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Childhood disclosure related issues and life experiences of children living  
with HIV in West Bengal, India and formulation of an instrument  
for assessment of their health related quality of life

A dissertation submitted in partial satisfaction of the  
requirements for the degree Doctor of Philosophy  
in Epidemiology

by

Aritra Das

2015



## **ABSTRACT OF THE DISSERTATION**

Childhood disclosure related issues and life experiences of children living with HIV in West Bengal, India and formulation of an instrument for assessment of their health related quality of life

by

Aritra Das

Doctor of Philosophy in Epidemiology

University of California, Los Angeles, 2015

Professor Roger Detels, Chair

**OBJECTIVES:** To explore the issues around health related quality of life (HRQoL) of children living with HIV (CLH) through qualitative inquiries and to formulate and validate a culturally acceptable HRQoL instrument.

**METHODOLOGY:** The study was conducted in three districts of West Bengal, India. During the qualitative phase, we conducted 34 in-depth interviews (IDI) with caregivers of CLH and 4 focus group discussions (FGD) with 8 to 15 year old CLH. We identified items affecting HRQoL through qualitative analysis to create 2 HIV-targeted scales –

'symptoms' and 'discrimination'. These 2 scales were combined with 4 generic core scales of the 'Pediatric Quality of Life Inventory (PedsQL)' to formulate the 'Quality of life (health-related) of children living with HIV/AIDS in India (QOL-CHAI)' instrument. In order to assess applicability and detect problems with understanding of intended meaning of items, cognitive interviews were conducted with 10 children (5 each from 8 - 12 years and 13 – 15 year age categories). In the quantitative phase we recruited 199 CLH and 194 children who were exposed but not HIV infected (HIV-affected) to evaluate psychometric properties of the QOL-CHAI instrument and to compare HRQoL between CLH and HIV-affected children.

**RESULTS:** IDIs with caregivers identified several barriers and facilitators related to pediatric disclosure of HIV status. Further, various perceptions and experiences associated with caregiving for CLH and issues such as discrimination, adherence to medication, grievances about available health care provisions were also revealed through qualitative inquiries. The QOL-CHAI showed acceptable psychometric properties with Cronbach's  $\alpha$  for the scales ranging between 0.69 and 0.85. Factor structure of the QOL-CHAI was found to be roughly in agreement with the domain specific categorizations. In terms of convergent validity, symptom scale score showed significant negative correlation with CD4 cell count (Pearson's coefficient=-0.23,  $p<0.01$ ). In linear regression analysis comparing between CLH and HIV-affected children, HIV infection was found to be associated with lower mean scores on all HRQoL domains except 'discrimination'.

**CONCLUSION:** Besides demonstrating that the QOL-CHAI can serve well as a brief, standardized instrument to measure HRQoL, the current study fills some of the existing knowledge gaps regarding pediatric disclosure and caregiving needs of Indian CLH.

The dissertation of Aritra Das is approved.

Abdelmonem A. Afifi

Marjan Javanbakht

Frank Sorvillo

Roger Detels, Committee chair

University of California, Los Angeles

2015

Dedicated to  
Mrs. Sandhya Das, my mother



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## LIST OF ACRONYMS

|         |   |
|---------|---|
| AIDS    | Acquired Immunodeficiency Syndrome                  |
| ART     | Antiretroviral therapy                              |
| CBO     | Community based organization                        |
| CLH     | Children living with HIV                            |
| HAART   | Highly Active Antiretroviral Therapy                |
| HIV     | Human Immunodeficiency Virus                        |
| HRQoL   | Health-Related Quality of Life                      |
| MTCT    | Mother-to-child transmission                        |
| NACO    | National AIDS Control Organisation, India           |
| PedsQL  | Pediatric Quality of Life Inventory                 |
| PLH     | People living with HIV                              |
| PVL     | Plasma viral load                                   |
| QoL     | Quality of life                                     |
| ThQLHC  | Thai Quality of Life for HIV-infected Children      |
| WBSAPCS | West Bengal State AIDS Prevention & Control Society |

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### Peer reviewed publications

1. Das A, Babu GR, Ghosh P, Mahapatra T, Malmgren R, Detels R. Epidemiologic correlates of willingness to be tested for HIV and prior testing among married men in India. *Int J STD AIDS* 2013;24(12):957-968.
2. Mahapatra T, Mahapatra S, Babu GR, Tang W, Banerjee B, Mahapatra U, Das A. Cholera Outbreaks in South and Southeast Asia: Descriptive Analysis, 2003–2012. *Japanese journal of infectious diseases* 2014;67(3):145-156.
3. Panda S, Das A, Samanta S. Synthesizing evidences for policy translation: A public health discourse on rotavirus vaccine in India. *Vaccine* 2014;32S1:A162-A170.
4. Goswami A, Chakraborty U, Mahapatra T, Mahapatra S, Mukherjee T, Das S, Das A, Dey SK, Ray S, Bhattacharya B, Pal NK. Correlates of treatment outcomes and drug resistance among pulmonary tuberculosis patients attending tertiary care hospitals of Kolkata, India. *PLoS One* 2014;9(10):e109563.
5. Das A, Li J, Zhong F, Ouyang L, Mahapatra T, Tang W, et al. Factors associated with HIV and syphilis co-infection among men who have sex with men in seven Chinese cities. *Int J STD AIDS* 2015;26(3):145-55.

# Chapter I: Introduction

## 1. BACKGROUND

The term quality of life vaguely represents well-being of individual(s); but in the realm of scientific literature it can pertain to a broad context of use, ranging from standard of living, policy making, and, of course, health. Enhancement of quality of life has been a policy goal across the nations and for a long period. Still, according to *Costanza et al*, proper definition and measurement of quality of life have remained elusive.(1)

Expectedly, definition and assessment of health related quality of life (HRQoL) have also been subjected to a multitude of diverging theories and concepts. In general, HRQoL refer to World Health Organization's (WHO) definition of health i.e. *a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity*. From an individual perspective it is often defined as an individual's satisfaction or happiness with domains of life insofar as they affect or are affected by "health" as defined above.(2) Thus, HRQoL distinguishes itself from the more general construct of quality of life by the fact that its purview is limited to factors related to health or healthcare. The factors or predictors related to HRQoL are broadly classified into two categories - individual level and community level factors. Individual level predictors comprise perceptions about health, both physical and mental, and related domains such as health risks, functional status, social support, and socioeconomic status.(3) On the community level, HRQoL determinants include the prevalent health policies and conditions, resources available at community level, and various health behaviors and practices that can shape the overall health status of a community.(3) Therefore, HRQoL is a multi-dimensional notion whose purview comprises physical, mental, emotional and

social functioning. Assessment of HRQoL is not limited to common physical indices such as morbidity/mortality rates or life expectancy, and involves evaluation of the influence of health status at individual and community levels.(4) Well-being, which consists of estimation of positive aspects of a person's life, is often touted as a related but abridged concept of HRQoL.(4)

HIV, other than being a chronic disease, is associated with tremendous amount of stigma. HIV associated stigma can severely diminish HRQoL, in addition to the physiological effects of being HIV-infected. It can also serve as a barrier for access to different health services. Thus, assessment of HRQoL among people living with HIV (PLH) is often vital for planning and implementing treatment interventions. This is especially true in developing nations such as India, as available treatment modalities are limited. Given the low number of reported HIV infection among Indian children, evaluation of HRQoL among children living with HIV (CLH) is often overlooked. The major mode of transmission of HIV among Indian children is mother-to-child transmission (MTCT). Being infected from birth often creates a developmental hurdle for these children - physical, social, and psychological. Further, many CLH are orphans, reducing their scope of care and, in turn, affecting their HRQoL. Thus, a tool to measure HRQoL among Indian CLH can aid the informed decision making process, and help the policy makers to implement targeted interventions for this group.

## **2. LITERATURE REVIEW**

The function of a HRQoL tool is not merely to measure the presence and severity of symptoms of disease, but also to assess how the manifestations of an illness or

treatment are experienced by an individual, whether descriptively or in terms of relative preferences for various health states.(5)

## **2.1. HIV infection among children**

### *2.1.1. Globally*

Since the description of the first AIDS case in 1981 in the USA, HIV has infected more than 60 million people across the globe.(6, 7) According to UNAIDS, 35.3 million [32.2 million–38.8 million] people were living with HIV at the end of 2012.(8) Although, the epidemic was first discussed among the gay men in USA, it swiftly spread to the developing world and currently is a leading cause of premature death in sub-Saharan Africa.(7) Among the people living with HIV (PLH), it is estimated that 3.3 million [3.0 million-3.7 million] are children under 15 years age.(8) The majority of the children living with HIV (CLH) were infected during the birth process or from breastfeeding.(9) The low proportion of children among the total PLH population can be attributed to the fact that, without treatment, more than half of the infected children die within 2 years of age.(10) With increasing access to anti-retroviral therapy (ART) to prevent mother-to-child transmission (MTCT), the number of newly infected children at birth declined by 24% between 2009 and 2011.(11) Prevention of mother-to-child transmission has indeed been one of the major success stories of the ART program.

### *2.1.2. India*

India has the third greatest burden of human immunodeficiency virus (HIV) infected people in the world, after South Africa and Nigeria, with an estimated 2.1 million people currently infected and an estimated adult (15-49 years) prevalence of 0.27%.(12, 13) It is estimated that children under 15 years account for about 7% of the prevalent

cases.(13) MTCT is the predominant route of transmission for HIV infected children and it is estimated that more than 21,000 children are infected every year through this route.(14) A National Pediatric Antiretroviral Treatment Initiative was launched in 2006, with the goal to provide ART to 40,000 children living with HIV by 2012. Even though the scaling-up of ART program in India has been impressive overall, it failed to meet expectation for CLH. Only about 28,000 CLH were receiving ART in 2011.(15) As maternal infection is the major route of transmission among CLH, lack of parental support due to death/ill health of the mother (or both parents) often acts as a barrier for providing better access to care for CLH in a resource-limited country such as India.

## **2. 2. Health-related quality of life measurement**

WHO definition of health transcends the previous conception about health i.e. absence of disease or infirmity. As the current concept of HRQoL is based on WHO definition of health, its scope is also not confined to physical disease and involves various aspects of patients' well-being (e.g. environmental, spiritual, and economic). The concept refers not only to the health personnel's assessment of the patients but also takes into account how the patients perceive their current level of health-related functioning and well-being.(16)

The initial HRQoL measures were mostly targeted towards the adult patients. The goals of these were to improve patient compliance and to develop cost effective interventions. HRQoL instruments specifically catering to children emerged much later as chronic, often non-curable diseases, became important even among the pediatric age group. A few of the broad categories of HRQoL instruments are as follows:(16)

- I. *Generic instruments:* As the name suggests these are applicable without regard to the populace or the involved disease. These non-specific instruments do not always work well in assessment of particular diseases but, in general, they can help in comparison of HRQoL between patients suffering from two separate but equally debilitating diseases. Examples of generic instruments are the SF-36 for adults and the Pediatric Quality of Life Questionnaire (PedsQL) for children.(16, 17)
- II. *Disease specific instruments:* These instruments are targeted towards patients affected with a particular disease. These types of targeted instruments are advantageous, at least conceptually, as they are more inclusive towards changes caused by the progression of specific diseases or effects of therapy. These can also help in detecting change in response due to inherent differences among patients suffering from same disease. Pediatric Rhinoconjunctivitis Quality of Life(18) and Pediatric Oncology Quality of Life Scale(19) are two examples of disease specific instruments.(16)
- III. *Combination of items of disease specific and generic instruments:* There are instances when a combination of generic and disease-targeted instruments perform better while evaluating HRQoL. These kind of combined questionnaires are often used when the patient population is diverse, both demographically and according to types of the same disease. In these scenarios, such combination instruments can be used to compare the HRQoL of different patient populations. Although these instruments are potentially less responsive to disease progression and treatment than the targeted instruments, these can prove to be



sufficiently sensitive, while allowing a broader range of comparison. Common examples(16) include the General Health Assessment for Children (GHAC), a combination of generic scales plus an HIV-related symptomatology module,(20) and the generic core of PedsQL supplemented with diabetes module for type-1 diabetes mellitus.(21)

- IV. An additional type, distinct from the above one, specifically uses combinations of domains belonging to discrete questionnaires into an all-inclusive battery of questions. There have been suggestions that this approach may allow the investigators to customize their instruments so that it becomes more pertinent to the study hypothesis. However, these are often more extensive than single instruments and, therefore, more difficult and time consuming to administer. Besides, the response categories in different questionnaires, used to create the battery, may not be uniform, leading to difficulties in compilation and interpretation. An example is the HRQoL instrument developed by Cleary and colleagues for use in AIDS patients.(22)

### **2. 3. Health-related quality of life (HRQoL) for HIV infected**

Availability of highly active antiretroviral therapy (HAART) has managed to reduce incidences of opportunistic infections and other AIDS defining illnesses. This has led to delayed, often to an indefinite period, progression to AIDS and, in turn, has prolonged lifespan of the infected. However, the current therapies fail to eliminate the latently infected T-cells and, therefore, are not successful in complete elimination of the virus or cure of the patient.(23) As complete cure is not possible, helping the HIV infected to attain an optimum quality of life remains a key goal of treatment. Assessment of HRQoL

for HIV infected not only indicates the outcome at the patient level, but also helps in evaluation of the treatment measures. It can help us identify treatment regimens that are not only efficacious but also produce lesser side effects, both physiological and psychological. HRQoL measures enable the policy makers to take into account efficacy, safety, tolerance, and cost (both direct and indirect) while estimating the effectiveness of a particular treatment regimen or other interventions.(20) Further, HRQoL assessment can be helpful in selecting the better one among interventions of apparently equal efficacy (such as similar levels of viral load suppression or rise in CD4 T-cells) by preferring the one that exhibits a superior score in one or more HRQoL domains such as loss of work/school days.(20) Therefore, a better evaluation of health status of children and families affected by HIV/AIDS can be achieved by integrating functioning and well-being with clinical parameters. Such evaluations can be further enhanced by considering the health status of other family members, family structure, and the quality of support networks and social environment.

