CHAPTER VI
SUMMARY, FINDINGS, CONCLUSIONS, IMPLICATION, LIMITATION
AND RECOMMENDATIONS

This chapter deals with the conclusions drawn from the findings of the present study. It also includes the implications for nursing practice, education, administration and research, recommendations and limitations. This study has attempted to compare the Physical and Psychosocial well-being of CLHIV in family-based and institutionalized care settings in Karnataka.

SUMMARY

The Primary objective of the study was to compare the Physical and Psychosocial well-being of CLHIV in family-based and institutionalized care settings. The identified Secondary objectives was to find the correlation between the Physical and Psychosocial well-being of CLHIV and to find the association between Physical and Psychosocial well-being of CLHIV in family-based and institutionalized care settings and the selected baseline variables.

The study attempted to examine the following Research Hypotheses:-

H₁: 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

H₂: There will be a significant correlation between the Physical and Psychosocial well-being of CLHIV at 0.05 level of significance

H₃: 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
The conceptual framework adopted for the study was Sister Callista Roy’s theory of adaptation. 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. The study adopted this model considering the objective of comparing the physical and psychosocial well-being of CLHIV in the selected care settings. Study incorporates the concepts of stimuli, coping mechanisms, effectors and output in the contexts of CLHIV who strives to live within a unique band.

Review of literature was organized as follows:

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

Cross-sectional interview technique was used to collect data from children living with HIV/AIDS and their care takers. The totals of 380 children were included in the study. 68 family based children were from KR Hospital Mysore, 152 children, out of which 58 family based and 94 institutionalized were from St. Johns Hospital Bangalore and 160 children, out of which 68 family based and 92 institutionalized were from Indiragandhi children’s hospital Bangalore. Children between the ages of 5-16 years were included in the study. In addition to interviewing the children, information about each child was gathered from the caregivers who had spent more than 15 hours/week with the children.

Height and weight were measured at the time of the interview and Z score standard deviations (SD) were calculated based on WHO criteria for anthropometric
measurements. The Pediatric Quality of Life Inventory (PedsQL 4.0) was used to measure Health Related Quality of Life (HRQOL). It comprises parallel child self-reports and caregiver proxy reports. The Strengths and Difficulties Questionnaire (SDQ) is an internationally well validated brief behavioral screening tool for children 3–18 years old, to assess behavioral and emotional needs and pro-social behavior.

**FINDINGS**

The findings revealed the following:

1. In both settings CD4 count, clinical staging and duration of ART years were comparable.

2. Children differed in the aspects such as age, gender, parental status, average years of schooling.

3. The mean year of stay in institution was 2.4 years.

4. Majority of children in both groups (69.5% in family based and 74.2% in institutionalized) are in the category of normal according to their BAZ. 122(64.2%) of the family based children were in the classification of stunting in comparison with 84(44.2%) in the institutionalized children, which showed statistical significance (p.001) between the group.

5. According to child self report HRQOL, the difference of perceived physical health status between the two study groups was statistically significant (p=.0001), with children living in institutionalized setting demonstrating better QOL in this domain. Also, institutionalized CLHIV perceived better psychosocial health score (85.9±10.3) which consisted of emotional, social
and school functioning domain and the total perceived HRQOL (85.2±8.9) in comparison with children reared at home (71.8±6.7) which was statistically significant (p=.001). Majority (91.6%) of the institutionalized CLHIV were not at risk of HRQOL according to their total score in the PedsQL™. Children residing in the family were almost equally distributed based on the risk status showing 49.5% with not at risk and 50.5% having at risk of HRQOL and the difference was statistically significant.

6. There was no statistically significant difference (p .621) between total score of Behavioral and emotional need between two groups. Significant difference (p .001) was noted in the area of emotion (4.1±1.7 vs 4.9±1.8), conduct (2.9±1.7 vs 3.9±1.4), and Prosocial (5.6 ±1.8 vs 4.4±2.1) between both group respectively but there was no statistical difference in the area of hyperactivity (4.35±2.0 vs4.38±1.9) and peer problems (4.66±2.1 vs4.62±1.8).

