CHAPTER V

RESULTS AND DISCUSSION

INTRODUCTION:

The analysis of the data collected during the study period has brought out certain useful and interesting aspects and recommendations, which are discussed below. The first objective of the study was to: - "Identify the psychosocial variables among the children suffering from AIDS and their principal care-givers".

The socio-demographic data was obtained from the principal care-givers of children suffering from AIDS and the data was assessed to subjects belonging to lower socio-economic background. The socio-demographic data consists of selected variables including the name of the subject /child, age of the principal care-givers, age of the child, sex of the principal care-givers, sex of the child, residence, marital status, number of children, nationality, educational level of the principal care-givers educational level of the child, employment status of the principal care-givers, house-hold income, relationship status, type of family, religion etc. all these factors are a clear indication of their quality of life.
Even though, these factors may not contribute directly to the impact of the illness AIDS, as experienced by the children and their principal care-givers but they definitely have their contribution in indirect ways, when the principal care-givers are educated, they would have broader views and this helps them to cope better by understanding the illness condition, and predict their child’s prognosis.

The socio-demographic data of the children suffering from AIDS and their principal care-givers were assessed. Majority of the principal care-givers were in the age group of 20-30 years (80.3%) and only a few of them were between 51-60 years (0.3%). This indicates that HIV/AIDS disease predominantly affects the younger age group of the principal care-givers i.e. the age group of 20-30 years, the peak period of one’s reproductive life. The age group between 0-5 years of children suffering from AIDS is 64% and few children were aged 15 years and above (4%).

Majority of the principal care-givers had come from an urban community (66%) and about (0.3%) of them were from sub-urban community. Similarly, the marital status of the principal care-givers indicate that most of them were ‘married’ (89.7%) and other principal care-
givers were ‘living together’ (7.7%) and few of them were ‘single’ 2.3% and other principal care-givers were ‘separated’ with the least percentage of 0.3.

The educational status of the principal care-givers shows that 22.7% of them had secondary school education and few of them were with collegiate education (0.3%). likewise, the educational status of the children ranged from 1st to 3rd std. (36.7%) and the rest of the children were studying between 8th & 10th std. (1.3%) majority of the principal care-givers had an monthly income which ranged between Rs. 1000-3000 (77.) and others with an income of Rs. 3001-6000 (23%).

Most of the principal care-givers were from ‘joint family’ set-up (89.7%) and a very few were ‘living alone’ (0.3%) The occupational status of the principal care-givers reveals that majority of them were un-skilled laborers with a percentage of (70.3) and few were semi-skilled laborers (0.3%).

The second objective of the study as prescribed by the investigator was to:

“Assess the psychosocial variables among the children suffering from AIDS and their principal care-givers”.

180
The association between the age of the principal care-givers and the variables related to the physical aspects indicates the significance of the sub-scales of diagnosis-health functioning and social support are significant. The age of the principal care-givers ranged between 20–60 years and the mean total of the respective age group was 29.77 and standard deviation 2.40, the significance was .000. The variables of social support had a mean total of 13.80 and a standard deviation of 1.96 and the significance was .000 with the P<0.001 whereas the other variables of family, psychological and spiritual are insignificant.

The sex of the principal care-givers of the children suffering from AIDS, in other words, the ‘family component’ corresponding to the male and female gender forms the significant unit of a family. The male group has a mean total of 23.75 and a standard deviation of 2.29, similarly, the female group has a mean total of 22.46 and a standard deviation of 2.32 and the significance is .032 with a P<0.05. All the other variables of diagnosis-health functioning, social support, psychological and spiritual are all insignificant.

The marital status of the principal care-givers vary from married, living together, single and separated The variables of psychological and
spiritual are significant. The ‘psychological’ variable has a mean total of 16.29 and a standard deviation of 2.24 with the significance .036 and the ‘spiritual’ variable has a mean total of 12.92 and a standard deviation of 2.09 and the significance is .052 and the $P<0.05$. The interpretation corresponds to the severity of the psychological distress experienced by the principal care-givers regarding their illness, i.e AIDS, as well as their children’s.

**Residence of the principal care-givers:** - of children suffering from AIDS includes three areas urban, rural, sub-urban and all the variables of diagnosis-health functioning, social support, psychological and spiritual are all insignificant.

