APPENDICES
Caregivers Burden and Perception of HIV Infected Children’s Behavior

Patient Name: __________________________

CLHA. No. _____________________________

ART No. ______________________________
APPENDIX -1
Informed Consent

My name is Prathima .S, I am currently working for my doctoral research titled Caregivers Burden and Perception of HIV Infected Children's Behavior. I am here to request you to participate in the above mentioned study. The aim of this study is to assess the psychosocial problems and needs of caregivers with HIV-positive children’s and their perception of behavioral issues involved in providing care to children. This will also help us in planning intervention programmes for caregivers of HIV infected children.

The Present study will be exploratory in nature. Caregivers burden, quality of life and perception of HIV infected children will be assessed There are two sections of assessments in this study which might last for one and half an hour. The sections of the assessment are on the caregiver and the child. During the interview session you will be asked about your illness, your psychological adjustment and quality of life. There will be questions on your family and child’s health, treatment and behaviors.

Your participation in this study will be most valuable. If you agree to participate, you have certain rights. Firstly, your participation in this study is voluntary. You have the freedom to refuse to answer a particular question and to withdraw from the study without giving any reasons. You also have the right to seek clarification and information about any aspect of the research topic. If you do not understand some of the words or concepts, I will take time to explain them as you go along and that you can ask questions at anytime. Please free to talk to anyone you feel comfortable talking with about the research and that you can take time to reflect on whether they want to participate or not.

I assure you that all information provided by you will be kept strictly confidential and in safe custody. No identifying information like your name etc. will appear in any part of this study.

If you are willing to participate, kindly sign your name or make a thumb impression below to indicate that you have read this document or had it read to you, that you have understood the contents, and that you are willing to participate in this study.

Name of the Respondent: ____________________  Date : ______________

Signature/thumb impression of the Respondent  Name and Signature of the interviewer: __________________________
APPENDIX -2
Socio Demographic Schedule

DATE __________________

Sl. No.

Caregiver’s Name ______________________________________

Address and phone no_____________________________________

_____________________________________

Who responded to the questions?

1. Biological mother
2. Biological father
3. Grand parents
4. Other relative, specify
5. Adoptive parent, specify
6. Foster parent, specify
7. Other reason, specify

1. Caregiver’s Age _________
2. Gender
   1. Male        2. Female
3. Religion
4. Caregiver’s Highest Education
   1. Illiterate  2. Primary     3. Middle    4. High      5. PUC
   6. Graduate    7. Above
5. Employment
6. Income ________________PM
7. Marital Status

8. Place of Origin

9. Type of Family
   1. Nuclear    2. Joint    3. Extended

   Currently living with
   - Own family
   - With grand parents
   - With relatives
   - Others, Specify

Family Genogram

Family Constellation

<table>
<thead>
<tr>
<th></th>
<th>Age</th>
<th>Education</th>
<th>Occupation</th>
<th>Income</th>
<th>HIV Status</th>
<th>ART</th>
<th>Duration</th>
<th>Alive</th>
</tr>
</thead>
<tbody>
<tr>
<td>Father</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sl. No.</th>
<th>Sibling</th>
<th>Age</th>
<th>Education</th>
<th>HIV Status</th>
<th>ART</th>
<th>Duration</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

**Addiction**   father/Mother
Alcohol   social/regular/problem drinking/never
Smoking   current smoke/ past smoker/ never

**Illness related information**
Who was tested for HIV in the family first?
   Father
   Mother
Study participant (CLHA)
Sibling

<table>
<thead>
<tr>
<th>Sl. No</th>
<th>Relation</th>
<th>Date of test</th>
<th>Place of test</th>
<th>Result</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Father</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Mother</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Brother</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Sister</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Study CLHA</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

In what year does the caregiver think He/She was infected?__________

Caregiver’s Risk factor for HIV?
Heterosexual/ MSM/ injecting drugs/blood transfusion/probable unsafe injection/ unknown/others specify__________

Has there been death of a family member due to HIV/AIDS
Yes          No

<table>
<thead>
<tr>
<th>Sl. No</th>
<th>Relation</th>
<th>Deceased</th>
<th>Duration</th>
<th>Cause</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Father</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Mother</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Sister</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Brother</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Does the study participant (infected child) know his/her HIV status?
1 Yes          2 No          3 Information not available/ Not known