7. In both groups there were no children belonging to the category of high need of support. Children requiring some need of support was higher in the institutionalized children (64.2%) as compared to family based children (35.8%).

8. There was also no significant correlation between the physical and psychosocial well-being in both the groups.

9. Variables such as BAZ and parental status ( p .046), HRQOL and Clinical staging in family based ( p .002) and institutionalized (p .001) CLHIV and Behavioral and emotional need with family income (p .026) showed statistically significant association

**IMPLICATIONS**

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The findings of the study have following implications.

The findings of the study have brought out certain facts that have far reacting implications for nursing in the areas of practice, education, administration and research.

Nursing practice

The nurse caring for a child with HIV is presented with various challenges. Professionally, he or she faces the challenge of helping the child to cope with their health concerns effectively. However, the nurse also has a practical challenge to ensure that the holistic need of the child is met effectively as possible. To deliver the best quality care, nurse need to equip oneself with adequate knowledge and understanding regarding the physical and psychosocial needs of the children living with HIV. The result of the study reveals that children reared in the family and institutions requires care and support both in general health and psychosocial aspects. Nurses rendering service in the ART centers, general hospital, care centers and all other health facilities should be well informed regarding the holistic needs of children living HIV. The developed module will help to train the health care workers to deliver quality care to these children. This will also help the health care providers especially nurse to educate children regarding health promoting behaviors thus improve their quality of life and general well-being.

Nursing education

HIV/AIDS is a condition that continues to generate fear, misunderstanding, misinformation, and discrimination. Nurses and caregivers lack understanding regarding care of children with HIV.

Caring for CLHIV demands special skill, as in addition to nature of chronicity of the disease, the accompanying stigma, lack of support, need for lifelong medications
insist comprehensive care and continuous support from the multidisciplinary team. Thus the curriculum of the nursing education should incorporate techniques of individualistic assessment including both physical and psychosocial as demonstrated in the present study. The developed training module can be adopted in the curriculum of the nursing education which aid as a tool to educate nurses in rendering holistic care. Educating nurses about the prevention of transmission and promotion of health is a promising strategy for changing nursing practice. Regular dissemination of updated information to nurses on such interventions is recommended to maintain the positive change. The study also emphasizes the need for the learners to utilize the developed module.

**Nursing administration**

The present study highlights the need for the nurse administrators to use Pediatric Quality of Life Inventory (PedsQL 4.0) to measures Health Related Quality of Life, and Strengths and Difficulties Questionnaire (SDQ) to screen the behavioral needs of CLHIV in addition to the assessment of physical parameters. It also highlights the need of nursing audit, guidelines, updating of nursing standards in care of children with HIV. The prepared manual can be implemented as three day training programme and reinforced through the continuing nursing education to assure quality care to the children. Nurses play an important role in orphan care. This care could include direct physical care, being an advocate on behalf of the child, and helping to influence policy changes to respect the rights and dignity of children. A nurse administrator can initiate measures to enlighten knowledge and skills of the nurses and related multidisciplinary team in promoting these children’s well-being.

**Nursing research**
The central goal in pediatrics health care is to facilitate the emotional and physical well-being of children. Research provides evidence that children reared in the families and institutions requires development and care. The developed module will help to train the health workers to improve better service to these vulnerable populations. The problems faced by the CLHIV are enormous and researches gaps exist regarding the interventions require meeting their need. Future research must address the long term impact of the disease and interventions to address the growing need.

LIMITATIONS

- Many environmental influences on health and wellbeing are cumulative, Cross-sectional analyses, such as the one presented here, cannot account for these effects.
- Details of care environments is not explored in the present study
- The limited number of study settings in a localized region rather than numerous settings at national level.

RECOMMENDATIONS

- Research on larger cohorts including the details of care environments could be conducted
• A study could be undertaken to identify the effectiveness of the training module
• Longitudinal study can be done to identify the long term impact on the children

Summary

This chapter dealt with the nursing implications, limitations, suggestions and recommendations of the study.