INTRODUCTION
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Children constitute principle assets of any country. India is the country with the highest number of child population in the world with 40% of its population below 18 years (Census Report, 2001). Children of today are the youth of tomorrow. HIV affects this very precious generation and bear grave consequences to our future, our nation, the continent and the world at large. Children and adolescents are an ever-growing part of the HIV/AIDS epidemic. The impact of paediatric AIDS on the families and on the society at large is only beginning to be fully appreciated. Providing home care for a child with a chronic illness can be stressful for the family. The occurrence of a life threatening illness during childhood has a profound effect on the psychological, social and spiritual integrity on the child, caregiver and on the family. The life threatening illness adds additional challenges to the family where multiple family members are often infected, ill, dying or dead (Lewis, Lewis & Schonfeld, 1991).

Increasing numbers of children are being diagnosed with the Human Immunodeficiency Virus (HIV) infection, the virus that causes Acquired Immunodeficiency Syndrome (AIDS). Worldwide, an estimated 2.5 million children younger than 15 years of age are living with HIV or AIDS. An estimated 90% of the world’s children living with HIV reside in sub-Saharan Africa (UNAIDS Global Report, 2010). India has an estimated 2.3 million people living with HIV, of these nearly one lakh (4%) are estimated number of infected children. In Karnataka, a cumulative of 10,915 children is registered and of these 3,330 children are on Anti-Retroviral Therapy (ART) (NACO, 2010). It is estimated that more than 16.6 million children around the world will be orphaned by the AIDS pandemic (UNAIDS Global Report, 2010). India has an increasing population of children living with HIV and those who have lost either one or both parents to an AIDS related illness. However, there are no official estimates available on children affected and orphaned by HIV and AIDS in our country.

The paediatric population was not a prominent part of the initial phase of the pandemic (Lewin, and Melvin, 2001). In the beginning, few children were recognized as being infected. The first groups of HIV-positive children to be recognized were those who had received infected blood products, particularly young boys with haemophilia, and children born to HIV-positive mothers. Today, those infected through Mother-To-Child
Transmission (MTCT) make up the vast majority of HIV-positive patients under the age of 15, an estimate of 3,70,000 children were infected through MTCT in 2009. Without treatment, nearly one third of HIV-positive infants die by their first birthday, and half of all children born with HIV die before they are two years old. Children still accounted for one in six new HIV infections in 2007. In 2009, 15,000 children under 15 died as result of AIDS-related illnesses (UNAIDS Global Report, 2010).

Overview of HIV/AIDS Caregiving

The changing demographics of the HIV epidemic, along with the growing complexity of medical care, has created major challenges for the caregivers who provide emotional and practical support to infected child or family member, relatives and friends living with the disease. As treatment options have expanded, so have the stresses experienced by the caregivers. Prolongation of the disease course, uncertainty about overall prognosis, and a ‘roller coaster’ pattern of repeated exacerbations and remissions in the later stages of HIV disease have intensified the emotional and physical demands of caregiving. Many of these caregivers face the additional burden of being HIV positive themselves. These developments underscore the importance of recognizing and meeting the needs of HIV/AIDS caregivers over the long term- both for their benefit and for the wellbeing of people in their care.

Caregivers

Caring for a family member with HIV/AIDS presents multiple challenges that strain a family's physical, economic and emotional resources. Family carers provide physical care and financial support and deal with changes in family relationships and roles, often with little support from outside of the family. Caregivers in developing countries like India, face even greater challenges, due to lack of medical and support services, poverty and widespread discrimination against those with HIV/AIDS. Caregivers assisted with many activities such as adhere to treatment regimens, avoid unnecessary hospital admissions, assist in personal hygiene, meal preparation, transportation, financial and legal assistance, and emotional support. Caregiving may also involve technical, skilled care such as administering injections, caring for Intra Venous cannula, cleansing wounds, keeping track of medications. Caregivers are generally
depend upon to interact with the health care system. Most often a caregivers provide emotional and social support as well.

