CHAPTER I
INTRODUCTION

Background of the Study

A good nurturing environment is crucial for physical and psychosocial development of the child. Millions of children live with sick and dying family members and large number of children around the world has lost one or both parents to AIDS. A child’s well-being and development is affected due to profound trauma of losing one or both parents, and it has devastating long-term implications not alone for the child, but for the stability of communities and society.\(^1\)

One of the world’s most serious health and development challenges is HIV, the virus that causes AIDS. According to the World Health Organization (WHO) in 2013, there were approximately 35 million people worldwide living with HIV/AIDS, of these 3.2 million were children less than fifteen years old. In 2013, an estimated 2.1 million individuals worldwide became newly infected with HIV. This includes over 240,000 children (<15 years). The majority of people living with HIV are in low- and middle income countries. The most affected region is Sub-Saharan Africa, with 24.7 million people living with HIV in 2013. Seventy-one percent of all people who are living with HIV in the world live in this region. HIV is the world’s leading infectious killer. The first case was reported in 1981 and an estimated 39 million people have died since then and 1.5 million people died of AIDS-related causes in 2013.\(^2\)

India has the third highest number of people living with HIV globally. The total number of people living with HIV/AIDS in India was estimated at around 20.9 lakhs in 2011. Children less than 15 years of age accounted for 7% (1.45 lakhs) of all
infections in 2011. In 2014, nearly 1, 06,824 Children Living with HIV (CLHIV) were registered in HIV care at ART centres.3

The number of people with HIV receiving treatment in resource-poor countries has dramatically increased in the past decade. At the end of 2013, 12.9 million people living with HIV were receiving antiretroviral therapy (ART) globally. 11.7 million people were receiving ART in low- and middle-income countries by 2013. About 740,000 of those were children.2

Figure 1: Distribution of adults and children estimated to be living with HIV in 2013

(Source: UNAIDS)
The first phase of National AIDS Control Programme (NACP-I) was launched by the Government of India in 1992 to combat the Human Immuno-deficiency Virus (HIV) infection and Acquired Immuno-Deficiency Syndrome (AIDS). However, with the evolving trends of the HIV/AIDS epidemic, the focus of the subsequent phases of the programme (NACP-II in 1999 and NACP-III in 2007) shifted from raising HIV/AIDS awareness to behaviour change, from a national response to a more decentralized response. Third phase also focus on involvement and support of NGOs and networks of People Living with HIV (PLHIV) in preventive care.\textsuperscript{70}

Among the states in India, Manipur has shown the highest estimated adult HIV prevalence of 1.40\%, followed by Andhra Pradesh (0.90\%), Mizoram (0.81\%), Nagaland (0.78\%), Karnataka (0.63\%) and Maharashtra (0.55\%). The total number of people living with HIV/AIDS (PLHA) in India is estimated as 24 lakhs (19.3 –30.4\%) in 2009. Children (<15 yrs) account for 3.5\% of all infections, while 83\% are the in the age of group 15-49 years.\textsuperscript{67}

78149 HIV positive children are registered with ART centers in India as of November 2010. Among that 10999 are from Karnataka. Thousand seven hundred and sixty six children died due to HIV/AIDS during 2007-2010. It is estimated that India has the world’s largest number of AIDS orphans, although the impact of the AIDS crisis has not begun to emerge fully in India, and AIDS-related orphaning has not yet been accurately documented.\, This number is expected to double in the next five years (World Bank).

A retrospective review was carried out to determine and characterize the prevalence of pediatric HIV/AIDS in India. Among 3,669 pediatric patients admitted to the hospital, 437(11.9\%) tested positive for HIV, 234 were males, while 203 were
females (M: F=1.15:1). Children under the age of five years accounted for 81.7% of the HIV positive children. Mother-to-child transmission was the major route of transmission of HIV, occurred in 73.7% of cases. Two other common routes included the use of blood/blood products (21 patients), implements due to punctures and hair dressing in 4.8% each, while sexual abuse/sex activities was the probable route in 3.8% others. Most mothers of HIV children were either housewives (45.3%) or petty traders (trade that is conducted on a small scale) (10.4%). Study revealed that the prevalence of pediatric HIV/AIDS was high in India. The most common mode of transmission was mother to child.

