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The caregiver’s subjective experience of problems or strains linked to the caregiver role is a well-studied phenomenon in western communities. Caregivers often experience instrumental and emotional stresses which results from physical, cognitive, and behavioural changes in their care and their health status. However, the caregiving experience may vary widely depending on the nature of the care, recipient’s illness or needs as well as the caregiver’s coping style.

Although the experience of the caregiver is documented for many illnesses, the research examining burden among caregivers of persons living with HIV/AIDS (PLWHA) is limited. The existing literature suggests that caring for a loved one with human immunodeficiency virus (HIV) presents unique demands for the caregiver. Because many HIV caregivers are sexual partners of the care recipients, or may be parents of the infected children. They may struggle with concerns about their own health risks in addition to that of their partner and children who could also be infected and affected with HIV. Also, the caregiver may receive less support from the partner’s family if there is conflict regarding the partner’s route of transmission or health status. The majority of the existing research on the impact of caregiving for a PLWHA examines adults in developed countries. There are scanty studies on caregiving Burden and the perception of the infected children’s behaviour.

This chapter outlines the procedures employed while conducting the research, including the selection of the research site and participants, the design and selection of tools, and the field testing process.

Site selection

Indira Gandhi Institute of Child Health (IGICH) has been set up by the state government in 1991 and this organization works in collaboration with WHO, UNICEF, the Ministry of Health and Family Welfare, and the Central as well as State governments. It is one of the premier institutes in the field of child care. It offers Pediatric health care facilities...
including emergency and intensive care, surgery, cardiology, nephrology, neonatology, psychiatry and orthopedics. It has outpatient, inpatient, X-ray and laboratory facilities. It runs super-specialty clinics in Pediatrics, Cardiology, Orthopedics, Surgery and Child psychiatry, and an Immunization clinic every Thursday. It focuses on Child mental health, research, training, community health, network, reproductive health. It provides counseling for family planning, and offers community and child health services in partnership with voluntary agencies. It organizes seminars and workshops to train medical and Para-medical staff, and undertakes research on childhood diseases. It conducts free rural health camps, and is the nodal training centre for doctors and nurses at the district level under the Karnataka Health System Project. IGICH was selected as the nodal Regional pediatric center by National AIDS Control organization in Karnataka. This Regional Pediatric ART center was selected for the study as it is first of its kind in India and most of the children living with HIV are registered and accessing treatment in this center.

**Regional Paediatric Anti-Retroviral Therapy centers in India**

India’s Paediatric AIDS initiative was launched by National AIDS Control Organisation on November 2006. This initiative allowed quick scaling up of the access to treatment for HIV infected children by making paediatric –formulated fixed dose combination drugs available for free in ART centers. The free availability of the combination of anti retroviral drugs has simplified and extended the lives of children. The goal of National Paediatric initiative is providing care, support, treatment for children infected and affected by HIV/AIDS. However, beyond taking medicines, children and their caregivers/parents require information and education to understand the condition and ways to address their emotional, psychosocial and development needs (NACO 2007). Currently there are 7 Regional Paediatric ART Centres providing services for children infected with HIV in India (Chennai, Mumbai, New Delhi, Kolkata, Hyderabad, Imphal and Bengaluru).
The services are provided by a multi-disciplinary team consisting of a Medical officer, Counsellor, Nutritionist, Pharmacist, Lab Technician and Care coordinator who is a PLWHA. The ART centre caters to provide Anti-Retroviral Treatment and therapeutic services to infected children and their families. Some of the suspected children screened in the outpatient department are also referred for services. The Regional paediatric ART centre offers the following services:

- Screening of HIV exposed children and their families
- Diagnosis of HIV infected children
- Counselling and psychosocial support
- Monitoring HIV infected children not on ART (Pre ART care)
- ART treatment for infants and children
- Monitoring and follow up after ART initiation
- Medical management of Opportunistic Infections and Drug toxicities in children
- Comprehensive medical and Psychosocial care for the family as a unit
- Home visits by care coordinator if the child has missed a visit to the clinic or not adhering to the treatment regimen
- Referrals and linkages with governmental and nongovernmental organizations based on the needs of the children

**Aim**

To assess the burden and psychosocial factors affecting the caregivers of HIV-infected children and their perception of behavioural issues in children.