Knowledge of the child regarding his/her illness
- Does not know
- The child is aware that he/she is sick with a chronic disease
- The child is aware of the name of the disease

Knowledge of the CLHA regarding parent’s illness
- Does not know
- The child is aware that he/she is sick with a chronic disease
- The child is aware of the name of the disease
APPENDIX -3
GENERAL HEALTH QUESTIONNAIRE – 12

Please Read this carefully:

We would like to know if you have had any medical complaints, and how your health has been in general, over the past weeks. Please answer ALL the questions simply by circling the answer, which you think most nearly, applies to you. Remember that we want to know about present and recent complaints, not those that you had in the past.

It is important that you try to answer ALL the questions.

Thank you very much for your co-operation.

1. Have you recently lost sleep over worry?
   0 Not at all usual
   1 No more than than usual
   2 Rather more than usual
   3 Much more than usual

2. Have you recently felt constantly under strain?
   Not at all usual
   No more than than usual
   Rather more than usual
   Much more than usual

3. Have you recently been able to concentrate on whatever you are doing?
   Better than Usual
   Same as usual
   Less than usual
   Much less than usual

4. Have you recently felt that you are playing a useful part in things?
   More so Than usual
   Same as usual
   Less useful than usual
   Much less useful

5. Have you recently been able to face up to your problem?
   More so Than usual
   Same as usual
   Less able than usual
   Much less able

6. Have you recently felt capable of making decisions about things?
   More so Than usual
   Same as usual
   Less capable
   Much less capable
7. Have you recently felt that you could not overcome your difficulties?

Not at all  No more than  Rather more  Much more
Usual      than usual      than usual

8. Have you recently been feeling reasonably happy, all things considered?

More so  About same  Less so  Much less
Than usual  as usual  than usual  than usual

9. Have you recently been able to enjoy your day-to-day activities?

More so  About same  Less so  Much less
Than usual  as usual  than usual  than usual

10. Have you recently been feeling unhappy and depressed?

Not at all  No more than  Rather more  Much more
Usual      than usual      than usual

11. Have you recently been losing confidence in yourself?

Not at all  No more than  Rather more  Much more
Usual      than usual      than usual

12. Have you recently been thinking of yourself as a worthless person?

Not at all  No more than  Rather more  Much more
Usual      than usual      than usual

Total score should be calculated by adding all the responses followed by the followings

Response 0, 1 = 0
Response 2, 3 = 1

Total  13
ABOUT YOU

Before you begin we would like to ask you to answer a few general questions about yourself: by circling the correct answer or by filling in the space provided.

How is your health?

Very poor/ poor/ neither poor nor Good/Good /Very Good

Are you currently ill? Yes No

If something is wrong with your health what do you think it is?_____________________

Instructions

This assessment asks how you feel about your quality of life, health, or other areas of your life. Please answer all the questions. If you are unsure about which response to give to a question, Please choose the one that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last two weeks. For example, thinking about the last two weeks, question might ask:

<table>
<thead>
<tr>
<th>Do you get the kind of support from others that you need</th>
<th>Not at all</th>
<th>Not much</th>
<th>Moderately</th>
<th>A great deal</th>
<th>Completely</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

You should circle the number that best fits how much support you got from others over the last two weeks. So you would circle the number 4 if you got a great deal of support from others as follows.
Do you get the kind of support from others that you need

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Not much</th>
<th>Moderately</th>
<th>A great deal</th>
<th>Completely</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

You would circle number 1 if you did not get any of the support that you needed from others in the last two weeks. Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>Very poor</th>
<th>Poor</th>
<th>Neither poor nor good</th>
<th>Good</th>
<th>Very good</th>
</tr>
</thead>
<tbody>
<tr>
<td>1(G1)</td>
<td>How would you rate your quality of life?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1(G4)</td>
<td>How satisfied are you with your health?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The following questions ask about how much you have experienced certain things in the last two weeks.