With global spread of the HIV epidemic, interest in creating targeted questionnaires to assess HRQoL of HIV infected children gained momentum. Assessing HRQoL of children living with HIV can help researchers to ascertain how their day-to-day lives and upbringing processes are affected by HIV. In resource-poor settings, like in India, where even perfectly healthy children are often deprived of basic amenities and social support, ensuring quality of life for children living with HIV is an arduous task. This can chiefly be attributed to stigma associated with HIV and (for orphans) lack of parental care. Thus, assessment of HRQoL for CLH in developing nations can be more vital compared to developed country settings. Development of a culturally appropriate tool to assess

HRQoL of CLH can help in identifying areas of concern among the domains of HRQoL spectrum. This can also help the policy makers to address those issues using specific interventions. However, although the importance of assessing HRQoL of children living with HIV has been widely recognized in literature, there has been a dearth of available measures, especially for developing nations. There are, in fact, very few pediatric HRQoL instruments – generic or disease targeted – that have been developed in a resource-limited setting.(24) In the realm of HRQoL instruments targeted to pediatric and adolescent population living with HIV, Garvie et al(25) identified 19 instruments developed between 1990 and 2008, and not a single one among them were from a developing country. It has been hypothesized that most such tools, designed for high-income countries, may have limited applicability in resource-poor settings.(16, 26) Punpanich et al recently formulated an HIV-targeted HRQoL instrument for the pediatric population.(16) It is the first known pediatric HRQoL instrument for HIV-infected specifically created for a developing country in south Asia. This ‘Thai Quality of Life for HIV-infected Children (ThQLHC)’ instrument incorporates the ‘Pediatric Quality of Life Inventory (PedsQL)’ as a generic core and a 17-item HIV-targeted scale. Among the five domains in this instrument - physical functioning, emotional functioning, social functioning, school functioning, and symptoms; the first four domains are based on PedsQL while the last one, symptoms, makes it HIV-targeted. Cronbach’s alpha, measuring internal consistency reliability of this instrument, was above 0.7 for all the domains except school functioning.

### **3. STUDY OBJECTIVES**

#### **3.1. Qualitative phase**

- I. To explore the domains related to HRQoL among CLH
- II. To elucidate the perspectives of caregivers pertaining to disclosure of HIV status to CLH and to identify the probable facilitators and barriers of the process
- III. To explore various life experiences of CLH and their caregivers related to the disease and their attitude about available health care provisions
- IV. To develop a culturally appropriate instrument for assessing HRQoL among children living with HIV

#### **3.2. Quantitative phase**

- I. Evaluation of the psychometric properties and applicability of the newly developed instrument
- II. To compare HRQoL domains between children living with HIV and children exposed to but not infected with HIV
- III. To identify if anti-retroviral therapy (ART) is associated with improvements in HRQoL among CLH
- IV. To evaluate if CD4 lymphocyte count predicts HRQoL among CLH

### **4. REFERENCES**

1. Costanza R, Fisher B, Ali S, Beer C, Bond L, Boumans R, et al. An integrative approach to quality of life measurement, research, and policy. SAPI EN S Surveys and Perspectives Integrating Environment and Society. 2008(1.1).

2. Wilson IB, Cleary PD. Linking clinical variables with health-related quality of life. JAMA: The Journal of the American Medical Association. 1995;273(1):59-65.
3. Health-Related Quality of Life (HRQOL) Centers for Disease Control and Prevention [cited 2015 March 2]. Available from: <http://www.cdc.gov/hrqol/concept.htm#six>.
4. Health-Related Quality of Life and Well-Being: HealthyPeople.gov; [cited 2015 March 2]. Available from: <http://www.healthypeople.gov/2020/about/golwbbabout.aspx>.
5. Eiser C, Morse R. A review of measures of quality of life for children with chronic illness. Archives of disease in childhood. 2001;84(3):205-11. Epub 2001/02/24. PubMed PMID: 11207164; PubMed Central PMCID: PMC1718699.
6. Gottlieb MS. Pneumocystis pneumonia—Los Angeles. American Journal of Public Health. 2006;96(6):980.
7. UNAIDS. 2008 Report on the global AIDS epidemic: World Health Organization; 2008.
8. Core Epidemiology Slides: UNAIDS; September, 2013 [May 22, 2015]. Available from: [http://www.unaids.org/sites/default/files/en/media/unaids/contentassets/documents/epidemiology/2013/gr2013/201309\\_epi\\_core\\_en.pdf](http://www.unaids.org/sites/default/files/en/media/unaids/contentassets/documents/epidemiology/2013/gr2013/201309_epi_core_en.pdf).
9. Treatment of children living with HIV: World Health Organization; 2012 [May 14, 2015]. Available from: <http://www.who.int/hiv/topics/paediatric/hiv-paediatric-infopage/en/>.
10. Newell ML, Coovadia H, Cortina-Borja M, Rollins N, Gaillard P, Dabis F. Mortality of infected and uninfected infants born to HIV-infected mothers in Africa: a pooled analysis. Lancet. 2004;364(9441):1236-43. Epub 2004/10/07. doi: 10.1016/s0140-6736(04)17140-7. PubMed PMID: 15464184.
11. UNAIDS. 2012 UNAIDS Report on the Global AIDS Epidemic. 2012.
12. UNAIDS country progress reports. 2012.

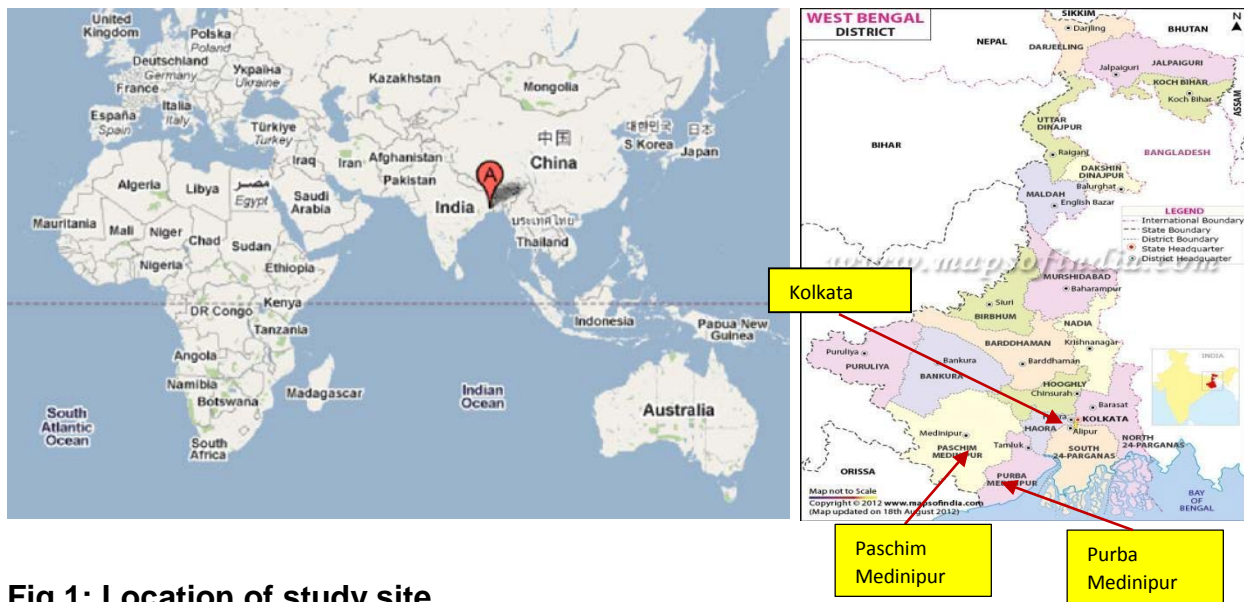
13. National AIDS Control Organisation Annual Report 2013-2014. Department of AIDS Control, Ministry of Health and Family Welfare, Government of India, 2014 5th January, 2015. Report No.
14. UNICEF India HIV/AIDS stories: UNICEF India; [May 14, 2015]. Available from: <http://www.unicef.in/Story/1123/HIV-AIDS>.
15. NACO Annual report, 2011-12. India: National AIDS Control Organisation, 2012 May 8, 2013. Report No.
16. Punpanich W. Development of a Culturally Appropriate Health-related Quality of Life Measure for HIV-infected Children in Thailand: ProQuest; 2009.
17. Varni JW, Seid M, Rode CA. The PedsQL: measurement model for the pediatric quality of life inventory. *Medical Care*. 1999;37(2):126-39. Epub 1999/02/19. PubMed PMID: 10024117.
18. Juniper EF, Rohrbaugh T, Meltzer EO. A questionnaire to measure quality of life in adults with nocturnal allergic rhinoconjunctivitis. *J Allergy Clin Immunol*. 2003;111(3):484-90. Epub 2003/03/19. PubMed PMID: 12642826.
19. Goodwin DA, Boggs SR, Graham-Pole J. Development and validation of the pediatric oncology quality of life scale. *Psychological Assessment*. 1994;6(4):321.
20. Testa M, Lenderking W. Quality of life considerations in AIDS clinical trials. *AIDS clinical trials*. 1995:150-9.
21. Varni JW, Burwinkle TM, Jacobs JR, Gottschalk M, Kaufman F, Jones KL. The PedsQL™ in type 1 and type 2 diabetes reliability and validity of the pediatric quality of life inventory™ generic core scales and type 1 diabetes module. *Diabetes care*. 2003;26(3):631-7.
22. Cleary PD, Fowler FJ, Jr., Weissman J, Massagli MP, Wilson I, Seage GR, 3rd, et al. Health-related quality of life in persons with acquired immune deficiency syndrome. *Med Care*. 1993;31(7):569-80. Epub 1993/07/01. PubMed PMID: 8326772.

23. Stevenson M. HIV-1 pathogenesis. *Nature medicine*. 2003;9(7):853-60. Epub 2003/07/02. doi: 10.1038/nm0703-853. PubMed PMID: 12835705.
24. Eiser C, Morse R. The measurement of quality of life in children: past and future perspectives. *J Dev Behav Pediatr*. 2001;22(4):248-56. Epub 2001/09/04. PubMed PMID: 11530898.
25. Garvie PA, Lawford J, Banet MS, West RL. Quality of life measurement in paediatric and adolescent populations with HIV: a review of the literature. *Child: care, health and development*. 2009;35(4):440-53. Epub 2009/07/30. doi: 10.1111/j.1365-2214.2009.00985.x. PubMed PMID: 19638021.
26. Skevington SM, O'Connell KA. Measuring quality of life in HIV and AIDS: A review of the recent literature. *Psychology and health*. 2003;18(3):331-50.