Most research related to caregiving for people with HIV/AIDS has 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. Extended family caregivers like grandparents, maternal and paternal relatives are increasingly needed to care for children infected with HIV. Many of these have a dual responsibility of caring for HIV infected and also non infected children. Siblings are severely affected emotionally due to knowledge of HIV in the family. When the diagnosis is known to sibling, they report resentment towards parental attention given to the sick child and a sense of guilt for escaping the infection (Wiener, Septimus & Grady, 1998). Many fear abandonment, worry about who will take care for them once their parents die and wish to be part of that decision making process. Often, children from families affected by AIDS drop out of school to care for sick parents or to earn a livelihood for their families.

Due to maternal death, disability from HIV disease, or chronic substance abuse, many HIV-infected children live with a caregiver other than their biological mother. For example, a study of long-term survivors found that only 26% of older children infected with HIV lived with a biological parent (Grubman, Gross, Lerner-Weiss, Hernandez, Mcsherry, Hoyt, Boland & Oleske, 1995). Another study by Smith and 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. Raveis and Siegel (1990) noted that as the HIV-infected person became more symptomatic and dependent, caregivers eventually helped with two thirds of total care required by these individuals. Because caregivers' donated time and services help to maintain the HIV-infected person at home, caregivers provided an alternative to institutionalization, and the care they gave resulted in substantial monetary savings.

An understudied aspect of the HIV/AIDS epidemic is the creation of hundreds of thousands of grandparent-headed households that have become home to children bereft of one or both of their parents. Such "skip-generation parenting" presents 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. Wrubel and Folkman (1997) describe how caregivers also provide emotional support and advocate for the health care of HIV-positive persons, thus adding to the well-being of the care receivers.

Types of care

Caregiver activities can be classified into 3 types of home care: technical, nontechnical, and health care management. Technical care consists of care in areas such as overseeing diagnostic procedures and provision of medications. Nontechnical care consists of care associated with activities of daily living such as feeding, bathing, laundry and housecleaning related to the child’s illness. Health care management consists of categories such as financial management and traveling for medical care (Wilson, Moskowitz, Acree, Heyman, Harmatz, Fernando & Folkman, 2005).

Chronically ill children required significantly more total home care time (mean=7.8 hours per day), the care needs of children who are HIV positive are similar to those of healthy children with the exception of the time necessary for giving medications, and this may be reflective of the success of antiretroviral therapy (ART) treatment. Today, children with HIV are much like healthy children in the care they require with the exception of time spent giving medications (Wilson et al, 2005).

Challenges of caregiver

Caregivers of children with chronic illness such as HIV/AIDS face unique challenges that make their lives more difficult. It is important to understand the long-term effects, challenges on the children and their caregivers. Caregivers face many challenges, such as depression, fatigue, exhaustion (Klunklin & Harrigan, 2002), similar to problems of those who care for children with life-threatening diseases (Iever, Brown, Drotar, Bunke, Lambert & Walker 2001). Diminished stamina and the physical demands of a HIV+ child leave many caregivers without adequate time for self-care and counselling. HIV, moreover, is associated with additional stressors, such as social stigma and isolation that may limit caregivers’ willingness to seek assistance for themselves or their families.
Caring for children with HIV/AIDS can be emotionally, cognitively, and behaviourally challenging. The cognitive challenge is to educate the child’s family about HIV/AIDS, including transmission, disease progression, and treatment. Family members must understand how the child’s life will be affected on a daily basis. They must also understand the importance of adherence to the prescribed medication regimen. If they understand how the medications work, family members can become an informed asset to the team providing the child’s medical care. The family should also be educated regarding the symptoms of disease progression and possible side effects of medications. This way the family will know what to look for if the child falls ill or develops new symptoms.

The behavioural challenge consists of incorporating the child’s chronic illness in the daily life of the child and the family. Amidst the required behavioural changes, the child’s caregivers must also try to maintain a sense of normalcy for the child. The child’s medications and clinic visits need to be a part of daily living, though they often require major adjustments and place a strain on family relationships and routines. To develop as fully as possible, the child still needs rules, discipline, and routines. Routines are especially important for children dealing with stressful or new situations, because they help provide a sense of security.