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>Not at all</th>
<th>A little</th>
<th>A moderate amount</th>
<th>Very much</th>
<th>An extreme amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>3 (F1.4)</td>
<td>To what extent do you feel that (physical) pain prevents you from doing what you need to do?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 (F11.3)</td>
<td>How much do you need any medical treatment to function in your daily life?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 (F4.1)</td>
<td>How much do you enjoy life?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6 (F24.2)</td>
<td>To what extent do you feel your life to be meaningful?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>Not at all</th>
<th>A little</th>
<th>A moderate amount</th>
<th>Very much</th>
<th>An extreme amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>7 (F5.3)</td>
<td>How well are you able to concentrate?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8 (F16.1)</td>
<td>How safe do you feel in your daily life?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9 (F22.1)</td>
<td>How healthy is your physical environment?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The following questions ask about how completely you experience or were able to do certain things in the last two weeks.

<table>
<thead>
<tr>
<th></th>
<th>Question</th>
<th>Scale</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>10</td>
<td>Do you have enough energy for everyday life?</td>
<td>Not at all</td>
<td>A little</td>
<td>Moderately</td>
<td>Mostly</td>
<td>Completely</td>
</tr>
<tr>
<td>11</td>
<td>Are you able to accept your bodily appearance?</td>
<td>Not at all</td>
<td>A little</td>
<td>Moderately</td>
<td>Mostly</td>
<td>Completely</td>
</tr>
<tr>
<td>12</td>
<td>Have you enough money to meet your needs?</td>
<td>Not at all</td>
<td>A little</td>
<td>Moderately</td>
<td>Mostly</td>
<td>Completely</td>
</tr>
<tr>
<td>13</td>
<td>How available to you is the information that you need in your day-to-day life?</td>
<td>Not at all</td>
<td>A little</td>
<td>Moderately</td>
<td>Mostly</td>
<td>Completely</td>
</tr>
<tr>
<td>14</td>
<td>To what extent do you have the opportunity for leisure activities?</td>
<td>Not at all</td>
<td>A little</td>
<td>Moderately</td>
<td>Mostly</td>
<td>Completely</td>
</tr>
<tr>
<td>15</td>
<td>How well are you able to get around?</td>
<td>Very poor</td>
<td>Poor</td>
<td>Neither poor nor good</td>
<td>Good</td>
<td>Very good</td>
</tr>
</tbody>
</table>

The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the last two weeks.

<table>
<thead>
<tr>
<th></th>
<th>Question</th>
<th>Scale</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>16</td>
<td>How satisfied are you with your sleep?</td>
<td>Very dissatisfied</td>
<td>Dissatisfied</td>
<td>Neither satisfied not dissatisfied</td>
<td>Satisfied</td>
<td>Very satisfied</td>
</tr>
<tr>
<td>17</td>
<td>How satisfied are you with your ability to perform your daily living activities?</td>
<td>Very dissatisfied</td>
<td>Dissatisfied</td>
<td>Neither satisfied not dissatisfied</td>
<td>Satisfied</td>
<td>Very satisfied</td>
</tr>
<tr>
<td>18</td>
<td>How satisfied are you with your capacity for work?</td>
<td>Very dissatisfied</td>
<td>Dissatisfied</td>
<td>Neither satisfied not dissatisfied</td>
<td>Satisfied</td>
<td>Very satisfied</td>
</tr>
<tr>
<td>19</td>
<td>How satisfied are you with yourself?</td>
<td>Very dissatisfied</td>
<td>Dissatisfied</td>
<td>Neither satisfied not dissatisfied</td>
<td>Satisfied</td>
<td>Very satisfied</td>
</tr>
<tr>
<td>20</td>
<td>How satisfied are you with your personal relationships?</td>
<td>Very dissatisfied</td>
<td>Dissatisfied</td>
<td>Neither satisfied not dissatisfied</td>
<td>Satisfied</td>
<td>Very satisfied</td>
</tr>
<tr>
<td>21</td>
<td>How satisfied are you with your sex life?</td>
<td>Very dissatisfied</td>
<td>Dissatisfied</td>
<td>Neither satisfied not dissatisfied</td>
<td>Satisfied</td>
<td>Very satisfied</td>
</tr>
<tr>
<td>22</td>
<td>How satisfied are you with the support you get from your friends?</td>
<td>Very dissatisfied</td>
<td>Dissatisfied</td>
<td>Neither satisfied not dissatisfied</td>
<td>Satisfied</td>
<td>Very satisfied</td>
</tr>
<tr>
<td>23</td>
<td>How satisfied are you with the conditions of your living place?</td>
<td>Very dissatisfied</td>
<td>Dissatisfied</td>
<td>Neither satisfied not dissatisfied</td>
<td>Satisfied</td>
<td>Very satisfied</td>
</tr>
<tr>
<td>24</td>
<td>How satisfied are you with your access to health services?</td>
<td>Very dissatisfied</td>
<td>Dissatisfied</td>
<td>Neither satisfied not dissatisfied</td>
<td>Satisfied</td>
<td>Very satisfied</td>
</tr>
<tr>
<td>25</td>
<td>How satisfied are you with your transport?</td>
<td>Very dissatisfied</td>
<td>Dissatisfied</td>
<td>Neither satisfied not dissatisfied</td>
<td>Satisfied</td>
<td>Very satisfied</td>
</tr>
</tbody>
</table>
The following question refers to how often you have felt or experienced certain things in the last two weeks.