# Chapter II: Methodology

## 1. STUDY AREA

The current study was conducted in three districts of West Bengal, India - Paschim Medinipur, Purba Medinipur and Kolkata. For field assessment and subject recruitment, we collaborated with a local community based organization (CBO) ‘Society for Positive Atmosphere and Related Support to HIV/AIDS’ (SPARSHA) that has been providing various need based services to PLH in several rural and urban districts of West Bengal. Paschim and Purba Medinipur districts, with six million and five million populations respectively, comprise mostly rural and semi-urban areas. Kolkata, on the other hand, is a major city and commercial hub in India with a population close to 14 million.



**Fig.1: Location of study site**

## 2. INITIAL FIELD ASSESSMENT AND STUDY SETUP

An initial field assessment was conducted in September – November, 2013, with help of the collaborating CBO, to understand the dynamics of the relation HIV-infected children



share with their caregivers and society, to become familiar with the prevalent practices, and to identify the potential areas of concern related to HRQoL.

SPARSHA, an organization registered under the West Bengal Societies Registration Act 1961 and constituted by “People Living with HIV/AIDS and their Friends (PLWHAF)”, has been running a community support and advocacy program for children and adults living with HIV in Kolkata, Paschim Medinipur and Purba Medinipur districts since 2006. This program has helped to reduce discriminatory attitudes towards these children, besides improving the knowledge about HIV/AIDS in the study area. In addition to the direct beneficiaries of their services, SPARSHA had also established contacts with other PLH in the study districts through their outreach workers. During the course of their work, they created a registry of individual PLH and families consisting of one or more PLH residing in the aforementioned districts.

In order to gain access to the study population and facilitate study conduct, we signed a legal agreement of collaboration with SPARSHA. As per the agreement, SPARSHA allowed the current study team to use their field offices for conducting interviews and for other study purposes. In addition, we were allowed to access their PLH registry for identifying/recruiting participants for the study. SPARSHA and its associates also helped us to recruit field staff/interviewers for the current study.

### **3. ETHICAL APPROVAL**

The study was approved by the institutional review board (IRB) of University of California, Los Angeles and the institutional ethics committee (IEC) of the National Institute of

Cholera and Enteric Diseases (under the Indian Council of Medical Research), the collaborating research institute located in Kolkata, West Bengal.

#### **4. STUDY DESIGN**

The study was carried out in two main phases: a) Qualitative, and b) Quantitative.

##### *Qualitative phase*

- In-depth interviews with the caregivers
- Focus group discussion with children living with HIV
- Qualitative data analysis
- Formation of the instrument for quantitative phase

##### *Quantitative study*

- Administration of the newly developed instrument to CLH and HIV-affected children
- Quantitative data analysis

#### **4. 1. Qualitative phase**

##### *In-depth interview with caregivers*

Between July and September, 2014, consenting caregivers responded to an in-depth interview (IDI), requiring approximately an hour, by a trained study staff. Interviews were conducted in a private room at the SPARSHA field office or in the participant's home. Eligibility criteria for participation were: i) being the primary caregiver looking after the needs of one or more CLH aged 8-15 years , ii) adult ( $\geq 18$  years), iii) living in the same

household as the concerned child, iv) being a native language speaker, and v) willing to provide informed consent. No gender specific criteria were used to determine eligibility. Caregivers of institutionalized children, or children who spent  $\geq 2$  weeks/month or  $\geq 6$  months/year away from the caregiver, were not considered. A semi-structured interview guide with broad questions aided by open-ended probes was used for this purpose. Permission for taking written notes and digitally recording the conversations were obtained prior to initiating the interviews. Written notes were used for the purpose of grasping the main points mentioned besides recording details about participants' characteristics, emotional expressions, body language, as well as interviewers' comments. All the interviews were conducted in Bengali, the native language of the area. As suggested by Green and Thorogood(1), it was initially decided to conduct 40 interviews (20 with caregivers who were biological parents and 20 with those who were not), or till thematic saturation was reached, whichever was lower. Based on the above principle, we finally conducted interviews with 20 biological parent and 14 non-parent caregivers.

#### *Focus group discussion with children*

We conducted four FGDs – two each involving CLH aged 8-12 years and 13-15 years. Within each age-group, one FGD involved CLH who were on ART, whereas the other one had participants who had not started ART. Informed consents were sought from caregivers for allowing their children to participate in the FGDs. In addition verbal assents were obtained from CLH taking part in FGDs. Participating children were assessed for their eligibility of participation in FGD using the following criteria: i) being diagnosed with HIV at a center approved by the West Bengal State Aids Prevention &

Control Society (WBSAPCS), ii) 8 -15 years age, iii) not being previously diagnosed with a disorder that would prevent the participating child from responding rationally to the questionnaire (such as psychiatric, neurologic or developmental disorders, but not limited to them), iv) consent from the accompanying caregiver to participate, v) verbal assent from the child. FGDs were also conducted in Bengali and each of them lasted about one and half hours. We used a semi-structured guide for FGDs.

### *Qualitative data analysis*

Audio recordings of interviews and group discussions were transcribed verbatim into *MS Word* in Bengali. The notes taken during IDIs/FGDs were used to facilitate the transcription process and to enhance the transcripts by insertion of relevant comments (e.g. mood, emotional status of interviewee etc.). These were also utilized later for content analysis. The transcripts were then imported into Atlas.ti 7.5 package for the purpose of coding and data analysis. At the time of initial reading we reviewed the transcripts line-by-line to identify distinct concepts from the data and create codes. During subsequent readings, we connected and categorized the identified codes (axial coding). The entire analysis was conducted in Bengali. We only translated some relevant quotations to English during final phase of analysis. Disagreement between study team members regarding the codes were settled through discussion.

### *Formulating an HIV-targeted HRQoL instrument*

In addition to identifying HIV-targeted items from the formative qualitative research, we performed a literature review and consulted experts regarding selection/modifications of items for the scale. The methodology followed for development of the Thai Quality of

Life for HIV-infected Children (ThQLHC),(2) a validated HIV-targeted instrument developed in south Asia, was followed for formulating the new instrument. The two new scales developed using the above methodology, namely 'symptoms' and 'discrimination', were incorporated alongside the Pediatric Quality of Life Inventory (PedsQL) generic core scales (child/teen report). The PedsQL generic core is a widely used and validated, disease-independent instrument for assessing HRQoL which contains 23 items in four domains - physical, emotional, social and school functioning.(3, 4)

In order to assess applicability and detect problems with understanding of intended meaning of items, cognitive interviews were conducted with 10 children (5 each from 8 - 12 years and 13 – 15 year age categories).(5, 6) The instrument was administered in 'assisted self-administered' format i.e. respondents were asked to complete the questionnaire in presence of interviewer.(7) The interviewer helped participants if they had any queries. Following completion of questionnaire, the interviewer probed respondents about individual items and instructions. Probing was done to assess whether the interviewees understood the intended meaning of directions, questions, and answer categories. Any difficulties in understanding, as reported by the participants, were noted by the interviewer and were used to modify the instrument accordingly.(8)

#### **4. 2. Quantitative phase**

The primary objective in the quantitative phase was to evaluate the psychometric properties and applicability of the newly developed instrument in the prevalent socio-demographic and cultural settings. The other important objectives were to compare

HRQoL between CLH and HIV-affected children and to identify associations of ART and CD4 cell counts with HRQoL among CLH. *Sample size calculation*

The required sample size for this phase was calculated according to the conventional cross-sectional study sample size calculation method as explained below. The actual sample size was determined by this statistical computation as well as by available time and budget.

For this study, sample size was determined using the sample size calculation method employed by SAS (Proc power) under different assumptions. The different parameters for sample size estimation are explained below:

- Significance level ( $\alpha$ ): It is defined as the probability of rejecting a true null hypothesis. It is also known as Type-I error. For this study alpha ( $\alpha$ ) level was fixed at 0.05.
- Power: It is defined as the probability of rejecting a false null hypothesis. It is represented as  $1 - \beta$  where beta ( $\beta$ ) is the probability of accepting a false null hypothesis.  $\beta$  is also known as Type-II error. For the current sample size calculation power was varied between 0.6 and 0.8.
- Mean difference between groups and standard deviation: Estimated mean difference in the index HRQoL scores between 2 comparison groups - CLH and HIV-affected – was used in this calculation. Further, for calculation of sample size, the distribution of HRQoL score was assumed to be normal and an anticipated range of standard deviation (for group difference) was used.

We based our sample size estimation on PedsQL which formed the generic core of the newly formulated instrument. PedsQL uses a 5 point Likert scale (0 – 4) for each of the 23 items in the generic core. Thus, without transformation, the total score for HRQoL ranged from 0 to 92. For the purpose of sample size calculation, we assumed that our newly formulated instrument would contain 23 items i.e. same as PedsQL and highest possible summary score being 92. Further, the mean difference in summary HRQoL score (sum of the item scores) between the CLH and HIV-affected was assumed to vary in the range of 5 to 10, with SD of mean difference varying from 15 to 25. Based on the above assumptions, the estimated sample sizes per group (equal group size) are as follows:

**Table 1. Sample size estimation for quantitative phase**

| Estimated sample size per group |         |               |              |             |            |           |               |              |             |
|---------------------------------|---------|---------------|--------------|-------------|------------|-----------|---------------|--------------|-------------|
| Mean Diff                       | Std Dev | Nominal Power | Actual Power | N per Group | Mean Diff  | Std Dev   | Nominal Power | Actual Power | N per Group |
| 5                               | 15      | 0.6           | 0.604        | 90          | 7.5        | 20        | 0.8           | 0.801        | 113         |
| 5                               | 15      | 0.7           | 0.704        | 113         | 7.5        | 25        | 0.6           | 0.601        | 110         |
| 5                               | 15      | 0.8           | 0.802        | 143         | 7.5        | 25        | 0.7           | 0.703        | 139         |
| 5                               | 20      | 0.6           | 0.601        | 158         | <b>7.5</b> | <b>25</b> | <b>0.8</b>    | <b>0.801</b> | <b>176</b>  |
| 5                               | 20      | 0.7           | 0.701        | 199         | 10         | 15        | 0.6           | 0.618        | 24          |
| 5                               | 20      | 0.8           | 0.801        | 253         | 10         | 15        | 0.7           | 0.704        | 29          |
| 5                               | 25      | 0.6           | 0.6          | 246         | 10         | 15        | 0.8           | 0.808        | 37          |
| 5                               | 25      | 0.7           | 0.701        | 310         | 10         | 20        | 0.6           | 0.609        | 41          |
| 5                               | 25      | 0.8           | 0.801        | 394         | 10         | 20        | 0.7           | 0.706        | 51          |
| 7.5                             | 15      | 0.6           | 0.609        | 41          | 10         | 20        | 0.8           | 0.801        | 64          |
| 7.5                             | 15      | 0.7           | 0.706        | 51          | 10         | 25        | 0.6           | 0.606        | 63          |
| 7.5                             | 15      | 0.8           | 0.801        | 64          | 10         | 25        | 0.7           | 0.705        | 79          |
| 7.5                             | 20      | 0.6           | 0.602        | 71          | 10         | 25        | 0.8           | 0.804        | 100         |
| 7.5                             | 20      | 0.7           | 0.701        | 89          |            |           |               |              |             |

From the above list, for the purpose of current study, we sought to recruit at least 176 (~220 assuming 20% non-response) participants in each group, assuming a mean difference of 7.5 units, standard deviation of 25 and 80% power. *Participant recruitment*

Participants for this phase were identified and recruited using the SPARSHA's registry of CLH and HIV-affected children. Eligibility criteria for participating CLH were as follows: i) being diagnosed with HIV at a center approved by the West Bengal State AIDS Prevention & Control Society (WBSAPCS), ii) 8 -15 years age, iii) not previously diagnosed with a disorder that would prevent the participating child from responding rationally to the questionnaire (such as psychiatric, neurologic or developmental disorders, but not limited to them), iv) consent from the accompanying caregiver to participate, v) verbal assent from the child. In terms of recruitment to the HIV-affected group, an eligible child had to be born to an HIV-infected mother and must have tested negative for HIV antibody at or after 18 months age. Other than HIV-diagnosis, the rest of the eligibility criteria for CLH applied to recruitment of HIV-affected children as well. Parents (or primary caregivers) of eligible participants were contacted by outreach workers from SPARSHA regarding participation of their children. Parents/caregivers who expressed a preliminary approval about participation of their children in the study were invited to bring their children to the nearby SPARSHA field office for an interview. In case the child or his/her caregiver wanted the interview to be conducted at their home, an interview team visited their home on the scheduled date and time. Each interview was preceded by obtaining an informed consent from the respective parent/caregiver, followed by verbal assent from the child.

