (non HIV) medical care (doctor, dentist etc.). Psychological details like getting good sleep, food intake, fear of disease, fear of death, depression, adjustment problems and other issues. Children under institution care experience psychological trauma due to Lack of care and support from parents, loss of parents, lack of acceptance and routine medical treatment.

Most of the children left orphaned by AIDS were being cared for by members of their extended family, especially grandparents or maternal aunts, and that many caregiving households were experiencing significant financial hardship which might have implications for the children's long-term well-being and stability and for their opportunities for educational advancement. Children under institution care experience psychological trauma due to Lack of care and support from parents, loss of parents, lack of acceptance and routine medical treatment. Children who have experienced an HIV/AIDS related death in their family, have had their parent's or sibling's diagnosis disclosed to them, have a lack of available social supports and/or lack a stable living
environment are at greater risk for developing behavioural and/or emotional problems.

**Caregivers Needs and Concerns**

**Caregivers Needs**

*Reidy, Taggart & Asselin (1991)* found that the natural caregivers were cognitively, socially, and financially circumscribed by the impact of AIDS. They needed help in coping with stress and their life situation. The need to learn how to protect themselves and other members of the family against both HIV and other infections and to know the course and the treatments associated with AIDS was important.

*Theis, Cohen, Forrest & Zelewsky (1997)* indicated that the most common health problems of the care recipient were fatigue and weight loss; care recipients needed help with climbing stairs, walking, and bathing; caregivers helped with the household chores, transportation, and companionship; caregivers were concerned about coping with loss and responsibilities; caregivers had help from family, case manager, and neighbour; caregivers wanted help such as a companion and counselling.

*Wiener, Heliman & Battles (1998)* examined the expressed needs of caregivers of HIV infected children. The study delineated the different needs articulated by caregivers for the HIV-infected children at three different developmental stages, and the caregivers' HIV-status and relationship to the children. The most urgent needs were found for mental health services and health education. The age of the child, the parent's HIV status, and the child's awareness of his or her diagnosis had the most impact on the type of services caregivers requested.

*Scott Douglas (2001)* attempted to examine the differences between birth mothers and other caregivers on key demographic, stressor and social support variables. In addition, this study explored the buffering effect of specific sources of social support upon the caregiver. Many caregivers were in poor health, with some also caring for additional sick children. However, birth mothers had more health difficulties that placed limits on their activities in the home, lower formal education, less support from their family, friends, and church/spirituality than their counterparts. Birth mothers also reported more perceived stress and less arousal than did other caregivers. Yet, it was also found that other caregivers provided care for significantly more HIV positive children, as well as more other ill children. There were no differences between birth
mothers and other caregivers on illness management, support from the index child, connections with the community, and formal service support. Support from friends has a main effect, and child support's interaction with illness management had a significant impact. Thus, it might be that some sources of social support exerted a buffering effect while others demonstrated a main effect, depending upon the specific crisis at hand.

**Daphne (2001)** reported that an understudied aspect of the HIV/AIDS epidemic was the creation of hundreds of thousands of grandparent-headed households that had become home to children bereft of one or both of their parents. Such "skip-generation parenting" presented a host of challenges to the families involved and the social programs designed to assist them. Despite this unprecedented caregiving responsibility, older surrogate parents remain relatively invisible, hidden in the shadows of HIV care and the demands of raising a child. Most social service programs were not able to identify the needs of older surrogates, often because these surrogate parents in HIV-infected families were reluctant to make their needs known for fear of social stigma or possible reductions of benefits. Multiple systemic barriers like professional ignorance or denial that HIV affects surrogates, eligibility restrictions through CARE, limited funding and a fragmented health and human service system.

**Grant, Murray, Grant & Brown (2003)** described the end-of-life experiences and care needs as they listened to patients with ongoing cancer or AIDS, and to their carers. Patients expressed how the support of close family relationships, and the care shown by their community and religious fellowships helped meet many of their emotional, social, and spiritual needs. But physical needs often went unmet. Patients died in pain. Some suffered in poverty; others were troubled by the guilt of using all available family resources to pay for treatment and care. Accessible pain relief, affordable clinic or inpatient care when required, and help to cope with the burden was among the key needs of patients.

**New, Lee & Elliott (2007)** assessed psychological adjustment in children living with human immunodeficiency virus (HIV) and their primary caregivers. Results revealed that of the 16 children who were assessed on current psychiatric diagnosis
using standardized interviews, 6 (38%) met the criteria for a psychiatric diagnosis. Of the 15 adults who met the screening criteria, 13 completed a computerized psychiatric interview and all 13 (100%) met the criteria for a psychiatric diagnosis.

In an ethnographic study, Aga, Kylmä & Nikkonen (2009) explored and described the conceptions of care among family caregivers of people living with HIV/AIDS (PLWAs) in Ethiopia. Four major themes representing family caregivers’ conceptions of care were identified: nourishing the PLWA while struggling with poverty, maintenance of cleanliness and hygiene of the person and surroundings, comforting the PLWA, and sacrificing self to sustain the PLWA.

No Indian studies on needs of caregivers of children living with HIV/AIDS were found.

Studies on caregivers needs have highlighted that they need help from family, case manager, and neighbors. Caregivers wanted help in coping with stress and their life situation, companion and counseling, mental health services and health education. The needs of elderly caregivers are fear of social stigma, aging, HIV services, child welfare, education, community health, public policy and mental health.

Caregivers Concerns

Pakenham, Dadds & Terry (1995) examined the correlates of carers' burden and adjustment to their caring for a person with HIV. The most common elements of carer's burden were distressing emotions, relationship difficulties, somatic symptoms, and grief. Living arrangement was significantly associated with carers' burden, with those carers co-residing experiencing more burden than those living apart from the patient. Carers' coping strategies were weakly related to carer's adjustment and burden. The patients' emotional and existential concerns were positively related to carers' burden and all domains of adjustment, while patients' instrumental concerns and measures of patients' health status were positively related to carers' burden. Patients had significantly poorer levels of adjustment than carers.

Hollander (1995), in a study examined the psychological concerns of family members, their expected gains from psychological assistance, the service needs and
interests of family members, common difficulties experienced. In terms of mental health assistance, HIV/AIDS affected family members were presenting professionals with problems involving the health of the HIV infected adult in the family, concerns about death and dying, and need for advocacy for services. Issues less widespread and more specific to this population included worries over the child (ren)'s health, child rearing concerns, and questions about disclosure, particularly to children. In seeking assistance, professionals felt family members most wanted emotional support and building of their self-esteem.

Caregivers were concerned about coping with loss and responsibilities (Theis et al, 1997).

Focus group discussions (Dolezal et al, 2003) were conducted with inner-city ethnic minority families with regard to current life concerns, mother/child communication of concerns, and the influence of maternal HIV on both of those issues. Early adolescents were most concerned about sexual activity, pregnancy, safety and violence, and drugs. Early adolescents whose mothers were HIV-positive were concerned additionally with their mothers' sickness and death, adult responsibilities, stigma and ostracism, and an even greater uncertainty about their futures. Mothers' concerns for their children included safety and violence, sexual activity, drugs, and parenting. Mothers who were HIV-positive also were concerned about their own HIV-related issues of stigma, disclosure, becoming ill, and children assuming adult roles.

**Concerns on Disclosure**

Lester, Chesney, Cooke, Whalley, Perez, Petru, Dorenbaum & Wara (2002) in their cross-sectional study of children (aged 4 yrs and older) with HIV infection found that only 43% of children had been told their HIV diagnosis. Factors influencing parental decision to disclose the child's HIV status included parental communication style, parental illness, child's rights, treatment adherence, child questions and provider pressures, whereas concerns about HIV stigma and potential emotional distress were most frequently identified as reasons for nondisclosure. Paediatric HIV disclosure represents a complex task for parents caring for the HIV-infected child, one in which the child's development and the family's community should be considered in the setting of a potentially stigmatizing infectious illness.
A study by Bordeaux, Loveland, Lachar, Stehbens, Bell, Nichols, Amodei & Adkins (2003) had revealed that Caregivers of HIV positive youths reported greater health concerns, social withdrawal, physical and adaptive limitations associated with illness in their sons, and more pessimism about their sons' future and negative attitudes about parenting. Caregivers of HIV positive youths with greater immune compromise reported greater concerns about their sons' health and greater pessimism about their futures, as well as lower levels of family integration and more limited family opportunities.

A preliminary survey (Goode, McMaugh, Crisp, Wales & Ziegler, 2003) of 18 parents of children receiving HAART in Australia showed that although parents reported high levels of child adherence to HAART, specific features of the medication regimen, such as taste and number of medications made administration of HAART extremely difficult. Moreover, interaction between the treatment regimen and the day-to-day lives of families increased the adherence challenge. While some agreement exists in relation to the concerns families have about negative aspects of HAART, the diversity of issues suggests the need for ongoing and individualized support and information to families.

Salter-Goldie, King, Smith, Bitnun, Brophy, Fernandes-Penney, Lefebvre, Louch.; MacDougall, Moore & Read, (2007) presented three primary reasons for disclosure. They were concerns for children's emotional well-being, fear that children would not be able to keep the secret within the family and maternal fear of blame when the virus was transmitted from mother to child.

Vaz (2008) focused study on experiences throughout the disclosure process, which to date was not documented in sub-Saharan Africa. Caregivers who had not yet told their child of her/his HIV status fell into one of three groups: nearly 50% had given their child no information, 15% had given partial information; and 33% had provided misleading information. Findings from the in-depth interviews on the moments before, during and after disclosure revealed that caregivers were influenced to disclose by concerns about treatment adherence, the eminent onset of adolescent sexual activity, and their desire to protect their child as well as others. Children
experienced disclosure as a discrete event; although many had subsequent questions and concerns, most did not discuss them with others.

**Thomas & Swaminathan (2009),** reported that mothers living with HIV are increasingly concerned about how and when to disclose their HIV status to their children and the repercussions which could result from disclosure.

**No Indian studies on concerns of caregivers of children living with HIV/AIDS were found.**

The studies on caregivers concerns have listed that they are concerned about coping with loss and responsibilities, health concerns, about their future, about treatment adherence, negative aspects of Highly Active Anti Retro viral Therapy(HAART), concerns for children's emotional well-being, Relationships within the family, about how and when to disclose their HIV status to their children and the repercussions which could result from disclosure, maternal blame safety and violence, drugs, and parenting, HIV stigma, potential emotional distress, onset of adolescent sexual activity, and their desire to protect their child as well as others, death and dying, and need for advocacy for services. Mothers who were HIV-positive also were concerned about their own HIV-related issues of stigma, pessimism about their future, lower levels of family integration, disclosure, becoming ill, and children assuming adult roles.

**Caregivers Disclosure related Issues**

**Concealing the status**

**Champion et al,1999** have revealed 2 modes of family communication: the secret (reserved for the youngest children) or silence. The child (**Nieves, 2000**) of a parent with a positive HIV/AIDS diagnosis could present indicators of depression, anxiety, low self-esteem, social isolation, academic problems, feelings of abandonment and rejection, somatic problems and sleeping difficulties. The death of a parent by itself was considered a traumatic event that would sensitize the child to other losses. Parents' decisions about this issue had a strong and long-term effect on their children's life. To keep their positive HIV/AIDS diagnosis in secrecy from their children, disregarding their age, maturity and emotional needs even during the last days of life.
or after death, could be devastating. This contradicts expectations of fulfilling their roles as protective parents.

**Smith & Niedermyer (2009)** in their privacy management research conducted in Namibia, Africa investigated variables related to family members’ desires to conceal HIV-status secrets. Two factors predicted potential co-owners’ desires to keep a family member’s HIV-positive status secret: (a) the sense of an environment inappropriate for disclosure, and (b) a lack of efficacy to oppose it. These findings suggested that many factors translated from disclosers to co-owners. From this investigation, one might consider the contexts that redistribute power so that confidants may limit discloser’s rights to share his or her own information. When people learn that they were tested positive for HIV, they may share their news with a family member; and this family listener may want them to keep their diagnosis a secret.

**Disclosure of parental HIV status**

**Mason, Simoni, Marks, Johnson & Richardson (1997)** examined patterns of disclosure to significant others among HIV+ African-American and European-American Men, predictors of disclosure, and the relationship between disclosure and psychological functioning. Analyses indicated that women disclosed at varying rates to six different categories of others. Disclosure to mothers (66%) was most common, followed by disclosure to partners (56%). Rates of disclosure to children (28%) and fathers (25%) were lowest. Women's illness status predicted disclosure to father and friends. Only disclosure to partner was significantly related to women's psychological functioning: Fewer symptoms of depression were evident in women who had disclosed their HIV status to their partners compared to those who had not disclosed

**Instone (1997)** explored what parents said about the illness and how children responded socially and emotionally. Results revealed that although most of the children were informed about the illness by the time of the study, their drawings and conversations suggested they did not perceive that communication and support were available within their families. Instead, signs of social isolation, poor self-esteem,
and severe emotional distress were found. The parents' readiness to tell determined the interval between diagnosis and disclosure, which was typically 4 years.

Disclosure strategies (Witte & Lewis, 1997) depend largely on the quality of relationship mothers have with their children, mother's level of social support, mother's own feelings of guilt regarding her infection, and mother's perceptions of children's coping abilities.

Armistead, Klein, Forehand & Wierson (1997) found that disclosure of HIV status was more common with older children, and in families in which fathers are more ill. A more positive parent–child relationship was related to lower levels of child depression and externalizing problems and to better grades.