**Objectives**

1. To understand the socio demographic profile of caregivers and children living with HIV/AIDS.
2. To assess the burden of the caregivers
3. To assess the psychological health of the caregivers
4. To assess quality of life of the caregivers.
5. To understand the family issues related to HIV
6. To understand the caregivers issues related to disclosure, and concerns
7. To study the caregivers perception of behaviour of their HIV infected child.
8. To understand the interrelationship between the variables.
9. To suggest social work strategies to deal with the issues raised by the caregivers of HIV infected children

OPERATIONAL DEFINITIONS

Caregiver

“Primary Caregiver” refers to the family member who spends most of the time caring for the Children Living with HIV/AIDS (CLHA). Caregiver is a person who assists the CLHA with at least one personal activity of daily living (e.g., bathing, meal preparation) or provides supervision and regular care to the child.

‘Parental caregivers’- refer to the biological and adoptive parents of the CLHA and non-parental caregivers refer to the extended family, relatives and siblings of the CLHA

Caregiver Burden

Caregiver burden refers to a high level of stress that may be experienced by people who are caring for another person (usually a family member) with some kind of illness. For example, a person caring for someone with a chronic illness may experience such stressors as financial strain, managing the person's symptoms, dealing with crises, the loss of friends, or the loss of intimacy.

Caregiver burden is defined as the “practical difficulties and mental pain” on both the objective and subjective levels (Schwartz & Gidron, 2002). Fatigue and sleep difficulties, for instances, are common among Alzheimer’s caregivers (Teel & Press, 1999). Barnes, Given & Given,( 1992 )describe six aspects of caregiver burden: financial, health, schedule, lack of family support, the amount of the caregiver’s responsibility, and social reactions.
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Child

For the purpose of this study, a child was defined as “A child is an individual having completed 3 years and not more than 16 years of age.” The sample for this study constituted children in the age group of 3-16 years for two reasons, first is that as per NACO guidelines (Paediatric ART counseling, participants manual, 2006) a child living with HIV can be on paediatric ART medicines up to the age of 14 years. Many CLHA though having attained 14 years of biological age would still be under growth due to various reasons. So the child will be monitored on ART in Paediatric ART center till the child’s physical age resembles that of a 14 year old child and then started on adult ART medicines and transferred to an adult ART center. The second reason for limiting the age of a child for 16 years was that the Strengths and difficulties questionnaire used to assess the behaviour of HIV infected children can be used up to 3-16 years.

Abbreviations:
HIV – Refers to Human Immuno Deficiency Virus.
AIDS - Refers to Acquired Immuno Deficiency Syndrome
PLWHAs - People living with HIV/AIDS.
CLHA- Children living with HIV/AIDS
ART- Anti Retroviral therapy

Research Design

The Present study was Descriptive in nature. Caregiver’s burden, quality of life and perception of HIV infected children was assessed. Descriptive research design is a scientific method which involves observing and describing the behaviour of a subject without influencing it in any way. Descriptive research classifies phenomena. Descriptive research is concerned with the description of data and characteristics about a population. The goal is the acquisition of factual, accurate and systematic data that can be used in averages, frequencies and similar statistical calculations. Descriptive studies seldom involve experimentation, as they are more concerned with naturally occurring phenomena than with the observation of controlled situations. Descriptive research is concerned with
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the description of the existing distribution of variables, as opposed to theory building. Descriptive studies focus on answering the basic W questions: Who, what, when, where. The fifth W, "why" falls outside of the scope of descriptive research, that by definition must not concern itself with the effect that one variable has on another. (Alan Valdez, 2010)

Universe / population

The population for the present study were caregivers of HIV positive children in India. In 2009, an estimate of 25 lakh children under the age of 15 are living with HIV infection (UNAIDS Global report, 2010). India has an estimated 1, 00,000 (4% of adult infections) children living with HIV (NACO, 2010). In Karnataka, a cumulative of 10,915 children living with HIV/AIDS are registered in various ART centers in Karnataka and of these 3330 children are on ART and are being followed up regularly in these centers (NACO 2010). By the end of data collection, there were 695 infected children who had availed services at the Regional Pediatric ART center. This constitutes the population of the study.

