CHAPTER II

REVIEW OF LITERATURE

Review of literature is regarded as a preparatory stage for gathering data and serves to acquaint the researcher with previous research findings on the topic under study. A literature review is a compilation of resources that provide the groundwork for further study. It is frequently found as a subsection of a published research study. 24

A systematic review of literature and appraisal of all the relevant scholarly literature on the specific topic involves an in-depth study. The investigator carried out an extensive review of literature on the research topic in order to gain deeper insights into the problem, as well as to collect maximum relevant information for building up the study.

In order to collect the information, the investigator used online sources, books, journals, published and unpublished dissertations in medical, nursing and allied health sciences.

In the present study, the review of literature is organized under the following headings:

- Physical well-being of CLHIV
- Psychosocial well-being of CLHIV
- Impact of caring environment in CLHIV
Physical well-being of CLHIV

Growth is an important indicator of a child’s health. Children who are unhealthy tend to grow and gain weight more slowly than healthy children of their age. Human immunodeficiency virus (HIV)-infected children are at particular risk for problems related to growth. HIV and opportunistic infections often negatively influence the growth of young children. A lack of nutritious food necessary for normal growth complicates the lives of many HIV-infected children. Many factors affect children’s growth, including general nutrition, overall health, diseases and caretaker nurturing.

Growth failure is one of the most sensitive indicators of disease progression and growth dysregulation is quite common in HIV-infected children. Beginning at birth, HIV-infected infants often have smaller size and lower birth weight than noninfected children born to HIV-infected women. The causes of growth dysregulation are many; it can be due to chronic or repetitive infections, alterations in gastrointestinal function, and alterations in metabolic and endocrine function. The endocrine and metabolic effects may be the consequence of the primary infection or secondary to the use of any of the medications required to treat HIV infection and its complications.  

A cross sectional study has described the prevalence of underweight, stunting, and wasting in HIV-infected children in south India. Anthropometric measurements and CD4 counts were performed on 231 HIV-infected children. Scores for height for age, weight for age, and weight for height were correlated with CD4 cell counts. Prevalence of underweight was 63%, stunting 58%, and wasting 16%, respectively. 33–45% of children were moderately or severely malnourished even at CD4 >25%; sensitivity and specificity of stunting or underweight to predict HIV disease severity
was low. The study reports that under nutrition and stunting common among HIV infected children at all stages of the disease in India.

In a cross sectional study among 97 CLHIV between the age of 5 and 12 years found that majority of children were within healthy Z score ranges based on WHO criteria for height (71%) and BMI (89%). One child qualified as obese. Three-quarters of children had CD4+ T cell levels greater than 500 cells/mm³. Accordingly, the majority of children had been diagnosed as Stage 1 or 2 by a clinician up to six months prior to the study (85%). About half of the children were on ART (54%), with average (SD) treatment duration of 2 years.

A prospective study was done to examine the clinical and immunological profile of HIV infected children attending the ART centre, correlate CD4 count with clinical staging at diagnosis; and to study the clinical and immunological response to antiretroviral treatment. Average age of enrolled children was 6.24yrs (range 1-14 years) and mode of transmission was parent to child in 92%. Most common clinical presentation was fever (83%), cough (50.8%) and diarrhea (38.9%).

Tuberculosis was the most common opportunistic infection seen in 11% of children. 59% of enrolled children were malnourished. Antiretroviral treatment (ART) was initiated in 33 children. Children who were initiated on ART had a significant improvement in both clinical and immunological staging at the 6 months follow up. Immunological response (rise in CD4 count) to ART was better in children with lesser degree of immune suppression. The measure of agreement between the clinical and immunological stage at presentation was poor. Nutritional status was normal in 41 children. Among the rest 59 children, 23 (38.9%) were stunted, 13 (22%) were wasted, and 23 (38.9%) were both wasted and stunted. Severe wasting and severe
stunting were present in 12/59 (20.3%) and 8/59 (13.5%) children. Mean body mass index in children more than 5 years was 13.92.26

A study was done among the Indian children to correlate the absolute CD4 count, CD4% and HIV viral load with different clinical manifestations of HIV. A total of 92 HIV-1-infected children were enrolled in this study. The CDC classification, clinical manifestations, age and sex of each patient was determined. CD4 count, CD4% and HIV-1 viral load were estimated at presentation and correlated with various clinical manifestations of HIV disease. CD4% was higher in infants (p < 0.001) and lower in children over 5 years of age (p = 0.01). Boys had a higher absolute CD4 count than girls (769 +/- 517 vs 532 +/- 430 cells/mm3, p = 0.02). Patients with lymphadenopathy (n = 43) had a high CD4 count (840 +/- 487 cells/mm3, p = 0.01) whereas patients with HIV cardiomyopathy (n = 4) had low CD4 counts (mean 182 cells/mm3, p = 0.04). In patients with failure to thrive (n = 29), the CD4% was low (14 +/- 9%, p = 0.02) and HIV-1 viral load was high (mean 4.5 x 10^5 copies/ml, p = 0.03). CD4 count, CD4% and HIV viral load did not correlate with the stage of the disease as per the CDC classification. HIV viral load, CD4 cell count and CD4% vary with age and disease complications in HIV-infected children. However, CD4 count, CD4% and viral load did not correlate with CDC classification.27

The prospective study conducted from January 2000 to October 2001 at a tertiary care referral teaching hospital in Mumbai, India to examine the clinical profile of HIV infected children. Fifty HIV-positive children (31 males and 19 females; M: F = 1.6:1) were enrolled. Eleven cases were not immunized, 9 were partially immunized and 30 were completely immunized. Forty-two were perinatally infected, while eight cases were infected via blood transfusion (patients with thalassemia major on chronic
transfusion therapy). Clinical features at presentation in 42 symptomatic cases included protein-energy malnutrition (90%), fever _1 month (50%), weight loss _1 month (50%), persistent generalized lymphadenopathy (24%) and skin manifestations (79%). The gastrointestinal (62%) and respiratory (52%) were the most commonly involved organ systems. Opportunistic infections noted included tuberculosis (19 cases), candidiasis (6 cases), Pneumocystis carinii pneumonia (4 cases), herpes zoster (3 cases) and giardiasis (1 case). Six patients died (mortality, 14%).

A study described the growth (height and weight) patterns in infected and uninfected children who are born to HIV-infected mothers. Since 1987, children who were born to HIV infected mothers in 11 centers in 8 European countries were enrolled at birth in the European Collaborative Study and followed prospectively according to a standard protocol. Height and weight were measured at every visit, scheduled at birth; 3 and 6 weeks; 3, 6, 9, 12, 15, 18, and 24 months; and every 6 months thereafter. Serial measurements of height and weight from birth to 10 years of age of 1403 uninfected and 184 infected children were assessed. Growth patterns were compared with British 1990 growth standards and by infection status. Of the 1587 children enrolled, 810 were male and 777 were female; 1403 were not infected (681 boys, 722 girls), and 184 were infected (88 boys, 96 girls). Neither height nor weight was associated significantly with the main effects of HIV infection status at birth, but differences between infected and uninfected children increased with age. Uninfected children had normal growth patterns from early ages. Infected children were estimated to be significantly shorter and lighter than uninfected children with growth differences increasing with age.
Differences in growth velocities between the infected and uninfected children increased after 2 years of age for height and after 4 years of age for weight and were more marked in the latter. Between 6 and 12 months, uninfected children grew an estimated 1.6% faster in height and 6.2% in weight than infected children; between ages 8 and 10 years, these figures were 16% and 44%, respectively. By 10 years, uninfected children were on average an estimated 7 kg heavier and 7.5cm taller than infected children. Uninfected children who were born before 1994, before the widespread use of ART prophylaxis to reduce vertical transmission, did not substantially differ in growth from that of children who were born after 1994. Infected children with mild or serious symptoms lagged behind asymptomatic children in both height and weight, and these differences increased with age. Infected children, who were born before availability of ART, before 1988, were more likely to reach a weight below the third centile for age than children who were born after 1994 when effective HIV treatment was widely available. Of the 184 infected children, 67 had been weighed and/or measured at least once while on combination (>2 drugs) ART. The z scores for height and weight gain improved substantially in several children who received combination therapy regardless of their CDC clinical classification. Weight and height significantly improved for severely ill children after combination therapy.  