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Seldom</th>
<th>Quite often</th>
<th>Very Often</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>26 (F8.1)</td>
<td>How often do you have negative feelings such as blue mood, despair, anxiety, and depression?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

Did someone help you to fill out this form? ..........................................................

How long did it take to fill this form out? .........................................................

Do you have any comments about the assessment?

........................................................................................................................................
........................................................................................................................................

THANK YOU FOR YOUR HELP
APPENDIX -5
ZARIT BURDEN INTERVIEW (ZBI)

Instructions: The following is a list of statements which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way; never, sometimes, quite frequently, or nearly always. There are no right or wrong answers.

Coding
(Give to caregiver as you conduct this interview)

<table>
<thead>
<tr>
<th>0</th>
<th>Never</th>
<th>1</th>
<th>Rarely</th>
<th>2</th>
<th>Sometimes</th>
<th>3</th>
<th>Quite Frequently</th>
<th>4</th>
<th>Nearly Always</th>
</tr>
</thead>
</table>

1) Do you feel that your relatives ask for more help than he/she needs?
   0  Never
   1  Rarely
   2  Sometimes
   3  Quite frequently
   4  Nearly always

2) Do you feel that because of the time you spend with your relative that you do not have enough time for yourself?
   0  Never
   1  Rarely
   2  Sometimes
   3  Quite frequently
   4  Nearly always

3) Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?
   0  Never
   1  Rarely
   2  Sometimes
   3  Quite frequently
   4  Nearly always

4) Do you feel embarrassed over your relative’s behavior?
   0  Never
   1  Rarely
   2  Sometimes
   3  Quite frequently
   4  Nearly always

5) Do you feel angry when you are around your relative?
   0  Never
1 Rarely
2 Sometimes;
3 Quite frequently
4 Nearly always

6) Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?
   0 Never
   1 Rarely
   2 Sometimes
   3 Quite frequently
   4 Nearly always

7) Are you afraid with the future holds for your relative?
   0 Never
   1 Rarely
   2 Sometimes
   3 Quite frequently
   4 Nearly always

8) Do you feel your relative is dependent upon you?
   0 Never
   1 Rarely
   2 Sometimes
   3 Quite frequently
   4 Nearly always

9) Do you feel stained when you are around your relative?
   0 Never
   1 Rarely
   2 Sometimes
   3 Quite frequently
   4 Nearly always

10) Do you feel your health has suffered because of your involvement with your relative?
    0 Never
    1 Rarely
    2 Sometimes
    3 Quite frequently
    4 Nearly always

11) Do you feel that you do not have as much privacy as you would like, because of your relative?
    0 Never
    1 Rarely
    2 Sometimes
    3 Quite frequently
    4 Nearly always
12) Do you feel that your social life has suffered because you are caring for your relative?
   0  Never
   1  Rarely
   2  Sometimes
   3  Quite frequently
   4  Nearly always

13) Do you feel uncomfortable about having friends over because of your relative?
   0  Never
   1  Rarely
   2  Sometimes
   3  Quite frequently
   4  Nearly always

14) Do you feel that your relative seems to expect you to take care of her/him, as if you were the only one she/he could depend on?
   0  Never
   1  Rarely
   2  Sometimes
   3  Quite frequently
   4  Nearly always