Inclusion criteria

1) Caregiver consent and willingness to participate.
2) Caregiver’s children aged 4 to 16 years with confirmed HIV positive status.
3) Caregivers who were aware of their child’s HIV status for at least 2 months
4) Caregiver who was not suffering from any kind of serious medical or psychiatric illness affecting their participation in the interview sessions.
5) An adult person who was most consistently involved in the day to day care of the child and had been staying with the child.

Exclusion criteria

1) Caregivers whose children were not infected with HIV
2) Siblings of HIV infected child who were below the age of 18 yrs
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3) Caregivers of children with chronic illness other than HIV
4) Caregivers of HIV positive children below 3 years
5) HIV positive children living in Residential care settings /Foster care
6) Caregivers with terminal illness
7) HIV positive children who self-reported for follow-ups without a caregiver

Sample:

For the present study 206 Caregivers’ of children living with HIV was interviewed by the researcher. The table given below provides information about the selection of the sample after applying inclusion and exclusion criteria.

<table>
<thead>
<tr>
<th>Particulars</th>
<th>Male</th>
<th>Female</th>
<th>Pre ART</th>
<th>ART</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Death</td>
<td>30</td>
<td>31</td>
<td>27</td>
<td>34</td>
<td>61</td>
</tr>
<tr>
<td>Transferred out to other ART centers</td>
<td>54</td>
<td>48</td>
<td>28</td>
<td>74</td>
<td>102</td>
</tr>
<tr>
<td>Lost for Follow-up</td>
<td>12</td>
<td>6</td>
<td>17</td>
<td>1</td>
<td>18</td>
</tr>
<tr>
<td>CLHA less than 3yrs</td>
<td>1</td>
<td>5</td>
<td>4</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>CLHA in residential care</td>
<td>131</td>
<td>160</td>
<td>112</td>
<td>179</td>
<td>291</td>
</tr>
<tr>
<td>CLHA who self-report</td>
<td>3</td>
<td>2</td>
<td>2</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>CLHA who could not be contacted for the study</td>
<td>2</td>
<td>4</td>
<td>4</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Study CLHA</td>
<td>112</td>
<td>94</td>
<td>71</td>
<td>135</td>
<td>206</td>
</tr>
<tr>
<td>Total</td>
<td>345</td>
<td>350</td>
<td>265</td>
<td>430</td>
<td>695</td>
</tr>
</tbody>
</table>

A list of CLHA was collected from the ART center depending on the follow up dates. Caregivers were met during the monthly follow up visits to explain the purpose of the study. Their consent was taken to participate in the present study. If the caregiver was not able to spend the required amount of time for the interview, an appointment was fixed up during their next visit to the center. The total duration of data collection for the present study was about 9 months.
Tools for data collection:

1. Socio Demographic Data Sheet (prepared for the study)
2. General Health Questionnaire (Goldberg, 1972)
3. WHO-QOL BREF (WHO, 1995)
5. Family issues related to HIV/AIDS (Krishna, Bhatti and Chandra, 2002)
6. Interview schedule to assess the caregivers’ disclosure of HIV status and concerns (prepared for the study)
7. Personal information Sheet (prepared for the study)
8. The Strengths and Difficulties Questionnaire (SDQ) (Goodman, 2001)

A description of the tools used is given below:

1) Socio Demographic Data Sheet (prepared for the study)

This schedule was developed specifically for the present study. It consists of personal details such as age, gender, marital status, place of origin, education, employment and type of family, family constellation, current living arrangements, alcohol and substance use in the parents, relationship to the child, children’s disease status, information related to the HIV infection in the family etc. The knowledge of the illness of self and of parents to the child was also assessed. Socio Demographic Schedule comprehensively assesses the personal, social, economic and other information regarding HIV infection of the family in which the child is currently residing (Appendix- 2 )

2) General Health Questionnaire GHQ-12 (Goldberg, 1972)