The educational status of the principal care-givers of children suffering from AIDS has been categorized as primary school, secondary school, higher education and college education. The variables of diagnosis-health functioning, social support, family, psychological, and spiritual are all insignificant.
The educational status of the principal care-givers of children suffering from AIDS included two categories of literate / illiterate and the variables of diagnosis-health functioning, social support, family, psychological, and spiritual are all insignificant.

The employment status of the principal care-givers of children suffering from AIDS includes different categories of unskilled laborers (coolie), office, self-employed, business, school-college. The variables of diagnosis-health functioning, social support, family, psychological, and spiritual are all insignificant.

The monthly income of the principal care-givers of children suffering from AIDS ranges from Rs. 1000-3000 and Rs. 3001-6000. The variable of ‘social support’ is significant to the monthly income of the principal care-givers with the mean of 13.83. and a standard deviation of 12.29 for Rs. 1000-3000. The range between Rs. 3001-6000 has a mean of 1.80 and a standard deviation of 1.95 and the significance is .039 with a P<0.05. and all other variables of diagnosis-health functioning, family, psychological, and spiritual were insignificant.
The type of family includes joint, nuclear and living alone, in relation to the ‘family’ component which is significant with a mean of 22.53 and a standard deviation of 2.34 and the significance is .000 with a P<0.001. The other variables of diagnosis-health functioning social support psychological and spiritual were insignificant. Thus the significance of the ‘family’ its structures / types are an important aspect for the formation of the social institution called ‘family’.

The religion of the principal care-givers of children suffering from AIDS, consisted of different religions of Hindu, Christian, Muslim and others. The variable diagnosis-health functioning is significant with the mean total of 29.77 and a standard deviation of 2.40 and the significance is .30 The variable ‘family’ is also significant, which has a mean of 22.53 and a standard deviation of 2.34 and the significance is .000. The variable ‘psychological’ is also significant with the mean of 16.29 and a standard deviation of 2.24 and the significance is .000 with a P<0.001. and the other variables of social support, spiritual are all insignificant.

**Children**

**The third objective was to:** -
“Determine the psychosocial variables and its impact on the children suffering from AIDS and their principal care-givers”.

The age of the children suffering from AIDS ranges from 0-5 years, 6-10 years, 11-15 years, 15 years above, its association with the variable of social support is significant with a mean of 15.30 and a standard deviation of 2.01 and the significance is .039. The ‘psychological’ variables is also significant with a mean of 12.42 and a standard deviation of 1.42 and the significance is .038 with a P<0.05 the other variable of physical-health functioning, medication, pain assessment and spiritual are insignificant.

The sex of the children suffering from AIDS comprises of both male and female children. The variable of pain assessment is significant with a mean of 15.13 for the male and a mean of 15.66, for the female and the standard deviation for the male is 1.62 and for the female is 1.73 and the significance is .008. The variable ‘psychological’ is significant with a mean of .172 for the male and a mean of .178 for the female, the standard deviation for the male is .864 and .859 is for the female and the significance is .009 with the P<0.05. And all other variables, such as physical–health functioning, medication, social support, spiritual are insignificant.
The educational status of the children suffering from AIDS ranges from upto 1-3 std, 4-7 std and 8-10 std. All the variables like physical - health functioning, medication, pain assessment, social support, spiritual are insignificant. The educational status of the children consisting of literate /illiterate status in association with the above mentioned variables are insignificant, thus indicating that the educational status of the child has no relationship to the child’s illness like AIDS.

The fourth objective was to:

“\textit{To correlate the psycho-social impact of children suffering from AIDS and their principal care-givers and the supportive role of the nurse in counseling them}”.

- The associated variables of pain assessment, social support, psychological, spiritual showing the Mean, Standard Deviation and Karl Pearson’s co-efficient of correlation of the principal care-givers of children suffering from AIDS. The paired samples association between physical-health functioning and social support is significant.

\begin{tabular}{|l|l|l|l|}
\hline
 & Mean & Std. Dev & Correlation & Significance \\
\hline
Diagnosis-health & 29.77 & 2.40 & .240 & .000 \\
Functioning & & & & \\
\hline
\end{tabular}
Social support 13.80 1.96

Second, the association between diagnosis-health functioning and family is significant.

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>Std. Dev</th>
<th>Correlation</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis- health</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Functioning</td>
<td>29.77</td>
<td>2.40</td>
<td>.187</td>
<td>.001</td>
</tr>
<tr>
<td>Family</td>
<td>22.53</td>
<td>2.34</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Third, the association between diagnosis-health functioning and spiritual is significant.