Armistead, Tannenbaum, Forehand, Morse & Morse (2001) found that mothers reported whether they disclosed their HIV status to the child and assessed the child's functioning. Less than one-third of mothers disclosed their HIV status to their children. Disclosure was associated with mother's income level and perceived severity of physical symptoms. Children disclosed to were more often older and female. Contrary to expectation, disclosure was not related to child functioning.

Shaffer, Jones, Kotchick, Forehand, Armistead, Morse & Morse (2001) found that a majority (68%) of children was not aware of their mother's HIV status; however, most mothers planned to disclose eventually. Of the children who knew their mother's HIV status, almost all had been told by their mothers. Mothers reported a significant increase in child behaviour problems and a decrease in mother-child relationship quality from pre- to post-disclosure. Children reported a significant increase in their understanding of HIV/AIDS, but no significant behavioural changes.

Lee & Rotheram-Borus (2002) found that parents were more likely to disclose to older than to younger children. Mothers were more likely to disclose earlier than were fathers, and they disclosed more often to their daughters than to their sons. Parents were more likely to disclose over time to children of all ages; disclosure did not vary according to parents' ethnicity, socioeconomic status, self-esteem, or mental health symptoms. Disclosure was significantly more common among parents with poor
health, more stressful life events, larger social networks, and those who perceived their children experiencing more HIV-related stigma. It is concluded that parental disclosure of HIV status is similar to disclosures by parents with other illnesses.

DeMatteo, Harrison, Arneson, Goldie, Lefebvre, Read & King (2002) reported that 'Trust' emerged as the major theme and core value upon which disclosure decisions rest for both parents and children. Disclosures to children take place within historical and social contexts that include current knowledge of HIV, adult belief systems, unique parent-child relationships, family dynamics, interactions with the health care system, and a family's place in society.

Positive aspects (Vallerland et al, 2005) of disclosure from the mother child dyads included open, honest communication, and closer relationships between mothers and their children. Common negative themes emanating from the data included fear, uncertainty, forced secrecy for fear of being ostracized based on the stigma associated with the disease, behavioural changes in the children, and shifting responsibilities between the mother and the child. Findings of the study suggest that disclosure, and all it entails, remains a vital issue for mothers who are HIV-positive. In addition, the findings reflected that children and their mothers have very different perspectives regarding the process and the effects of disclosure of the mother's HIV status.

Tompkins (2007) reported that 61% of mothers disclosed. Disclosure was not related to child functioning. Differential disclosure, which occurred in one-third of the families, was associated with higher levels of depressive and anxiety symptoms.

Marques, Silva, Gutierrez, Lacerda, Ayres, Dellanegra, França, Galano, Paiva, Segurado & Silva (2006) in a qualitative study included adolescents living with HIV/AIDS and their parents and caregivers. The main reasons for disclosure were: poor treatment adherence, sexual maturity, adolescent's request, and inadequate procedures by medical staff. Disclosure was a critical moment for adolescents, with a strong impact on their life plans and horizons. Adolescents infected through sexual transmission and drug use reported the most problematic scenes involved in disclosure. Despite its initial negative impact, disclosure resulted in improved healthcare and better dialogue among the adolescents, caregivers, and healthcare providers. The adolescents also requested clear, no-nonsense, honest information.
Little is known about the impact of maternal disclosure of HIV+ positive serostatus on young children. Murphy, Roberts & Hoffman, (2006) found that the most prevalent child response was anxiety, primarily focused on the mother's health and fear of her death. A number of children also worried about other people finding out, and seemed aware of the stigma surrounding HIV. For most children anxiety decreased over time, although for a small number it sustained and became maladaptive. The majority of children appeared to adjust well to maternal disclosure.

Indian study

Bhonsle, Gabhale, Kulkarni, Ladhra, Pokharna & Mangalani (2010) They had undertaken a study to determine the parental knowledge regarding disclosure, their concerns and their explanations to the child about disease prior to the disclosure and their perception about the appropriate age of disclosure to the children. The ages of the children, whose parents were interviewed ranged from 6 to 15 years, 23 (35.4%) patients were between 5 – 10 years and 42 (64.6%) were between 10 – 15 years. Thirty-four (52.3%) of these were males and 31 (47.7%) were females. The parental age was between 20 – 50 years. Among these 65 children, 10 (15.4%) were aware of their status, whereas 55 (84.6%) were not. Ten children who were aware of their status were in the 12 – 15 year age group. Seven of these children were also aware of their parental status. 60% of these 10 children who were aware of their status also had the discussion regarding possibility of death and separation; parents explained that they were required to take daily medications due to decreased immunity. 16.9% children had started questions about the diseases from the age of 8-10 yrs, 18.4% of them between the ages of 11 to 15 years. 64.6% children however never inquired about their illness. When the parents asked, according to them what the child feared most, the answers were as follows: children feared death, 6.15% had fear of being bedridden, and 29.2% were concerned about hospitalizations. 40% children had no specific fear.

Disclosing HIV Status of Care Receiver by Caregivers

Studies indicate that family members who take care of a PLWA often face stigma, so many caregivers avoid disclosing to their family and friends (Powell- Cope &
Brown, 1992; Poindexter & Linsk, 1999). One qualitative study explored the spiritual aspects of HIV/AIDS caregiving provided by African American mothers and other family members in Chicago (Poindexter, Linsk & Warner, 1999). These authors found that although the women were regular church attendees, few had told their pastors or any other church members about their roles as caregivers for a family member with HIV/AIDS. Instead, they relied on their faith in God as their primary coping mechanism. They regarded the HIV/AIDS issue as a private one, so they even avoided attending support groups for AIDS caregivers.

Another qualitative study by Poindexter & Linsk (1999) discussed the stigma faced by older female African American caregivers. The researchers reported that five out of the nineteen caregivers said that their families refused to visit the PLWA or even disowned both the PLWA and the caregiver. Other caregivers limited their disclosure to a select few, so they faced little or no negative reactions, to receive support, relationship ties, associated with disclosure to all target types; explaining change in behaviour or appearance, and HIV prevention.

(Ssali, Atuyambe, Tumwine, Segujja, Nekesa, Nannungi, Ryan & Wagner, 2010). The most common reasons for nondisclosure were: fear of abandonment, particularly among young women disclosing to spouse/partner; inaccessibility to the disclosure target; and not wanting to worry/upset the disclosure target.

Reasons for Disclosure

The main reasons for disclosure were: disclosure was the “right thing to do” and the need to make arrangements for children's future in case of maternal death or incapacity (Shaffer et al, 2001), parental communication style, parental illness, child's rights, treatment adherence, child questions and provider pressures (Lester et al, 2002), sexual maturity, adolescent's request, and inadequate procedures by medical staff (Marques et al, 2006), poor treatment adherence (Vaz, 2008), the eminent onset of adolescent sexual activity, and their desire to protect their child as well as others (Vaz, 2008). The risk of the teen's transmitting the virus to others (Aiges, 2008) children being HIV positive, the rest of the family knowing, or the parent becoming very sick (Nam et al, 2009).
Indian study
Although parents of 95.3% children were willing to disclosure, only 15.4% had been able to do so (Bhonsale, et al, 2010).

Reason for non-disclosure

The literature presents primary reasons for the non-disclosure: Fear of rejection, decreasing the child’s quality of life, and not wanting to worry others (Nehring, Lashley & Malm, 2000), fear of causing the child psychological harm (Nieves, 2000), Maternal concern about discussing death and dying with children (Shaffer et al, 2001), concerns about HIV stigma and potential emotional distress (Lester et al, 2002) the fear that disclosure might have negative psychological consequences to the child (Oberdorfer, Puthanakit, Louthrenoo, Charnsil, Sirisanthana & Sirisanthana, 2006), concerns for children's emotional well-being, fear that children will not be able to keep the secret within the family and maternal fear of blame when the virus is transmitted from mother to child (Salter-Goldie et al, 2007). Almost all agreed that they should tell the children their diagnosis in the future but half needed health-care providers to help them at the event. The caregivers were unprepared, had limited understanding about disclosure and were willing to lie to the child (Siripong, Bunupuradah, Apatpeerapong, Boonrak, Pancharoen, & Ananworanich, 2007) believing the child to be too young, not knowing how to address the issue of HIV, that it would be "too painful" for the children and concern that other people might find out about their status or fear of children experiencing stigmatizing behaviour (Nam, Fielding, Avalos, Gaolathe, Dickinson & Geissler, 2009).

Indian study
The Indian study presents primary reasons for the non disclosure: Fear that the child might get depressed, child might disclose to another people and the child will not understand, the parents had no self confidence to disclose (Bhonsale, et al, 2010)

Stigma and disclosure of HIV status

Caucasian caregivers found stigma to be a considerable component of their experience (Powell-Cope & Brown, 1992). The caregiver had to balance the
advantages of disclosure against keeping the AIDS diagnosis a secret, thus avoiding the AIDS stigma. Besides the judgmental attitudes, the caregivers also had to face the fear of contagion that led people to avoid them.

Stigma, was directly related to the decision of whether to disclose the care receiver’s HIV status. A longitudinal study of family members (Demi, Bakerman, Sowell, Moneyham & Seals, 1997), examined the relationship between stressors and resources with perceived burden and depression to family caregivers of HIV-positive women. The researchers conclude that the only predictive variable for feelings of burden and depression was the amount of stigma felt by the family member.

African American mothers (Boyle, Hodnicki & Ferrell 1999), who were caring for their HIV-positive adult children, only half of the mothers disclosed to their friends, family and churches, since both mothers and sons worried about the impact of the AIDS stigma upon their families.

Most mothers with HIV/AIDS report carefully weighing the risks and benefits of disclosing their status to others (DeMatteo et al. 2002), with mothers more likely to disclose to older children and to girls (Shaffer et al. 2001). There did not appear to be clear guidelines on the benefits of disclosing to children, the most appropriate age at which to disclose and the most suitable method of disclosure. One study found that 68% of mothers did not disclose their HIV status to their children, and, of those who did, the majority told their child not to disclose her status to other people for fear of repercussions such as stigma and ostracism for both themselves and their child (Murphy, Marelich & Hoffman 2002).

Among the many other challenges faced by mothers with HIV/AIDS that placed their emotional well-being at risk, were AIDS-related stigma and decisions regarding disclosure. While disclosure would facilitate access to social support and health benefits, reduce risks of stigma and infecting significant others, and provided an opportunity to openly discuss custody planning (Khan, 2004), the fear of stigma, rejection, relationship changes, social isolation, violence, and discrimination against the individual and other family members, remained significant barriers (Shaffer et al. 2001; Kirshenbaum & Nevid 2002; Murphy, Marelich & Hoffman 2002;
Letteney & Heft LaPorte 2004). Clearly, all of the negative consequences of disclosure had potentially adverse effects on women’s psychological well-being.

Research has shown that mothers often perceive the consequences of disclosure as considerably more negative than their children. Studies had found that children reported increased understanding of HIV/AIDS, displayed less aggression and lower levels of negative self-esteem than children who were unaware of their mother’s status, and did not report significant psychological distress or behaviour change in response to disclosure (Murphy, Marelich & Hoffman 2002; Shaffer et al. 2001). However, their mothers perceived an increase in negative mood changes in their children immediately after disclosure (Murphy, Marelich & Hoffman 2002), as well as increased child behaviour problems and poorer mother-child relationship (Shaffer et al. 2001). A more consistent finding was that instructing a child to keep one’s status a secret was likely to be burdensome to the child, and to be associated with more behaviour problems than found in children not asked to HIV status secret (Kirshenbaum & Nevid 2002; Murphy, Marelich & Hoffman 2002).

No published Indian articles on the relationship between stigma and disclosure were found.

COPING AND SUPPORT FOR THE CAREGIVERS

Adnopoz, Forsyth & Nagler (1994) described some of the physical and psychological aspects of AIDS and HIV infection in children and families, outlined some of the challenges that were presented to those who develop interventions on their behalf, and detailed an innovative program developed by the authors. Children and families affected by AIDS struggled not only with the devastating physical effects of the disease, but also with a complex, interdependent set of environmental, psychological, and societal factors. Attempts to cope with separation and loss as well as significant issues of secrecy and stigmatization frequently isolated these families and prevented them from receiving appropriate physical and mental health care.

Lesar & Maldonado (1996) compared parents of HIV-infected children and parents of uninfected HIV-exposed children to assess the coping behaviours they used to
mediate the impact of HIV infection on the family system. Coping behaviours that focus on strengthening family life and relationships and developing and maintaining a positive outlook on life were most often reported as helpful by parents in both groups. No differences were found between the groups on measures of parental coping. The family integration, cooperation and optimistic view of situation coping pattern was significantly related to personal impact, familial and social impact, coping impact, and caregiver burdens impact. Coping behaviours directed at understanding the medical situation were significantly related to impact on caregiver burdens.

**Abenis-Cintron (1996)** examined the health-related beliefs, stressors, coping strategies, and help seeking behaviours of 17 inner-city Latino caregivers with HIV infected Children. Results indicated that most caregivers perceived both biological and supernatural etiological agents for their child's illness. Caregivers used a variety of coping strategies including emotion and problem-focused approaches. Spirituality was a major coping strategy. Use of traditional curative practices served to enhance caregivers' positive sense of parental competency. In terms of help seeking behaviour, caregivers sought a few members of their immediate and extended family. Latina homemakers were considered extended family and often mitigated the stress caregivers experienced managing multiple demands.