Growth in HIV-infected children generally improves with antiretroviral therapy (ART). A cross-sectional study evaluated prospectively the effect of pre-existing malnutrition on growth of HIV-infected children commenced on ART compared with those without pre-existing malnutrition. Inclusion criteria were children (2 months to 8.5 years) who were commenced on ART. Exclusion criteria were pre-treatment with ART, virological non-responders and co-existing tuberculous infection. Weight-for-
age (WAZ) and height-for-age Z scores (HAZ) < or =-2 at the initiation of treatment were the criteria for malnutrition. Monthly weight and height measurements were made for 18 months (2007-2008) after initiation of ART. Z scores were used to express changes in standard deviation (SD) units for each of the children of the study using WHO height and weight reference curves for age and gender at 0 and 18 months. The changes in Z score were compared within the groups by paired t-test and in both groups by the Mann Whitney U test. There was a significant increase in HAZ score (mean -0.15, p=0.006) and WAZ score (mean -0.09, p=0.034) in G1 and also HAZ score (mean -0.29, p<0.001) and WAZ score (mean -0.30, p=0.001) in G2. There was a trend toward a significantly greater Z-score change in G2 than in G1 for height (p=0.027) and weight (p=0.046). Study showed that in HIV-infected children, pre-existing malnutrition may impair nutritional response to ART.16

Prospective study of clinical profile of human immunodeficiency virus (HIV) infection in children was conducted in HIV clinic at a pediatric tertiary care center in an Indian urban metropolis from August 1994 onwards. 285 HIV positive children attending the HIV clinic were included for the study. Two hundred and thirteen (74.73%) patients were below the age of five years. Vertical transmission as the route of infection was documented in 247 (86.66%), 33 (11.57%) were infected through blood and in 5 (1.75%), the mode of transmission could not be ascertained. The clinical features noted were protein energy malnutrition in 127 (44.56%), pulmonary and extrapulmonary tuberculosis in 84 (29.47%), hepatosplenomegaly in 82 (28.77%), persistent generalized lymphadenopathy in 67 (23.50%), skin lesions in 63 (22.10%), chronic diarrhea in 43 (15.08%), oral thrush in 42 (14.73%), pyrexia of unknown origin in 36 (12.63%), chronic lung disease in 32 (11.22%), chronic hypertrophic parotitis in 27 (9.47%), chronic ototrhea in 26
(9.12%), recurrent lower respiratory tract infection in 24 (8.42%), neurological manifestations of non-tuberculous origin in 13 (4.56%) and Pneumocystis carinii pneumonia in 11 (3.88%). Forty-eight (16.84%) were asymptomatic, 30 (10.52%) died of AIDS during the study period and 39 (13.68%) have been lost to follow up. Vertical transmission was the commonest mode of infection. Perinatally infected children become symptomatic by five years of age. Protein energy malnutrition, hepatosplenomegaly and persistent generalized lymphadenopathy were common presenting features. Tuberculosis was the major co-infection. Chronic hypertrophic parotitis and chronic lung disease were distinguishing features of this study. Encephalopathy was associated with poor outcome. 29

A retrospective study sought to describe nutritional status and anemia burden among HIV infected children in India. Data was collected from 248 HIV-infected children aged 1–12 years attending three outpatient clinics in South India (2004–2006). Standard WHO definitions were used for anemia, HIV staging and growth parameters. The overall prevalence of anemia (defined as hemoglobin < 11 gm/dL) was 66%, and 8% had severe anemia (Hb < 7 gm/dL). The proportion of underweight and stunted children in the population was 55% and 46% respectively. Independent risk factors of anemia by multivariate analysis included the pre-school age group (age younger than 6 years) (OR: 2.87; 95% CI: 1.45, 5.70; p < 0.01), rural residence (OR: 12.04; 95% CI: 5.64, 26.00; p < 0.01), advanced HIV disease stage (OR: 6.95; 95% CI: 3.06, 15.79; p < 0.01) and presence of stunting (Height for-age Z Score < -2) (OR: 3.24; 95% CI: 1.65, 6.35; p < 0.01). Use of iron/multivitamin supplementation was protective against risk of anemia (OR: 0.44; 95% CI: 0.22, 0.90; p = 0.03). Pulmonary tuberculosis was an independent risk factor in multivariate analysis (OR: 3.36; 95% CI: 1.43, 7.89; p < 0.01). Use of antiretroviral therapy (ART) was associated with a
reduced risk of anemia (OR: 0.29; 95% CI: 0.16, 0.53; p < 0.01). No significant association was found between anemia and gender, cotrimoxazole, or ART type (zidovudine versus stavudine). The study reports that there is a high prevalence and strong interrelationship of anemia and poor nutrition among HIV-infected children in India, particularly those living in rural areas.\textsuperscript{14}

A possible explanation for the growth failure observed in HIV-infected children is that the altered metabolism in HIV-infected children redirects fuel utilization such that axial skeletal growth is impeded. If this is the case, there are several predictions that might follow:

1. Decreasing viral load would decrease the alterations in cellular metabolism and increase growth.
2. Increasing the amount of fuel would not increase growth, but would increase total body fat.
3. Increasing the concentrations of anabolic growth factors would redirect fuel utilization so that skeletal growth would occur.
4. Increasing concentrations of particular cytokines would increase resting energy expenditure, while decreasing them would lower resting energy expenditure.
5. Silencing of dysregulated cells would restore metabolism to normal parameters.