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>Std. Dev</th>
<th>Correlation</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis- health</td>
<td>29.77</td>
<td>2.40</td>
<td>.171</td>
<td>.003</td>
</tr>
<tr>
<td>Functioning</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spiritual</td>
<td>12.92</td>
<td>2.09</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Fourth, the association between social support and spiritual is significant

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>Std. Dev</th>
<th>Correlation</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social support</td>
<td>13.80</td>
<td>1.96</td>
<td>.158</td>
<td>.006</td>
</tr>
<tr>
<td>Spiritual</td>
<td>12.92</td>
<td>2.09</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The P<0.01 for all the above-mentioned associated variables. And these variables have a positive Karl-Pearson’s co-efficient of correlation. The other associated variables of diagnosis-health functioning and psychological, social support and psychological, social support and family, spiritual and family, family and spiritual, and psychological and family are all insignificant.

Fifth objective

To associate the psycho-social impact of children suffering from AIDS and their principal care-givers with selected socio-demographic data

- The associated variables of pain assessment, social support psychological and spiritual showing the Mean, Standard. Deviation.
  And Karl Pearson’s co-efficient of correlation of the principal care-givers of children suffering from AIDS.

  The Paired samples association between physical- health functioning and medication is significant.

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>Std. Dev</th>
<th>Correlation</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical- health</td>
<td>17.71</td>
<td>1.78</td>
<td>.302</td>
<td>.000</td>
</tr>
<tr>
<td>Functioning</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medication</td>
<td>8.38</td>
<td>1.04</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Second, the association between physical health functioning and pain assessment is significant.

<table>
<thead>
<tr>
<th>Mean</th>
<th>Std. Dev.</th>
<th>Correlation</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical-health Functioning</td>
<td>17.71</td>
<td>1.78</td>
<td>.192</td>
</tr>
<tr>
<td>Pain assessment</td>
<td>15.33</td>
<td>1.68</td>
<td></td>
</tr>
</tbody>
</table>

Third, the association between physical health functioning and social support is significant.

<table>
<thead>
<tr>
<th>Mean</th>
<th>Std. Dev.</th>
<th>Correlation</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical-health functioning</td>
<td>17.71</td>
<td>1.78</td>
<td>.230</td>
</tr>
<tr>
<td>Social support</td>
<td>15.30</td>
<td>2.01</td>
<td></td>
</tr>
</tbody>
</table>

Fourth, the association between medication and pain assessment is significant.

<table>
<thead>
<tr>
<th>Mean</th>
<th>Std. Dev.</th>
<th>Correlation</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medication</td>
<td>8.38</td>
<td>1.04</td>
<td>.303</td>
</tr>
<tr>
<td>Pain assessment</td>
<td>15.33</td>
<td>1.68</td>
<td></td>
</tr>
</tbody>
</table>

Fifth, the association between medication and spiritual is significant.
P<0.01 for all the above mentioned variables is significant and Karl Pearson’s co-efficient of correlation is positive. The other variables of physical-health functioning and psychological, physical-health functioning and spiritual, medication and social support, medication and psychological are all insignificant.

The associated variables of pain assessment, social support, psychological, spiritual showing the Mean, Standard Deviation and Karl Pearson’s co-efficient of correlation of children suffering from AIDS. The paired samples association between pain assessment and spiritual is significant.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>Std. Dev.</th>
<th>Correlation</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain assessment</td>
<td>15.33</td>
<td>1.68</td>
<td>.197</td>
<td>.001</td>
</tr>
<tr>
<td>Spiritual</td>
<td>13.06</td>
<td>2.17</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Second, the association between pain assessment and spiritual is significant.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>Std. Dev.</th>
<th>Correlation</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain assessment</td>
<td>15.33</td>
<td>1.68</td>
<td>.197</td>
<td>.001</td>
</tr>
</tbody>
</table>
Spiritual 13.06 2.17

Third, the association between social support and psychological is significant.

<table>
<thead>
<tr>
<th>Mean</th>
<th>Std. Dev.</th>
<th>Correlation</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social support</td>
<td>15.30</td>
<td>2.01</td>
<td>.481</td>
</tr>
<tr>
<td>Psychological</td>
<td>12.42</td>
<td>1.42</td>
<td></td>
</tr>
</tbody>
</table>

Fourth, The association between psychological and spiritual is significant.