Poor health, socio-economic hardships, and compromised rearing environment are some factors that contribute to the childhood adversities. HIV as a medical condition is usually accompanied by perinatal co morbidities, poverty, parental substance abuse and illness, and increased risk of child neglect, maltreatment and abandonment.

Orphans are defined in three mutually exclusive categories: maternal orphans (mother deceased or vital status unknown, father alive); paternal orphans (father deceased or vital status unknown, mother alive) and double orphans (both parents deceased or vital status unknown).

One in every three malnourished children in the world lives in India. Child malnutrition is generally caused by a combination of inadequate or inappropriate food intake, gastrointestinal infections and other childhood diseases, and improper care during illness. Twenty percent of children less than five years of age suffer from wasting due to acute under nutrition in India. More than one third of the world’s children who are wasted live in India. Forty eight per cent (i.e. 61 million children) are stunted 43% of Indian children under five years are underweight. Under nutrition
is substantially higher in rural than in urban areas. Undernutrition is more common for children of mothers who are undernourished themselves (i.e. body mass index below 18.5) than for children whose mothers are not undernourished.

Psychosocial well-being is very critical for children, creating the foundation from which they can establish their identity and place in society, manage their care and live positively, cope with challenges, and plan for their future.

Children living with HIV experience more subjective distress than their HIV-negative peers and face multiple HIV related stressors, including the death of a parent, isolation, loneliness, disclosure, stigma, discrimination, and family conflict or uncertainty. Several studies also suggest that the psychosocial well-being of children and their caregivers can improve adherence to ART and clinical outcomes. There is a critical need to ensure that continuous and individualized psychological and social services are to be provided by parents, caregivers, and service providers (facility, community, and home-based) and adapted over time as children develop and mature.

AIDS weakens traditional protective mechanisms such as parental care and support, provokes stigma and discrimination, and intensifies vulnerability and income poverty. This increases risk of exposure to abuse, exploitation and neglect among children. Children and adolescents whose right to personal safety and well-being is violated are at increased risk of lifelong developmental challenges, and other physical, emotional and social problems. These outcomes compromise national and international development goals, including those set out in the Millennium Declaration and the Millennium Development Goals, Education for All and ‘A World Fit for Children’.
The Government of India is committed to work towards achievement of the global target of “Elimination of new HIV infection among children” by 2015.¹³

NEED FOR THE STUDY

Adult population living with HIV declined from 2.74 lakhs in 2000 to 1.16 lakhs in 2011, as a result of various interventions and scaled-up prevention strategies under the National AIDS Control Programme (NACP). The trend of annual AIDS deaths is showing a steady decline since roll out of the free Anti-Retroviral Therapy (ART) programme in India in 2004; estimated 1.5 lakhs lives have been saved due to ART till 2011.⁴

Deaths among children younger than 15 years are declining. The estimated 250 000 [220 000–290 000] children who died from AIDS-related illnesses in 2010 in comparison with 20% fewer death i.e.320 000 [280 000–360 000] in 2005. This declining death rate trend reflects the steady expansion of services to prevent HIV from being transmitted to infants and, to a lesser degree, the slow expansion of access to treatment for children.⁶⁹

Most AIDS orphans are clustered in extended families or communities. In addition to the emotional difficulties faced by CLHIV due to lack of resources available in most of these extended families, children often shoulder the adult responsibilities of income generation and caring for the sick. Many orphans and other vulnerable children are themselves living with people infected with HIV/AIDS, takes the burden of caring for siblings and chronically ill family members, and living in financially stretched
situations. The AIDS epidemic has made these children particularly vulnerable and is more likely to be uneducated, malnourished, and lack access to basic health care facilities. They also face psychological and emotional difficulties.