The first prediction has been shown by numerous published studies. The second prediction has been shown by who increased caloric intake in HIV-infected children, but did not increase lean body mass or growth velocity. The third prediction is being tested in a clinical trial at the Pediatric Branch of the National Cancer Institute, and preliminary data show that both height velocity and immune function can be improved with the addition of either human recombinant growth hormone or human
recombinant insulin-like growth factor I. The fourth prediction is also being tested in a clinical trial at the Pediatric Branch of the National Cancer Institute where human recombinant interleukin-2 (IL-2) will be given to HIV-infected children and resting energy expenditure will be measured before, during and after IL-2 therapy. The exact physiologic nature of the metabolic dysregulation of HIV-infected children is not well characterized and may involve not only thyroid function, abnormal cytokine secretion, and altered fat metabolism but other factors as well. The fifth prediction is not being formally tested, but studies in adults have indicated that adding corticosteroids to selected HIV-infected patients may improve their clinical status. While corticosteroids are known to inhibit axial skeleton growth and inhibit the formation of bone matrix, another approach that is anti-inflammatory may be of benefit.18

Poor growth is reported in as many as 50% of HIV-infected children. HIV infection adversely affects pregnancy outcome; infants born to HIV-infected women have significantly lower mean birth weight and length, regardless of the infants' HIV status, compared with infants born to uninfected women. Pediatric HIV further reduces birth weight. Progressive stunting, that is, proportionately decreased linear and ponderal growth, appears to be the most common abnormality in perinatally infected children and is accompanied by preferential decreases of fat-free or lean body mass. Although data are inconsistent, deficiencies of several micronutrients with the potential to affect growth adversely have been identified, including that of vitamin A. Neuroendocrine abnormalities also occur, including abnormal thyroid, growth hormone/insulinlike growth factor-1, and adrenal function; however, no consistent endocrine abnormality is observed in HIV-associated growth failure. Infections of the gastrointestinal tract and malabsorption of carbohydrates, fat, and protein are common, but no relationship between these disorders and poor growth has been demonstrated. Despite normal rates
of resting and total energy expenditures, the mean daily dietary intake of children with growth failure (GF) appears to be inadequate. Inadequate dietary intake is not the sole cause of GF; dietary supplementation improves weight but does not correct deficits in lean tissue or height. Levels of HIV RNA are greater in children with poor growth compared with infected children with normal rates of growth. How HIV replication impedes growth has not been established but suppression of HIV appears to have a favorable effect on ponderal and linear growth.\textsuperscript{18}

Indexes of children’s physical development such as weight-to-growth, height-for-age, weight-for-age, and BMI-for-age of 241 HIV-infected children were studied, depending on the age (less than 12 months, 12-35 and 36-59 month-old children), stage of disease, immunosuppression severity and HIV replication activity. It was revealed that physical development indexes of children less than 12 months may not be used as predictors of HIV severity and progression rate. Adequate prognosis in regard of severity and progression rate according to physical development indexes is possible only in children older than 1 year old.\textsuperscript{30}

A study described the growth in a cohort of black South African children born to HIV-1-infected women. Children born to HIV-1-seropositive women were followed up from birth to early childhood. At birth and at each visit, growth parameters were measured. Mean Z-scores were calculated for weight-for-length, weight-for-age and length-for-age and, if they were low, the children were regarded as wasted, malnourished or stunted, respectively. At the end of the study, there were 48 infected and 93 uninfected children. There were no significant differences between the two groups at birth. Thereafter, the infected group was found to have early and sustained low mean Z-scores for length-for-age and weight-for-age but not for weight-for-
length. The means reached significance at ages 3, 6 and 12 months for length and at 3, 6 and 9 months for weight. Infected children who died early had more severe stunting, wasting and malnutrition than infected children who survived. Infected children born to HIV-positive women had early and sustained stunting and were malnourished but not wasted. Children with rapidly progressive disease had both stunting and wasting and were more severely affected. 31

A community-based cross sectional survey reports on associations between orphan status and health and nutrition parameters in young children of urban Uganda. A two stage cluster sampling scheme was used for recruitment of study participants. Questions concerned information on demographic and socio-economic background, orphan status, history of morbidity during last 2 weeks, health care seeking behaviour, nutritional aspects, and HIV/AIDS status of deceased parents. In all study children, recumbent length and standing height were measured. 12% of orphans and 2% of non-orphans were underweight or severely underweight, 24% and 8% were stunted or severely stunted, and 4% and 1% were wasted or severely wasted respectively. In univariate analysis, there were no differences in anthropometric parameters between orphans and non orphans, or between AIDS orphans and non-AIDS orphans. Although there was a higher prevalence of self-reported morbidity in orphans than non orphans, there were no differences in reported treatment seeking behaviour and measured anthropometric parameters. Factors found to be associated with underweight were younger age (P < 0.01) and history of sickness in past 2 weeks (P < 0.05), while younger age (P < 0.001) and living with the grandmother (P < 0.05) were significantly associated with stunting. There was no association between orphan status and any form of malnutrition. Hence it seems that the extended family system still manages to care for young orphans. 32
HIV adversely affects growth in children. Pediatric AIDS Clinical Trial Group (PACTG) protocols often use weight velocity [changes in weight z-score for age (WAZ)] as a part of the composite endpoint for phase II and III clinical trials. HAZ and WAZ were compared to predict laboratory and clinical progression of HIV in a retrospective cohort study of HIV-infected children with data from PACTG Protocol 300. In both bivariable and multivariable analyses, changes in HAZ were more closely linked to subsequent progression than WAZ. Children with improved HAZ were somewhat less likely to exhibit virological failure [odds ratio (OR), 0.76; 95% confidence interval (CI) 0.51–1.14], than children with improved WAZ (OR, 1.45; 95% CI, 0.99,2.11). Children who had improved HAZ were less likely to exhibit immunological failure (OR, 0.7; 95% CI, 0.49–1.00), than children with improved WAZ (OR, 1.13; 95% CI, 0.82–1.57). Children who had improved HAZ were less likely to have other forms of clinical progression of HIV (OR, 0.55; 95% CI, 0.31–0.99), than children who had improved WAZ (OR, 1.0; 95% CI, 1.58–1.94). Increases in HAZ were associated with reduced risk of subsequent clinical progression and subsequent immune reconstitution and weakly associated with declines in HIV RNA. Changes in WAZ were not associated with laboratory outcomes relevant to pediatric HIV infection. 32

Data from a population-based study in rural western Kenya compared the basic health and nutritional indicators between non-orphaned children <6 years old and children who lost either or both of their parents. 1190 children <6 years old had been recruited for a cross-sectional survey from 60 villages of Rarieda Division, western Kenya. Basic demographic characteristics, including the vital status of the child’s parents, and health histories were requested from all participants, along with a finger-prick blood sample for determination of malaria parasite status and haemoglobin (Hb) levels.
Height-for-age (H/A) and weight-for-height (W/H) Z-scores were also calculated from anthropometric measurements. Overall, 7.9% of the children had lost one or both their parents (6.4% had lost their father, 0.8% had lost their mother and 0.7% had lost both parents). While there was no difference between orphans and non-orphans regarding most of the key health indicators (prevalence of fever and malaria parasitaemia, history of illness, Hb levels, H/A Z scores), W/H Z-scores in orphans were almost 0.3 standard deviations lower than those of non-orphans. This association was more pronounced among paternal orphans and those who had lost a parent more than 1 year ago. The W/H Z scores of children who had lost a parent more than a year ago were on average 0.49 SD (adjusted 95% CI: 0.77, 0.22) lower than non-orphans, although the Z scores of children who had been orphaned more recently were not significantly different from nonorphans (adjusted difference – 0.01 SD, 95% CI: 0.33, 0.31). There were no differences among any of the other demographic or health characteristics by time. These results suggest that the health status of surviving orphans living in their community is similar to that of the non-orphan population.  