**Problems of Caregivers**

Powell-Cope and Brown (1991) described issues that are 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. There is a transition from viewing HIV/AIDS as a terminal illness to a chronic illness which brings critical decisions and turning points for which proper guidance is needed. In addition, persons with HIV are living longer, which may increase the length of time and the intensity of caregiver involvement. With development and availability of ART, the life span of the people living with HIV/AIDS has increased, 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.

Most social service programs are not able to identify the needs of older surrogates, often because these surrogate parents in HIV-infected families are reluctant to make
their needs known for fear of social stigma or possible reductions of benefits. Multiple systemic barriers to case management and other services also frustrate attempts to bring available resources to elder caregivers. These barriers include professional ignorance or denial that HIV affects surrogates, limited funding and a fragmented health and human service system. Because the issues facing elder caregivers are many and varied, this collection covers a host of issues: community health, aging, HIV services, child welfare, education, public policy, and mental health.

**Caregivers Burden**

The term ‘Caregiver burden’ is used to describe the physical, emotional, financial and social problems associated with caregiving. Caregiving burden is the extent to which the caregiver is bothered by caregiving-related disruptions. The disruptions may have to do with work, privacy, free time, relationships, goals and plans for the future. Caregiver burden refers to a high level of stress that may be experienced by people who are caring for another person (usually a family member) with some kind of illness. For example, a person caring for someone with a chronic illness may experience stressors such as financial strain, managing the person's symptoms, dealing with crises, the loss of friends, or the loss of intimacy. Fatigue and sleep difficulties (Teel & Press, 1999). In a conceptual overview of the caregiver experience, another study divides the caregiver’s stressors into three categories: primary (e.g., exhaustion), secondary (e.g., social isolation) and intrapsychic (Pearlin, Mullan, Semple & Skaff, 1990).

The economic and emotional burden of caring for ill children in the home is often hidden under the veil of care already provided for healthy children. Additional family burdens occur when a caregiver elects to withdraw from the workforce to care for a sick child. Burden can be assessed in terms of objective or subjective impact. The objective impact of a burden is assessed by the extent to which caregiving disrupts daily routine and social relationships, and negatively affects resources. Examples include forced changes in household routines, missed days of work, family friction, reduced social contact, loss of income and/or reduced energy. The subjective impact of a burden is assessed by the caregiver’s perception of and reactions to caregiving demands. Caregivers with high levels of subjective burden may report ‘feeling
trapped’; ‘feeling nervous or depressed about their relationship with the care recipient’, or ‘resenting caregiving tasks’ even their objective burden is relatively low (NACO, 2006). The impact of the illness is enormous both on the infected individual and the family. It has been seen that it is almost impossible to isolate and treat the individual alone for better results.

Studies of caregivers demonstrate that the effects of caregiving can be both negative and positive. Negative effects, such as burdens, have been more widely studied than positive effects. Multiple factors contribute to caregiver burden, caregiving usually comes as an unexpected role, one for which people are neither trained nor prepared. To assume this new role, caregivers must restructure pre-existing role obligations and social activities, and the ways in which they relate to the care recipient. The factors contributing to burden are the physical demands of caregiving, the emotional issues surrounding caregiving, the financial impact of caregiving and the stigma surrounding HIV disease (NACO, 2006). Burdens include social isolation and decreased interactions with other family members, depression, and lowered life satisfaction or well-being. Turner, Pearlin and Mullan (1988), Theis, Cohen, Forrest, and Zelewsky (1997) in their study found that self-reported physical health was better before beginning caregiving, and caregivers attributed the decline in their own health to their caregiving role, identified a higher incidence of chronic fatigue and exhaustion in caregivers. Their study concluded that caregiving also contributed to isolation, physical morbidity, diminished work performance, anger, psychological distress, and a smaller social support network. The study also highlighted positive responses to caregiving including self-satisfaction, gratification, and increased self-respect. Positive aspects of providing care are ‘it brings a mission and purpose to one’s life’, develop empathy and self knowledge’, ‘gain a sense of personal effectiveness by demonstrating competence under very difficult circumstances’, ‘experience the positive feelings associated with loving, caring and feeling needed’(NACO, 2006).