*Data collection*



Between November, 2014 and February, 2015, caregivers of 217 CLH and 232 children who were exposed but not HIV infected (HIV-affected) were approached for participation, of whom we managed to conduct interviews with 199 CLH and 194 HIV-affected children. Following informed consent from caregivers about interviewing their child and assessing treatment records, some socio-demographic information were obtained from respective caregivers about the children and their families. Treatment related information of respective CLH (CD4 cell count, ART intake etc.) were recorded from their 'ART card' issued by treatment center. Children providing verbal assent were then requested to complete the 'Quality of life (health-related) of children living with HIV/AIDS in India (QOL-CHAI)' instrument with assistance from a trained interviewer. The QOL-CHAI is a 45 item instrument comprising of six domains. The first four domains – physical (8 items), emotional (5 items), social (5 items) and school (5 items) functioning were adapted from the 'Pediatric Quality of Life Inventory (PedsQL)' generic core scale.(3, 4) The other two domains contain questions related to disease symptoms (18 items) and experiences of discriminating behavior (4 items). Participants were required to answer how much of a problem they had to face regarding each item in the instrument during the past month, except for the 'discrimination' domain which dealt with problems during the past year. Severity of the problems associated with each item were classified as follows; never (0), almost never (1), sometimes (2), often (3), and almost always (4). Interviews with children took approximately 15 minutes to complete.

#### *Quantitative data analysis*

Descriptive analyses were performed for items in each scale/domain of the QOL-CHAI instrument to determine parameters such as mean, median, standard deviation,

proportion of 'ceiling' and 'floor' values etc. Cronbach's  $\alpha$  was calculated for each domain to determine internal consistency reliability. Additionally, for each item we determined correlation of that item with the scale it belonged to and the resultant change in Cronbach's  $\alpha$  with deletion of each item from the scale. Convergent validity of 'symptoms' and 'discrimination' scales, respectively, were assessed by estimating Pearson correlation coefficients with last reported CD4 cell count and social functioning scale score.(9) To assess known groups validity, we used a priori hypothesis that scores for each HRQoL domain would be significantly lower for CLH, compared to HIV-affected children. Wilcoxon rank sum tests were performed to evaluate if scale scores differed based on infection status.

We sought to ascertain, using 'backward elimination' regression analysis,(10) if the newly incorporated scales, 'symptoms' and 'discrimination', yielded additional information on clinical status of CLH beyond that captured by PedsQL. This was assessed by regressing scale scores on last measured CD4 cell count and by checking if the scores from 'symptoms' and 'discrimination' scales accounted for significant unique variance. We also attempted to determine which scales in the newly developed instrument differentiated between HRQoL status of CLH and HIV-affected children by discriminant analysis. We performed stepwise discriminant analysis on 'infection status' with summary scores for each scale - to determine the scale scores that differed significantly between CLH and HIV-affected children.

We performed exploratory factor analysis with principal component extraction and 'varimax' rotation methods to examine if the factor loadings were consistent with the constructs being measured.(10) The number of factors to be extracted was determined

by setting a cut-off of 75% of initial communality estimate(11) i.e. number of extracted factors were increased until the sum of eigenvalues for the retained factors exceeded 75 percent of the common variance.

In order to evaluate the associations between HIV infection status and QOL-CHAI scale scores, we employed simple and multiple linear regression models. Further, among the CLH, the association of ART regimen and CD4 lymphocyte count with QOL-CHAI scores were determined using separate unadjusted and adjusted linear regression models. All multiple regression models were adjusted for age, gender, parental status (parents alive or not) and per-capita family income. Model fit was assessed by adjusted R<sup>2</sup> statistic and residual plot.

All statistical analyses were performed using SAS 9.4.

## **5. REFERENCES**

1. Green J, Thorogood N. Qualitative methods for health research: Sage; 2013.
2. Punpanich W, Hays RD, Detels R, Chokephaibulkit K, Chantbuddhiwet U, Leowsrisook P, et al. Development of a culturally appropriate health-related quality of life measure for human immunodeficiency virus-infected children in Thailand. *Journal of paediatrics and child health*. 2011;47(1-2):27-33. Epub 2010/10/27. doi: 10.1111/j.1440-1754.2010.01886.x. PubMed PMID: 20973862; PubMed Central PMCID: PMC3033216.
3. Varni JW, Seid M, Kurtin PS. PedsQL 4.0: reliability and validity of the Pediatric Quality of Life Inventory version 4.0 generic core scales in healthy and patient populations. *Medical Care*. 2001;39(8):800-12. Epub 2001/07/27. PubMed PMID: 11468499.
4. Varni JW, Seid M, Rode CA. The PedsQL: measurement model for the pediatric quality of life inventory. *Medical Care*. 1999;37(2):126-39. Epub 1999/02/19. PubMed PMID: 10024117.

5. Young TL, Kirchdoerfer LJ, Osterhaus JT. A Development and Validation Process for a Disease-Specific Quality of Life Instrument\*. *Drug Inf J*. 1996;30(1):185-93.
6. Juniper EF, Guyatt GH, Jaeschke R. How to develop and validate a new health-related quality of life instrument. *Quality of life and pharmacoeconomics in clinical trials*. 1996;2:49-56.
7. Harris LR, Brown GT. Mixing interview and questionnaire methods: Practical problems in aligning data. *Practical Assessment, Research & Evaluation* [Internet]. 2010 May 15, 2015; 15(1). Available from: <http://pareonline.net/pdf/v15n1.pdf>.
8. The linguistic validation - PedsQL™. Mapi Research Institute, 2002 June 30, 2014. Report No.
9. Elkin E. Are You in Need of Validation? Psychometric Evaluation of Questionnaires Using SAS. *SAS Global Forum* [Internet]. 2012 March 15, 2015. Available from: <http://support.sas.com/resources/papers/proceedings12/426-2012.pdf>.
10. Afifi A, Clark VA, May S. *Practical multivariate analysis*: Chapman & Hall; 2011.
11. Pett MA, Lackey NR, Sullivan JJ. *Making sense of factor analysis: The use of factor analysis for instrument development in health care research*: Sage; 2003.

## **Chapter III: Issues around childhood disclosure of HIV status – findings from a qualitative study in West Bengal, India**

### **1. INTRODUCTION**

Globally an estimated 3.2 million children under 15 years of age were living with the Human Immunodeficiency Virus (HIV) at the end of 2013.(1) In India, which ranks third in the world in terms of number of people living with HIV (PLH), under-15 children constitute 7% of its approximately 2.1 million PLH.(2) Previously, a dearth of access to anti-retroviral therapy (ART) made these children face an uncertain future and most of them failed to make it to adulthood. Recent emphasis on early infant diagnosis and scaling up of the ART program have led to drastic reductions in childhood and adolescent mortality due to HIV. However, improvements in pediatric HIV diagnosis, treatment, and resulting improved longevity pose further challenges for health systems in resource poor countries such as India. Some of these newer challenges include, but are not limited to, improving and maintaining adherence to ART, reducing secondary transmission, and comprehensive betterment of psychological and physical health of children living with HIV (CLH).(3)

Informing a CLH about his/her diagnosis (disclosure) is considered critical – from the perspectives of disease treatment and overall psychosocial development.(4) The decision about disclosure of HIV status to a CLH has also been recognized as one of the principal dilemmas faced by caregivers.(4) As with other life-threatening diseases, disclosure of HIV status to a child or adolescent can either be partial or full. While in partial disclosure some disconcerting or stigmatizing aspects about HIV (such as disease name) are not revealed, full disclosure involves discussing the specifics about

the disease.(5) However, recent guidelines suggest that disclosure to children should be a continuing process rather than a one-off phenomenon i.e. complete disclosure should occur over a period of time, increasing the amount of information to be shared with children as their mental faculties mature.(6)

Our literature search revealed only two Indian studies that specifically dealt with the issue of HIV status disclosure to children. Among those, a study conducted in a tertiary care hospital(7) reported a dismal 14% disclosure proportion, but a larger study from north India(8) found that 41% of children and adolescents knew about their disease status. Both studies captured various parameters related to disclosure quantitatively, but neither of them qualitatively explored the knowledge, attitude, and practice of caregivers or various barriers/facilitators related to the process of disclosure. Such contextual issues demand a deeper understanding in order to create an effective and locally appropriate framework for HIV related disclosure to children. In view of this information gap, the present study aimed to explore perception of the caregivers in West Bengal, an eastern Indian state, about the overall concept of disclosure to children. Our study findings can inform India's national HIV program on this emerging public health need. We collaborated with a civil society community-based organization (CSCBO) named 'Society for Positive Atmosphere and Related Support to HIV/AIDS' (SPARSHA) to conduct this investigation.(9)

## **2. METHODS**

### ***2.1. Study setting***

Participants in this study were primary caregivers of eight to fifteen year old children living with HIV, residing in the districts of Purba Medinipur and Paschim Medinipur, West Bengal. Access to the study population was gained with the help of SPARSHA. Since 2000, SPARSHA, an organization constituted of and managed by people living with HIV and their friends (PLWHAF), has been working for children and adults living with HIV in rural and urban settings of West Bengal. The various services offered by SPARSHA include 'facilitating access to antiretroviral therapy', 'conducting community awareness programs', 'HIV stigma reduction activities' and 'HIV/AIDS counseling services'. As part of its activities SPARSHA had prepared a roster of its service recipients residing in the two study districts. Primary caregivers of CLH identified from this roster were contacted by outreach workers from SPARSHA. Those who expressed willingness to participate were invited to come to the nearby SPARSHA field office for an interview. In case the participants wished to be interviewed at their home, an interview team visited their home on the scheduled date and time.

## ***2.2. Ethical approval***

The study was approved by the institutional review board (IRB) of University of California, Los Angeles and the institutional ethics committee (IEC) of the National Institute of Cholera and Enteric Diseases (under the Indian Council of Medical Research), the collaborating research institute located in Kolkata, West Bengal.

## ***2.3. Participants***

Eligibility criteria for participation were: i) being the primary caregiver looking after the needs of one or more CLH aged 8-15 years, ii) adult ( $\geq 18$  years), iii) living in the same household as the concerned child, iv) being a native language speaker, and v) willing to

provide informed consent. No gender specific criteria were used to determine eligibility. Caregivers of institutionalized children, or children who spent  $\geq 2$  weeks/month or  $\geq 6$  months/year away from the caregiver, were not considered. As the most likely route of transmission for HIV infected children is parent-to-child transmission, it seemed likely that the biological parents of some of the CLH might have died or were too sick to be their caregiver. Our interaction with SPARSHA outreach workers, who have been working in study area, also suggested the presence of single parent and both parent orphans living with HIV. Thus, we expected some of the CLH to be under care of persons other than their biological parents and we recruited both kinds of caregivers (biological parents and non-parents) to the interview pool.

#### **2.4. Interviews**

Between July and September, 2014, consenting caregivers responded to an in-depth interview (IDI), requiring approximately an hour, by a trained study staff. Interviews were conducted in a private room at the SPARSHA field office or in the participant's home. Permission for taking written notes and digitally recording the conversations were obtained prior to initiating the interviews. Written notes were used for the purpose of grasping main points mentioned besides recording details about participants' characteristics, emotional expressions, body language, as well as interviewers' comments. All the interviews were conducted in Bengali, the native language of the area. A semi-structured interview guide with broad questions aided by open-ended probes was used for this purpose. Questions/issues included in the guide were formulated from the review of relevant literature and probable themes that were anticipated to emerge by the team of investigators on the basis of their prior interaction



with CLH and their caregivers. As suggested by Green and Thorogood(10), it was decided to conduct 40 interviews (20 with caregivers who were biological parents and 20 with those who were not), or till thematic saturation was reached, whichever was lower. Twenty biological parent and 14 non-parent caregivers were thus interviewed.

## ***2.5. Data management and analysis***

Audio recordings of the interviews were transcribed verbatim into *MS Word* in Bengali. The notes taken during interview were used to facilitate the transcription process and to enhance the transcripts by insertion of relevant comments (e.g. mood, emotional status of interviewee etc.). These were also utilized later for content analysis. Electronic transcription for each interview was completed within 24 hours of completion of the interview. The transcripts were then reviewed for preliminary coding by the investigators, before next interview. This process continued till the study team felt that theme saturation had been achieved.(11) The interview transcripts were then imported into Atlas.ti 7.5 package for the purpose of coding and data analysis. At the time of initial readings 'open coding' technique was used, followed by 'axial/thematic coding' during re-readings. The entire coding process was performed on Bengali transcripts, and only relevant quotations were later translated into English. Any disagreement regarding coding were resolved by discussion between study team members. Quotations and codes were grouped according to the perceived themes for further comparison.