<table>
<thead>
<tr>
<th>Mean</th>
<th>Std. Dev.</th>
<th>Correlation</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychological</td>
<td>12.42</td>
<td>1.42</td>
<td>.244</td>
</tr>
<tr>
<td>Spiritual</td>
<td>13.06</td>
<td>2.17</td>
<td></td>
</tr>
</tbody>
</table>

The P<0.01 for the above mentioned variables is significant and Karl Pearson’s co-efficient of correlation is positive. The other associated variables of pain assessment and social support, pain assessment and psychological, social support and spiritual are all insignificant. with P>0.05.
DISCUSSION

INTRODUCTION:

The findings of the study further interprets, the impact of a child infected with HIV in this sample (n=300) was primarily, due to the additional and unusual care burden demands created by HIV infection. It also appears that caregiving demands are important issues for families of HIV-infected children and constantly, an important target for intervention.

The effects of HIV infection of the family system was examined by 27 Lesar-Sharon, Maldoriado et al 1997, reported that the psychological burden of the illness was significantly related to the child’s HIV status. Financial burden, social, familial impact differed as a function of the child’s and care-givers HIV status.

The results of this study suggest several significant implications pertaining to the impact of HIV-infection on the family system. First, majority of the families of children who are HIV positive reported more personal strain was experienced by the primary care-givers related directly to the demands of the illness, than did families of children with HIV negative.
Lesar Sharon, Gerber et al, 1996, examines the relationship of family functioning, presenting stress and social support of care-givers, who are parenting children with HIV infection.

The results of the study suggests that social support is significantly related to the quality of life in this sample of subjects which includes children (n=300) suffering from HIV/AIDS and their care-givers (n=300). All families were selected to participate in the study and were not randomly chosen. The children and their care-givers participated in the study, may in fact compose a somewhat difficult group, than the total sample of pediatric HIV group, composed of children from the northern and southern parts of India. Social support has been linked to positive health status in persons with HIV (Nicholas and Webster 1993).

Although the relationship of social support to physical, -health functioning, family, psychological, and spiritual aspects in other studies. Is similar. Solomon, et al (1991), this current study of quality of life across the spectrum of HIV disease represents a critical area of HIV research.
Lubeck and fres, 1992, examined changes in children and their principal care-givers with HIV/ AIDS showed a significant deterioration in role functioning and increase in disease symptoms, over a 12 month period because of the nature of the disease. In HIV-related outcome variables, such as quality of life, are subjective measures in psychosocial research. The socio-demographic variables identified in children and their care-givers, have important correlation of living with HIV/AIDS. Another possible shortcoming of the study, is that majority of the care-givers had responded to the questionnaire approximately. However, the difference is due to a large number of care-givers who were of a ‘single parent family’.

Ragsdale and Morrco (1990) found that quality of the life varied as a function of HIV classification. The relationships between the psychosocial variables were examined and Tenoshok (1988) found that anxiety, mood state and hopelessness, were positively correlated with the four domains: - physical, social, psychological, and spiritual items and their subscales. The findings of a significant relationship between social support and quality of life suggests the importance of further research in this area. McGough 1990, addressed with significance of the psychological consequences of
people with HIV, including social stigma, loss of family, or significant others, loss of occupational and financial resources and loss of shelter and health care.

The perceived health status of the children and their care-givers was significantly correlated with social support and quality of life in this sample of persons living with HIV. The HIV positive individuals with higher scores on social support indicated a more positive self-rating of their health and those individuals with higher scores on quality of life indicated a more positive self-perception of health. Further social support is linked to the quality of life and perceived health status. And the quality of life is linked to the measure of immune status, CD4 lymphocyte count because the quality of life measurement has an importance in nursing research and practice.

The W.H.O.- bref field version, 1996, measures have also been used more extensively in HIV positive related children and their caregivers. In addition, to measuring physical, social, psychological, and spiritual items.

These functional items correlates with the limitations, to intermediate activities of daily living of both the children and their caregivers infected with HIV/AIDS. In this study, the women scored lower than men in
several areas of life including social role and psychological aspects of mental health.

44

Rose 1993, studied that women with children identified, findings of depression and worry, over their children’s / future. As one of the most important issues related to quality of life in both genders, males and females are identified as important components for longitudinal study in HIV disease.