The AIDS pandemic has left millions of children without the essential time they need with adults. While the loss of parents places orphans particularly at risk, they are not the only children affected. When parents are critically ill, the quality of care that they can provide for their children are limited. Parents caring for orphaned children or for chronically ill family members also have limited time for their own children. The data from Botswana illustrate the pandemic’s contribution to time poverty. After providing care to ill relatives, friends, and neighbors, it was found that parents had less time for their own children. This deficit was most pronounced for children under six years of age: parents with additional HIV/AIDS care giving responsibilities spent 22 hours less per month with their young children. To fill this gap, older siblings often provided childcare. This simultaneously lowered the quality of care that young children received and jeopardized the welfare of older children.

When parents suffer AIDS-related illnesses, children are deprived of more than adult time; they are also deprived of financial resources essential for their welfare. The medical costs and loss of work drain resources away and are detrimental to child welfare. In a study it was noted that 48% of HIV-positive adults experienced health-related financial difficulties, while 23% reported profound difficulties in obtaining food, water, fuel, and transportation. Financial difficulties mount when families take on additional care giving responsibilities without additional income. Approximately half (47%) of the orphan caregivers and 64% of the HIV/AIDS caregivers surveyed in
Botswana reported financial difficulties due to extra care giving, these hardships were greatest among caregivers with only a primary-school education. 

While over 90 per cent of the 15 million children who have been orphaned by HIV/AIDS are cared for by family members, there is little information about whether adults can meet orphans’ essential care giving needs while working to economically survive. A survey was conducted in among 1033 working adults. Over one-third of working adults were caring for orphans and many with few financial resources: 82% were living on household incomes below US$10 purchasing power parity adjusted per person per day. Because of their care giving responsibilities, they were less able to supplement income with overtime, weekend, evening, or night work. At the same time care giving responsibilities meant orphan caregivers spent fewer hours caring for their own children and other family members. Nearly half of orphan caregivers had difficulties meeting their children's needs, and nearly 75% weren't able to meet with children's teachers. Pay loss at work compounded the problems: One-quarter of orphan caregivers reported having to take unpaid leave to meet sick childcare needs and nearly half reported being absent from work for children's routine health care. 

With the availability of anti-retroviral therapy, HIV disease in India and throughout the world has shifted from a disease that is typically seen as fatal, to one with a more chronic disease course. As a result, there are large numbers of HIV infected children surviving into adolescence and adulthood. One of the biggest challenges of present health care efforts in the area of HIV/AIDS is how to provide care and support for the soaring numbers of orphaned children being created by the disease.

A number of cross-sectional studies have found that chronically ill children are at increased risk of physical and psychosocial problems. In comparison to those
without chronic conditions, these children have been reported to have lower self-esteem, poorer body image and more problems in psychological well-being, behavior and social adjustment.

The importance of growth to HIV infection has long been appreciated and is reflected in the nearly universal inclusion of growth measures as study endpoints in therapeutic trials as well the inclusion of growth abnormalities as criteria for severe disease in both the World Health Organization (WHO) and the Centers for Disease Control and Prevention (CDC) classification systems. Children with growth failure (e.g., attained weight for age <60%) meet WHO stage 3 (severe) disease criteria. Abnormal growth is also included in the criteria diagnosis of AIDS wasting, which is a category C criterion (AIDS-defining illness) within the CDC classification system for HIV-infected children. AIDS wasting is defined as weight loss of 10% or more of body weight or deceleration in weight gain resulting in downward crossing of 2 or more of the percentile lines for age (e.g., 95th, 75th, 50th, 25th, 5th) in a child older than 1 year or in the 25th percentile of weight for height on consecutive measurements separated by more than 30 days in addition to the presence of chronic diarrhoea or chronic fever.\(^\text{17}\)

Nearly every clinical trial conducted by the Pediatric AIDS Clinical Trial Group has included growth, most commonly as weight-for-age Z-scores, as a study outcome measure. An important limitation of weight-based definitions is that they fail to identify children with compromised statural growth, which in some populations is the most common growth abnormality. Compromised statural growth is arguably superior to weight-based criteria as an indicator of disease progression. Height velocity was more strongly associated with disease progression than was weight velocity. Other
terms such as growth faltering, failure to thrive, growth retardation and growth failure, which indicate declining weight for age, height for age or both, have also been used in some studies of children with HIV infection.\textsuperscript{17}