15) Do you feel that you do not have enough money to care for your relative, in addition to the rest of your expenses?
   0  Never
   1  Rarely
   2  Sometimes
   3  Quite frequently
   4  Nearly always

16) Do you feel that your will be unable to take care of your relative much longer?
   0  Never
   1  Rarely
   2  Sometimes
   3  Quite frequently
   4  Nearly always

17) Do you feel you have lost control of your life since your relative’s illness?
   0  Never
   1  Rarely
   2  Sometimes
   3  Quite frequently
   4  Nearly always

18) Do you wish you could just leave the care of your relative to someone else?
0  Never
1  Rarely
2  Sometimes
3  Quite frequently
4  Nearly always

19) Do you feel uncertain about what to do about your relative?
  0  Never
  1  Rarely
  2  Sometimes
  3  Quite frequently
  4  Nearly always

20) Do you feel you should be doing more for your relative?
  0  Never
  1  Rarely
  2  Sometimes
  3  Quite frequently
  4  Nearly always

21) Do you feel you could do a better job in caring for your relative?
  0  Never
  1  Rarely
  2  Sometimes
  3  Quite frequently
  4  Nearly always

22) Overall, how burdened do you feel in caring for your relative?
  0  Not at all
  1  A little
  2  Fairly
  3  Quite a bit
  4  Very
# APPENDIX -6

## Family Issues Related To HIV/AIDS

<table>
<thead>
<tr>
<th>Sl. No.</th>
<th>Item</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>These days our family is discriminated by others in several aspects.</td>
</tr>
<tr>
<td>2.</td>
<td>We are afraid that others would come to know about our family aspects.</td>
</tr>
<tr>
<td>3.</td>
<td>Of late we are not comfortable with our own relatives and friends</td>
</tr>
<tr>
<td>4.</td>
<td>We hesitate to invite anybody to our house</td>
</tr>
<tr>
<td>5.</td>
<td>Others have got to know about our family member’s</td>
</tr>
<tr>
<td>6.</td>
<td>Our relatives and friends are not visiting our family as frequently as before</td>
</tr>
<tr>
<td>7.</td>
<td>We are not visiting our relatives and friends as frequently as before (due to the fear of discrimination).</td>
</tr>
<tr>
<td>8.</td>
<td>Of late we worry for depending on others to a large extent to meet our needs (material, information, emotional and so on).</td>
</tr>
<tr>
<td>9.</td>
<td>These days we frequently seek assistance from our relatives and friends unlike earlier.</td>
</tr>
<tr>
<td>10.</td>
<td>Our relatives and friends began to offer us help more often than before.</td>
</tr>
<tr>
<td>11.</td>
<td>We hesitate to visit hospitals or other service centers for help.</td>
</tr>
<tr>
<td>12.</td>
<td>The doctors, nurses and other staff in the hospitals and service centers do not pay us enough respect.</td>
</tr>
<tr>
<td>13.</td>
<td>HIV in our family increased the financial expenditure.</td>
</tr>
<tr>
<td>14.</td>
<td>Of late we run short of money very frequently unlike before.</td>
</tr>
<tr>
<td>15.</td>
<td>We have incurred loans to meet the requirements of our infected family members.</td>
</tr>
<tr>
<td>16.</td>
<td>We began to compromise with our needs, as the priority is care for the infected family members.</td>
</tr>
<tr>
<td>17.</td>
<td>HIV infection in our family has not caused any changes in our finance position.</td>
</tr>
<tr>
<td>18.</td>
<td>We are worried too much about the expenses we may have to bare in future.</td>
</tr>
<tr>
<td>19.</td>
<td>Of late we feel supported and encouraged by others.</td>
</tr>
<tr>
<td>20.</td>
<td>We want to talk to someone, who listen and understand our difficulties.</td>
</tr>
<tr>
<td>21.</td>
<td>These days we hesitate to talk to each other in the family.</td>
</tr>
<tr>
<td>22.</td>
<td>Of late there seems to be always some sort of tension in our family.</td>
</tr>
<tr>
<td>23.</td>
<td>We always look for somebody to confide our fears and worries.</td>
</tr>
<tr>
<td>24.</td>
<td>HIV diagnosis in a way brought our family members closer (strengthened the bond).</td>
</tr>
<tr>
<td>25.</td>
<td>We are forced to take additional responsibilities in the family than before.</td>
</tr>
<tr>
<td>26.</td>
<td>Many a time we feel burnt out because of our additional responsibilities.</td>
</tr>
<tr>
<td>27.</td>
<td>HIV infection in our family has not brought any significant changes in the ways we function.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Item</th>
<th>True</th>
<th>Don’t Know</th>
<th>False</th>
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<td>2</td>
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<td>12.</td>
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<td>16.</td>
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<td>27.</td>
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<tr>
<td>28.</td>
<td>Of late our family members have taken up additional roles for the smooth functioning of the family.</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>29.</td>
<td>We constantly fear of getting infected while caring for our family member.</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>30.</td>
<td>We do not have any fears or apprehensions caring for our family members.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>31.</td>
<td>We constantly worry about the loss of our family member by death.</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>32.</td>
<td>Death is inevitable hence we do not think and worry about it.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>33.</td>
<td>We worry a lot about the future without our family member.</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>34.</td>
<td>It will be very difficult to run the family without the infected member in future.</td>
<td>3</td>
<td>2</td>
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</tbody>
</table>