Results from this study was interpreted to support the hypothesis, that children and care-givers HIV status, in addition to unusual caregiving demands. And children’s developmental delay status significantly influences patients perceived stress. In addition, to parenting stress, care burden demands and children’s developmental delay status, also helps to account for variables in family adaptation or functioning. This study provides empirical evidence in supporting the utility and validity of family adaptational model for studying families with HIV-infected children and their care-givers. In particular, among social support, stress status of the child and care-givers support, is characteristic to HIV.
This study attempted to identify predictive systemic factors that contribute in the outcome of family adaptation and functioning by implementing the family adaptational model. Many of the families in the study reported that they have adapted to the sustained, stressful experience associated with their child’s condition and prolonged interaction with the health care system.

Despite the devastating problems they faced, the families which were interviewed showed remarkable resilience in their attempts to adapt and sustain themselves as families.

At first, care-givers were overwhelmed and despondent about their perception of their child’s HIV status. Some care-givers withdrew from social involvement or coped by denying the reality of their child’s diagnosis, searches of support and services for their child’s or tried to bring about societal changes, that would be supportive of families with HIV-infected children, but the parents began to gather information for themselves and to gain skills and knowledge related to child’s care. These families struggled to achieve a fix with respect to both as individuals relate within a family and in families within the communities.
This study examined family adaptation in families with HIV-infected children from a theoretical system perceptive. Changes would be presence in the amount and type of stress, families of HIV-infected children experience. Child characteristics outcome and family variables are needed. In addition, families of children with HIV infection will provide an opportunity to study longitudinal coping pattern and integrate individual including families its network and communicating variables immunologically.

The HIV positive children and their care-givers have reported more economic burdens, social impact, and personal strain than HIV-negative care-givers. The study demonstrates the financial physical, social, and economic burden placed on parents, who are HIV-infected, which includes the various components of family life, mostly affected by parents who are HIV-infected. The changes are related to the financial situation in the family, social interaction within and without the family unit and degree of subjective distress, as felt by the children, as well as their primary care-givers. For in many of the families, the diagnosis of HIV-infection added on additional burden in their lives. Finance became worse for families, when a
parent had to relinquish employment and income in order to stay at home, and care for his or her illness as well as for their child’s.

W.H.O. bref – field version 1996, are associated with family income, lack of social support a care-givers perception increased care burden of the child, due to poor health functioning on the part of the child. Increased number of hospitalizations, the care-givers report consisted of the impact of the illness in his / her life and that of the child had pressing demands of the illness. All these factors severely affects the functioning of the family system.

The child’s and their care-givers characteristics includes the amount of stress experienced by the care-givers, such as care burden demands, children’s developmental delay status, disclosure of the child’s and care-givers diagnosis of HIV status. These results were similar to those found by other resources and these children who display developmental delay status, needs special education, which the parents feel that bright spots of support would appear in a bleak landscape. The observed relationship in this sample between children’s HIV status and family impact can exhibit several inter operations, which noted that higher scores had an greater impact on the children suffering from AIDS and their care-givers.
Consequently, the general impact of the child’s HIV status as well as the care-givers and the associated disruption of social relationship may be attributable to factors other than specific physical manifestations of the illness.

Therefore, interventions were aimed to provide support and sources, to families caring for HIV exposed children, would have second order influence by buffering stress, in ways that a more longitudinal study might detect. Most notable in the interviews with the children as well as the care-givers suffering from AIDS, were the powerful effect of negative social climate and the stigma attached to the disease. The stigma that these families face is unique, with burdens they face with great guilt and anger about transmitting the disease to their children. All the HIV-infected care-givers expressed their worry and concern, over their children’s HIV health status, when they were no longer around. In many ways these families have less communicating support, less peer group identity and subsequently, less support in the HIV experience.

In this study some of the children and their care-givers were open about their diagnosis, most of the families kept it in a well-guarded secret.
Families often kept the diagnosis a secret to maintain a sense of normalcy in their lives, for some families and others; the desire to be treated no differently from others was a common thread. The impact of HIV-infection on quality of life was the greatest in a person with symptomatic HIV and the least in individuals with asymptomatic HIV disease. Solomon 1987, reported that psychosocial factors and stress may affect the course of HIV disease progression to AIDS and length of survival. Further studies are needed to classify the differential impact of pediatric HIV on both the quality and number of indirect demands imposed on families.

Lesar-Sharon et al, 1997, describes “No other diagnosis evolves such a social response and threatens the very existence of efficacy of a family unit as does HIV”. The investigator identified that the children suffering from AIDS and their principal care-givers were not willing to share their HIV diagnosis with their friends and relatives which conforms that these families experience loss of social support.