Diminished growth is highly prevalent in HIV-infected children. Estimates of growth failure vary by study population and according to the criteria used. Studies from Europe performed with children receiving antiretroviral drugs (ARVs) of modest efficacy (before the availability of potent multiclass combination ARV regimens) reported a failure-to-thrive prevalence of approximately 50\% in children surviving to age 5 years (4). Fewer data are available from birth cohorts in developing countries.\textsuperscript{17}

Poor growth is often attributable to recognizable illnesses and secondary conditions that accompany HIV infection. Secondary causes of growth faltering or failure, many of which are potentially preventable, reversible or modifiable, are involved. These include dietary insufficiency, diarrheal illnesses, and anemia. Poor growth is also encountered in HIV-infected children with no discernible secondary illnesses (i.e., much of the variance in growth appears to be independent of HIV infection and suppression of viral replication with ARVs is an importance means of enhancing growth). Research in this area has also provided insight into several potentially important mechanisms involved in impairment of normal growth.

A deficiency in dietary intake, however, is unlikely the sole source of growth failure in these children. Several studies performed before potent ARVs were available showed that increasing the nutritional intake in children with HIV-associated growth failure with supplemental enteral and tube feedings improves weight but does not affect linear growth or lean body mass.\textsuperscript{17}
There is limited data on the prevalence and type of malnutrition (underweight, stunting, and wasting) among HIV-infected children in India.\textsuperscript{16} Though it is known that protein energy malnutrition is one of the commonest manifestations of HIV in this region.

A study among 100 HIV children attending ART services in the age group 1-14 years explored their clinical and immunological profile. 22% of them were wasted, 38.9% were stunted, and 38.9% were both wasted and stunted. Severe wasting and severe stunting were present in 20.3% and 13.5% children respectively.\textsuperscript{17}

Previous research demonstrates that HIV infection is usually accompanied by physical growth delays.\textsuperscript{10,11,14} Growth delays can also occur as a result of perinatal and postnatal insults, unrelated to HIV infection, such as prenatal malnutrition, prematurity, and malnutrition prevalent among children, as well as due to the impact of other HIV clinical symptoms, concurrent diseases, and treatment toxicity.

A child’s basic needs (e.g., food, clothing, shelter, health) have to be met in order for the child’s psychosocial needs to be addressed. Globally, children whose parents die of AIDS are often doubly burdened, losing not only the attention, care, and love that a parent gives, but also losing access to basic resources, such as housing and land. Households impoverished through the long illness of a parent and the cost of medical care leave few assets for surviving children.\textsuperscript{22}

Poor growth is common in HIV-infected children and has a significant adverse effect on survival independent of the degree of immune deficiency. The cause of abnormal growth is multi factorial. Intrauterine growth may be compromised in children born to HIV-infected women. Traditional risk factors such as insufficient food intake and
diarrhoea contribute to poor growth in children with HIV. However, in children not receiving ARVs, energy supplementation alone improves weight gain but does not reverse deficits in height. Other factors associated with impaired ponderal and linear growth includes level of HIV replication and use of ARVs for suppressing viruses and improving immune status. Results of studies also suggest that prevention, early detection and treatment of diarrhoeal illnesses may be effective targets for enhancing childhood growth and survival in children with HIV. Malnutrition has been shown to be an important co-morbid condition, as the same populations that are vulnerable to HIV also have a high prevalence of food insecurity.  

The psychological well-being of children is compromised in different ways by the HIV pandemic. The needs of Children living with HIV are often neglected due to reasons such as loss of one or both parents, living in a household where one or more people are ill, dying or deceased. In many situations, as the parents are too ill or no longer present, the caregivers for these children are often grandparents who are willing, but too ill or old to look after them. Furthermore HIV-related stigma and discrimination continue to be major obstacles for the extended family members to care for these children after the child has lost one or both parents. 