**Caregiver’s Quality of life**

Quality of life is looked at as a product of physical, social, emotional and environmental harmony of an individual. A person with a good quality of life is found to cope more effectively with his illness. HIV shifts the lifestyle of not only parents living with HIV/AIDS, but also their children, partners, and extended families. During
the last decade, there has been a significant paradigm shift from symptom management to improving the overall quality of life, especially in case of terminal illnesses such as cancer and AIDS. Disclosure is an important factor that contributes to the psychological wellbeing and needs special attention in this context.

Research has demonstrated that voluntary self-disclosure of one’s sero-positivity may contribute to improved psychological wellbeing if those disclosed to respond in a helpful manner. The helpfulness of significant others in response to disclosure has been associated with less depression and anxiety demonstrating the potential benefits of disclosure. Significant others can provide HIV-infected individuals with a wide range of valuable resources—both tangible and emotional for example, information about treatment options, financial assistance, care in sickness, sharing feelings and reassurance that one is loved and valued.

**Psychological adjustment of Caregivers to HIV infection**

Psychological adjustment to HIV is dependent on the age, gender and the type of coping strategies or the response to the illness adopted by the individual. Response to illness is an important dimension of the illness itself and illness behaviour. This is particularly true in case of life-threatening illnesses where the response may have an impact on the outcome, such as cancer and HIV infection.

Children with perinatal HIV infection identify entire families at risk for psychological difficulties, as they have mothers and possibly siblings who are also infected. The strain of caring for a sick child while also managing their own illness and caring for other children and family members is a tremendous burden for many mothers with HIV infection. Previous studies have shown that mothers who are HIV-infected have high levels of psychological distress, depressive and anxiety symptoms due to the multiple losses they have sustained from other family members dying of AIDS and the burden of caring for an HIV-infected child with an uncertain future, even when compared to mothers of similar backgrounds. Although high rates of psychiatric disorders have been documented in women with HIV, many of the psychiatric diagnoses predated their HIV diagnosis (Biggar and Forehand, 1998; Miles, Burchinal, Holditch-Davis, Wasilewski, & Christian, 1997).
It has been well documented in the literature that childhood chronic illness significantly affects family functioning.

**Family issues related to HIV**

The occurrence of a life threatening illness during childhood has a profound effect on the psychological, social and spiritual integrity of the caregiver, child and the family. The life threatening illness adds additional challenges to the family where multiple family members are often infected, ill, dying or dead.

**Difficulties resulting from long-term care**

Family members must understand how the child’s life will be affected on a daily basis. They must also understand the importance of adherence to the prescribed paediatric ART. The child’s medications and clinic visits need to become a routine, though they often require major adjustments and place a strain on family finances and relationships. Routines are especially important for children dealing with stressful or new situations, because they help to provide a sense of security and continuity.

**Financial Concerns**

Providing care to someone with a chronic illness including HIV/AIDS results in additional financial costs on the caregiver which can lead to negative economic consequences. Direct costs arise from expenditure on goods and services relating to care and indirect costs are associated with income forfeited by the care recipient or the caregiver through loss of employment or reduced productivity causing financial strain on the caregiver (Langat Chepngenyo, Falkingham, Madise & Evandrou, 2008)

Financial concerns can be overwhelming for a family with a chronically ill child. Medication regimens can overwhelm family resources. Daily medication regimens are extremely expensive, and frequent visits to hospitals and care providers for monitoring and treatment are burdensome to families. These demands can either financially bankrupt a family or create such a financial burden that families become vulnerable to a variety of related stressors (Lesar, 2008).
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Familial substance abuse

For children with alcohol/drug abusing parents risk factor for mental health problems cluster in two areas. They can be broadly conceptualized as sequalae 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 are prenatal drug exposure, heritable psychiatric disorder like affective and anxiety disorders and childhood histories of attention deficit hyperactivity disorders (Wiener et al, 2003).