## **3. RESULTS**

### ***3.1. Participant characteristics***

The major characteristics of the participants are described in Table 1. Forty eight eligible primary caregivers identified from the SPARSHA roster were approached for participation, among them 34 agreed to be interviewed. The principal reason for refusal to participate was time constraint on the part of the caregivers. Among the 34 participants, 20 were biological parents (19 mothers and one father) of the CLH under their care, while the rest were comprised of grandfathers, grandmothers, uncles and aunts. There was a single case where a both parent orphan male child was being taken care of by a neighbor, who herself was living with HIV. Among participating caregivers, 17 (50%) were living with HIV. Among the CLH, only four were infected by means of blood transfusion received during thalassemia care, and the rest reportedly received the infection through vertical transmission.

### ***3.2. Emerging themes***

The broader themes that emerged from content analysis of the interview transcripts were: a) perceived difficulties around disclosure process, b) rationale for disclosure, c) reluctance to disclose, d) individuals best suited to disclose HIV status to children, and e) approaches to employ for the disclosure process. We could not identify any important differences between perspectives of biological parents and non-parents.

#### ***3.2.1. Perceived difficulties (and their solutions) around disclosure process***

Disclosure of HIV status to their children was like revealing a dark secret about life for many. They were afraid to face questions from children on the topic and were often unsure about the way to answer. Some circumvented the questions, and some

remained ambiguous while answering. Such questions posed quite a challenge to caregivers as revealed through the following verbatims.

**HIV +ve widow and mother of a 9 year old girl.....** *“One day my daughter asked me questions about her disease. She had taken boiled drinking water to school.... and her classmates asked her why she had carried boiled water to school. She told them that her mother was sick and always had boiled water.... and gave her boiled water too. That day she came home and asked me about our disease.... I told her nothing about HIV that day.... I told her that I had skin lesions and got operated and the doctor advised me to drink boiled water.....”*

**HIV +ve mother of an 11 year old boy.....** *“He always asks, ‘Mom, how did we get this disease?’ Kids will always ask such questions. He is afraid of his dad, so it’s me who has to listen (to his questions). He gets all the love from me, his dad drives trucks and doesn’t stay much at home. He lives with me and keeps bothering me with questions. I tell him, ‘I don’t know about diseases, anybody can get any disease’. That’s what I say. ”*

Nevertheless, some caregivers expressed their perceptions and experiences on how external assistance could make discussing HIV easier. Parents who themselves were living with HIV mentioned about various awareness programs and interventions that helped them talk to their children.

**HIV +ve mother of a 14 year old boy.....** *“If they (health care providers) say it instead of mother, or other family members.... That’ll be great, simply great!*

*They can explain it better. We feel scared to tell him about it. I'm saying it because you asked. We feel really scared, I mean we will be hurt during the process. But if they (health care providers) say it, we will give it a thought."*

**HIV +ve widower and father of 11 year old and 14 year old boys.....**

*"When the test results of my sons came positive.....they underwent counselling..... the adults are also instructed (by counsellors) on how to deal with children, besides care and nutritional advice. Then I told them 'see this is the case..... I'm as helpless as you are..... you have this disease.... I have to live with it and you, too'."*

**HIV +ve mother of an 11 year old boy.....** *"The counsellors even told us what to eat, how to stay healthy, when to visit the doctor. They told us to visit the doctor even for any minor cold, cough, sneezing etc.... for whatever little things that may happen to us. We should always visit the doctor. The doctor will take care and we'll become healthy again.... otherwise we may remain sick for long. (They told us) inform kids to make them take medicines (ART).*

**3.2.2. Rationale for disclosure**

Rationale for disclosure of HIV status were presented by study participants from different perspectives. Being guided by the nature of responses, we have grouped them as follows; a) perceived health benefits to self and others, b) anticipation of caregiver's impending death, and c) fear of negative repercussions due to late disclosure.

*Perceived health benefits to self and others*

A commonly perceived benefit of disclosure, as expressed by caregivers, was that knowledge about the disease might motivate children about maintaining their own health. On the aspect of health of the children under their care, most caregivers, who saw disclosure in a favorable light, felt that regular intake of ART (and other medications) was essential for staying healthy. They had the opinion that telling their child about the disease would make them understand the harm that HIV poses, and subsequently would improve their health seeking behavior and motivate them to take the medicines regularly.

**HIV +ve widower and father of 11 year old and 14 year old boys .....**

*“When the drug (ART) started he (elder son) was just eight. If I had not told him about the disease at that time, he would have asked me ‘Why do you make me take the drugs? Why are you taking me there (ART center)?’ It would have been an impossible task without letting him know. So, it’s better to say it at the beginning (after diagnosis).”*

**HIV +ve mother of an 11 year old boy.....** *“In order to make the kids take the drugs(ART), one has to tell them. Once you get started on the drugs, you’ll have to know it (to stay healthy).”*

Participants were also concerned about protecting others from being infected. Most said that it was the responsibility of the persons living with the HIV that they did not accidentally transmit the disease to others, and caregivers of CLH should help the children under their care to achieve that goal. They felt that such knowledge would prepare their cared for children for future so that they can control any behavior that

poses further threat to their health and/or might lead to transmission of disease to playmates or potential partners.

**HIV +ve widower and father of 11 year old and 14 year old boys.....** *“If they are not told, there can be many problems. I have even told them to be careful so that they don’t bruise or cut their limbs while playing, not to quarrel, not to go near sharp objects etc. I have even told them that, ‘If your blood touches someone he/she may get infected, so try to be careful. Don’t scratch or bite anyone’....”*

**HIV –ve aunt of a 13 year old girl.....** *“We could not tell her (niece) yet, but we know we have to. Yes, she might not understand now, but as she has this (HIV) we cannot marry her off to a healthy boy. She also cannot get into an affair with someone. You cannot marry a normal guy, lead a normal life. We have to tell her. It’s our responsibility to see that the infection doesn’t spread.”*

**HIV –ve mother of a 14 year old thalassemic boy.....** *“I think I should inform my child about HIV....and explain to him about the preventive measures... so that he becomes conscious...and could protect himself and others.”*

**HIV +ve neighbor of a 14 year old both parent orphan boy.....** *“I told him bluntly.... ‘You have HIV.... do not get involved with girls..... Why are you late? I will spank you if I get to hear that you are having an affair’..... I always tell him not to look or think about girls.... ‘You should study hard to get a job and become independent, girls should never be your priority” [laughs]*

*Anticipation of caregiver’s death*

Some of the caregivers who themselves were living with HIV often thought about their untimely death. They were worried about the care of the children after their demise. They felt that timely disclosure might provide the children a better chance to live a better and healthier life. Even HIV uninfected but aged caregivers were concerned about the situation of the children after their demise. They were worried that the children under their care would be at a disadvantage, if caregivers did not tell the children about their disease and its implications before their death.

**HIV +ve mother of a 14 year old boy** ..... *“We always think about him (her son). How will he live (after their death)? He is still so young, he has to live for many years. That’s what we discuss, how can he survive for long. Whatever may happen to us, he has to survive.”*

**HIV –ve grandfather of an 8 year old boy**..... *“When he (grandson) comes to know about the virus inside his body, I’m not sure how would he react. But you know, he has to be told someday. However, what would happen if I am not there? He might not understand it now... Everyone else in the family knows about it. But how would he perceive when we tell him? Today he doesn’t know, but he has to know it soon. I have to tell him before I die. This (non-disclosure) can’t go on like this, because we don’t want him to get married and give it to someone else.”*

#### *Fear of negative consequences due to late disclosure*

Interestingly, a few interviewees, usually the biological parents, were worried that if they did not start priming their children about HIV at an early age, there would be negative

repercussions when their children would come to know about the disease status in future. Responses revealed that, if a grown up child was subjected to disclosure, it might be uncomfortable for both the caregiver and the child under care. The caregiver might feel awkward to answer subsequent questions, whereas the child might experience mental trauma.

**HIV +ve widow and mother of an 8 year old girl.....** *“I think parents should inform the kids as early as possible, otherwise when they grow up and come to know, they might ask several questions. Say in my case, if I had not informed her (daughter), she would have definitely questioned me, ‘Why did not you tell me before? You have the same disease, my father died because of this disease, and you did not even bother to inform me?’ Also, she might have asked (uncomfortable) questions, like ‘How did my father get the disease?’ So, it’s always better to tell them (early)”*

**HIV +ve widower and father of 11 year old and 14 year old boys.....** *“It’s better that we tell them at the beginning. You know the thing about their mind..... gradually learning about it (HIV) from an early age may help them mentally. But if they are told when they have become adults, they might be in for a shock. So, if they are told from the beginning, that I have it.....”*

### **3.2.3. Reluctance to disclosure**

Among 34 caregivers participating in in-depth interviews, 16 said that they did not want their cared for children to know about their HIV status in the immediate future. These caregivers were apprehensive about the potential negative consequences following



disclosure. Contextual exploration revealed three main concerns regarding this topic, namely – a) mental stress brought to their cared for children, b) fear that disclosure might cause children to blame biological parents, and c) apprehension about stigmatizing behavior.

*Distress caused by disclosure*

Among the caregivers who were averse to the idea of disclosure to children, the most common reason that came up was that informing about the disease might cause distress to the children. They mentioned several negative consequences of disclosure such as causing sorrow, hopelessness, shame to the children. Because of these concerns, caregivers said they did not want their children to be burdened by unnecessary stress due to disclosure.

**HIV –ve mother of a 12 year old thalassemic boy**..... *“I cannot inform my son about the disease. Why should I? If he comes to know (about the HIV), he would keep thinking about it....that he is sick, that he is not like other kids. Let him grow up and he himself will understand, what this disease means.”*

**HIV +ve mother of a 15 year old girl**..... *“If you ask us, we will say there is no need to say it (disease disclosure). If they get to know it, they will think, ‘We have this disease, we may not live for long’. They will be unnecessarily worried. Thus I would say it’s better not to say it, but she knows it now and we can’t help it.”*

**HIV +ve mother of an 8 year old girl**..... *“See she is a kid, and every kid or even adults doesn’t have the same mindset. Some may get easily upset,*

*whereas some may not... the decision to tell depends on that. If you want to do it the same way for everyone, some may get agitated, 'why did it happen, how did the disease come to me etc'. The family will collapse. Not every children are same. Not every adults are same. So you cannot say to everyone."*

#### *Apprehension about being blamed by children*

Caregivers who were living with HIV and were biological parents of a CLH, were concerned that revelations about the disease and its mode of transmission might alienate them from their children, and the children might hold them responsible for their condition.

**HIV +ve widow and mother of an 8 year old girl.....** *"(Following disclosure) many kids may think that, 'my father was an immoral person or my mother was an immoral person, they are the reason I got this disease'. But they might not understand that this disease doesn't depend on a person's character."*

**HIV +ve mother of a 14 year old boy.....** *"He always says, 'so, you have the disease, but why me, too?'. .... I feel so sorry for him [crying]. Sometime he may say, 'you have this disease, I have this disease, too.... you are solely responsible (for his disease).' "*

However, above concerns did not seem to affect the caregivers of children who were infected through contaminated blood transfusion.

**HIV –ve mother of a 14 year old thalassemic boy.....** *"Some people say that we should not tell our children (about HIV). I do not understand the*

*reason, if I tell him would I turn into a bad person? I would still remain the same human being, and not become some obnoxious animal.”*

#### *Fear about discrimination*

Another concern among the caregivers were fear of discrimination owing to their HIV positive status. They feared that, following disclosure, the children owing to their lack of cognitive maturity might not completely understand the social implications of being infected with HIV. Thus, they might fail to keep it confidential and inadvertently share the information with the uninitiated, resulting in stigmatizing behavior, and even social isolation.