It was suggested that the death of a parent, regardless of its cause could place children at risk for internalizing problems such as depression, anxiety, withdrawal, and low self-esteem. The expressions of externalizing problems among orphaned children are much less consistent. AIDS orphaned children might not only be traumatized by the loss of parents (whose physical deterioration they may often have witnessed), they may also lack the necessary parental guidance through crucial life-stages of identity
formation and socialization into adulthood amidst AIDS related stigma and discrimination.  

The majority of children orphaned or made vulnerable by HIV/AIDS are living with a surviving parent, or within their extended family (often a grandparent). There are localized efforts, many of them initiated by faith-based groups, to address the needs of children made vulnerable by AIDS. According to UNAIDS, stigma and discrimination continue to accompany the HIV/AIDS epidemic. Children are not immune from stigmatization. In cases of stigma, children begin to be rejected early as their parents fall ill with AIDS. Children who are orphaned by AIDS often have a lower performance in school than children who are not. The preoccupation with the illness or death of their parents, the isolation due to the loss of friends, and the undertaking of additional work that comes with caring for ill parents or supporting oneself after one’s parents has died, often make it difficult for orphaned children to concentrate in school.  

Children orphaned by AIDS may face psychological and social challenges, including stigmatization, the impending or actual death of the surviving parent, disruptions in subsequent care, and financial hardship; these challenges may further impede the grieving process, placing these children at heightened risk of prolonged mental and behavioral problems.  

After parents die, some children go to live with relatives, who are themselves often impoverished and without sufficient resources to take on these orphans. Many AIDS orphans suffer from a diminished standard of living due to AIDS morbidity long before their parents die. As a result, orphaned children are especially vulnerable and potentially at increased risk of poor health. Because of the lack of resources and
supports for basic needs, concerns about poverty among AIDS orphans in developing countries often outweigh concerns about psychosocial needs. In addition to other risks, AIDS orphans’ own HIV infection or vulnerability to HIV/STD infection may serve as additional stressors for psychosocial adjustment. There are limited data from developing countries on the sero prevalence among AIDS orphans and its impact on their bereavement and psychosocial needs.\textsuperscript{23}

A descriptive correlational survey was performed to find the quality of life and social support of CLHIV. Poor quality of life was found among 60% children and majority (86%) of the subjects were found to have low social support.\textsuperscript{19}

By and large CLHIV are brought up in either home environment where they are looked after by both parents/one parent/grandparents/other caretakers. A small proportion of the children are brought to a structured institution either because they were orphaned or due to inability on the part of the caretakers to care for them.

Previous research appears to suggest that, institutional care jeopardizes children’s optimal development\textsuperscript{8,33}. Nevertheless, several studies indicate that in some cases of extremely adverse rearing circumstances well-functioning child-care institutions may offer children a better rearing environment than their own dysfunctional families. Early separation from parents, deprivation of parental care, love, affection, warmth, security, acceptance and discipline during childhood disrupts their normal socio-emotional development resulting in adjustment problems when a child is institutionalized.\textsuperscript{9}

A study compared the early institutional rearing on the physical and cognitive development of uninfected and HIV-infected institutionalized and family-reared
children. Both HIV infection and institutional care were related to delays in physical and cognitive development, with a larger effect of the rearing environment. This study revealed that family care, even of compromised quality, was found to be more favorable for children’s physical and cognitive development than institutional care.\textsuperscript{20}

However data from various studies\textsuperscript{5,9} highlighted the advantages of institutional care setting, which included better monitoring of adherence to ART medication, increased HIV information, future orientation, and increased social support. These aspects are important for CLHIV and are often compromised in unfavorable family care settings.