A- Agree  
UD- Undecided  
D- Disagree
APPENDIX -7

Interview schedule to assess the caregivers’ disclosure of HIV status and concerns

1) Under what circumstances the Caregiver got to know?
   1. Antenatal visit/
   2. Post natal
   3. When Spouse was tested positive/
   4. When the study CLHA was tested positive/
   5. When caregiver was sick and tested/
   6. When caregiver got tested for sexually transmitted illness
   7. After father died due to AIDS
   8. When the sibling of the child was tested
   9. Tubectomy
   10. When went to donate blood

2) What was the Caregiver’s immediate reaction? What did the Caregiver do next?

3) What were the reasons for disclosure? Did you get them ultimately?
   1. Emotional support
   2. Financial assistance
   3. Medical care/Counselling
   4. Information
   5. Social status

4) How much do your close relatives and friends know about your status? OR what exactly do they think your illness is?
   1. No one knows
   2. Only few know
   3. Only friends know
   4. Only immediate family knows
   5. All of them know
   6. Only one side of relatives know
   7. Only positive friends know

5) “I should not disclose my status to any one” – How much do you feel like this?
   0. Not at all
   1. Completely
   2. To some extent
6) What are the consequences of disclosure?
   1. Discrimination
   2. Fear of spreading the information to others
   3. Maintain distance
   4. Did not believe her
   5. Ask many questions
   6. Gives more information about the illness
   7. More financial responsibilities
   8. Blame
   9. Difficulties in relationships
   10. Suspicion if the partner is negative
       11. No support

7) What are the positive things that have happened to you for having either disclosed or not disclosed?
   1. Supportive
   2. Treat us with respect
   3. No discrimination
   4. Relatives do not visit
   5. Knowledge about the health and treatment
   6. Financial support
   7. Sharing of responsibilities
   8. Help for treatment, hospitalization
   9. Others have got tested for HIV
   10. Improvement in relationships
   11. Husband has given up drinking
   12. Living only for that day
   13. Moved out of joint family
   14. Uses condoms
   15. Other child is negative

8) What are the negative things that have happened to you for having either disclosed or not disclosed?
   1. Fights over property
   2. Nothing
   3. Child is infected
   4. Relative spread the information
   5. Death due to AIDS
   6. Discrimination
   7. Having to start working
   8. Having got this illness with no mistake of mine
   9. Financial difficulties
   10. Loss of job
   11. More responsibilities
   12. No support
   13. Find it difficult to bear all alone
   14. Spouse got separated
   15. Sexual harassment from positive people
16. Health problems
17. Adjusting with the situation and living with it
18. Conflicts with husband
19. Spoken ill about self

36) Caregivers needs and concerns on Children living with HIV/AIDS

1.
2.
3.

Psychosocial issues

1.
2.
3.
APPENDIX -8

Personal Information Sheet on CLHA

Child’s name:

Age: Birth order of the study CLHA: ____ of ______
sibs

Date of Birth: Date of First Visit to Art Centre

____________

Sex: Date of Enrolment to Art ______________

Mother Tongue:

Is the child in school Yes No

If in school which class

Satisfactory performance Yes No

How would you describe your child’s academic performance in

Mathematics: Poor / fair / good / very good

Reading: Poor / fair / good / very good

Has your child failed in any class

Yes No

Does your child fall ill very often?