**Engler (2000)** explored the role of coping on caregiver burden among a heterogeneous group of caregivers of persons living with HIV during the era of highly active antiretroviral therapy. A total of 58.8% of the caregivers were women. They had a mean age of 42 years; 61.9% cohabited with the persons living with HIV who had a mean CD4 count of 401. All three styles of coping were significantly positively correlated with caregiver burden. After controlling for demographic variables and caregiver depression, active-approach coping and distancing coping independently moderated the relationship between perceived severity of HIV-related symptoms (stress) and caregiver burden; however, some caregivers experienced burden even at low levels of stress. These results indicated that in the era of highly active antiretroviral therapy, coping mitigated the effect of stress on most influential predictor of caregiver burden, white and male caregivers experienced greater burden, independent of level of involvement and other caregiver characteristics. Receiving
instrumental support with caregiving, buffers the impact of high objective demands on subjective burden.

Author (2005) explored how caregivers, children, and young people cope with the impacts of the HIV/AIDS epidemic in the Tanzania. Female members of the extended family, especially grandmothers, were a vital source of support for women living with HIV, whose ability to care for their children was reduced due to their illness. Young people took on responsibilities to care for their immediate relatives and helped to meet the survival needs of the household. Some young people, shunned by their extended family following the death of a parent, migrated to urban areas and to seek a living in the informal sector as a survival strategy.

Maternal Coping

Hardy, Routh, Armstrong & Albrecht (1994) Compared coping strategies and communication of 3 groups of preschool children and their parents. One group was composed of children infected with HIV who displayed clinical symptoms of the disease; the 2nd group was composed of children diagnosed with cancer; and the 3rd comparison group was composed of healthy children. Results indicated that the parents of children with life-threatening illnesses reported greater degrees of wishful thinking than did parents of controls. Parents of healthy children reported more self-criticism than did parents of children in the 2 disease groups, a finding that seems to be related to SES and the child's age. Parents of children with HIV reported more wishful thinking than did parents of children with cancer. Significantly more children with cancer were aware of their diagnosis than were children with HIV.

Riccobono (1995) studied maternal coping, depression and stress and their relationship to infant development were examined in HIV+ mother-infant dyads. Mothers utilized emotion-focused coping significantly more often than both problem-focused and avoidant strategies. Avoidant coping was the least used mode of coping. Emotion-focused coping was associated with lower levels of maternal depression and lower perceived stress, and was favourably related to both infant cognitive development and infant sero-reversion to HIV negative status. Avoidant coping was associated with increased maternal depression. Problem-focused coping
had virtually no effect on maternal or infant variables. Stress accounted for 42% of
the variance in maternal depression.

Gay (1996) brought out the relationship of risk and resistance factors to level of
psychological distress among HIV infected mothers. As a group, mothers infected
with HIV reported significantly higher levels of distress and less satisfaction with
their social support, even when compared to a demographically similar control group.
A disengaged style of coping and low satisfaction with social support were
significantly associated with self-reported psychological distress. In addition, the use
of a disengaged coping style was associated with lower ratings of maternal positive
affect. An engaged coping style was found to have no relationship to self-reported
psychological distress or to maternal positive affect and maternal engagement during
mother-child interaction.

Latham, Sowell, Phillips & Murdaugh (2001) examined family composition and
functioning in a cohort of HIV-infected women of reproductive age. Results show that
women reported that their families functioned moderately well. Multiple regression
analysis showed that level of education, life satisfaction, and coping through
avoidance and coping by seeking social support were positively associated with
family functioning. In contrast, a history of interpersonal verbal violence and a
history of drug use were negatively associated with family functioning. These 6
factors accounted for 26% of the variance.

Coping in families

Martin, Wolters, Klaas, Perez & Wood (2004) described the coping strategies
among families of HIV-infected children and how they relate to medical, central
nervous system (CNS) and family environment factors. Results indicated that
families' passive coping and spiritual support were among the coping techniques
used most often, and social support was used least often. Medical variables were
unrelated to any coping styles. Families of children with CNS impairment endorsed
more passive coping techniques than families of children with no apparent deficits.
A trend was found for non-biological caregivers to seek out more community
resources and support than biological caregivers.
Children and families affected by AIDS struggle not only with the devastating physical effects of the disease, but also with a complex, interdependent set of environmental, psychological, and societal factors. Attempts to cope with separation and loss as well as significant issues of secrecy and stigmatization frequently isolate these families and prevent them from receiving appropriate physical and mental health care. Caregivers used a variety of coping strategies including emotion and problem-focused approaches. Spirituality was a major coping strategy. Coping behaviours that focus on strengthening family life and relationships and developing and maintaining a positive outlook on life were most often reported as helpful by parents. The family integration, cooperation and optimistic view of situation coping pattern was significantly related to personal impact, familial and social impact, coping impact, and caregiver burdens impact. Coping behaviours directed at understanding the medical situation were significantly related to impact on caregiver burdens. Families' passive coping and spiritual support were among the coping techniques used most often, and social support was used least often. A trend was found for non-biological caregivers to seek out more community resources and support than biological caregivers.

No Indian articles on coping of the caregivers of children living with HIV/AIDS were found.

Sources of support for the caregiver

Mellins & Ehrhardt (1994) explored stress and coping among inner-city, ethnically diverse families with HIV-infected children. Results revealed that the majority of caregivers were single mothers who were overextended with caregiving responsibilities. Compared with uninfected caregivers, HIV-infected parents reported more isolation and fewer financial and support resources. All children were particularly vulnerable to separations and loss, with uninfected siblings reporting anger and burden from caregiving tasks. Although some families had coping resources, many families would benefit from family-focused mental health services.
Caregivers (Abenis-Cintron, 1996) reported their major stressors as comprised of managing multiple demands including their own and their child's health care needs, emotional demands such as depression and anxiety, diminished sources of support, and recent life events including death of loved ones due to AIDS. Differences in health-related beliefs and expectations between caregivers and health professionals were another source of stress for some caregivers.

Scott Douglas (2001) attempted to study the differences between birth mothers and other caregivers on key demographic, stressor and social support variables. In addition, this study explored the buffering effect of specific sources of social support upon the caregiver. Many caregivers were in poor health, with some also caring for additional sick children. However, birth mothers had more health difficulties that placed limits on their activities in the home, lower formal education, less support from their family, friends, and church/spirituality than their counterparts. Birth mothers also reported more perceived stress and less arousal than did other caregivers. Yet, it was also found that other caregivers provided care for significantly more HIV positive children, as well as more other ill children. There were no differences between birth mothers and other caregivers on illness management, support from the index child, connections with the community, and formal service support. Support from friends had a main effect, and child support's interaction with illness management had a significant impact. Thus, it might be that some sources of social support exert a buffering effect while others demonstrate a main effect, depending upon the specific crisis at hand.

The support of close family relationships and the care shown by their community and religious fellowships helped meet many of patient’s emotional, social, and spiritual needs, accessible pain relief, affordable clinic or inpatient care when required, and help to cope with the burden of care was among the key needs of patients (Grant, Murray, Grant & Brown, 2003).

Aga et al (2009) have presented the cultural and social - structural factors that influence care and caregiving from the perspectives of the family caregivers of people living with HIV/AIDS. The socio cultural factors that influence care and caregiving vary from place to place, with both beneficial and harmful effects on the health of the
caregivers. Four important socio cultural factors that influence care and caregiving have been identified: religious beliefs, economic issues, education, and social stigma and discrimination.

**Social support and coping**

Among the findings which emerged from particular studies were that HIV-infected women received the highest support from medical personnel and the least from families (*Sienhold 1999*), just over half of women were actively involved in a social support network, and less than half of all family members who were aware of their HIV status are supportive (*Weiner & Lorber 1998*). Similarly, some studies reported a decline in traditional networks of support in the community (within the African context) (*Mbaye & Mbaye 1998*). In contrast, many women received relatively high levels of support from their children (*Weiner & Lorber 1998*), a factor which was associated with increased levels of maternal distress (*Kotchick et al. 1997b*). This was indicative of the fact that supportive children tend to act as substitutes in the absence of more adaptive sources of adult support, and further that children were unable to effectively meet the emotional needs of their ill parents/caregivers (*Klein et al. 2000*). Alternatively, mothers were more likely to experience their children’s need to support them as symptomatic of the failure of their caregiving role. This interpretation was further supported by the fact that higher levels of parenting support were associated with reduced perceptions of parenting self competence in HIV-infected women in contrast to non-infected women (*Dorsey, Klein & Forehand 1999*).

The lack of support for women and mothers was further likely to strain their caregiving capacity, given that support available to the caregiver can improve quality of caregiving, thereby protecting children from maladjustment (*Black, Nair & Harrington 1994*). Further, research had shown that support from parents was more protective of children’s well-being than support from less significant or less proximal others. Thus while higher levels of emotional support from neighbours and friends were associated with less psychological distress amongst children (and women) (*Klein et al. 2000*), the association was weaker than with children’s perceptions of parental support (*Kotchick et al. 1997b*). Further, while extra familial support served
as a buffer against internalising problems, parental support served as a buffer against both internalising problems (as reported by parents) and child-reported depression (Kotchick et al. 1997b). In addition to HIV positive women’s lack of support which had potential adverse implications for both their and their children’s well-being, they frequently used ineffective coping strategies. Women, especially those with lower incomes, were shown to disengage behaviourally and emotionally from coping with illness and to approach their interpersonal relationships in a less secure and more anxious style, resulting in higher levels of stress in their daily lives than those who used more adaptive strategies (Koopman 2000). Other ineffective strategies which HIV-infected women frequently used included emotion-focused ones such as denial (due to refusal to accept their status), concealment (due to fear of abandonment and the desire to avoid placing additional stressors on uninfected children), and isolation and crying (due to depression and attempts to avoid potential rejection) (Hackl et al. 1997; Uthis 2000). Another study, however, found that HIV positive mother’s emotion-focused, as opposed to avoidant or problem-focused, coping was associated with lower levels of maternal depression and healthy infant cognitive development (Riccobono, 1995).

Other research on coping had found that the appraisal of stress as challenge rather than threat or loss, and more problem-focused coping, tended to be associated with higher role satisfaction amongst HIV-infected caregivers (Uthis 2000). Further, children’s increased use of avoidant coping strategies that gave rise to increased internalising problems was predicted both by parent-child relationship problems and parents’ depressive symptoms (Steele, Forehand & Armistead 1997). The latter finding provides support for the link between maternal well-being, parent-child relationships or caregiving, and child adjustment.

Several studies had found evidence for the positive effects of social support for people living with HIV/AIDS (PLWHA), including the benefits to overall quality of life for those with and without access to antiretroviral treatments (Burgoyne & Renwick 2004; Kirksey, Hamilton & Holt-Ashley 2002). However, one study showed that HIV positive women and mothers were 50% more likely than HIV positive men to have unmet needs for social support (Sambamoorti, Crystal & Dermatis 1995), while another found that both HIV infected women and their children received lower
levels of socio emotional support than a matched group of non-infected mothers and children (Klein et al. 2000). HIV positive women were found to experience significantly less socio-economic, spiritual and family support than HIV negative women (Majumdar 2004). Many infected mothers were either reluctant to, or desist altogether, from seeking assistance (Ciambrone 2003; Thorne 1990). For these women, soliciting support was equated with being a failure as a caregiver, thereby resulting in isolation that places their mental health at further risk (Freeman, 2004).

No Indian studies on the relationship between social support and coping were found.

ART Adherence

In a study (Wrubel, Moskowitz, Richards, Prakke, Acree & Folkman, 2005) found that adherence practices were impacted in a positive way by mothers' commitment to adherence, and in a negative way by feelings of stigma and guilt, by the effects of bereavement on children and by children adopting their mothers' attitudes about medications. The interactive process of giving medication was shaped by children's behaviour, mothers' developmental expectations for children, and, for mothers with HIV, their adherence for themselves. They found that pediatric adherence often came at a cost to the caregiving mother's well-being.

Polisset, Ametonou, Arrive, Aho & Perez (2009) assessed paediatric adherence to ART and examined associated factors among children in West Africa. Of these, 42% of caregivers declared perfect adherence. The major factors relating to child non-adherence were: being female, living in an individual setting (vs. compound with enlarged family), receiving other ART than an NNRT-based regimen, drug regimens with six pills/spoons or more per day, caregiver other than biological parent, caregiver not declaring HIV-status, not participating to support groups and having perceived difficulty of antiretroviral (ARV) administration.

Weigel, Makwiza, Nyirenda, Chiunguzeni, Phiri & Theobald (2009) followed children who were started on ART between 8 months and 12 years of age over a median time on ART of 33 weeks. 72% never missed a single dose according to
caregivers' report and 82% of clinic visits were either as scheduled, or before or within 1 week after the scheduled appointment. Caregivers were generally knowledgeable about ART and motivated to support children to adhere to treatment despite facing multiple challenges. Caregivers were particularly motivated by seeing children begin to get better; but faced challenges in meeting the costs of medicine and transport, waiting times in clinic, stock outs and remembering to support children to adhere in the face of multiple responsibilities.

Indian studies

Gupta (2010), assessed adherence to ART and factors influencing it in HIV infected children in New Delhi. 6% subjects took medication themselves, while mother, father or other relatives were responsible for administering drugs in 57%, 4% and 17% respectively. The reasons for non adherence were forgetfulness of the caregiver, neglect at an orphanage, recent stressful event and change of caregiver. 6% of cases experienced side-effects on ART, but this did not affect adherence. Additional burden of co-medication was also not found to be associated with non-adherence.