**HIV +ve, separated from husband, mother of an 8 year old boy.....** *“We cannot tell him now, because his mind is not mature enough. He might go around telling people about his disease. Then people may start avoiding him. We have to explain to him so that he doesn't talk about it to anyone.”*

**HIV +ve widow and mother of a 9 year old girl.....** *“The villagers doesn't know much about our disease. And, leave alone the villagers, even the people at the hospital are scared of people like us (HIV +ve). So if I tell my child about this, she would have to live under a scare. Even her friends may treat her badly. Then I don't think she will be able to survive such (discriminating) behavior. That's why I don't want to tell her.”*

#### **3.2.4. Individuals performing disclosure**

Participants suggested about the persons they considered to be most suitable for disclosing HIV status to the children under their care. Our analysis in this area revealed two major sub-themes; a) identifying suitable individuals for disclosure, and b) allowing children to know about their disease by themselves.

#### *Identifying suitable individuals for disclosure*

As table 2 depicts, majority of the caregivers, biological parents and non-parents, felt that health care providers (HCP) were best suited for this job. The principal reasoning behind this choice was that HCPs were much more well-informed about the disease than the caregivers, and they would be able to explain it better. Some caregivers thought that hearing it from the HCPs would hurt the child less. Children paying more attention to a doctor's (or other HCP) advice, compared to anything told by a close person, was cited as another reason.

**HIV +ve mother of an 8 year old girl.....** *“If they (health care providers) say it, or those who are in this field, inform us about how to disclose, I believe it will help... because, we are not sure how to disclose it to kids.”*

**HIV –ve grandfather of an 8 year old boy.....** *“Yes, health workers should be present in the process. They should visit our homes and tell the children. We tell our kids ...but health workers can be more open and say about it in detail...like how the infection spreads....what we should do or not do... I think we should appeal to the local administrators about this service by health workers. These issues should be addressed like.... how it gets transmitted....how we are affected.”*

**HIV –ve aunt of a 14 year old girl....** *“It is better if a medical professional tells her. She may be hurt if I tell her. It would be good if the NGO workers tell her or if the health center people, from the place she goes to get her medicines, tell her.”*

**HIV –ve uncle of an 11 year old girl.....** *“It is better if the doctors tell the children about their HIV. The counsellors or nurses may also tell them. But the children will take the doctors seriously. To me, it is best if the doctors tell them at an early age, because as the doctors are experienced they can explain everything to them properly.”*

Among the rest of the caregivers, most felt that responsibility of disclosure should better be left with the caregivers themselves, or some other family members or friends.

Although they recognized the difficulty associated with it, those caregivers reasoned that they understood their children better than anyone else, and hence were better equipped to handle the disclosure process. Some of these caregivers also appeared to believe that it was solely the obligation of parents living with HIV to share disease related information with their children because it was no one else’s business.

**HIV +ve mother of an 8 year old girl .....** *“No, it’s better that I say it. If anyone else tells her (her daughter) that you have the disease, however good he explains it... if anyone else tells her, I may not like it...she will not like it too. You know it’s always better to hear the bitter truth from your own mother, rather than an outsider.”*

**HIV +ve widow and mother of a 9 year old girl.....** *“I think when children grow up, it is the responsibility of the parents to tell, ‘see, we have such a condition’.*

*We should explain facts about living a healthy life. Take care that they do not transmit HIV to anyone else. That they should take care of themselves. It is the parents' responsibility.”*

Further, there were caregivers who said that they did not have any particular preference regarding the choice of disclosing persons. A non-parent caregiver suggested that even if there was a preference, that could change based on individual scenario.

**HIV +ve neighbor of a 14 year old both parent orphan boy.....** *“I think parents should say it, whenever the time is right....depends on situation, overall mood etc.....Parents have an advantage as they are always around. Whenever they think that it’s a suitable time..... that is if the child is told at that time it may cause less hurt, then they should (say it)..... But in other cases, if parents are finding it difficult, they may have to resort to other options..... Say counselling, or may tell their children through friends that is who have what at their disposal.”*

While describing her ideal scenario of disclosure, a mother of a thalassemic son raised a rare viewpoint. She suggested that children would be more at ease with the big revelation about their disease status if that information was shared by CLH who had been undergoing a similar experience. She thought that such peer to peer information sharing could also help in raising awareness.

**HIV –ve mother of an 8 year old thalassemic boy....** *“My suggestion is that a (positive) kid may tell others (other positive children) that ‘I have got this disease,*

*you should take such and such precautions, so that it doesn't get any worse'. A kid should be able to share that with other kids..."*

#### *Allowing children to know about disease by themselves*

A few caregivers said they would prefer to leave the onus of disclosure on the child under their care. They seemed to think that their school-going children were getting better education than them, and were also more exposed to the outside world. Their children, they thought, were quite capable of learning about the disease by themselves when they would achieve appropriate maturity. Caregivers also suggested that learning on its own could probably lead to better understanding about the disease and its implications.

**HIV +ve mother of an 11 year old boy.....** *"When such kids grow up, they will know by themselves..... they will become aware. Nowadays kids study a lot, they will definitely become aware. All the kids who are on ART have become aware, my kids will know about it, too.*

**HIV –ve mother of an 8 year old thalassemic boy....** *"When he asks, 'Mother, what has happened to me? What disease do I have? How come you don't have it but I have?'" He asks me again and again. I just tell him when you will grow old you will understand yourself.*

#### **3.2.5. Approach towards disclosure process**

Another broad theme that emerged from content analysis was caregivers' perception about the ideal scenario or circumstances favorable to disclosure process. The 'how'

and 'when' of approaching disclosure are captured under two sub-themes; a) suitable environment and way to initiate disclosure, and b) appropriate age of the child.

*Suitable environment and way to initiate disclosure*

Caregivers expressed their thoughts about the way of initiating disclosure process. They also described the environment they considered ideal to initiate dialogue about HIV. Most participants said, in order to make the process easier, they will have to talk to children like a friend.

**HIV +ve widow and mother of a 9 year old girl.....** *“At that time (during disclosure related discussion) mother has to become a friend to her daughter. It doesn't matter whether it's a son or daughter, she has to interact like a friend while saying it. Do it when both of you are healthy, and maintain your cool during the process.”*

**HIV +ve, separated from husband, mother of an 8 year old boy.....** *“One has to treat them like a friend and discuss about the disease. Then the child will easily understand and the mother would feel relaxed, too. '(Child) my mother has told me that I have this disease and she also asked me to be careful (not to transmit) in future.’ “*

Widowed mothers who had got the infection from their husbands and mothers whose children were infected from contaminated blood transfusion, opined that blaming the father or contaminated blood might help them talk about HIV.



**HIV +ve mother of an 11 year old boy.....** *“I’ll tell him.... I have to take him into confidence first by saying that ‘I did not do it to you, it (infection) has come from your dad. You can’t undo whatever has happened, but you need to undergo treatment.’ That’s how it should be explained (to her son).”*

**HIV –ve mother of an 8 year old thalassemic boy.....** *“When I’ll tell him (about the disease) for the first time I’ll say, ‘see you have got the disease from the blood that you received (for thalassemia)’. He might ask, ‘how come I have the disease but you don’t?’ I’ll reply that it came through blood, and nobody can help it.*

Regarding the environment at the time of disclosure, some interesting opinions came up during the interviews. An aunt of a CLH commented that it was better to undertake disclosure during evening as it was the time of the day when kids were more likely to be calmer. A mother said that her assignment to disclose was helped by television commercials on HIV awareness.

**HIV –ve aunt of a 14 year old girl.....** *“One should sweetly ask them to sit in the evening, and say that ‘you have this disease, try to take care of yourself’. He will understand better if told in the evening. Your mind can be diverted by other things during the day, while you are more likely to be at peace in the evening.”*

**HIV +ve mother of an 8 year old girl.....** *“The commercial (HIV awareness) that comes on TV..... that’s what I mean... (I told her) that ‘you have*

*the same disease, take care of yourself, eat properly'. That's how I can make her understand easily."*

### *Appropriate age of child*

Overall, age of the child emerged as the most common, and also probably the most important, factor that determined caregiver's decision about disclosure. There was consensus among the caregivers who were yet to tell their children about HIV that disclosure should come only after the child had reached a certain age, or when they had, apparently, attained maturity. When the topic of appropriate age of disclosure came up during interviews, many participants provided an age range, instead of specific age. Some participants replied that disclosure should be initiated when the children could understand about HIV/AIDS, without referring to any particular age (vide table 3).

**HIV –ve grandfather of 10 year old orphan boy.....** *"He should be informed when his age..... when he becomes mature, only then he should know. It's good to tell him then, maybe I'll do that. I see no reason to tell him before that. It (disclosure) should be done when they grow up."*

Others shared their thoughts about the age at which they believed their child would become mature, and concurrently become eligible for disclosure.

**HIV +ve widow and mother of a 9 year old girl.....** *"It is our (parent's) responsibility to disclose about the disease when they turn 12 years old, because at twelve, I think, she would be mature enough to understand."*

**HIV +ve mother of an 8 year old girl.....** *“Whenever she achieves the capacity to understand. There is no point explaining (to her) now. Whenever she gets to standard 5 or 6 (in school), maybe she can understand a bit... When they study in standard 5 or 6 or 7 or 8. You know, those studying in standard 5 or 6 develop some understanding, when they are at least 12 to 13 years old..... she doesn't understand much at this moment.”*

**HIV +ve mother of a 14 year old boy.....** *“I think one should tell about it after 18 - 19 years age. Before that they don't understand what is happening in their body. He (her son) had been exposed to so much talk (at health facility) about CD4 count. As a 14 - 15 year old kid, I don't think he understands any of that. ‘What am I suffering from, why have I come here (for CD4 testing)’, he understands nothing.”*

A number of caregivers wanted to delay disclosure till the child reached marriageable age or might start seeking a partner. As mentioned previously, caregivers were aware about the risk of inadvertent sexual transmission if their children were kept oblivious about the hazards posed by HIV, and they wanted to disclose about HIV status as a preventive measure when the children reached reproductive age.

**HIV +ve widow and mother of a 15 year old girl.....** *“I will let her know when she is of marriageable age. If we could find a suitable boy with HIV (for her daughter's marriage)..... I am a mother, too. She (daughter) has this disease, but I cannot let her infect others. So, if we come across such a boy (HIV*

*infected), we will consider marriage. It (disclosure) should be told at the age of marriage.”*

**HIV –ve grandfather of an 8 year old boy.....** *“This disease..... when he is of age of 16-17-18, then there will be chance that he might transfer it to others. Then I’ll tell him, ‘you can’t do it, you should know about prevention’. I’ll have to think over it then. At that time, it will be good to tell (disclosure) him. Saying it now.... I mean, when you have to talk about sex, the kid may start trying different things.... Telling him will be right. Saying it before will weaken his mind, may traumatize his mind. If I say it after another 8-10 years, when he can understand..... can think of different things..... That’s why I’m not making an effort to let him know.*

#### **4. Discussion**

Disclosure of HIV status to children is an emotional affair, both for the caregiver and concerned child. This is especially true for a developing nation like India, where anticipation of stigma often prompts HIV-infected individuals to keep their diagnosis secret.(12) Further, if children and adolescents living with HIV are not informed systematically about their disease status they might remain unprepared for an uncertain future. It has been reported that non-disclosure can undermine efforts to reduce discrimination, make the child secretive, hamper formation of health-seeking behavior, and even increase the possibility of accidental sexual transmission.(13) Thus, current consensus is, if done in an age-appropriate way and followed as a continuing process

rather than a one-off interaction, disclosure of disease status is likely to be beneficial for both CLH and their caregivers.(14)

Findings of the current study reveal the multilayered context surrounding the issue of disclosure of HIV status to children. In terms of rationale pertaining to disclosure, a number of perceived benefits were cited by caregivers, and they aimed to obtain those benefits for themselves and their children through disclosure. Improved treatment adherence was an important perceived benefit that motivated caregivers towards disclosure. This is similar to findings from other resource-limited settings.(15) However, the association between children's awareness about their own disease status and medication adherence have been reported to be inconsistent.(16) As reported in studies from resource-limited settings,(17, 18) other positive goals about disclosure included willingness to protect healthy individuals from getting infected, and perceived immunity from souring of caregiver-child relationship due to late disclosure. Similar to a Chinese study,(19) caregivers who were expecting impending death felt it was their responsibility to reveal the disease status to their children in order to better prepare them for the future. As has been suggested by others,(20) caregivers in India and other similar settings probably assume that in the unfortunate event of their death, they may miss the chance to communicate to their children, and, thus, may deny him/her potential sources of future support.