Cross-sectional analysis from the Positive Outcomes for Orphans (POFO) study that assessed intellectual functioning, memory, and behavior among orphans aged 6-12 years included 1,357 children in 83 institutional care settings in 6 study sites across 5 countries; these children were compared with 1,480 orphaned and abandoned community dwelling children from 311 community clusters (geographically bound sampling areas) in the same regions. The results showed that health, emotional and cognitive functioning, and physical growth were no worse for institution-living than community-living OVC, and generally were better than for community-living OVC cared for by persons other than a biological parent. The results of this analysis cast doubt on the generalizability of past studies indicating that institutions are systematically associated with poor child outcomes to children of this age group, 6 to 12 years of age, in less wealthy nations.\textsuperscript{5}

An exploratory study identified several areas for future research in the care of CLHIV. First, there is the need to identify and quantify extent of care challenges in high HIV-prevalent communities. Related to this is the need to identify the specific caregivers of these children and to quantify how challenges vary according to
caregiver type (e.g. kin vs. non-kin, different types of kin carergivers). A second area for future research includes the need to investigate caregiver well-being; the systematic review showed the need to investigate the health of those caring for AIDS-orphaned children in addition, longitudinal studies are needed to determine whether differences in child outcomes arise because of changing care circumstances including, for example, parental illness, parental death and placement into a new care situation.68

The care centers that preserve a family-style care with appropriate government and community support can result in better psychosocial wellbeing than kinship care models.10 In resource-poor regions and areas hardest hit by the HIV epidemic, positive outcomes have been cited to support institutionalized care.

Having gone through the various literatures felt the need to compare the physical and psychosocial wellbeing of children living with HIV/ in family based and institutionalized care settings which is an area unexplained in the Indian scenario.

No training module addressing the needs of children living with HIV currently exists in India. Developing a comprehensive module may help to train and build capacity of health care providers specially nurses and caretakers. Due to the lack of adequate data exploring the well-being of CLHIV in both care settings in India, as well as the need to develop a training module for care of these children, there was a felt need for this study.
Statement of the problem

A STUDY TO COMPARE THE PHYSICAL AND PSYCHOSOCIAL WELL-BEING OF CHILDREN LIVING WITH HIV (CLHIV) IN FAMILY-BASED AND INSTITUTIONALIZED CARE SETTINGS IN KARNATAKA.

Primary objective

Compare the Physical and Psychosocial well-being of children living with HIV (CLHIV) in family-based and institutionalized care settings.

Secondary objective

- To find the correlation between the Physical and Psychosocial well-being of CLHIV.
- To find the association of Physical and Psychosocial well-being of CLHIV in family-based and institutionalized care settings with selected baseline variables.
- To develop a comprehensive training module for nurses on care and support for CLHIV

Operational definitions

*Children Living with HIV (CLHIV)*: In this study CLHIV refers to Children between 5-16 years with a diagnosis of Human Immunodeficiency Virus infection.

*Physical well-being*: In this study physical well-being is measured through height and weight and Z score calculated based on WHO criteria for anthropometric measurements (WHO 2006).
**Psychosocial well-being:** In this study psychosocial well-being refers to Health Related Quality of Life as measured by PedsQL™ 4.0 generic core scale and behavioral and emotional need and pro-social behavior as measured and scored by using strength and difficulty questionnaire (SDQ)

**Family based CLHIV:** It refers to the children cared in home setting by

- Parents/ grand parents
- Extended family member

**Institutionalized CLHIV:** In this study it refers to the children cared in residential care settings.

**Hypothesis**

**H_1:** There will be a significant difference in the Physical and Psychosocial well-being of CLHIV in family-based and institutionalized care settings at 0.05 level of significance

**H_2:** There will be a significant correlation between the Physical and Psychosocial well-being of CLHIV at 0.05 level of significance

**H_3:** There will be a significant association between the Physical and Psychosocial well-being of CLHIV in family-based and institutionalized care settings with selected baseline variables at 0.05 level of significance
Conceptual frame work

Conceptualization is a process of forming ideas, designs and plans. A conceptual framework deals with the concepts assembled together by virtue of their relevance to the research problem which provides a certain frame of reference for clinical practice, research and education. The present study is aimed to compare the physical and psychosocial well-being of children living with HIV (CLHIV) in family-based and institutionalized care settings. An extensive literature search was done by the investigator found that theory of adaptation proposed by Sister Callista Roy is found to be best suited for the present study.