Kinikar et al (2010) conducted a study to understand the factors that may help to improve ART adherence in paediatric age group. Factors associated with poor adherence were male sex, WHO stage I and IV, school going children, Mother to child mode of transmission and immunological stage III.

Caregivers were generally knowledgeable about ART and motivated to support children to adhere to treatment despite facing multiple challenges. Caregivers were particularly motivated by seeing children begin to get better; but faced challenges in meeting the costs of medicine and transport, waiting times in clinic, stock outs and remembering to support children to adhere in the face of multiple responsibilities. The study found that adherence practices were impacted in a positive way by mothers' commitment to adherence, and in a negative way by feelings of stigma and guilt, by the effects of bereavement on children and by children adopting their mothers' attitudes about medications. Some of the caregiver characteristics are common for reasons in non-adherence in international studies and studies from India except gender differences.
Psychosocial and family factors

Goode et al (2003) in a preliminary survey of parents of children receiving Highly active anti retro viral therapy( HAART) in Australia showed that although parents report high levels of child adherence to HAART, specific features of the medication regimen, such as taste and number of medications made administration of HAART extremely difficult.

Dolezal et al (2003), compared children's reports of their HIV medication adherence to those of their adult caregivers. Results showed that adherence problems were common, although the level of agreement between the child and the adult was quite low. Compared to adult-child dyads that agreed, dyads that disagreed tended to include older children who had more responsibility for managing their own medications.

Mellins et al (2004) examined child psychosocial and caregiver/family factors influencing adherence to ART in perinatally HIV-infected children. Results showed that non-adherence was significantly associated with older child age, worse parent-child communication, higher caregiver stress, lower caregiver quality of life and worse caregiver cognitive functioning, and of borderline significance in its association with increased (child responsibility for medications, HIV disclosure to the child and child stress, caregiver/family factors were the most strongly associated with non-adherence, including worse parent-child communication, higher caregiver stress, less disclosure to others and quality of life.

Hansudewechakul, Jourdain & Plangraun (2006) in a comprehensive programme to strengthen adherence to antiretroviral drug therapy in HIV infected children in Thailand. Results revealed that ninety per cent of children during the first 6 months of therapy and 87% during the following 6 months adhered to over 95% of the scheduled drug intakes (pill count). Children over 9 years old and children cared for by grandparents were less likely to be adherent.

Naar-King et al (2006) explored which psychosocial factors associated with caregivers' adherence and child health outcomes. Caregiver drug and alcohol use and
HIV+ status were associated with non-adherence and elevated viral load. Negative outcome expectancy was associated with lower adherence but was not significant in the multivariate analyses. Family factors were not significant, but these measures had low reliability in this sample. Extra-familial factors such as dissatisfaction with medical specialty care and more stressful life events were not directly associated with adherence but were related to increased caregiver substance use.

Nicolson et al (2006) examined whether caregivers' knowledge and self-efficacy was associated with better clinical outcomes and ART adherence among HIV-infected children. While caregivers correctly answered 74% of the knowledge questions, specific misconceptions were noted. Caregivers rated themselves as having high adherence self-efficacy, but were least confident in their ability to adhere to ART if it caused side effects or might result in social disclosure. Higher caregiver treatment-related knowledge and self-efficacy were associated with better clinical outcomes.

Naar-King et al (2009) described allocation of responsibility for illness management in families of children and adolescents perinatally infected with HIV. Approximately one-fourth of the youth reported being fully responsible for taking medications. A smaller percentage of caregivers reported full youth responsibility. Older youth and caregivers of older youth reported higher degree of youth responsibility for medication-related tasks, though age was unrelated to adherence. Caregiver report of greater responsibility for medications was associated with better adherence.

Vreeman et al (2008) described self- and proxy-reported pediatric ART adherence in a resource-limited population in western Kenya and investigated associated contextual factors. Results revealed that only 33% of children had both parents living when they started ART. Twenty-one percent had only father dead, 28% had only mother dead, and 18% had both parents dead. Twenty-nine percent reported imperfect ART adherence. The odds of ART non adherence increase for children with both parents dead. Fifty-seven percent of children had imperfect clinic adherence. There was no significant association between orphan status and imperfect clinic adherence.
Indian study

Mary Julie & Jeyapaul Sunder Singh (2010) conducted a study among children living with HIV between the age group of 7 and 14 years as the need to encourage children towards adherence was felt essential. The infected children through parental transmission were not aware of the importance of adherence to treatment. This had resulted in many being casual of their treatment often related to family problems, peer tensions and educational problems. 20 children between the age group of 12 and 15 years were selected for treatment education programme. The treatment related information was developed in making it more child friendly using child friendly participatory techniques. The sessions were conducted over a period of six months and were followed-up to ensure adherence among children in the group. The care takers, mostly grandparents and widows from rural areas were also trained on the HIV and AIDS treatment information. There was a massive change in the majority of children in adhering to treatment. Out of the 20 children, about 18 showed good adherence to treatment and supported by their informed care takers, while the 2 children showed casual attitude towards treatment, as there were no proper care by their care takers.

Caregiver report of greater responsibility for medications was associated with better adherence. Caregivers rated themselves as having high adherence self-efficacy, but were least confident to adhere to ART if it caused side effects or might result in social disclosure. Adherence problems were common, although the level of agreement between the child and the adult was quite low. Compared to adult-child dyads that agreed, dyads that disagreed tended to include older children who had more responsibility for managing their own medications.

Disclosure and ART adherence

Lester et al (2002) found that only 43% of children had been told their HIV diagnosis. They studied that factors influencing parental decision to disclose the child's HIV status including parental communication style, parental illness, child's rights, treatment adherence, child questions and provider pressures, whereas concerns
about HIV stigma and potential emotional distress were most frequently identified as reasons for nondisclosure.

_Bikaako-Kajura et al_ (2006), found that complete disclosure of HIV status by caregivers to children and strong parental relationships were related to good adherence. Structural factors including poverty and stigma were barriers to adherence even for children who had had complete disclosure and a supportive relationship with a parent.

_Ferris, Burau, Schweitzer, Mihale, Murray, Preda, Ross & Kline_ (2007) found significant associations between not knowing the HIV diagnosis and death, and knowledge of one's own HIV infection status is associated with delayed HIV disease progression.

_Vaz_ (2008) found that nearly 50% had given their child no information, 15% had given partial information; and 33% had provided misleading information. He also found these patterns to be associated with: caregiver gender, age, and stigmatizing attitudes placing blame for infection; child's age; and characteristics of the caregiver-child relationship. Caregivers were influenced to disclose by concerns about treatment adherence, the eminent onset of adolescent sexual activity, and their desire to protect their child as well as others. Children experienced disclosure as a discrete event; although many had subsequent questions and concerns, most did not discuss them with others.

_Vreeman et al_ (2010) found that most of the caregivers had not told the children they had HIV. Caregivers believed that disclosure might have benefits such as improved ART adherence, especially for older children, and better engagement of a helping social network. They also feared, however, that disclosure might have both negative psychological effects for children and negative social effects for their families, including discrimination.

No Indian studies on the associations between disclosure and ART Adherence were found.
Challenges in paediatric HIV are extremely unique, especially those concerning disclosure of their status. Parental dilemma regarding disclosure should never be ignored. A number of studies have been conducted in the developed countries. But Indian studies are sparse. The researcher studied the parental awareness and concerns related to disclosure in the present study.

**BARRIERS to ART adherence**

**Marhefka (2003)** assessed adherence to antiretroviral medications among children with HIV infection. Results show that 33% of caregivers failed to correctly identify at least one of their child's medication names, 31% of caregivers failed to correctly identify the dosage for at least one medication, and half of the caregivers failed to correctly identify the specific dietary requirements for at least one medication. Adherence to medication-taking frequency varied by assessment modality. Results of the 24RI suggest that 87% of children were at least 80% adherent; however, results of the pharmacy refill history suggest that only 46% of children were at least 80% adherent. When adherence to the prescribed interval was examined with the 24RI, 47.3% of doses given were deviant from the prescribed interval by at least one hour, while 17.3% of doses given were deviant by at least 2 hours. Results of the 24RI also suggested that the average child was adherent to medication-specific dietary requirements 75% of the time. Twenty-two different barriers were reported and fall into three general categories: (a) medication-specific attributes, such as the size or taste of pills; (b) problems with scheduling or routine; or (c) problems with the child resisting, refusing, or hiding the medication.

**Roberts, (2005),** examined from the perspectives of both HIV-infected children and such children's primary guardians, the barriers children faced in adhering to combination antiretroviral therapies in an exploratory study. The barriers children faced in adhering to combination antiretroviral therapies were family daily routines; medication side effects; medication taste, size, and shape; the stigma of HIV/AIDS; medications as a reminder of HIV/AIDS; and child deception. The findings underscored the difficult nature of the antiretroviral regimens and illuminate the daily obstacles children faced in adhering to therapy.
No published Indian studies were found on barriers to ART Adherence.

Twenty-two different barriers children face in adhering to combination antiretroviral therapies fall into three general categories: (a) medication-specific attributes, such as the size or taste of pills; (b) problems with scheduling or routine; or (c) problems with the child resisting, refusing, or hiding the medication. The findings underscore the difficult nature of the antiretroviral regimens and illuminate the daily obstacles children face in adhering to therapy.

2.2 Studies on HIV Infected Children’s Behavior

The studies on HIV infected children have been further sub grouped under various categories for better clarity and understanding.

A. Profile of Infected children
B. Academic performance
C. Behavior of children living with HIV/AIDS
D. Psycho social impact of HIV on Children living with HIV/AIDS
   - HIV and its impact on child development
   - Psychosocial adjustment
   - Mental Health of HIV infected children
   - Quality of life of HIV infected children
   - Disclosure of HIV status to children
   - HIV and growth/nutrition
   - Caregiver-child relationship and parental monitoring
   - Children as caregivers

2.2. A: Profile of HIV infected children

This section describes on socio demographic profile of HIV infected children.

Burgous, Hernandez-Reif, Mendoza, Castillo, and Shor-Posner (2007) assessed the 52 Dominican Caregivers’ perception of HIV-infected Dominican children’s behavior. As the majority of HIV+ Dominican children were infected through vertical
transmission, mothers were assumed to be infected as well. In the total group, More of the males tended to be in school (87.5%) compared to females (33%). The majority (82%) of the younger children (< 6 years) had CD4 cell counts $ 500 cells/mm$^3$, with similar counts among females and males. Whereas most of the young children (2–5 years) were female (68 %), in the older group (n = 14, $ 6 $ years of age), most were male (57%). The majority (86%) of the older children had CD4 cell counts $ 200 $ cells/mm$^3$ with a similar proportion among females (83%) and males (88%).

Gathia (2008) reported that around 90% of children living with HIV acquired the infection from their mothers during pregnancy, birth or breastfeeding.

Indian studies

Sarna (2006) Most children were diagnosed as being HIV positive after they were two and a half years or older and most often they were tested only when one or both parents report positive, 77 percent of the children were more than 5 years of age and more than 80 percent had been diagnosed after the age of two and a half years. The late diagnosis of the positive status of children indicated a delay in treatment. It also means there is a gap with regard to PPTCT (prevention of parent to child transmission) as an entry point for diagnosis and access to treatment. Among the key findings of the study were the difficulties faced by a third of the caregivers in getting confirmed a HIV diagnosis and getting referred to treatment centers. Since 60 per cent of the infected were extremely poor, earning about Rs 3000 a month and they had financial problems to get the tests done and to access drugs. The average duration of the treatment for children studied was 14 months.

Shivakumara (2010), in a retrospective cohort study done among 61 children to assess the outcome of Care, Support and treatment of Children Living with HIV at a Community Care Centre (CCC) reported that 89% of the Children Living with HIV were provided care at the CCC had been registered at ART centres with 30% ever started on ART. 3% of children had died during the follow up period. 10% of children were orphans and 36% were with single parents. All the children had contracted infection through mother to child transmission but 36 % of adolescents were infected through the heterosexual route.
Lokesh, Gupta, Sanjeev & RoopKumari (2010) provided important information regarding the epidemiological profile, socio-demographic characteristics, clinical profile, and follow-up pattern of HIV-positive children attending the ART centre. The results show that the median age for children attending ART centre was 10 years 5 months. The median time from diagnosis of HIV-infection was 36.5 months. Vertical transmission was seen in 89.5%, 72.4% were on ART with median time on ART of 25 months. Adherence of >95% was observed in 99% children on ART. 27.61% were normal weight for age, 72.39% children with varying degrees of malnutrition. Stunting was observed in 47.62%. 83.3% children were in WHO stage II of HIV infection, 11.9% in stage III and 4.3% in stage IV. Tuberculosis was most common opportunistic infection with 17.6% among infected children.

Biswas, Goverdhan & Shaleen (2010) conducted a midline survey in order to track the changes against the child-centered Home and Community-Based Care and Support programme (CHAHA) programme indicators comparing the baseline at different levels to increase the effectiveness. A multi stage sampling design was adopted. 1630 children in the age group 10-17 years were covered along with their parents/caregivers in 1330 households across the four states. Study results revealed that one fifth percent belonged to the 'low SLI' households. 75 percent children in the age group 0-17 years got registered under the CHAHA. One fifth of the children were orphans, out of them 26 percent were staying with their grand- parents or relatives. Orphaned Children living with HIV/AIDS (CLHIV) and Children affected by AIDS (CAA) were attending school.