Another dimension of our finding was related to emotional and cognitive barriers that might prevent caregivers from supporting disclosure. Perceived immaturity of the child that makes him/her unable to understand the information shared about HIV, was considered a major cognitive barrier. However, this indicates that caregivers probably

conceive disclosure as a single-time event rather than an ongoing and evolving process. As have been suggested in the literature, the results of such one-time disclosure is often unsatisfactory, as a child needs to assimilate a lot of new knowledge and probably has to deal with whatever prior understanding he/she had – often leading to confusion, isolation, and depression.(21) Thus, any programmatic intervention on systematic disclosure to children should be recommended as a continuum rather than a single event.

There was no consensus among participants regarding the appropriate age of disclosure, which is similar to what has been suggested by a recent review.(22) Overall, in the current study, biological parents were found to favor earlier (i.e. at or before early teen age) than non-parents. Although a prior study from India(7) reported that mid-teenage was the preferred age of disclosure, we did not find any age-group that was clearly favored by caregivers. Interestingly, age of the child came up as both facilitator and barrier of disclosure. Some caregivers, mostly biological parents, reasoned that children should be primed about their disease status from an early age as late disclosure might lead them to blame parents. On the other hand, as mentioned earlier, many considered immaturity related to younger age a barrier for HIV status disclosure. In the Indian scenario, frank communication between caregivers and child is often absent, and it is unlikely to be different for a sensitive issue like HIV. Thus, it is essential to develop context-specific interventions that endorse communication about the disease that take into account the child's age or developmental maturity, domestic environment and cultural factors, as has been suggested by Wiener et al.(4) In order to facilitate the communication process, studies from other resource-limited settings have proposed

that any such planned intervention need to reflect the nuances of the communication process within families.(23) As the age of child has been reported to be an essential element, the formulation of age- and culture-sensitive guideline on nature and content of communication is an absolute necessity for such intervention to be effective.(24)

Caregivers expressed a number of fears, personal and societal, as hindrances for opening up to the child. On a personal level, they feared that disclosure might cause unwanted psychological stress to the child. While it is likely that some caregivers spoke from their personal experiences, published literature does not substantiate the caregivers' concerns. It has been suggested that although children might suffer an initial setback after being informed about their HIV status, possibilities of any long term psychological adverse effects e.g. depression, behavioral problems are not greater for CLH who have undergone disclosure than those who were yet to be informed.(21, 23, 25, 26) At the other end of the fear spectrum, some HIV-positive parents reported their concern that they might be subjected to emotional backlash from the child, who may end up blaming the parents for their condition. Many parents, thus, considered themselves guilty, and expressed their inability to discuss HIV with their children out of this fear of repercussion. As has been suggested by Chew et al,(18) this issue of self-blaming might be more pronounced in Asian scenario, where parents are expected to assume a central and protective role in the family. Thus, it is important to implement interventions helping caregivers to come to terms with their own HIV status and relationship to their children, in order to improve the likelihood of disclosure to children.

There was also widespread concern that the caregiver and/or child might be subjected to discrimination in case the concerned child, due to his/her lack of understanding of the

implications, revealed the new found information to others. This finding was in agreement with that which had been reported from various studies conducted in different settings.(15, 19, 27) It has been suggested in other studies conducted in Asian setting that caregiver's often feared that they might lose their reputation or social status, if the concerned child inadvertently told others about their diagnosis.(18) We maintain, as has been recommended by others, that national HIV programs should address apprehensions about discriminatory behavior and psychosocial impact, before embarking on interventions related to disclosure.(15)

Interview excerpts reveal that health care providers were mentioned by most caregivers as their preferred choice for the disclosing person, which is in contrast to previous findings from India(7) and China(19) that reported parents/caregivers as primary choices. The principal reason cited behind this choice was that their wider knowledge about the disease made the HCPs better equipped to perform disclosure. It can be reasoned that low educational level of our study participants, with about 90% being educated only up to the primary school level or lower, led them to such 'disease centric' choice for disclosing person. Informal caregivers were favored as disclosing persons by those who felt that they 'understood their children best', and those HIV-infected caregivers who thought sharing disease status and related information as their 'duty'. A number of caregivers wanted to take the 'evasive route' by leaving the onus of knowing about HIV status to children themselves. The presence of a policy gap on the issue of health care providers' assistance to informal caregivers about disclosure has been identified in many studies, according to a recent review on childhood disclosure.(22) We suggest that this area be addressed through future operational research. Being



prompted by the varied context-specific findings revealed in this research, we propose that the ongoing HIV prevention and care program in India should provide multi-component strategies for disclosure of HIV status to children.

Several possible limitations might limit the scope of interpretation of the findings in this study. Although we interviewed 34 primary caregivers (20 parents and 14 non-parents), which may be considered adequate based on the broader categorization,(10) some demographic categories could be considered under-represented. Among the parent caregivers only one out of twenty was the father (widower) of an infected child, making the mother's perspectives dominant in our findings. However, this was not an unexpected occurrence as local cultural beliefs dictate that it is the mothers' duty to look after her children, whether the father and other senior family members are alive or not. In addition, non-parent caregivers participating in this study were a heterogeneous population, with representation from a diverse group comprising of grandparents, uncles, aunts, and even neighbors. As number of interviews from each group were small, it could not be assessed whether opinions varied among different groups of non-parent caregivers. Moreover, in terms of broader representativeness, the participants were recruited through a CBO that provided various preventative and awareness services to adults and children living with HIV. In the Indian scenario, recipients of such services mostly belong to the lower socio-economic strata of the society. Low educational level among participants of the current study corroborate the above. Thus, we cannot assume that our study participants were representative of the caregivers of CLH from all strata of society.

However, capturing the perception of both parent and non-parent caregivers was a major strength of this study, as prior studies from Asian settings often restricted themselves to parental opinion only.(17-19) A caregiver's perception about his/her child's quality of life might depend on the health related condition of him/herself. Interviewing both kinds of caregivers (biological parents and non-parents) helped us explore differing concerns that these caregivers had about the CLH under their care. Further, not all caregivers participating in this study cared for children who were perinatally infected, some of them had children who got infected through contaminated blood transfusion. Thus, it was possible to record the disclosure related perceptions of a varied group of caregivers. Additionally, CLH and their caregivers were recruited from the community through a local CBO, and interviews were conducted in an informal setting - either at home or field office of the CBO – with which the participants had been previously familiar. As recruitment and interviews were conducted away from hospital or treatment settings, we believe, interviewees could 'open-up' as they did not fear any negative consequences on treatment or discriminatory behavior based on what they said.

The above limitations notwithstanding, the current research, to the best of our knowledge, is the first one in India to qualitatively explore caregivers' perception about diagnosis disclosure to CLH, and, thus, may inform policy making in this regard. Several organizations such as WHO and Medecins Sans Frontieres have suggested frameworks on disclosure of HIV status to CLH.(5, 6) There are also guidelines from different countries, with culturally appropriate recommendations regarding the process.(28, 29) However, as with other resource-limited settings,(30) there is paucity of

context-specific paradigms in India and a standardized, age-appropriate procedure for disclosure is rarely followed. This study is in agreement with the existing literature that any intervention on the issue of childhood disclosure of HIV demand a multifaceted approach and should not only consider the disease but also take the entire family/social structure into account.

## 5. TABLES

**Table 1. Characteristics of caregivers and children under their care (n = 34).**

| <b>Characteristic</b>                    | <b>Frequency</b> | <b>%</b> |
|--|------------------|----------|
| <i>Caregiver's age (in years)</i>        |                  |          |
| 21–30                                    | 9                | 27       |
| 31–40                                    | 15               | 44       |
| 41–50                                    | 2                | 6        |
| 51–60                                    | 4                | 12       |
| 61–70                                    | 4                | 12       |
| <i>Caregiver's gender</i>                |                  |          |
| Male                                     | 6                | 18       |
| Female                                   | 28               | 82       |
| <i>Caregiver's relation to the child</i> |                  |          |
| Biological parents                       |                  |          |
| Mother                                   | 19               | 56       |
| Father                                   | 1                | 3        |
| Other than biological parents            |                  |          |
| Grandmother                              | 5                | 15       |
| Grandfather                              | 3                | 9        |
| Aunt                                     | 2                | 6        |
| Uncle                                    | 3                | 9        |
| Neighbor                                 | 1                | 3        |
| <i>Caregiver's educational status</i>    |                  |          |
| Illiterate                               | 5                | 15       |
| Literate but no formal education         | 9                | 27       |
| Primary                                  | 16               | 47       |
| Secondary or higher                      | 4                | 12       |
| <i>Caregiver's HIV status</i>            |                  |          |

|            |    |    |
|------------|----|----|
| Infected   | 17 | 50 |
| Uninfected | 17 | 50 |

*Age (in years) of under care CLH*

|       |    |    |
|-------|----|----|
| 8–12  | 19 | 56 |
| 13–15 | 15 | 44 |

*Mode of transmission to under care CLH*

|                   |    |    |
|-------------------|----|----|
| Vertical          | 30 | 88 |
| Blood transfusion | 4  | 12 |

*Gender of under care CLH*

|        |    |    |
|--------|----|----|
| Male   | 21 | 62 |
| Female | 13 | 38 |

*Under care CLH taking ART*

|     |    |    |
|-----|----|----|
| Yes | 19 | 56 |
| No  | 15 | 44 |

**CLH - Children living with HIV**

**Table 2. Choice of disclosing person**

|                                      | Parents (%) | Non-parents (%) | Total (%) |
|--------------------------------------|-------------|-----------------|-----------|
| HCP                                  | 9 (45)      | 6 (43)          | 15 (44)   |
| Caregiver/close persons              | 4 (20)      | 2 (14)          | 6 (18)    |
| Know by him/herself                  | 2 (10)      | 1 (7)           | 3 (9)     |
| HCP or close persons                 | 1 (5)       | 1 (7)           | 2 (6)     |
| HCP or know by him/herself           | 2 (10)      | 3 (21)          | 5 (15)    |
| Close persons or know by him/herself | 1 (5)       | 1 (7)           | 2 (6)     |
| HCP or other kids                    | 1 (5)       |                 | 1 (3)     |

**Table 3. Suggested age for disclosure**

|  | Parent (%) | Non-parent (%) | Total (%) |
|--|------------|----------------|-----------|
| Early teenage or before ( $\leq 15$ years) | 7 (35)     | 5 (36)         | 12 (35)   |
| Late teenage /adulthood ( $>15$ years)     | 4 (20)     | 7 (50)         | 11 (32)   |
| Whenever the child can understand          | 9 (45)     | 2 (14)         | 11 (32)   |

## 6. REFERENCES

1. Treatment of children living with HIV: World health Organization; [November 15, 2014]. Available from: <http://www.who.int/hiv/topics/paediatric/hiv-paediatric-infopage/en/>.
2. NACO Annual report, 2013-14. India: 2013-14.
3. Vreeman RC, Scanlon ML, Mwangi A, Turissini M, Ayaya SO, Tenge C, et al. A cross-sectional study of disclosure of HIV status to children and adolescents in western Kenya. PLoS ONE. 2014;9(1):e86616. Epub 2014/01/30. doi: 10.1371/journal.pone.0086616. PubMed PMID: 24475159; PubMed Central PMCID: PMC3903588.
4. Wiener L, Mellins CA, Marhefka S, Battles HB. Disclosure of an HIV diagnosis to children: history, current research, and future directions. J Dev Behav Pediatr. 2007;28(2):155-66. Epub 2007/04/17. doi: 10.1097/01.DBP.0000267570.87564.cd. PubMed PMID: 17435473; PubMed Central PMCID: PMC2440688.
5. Chazal E. Therapeutic education: recommendations regarding disclosure of HIV status to children under ARV in MSF projects. Paris: Medecins Sans Frontieres. 2005.
6. Organization WH. Guideline on HIV disclosure counselling for children up to 12 years of age. 2011.