Death and Bereavement

Despite the increased availability of ART and the modest decline in HIV adult prevalence worldwide, death is still a common outcome of HIV/AIDS. The total number of children aged 0–17 years who have lost their parents due to HIV is 16.6 million in 2009. (UNAIDS GLOBAL REPORT, 2010). AIDS has caused children to experience the loss of their siblings, friends, relatives, teachers, doctors, and other significant people in their lives. Consequently, children are not properly supported during mourning. For children who have lost parents or family members, grief can be overwhelming and hard to understand. Grief can cause a series of different types of responses, including physical, emotional, behavioural, cognitive, spiritual, and social. Social responses are particularly important because of the high rate of stigmatization associated with HIV/AIDS. It is also imperative that grieving children be able to acknowledge their loss and be provided with an opportunity to release their grief. Without such an opportunity, they may experience psychological ramifications well into adult and may indeed never recover from their loss (Close & Rigamonti, 2006).

When a parent or caregiver approaches the end stages of AIDS, it is extremely important that a plan of care be created for the children. This is referred to as permanency planning. When this step is not taken, children are left in a state of uncertainty about who will care for them. This can compound the loss felt by the child after a parent’s death. The child may be separated from siblings and may experience frequent shifts from place to place in search of a proper home (Oneill, Selwyn & Schietinger, 2003). However, for millions of children whose parents have died of AIDS, survival and well-being are in jeopardy. Besides experiencing multiple losses, children orphaned by AIDS are likely to suffer economic hardship, malnutrition,
illness, loss of property and inheritance. Older orphans may drop out of school, to work or care for younger siblings. Feeling powerless and lost, some orphans end up living on the streets, trading sex for money or food. Others live in orphanages or institutions, which often fail to provide adequate care to meet the physical and psychosocial needs of children. Parents who do not plan for their children after their death are at increased risk of developing emotional and behavioural problems (Rotheram-Borus et al, 2004).

Issues related to disclosure of HIV status

All individuals who have learnt about their HIV antibody status have been faced with an important decision regarding whom they should share this information with. The phenomenon of disclosure of one’s seropositivity to significant others is often perceived as a double-edged sword. It may open up the opportunity to receive social supports; however, it may also lead to added stress due to stigmatization, discrimination and disruption of personal relationships. Conversely, concealing one’s HIV status from others may be stressful in itself, and it can interfere with obtaining and adhering to potentially critical medical treatments. It has also been reported that those who disclose freely tend to visit physicians less frequently, demonstrate unimpaired immune function and exhibit more autonomic nervous system regularities to greater degrees than their non disclosing counterparts. Researchers have also documented direct relationship between the mental health status of an individual and the degree and comfort of disclosure of one’s seropositive status (Hays, McKusick, Pollack, Hilliard, HoffC, Coates et. al, 1993)

It has also been observed that disclosure itself can be of various types and the decision to disclose can be influenced by a wide range of factors including demographic characteristics of the individual, degree of symptomatology, apprehensions about the societal reactions to disclosure. There are also instances where disclosure to others is indirect, occurring due to circumstances beyond patients control and occasionally without the consent of the patient. Hence, types of disclosure may range from voluntary self- disclosure to forced disclosure due to the circumstances and, at times, disclosure to significant others by the professionals/family members without the consent of the patient. Different types of disclosure may have different effects on the emotional well being of the individual.
Disclosure is important for promoting adherence to treatment; to safeguard 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 disclose to others, creating fewer complications for the families. Various researches reveals that 25 to 90 percent of CLHA are unaware of their own HIV status (American Academy of Paediatrics, 1999). Many caregivers feel that if children know their diagnosis, they will internalize the stigma and give up. In this way, family creates an atmosphere of secrecy that the child often senses. Labelling the diagnosis a secret and should not be discussed only serves to increase the stigma. Many parents are 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 may feel guilty about their role in infecting the child and fear that the child will become angry or blame them.