From the above studies, Most of the children had contracted infection through mother to child transmission but 36 % of adolescents were infected through the heterosexual route. Most of the Children Living with HIV had been registered at ART centres with 30% ever started on ART. One third of the children were living with single parents. The median time from diagnosis of HIV-infection was 36.5 months. The studies revealed that many belonged to the low income households. One fifth of the HIV infected children were orphans, out of them 26 percent staying with their grand- parents or relatives.
2.2. B: ACADEMIC PERFORMANCE

A more positive parent–child relationship (Armistead et al, 1997) was related to lower levels of child depression and externalizing problems and to better grades.

Yang, Wu, Duan, Li, Li, X. Shen, Mathur & Stanton (2006) conducted a survey to on living environment and schooling of children with HIV-infected parents in southwest China to study the lives of children with HIV-infected parents. Registered HIV-infected drug users and their households were approached and information about the living environment of children ≤ 15 years of age was collected. Of the 266 households interviewed, there were 213 children ≤ 15 years old. Forty percent of the children had lost at least one parent. Most of the children resided in a household with low economic status and a high dependency ratio. One-half of the children experienced discordant family relations, family anxiety and shame. Compared to orphans, non-orphans and their families were less likely to receive social support from the community. Orphans and older children were less likely to attend school and more likely to be truant if enrolled in school. Findings in the current study suggested that many children whose parents were infected with HIV or had died from HIV were living in stressful environments with minimal support from the community.

Brackis-Cott, Kang, Dolezal, Abrams & Mellins (2009) explored the language ability and school functioning of early adolescents with perinatal HIV/AIDS of 9-15 year old infected children. They had reported poor performance of 9-15 year old infected children on tests of verbal and reading ability while describing the language ability and school functioning of early adolescents with perinatal HIV/AIDS. They have also demonstrated that although language and attention functioning were generally found to be not different from the normal children, intellectual functioning seemed to be less compared to normative group.

Using both self-report and teacher evaluation data of 1625 children from rural central China, (Xu, Yan, Duan, Wang, Rou & Wu, 2009) examined the impact of parental HIV/AIDS on children's school performances (academic marks, educational expectation, and student leadership) and school behaviours (e.g., aggression, shy/anxious and assertive social skills). Results indicated that AIDS orphans and
vulnerable children had disadvantages in school performances in comparison to their peers from the same community who did not experience AIDS-related death and illness in their family (comparison children). AIDS orphans had the lowest academic marks based on the reports of both children and teachers. Educational expectation was significantly lower among AIDS orphans and vulnerable children than comparison children from teacher's perspective. AIDS orphans were significantly more likely to demonstrate aggressive, impulsive and anxious behaviour than non-orphans. Moreover, orphans had more learning difficulties. Vulnerable children were also at a disadvantage on most measures.

No Indian studies were found on Academic performance of Children living with HIV/AIDS.

AIDS orphans and children with AIDS, had disadvantages in school performances, reported more of learning difficulties. Educational expectation was significantly lower among AIDS orphans and vulnerable children from teacher's perspective. Studies had reported poor performance of infected children on tests of verbal and reading ability. Studies had also demonstrated that although language and attention functioning were generally found to be not different from the normal children, intellectual functioning seemed to be less compared to normative group. A more positive parent–child relationship was related to lower levels of child depression and externalizing problems and to better grades.

2.2. C: BEHAVIOR OF CHILDREN LIVING WITH HIV/AIDS

Caregiver concerns (Coleman, 1991) often involved the ambiguity of certain caregiving situations, such as dealing with toddlers who displayed frequent biting behaviour, changing diapers, and dealing with a family's emotional needs. They found that children whose mothers were seropositive reported more externalizing problems. Infected mothers reported less age-appropriate supervision / monitoring relative to non-infected mothers. Only among HIV-infected mothers was refraining from engaging in inconsistent disciplinary tactics associated with lower reports of internalizing and externalizing problems. Caregiver concerns often involved the ambiguity of certain caregiving situations, such as dealing with toddlers who display frequent biting behaviour, changing diapers, and dealing with a family's emotional
needs. Children sworn to secrecy demonstrated lower social competence and more externalizing problems. Knowing more than mothers had themselves disclosed was related to child maladjustment across multiple domains.

A medical overview of paediatric HIV, a review of natural history studies (Lewis, Haiken & Hoyt. 1994) and study of older children provided the basis for a definition of long-term survivors of paediatric HIV infection. The non-categorical approach to examining the common consequences of paediatric chronic illness and a description of unique aspects of HIV disease provided the framework for a discussion of the psychosocial and developmental issues for long-term survivors of paediatric HIV. This analysis lead to the conclusion that long-term survivors of paediatric HIV, with a few exceptions, were in many ways like their peers with other chronic illness.

Campbell, (1997) reported that neurological and associated conditions were common in children and frequently take the form of developmental delay, neurological symptoms, specific cognitive difficulties and sometimes behavioural problems. However, there were a growing number of children who survive for longer, due in part to advance in medical understanding, but in whom visuo-spatial and language problems were common. It was difficult to separate the effects of HIV and in utero drug exposure but recent studies point to the effects of parental IV drug use as more important than HIV in the emergence of behavioural difficulties in HIV positive children. Factors such as chronic illness, stigmatization of HIV and missed schooling might also contribute to psychological and emotional difficulties.

Hoover (1998) investigated the frequency and intensity of behaviour problems exhibited by Human Immunodeficiency Virus (HIV)-infected toddlers ages 16 to 40 months by comparing them to HIV-exposed toddlers, toddlers at risk for developmental delays, and healthy toddlers. The role of maternal factors, such as depression, insularity, and stress, in behaviour ratings also was considered. It was hypothesized that HIV-infected children would demonstrate a higher frequency and intensity of behaviour problems than children in the three equivalent control groups. With regard to maternal factors, it was expected that mothers of HIV-infected and HIV-exposed children would endorse higher levels of depression, insularity, and stress than mothers of developmentally at-risk or healthy toddlers. Results indicated that HIV-exposed
toddlers exhibited a significantly higher frequency of behaviour problems than healthy control toddlers. Contrary to expectation, HIV-infected toddlers' behaviour did not significantly differ from any group. HIV-infected mothers reported higher levels of depression and insularity than uninfected mothers. For HIV-infected mothers, a higher frequency of behaviour problems was significantly associated only with parental stress.

Mothers reported (Armistead et al, 2001) whether they disclosed their HIV status to the child and assessed the child's functioning. Less than one-third of mothers disclosed their HIV status to their children. Disclosure was associated with mother's income level and perceived severity of physical symptoms. In addition, children disclosed to were more often older and female. Contrary to expectation, disclosure was not related to child functioning.

Bauman, Camacho, Silver, Hudis & Draimin (2002) in their study examined the relationships between selected risk and resistance factors and maternal reports of child behaviour problems on the Child Behaviour Checklist (CBCL) in families affected by maternal HIV/AIDS. Data were obtained from 193 mothers with late-stage HIV/AIDS who were included in a sample consecutively recruited from the New York City Division of AIDS Services Income Support to participate in Project Care, a randomized trial of a permanency planning intervention. Results indicated that Child behaviour problems were related significantly to the mother's psychological distress and marginally to her having illness-related activity restrictions, but not to other measures of maternal physical health, stigma or disclosure of her HIV to the child. Two child dispositional factors, productivity and independence, and two family factors, adaptability and a good parent-child relationship, were related to better child functioning, but family cohesion was a risk factor for poorer adjustment in this sample.

Jeifez-Zagagi (2005) investigated the role of family system, illness knowledge and demographic factors in the prediction of child Health Related Quality of Life (HRQoL) in HIV-infected children between the ages of 6 and 16. Factors examined included parental mental and physical health, family functioning, social support, stressors, and parental HIV knowledge. Demographic factors examined were child's
gender and child's placement with parent or other caretaker. Children's responses on five domains of the Child Health Questionnaire - Child Form (CHQ-CF87), a measure of paediatric HRQoL, served as the outcome measure. The five domains of HRQoL were self-esteem, behavior, mental health, physical functioning and general health perceptions. Secondary analyses were conducted and revealed that parental mental health was significantly associated with general health perceptions, one of the domains of child HRQoL. Furthermore, children living with biological parents reported significantly lower self-esteem scores and more behaviour problems than children living with another relative (e.g. aunt, grandmother).

Rotheram-Borus, Stein & Lester (2006) evaluated the longitudinal impact of a family-based intervention on grandchildren of parents with HIV (PWH). Results indicated grandchildren in the intervention condition reported significantly fewer internalizing and externalizing behavioural symptoms compared with grandchildren in the control condition. There was weak evidence that grandchildren in the intervention condition had higher scores on measures of cognitive development and more positive home environments.

Burgos et al (2007) explored an understanding of the potential behavioural issues involved in providing care to (2-8 years old) children without access to antiretroviral therapy, the Child Behaviour Checklist was administered to 52 caregivers of HIV Dominican children. The children were not receiving antiretroviral treatment. Both mothers and non-mothers perceived significant pathological internalizing behavioural symptoms in immuno-suppressed children, compared to children with less disease progression. Descriptive statistics revealed a high proportion of the children, both younger (approximately 40%) and older (46%) scored in the borderline/clinical ranges for internalizing problems, including anxiety, withdrawn-depressed and somatic complaints. In addition, 46% of the older children were perceived as having externalizing problems (rule breaking and aggressive behaviour). Analyses of gender comparisons revealed that older female children were perceived as withdrawn/depressed by their caregivers. These findings suggested that a high incidence of behavioural and mood problems may be prevalent among Dominican children with HIV.
Tompkins (2007) Disclosure was not related to child functioning. However, children sworn to secrecy demonstrated lower social competence and more externalizing problems. Differential disclosure, which occurred in one-third of the families, was associated with higher levels of depressive and anxiety symptoms. Knowing more than mothers had themselves disclosed was related to child maladjustment across multiple domains.

Tompkins & Wyatt, (2008) examined child psychosocial adjustment and parenting in 9-16-year-old youth from families affected by maternal HIV infection and same-age peers whose mothers were not infected. They found that children whose mothers were seropositive reported more externalizing problems. Infected mothers reported less age-appropriate supervision/monitoring relative to non-infected mothers. Better mother-child relationship quality and less impairment in parental supervision/monitoring of age-appropriate youth behaviours were found to be associated with externalizing difficulties among the HIV-positive group. Similarly, only among HIV-infected mothers was refraining from engaging in inconsistent disciplinary tactics associated with lower reports of internalizing and externalizing problems.

Among families (Murphy, Roberts & Hoffman, 2009) with more frequent family routines, over time adolescents showed lower rates of aggression, anxiety, worry, depression, conduct disorder, binge drinking, and increased self-concept. Among families with higher levels of parental monitoring, adolescents showed significant declines in anxiety and depression, conduct disorder, and binge drinking, along with increased self-concept. Mothers' level of illness was associated with parenting. Greater variability in parental monitoring resulted in higher levels of problem behaviours.

No Indian published articles on behavior of children living with HIV/AIDS were found.

Both mothers and non-mothers perceived significant pathological internalizing behavioural symptoms in HIV infected children. Studies have indicated that Child behaviour problems are related significantly to the mother's psychological distress and
marginally to her having illness-related activity restrictions. Toddlers infected with HIV exhibited a significantly higher frequency of behavioral problems. They were reported to be at risk for development delays. Parental stress with HIV infected mothers was found to be contributory factor for toddler’s behavioural problems. Analyses of gender comparisons revealed that older female children were perceived as withdrawn/depressed by their caregivers. Young children reported to exhibit internalizing problems including anxiety, depression and somatic complaints. Older children were perceived as having externalizing problems like oppositional and aggressive behaviour. Factors such as chronic illness, stigmatization of HIV and missed schooling also contributed to psychological and emotional difficulties. Children living with biological parents reported significantly lower self-esteem scores and more behaviour problems than children living with another relative (e.g. aunt, grandmother). The non-categorical approach to examining the common consequences of paediatric chronic illness, found that in a long-term survivors of paediatric HIV, were in many ways like their peers with other chronic illness.

2.2. D: PSYCHO SOCIAL IMPACT OF HIV ON CHILDREN LIVING WITH HIV/AIDS

HIV and its impact on child development

Several studies have found that parental illness and HIV/AIDS specifically, effects children’s development in a range of ways.

(a) Psychological effects

There was considerable evidence to indicate that the children of HIV positive women were likely to be at high risk for emotional and psychological problems (Armistead, Klein & Forehand 1995; Forehand et al. 1998a; Wild 2001). The nature of HIV/AIDS itself was found to lead to children’s experience being characterised by uncertainty, stigma, secrecy and isolation (Geballe, Gruendel & Andiman 1995; Antle et al. 2001; Wild 2001) resulting in their parents’ experience of HIV/AIDS becoming “unnamed, unspoken, and often unspeakable to children” (Nagler, Adnopoz & Forsyth 1995).
Children were reported to experience bio-psychosocial symptoms such as malaise, loss of appetite and sleep disturbance, increased attachment behaviours, regression, frightening fantasies, and the reactivation of premorbid psychiatric symptoms (Lewis 1995). At least some of these symptoms, in particular regression and the reactivation of previous symptoms, were likely to be the consequence of children’s feelings of hopelessness, loneliness, anger and confusion (Wild 2001). Adolescents reported feeling different, having secrets, worrying and difficulties with caretaking, grappling with core assumptions about life, and fearing death (Reyland, Higgins-D'Alessandro & McMahon 2002). They were also more likely to display destructive coping behaviours such as acting out (Hudis 1995), impaired school performance (Woodring 2000), and had (illegitimate) children and conflictual relationships with their mothers (Duggan 2000).