In a study to assess the influence of orphanhood due to AIDS on children’s nutritional status, psychological well-being and life quality, and to explore appropriate intervention strategies in China, 186 children aged 8–15 years (93 AIDS orphans and 93 non-orphans) from a rural area of Henan Province were surveyed in a cross-sectional and matched pairs study on nutritional status, psychological health and life quality. It was found that no compelling evidence for poorer nutritional status in orphans. The nutritional status of both orphans and non-orphans was extremely poor according to the prevalence of stunting, underweight, wasting and anaemia. Depression, low self-esteem and lower quality of life were more frequent in orphans. These differences mainly existed in boys’ groups. No significant differences were
found between paternal, maternal and double orphans, or orphans in orphanages or extended families. Regression analysis revealed that orphanhood leads to low self-esteem and more depression which contributes to lower quality of life and mediates the association between orphanhood and quality of life. The high prevalence of poor nutritional status indicates that basic material needs of children, including AIDS orphans, which are unmet. Psychological problems were prominent among orphans had become the most important contributor of lower life quality. Boys were at least as vulnerable as girls. School based care and supports are crucial and would be a cost-effective way to improve the overall life quality of AIDS orphans.  

Prospective cohort study explores nutritional recovery in HIV-infected and HIV-uninfected children during inpatient nutrition rehabilitation and 4 months of follow-up. Weight gain, anthropometrics were the outcome measures. Sample included 454 children with severe acute malnutrition (SAM), 17.4% of children were HIV infected. None of the children were on antiretroviral therapy upon admission. Among the HIV-infected children, 35.4% (28/79) died, compared with 10.4% (39/375) in HIV-uninfected children (p<0.001). All children who survived achieved nutritional recovery (>85% weight for height and no oedema), regardless of HIV status. HIV-infected children had similar weight gain to HIV-uninfected children (8.9 vs 8.0 g/kg/d). Mean increases in z-scores for both subscapular (2.72 vs 2.69, NS) and triceps (1.26 vs 1.48, NS) skin folds were similar between HIV-infected and HIV-uninfected children, respectively, during nutrition rehabilitation. 362 children were followed for 4 months, at which time mean weight for height z-score was similar in HIV-infected and HIV-uninfected children (−0.85 vs −0.64, NS). HIV-infected children with SAM have higher mortality rates than HIV-uninfected children. Among
those who survive, however, nutritional recovery is similar in HIV-infected and HIV-uninfected children.\textsuperscript{35}

The above reviews on physical well-being of CLHIV depicts that growth failure is a common problem among Children infected with HIV. The reviewed studies also reveal that HIV-infected children frequently presents with stunting than wasting. Orphan status had reported malnutrition in some of the reviewed studies.

**Psychosocial well-being**

Psychological well-being is one of the important elements of children’s health and development. Psychological well-being is “a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community”. The exposure to a number of stressors associated with parental HIV/AIDS is likely to threaten children’s psychological well-being. Psychological well-being refers to the procession of emotional, behavioral and social competence appropriate to their developmental stages and the resilience in the adversity of parental illness and death.\textsuperscript{36}

A comparative, cross-sectional survey conducted to assess the quality of life (QOL) and the psychosocial problems of HIV infected children in the clinic of a tertiary care hospital in north India from July- December 2007. Children suffering from cystic fibrosis (CF) were chosen as a comparison group. Children ≥ 6 yr of age with HIV infection or Cystic Fibrosis, with no acute illness at the time of survey were included in the study. Quality of life of the enrolled children was assessed by using the Pediatric Quality of Life Inventory (PedsQLTM). Pediatric Symptom Checklist (PSC)
was used for assessing the psychosocial problems in the enrolled children. Forty one HIV infected and 30 children with cystic fibrosis were enrolled. According to child self-report in the PedsQLTM 4.0, the difference of perceived physical health status between the two study groups was statistically significant (p=0.04), with HIV infected children demonstrating a better QOL in this domain. A significantly greater number of children with cystic fibrosis (8/30 or 26.67%) suffered from psychosocial problems as compared to HIV children (3/41 or 7.32%) [p=0.026]. Study concluded that the quality of life and psychosocial functioning is reasonably good in children with HIV infection.  

It is important to understand how and to what degree HIV as a chronic illness and parental HIV/AIDS affects the psychological well-being of children. A study reviewed 24 published and unpublished empirical studies that examined mental health of children orphaned by AIDS. Sixteen of the reviewed studies included a comparison group. Three of the studies with a comparison group were conducted in the US and the other studies were in Africa. Their review suggested that children orphaned by AIDS might experience higher levels of psychological difficulties. Also, they found that studies revealed more internalizing problems than externalizing problems among children orphaned by AIDS. Based on this finding, they speculated that orphans were likely to experience more emotional problems such as depression and anxiety than conduct problems or other problem behaviors. They also indicated the increasing need of research in regions of emerging HIV epidemics such as China, India, and Eastern Europe. 

A study uses a screening questionnaire (the Strengths and Difficulties Questionnaire, SDQ) to indicate levels of parental or carer concern about behavioural or emotional difficulties in a representative group of school-age children with vertically acquired
HIV attending London clinics. Fourteen per cent of the total 107 children screened were reported to have behavioural and emotional difficulties scoring in the “abnormal” range. Older children tended to have higher scores. Overall, levels of reported difficulties were found to be similar to those reported for other chronic childhood illnesses and slightly higher than in the general child population.39

A descriptive correlational survey compared quality of life and social support of CLHIV. The subjects were 50 children living with HIV attended ART Plus centre of one of the districts of South India. CLHIV in age between 10-18 years, diagnosed positive for HIV/AIDS and are on anti-retroviral therapy attending ART Plus centre of District Hospital were included in the study. Children who were diagnosed positive for HIV/AIDS but not on ART and children with known or documented mental illnesses were excluded from the study. For assessing quality of life, standardized Horizon’s questionnaire and for social support, standardized Horizon’s tool was used. Frequency and percentage distribution of quality of life and social support showed that 60% of the subjects were found to be poor quality of life and (86%) of the subjects were found to have low social support. There was a significant association found between, father living/dead (p=0.018) with quality of life. Whereas no association was observed between variables includes age, gender, both parent’s status includes parents living or dead.19

Effect of HIV-Related Parental Illness and Death was explored in a systematic review. It reports that in comparison with children from HIV-free families, children affected by HIV/AIDS had poorer emotional, behavioral and social adjustment. The studies that compared emotional adjustment of children affected by HIV/AIDS (either AIDS orphans or vulnerable children) with children from HIV-free families reported that
children affected by HIV/AIDS scored higher in emotional/internalizing problems, such as depression, traumatic stress, somatization, anxiety, loneliness, suicidal ideation, and hopelessness. Sixty one percent of the studies that assessed behavioral adjustment reported that children affected by HIV/AIDS presented more behavioral/externalizing problems, such as delinquency, conduct problems, disruptive behaviors, early and high-risk sexual activities, and hyperactivities. About 69% of studies that measured social adjustment found that children affected by HIV/AIDS demonstrated poorer scores on peer problems, peer social skills, school interest, self-esteem, life quality, hope and control toward future, social competence and locus of control. A few studies did not find such differences between the children affected by HIV/AIDS and children from HIV-free families. The review also found that AIDS orphans did not show more conduct and emotional problems, more peer problems, more attention difficulties, or less prosocial behaviors than children from HIV-free families. As discussed by the authors, this result may be due to the high exposure to violence and hunger affecting not only AIDS orphans but also children from HIV-free families in their research site. Another study in the review found that AIDS orphans were no different than children from HIV-free families on depression and externalizing problems. They suggested that the stable family transition after maternal death may buffer the traumatic effect of maternal death. In their sample, most orphans moved to a new household of a close relative and had no more than one transition in residence. Regarding the social adjustment, another study explored that AIDS orphans in Uganda did not score lower than children from HIV-free families on self-concept.