HIV/AIDS and Stigma

A major factor that distinguishes HIV/AIDS from other chronic or terminal illness is the stigma associated with the illness. The stigma comes from lack of knowledge about HIV infection and seen as punishment for the sinful acts. Stigma can adversely affect the living children of infected parents. It may affect caregivers who step in to care for infected or affected children of whose parents have died. Stigma takes a particularly damaging form when a person is aware of social stigma and accepts or internalizes society’s negative views. Internalized stigma has a big impact on the paediatric population. Stigma damages the self esteem of the person and gives him or her a negative sense of self-worth (Poindexter & Linsk, 1999).

Three concepts are helpful in understanding stigma as it relates to the paediatric population: associative stigma, internalized stigma, and stigma management. Stigma is associative when it affects people because of their association with a stigmatized person (in this case, a person with HIV or AIDS). 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. Stigma management is a way of coping with HIV/AIDS stigma by being aware of possible negative reactions and finding ways to minimize them (Poindexter & Linsk, 1999). 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.

In many parts of the world, however, stigma is still a harsh reality, sometimes barring children from school and other community activities. 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. Almost all children living with HIV have experienced discrimination and faced the effects of stigma. Parents who have disclosed their and their child’s HIV status had undergone rejection from the families and the society. They are isolated from the community. Children living in residential care settings are uncertain about their future or more fearful about the death and infections. The support of the extended families is not seen in these children. The routine activities like (taking medicine in queue, visiting hospitals in groups etc) in the residential homes hinder their growth and development as they do not have parental touch. Frequent changing of caregivers in the residential homes disturbs the child’s emotions and lacks attachment figure. This also affect the treatment plan for HIV infected children.

**Needs of children living with HIV/AIDS**

Children have specific needs for growth and development, and of early diagnosis of infection besides needing a strong family support. Growth and development are important indicators of child’s health. HIV infection can lead to growth problems, developmental delays and developmental regression. Treatment options and nutritional needs are based on the child’s growth and development. Orphaned and vulnerable children (OVC), both infected and uninfected add to the complexity of the issue in terms of vulnerability, social security, livelihood, poverty etc. Besides experiencing multiples losses, children infected by HIV/AIDS are likely to suffer from economic hardship, malnutrition, illness, abuse, lack of family support, unhygienic living conditions, loss of property and inheritance, etc.

Practical and material needs are important for an infected HIV child, but emotional aspects are also very important for them. There are critical periods in the child's life that they could use extra support. These include when they are diagnosed, discrimination from peers as well as dealing with death. It might be beneficial for both the child and the parent/caregiver to seek the advice or assistance of a counsellor to
help through these rough times. Trauma may strike the child, if they happen to encounter the death of their parent(s) due to HIV as well. This will definitely be an emotionally trying step in their lives.

**Caregiver’s perception of HIV infected child’s Behaviour.**

The stress of raising HIV-infected children may precipitate or exacerbate chronic psychological conditions in caregivers, impacting on their perception of the child’s behaviour (Harrison, 2002). Infected mothers often describe their children as exhibiting more internalizing (anxiety, somatic) behaviour problems than other caregivers (Bachanas, kullgren, schwartz, lanier, Mcdanil ,Smith & Nesheim 2001). Additionally, grandmothers as primary caregivers, also experience the negative impact of caregiving on their physical and emotional stability. Fatigue has been related to financial concern and caring for the ill child, whereas emotional burden involves the lack of social support. (Caliandro & Hughes, 1998).

Caregivers of Children infected with HIV many a times perceive their children as different from their peers. They frequently find their children behind in academic performance because of repeated absences. Another factor that adds to their sense of being different is the real disparity in their physical appearance compared to their healthy peers. These children often grow up smaller and weaker than their peers and siblings. Healthy children do not have to spend time in a clinic, take medication, or require hospitalizations for specific illnesses or infections. Children infected with HIV frequently struggle between a “healthy, normal” life, and the life of the sickly child. Because of absenteeism these children often find themselves behind in school work, which makes for a painful and difficult school environment.