An important finding of the literature on the psychological effects of parental HIV/AIDS was that children were more likely to display internalising such as anxiety, depression, withdrawal and attention problems, than externalising symptoms such as aggression and behaviour problems (Elkin, Mellins, Ehrhardt, Grant & DuBose, 1995; Forsyth, Damour, Nagler & Adnopoz (1996); Kotchick, Summers, Forehand & Steele 1997b; Forehand, Jones, Kotchick, Armistead, Morse & Morse 2002; Gerstadt 2003; Wild 2001). Consequently, symptoms were masked from the attention of significant adults in the children’s environments (Forsyth et al., 1996; Kotchick et al. 1997b; Forehand et al., 2002; Gerstadt 2003). Alternatively, others suggested that children might under-report their symptoms and problems because they were not permitted by their mothers to discuss these topics openly (Gerstadt 2003).

(b) Cognitve effects
Research had shown that children of HIV positive mothers were at greater risk for lower levels of cognitive and social competence (Forehand et al. 1998a), as well as language disorders (Elkin et al. 1995).
(c) Psychosocial effects
HIV/AIDS also had a considerable range of psychosocial implications for children. Children were likely to be faced with the cumulative presence of “a set of material and psychosocial stressors” during the course of a caregiver/mother’s illness, as well as following their eventual death (Wild 2001; Hunter & Williamson 2002; Richter, Manegold & Pather 2004;). Studies showed that children were likely to experience economic deprivation and disrupted schooling, which could result in them becoming care providers and assuming increasing household responsibility in order to ward off problems regarding shelter, material needs and access to adequate health services (Fair et al. 1995; Foster & Williamson 2000; Wild 2001). Consequently children would become more vulnerable to abuse and exploitation (Foster & Williamson 2000; UNICEF 2004), and would experience a loss of educational opportunities and health status, and even increased exposure to HIV infection (Hunter & Williamson 2002). Adolescents reported frequent changes of residence (Duggan 2000), family role reassignments (Reyland, Higgins-D’Alessandro & McMahon 2002) and a lack of social supports and other resources (Hudis 1995; Reyland, Higgins-D’Alessandro & McMahon 2002); and experienced multiple losses, including loss of caregivers, stigma and isolation (Hudis 1995; Reyland, Higgins-D'Alessandro & McMahon 2002; Woodring 2000), and difficulties identifying and maintaining custody placements (Hudis 1995).

Psychosocial adjustment
Bettoli-Vaughan, (1995) conducted a study to investigate the psychosocial functioning of 37 siblings of HIV infected or HIV exposed children, by comparing them to 20 siblings of healthy children (controls). The children’s' HIV infection or exposure was due to perinatal transmission. Thus, each of the siblings' mothers was HIV positive. In addition, regression analyses were performed to examine the relationships between the independent variables (diagnostic group, demographic factors, family constellation variables, availability of social support and family resources, and maternal psychopathology) and the dependent variables (psychological adjustment, adaptive behaviour and general academic functioning), for all healthy siblings. Finally, the psychosocial effects of exposure to violence and maternal disclosure of the HIV/AIDS diagnoses were examined. All data were collected by maternal report because 73% of the siblings were reportedly unaware of their
brothers' or sisters' HIV diagnoses. Results indicated that there were no significant differences among the siblings in the three diagnostic groups (HIV infected, HIV exposed, and controls) on any of the dependent variables. The mothers' level of psychopathology, as measured by the SCL-90-R, was the only significant predictor of the siblings' internalizing and externalizing behaviour. The siblings' adaptive behaviour, in terms of daily living skills, could best be predicted by knowledge of the siblings' age only. The siblings' academic performance was not affected by having a brother or sister infected or exposed to HIV. Exposure to violence was a significant predictor of the siblings' externalizing behaviour problems. In contrast, knowledge of their brothers' or sisters' diagnoses did not adversely affect sibling functioning.

**Bose (1997)** examined adaptive functioning in HIV infected children as it related to neurodevelopment skills, disease parameters, and psychosocial characteristics. A secondary component of this study examined the effects of interim changes on adaptive functioning over a period of six months. Adaptive behaviour relates to a child's ability and willingness to engage in the activities of personal and community life in a developmentally appropriate manner. Adaptive functioning was not systematically or extensively examined in children infected with HIV or suffering from other chronic illnesses. Results indicated that adaptive functioning was generally related to neurodevelopment functioning, social-emotional and gross motor functioning, and mode of HIV infection. HIV related disease progression was generally a poor predictor of adaptive functioning at both baseline and follow up, but might have an indirect impact.

**Collins-Jones, (1997)** conducted a study to assess the emotional adjustment of children who had multiple family members diagnosed with an Acquired Immune Deficiency Syndrome (AIDS)/Human Immunodeficiency Virus (HIV). Specifically, descriptive data was collected to determine the degree of relationship among various combinations of the predictor variables (knowledge of parent/sibling illness, previous death experiences, participation in choosing future living situation, social support, and a history of a stable living situation) and each of the dependent measures. Fifty-two uninfected children of HIV positive women who had a sibling who was followed by the Paediatric AIDS Clinic at a large mid-Atlantic urban paediatric medical centre participated in this study. Children ranged from 6-16 years of age (M = 10.29, SD =
3.25). Four separate measures were used; three were completed by the uninfected sibling: The Children's Depression Inventory (CDI), the Revised Children's Manifest Anxiety Scale (RCMAS), and the Kidcope. The remaining measure, the Child Behaviour Checklist (CBCL), was completed by the caregiver. Descriptive statistics and multiple regression analyses were performed to test the theoretical model of adjustment created to assess the emotional adjustment of children who had multiple family members diagnosed with HIV/AIDS. As a group, these children were characterized by clinically elevated levels of psychological distress. Specifically, children who had experienced an HIV/AIDS related death in their family, had their parent's or sibling's diagnosis disclosed to them, had a lack of available social supports and/or lack a stable living environment were at greater risk for developing behavioural and/or emotional problems.

Steele, Tripp & Kotchick (1997) examined the relationships among parental and child uncertainty about fathers’ chronic illnesses and child internalizing problems. Results indicated that child’s uncertainty about the father's illness predicted both anxiety and depressive symptoms in the child, and that mother's uncertainty predicted child-reported anxiety beyond the child's uncertainty.

Campbell, (1997) reported that neurological and associated conditions were common in children and frequently took the form of developmental delay, neurological symptoms, specific cognitive difficulties and sometimes behavioural problems. However, there were growing number of children who survived for longer, due in part to advance in medical understanding, but in whom visuospatial and language problems were common. It was difficult to separate the effects of HIV and in utero drug exposure but recent studies pointed to the effects of parental iv drug use as more important than HIV in the emergence of behavioural difficulties in HIV+ children. Factors such as chronic illness, stigmatization of HIV and missed schooling also contributed to psychological and emotional difficulties.

Bisiacchi, Suppiej & Laverda (2000) evaluated neuropsychological profiles of 42 neurologically asymptomatic 6–15 yr olds born to HIV positive mothers; 29 of the subjects were infected at different stages of the disease, and 13 were non infected. Infected children were either mildly or more severely symptomatic, or had full-blown
AIDS. Results indicted Executive function impairments were present in all infected children, whereas memory and visuo-prassic deficits were evident only in those with full-blown AIDS. Language abilities and overall intelligence were spared. Performance of seroreverters was normal. These findings suggested that even in neurologically asymptomatic children, neuropsychological evaluation can identify early impairment of specific cognitive functions.

Holditch-Davis, Miles, Burchinal, O'Donnell, McKinney & Lim (2001) in their study described the development of infants of mothers with HIV and determined, using hierarchical linear models, the longitudinal effects of child characteristics, parental caregiver characteristics, family characteristics, and parenting quality on development. Eighty-one infants born to women with HIV and their primary parental caregivers were followed-up until 18 to 24 months of age; 53 infants were always cared for by their biologic mothers, 16 were always cared for by kin or foster parents, and 12 had primary caregiver changes. Predictor variables and developmental outcomes were obtained at enrolment and 6, 12, 18, and 24 months. Results showed that mental development and adaptive behaviour scores decreased over age. Infants with changes in their primary caregiver had lower motor and adaptive behaviour scores than infants remaining with consistent caregivers. Higher mental, motor, and adaptive behaviour scores were associated with more positive attention and more negative control, whereas better language abilities were associated only with more positive attention. Child, maternal, and family characteristics had lesser effects.

Bachanas, et al (2001) assessed for significant differences in psychological functioning between HIV-infected children and a demographically matched healthy control group and examined the utility of applying a stress and coping model to children with HIV disease. Participants included HIV-infected children and their 36 caregivers and a control group of 32 healthy children and their caregivers. The children's ages ranged from 6 to 16 yrs. During routine clinic visits, children completed measures of psychological adjustment, health locus of control, and coping style, and caregivers completed measures of their own and their child's psychological adjustment. Caregiver-reported and child self-reported psychological adjustment scores did not significantly differ between the HIV and control groups, with the
exception of significantly more internalizing behaviour problems reported in the control group. Hierarchical multiple regression analyses revealed that the stress and coping model accounted for 36% of the variance in HIV-infected children's self-reported psychological adjustment. In addition, child age and coping style were significant predictors of child self-reported psychological adjustment, but not of caregiver-reported child adjustment.

**McKee, Jones, Roland, Coffelt, Rakow & Forehand (2007)** examined whether child-reported maternal warmth and support moderated the association between knowledge of maternal illness and child psychosocial adjustment among 86 low-income, African American mothers with HIV/AIDS and their non-infected children. Mother-child relationship quality moderated the association between children's knowledge of maternal HIV/AIDS and children's externalizing, but not internalizing, difficulties. Consistent with the stress-buffering hypothesis, a warm and supportive mother-child relationship afforded a more robust buffer against externalizing difficulties for children who knew of their mother's illness than for children who did not.

**Tompkins & wyatt (2008)** examined child adjustment and parenting in twenty-three 9-16-year-old youth from families affected by maternal HIV infection and 20 same-age peers whose mothers were not infected. Results indicated that children whose mothers were seropositive reported significantly more externalizing problems. Infected mothers reported less age-appropriate supervision/monitoring relative to non-infected mothers. Better mother-child relationship quality and less impairment in parental supervision/monitoring of age-appropriate youth behaviours were associated with fewer externalizing difficulties among the HIV-positive group only. Similarly, only among HIV-infected mothers was refraining from engaging in inconsistent disciplinary tactics associated with lower reports of internalizing and externalizing problems.

**Indian study**

**Geeta, Krishnakumar, Ajil. Sona & Riyaz (2010)** had studied the psychological problems of early adolescents with HIV in a Pediatric HIV clinic in New Delhi. Case control design was used and 20 children (12 boys and 8 girls) were taken up for
analysis. The children in the study group were compared with a age and sex matched control group of children in the control group for psychological disorders. The children in the control group were selected from among those attending the hospital for minor illnesses. The results revealed that the adolescents with HIV scored high on the behaviour problems, conduct disorder and depression. Adolescents with HIV had significantly more anxiety compared to the control group.

The psychological problems of early adolescents with HIV revealed that they scored high on the behaviour problems, conduct disorder and depression. Adolescents with HIV had significantly more anxiety compared to the control group. Major themes highlighted by adolescents included loss, transitions, disclosure, coping, school implications, uncertainty, paradoxical situations, and support networks. Also of importance were the impact of parental attitudes and behaviour, AIDS education and awareness, and adolescents' cognitive capabilities. Children whose mothers were HIV positive was found to be having more externalizing problems. Infected mothers reported less age-appropriate supervision/monitoring compared to non-infected mothers.

The psychosocial functioning of HIV infected or HIV exposed children indicated that the siblings' academic performance was not affected by having a brother or sister infected or exposed to HIV. Exposure to violence was a significant predictor of the siblings' externalizing behaviour problems. In contrast, knowledge of their brothers' or sisters' diagnoses did not adversely affect sibling functioning. Child’s uncertainty about the father's illness predicted both anxiety and depressive symptoms in the child, and that mother's uncertainty predicted child-reported anxiety beyond the child's uncertainty. African - American Studies demonstrated that, a warm and supportive mother-child relationship afforded a more robust buffer against externalizing difficulties for children who knew of their mother's illness than for children who did not.

Emotional adjustments of children with multiple family members diagnosed with an HIV / AIDS was another area of interest for some researchers. It was found that as a group, these children were characterized by clinically elevated levels of psychological distress. Specifically, children who had experienced an HIV/AIDS related death in
their family, had their parent’s or sibling’s diagnosis disclosed to them, had a lack of available social supports and/or lack a stable living environment were at greater risk for developing behavioural and/or emotional problems.

Research studies have shown that mental development and adaptive behaviour scores decreased over age. Adaptive functioning was generally found to be related to neuro-developmental functioning, social-emotional and gross motor functioning, and mode of HIV infection. HIV related disease progression generally had an indirect impact on adaptive functioning. Neurological and associated conditions were common in children and frequently seen in the form of developmental delay, neurological symptoms, specific cognitive difficulties and sometimes behavioural problems.