Nursing theories frame, explain or define the provision of nursing care. In 1976, Sister Callista Roy developed the *Adaptation Model of Nursing*, a prominent nursing theory. Roy's model sees the individual as a set of interrelated systems (biological, psychological and social). The individual strives to maintain a balance between these systems and the outside world, but there is no absolute level of balance. Individuals strive to live within a unique band in which he or she can cope adequately. The concepts in this study are as follows;
Figure 2: Conceptual frame work based on Sr. Callista Roys theory of adaptation
**Focal stimulus**

A focal stimulus is the degree of change or stimulus most immediately confronting the person and the one to which the person must make an adaptive response, that is the factor that precipitate the behavior. HIV diagnosis and care settings of CLHIV are the focal stimulus in the study.

**Contextual stimuli**

Contextual stimuli are all other stimuli present that contribute to the behavior caused or precipitated by the focal stimuli. Age, Sex, parental status, number of years in the school, Duration of stay in institution, CD4 count, Clinical staging and Duration of ART years are the identified contextual stimuli that may contribute to the well-being of CLHIV.

**Residual stimuli**

Residual stimuli are factors that may be affecting behavior but whose effects are not validated. CLHIV may have perceptions and expectation about their life and well-being. That may have an impact on their well-being which is not validated in the study.

**Regulator**

A regulator is a subsystem coping mechanism which responds automatically through neural chemical endocrine processes. Physical well-being of CLHIV as reflected growth parameters and psychosocial well-being of the children are the regulators in the study.
Cognator

A cognator is a subsystem coping mechanism which responds through complex processes of perception and information processing, learning, judgment and emotion. Cognators in the study are the interactions in the family, with peers, society and interaction with health care providers in family environment as well in the institutionalized settings which helps in coping with the challenging life events.

Adaptive (Effectors) modes

Adaptive or effectors modes are a classification of ways of coping that manifest regulator and cognator activity, that is physiologic, self concept, role function and interdependence. Physical well-being of CLHIV as reflected through the weight and height and psychosocial well-being of the children which is subjective but can be measured through the PedsQL™ and SDQ are the manifestations of adaptive response in the study.

Physiological mode

Physiological needs involve the body’s basic needs and ways of dealing with adaptation in fluid and electrolytes, exercise and rest, elimination nutrition, circulation and oxygen and regulation which includes the senses, temperature and endocrine regulation. Physical well-being as assessed by Weight and Height reflect the physiological need. Psychosocial well-being assessed by using PedsQL TM 4.0 and Behavioral and emotional difficulties and pro-social behavior assessed by using Strengths and Difficulties Questionnaire (SDQ) will examine the holistic nature of the child.
Self concept mode

Self concept is the composite of beliefs and feelings that one holds about oneself at a given time. It is formed from perceptions, particularly of others reactions, and directs ones behavior. Its components include: the physical self, which involves sensation and body image, and the personal self, which is made up of self consistency, self ideal or expectancy and the moral, ethical self. Physical, emotional, social and school functioning, behavioural and emotional need of the CLHIV composed of the self concept mode in the study.

Role performance mode

Role function is the performance of duties based on given positions in society. Health promoting behaviours of CLHIV like adherence to Anti Retroviral Therapy and other prescribed medications and positive living are the expected role performance of CLHIV in the study.

Interdependence mode

The interdependence mode involves ones relations with significant others support systems. Collaborative and mutual goal setting of CLHIV with care providers would help in positive living.

Output

The output of the study is expresses in terms of physical well-being and psychosocial well-being. Physical well-being consists of growth parameters measurement such as weight and height and categorized into normal, wasted or stunted. Psychosocial well-being is evaluated as high or low HRQOL and behavioural and emotional need
categorized as high, some or low need of support. The plan of action committed in this study is to develop a training module to promote well-being of CLHIV in all levels.

**Delimitations**

1. The study is delimited to children living with HIV aged 5-16 years

2. The study is delimited to children who are seeking ART services in the selected hospital.

**Summary**

This chapter has briefly dealt with the background of the study, the need for the study and the statement of the problem, objectives, hypothesis and the conceptual framework used for the study.