There will be increasing numbers of children infected by HIV/AIDS attending schools. It is vital that schools are prepared to meet the needs of these children and their families. Children diagnosed with HIV/AIDS experience psychosocial and neurological difficulties associated with infection, difficulties that will have educational implications.
**Paediatric Anti Retroviral therapy**

While many medicines are used to treat HIV infection, none can cure HIV/AIDS. Antiretroviral drugs can reduce the ability of the virus to replicate, and they can thus reduce the damage the virus does over time to the person’s immune system and other vital organs.

The primary goal of antiretroviral therapy is to improve the health and prolong the life of the HIV infected child or adult. Drug adherence is critical to the success of any treatment regimen. Mastering the skills involved in adopting complex treatment regimens involves a learning process for most people. Furthermore, most drugs taken for chronic conditions demonstrate acceptable efficacy even when a considerable number of doses are missed making occasional lapses harmless. Antiretroviral regimens, on the other hand, are far less forgiving since poor adherence to an ART regimen can lead to incomplete suppression of viral replication, resulting in the emergence of drug-resistant virus.

Children rely on adults for treatment and vigilance. Because of cognitive and developmental challenges, most children are not mature enough to follow complicated medication dosing regimens. Medication adherence may continue to be a challenge as the child matures, along with multiple medications, poor palatability, side effects, and simple forgetfulness regarding dosing regimens (Dolezal, Mellins, Brackis-Cott, 2003). Other factors related to adherence include caregiver characteristics, developmental level of the child, and the child's awareness of the diagnosis. Given the nature of the disease and its treatment, poor adherence to medication regimens may cause the condition to worsen (Nabukeera-Baurngi et al, 2007, Naar-King et al, 2006, Reddington, et al., 2000).

As new treatments become available for people with HIV infection, there is a shift from an emphasis on acute infection towards considering AIDS as a chronic illness. The need for more extended care is likely to increase the importance of informal and community-based services.
Rationale for the Present Study

The nature of HIV/AIDS has shifted since 1996 when the antiretroviral medications became widely available and the mortality rate dropped dramatically. It now exists as less of a terminal disease and more of a chronic and sometimes manageable condition (Mitchell and Linsky, 2004). As access to services for preventing the mother-to-child transmission of HIV has increased, the total number of children being born with HIV has decreased. An estimated 3,70,000 children were newly infected with HIV in 2009 (a drop of 24% from five years earlier) (UNAIDS GLOBAL REPORT, 2010). This changes the nature of caregiving for persons with HIV/AIDS, which may no longer necessarily involve the intense but short term care of a dying person. Instead, HIV/AIDS caregiving may involve helping an intermittently sick person for a longer period of time. Care and support for children infected and affected by HIV/AIDS comes from families and communities. As the number of orphaned and vulnerable children continues to grow, caregivers who are supporting those infected children and families, themselves require support.

The contributions of the family/ informal caregivers to society have economic consequences, since the monetary value of caregiving for all illnesses is estimated at often a part-time job with an intense level of care. The present study focuses on caregivers and children living in family rather than the children living in institutions as they had one caregiver for many infected children and there was frequent change in the caregivers. The children living in institutions was a mixed group with orphans, children of single parents, abandoned/ destitute children and also children who could not be taken care of by the family due to their regular hospital expenses. However there has been little work carried out on measuring the response of caregivers of HIV infected children. While international research has investigated on concerns, social support, coping strategies, disclosure, ART adherence etc. have not been specifically investigated in the Indian context.

Need for the present study

Although there continues to be considerable research on the prevalence and specific medical treatment of HIV/AIDS in children, there are several areas of special need for study, particularly from the perspective of family and child, needs related to hospice
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and palliative care. As treatment transforms the disease to a chronic illness, there is a need to study its implications on the growing child. There is a special need for study that examines the implications of HIV/AIDS among children and cultural implications of long term care of infected children.