The questionnaire was used to detect the presence of non-psychotic psychiatric morbidity in community settings. The GHQ -12 was originally designed for use in general practice settings as a screening tool and cannot be used to diagnose specific psychiatric problems. The questionnaire comprises of twelve questions, asking informants about their general level of happiness, experience of depressive and anxiety symptoms, and sleep disturbance over the last four weeks. Interpretation of the answers is based on a four point response
scale scored using a bimodal method (symptom present: 'not at all' = 0, 'same as usual' = 0, 'more than usual' = 1 and 'much more than usual' = 1). A score of two or more as the threshold, and these are referred to as 'high GHQ-12 scores'. It has been used in a variety of cultural settings and was found to have adequate psychometric properties and easy to administer. The questionnaire has a test- retest reliability of 0.73 and a criterion validity of 0.81. (Appendix-3)

3) **WHOQOL- BREF (WHO, 1996)**

Quality of life is defined as “an individual’s perception of his/her position in life in the context of the culture and value systems in which he/she lives, and in relation to his/her goals, expectations, standards and concerns” (WHOQOL Group, 1995). Quality of life was evaluated using the World Health Organization Quality of life (WHOQOL- BREF) instrument. This contains 26 items, is the shorter version of the WHOQOL100 and has four domain scores. There are also two items that are examined separately, i.e, an individual’s overall perception of quality of life and the individual’s overall perception of his or her health. The main domains assessed by the assessor are physical domain, psychological domain, social relationships domain and environmental domain. The domains are scaled in appositive direction (i.e higher the score denotes higher quality of life). The mean scores are then used to calculate the domain score. The tool has been simultaneously developed in several countries across the world including India. Kannada version of the scale which was developed at NIMHANS has been used for the study. The translated scale has been used for various research projects in Karnataka. Mean scores are then multiplied by 4 in order to make domain scores comparable with the scores used in the WHOQOL-100, so that scores range between 4 and 20. Each item uses a Likert-type five-point scale where 1 indicates low, negative perceptions and 5 indicates high, positive perceptions. For example, an item in the positive feeling facet asks” How much do you enjoy life?” and the available responses are 1(not at all), 2(a little), 3(a moderate amount), 4(very much) and 5(an extreme amount). As such, domain and facet scores are scaled in a positive direction where higher scores denote higher quality of life. Some facets (Pain and Discomfort, Negative feelings, Dependence on Medication, Death and
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Dying) are not scaled in a positive direction. Meaning that for these facets higher scores do not denote higher quality of life. These need to be recoded so that high scores reflect better quality of life. Items are organized by response scale (capacity, frequency, intensity or satisfaction). Instructions for calculation of scores are given in a syntax file, An SPSS syntax file that automatically checks, recodes data and computes domain scores.

Domain scores produced by the WHOQOL-BREF have been shown to correlate at around 0.9 with the WHO-QOL100 domain scores, and hence provide an excellent alternative to the assessment of domain profile using WHOQOL-100. The BREF scale is useful in busy clinics and wards since it takes only 5-8 minutes to complete. (Appendix-4)

3) Zarit Burden Interview (ZBI) (Zarit, Reever and Peterson, 1986)

It is a structured interview schedule, which helps in the assessment of the overall subjective burden on the caregivers. This is a widely used instrument and has an advantage over other measures for stress and burden. Caregivers were asked to respond to the series of 22 questions about the impact of child’s disabilities /illness on their lives. For each item, caregivers indicate how often they felt in a particular way (never, rarely, sometimes, quite frequently, or nearly always). On each of the 22 items, scores range from 0-4. thus the total scores of a caregiver range from 0-88. Estimates of the degree of burden can be made as little burden (scores 0-20), mild burden (scores 21-40), moderate burden (scores 41-60) and severe burden scores 61-88). Inter-reliability has been estimated using Chronbach’s alpha at 0.91. Test retest reliability is reported at 0.71 (Appendix-5 )

4) Family issues related to HIV/AIDS (Krishna, Bhatti and Chandra, 2002)

As there is no published scale available to study the impact of HIV/AIDS on the family or HIV/AIDS related issues in the family. This scale was developed by a Ph.D Scholar (Krishna, Bhatti and Chandra, 2002) and used in his research thesis. This scale is based
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on prior clinical experience of working with PLWHAs and their families and review of literature on families and HIV and discussions with experts in the field of HIV and family. This schedule has 34 statements assessing the specific family issues related to HIV/AIDS. The items are rated either agree, undecided or disagree and are given scores of 1, 2, and 3 respectively. A minimum of 34 and a maximum of 102 score can be obtained and higher scores indicate severity of effects of HIV on the family. This schedule has 3 domains, stigma-12 items; Burden -16 items, and fears of family members – 6 items. The domain on stigma assesses the perceived stigma and discrimination and available social support. Burden on the family was assessed on financial burden (including material), emotional burden on family members and burden on the roles and responsibilities of family members. The fears of family members included issues related to death and dying and future management of family without the patient. The scale is yet to be standardized and validated (Appendix-6)