A cross-sectional study was done to compare the quality of life (QOL of HIV infected children aged 2-18 years attending antiretroviral treatment (ART). Forty age- and
gender-matched children suffering from other chronic ailments admitted in pediatric ward during the study period served as controls. Quality of life was assessed using Pediatric quality of life inventory (PedsQL4.0). Clinical and immunological staging of HIV infection as per World Health Organization (WHO) guidelines was recorded among the cases. Clinical diagnosis and duration of symptoms of control subjects were also recorded. In accordance with the child self-report, quality of life among HIV infected children was better compared to controls with significantly better scores in the psychosocial ($P=0.008$), emotional ($P=0.001$) and school ($P=0.039$) functioning among the former. Similarly, a parental proxy report on perceived quality of life of their HIV infected children was better than controls with significant difference in emotional functioning domain ($P=0.038$) Demographic factors did not significantly influence the total QOL scores among HIV infected children. In subgroup analysis, it was observed that children with milder clinical stage had significantly better quality of life scores in physical functioning domain ($P=0.021$). Similarly, younger aged children performed better QOL scores than their older counterparts in physical functioning domain ($P=0.014$).

A study assessed significant differences in psychological functioning between HIV infected children and a demographically matched healthy control group and to examine the utility of applying a stress and coping model to children with HIV disease. Participants included HIV-infected children (ages 6-16) and their caregivers ($n = 36$) and a control group of healthy children and their caregivers ($n = 32$). 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 behavior 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. Approximately 25% of children with HIV disease exhibited clinically significant emotional or behavioral problems; however, even higher rates of psychological adjustment problems were found in healthy children. Children with HIV disease who have not been told their diagnosis and children who endorse more emotion-focused coping strategies tend to exhibit more psychological adjustment problems.  

Findings of the previous studies indicate that parental death may be a specific risk factor for depressive and anxiety disorders in children. Several decades of clinical research have documented links of early parental death and prolonged parental separations with depression.

In a cross-sectional survey, 4 groups of 200 children (children whose parents died of AIDS, children whose parents died of causes other than AIDS, children living with parents infected with HIV/AIDS, and non-orphaned children whose parents are not known to be infected with HIV/AIDS) aged between 10 and 19 were interviewed on their hyperactivity, emotional, conduct, and peer problems using the Strengths and Difficulties Questionnaire. Children whose parents died of AIDS showed very high levels of peer problems [F (3,196)= 7.34, p < .001] whilst both orphaned groups scored similarly high on conduct problems [F (3,196) = 14.85, p<.001]. Hyperactivity showed no difference and was very low in the entire sample. Emotional problems
were very high in all the groups except among the non-orphaned children \(F (3, 196) = 5.10, p < .001\). Thus it highlights the fact that Orphans and children living with parents infected with HIV/AIDS are at heightened risks for emotional and behavioural disorders and that efforts to address problems in children affected by HIV/AIDS must focus on both groups of children.\(^{43}\)

Effect of HIV-Related Parental Death vs. Illness was assessed in a systematic review. All the studies that compared the emotional and behavioral adjustment between AIDS orphans and vulnerable children showed that the two groups of children did not differ from each other. A study with a large sample size in a central province of China showed that AIDS orphans (\(N = 755\)) and vulnerable children (\(N = 466\)) demonstrated similarly poorer psychological adjustment in terms of loneliness, self-esteem, future expectation, and hopefulness, than children from HIV-free families in the same rural community. In the same study, vulnerable children even reported higher levels of loneliness and lower levels of self-esteem than AIDS orphans, suggesting that vulnerable children were at higher risk for psychological problems. Similarly, the review also found that AIDS orphans and vulnerable children manifested similarly high levels of emotional distress and conduct problems. However, review found that, around the time of parental death, AIDS orphans experienced higher levels of emotional distress and had more contact with the criminal justice system than vulnerable children. Most of the AIDS orphans reported that they had just one or no friends at all and expressed the feelings that their peers did not like them.\(^{40}\)

Psychosocial effect of orphan hood was explored in a sub-Saharan African population and evaluated a new framework for understanding the causes and consequences of psychosocial distress among orphans and other vulnerable children.
Data from 5321 children aged 12 to 17 years who were interviewed in a 2004 national survey in Zimbabwe. Orphans had more psychosocial distress than did non orphans. For both genders, paternal, maternal, and double orphans exhibited more-severe distress than did non orphaned, non vulnerable children.  

An explorative study was done to find the main influencing factors of the health related quality of life of children living in HIV/AIDS-affected families in rural areas in Yunnan, China. The HRQOL of 116 children aged 8 to 17 from HIV/AIDS-affected families and of 109 children from unaffected families was evaluated by the Chinese Version of PedsQL TM 4.0. Children from HIV/AIDS-affected families reported lower scores of HRQL than those from unaffected families, especially in the psychosocial functioning, emotional functioning and school functioning domains. Children living with grandparents reported higher PedsQL scores in psychosocial health, social functioning and school is functioning. Disclosure of parental HIV/AIDS status reduced children’s PedsQL scores in emotional functioning and social functioning. Caregivers spending more hours accompanying the children appeared to increase the PedsQL scores in psychosocial health and school functioning. The findings indicate the child’s self-esteem, the caregiver's perceived quality of life, the child’s foster pattern, the average hours of company provided by the caregiver, and whether the child was informed of the parent’s HIV/AIDS status are important factors influencing HRQL.

A cross sectional study was conducted to measure the quality of life in human immunodeficiency virus-infected children. The QOL instrument modified from the GHAC (General Health Assessment for Children) consisted of 5 main domains: general health, physical functioning, symptoms, psychological well-being, and social and role functioning was used for the study. A total of 131 main caregivers (21%
males, average age 42.5 years) of human immunodeficiency virus-infected children (28% male, average age 10.1 years) answered the questionnaires. General health perception ratings for most children were at the upper end of the scales, and 38.3% of children ranged over the lower 70% of possible scores. When asked caregivers about their ratings on each subitem, 35.3%, 39.8%, and 49.6% of children were ranked in the lower 70% of possible scores for physical well-being, emotional functioning, and daily activities, respectively. About one-fourth (26.3%) of the children had at least some limitation in physical functioning, with more frequent limitations in vigorous activities (22.6%) than in basic activities of daily living (8.3%). Almost all (97%) children had at least one psychological problem. Four out of 5 domains showed that children without immune suppression had a significantly higher quality of life than children with immune suppression. There was a significant correlation between health care utility and physical functioning (p<.001, symptoms p<.002), and social and role functioning (p<.008).