**Mental Health of HIV infected children**

The HIV-positive infants (Peterson, 1995) were significantly less affectively expressive, and were significantly less securely attached than HIV-negative infants.

Each stage of HIV disease, including diagnosis of HIV infection, illness progression, late-stage illness, death, and family reconfiguration presents particular mental health challenges to infected parents and their affected children (Havens, Mellins & Pilowski, 1996). Children who were themselves HIV-infected would also confront the psychological issues of adapting to a chronic, terminal illness as well as the effects of HIV progression on development and cognition. HIV illness commonly struck in families already struggling with substance abuse, psychiatric disorder, and multi-generational histories of victimization and trauma. Where present, these problems complicated family adaptation to the stressors of HIV disease.

Pilowsky, Wissow & Hutton, (2000) discussed the plight of HIV-affected children, the work of mental health professionals with HIV-affected children and their families. A parent’s HIV infection was not the most pressing family issue. All HIV-affected children needed extensive support, particularly emotional support. Organizing mental health care for HIV-affected children required attention in the areas of prevention, resilience, and family and child development. School-age children exhibited more
internalizing problems or more global problems than those with HIV-negative parents. Disclosure of parental HIV status to children seemed to present more short-term problems, but fewer long-term effects.

**Rao, Sagar, Kabra & Lodha (2007)** reviewed on psychiatric morbidity in HIV-infected children, in the existing studies, a number of psychiatric illnesses including: depression, anxiety, disruptive disorders and hyperactive disorders were observed in HIV-infected children. A number of variables had a bearing on psychiatric morbidity, including experience and expression of physical illness as well as adherence to medications.

**No Indian published articles on mental health of children living with HIV/AIDS were found.**

Studies found that a number of psychiatric illnesses including: depression, anxiety, disruptive disorders and hyperactive disorders was observed in HIV-infected children. Children who were themselves HIV-infected would also confront the psychological issues of adapting to a chronic, terminal illness as well as the effects of HIV progression on development and cognition. HIV illness commonly affected families already struggling with substance abuse, psychiatric disorder, and multi-generational histories of victimization and trauma.

**Quality of life of HIV infected children**

Quality of life is a major area of interest for many studies. **Jeifez-Zagagi (2005)** found that the role of family system, illness knowledge and demographic factors were the key variables that affect quality of life. Factors examined included parental mental and physical health, family functioning, social support, stressors, and parental HIV knowledge. Demographic factors examined were child's gender and child's living arrangement with care taker. Furthermore, children living with biological parents reported to be having significantly lower self-esteem and more behavior problems than children living with other relatives.
Quality of life (Byrne & Honig, 2006) as perceived by parents was studied extensively by many researchers concepts. Parents perceived their children to be functioning at a level significantly lower than the normal in general health and physical functioning.

**Indian study**

HIV infection was associated with a negative impact on Quality of Life among children (Pensi Manohar & Haemal, 2010) with lower scores for physical, school, emotional functioning subscales, and health symptoms for children 8–12 years of age. The uninfected children had lower social functioning scores which was attributed to the fact that infected children had better access to support and social services from health care providers in HIV clinics. On comparing Quality of Life with the antiretroviral regimen they found that children who were not receiving any antiretroviral therapy reported worse on Quality of Life. Their results identified infected children living at home were at a higher distress of psychosocial functioning and health symptoms when compared with children living in care homes.

HIV infection was associated with a negative impact on Quality of Life among children. They found that children who were not receiving any antiretroviral therapy reported worse on Quality of Life. The infected children living at home was found to be at a higher distress of psychosocial functioning and health symptoms when compared with children living in care homes. Factors like illness knowledge and demographic variables were the key factors that affect quality of life. Parents perceived their children were functioning at a level significantly lower than the normal in general health and physical functioning.

**Disclosure of HIV status to infected children**

Instone (1997) explored what parents say about the illness and how children respond socially and emotionally. The results revealed that although most of the children were informed about the illness at the time of the study, their drawings and conversations suggest they did not perceive that communication and support were available within their families. Instead, signs of social isolation, poor self-esteem, and
severe emotional distress were found. The parents' readiness to tell determined the interval between diagnosis and disclosure, which was typically 4 years.

**Wiener, Battles & Heilman (1998)** examined 3 components of disclosure: (1) parental disclosure of child's HIV status to the child, (2) parental disclosure of their own HIV status to the child, and (3) the factors underlying parental disclosure. Results showed that 59% of the sample had not yet disclosed their diagnosis to their children. Results also show that disclosers were less depressed and had more cohesive families.

A qualitative study (**Ledlie, 1998, 1999**) was conducted to generate a substantive theory that describes and explained how family caregivers manage diagnosis disclosure to a child who has perinatally acquired HIV disease (PAHD). Results indicated when the Time Comes was identified as the central phenomenon linked to the problem of caregiver readiness. Causal conditions, intervening conditions, and strategic responses of caregivers and children were discovered and were inextricably linked to the central phenomenon. The process by which family caregivers responded to diagnosis disclosure to children with PAHD was based on the perceived self-readiness of the caregiver to disclose the diagnosis and illness-related information to their child.

The literature reviewed (**Nieves, 2000**) reported that a child of a parent with a positive HIV/AIDS diagnosis could present indicators of depression, anxiety, low self-esteem, social isolation, academic problems, feelings of abandonment and rejection, somatic problems and sleeping difficulties. The death of a parent by itself was considered a traumatic event that would sensitize the child to other losses was observed. Parents' decisions about the disclosure had a strong and long-term effect on their children's life. To keep their positive HIV/AIDS diagnosis a secret from their children, disregarding their age, maturity and emotional needs even during the last days of life or after death, could be devastating. This contradicted expectations of fulfilling their roles as protective parents. The main reason for non-disclosure was fear of causing the child psychological harm.
Nehring, Lashley & Malm (2000) examined why and to whom biological and foster mothers of HIV-positive children disclosed their child's diagnosis, the rationale for their decision, and the reaction of the recipient. No uniformity was found in who was told, except that recipients tended to be family members or close friends. Most subjects reported that recipients were supportive. Only 2 children knew of their illness, because their mothers spoke publicly about HIV. Most biological mothers told unaffected siblings and the foster mothers told their own children. Reasons cited by Ss for not disclosing the condition included a fear of rejection, decreasing the child's quality of life, and not wanting to worry others.

Uninfected parents and carers were significantly more likely to want professional help with disclosing to an infected child than infected parents (Thorne, Newell & Peckham, 2000). Disclosure of both the child's and the parent's infection status was rare and found to be associated with child's age in both cases. Infected children living with their parents were less likely to know their diagnosis than those living in alternative care. Infected parents also face difficult decisions regarding the issue of who will care for their children when they are unable to. Half of the infected parents had made long-term plans for their children's future social care. European parents were more likely to have made such plans than those from elsewhere (mainly Africa) and parents with plans had known about their HIV infection for significantly longer than those without.

The majority of mothers (Murphy, Marelich & Hoffman, 2002) explicitly tell their child not to disclose to other people that she was HIV-positive because they feared repercussions in the way of stigma and ostracism for both themselves and their child. Approximately one-fourth of the mothers identified "safe people," to whom their child could discuss her serostatus, such as family members, health care providers, or therapists. The majority of the children respected their mothers' wishes; only four children disclosed to someone after being explicitly told not to do so. A significant number of children expressed concerns about their friends finding out, fearing that they would be ostracized or that it would be assumed they were also infected. In addition, the children did not want others to find out because they wanted to protect their mothers. The burden of keeping the secret of their mothers' serostatus does seem to be a stressor for some of the children.
Mellins, Brackis-Cott, Dolezal, Richards, Nicholas & Abrams (2002) conducted a study to examine patterns of HIV status disclosure to 77 perinatally HIV-infected ethnic minority children (aged 3–13 years), and explored the association between knowledge of HIV status and emotional and behavioral outcomes. The majority of children in this study (70%) did not know their HIV status. On average, children who knew their HIV status were older and tended to have lower CD4%. Child knowledge of HIV status was not associated with gender, ethnicity, caregiver education, parent–child relationship factors, type of placement (biological v/s adoptive), or other health status indicators. As hypothesized, HIV status disclosure to infected children did not result in increased mental health problems. There was a statistical trend for children who knew their HIV status to be less depressed than children who did not know. Also, greater social disclosure (e.g. communication of child’s status to family and friends) was found when the child had an AIDS diagnosis or lower CD4%, as well as when the caregiver was HIV negative, African American and not the child’s biological parent. Paediatric HIV infection remained a highly stigmatized issue that was difficult to discuss with the infected child and others. Yet, contrary to the beliefs of many caregivers, disclosure did not result in increased mental health problems.

Lester, Chesney, Cooke, Whalley, Perez, Petru, Dorenbaum & Wara (2002) assessed about illness disclosure to HIV-infected children. Only 43% of children had been told their HIV diagnosis. Parental decision making about illness disclosure varied by the child developmental level.

Fielden, Sheckter, Chapman, Forbes & Cadell (2006) In a qualitative case-study examined the needs of a select group of older children (9-16 years old) with perinatally-acquired HIV in Canada through focus groups and interviews conducted with HIV-infected children, family members and service providers. The results revealed that the needs of this population were diverse, reflecting its heterogeneity. However, participants consistently highlighted issues of stigma, sexual health and mental health as major areas of current and future concern. Continued support, education and future planning in these areas were necessary for older HIV-infected children as they transition out of childhood.
Tompkins (2007) found that disclosure was not related to child functioning. Differential disclosure, which occurred in one-third of the families, was associated with higher levels of depressive and anxiety symptoms. Knowing more than mothers had themselves disclosed was related to child maladjustment across multiple domains.

The complex issue of disclosure of parental HIV/AIDS to children in rural China was examined by (Xu, Yan, Rou, Wang, Ye, Duan & Wu, 2007). Findings showed that most children were shielded from knowing the HIV/AIDS status of their parents, although many children may have drawn their own conclusions through observation or sources outside the family. Caregivers felt discouraged and hesitated to discuss parental HIV/AIDS with children due to societal stigma and lack of knowledge and skills.

Vaz (2008) identified factors associated with disclosure patterns to HIV-infected children. Results revealed that caregivers who had not yet told their child of her/his HIV status fell into one of three groups: nearly 50% had given their child no information, 15% had given partial information; and 33% had provided misleading information.

Vreeman, Nyandiko, Ayaya, Walumbe, Marrero & Inui (2010) described how parents and guardians of HIV-infected children viewed the impact of disclosing a child's HIV status, particularly for children's antiretroviral therapy (ART) adherence. Most of them had not told the children they had HIV.

Indian study

Bhonsale, Gabhale, Kulkarni, Laddha, Pokharna & Mangalani (2010) undertook a study to determine the parental knowledge regarding disclosure, their concerns and explanations to the child about the disease prior to disclosure to the children. Results indicated that only 15.4% were aware of their status; whereas 84.6% was not. Seven of these children were also aware of their parental status.

The needs of children peri-natally acquired HIV are diverse, reflecting its heterogeneity. They consistently highlighted issues of stigma, sexual health and
mental health as major areas of current and future concern. There was a statistical trend for children who knew their HIV status to be less depressed than children who did not know. Disclosure did not result in increased mental health problems. The children who were informed about the illness indicated that they did not perceive that communication and support were available within their families. Instead, signs of social isolation, poor self-esteem, and severe emotional distress were found.

The literature reviewed reported that a child of a parent with a positive HIV/AIDS diagnosis can present indicators of depression, anxiety, low self-esteem, social isolation, academic problems, feelings of abandonment and rejection, somatic problems and sleeping difficulties. The death of a parent by itself was considered a traumatic event that will sensititize the child to other losses was observed. Parents' decisions about disclosure had a strong and long-term effect on their children's life. The main reason for non-disclosure was fear of causing the child psychological harm.

Differential disclosure, which occurred in one-third of the families, was associated with higher levels of depressive and anxiety symptoms. Knowing more than mothers had themselves disclosed was related to child maladjustment across multiple domains.

**Caregiver-child relationship and parental monitoring**

Quality of caregiving, as well as parental monitoring, served as key mechanisms whereby children were either placed at risk or protected from the adversity associated with parental HIV/AIDS (Dutra, Forehand, Armistead, Brody, Morse, Morse & Clark, 2000, Bauman, Camacho, Silver, Hudis & Dainin, 2002, Forehand, Forehand, Jones, Kotchick, Armistead, Morse & Morse, 2002). Research had shown that parental monitoring, regardless of age and ethnicity, was positively associated with a range of child and adolescent outcomes, including enhanced self-esteem and academic performance (Jones, Forehand, Brody & Armistead, 2002). Similarly, further research found that parenting quality and consistency of the primary caregiver were more predictive of children’s cognitive development than parents’ HIV status (Jacquess 1994, Holditch-Davis et al. 2001).
The role of parental monitoring accounted for by the lower levels of effective parenting behaviours which was found amongst HIV positive caregivers (Armistead, Klein & Forehand 1995; Fair, Spencer, Weiner & Riekert, 1995; Forehand, Armistead, Morse, Simon & Clark, 2001; Kotchick, Forehand, Brody, Armistead, Morse & Simon, 1997a; Wild 2001). These included: reduced parental support for the child, fewer efforts at discipline and supervision more generally, neglect of the child due to reorganisation of the family around illness, changes in family routines, and parental absence. The lack of adequate care and control was the result of caregivers wrestling with their own feelings of guilt and anxiety (Fair et al. 1995; Foster & Williamson 2000; Wild 2001), together with the fact that the dynamic nature of symptoms in HIV disease was distressing and frustrating to caregivers (Hudson, Lee & Portillo 2003).