6) Interview schedule to assess the caregivers’ disclosure of HIV status and concerns (prepared for the study)

An interview schedule to assess the caregiver’s disclosure of HIV status and concerns was developed for the present study. This information was gathered from the caregivers whose children were included in the present study. In this schedule, the caregiver was required to reveal details regarding circumstances under which the Caregiver got to know his/her HIV status, Caregiver’s immediate reaction after getting to know his/her HIV status, Caregivers reasons for disclosing his/her HIV status to others, Knowledge of close relatives and friends regarding Caregiver’s/ child’s HIV status, Consequences of Disclosure, caregivers positive and negative experiences after having disclosed their HIV status, concerns regarding CLHA and Psychosocial issues reported by the caregivers. (Appendix-7)
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7) Personal information Sheet (prepared for the study)

A personal Information sheet was developed for the present study. This information was gathered from the caregivers whose children were included in the present study. In this form, the caregiver of the child was required to furnish details regarding the child’s date of birth, gender, schooling and performance at school, hobbies and details regarding to the child’s health (Appendix- 8).

8) The Strengths and Difficulties Questionnaire (SDQ) (Goodman, 2001)

The Strengths and Difficulties questionnaire was designed to assess children’s social and emotional behaviour. SDQ is a brief behavioural screening questionnaire for 3-16 year olds. The parent version was used, it has 25 items on psychological attributes, some positive and others negative. It exists in several versions to meet the needs of researchers, clinicians and educationalists. These 25 items are divided between 5 scales: emotional symptoms (5 items), conduct problems (5 items), hyperactivity/inattention (5 items), Peer relationship problems (5 items), prosocial behaviour (5 items). All the items are added together to generate a total difficulties score based on first four domains. The caregiver was asked to respond to a series of questions about the child’s behaviour and emotions on a there point likert scale (0-2 responses) using the responses’ not true’, ‘ somewhat true’ and ‘certainly true’. The maximum score that can be obtained is 10 in each domain. higher score indicates problem in the all the areas except prosocial behaviour. Translated Kannada version available in the website was used for the study. A slightly modified informant-rated version for the parents or nursery teachers of 3 (and 4) year olds is available for 3 years old children. 22 items are identical, the item on reflectiveness is softened, and 2 items on antisocial behaviour are replaced by items on (of) oppositionality.

The norms for Indian population has not been developed. So the researcher used the norms for the American children for the interpretation of the results of the study.
Scores derived from the SDQ and Rutter questionnaires were highly correlated; parent-teacher correlations for the two sets of measures were comparable or favored the SDQ. The SDQ functions as well as the Rutter questionnaires while offering the following additional advantages: a focus on strengths as well as difficulties; better coverage of inattention, peer relationships and prosocial behaviour; a shorter format; and a single form suitable for both parents and teachers, perhaps thereby increasing parent-teacher correlations (Appendix-9)

**Translation and Back Translation**

After selection of the above instruments, the logistics involved in the administration of the tools was considered. The study was conducted in Karnataka where majority of them speak Kannada (vernacular language). This necessitates the use of Kannada while collecting the data. Wherever available the Kannada version of the questionnaires was collected. And for those questionnaires where the translated version was not available, the tools used in the study were translated from English to Kannada by a professional translator who is familiar with the field and back translated from Kannada to English, independently by two research officers and a mental health professional. This was done to test the accuracy and applicability of all the tools in vernacular. Face validity was established by comparing the retranslated English version of the tools with the original scale versions.
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Data collection

Data required for the study was obtained by using an interview schedule comprising the above mentioned instruments. Interview method was used for the present study to collect the data. Each interview took about two hours to collect the information. The identified psychosocial issues were discussed with the counselors for the further interventions. Emotional support was provided for caregivers who had difficulties in dealing with their HIV status as part of ethical considerations. The data collection process started in the month of June 2010 and continued till February 2011. A total of 206 caregivers were interviewed for the present study.