Observational, prospective, cohort study was done to assess the long-term outcomes of HIV-infected and -exposed children, including survival, QOL, growth and neurologic development, drug related toxicity, and disease complications. Perinatally exposed, HIV-infected (1847) and uninfected (712) children and adolescents were studied. Three age-specific instruments were used to assess QOL. QOL domain scores were assessed for subjects 6 months to 4 years, 5 to 11 years, and 12 to 21 years of age, and the impact of infection status and alternative treatment regimens on QOL domains was evaluated. HIV infection was associated with significantly worse mean adjusted scores for functional status among children 6 months to 4 years of age and health perceptions, physical resilience, physical functioning, and social/role functioning among those 5 to 11 years of age. However, uninfected children 5 to 11
years of age reported significantly worse psychological functioning. HIV-infected children (5–11 years of age) and adolescents (12–21 years of age) receiving no antiretroviral treatment had worse health perceptions. Adolescents receiving no antiretroviral agents also had worse symptoms. When antiretroviral regimens were compared, adolescents receiving protease inhibitor plus nonnucleoside reverse transcriptase inhibitor-containing therapy had worse symptoms, compared with those receiving protease inhibitor-containing therapy; otherwise, no significant differences were found.46

A qualitative assessment aimed to identify unique situations and concerns of children living with HIV/AIDS and their caregivers experienced in dealing with the disease and ongoing treatment process. Individual in-depth interviews using a semi-structured interview guide were employed. Thirty-four children (12 boys and 22 girls) aged 8–16 and thirty-five primary caretakers (6 males and 29 females) aged 21–66 participated in this study. Results identified some of the common concerns and challenges shared among this population, including impact of the illness on loved ones, disclosure, adherence, behavioral problems, discrimination, treatment affordability, and financial constraints. Certain issues that emerged as important themes specific to this population include unwarranted concerns about certain aspects of the illness, misinterpretation of the nonverbal clues within families, future child guardianship and placement planning, treatment availability during transitional period, and the challenge of maintaining the confidentiality of the diagnosis. The needs and suggestions of the target groups provided the framework for improving the current services such as the provision of private sessions with children separated from their caregivers (especially for older children and adolescents), disclosure intervention, behavioral screening, life skills building, and empowerment mobilization.47
A cross-sectional study was conducted in an urban slum in Andhra Pradesh among 370 children selected by simple random sampling. Strength and difficulty questionnaire (SDQ) was used to estimate the prevalence of emotional and behavioral disorder. A semi-structured questionnaire was used to evaluate the social predictors of the condition, health-seeking behavior, and its impact on educational status of the children. Maternal depression was evaluated using Patient Health Questionnaire (PHQ-9). Eighty-three (22.43%) children had an abnormal score on at least one domain of SDQ. Logistic regression analysis indicated that male gender (OR = 5.51), under-nutrition (OR = 2.74), low socioeconomic status (OR = 3.73), nuclear family (OR = 1.89), working status of the mother (OR = 2.71), younger age of the mother at the birth of the child (OR = 3.09), disciplinary method (OR = 2.31), financial problem at home (OR = 13.32), alcoholic father (OR = 11.65), conflicts in family (OR = 7.29), and depression among mother (OR = 3.95) were significant predictors. There was a significant impact on educational performance (p = 0.008) and parents had little awareness regarding the condition. The high frequency of emotional and behavioral problems, its impact on educational performance of the children, associated adverse social factors, poor knowledge, and treatment-seeking behavior of the parents in an urban slum warrants immediate attention. Study recommended considering the interrelation of all these factors to plan a continuum of comprehensive services that focus on prevention, early identification, and effective intervention strategies with community involvement.

The review reveals that emotional and behavioral problems were prevalent in children living with HIV but no major psychiatric disorders. Orphanhood frequently reported an impact on quality of life and behavioral well-being.
Impact of caring environment in CLHIV

Families play central roles in the HIV/AIDS pandemic, caring for both orphaned children and the ill. This extra caregiving depletes two family resources essential for supporting children: time and money.

Published studies in sub-Saharan Africa illustrated that parents caring for the chronically ill had less time for their preschool children (74 versus 96 hours per month) and were almost twice as likely to leave children home alone (53% versus 27%); these children experienced greater health and academic problems. Care giving often prevented adults from working full time or earning their previous level of income; 47% of orphan caregivers and 64% of HIV/AIDS caregivers reported financial difficulties due to care giving.49

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suggestions of the target groups provided the framework for improving the current services such as the provision of private sessions with children separated from their caregivers (especially for older children and adolescents), disclosure intervention, behavioral screening, life skills building, and empowerment mobilization.⁴⁷

A systematic review reported that the psychological well-being of AIDS orphans was significantly poorer than non-AIDS orphans. Of the six studies that compared the emotional adjustment between AIDS orphans and non-AIDS orphans, five studies reported that AIDS orphans demonstrated more emotional problems, such as depression, anxiety, traumatic stress, anger, and sleeping difficulties. Of the two studies that compared behavioral adjustment between the two groups, one study found that AIDS orphans presented more behavioral problems, such as conduct problems, and delinquency. However, one study in the review showed that AIDS orphans and non-AIDS orphans had similar degree of emotional problems and behavioral problems. Only three studies compared social adjustment between AIDS orphans and non-AIDS orphans and the results consistently showed that AIDS orphans presented poorer social adjustment.⁴⁷

An explorative study was conducted to assess the relationship between parental HIV/AIDS and psychosocial adjustment of children in rural central China. Participants included 296 double AIDS orphans (children who had lost both their parents to AIDS), 459 single orphans (children who had lost one parent to AIDS), 466 vulnerable children who lived with HIV-infected parents, and 404 comparison children who did not experience HIV/AIDS-related illness and death in their families. The measures included depressive symptoms, loneliness, self-esteem, future expectations, hopefulness about the future, and perceived control over the future.
AIDS orphans or vulnerable children scored significantly higher on depression (F[2,1576] = 39.12, p < .0001) and loneliness (F[2,1576] = 48.23, p < .0001), and scored significantly lower on self-esteem (F[2, 1576] = 20.22, p < .0001), positive future expectations (F[2, 1576] = 3.26, p < .05), hopefulness about future (F[2, 1576] = 15.33, p < .0001), and perceived control over future (F[2, 1576] = 9.63, p < .0001). The level of psychosocial adjustment was similar between single orphans and double orphans, but differed by care arrangement among double orphans. The findings underscore the urgency and importance of culturally and developmentally appropriate intervention efforts targeting psychosocial problems among children affected by AIDS and call for more exploration of risk and resilience factors both individual and contextual, affecting the psychosocial wellbeing of these children.50

An exploratory qualitative study with carers of AIDS-orphaned children and informants from nongovernmental organizations in KwaZulu-Natal (KZN) province, South Africa, was conducted to explore challenges associated with caring for AIDS-orphaned children and to identify areas for more detailed quantitative studies. Respondents noted that HIV had not changed capacity of extended family to take children into their home after parental deaths because historically extended family played a significant role in childcare. When respondents were asked to name the top challenges associated with care, three key themes emerged around economic challenges, challenges related to meeting children’s needs, and carers’ health problems. Respondents highlighted how parental deaths created challenges related to meeting children’s needs. Carers argued that parental deaths resulted in the absence of adult family members who played important roles in child socialization. Carers described the impact of deaths on the child-rearing process, stating it was “hard to
provide guidance to our children because many family members have died from AIDS”.