The caregivers experience intense stress especially due to progressive, terminal and stigmatizing nature of HIV infection, with its opportunistic infections and intermittent periods of normalcy. An aspect of critical importance in family care for children living with HIV/AIDS is that parents, who are themselves infected, have to take care of the children. On the other hand due to the death of one or both parents due to AIDS, grandparents or relatives have to take the responsibility of caring for the infected children.

Caregiver burden is one of the patient-related outcomes, which is the most common outcome measure in caregiver research. The demands on the family caregivers of these children are enormous. The determinants that are associated with caregiver burden such as caregiver characteristics, infected child characteristics and social stigma are important for social workers to minimize the burden of care so that appropriate interventions can be developed for children with HIV/AIDS and family members who share the work of managing their care at home.

Research is especially limited in each of the specific areas of need discussed above. For example, little is known regarding how and when to share information with and disclose diagnosis to children. Research on caregiver burden in terms of time and amount of care required for the families with infected child is largely absent from the literature. There is a need to understand caregiver burden and develop effective interventions to reduce it. As treatment improves and children with the diagnosis begin to reach young adulthood, a myriad of social and healthcare issues arise that call for understanding and develop intervention package through conducting research. The dearth of research in this area in India is especially alarming. Indeed, all aspects of caring for the vulnerable population of children with HIV/AIDS continue to cry for creative exploration, design, and application of effective interventions to improve the care and health of this group.
Formulation of the Research Problem

Caregivers of HIV infected children face many challenges related to both physical demands and emotional well-being and trying to cope with the behavioural issues/problems involved in providing care to children. Though the distress and burden associated with caregiving has been studied in association with other debilitating diseases like Alzheimer’s, Dementia, Parkinson’s disease as well as many other chronic diseases, not many studies in India have focused on Caregivers burden, psychosocial needs, and perception of the children’s behaviour who are infected with HIV. In fact, this is the first study which will attempt look at perception of the children’s behaviour who are infected with HIV. The diagnosis of a chronic and potentially life threatening illness in a child catapults the family into a maze, which they have to navigate on their own, through a constellation of adaptive tasks, both emotional and instrumental. It is necessary that serious efforts be made to assess the existing situation and explore the possibilities in alleviating the stress. In the event of a chronic illness that is terminal, the dimension of ‘time’ becomes a major reference point. The task of coping with such an illness involves mastering the practical and emotional tasks of the immediate caregiving situation, at the same time preparing and planning for dealing with the uncertainties and complexities of the illness and what it entails in an unknown future.

The present study aims to explore the emotional, social, and economic strain the family members undergo while caring for an HIV infected child. The researcher proposes to study profile and types of caregivers, psychological health, burden of caring, psychosocial problems and family issues related to caregivers, quality of life, and perception of HIV infected children’s behaviour. The study focuses on bringing out psychosocial factors and their role in caregiver burden while presenting a rationale for a structured and systematic intervention process focusing on the distress associated with caregiving. The focus is on family caregivers (parental and non-parental) who have the major responsibility for the day to day management of the infected child. The researcher proposes an intervention model of the multiple dimensions of caregiving that includes burden, rewards, support, needs, role clarification, motivations and future. Although most of these dimensions could be applied to caregivers of persons with any health condition besides HIV/AIDS, the stress on stigma is unique to people living with HIV/AIDS as it may add to the caregiver burden.
Conclusion

The current study does not test out any specific theoretical models, but attempts to describe the caregivers burden and perception of HIV infected children’s behaviour. Such studies are a necessity in a country like India, where many children are being orphaned and need family members to take care of them. The data proposed from the study could go a long way in understanding Caregiver related issues and HIV infected children’s behaviour. With limited research on caregivers, the current study envisages to provide findings to professionals that can be utilized to help caregivers who experience concerns regarding psychosocial issues affecting them and also about the behavioural issues affecting the infected children. It also provides empirical data on caregivers and their perception of HIV infected children’s behaviour which can be utilized to develop effective programmes. The findings of this study also form a baseline data to facilitate comparative studies with other chronic illnesses in children.