Yes No

Does your child attend school regularly?

Attends / rarely / absent three / frequently /

always

Regularly absent

absent
days per wk

absent

Days per wk

Does your child like going to school?

Yes Most of the time No

In which language(s) does your child usually speak to siblings and friends?

English Kannada Hindi Malayalam Tamil Telugu Others
Does your child watch television?

Yes  No
If yes, which type of programmes does he/she watch?

Cartoons/ Serials/ Cinemas/ Educational programmes/ news/ others (specify)

What is the language(s) of television programmes that your child usually watches?

English  Kannada  Hindi  Malayalam  Tamil  Telugu  Others

Does your child read newspapers/children’s magazines/story books?

Yes  No

In which language(s) does your child read?

English  Kannada  Hindi  Malayalam  Tamil  Others

Are there any other extra-curricular activities that your child participates in?

Dance/ Drawing/ singing/ Musical instrument/ sports/ others (specify)
APPENDIX - 9
Strengths and Difficulties Questionnaire

For each item please mark the box for Not True, Somewhat True, or Certainly true. It would help us if you answered all items as best as you can even if you are not absolutely certain or the item seems daft! Please give your answers on the basis of the Child’s behaviour the last six months.

<table>
<thead>
<tr>
<th></th>
<th>Not True</th>
<th>Somewhat True</th>
<th>Certainly True</th>
</tr>
</thead>
<tbody>
<tr>
<td>Considerate of other people’s feelings</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Restless, overactive, cannot stay till long</td>
<td></td>
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<tr>
<td>Often complains of headaches, stomachaches or sickness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shares readily with other children</td>
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<tr>
<td>Often has temper tantrums or hot tempers</td>
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<tr>
<td>Rather solitary, tends to play alone</td>
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<tr>
<td>Generally obedient, Usually does what adults request</td>
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<tr>
<td>Many worries, Often seems worried</td>
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<tr>
<td>Helpful if someone is hurt, upset or ill</td>
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<tr>
<td>Constantly fidgeting or squirming</td>
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<tr>
<td>Has at least one good friend</td>
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<tr>
<td>Often fights with other children or bullies them</td>
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<tr>
<td>Often unhappy, down-hearted or tearful</td>
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<tr>
<td>Generally liked by other children</td>
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<tr>
<td>Easily distracted, Concentration wanders</td>
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<tr>
<td>Nervous or clingy in new situations, easily loses confidence</td>
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<tr>
<td>Kind to younger children</td>
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<tr>
<td>Often lies or cheats</td>
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<tr>
<td>Picked on or bullied by other children</td>
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<tr>
<td>Often volunteers to help others (parents, teachers, other children)</td>
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<tr>
<td>Thinks things out before acting</td>
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<tr>
<td>Steals from home, school or elsewhere</td>
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<tr>
<td>Gets on better with adults than with other children</td>
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<tr>
<td>Many fears, easily scared</td>
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<tr>
<td>Sees tasks through to the end, good attention span</td>
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</table>

Do you have any other comments or concerns?
Overall, do you think that your child has difficulties in one or more of the following areas:

<table>
<thead>
<tr>
<th>Emotions, Concentration, Behaviour or Being able to get on with Other people?</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
</tr>
</tbody>
</table>

Yes Minor difficulties Yes Minor difficulties Yes minor difficulties
Yes severe difficulties Yes severe difficulties Yes severe difficulties

If you have answered “Yes” please answer the following questions about these difficulties

- **How long have these difficulties been present?**
  - Less than 1-5 6-12 Over
  - A month months months a year

- **Do the difficulties upset or distress your child?**
  - Not Only a Quite A great
  - At all little a lot deal

- **Do the difficulties interfere with your child’s everyday life in the following areas?**
  - Not Only a Quite A great
  - At all little a lot deal

  Home life
  Friendships
  Classroom learning
  Leisure activities

- **Do the difficulties put a burden on you or the family as a whole?**
  - Not Only a Quite A great
  - At all little a lot deal