Psychosocial well-being between paternal and maternal orphans was compared in a sample \( (N = 459) \) of children who had lost one parent to HIV and who were in family-based care. Measures included academic marks, education expectation, trusting relationships with current caregivers, self-reported health status, depression, loneliness, posttraumatic stress, and social support. No significant differences were found between maternal and paternal orphans, except that paternal orphans reported better trusting relationships with caregivers than maternal orphans. Children with a healthy surviving parent reported significantly better; depression, loneliness, Posttraumatic stress and social support scores than children with a sick parent. Analyses revealed significance with regard to orphan status on academic marks and trusting relationships with caregivers while controlling for age, gender, surviving parent’s health status, and family SES. Findings underscore the importance of psychosocial support for children whose surviving parent is living with HIV or another illness.

In the face of the HIV/AIDS epidemic that has contributed to the dramatic increase in orphans and abandoned children (OAC) worldwide, caregiver attitudes about HIV, and HIV-related stigma, are two attributes that may affect caregiving. Little research has considered the relationship between caregiver attributes and caregiver reported HIV-related stigma. Baseline data were collected between May 2006 through February 2008. The sample included 1,480 community-based and 192 institution-based caregivers. Characteristics of the community-based and institution based caregivers are described using means and standard deviations for continuous variables
or counts and percentages for categorical variables. Approximately 80% of both community-based and institution-based caregivers were female; and 84% of institution-based caregivers, compared to 66% of community-based caregivers, said that they would be willing to care for a relative with HIV. Similar proportions were reported when caregivers were asked if they were willing to let their child play with an HIV-infected child. In a multivariable model predicting willingness to care for an HIV infected relative, adjusted for site fixed effects, being an institution-based caregiver was associated with greater willingness (less stigma) than community-based caregivers. Decreased willingness was reported by older respondents, while willingness increased with greater formal education. In the adjusted models predicting willingness to allow one’s child to play with an HIV-infected child, female gender and older age was associated with less willingness. However, willingness was positively associated with years of formal education. The caregiver-child relationship is central to a child’s development. OAC already face stigma as a result of their orphaned or abandoned status; the addition of HIV-related stigma represents a double burden for these children.  

A monograph explored the effects of early social-emotional and relationship experience on the development of young orphanage children. It reported that children reared in severely deficient institutional environments in numerous countries over six decades to showed a variety of developmental delays such as physical growth and behavioral development. It further noticed institutionalized children, nearly every aspect of their early environment is deficient; consequently, it is usually not possible to determine the role of their early social–emotional-relationship experiences apart from diet, nutrition, physical exercise, medical care, toys, and so forth in this growth retardation. Nevertheless, although some orphanage children are malnourished,
nutrition does not seem to be the primary factor in the children's short stature. Orphanage children are often observed to eat substantial amounts of food, and their weight is consistently higher than their height, especially the weight/height index, that psychosocial deprivation is a major cause. Children living in substandard orphanages have been reported to display a variety of other atypical behaviors, including stereotyped self-stimulation, a shift from early passivity to later aggressive behavior, over-activity and distractibility, inability to form deep or genuine attachments, indiscriminate friendliness, and difficulty establishing appropriate peer relationships. In contrast, it was also found that young children reared in an orphanage that met standards of best practice developed Stanford-Binet IQs typical of the parent-reared population.53

The aim of this study was to explore the psychosocial problems and coping strategies of orphan and vulnerable children living in two orphanages, namely Yenege Tesfa and Bridge of Hope Ethiopia orphan and vulnerable children care and support centers in Gondar town, North West Ethiopia. The research primarily used a phenomenological study design of the qualitative method. A total of 20 in-depth interviews and 4 focus group discussion sessions were carried out. The study revealed that orphan and vulnerable children in the orphanages accessed all the basic services necessary to sustain their lives. Conversely, the study also revealed that the children suffered from a set of multidimensional and intertwined psychosocial problems that were the least addressed in the orphanages. Most of the children reported that they felt so happy and led better life than before due to the basic services they received at the orphanages. They witnessed that they were able to access basic needs, such as food, clothing, shelter, medical care and education. The study revealed that the majority of the children felt sad, depressed, and in stress due to lack of good relationship with
service providers and the community, and due to grief and bereavement of their parental loss. Most of the participants during the FGDs reflected that they experienced feelings of loneliness during their stay in the orphanage due to poor relationship with the staff, particularly caregivers, lack of love from the community, and memory of parental death. Thus, interventions to promote the psychosocial wellbeing of the children should focus on addressing psychological problems, advancing socialization skills, organizing extracurricular activities and entertainments, and improving coping strategies.54

A study had compared psychological symptoms among double AIDS orphans (i.e., children who lost both of their parents to HIV/AIDS) who were in the care of different family-based caregivers (i.e., surviving parent, grandparents, other relatives, & non-relatives) before they were replaced in orphanages. The participants include 176 double AIDS orphans from four AIDS orphanages in rural China. Prior to being replaced in AIDS orphanages, these children had received family-based care by different caregivers, which included surviving parent (38%), grandparents (22%), other relatives (19%) and non-relatives (22%). The psychological measures include traumatic symptoms, depression, and loneliness. Both bivariate and multivariate analyses suggested that children who were previously cared for by non-relatives scored significantly higher in traumatic symptoms, depression and loneliness scales than children who were previously cared for by their surviving parent, grandparents, and other relatives. The children in the care of grandparents reported the best scores on all psychological measures among children in the care of non-parent relatives. Multivariate analysis, controlling for children’s gender, age, length in orphanages, number of household replacements, and total duration of replacement, revealed that the type of caregivers was significantly associated with psychological problems.55
A study explored the symptoms of depression among caregivers of rural AIDS orphans (i.e., children who had lost one or both of their parents to HIV/AIDS) and vulnerable children (i.e., children who were living with HIV-infected alive parents), and to explore factors associated with the presence of symptoms of depression among caregivers. Cross-sectional data were collected from 160 adult caregivers (parents, relatives or other adults) from a rural area in China where many residents were infected with HIV through unhygienic blood collection. The sample included 120 caregivers from households caring for AIDS orphans and vulnerable children (OVC) and 40 from households without OVC. The Center for Epidemiological Studies Depression Scale (CES-D) was used to assess the symptoms of depression among the caregivers. Multiple regression analysis was performed to assess the associations of depressive symptoms with various individual and family factors among caregivers. The mean score of CES-D for the entire sample was 19.18 (17.84 for men and 20.44 for women). The univariate analysis indicated that the score of CES-D was significantly higher among caregivers with lower education, fewer household items/assets, from families with adult or pediatric HIV infection. Controlling for age, gender, and caregivers’ education, multiple regression analysis revealed significant associations between symptoms of depression and reduced family SES, adult or pediatric HIV infection in family. The results indicated an elevated level of depression symptoms among caregivers of OVC and underscored the needs for psychological support and intervention for their caregivers, especially for those with lower family SES, from families with an adult or pediatric HIV infection.56

Prevalence and predictors of HIV-related stigma among institutional- and community-based caregivers of orphans and vulnerable children living in five less-wealthy countries was explored in a study. 1,480 community-based and 192 institution-based
caregivers were included as sample. Approximately 80% of both community-based and institution-based caregivers were female; and 84% of institution-based caregivers, compared to 66% of community-based caregivers, said that they would be willing to care for a relative with HIV. Similar proportions were reported when caregivers were asked if they were willing to let their child play with an HIV-infected child. In a multivariable model predicting willingness to care for an HIV-infected relative, adjusted for site fixed effects, being an institution-based caregiver was associated with greater willingness than community-based caregivers. Decreased willingness was reported by older respondents, while willingness increased with greater formal education. In the adjusted models predicting willingness to allow one’s child to play with an HIV-infected child, female gender and older age was associated with less willingness. However, willingness was positively associated with years of formal education. This study points out that OAC already face stigma as a result of their orphaned or abandoned status; the addition of HIV-related stigma represents a double burden for these children.\textsuperscript{57}