The psychosocial support addresses ongoing psychological and social problems of HIV infected children and their care-givers. HIV infection affects all dimensions of a person’s life; physical, psychological, social, and
spiritual. Counseling and social support can help children and their care-givers to cope more effectively with each stage of infection and further enhances their quality of life. Children and their care-givers infected by HIV, is likely, to develop stress and serious mental health problems. Immediate assessment and intervention of HIV infection by the medical and nursing personnel can ensure better adjustment, in the process of treating children and their care-givers with chronic symptomatic HIV infection and disease progression.

Thus the findings of this study reveals the presence of significant psychosocial impact on the children suffering from AIDS and their principal care-givers. Which further implies that they have experienced severe psychosocial distress which is quite alarming, to the views and concerns of the investigator.
ADAPTATIONAL MODEL WITH AN HIV-INFECTED CHILD:

- Sources of support: Informal/formal
- Stressor: Presence of HIV-infected child
- Stressor: Health of caregiver
- Stressor: Number of risk factors
- Stressor: Fragmented services

- Adequacy of Resources: Personal, financial, family roles, support groups, medical services
- Existing and new resources

- Perception of stressor
- Coping
  - Functional coping behavior: Normalize child's life, increase sources of support, optimism, faith
  - Dysfunctional coping behavior: Withdrawal, denial, ignoring special needs

- Bon adaptation
  - Adaptation
    - Mal adaptation

- Personal health and well-being
- Inter-actonal characteristics
  - Child behavior and development
  - Family, parent, and child functioning

- Family stress
FAMILY ADAPTATIONAL MODEL

This study attempted to identify predictive systemic factors that contribute in the outcome of family adaptation and functioning. Many of the families in the study reported that they have adapted to the sustained, stressful experience associated with their child’s condition and prolonged interaction with the health care system.

Despite the devastating problems they faced, the families which were interviewed showed remarkable resilience in their attempts to adapt and sustain themselves as families.

At first, care-givers were overwhelmed and despondent about their perception of their child’s HIV status. Some care-givers withdrew from social involvement or coped by denying the reality of their child’s diagnosis, searches for support and services for their child or trying to bring about societal changes, that would be supportive of families with HIV-infected children, but the parents began to gather information for themselves and to gain skills and knowledge related to child’s care. These families struggled to achieve a fix with respect to both as individuals, relate within a family and in families within the communities.
This study examined family adaptation in families with HIV-infected children from a theoretical system perspective. Changes would be present in the amount and type of stress, that the families of HIV-infected children experience. Child characteristics outcome and family variables are needed. In addition, families of children with HIV infection will provide an opportunity to study longitudinal coping pattern and integrate individuals including families, its network.
REACTION TO LOSS

- WHY ME?
- IT CAN’T BE TRUE!
- THE DOCTOR MUST BE WRONG.

- DENIAL AND ISOLATION.

- ANGER – BARGAINING – DEPRESSION.

- WHY ME?
- IT CAN’T BE TRUE!
- THE DOCTOR MUST BE WRONG.

- WHY ME?
- IT CAN’T BE TRUE!
- THE DOCTOR MUST BE WRONG.

- NURSES ARE NOT DOING ANYTHING!
- GOD IS UNJUST.
- IT’S A CURSE OF GOD.
- GOD MAKE ME ALRIGHT; I WILL DONATE MY MONEY FOR A GOOD CAUSE.
- NO VISITORS PLEASE!

- ACCEPTANCE.

- WHY ME?
- IT CAN’T BE TRUE!
- THE DOCTOR MUST BE WRONG.

- NURSES ARE NOT DOING ANYTHING!
- GOD IS UNJUST.
- IT’S A CURSE OF GOD.
- GOD MAKE ME ALRIGHT; I WILL DONATE MY MONEY FOR A GOOD CAUSE.
- NO VISITORS PLEASE!

- ACCEPTANCE.

- WHY ME?
- IT CAN’T BE TRUE!
- THE DOCTOR MUST BE WRONG.

- NURSES ARE NOT DOING ANYTHING!
- GOD IS UNJUST.
- IT’S A CURSE OF GOD.
- GOD MAKE ME ALRIGHT; I WILL DONATE MY MONEY FOR A GOOD CAUSE.
- NO VISITORS PLEASE!

- I HAVE TO ACCEPT THE CONSEQUENCES.
- I AM READY TO GO!
- I WANT TO MAKE MY WILL.

SOURCE: -

“Training Module for Nurses”
Ministry of Health & Family Welfare,
National AIDS Control Organization,
Pg. No. 93.