Adolescent's emotional distress (Lee, Lester & Rotheram-Borus, 2002) was significantly related to maternal disclosure of HIV status. Daughters who perceived their mothers as highly caring also perceived them as low in overprotection. Daughters who perceived their mothers as low in caring were more emotionally distressed and reported more conduct problems and lower self-esteem.

No Indian studies on caregiver children living with HIV/AIDS relationship and parental monitoring were found.

HIV and Growth/Nutrition

Scott, Fulton & Letro (2006) stated that inadequate weight gain and growth was one of the common problems and could manifest before other symptoms of HIV. Unlike infected adults, infants needed to increase their weight; therefore, they were more susceptible at an early stage to develop nutritional deficiencies. This would impact their growth, immunological integrity, and brain development.

Gibb (2008) evaluated the short-term risk of mortality in untreated HIV-infected children in resource-limited settings. Results showed that young children who were both severely malnourished and anaemic had high mortality regardless of CD4 values, particularly those aged 1-2 years. By contrast, high CD4% or CD4 cell count
values predicted low mortality level amongst either children older than 5 years or those younger with neither severe malnutrition nor anaemia.

**Abubakar, Holding, Newton, Van Baar, Van de Vijver & Fons (2009)** investigated the contribution of disease stage and weight for age to the variability in psychomotor outcome observed among children with HIV infection. Results revealed that weight for age and disease stage provided viable, easily measurable benchmarks to specify when frequent developmental monitoring and psychomotor rehabilitation were required. Nutritional intervention and other measures aimed at slowing disease progression might delay the onset and severity of psychomotor impairment in the pediatric HIV population.

**Indian studies**

**Lokesh et al (2010)** provided information regarding epidemiological profile. The results showed that the median age for children attending ART centre was 10 years 5 months. The median time from diagnosis of HIV-infection was 36.5 months. Vertical transmission was seen in 89.5%, 72.4% were on ART with median time on ART of 25 months. Adherence of >95% was observed in 99% children on ART. 27.61% were normal weight for age, 72.39% children with varying degrees of malnutrition. Stunting was observed in 47.62%. 83.3% children were in WHO stage II of HIV infection, 11.9% in stage III and 4.3% in stage IV. Tuberculosis was most common opportunistic infection with 17.6%, The overall ART adherence was high. Varying degrees of malnutrition was documented among most children. Provision of free treatment without adequate nutritional support and counselling on diet would compromise the success of ART scale up programmes specially in children.

**Babu Raj et al, (2010)**, reported on the experiences of single mothers living with HIV from Karnataka. They had poor access to HIV treatment, family support and stigma and discrimination resulted in poor quality of life and forced migration. Thus children had poor nutrition, education and emotional support; become school dropout and joined trivial jobs. 20 children were linked to hostels. 61% had site and 49% land were willed in favour of the children. Thus nutrition, education and emotional wellbeing had showed improvement in children. BMI index showed 26% normal,
30% shifted from underweight to normal. 44% remained underweight and was related to the fact that their mothers take ART.

Varying degrees of malnutrition was documented among most children. Only some children were normal weight for age, Stunting was observed in almost half of the children. Infected infants need to increase their weight; therefore, they are more susceptible at an early stage to develop nutritional deficiencies. This would impact their growth, immunological integrity, and brain development. They also stated that inadequate weight gain and growth is one of the common problems. Studies showed that young children who were both severely malnourished and anaemic had high mortality regardless of CD4 values, particularly those aged 1-2 years. By contrast, high CD4% or CD4 cell count values predicted low mortality level amongst children with neither severe malnutrition nor anaemic. Thus children who had poor nutrition, education and emotional support; became school dropouts and joined trivial jobs.

**Children as caregivers**

HIV-infected parents (Mellins & Ehrhardt, 1994) reported that all children were particularly vulnerable to separations and loss, with uninfected siblings reporting anger and burden from caregiving tasks.

HIV/AIDS Orphaned children (Bauman et al, 2006) experienced not only the trauma of a parent's death, but the stress of living with and often caring for an ill and dying parent. Children provided substantial amounts of personal care; took responsibility for cooking, cleaning, shopping and other household tasks; and some were their parents' confidants. The amount of care provided was related to maternal disability, not child age, gender, or presence of other adults/siblings. Children reported performing more tasks than their mothers reported. Almost half of New York and 80% of Mutare children said they had too much responsibility, and most reported reduced after-school and peer activities. Both children and parents felt children were more capable because of their responsibilities. Depression rates in New York and Mutare children were high but Mutare children were extremely vulnerable; two-thirds had depression scores in the clinically significant range. However, child caregiving was unrelated to depression.
A study was designed (Zhang, Li, Kaljee, Fang, Lin, Zhao, Zhao & Hong, 2009) to address issues by using qualitative data collected from children affected by HIV/AIDS in China. Findings of this study suggest that many children affected by AIDS had experienced increased responsibilities in housework and caregiving for family members. Such caregiving included, caring for self and younger siblings, caring for parents with illness and caring for elderly grandparents. Positive impacts from children's participation in family caregiving included personal growth and emotional maturity. Negative consequences included physical fatigue, psychological fear and anxiety and suboptimal schooling (dropping out from school, repeated absence from school and unable to concentrate in class).

No Indian studies on children living with HIV/AIDS as caregivers were found.

Coping in children as Caregivers

Hardy, Routh, Armstrong & Albrecht (1995) compared interpersonal destiny and coping among pediatric patients diagnosed with HIV, pediatric patients diagnosed with cancer, and healthy children (all Ss aged 4–7 yrs). Subjects with HIV indicated greater mother–child interpersonal distance, a finding that correlated with mothers' reports of social withdrawal. Data also indicated increased father–child distance and mother–child discrepancies of perceived interpersonal distance in the HIV population. Seven of the Subjects with HIV indicated that the adults turn away; this finding correlated with the Subjects’ knowledge of their illness.

Young carers (Skovdal, Ogutu & Aoro, 2009) coped by mobilising social support, engaging in income generating activities and constructing positive social identities around their caring roles.

No Indian studies on coping in children living with HIV/AIDS.

HIV/AIDS Orphaned children experience not only the trauma of a parent's death, but the stress of living with and often caring for an ill and dying parent. Children provided substantial amounts of personal care; took responsibility for cooking, cleaning, shopping and other household tasks; and some were their parents' confidants. Almost
half of children said they had too much responsibility, and most reported reduced after-school and peer activities. Both children and parents felt children were more capable because of their responsibilities. Depression rates in children were high and were extremely vulnerable. HIV-infected parents reported that all children were particularly vulnerable to separations and loss, with uninfected siblings reporting anger and burden from caregiving tasks. AIDS had experienced increased responsibilities in children’s caregiving for family members include both positive and negative impacts.

REVIEW AT A GLANCE

The review articles have been condensed into a tabular format for the purpose of summarizing. This portion has two sections as in the order of review articles presented. This table gives information on caregivers in 7 columns
Column 1- gives information on area of study
Column 2- gives number of non-Indian studies reviewed
Column 3- gives information pertaining to the population studied
Column 4 – gives information on research design
Column 5- gives information on Indian studies reviewed
Column 6- gives information pertaining to the population studied
Column 7 – gives information on research design

Further information on each study is available in the text form of this chapter

REVIEW OF STUDIES ON CAREGIVERS AT A GLANCE
### REVIEW OF STUDIES ON CAREGIVERS AT A GLANCE

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# REVIEW OF STUDIES ON CHILDREN LIVING WITH HIV/AIDS AT A GLANCE

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CRITICAL REVIEW

Review of studies on Caregivers

The review of literature presented for the present study constituted several studies associated with caregiving process, and related aspects of burden, psychosocial issues in caregiving like psychological health, quality of life, impact of HIV/AIDS on family, disclosure, adherence to ART, caregivers support systems available and coping strategies used.

Most of the studies are from developed or countries where HIV/AIDS was declared a pandemic.

Research studies stated in the review are on caregiving stress, burden, coping, support and psychological adjustment. There have been limited studies on positive aspects of caregiving.

Most of the studies on caregivers have focused on women as caregivers and there is paucity of research studies on male caregivers. The grandparents as caregivers of CLHA are an understudied area which requires attention.

Research has shown significant relationships among parenting stress, children living with HIV/AIDS developmental delay, HIV status of caregivers and CLHA and caregiving burden.

Some of the studies have compared between different types of caregivers like parents, non –parental caregivers of children living with HIV/AIDS, caregivers of normal children and caregivers of children with chronic illness.

Studies have highlighted that caregivers need help in coping with stress and their life situation, companion and counseling.

Further, several studies have made use of quantitative methods to assess various issues, though the importance of qualitative data and its implications for better understanding of the caregiving process has been frequently reiterated.
In Indian context, specific studies related to caregivers and their experience in many of the above mentioned areas of caregiving has not been well documented. There has been a paucity of research studies on caregivers of children living with HIV/AIDS. There has been limited studies on economic burden, quality of life, impact of HIV and death.

**Review of studies on Children Living with HIV/AIDS**

The existing literature on caregivers of children living with HIV/AIDS focusses predominantly from the maternal/female perspective and literature searches reveal a paucity of studies on fathers/male perspective.

The studies on children living with HIV/AIDS have focused on academic performance, behavioral problems, psycho social issues affecting the CLHA like psychosocial adjustment, Mental health, quality of life, disclosure of HIV status, HIV growth and nutrition and children as caregivers. There are scanty studies in many of the above mentioned areas in India.

Most of the Indian studies on children living with HIV/AIDS are from the proceedings of the 1st National Conference on Paeditric HIV organized by National AIDS Control Organisation (NACO) in December 2010. Some of the Indian studies have looked at keeping every infected child alive and healthy, care, support and treatment for HIV infected children, strategies and approaches to prevent and control Pediatric HIV in India and operational challenges in reaching the unreached children. Thus there is an obvious and urgent need for in-depth research that yields accurate and richer information concerning the contextual and environmental factors that determine the caregivers burden, disclosure and perception of behavioral difficulties among the HIV infected children.

There is a scarcity of studies which have looked at caregivers’ perception of their HIV infected children, living in developing countries such as India. Karnataka is one of the six high prevalent states having increased number of people living with HIV/AIDS in India. Hence, the need to examine the caregivers’ burden and perception of their HIV infected children’s behavior from Indian context is strongly felt. The present study is an attempt to explore these issues.
Conclusion

To sum up, brief review of various studies regarding caregiver burden and perception of HIV infected children’s behaviour has been documented in this section.

From the above literature it is evident that a large number of studies have been done on various aspects of caregivers’, needs, stressors, social support, burden, impact of HIV on the family, disclosure, HIV infected children’s behaviour and academic performance from the developed or AIDS affected countries. Currently the focus is more on disclosure and ART adherence.

There is no published evidence regarding any studies that has looked at the various contextual factors that affect the caregivers and the behaviour of children living with HIV/AIDS in an Indian setting. This study aims to fill this vacuum and provide baseline data, based on which further explorations can be carried out. Therefore, a research on Caregivers’ burden and perception of HIV infected children’s behavior was conducted as

- HIV/AIDS is changing from a terminal illness to an illness more chronic in nature, due to the advent and subsequent improvements of antiretroviral therapy. In step with this shift, more emphasis is on home based care than on hospital based care. As the children need to be taken care by the caregivers, studying caregivers’ problems will help plan for need based interventions
- The perception of caregivers with regard to their children's behavior in Karnataka, an high prevalent state in HIV/AIDS, had not been investigated to date. Hence, the present study would help provide psycho social support for the caregivers.
- The study will lead to the common welfare of the Caregivers and will be helpful for the government agencies for the improvements and the developments in the implementation of HIV/AIDS programme.

To conclude, pediatric HIV infection has remained a highly stigmatized issue that is difficult to discuss with the infected child and others. The results would form a sound basis to improve the provision of support and services for both caregivers and children thus ultimately improving their quality of life.
Scope of the Study

The significance of this study are multiple. First, the research gap described in the literature review includes little research on the post-1996 aspects of HIV/AIDS in India. Most of the studies/published articles are from developed countries or from countries where AIDS is an epidemic. There is a paucity of research on Caregivers of HIV infected children from developing and resource-poor settings. Therefore, understanding of barriers and facilitators regarding CLHA helps in planning interventions to address caregivers’ treatment and adherence concerns.

The availability of free ART drugs has prolonged HIV disease progression and survival of HIV infected children. However, the long-term effects, whether they are benefits or side effects, need to be studied as well. These long-term effects may have a greater impact on infants and children who are still growing and developing.

Research on caregivers will also lead to an understanding of the multiple ways of psycho social and environmental factors that affect their experience of caregiving and their perception of children’s behavior.

It is evident that families play a major role of support for HIV/AIDS patients in Indian society. The findings of this proposed study will provide an empirical data on the various factors that affect caregiving. This data can also be utilized in developing effective programmes for both the promotion of caregivers’ well-being and also prevention of various behavioural problems affecting HIV infected children. The findings of this study can also form a baseline data to facilitate comparative studies for the children with chronic illnesses. It can also be utilized by the professionals to help people who experience concerns and burden regarding issues related to caregiving and the behavioral difficulties of HIV infected children.