Review was conducted from secondary data and reports from scientific literature, government, non-governmental organizations, and public media regarding children orphaned by AIDS in China to address their living situation, bereavement process, and psychological problems. It suggests that AIDS orphans in China are living in a stressful environment with many orphans struggling with psychological problems and unmet basic needs such as food, shelter, education, and medical care. The review recommends to address the psychosocial needs of AIDS orphans in China and to develop health promotion programs to mitigate the negative impact of parental death on the physical and psychosocial well-being of orphans.\textsuperscript{58}
A study, based on qualitative data from children and workers in AIDS orphanages, examines the daily lives, needs, and feelings of orphans and explores the advantages and disadvantages of institutionalized care of AIDS orphans in China. The current study was conducted in 2006–2007 in two rural counties of central China. Data in the current study included individual in-depth interviews with 23 children who lost both of their parents to HIV/AIDS (ages 8 to 17 years) living in AIDS orphanages and 5 AIDS orphanage workers. Findings in this study reveal that children living in orphanages mostly felt that the living conditions were better than the families they lived with after the death of their parents. However, according to the children and orphanage workers, the institutional care has some disadvantages, such as administrative restraints, limited psychological guidance, stigma, lack of education on AIDS, and financial burdens of the operation. Implications for intervention programs include continuing support from the government and nongovernmental organizations, improvements in administrative styles, and the need of incorporating psychological support within the institutions.59

A cross-sectional survey of primary caregivers of HIV-infected children aged 5–18 years was done to explore the burden of disease on HIV-infected orphaned and non-orphaned children accessing primary health facilities in a rural district with poor resources in South Africa. Four hundred and six primary caregivers of HIV-infected children aged 5–18 years were interviewed by using structured questionnaire. The sample consisted of 406 primary caregivers: 319 (78.6%) brought the child to the health facility for HIV testing because of chronic and recurrent infections. Almost half (n = 183, 45.1%) of the children were maternal orphans, 128 (31.5%) were paternal orphans, and 73 (39.9%) were double orphans. A univariate analysis showed that maternal orphans were significantly more likely to be older (OR = 2.57, p =
0.000, CI: 1.71–3.84), diagnosed late (OR = 2.48, p = 0.009, CI: 1.26–4.88), and to start ART later (OR = 2.5, p = 0.007, CI: 1.28–4.89) than non-orphans. There was a high burden of infection among the children prior to HIV diagnosis; 274 (69.4%) presented with multiple infections. Multiple logistic regression showed that ART start age (OR = 1.19, p = 0.000, CI: 1.10–1.29) and time on ART (OR = 2.30, p = 0.000, CI: 1.45–3.64) were significantly associated with orphanhood status. Half (n = 203, 50.2%) of the children were admitted to hospital prior to start of ART, and hospitalization was associated with multiple infections (OR = 1.27, p = 0.004, CI: 1.07–1.51).60

Study was designed to evaluate the quality of life of children living with HIV at an institutional care home in, India. Cross-sectional health measures and interview data were collected from 97 residents between 5 and 12 years of age. The Strengths and Difficulties Questionnaire, SDQ, was used to measure levels of caregiver concern about emotional or behavioral difficulties. SDQ scores showed 53% of children scored in the “borderline range”, 47% were in the “abnormal range”, and peer problems were most frequently reported. The Quality of Life (QOL) of each child was measured with the Pediatric Quality of Life (PedsQL) Inventory. Caregivers perceived children to have an overall higher QOL than was self-reported by children (Total Score 83 vs. 78). Emotion and School functioning means were higher according to child self-report than caregiver proxy-report (Emotion 72 vs. 65; School 79 vs. 76, resp.). PedsQL subcategory scores that were indicative of potentially impaired QOL were in social functioning (21%), according to child report, and school functioning (26%), according to caregiver-report. Our findings indicated maternal orphans to be six times more likely to have psychological difficulties compared to children whose parents were living but unable to care for their child. The age of the
child and age of joining the care home were found to be significantly negatively associated with quality of life reported by children and positively associated by caregiver-proxy reports. Physical measures showed the children’s clinical severity of disease remained well-controlled living in a residential, values-based care home.\textsuperscript{61}

A study was done to determine the association of HIV infection, treatment regimens, and type of care received on quality of life (QOL) in pediatric patients. Study was conducted from January to December 2008 at Dr. Ram Manohar Lohia Hospital, New Delhi, India at the HIV pediatric outpatient department. PedsQL(TM) 4.0 was administered to 100 HIV-infected and 200 uninfected children aged 8-12 years and their primary caregivers. HIV infection was associated with a negative impact on QOL among children with lower scores for physical, school, and emotional functioning and health symptoms. In contrast, uninfected children had lower social functioning scores. Results showed antiretroviral treatment to be associated with improved QOL among HIV-infected children. It was also identified infected that children living at home to be at a higher distress of psychosocial functioning and health symptoms when compared with children living in care homes.\textsuperscript{62}

The increasing HIV and AIDS epidemic in South Africa poses a substantial burden to older people, in particular older women who mainly provide care for sick adult children and their grandchildren who have become orphaned and rendered vulnerable by the death or illness of their parents. In this study, 202 isiXhosa speaking older caregivers from Motherwell in the Eastern Cape Province of South Africa were trained to provide care for grandchildren and adult children living with HIV or AIDS. Based on a community needs assessment, a health education intervention comprising four modules was designed to improve skills and knowledge which would be used to
assist older people in their caregiving tasks. Some topics were HIV and AIDS knowledge, effective intergenerational communication, providing home-based basic nursing care, accessing social services and grants, and relaxation techniques. Structured one-on-one interviews measured differences between pre-intervention and post-intervention scores among those who attended all four modules vs. those that missed one or more of the sessions. The results demonstrated that older people who participated in all four workshops perceived themselves more able and in control to provide nursing care. The participants also showed a more positive attitude towards people living with HIV or AIDS and reported an increased level of HIV and AIDS knowledge. The results provided valuable information upon which the development of future interventions may be based and psychosocial and structural needs of the older caregivers may be addressed by relevant stakeholders.63

Conclusion

The concern of this chapter was to review the literature available on various studies related to the present study. In this chapter, studies that have examined CLHIV’s vulnerabilities related to key aspects such as physical well-being i.e. nutritional and health status, as well as the literature on the specific behaviors and QOL on the care and support available for CLHIV. The review of literature provided an orientation to what is known and not known about the area of enquiry.

It is evident that research and commentary on CLHIV are based on studies conducted mostly in African countries. This study focus on the CLHIV in Karnataka, where increasing number of CLHIV have been identified in the state, and considerable number of programmes targeting CLHIV have been implemented in the past few years.
The review helped the researcher to refine the study objectives. After the in-depth review of the literature, the conceptual framework was adopted for the study. It helped the researcher to know about studies done in the area of psychosocial and physical well-being of family cared and institution reared CLHIV.

Conversely, the next chapter shall deal with the methodology used for the study.