PROCEDURE

The research was carried out in two phases.

1. Pilot study
2. Main study

Pilot study

The objectives of the pilot study were

- To develop and administer a interview schedule in order to get detailed perspectives regarding the burden, quality of life, disease status and disclosure of HIV to others and behaviour of infected children as reported by the caregivers.
- To get familiarized with administration and scoring procedures of the tools used for the present study
- To assess the suitability of the proposed and translated tools.
- To find out the total time taken to complete the interview schedule
- To identify other difficulties/issues related to CLHA, if any.

In the Pilot phase of the study, tools were administered to 10 caregivers and the time taken to administer the tools was assessed. Following pilot modifications were made in the content of interview schedule used. Few questionnaires were administered only on
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the parents of the CLHA. The order in which the tools to be administered was also decided. The interview schedule was divided into two subsections; one on information related to caregivers and the other on information related to the child. An additional checklist on family issues related to HIV was included by the investigator for the present study.

Main study

After explaining about the nature of the study, informed consent was obtained from the caregivers and they were assured of confidentiality and anonymity. They were informed about their participation in the present study without any monetary benefits. Socio Demographic Data sheet was filled as a preliminary step. GHQ-12 was administered to find out the stress, followed by quality of life questionnaire to find out the subjective well being of the caregivers. Caregiver’s burden and Family issues related to HIV was administered. The Personal information pertaining to the infected child along with details on school and hobbies was elicited The strengths and difficulties questionnaire was administered, followed by the concerns about the child as reported by the caregiver. The study process is presented in a flow chart below for clarity.
THE STUDY PROCESS

Research protocol

Conceptual study
Review of literature

Construction of Interview Schedule

Pretesting of tools, translation and back translation

Identification of potential participants

Screening

Inclusion criteria met and selected

Informed concept, rapport

Recruitment & administration of semi structured interview schedule

Clarification of new issues, linkages if required

Data entry and analysis

Report writing

Inclusion criteria not met

Not selected
DATA ANALYSIS

Descriptive statistical analysis was carried out in the present study. The quantitative data was entered in the Statistical Package for Social Sciences (SPSS Version 14.0.) for analysis. The objective of the analysis was to understand the distribution of the sample on the Socio demographics and other variables. Results on continuous measurements are presented on Mean ± SD (Min-Max) and results on categorical measurements are presented in Number (%). Significance was assessed at 1%, 5 % level of significance.

- Analysis of variance (ANOVA) was used to find the significance of study parameters between three or more groups of patients,
- Student t test (two tailed, independent) was used to find the significance of study parameters on continuous scale between two groups Inter group analysis on metric parameters,
- Chi-square/ Fisher Exact test was used to find the significance of study parameters on categorical scale between two or more groups.

Appropriate statistical tests were used to analyze the data, in consultation with the statistician, and the findings subsequently reported.

The caregivers were allowed to express all their thoughts, doubts, worries about issues related to disclosure of the infected children. The narratives were transcribed from notes immediately after the interviews. The interview notes were read thoroughly to understand the processes, links and various issues. The information obtained from caregivers on concerns, disclosure and behaviour related to Children living with HIV was entered in the Microsoft Excel, the common issues were identified from the 206 interview schedules. Discussion with subject experts resulted in forming of themes.

1. Around 8 concerns on CLHA were identified.
2. About 5 psychosocial issues were identified.
3. Sub-themes on disclosure related issues were identified.
4. Around 6 areas on behavioural difficulties in CLHA were identified.
ETHICAL CONSIDERATIONS

1. The participants /caregivers were provided with the information regarding aim, objectives and methods of research and the expected duration of time required for the interview.
2. Informed consent was sought in kannada from caregivers for participation in the study (Appendix-1).
3. The psychosocial issues of the caregivers were addressed through referrals to the counselors and linkages to other services.
4. Maintenance of confidentiality was assured to the participants.
5. The participants were explained and provided freedom to participate and withdraw from research at any time.
6. Caregivers who did fulfill the inclusion and exclusion criteria were offered necessary help, such as referral for services or further management.
7. The emotional support was provided for caregivers who had difficulties in dealing with their HIV status.