7. Arun S, Singh AK, Lodha R, Kabra SK. Disclosure of the HIV infection status in children. *Indian J Pediatr.* 2009;76(8):805-8. Epub 2009/10/06. doi: 10.1007/s12098-009-0177-z. PubMed PMID: 19802549.
8. Bhattacharya M, Dubey AP, Sharma M. Patterns of diagnosis disclosure and its correlates in HIV-infected North Indian children. *J Trop Pediatr.* 2011;57(6):405-11.
9. Panda S, Das RS, Maruf SKA, Pahari S. Exploring Stigma in Low HIV Prevalence Settings in Rural West Bengal, India: Identification of Intervention Considerations. *Journal of Mixed Methods Research.* 2014. doi: 10.1177/1558689814535843.
10. Green J, Thorogood N. *Qualitative methods for health research*: Sage; 2013.
11. Corbin J, Strauss A. *Basics of qualitative research: Techniques and procedures for developing grounded theory*: Sage; 2008.
12. Bailey A, Darak S. *Spaces of Disclosure and Discrimination: Case Studies from India. Stigma, Discrimination and Living with HIV/AIDS*: Springer; 2013. p. 229-45.
13. Kohrt B, Wiener L, Pao M. Psychosocial issues in children infected/affected with HIV. In: Lala MM, Merchant RH, editors. *Principles of Perinatal and Pediatric HIV/AIDS*. India: Jaypee Brothers Medical Publishers (P) Ltd; 2012. p. 573-85.
14. Watermeyer J. 'Are we allowed to disclose?': a healthcare team's experiences of talking with children and adolescents about their HIV status. *Health expectations : an international journal of public participation in health care and health policy.* 2013. Epub 2013/10/12. doi: 10.1111/hex.12141. PubMed PMID: 24112299.
15. Vreeman RC, Gramelspacher AM, Gisore PO, Scanlon ML, Nyandiko WM. Disclosure of HIV status to children in resource-limited settings: a systematic review. *Journal of the International AIDS Society.* 2013;16:18466. Epub 2013/05/30. doi: 10.7448/ias.16.1.18466. PubMed PMID: 23714198; PubMed Central PMCID: PMC3665848.

16. Simoni JM, Montgomery A, Martin E, New M, Demas PA, Rana S. Adherence to antiretroviral therapy for pediatric HIV infection: a qualitative systematic review with recommendations for research and clinical management. *Pediatrics*. 2007;119(6):e1371-83. Epub 2007/05/30. doi: 10.1542/peds.2006-1232. PubMed PMID: 17533177.
17. Liamputtong P, Haritavorn N. To tell or not to tell: disclosure to children and family amongst Thai women living with HIV/AIDS. *Health promotion international*. 2014. Epub 2014/07/19. doi: 10.1093/heapro/dau057. PubMed PMID: 25034726.
18. Chew J, Beng AL, Mun S. Parental concerns about disclosure of a child's HIV/AIDS status in Singapore. *Soc Work Health Care*. 2012;51(1):5-21.
19. Qiao S, Li X, Stanton B. Practice and perception of parental HIV disclosure to children in Beijing, China. *Qual Health Res*. 2014;24(9):1276-86. Epub 2014/08/01. doi: 10.1177/1049732314544967. PubMed PMID: 25079498.
20. Mothi SN, Swamy VH, Lala MM, Karpagam S, Gangakhedkar RR. Adolescents living with HIV in India - the clock is ticking. *Indian J Pediatr*. 2012;79(12):1642-7. Epub 2012/11/15. doi: 10.1007/s12098-012-0902-x. PubMed PMID: 23150229.
21. Kiwanuka J, Mulogo E, Haberer JE. Caregiver perceptions and motivation for disclosing or concealing the diagnosis of HIV infection to children receiving HIV care in Mbarara, Uganda: a qualitative study. *PLoS ONE*. 2014;9(3):e93276. Epub 2014/03/29. doi: 10.1371/journal.pone.0093276. PubMed PMID: 24667407; PubMed Central PMCID: PMC3965550.
22. Pinzon-Iregui MC, Beck-Sague CM, Malow RM. Disclosure of their HIV status to infected children: a review of the literature. *Journal of tropical pediatrics*. 2013;59(2):84-9. Epub 2012/10/17. doi: 10.1093/tropej/fms052. PubMed PMID: 23070738; PubMed Central PMCID: PMC3693505.

23. Vaz LM, Eng E, Maman S, Tshikandu T, Behets F. Telling children they have HIV: lessons learned from findings of a qualitative study in sub-Saharan Africa. *AIDS patient care and STDs*. 2010;24(4):247-56. Epub 2010/04/20. doi: 10.1089/apc.2009.0217. PubMed PMID: 20397899; PubMed Central PMCID: PMC2864057.
24. Kajubi P, Whyte S, Muhumuza S, Kyaddondo D, Katahoire AR. Communication between HIV-infected children and their caregivers about HIV medicines: a cross-sectional study in Jinja district, Uganda. *Journal of the International AIDS Society*. 2014;17:19012. Epub 2014/07/10. doi: 10.7448/ias.17.1.19012. PubMed PMID: 25005046; PubMed Central PMCID: PMC4087168.
25. Lester P, Chesney M, Cooke M, Whalley P, Perez B, Petru A, et al. Diagnostic disclosure to HIV-infected children: how parents decide when and what to tell. *Clinical child psychology and psychiatry*. 2002;7(1):85-99.
26. Riekert KA, Wiener L, Battles H. Prediction of psychological distress in school-age children with HIV. *Children's Health Care*. 1999;28(3):201-20.
27. Vaz LM, Maman S, Eng E, Barbarin OA, Tshikandu T, Behets F. Patterns of disclosure of HIV-status to infected children in a sub-Saharan African setting. *Journal of developmental and behavioral pediatrics: JDBP*. 2011;32(4):307.
28. South to South. Disclosure process for children and adolescents living with HIV: practical guide. 2010 November 19, 2014. Available from: [http://sun025.sun.ac.za/portal/page/portal/South\\_to\\_South/uploads/FXB%20DISCLOSURE%20PROCESS%20PRAC%20GUIDE.pdf](http://sun025.sun.ac.za/portal/page/portal/South_to_South/uploads/FXB%20DISCLOSURE%20PROCESS%20PRAC%20GUIDE.pdf).
29. Disclosure of illness status to children and adolescents with HIV infection. American Academy of Pediatrics Committee on Pediatrics AIDS. *Pediatrics*. 1999;103(1):164-6. Epub 1999/01/26. PubMed PMID: 9917458.



30. Oberdorfer P, Puthanakit T, Louthrenoo O, Charmsil C, Sirisanthana V, Sirisanthana T. Disclosure of HIV/AIDS diagnosis to HIV-infected children in Thailand. *J Paediatr Child Health*. 2006;42(5):283-8.

# **Chapter IV: Life around HIV in West Bengal, India: perceptions of children living with the virus and family members caring for them**

## **1. INTRODUCTION**

Under-15 children constitute about 7% of India's approximately 2.1 million people living with HIV (PLH).(1) Nationwide scale-up of ART, coupled with earlier diagnoses have made it possible for an increasing proportion of children living with HIV (CLH) to move into adolescence and adulthood. This, however, poses newer challenges for the limited health resources India has at its disposal. The major focus of India's HIV program has been 'treatment-centric' i.e. improving access to ART and other medical care for the infected. Although importance of families and informal caregivers in providing care and support to PLH has been highlighted in the literature,(2, 3) interventions centered on families, which consist of HIV-infected individuals, have been found wanting. This assumes a greater importance for the CLH, as informal caregivers are often their only hope for healthy living.(4) As has been recognized since an early stage of the epidemic, HIV infection does not only cause pathological disease but also leaves an impact on the psyche of the infected individuals.(5) Informal caregivers, who are most often members of the family that CLH belongs to, help these children face various psychosocial challenges associated with HIV/AIDS, besides determining their access to medical care. Compared to healthy children of their age, CLH, especially those from resource-limited settings, face an array of hindrances in their daily lives including frequent bouts of various ailments, hospitalization and poor attendance in schools.(6, 7) Besides physical obstacles such as below-average build, delayed puberty, dermatological manifestations

etc.,(6) these children often face the risk of various psychosocial and behavioral problems.(8, 9) The emotional impacts arising from HIV infection of a child are not limited only to the concerned CLH, but also affect the caregiver of the child. Caregivers, whether infected or not, face enormous stress in the process of raising such children, and may need emotional and social support themselves.(10) Thus, assessing how such families, comprising of CLH and their caregivers, deal with the adverse psychosocial, behavioral and economic influences of HIV turn out to be vital from the perspective of HIV care and support programs.(11)

In south-east Asia, several studies have recorded the experiences and perceptions of CLH and their caregivers, and have tried to assess the impact of pediatric HIV, irrespective of the HIV status of caregivers, on the family as a whole.(8, 12) In the Indian context Nyamathi et al conducted a qualitative inquiry(13) on the perception of mothers living with HIV, but exploration of caregiving experiences and concerns from the perspective of CLH and their caregivers is rare. The goal of the current study is to understand the psychosocial needs associated with caregiving for CLH by qualitatively exploring the experience, knowledge, apprehension and perception of caregivers and CLH about their life situations. The study findings will inform India's HIV program improving the quality of life for CLH through implementation of newer interventions and improvement of existing service provisions.

## **2. METHODS**

### ***2.1. Study setting***

Participants in this study were eight to fifteen years old children living with HIV and their caregivers, residing in the districts of Purba Medinipur and Paschim Medinipur, West Bengal. Reaching to the study population was facilitated by a community based organization (CBO) named 'Society for Positive Atmosphere and Related Support to HIV/AIDS' (SPARSHA), which have been conducting various care and support programs for children and adults living with HIV since 2000. This organization is composed of and managed by people living with HIV and their friends (PLWHAF). A registry of CLH and their principal caregiver, created by SPARSHA, residing in the two study districts was accessed to identify potential participants, who were then contacted by the outreach workers. The principal caregivers were requested to attend in-depth interviews (IDI), and also to allow the CLH under their care to participate in a focus group discussion (FGD). While all the FGDs were held at the local field offices of SPARSHA, IDIs were conducted either at the participant's home or the field office, depending on the participant's preference.

## ***2.2. Ethical approval***

The study was approved by the institutional review board (IRB) of the University of California, Los Angeles and the institutional ethics committee (IEC) of the National Institute of Cholera and Enteric Diseases (under Indian Council of Medical Research), the collaborating research institute located in Kolkata, West Bengal.

## ***2.3. Participants***

Eligibility criteria for principal caregivers were: i) being the primary person (caregiver) looking after the needs of (one or more) CLH aged 8-15 years , ii) adult ( $\geq 18$  years), iii) living in the same household as the concerned child, iv) being a native language

speaker, and v) physically and psychologically able and willing to provide informed consent. Caregivers of institutionalized children, or children who spent  $\geq 2$  weeks/month or  $\geq 6$  months/year away from the caregiver, were not considered. Experiences gathered from previous work by SPARSHA suggested presence of single parent and both parent orphans living with HIV in the study area. Thus, we recruited both - caregivers who were biological parent and those who were not. Participating children were assessed for their eligibility of participation in FGD using the following criteria: i) being diagnosed with HIV at a center approved by the West Bengal State Aids Prevention & Control Society (WBSAPCS), ii) 8 -15 years age, iii) not being previously diagnosed with a disorder that would prevent the participating child from responding rationally to the questionnaire (such as psychiatric, neurologic or developmental disorders, but not limited to them), iv) consent from the accompanying caregiver to participate, v) verbal assent from the child. No gender specific criteria were used to determine eligibility - either for the caregivers or children.

#### ***2.4. Data collection***

Informed consent was sought from caregivers regarding IDI and also for allowing their children to participate in FGDs. In addition verbal assent was obtained from CLH taking part in FGDs. In-depth interviews with caregivers, and FGDs with children were conducted using semi-structured guides focusing on the following areas; general understanding about physical and mental health, issues related to illness perception, key areas affecting quality of life, apprehension(s) and strategies to cope with them, and attitude towards available health services. Twenty biological parents and 14 non-parent caregivers were interviewed and four FGDs were carried out – two each involving CLH

aged 8-12 years and 13-15 years. Within each age-group, one FGD involved CLH who were on ART, whereas the other one had participants who had not started ART.

Interviews and FGDs, held from July to September, 2014, were conducted in Bengali, native language of the area.

### ***2.5. Data management and analysis***

Audio recordings of interviews and group discussions were transcribed verbatim into *MS Word* in Bengali. The notes taken during IDIs/FGDs were used to facilitate the transcription process and to enhance the transcripts by insertion of relevant comments (e.g. mood, emotional status of interviewee etc.). These were also utilized later for content analysis. The transcripts were then imported into Atlas.ti 7.5 package for the purpose of coding and data analysis. At the time of initial reading we reviewed the transcripts line-by-line to identify distinct concepts from the data and create codes. During subsequent readings, we connected and categorized the identified codes (axial coding). The entire analysis was conducted in Bengali. We only translated some relevant quotations to English during final phase of analysis. Disagreement between study team members regarding the codes were settled through discussion.

## **3. RESULTS**

### ***3.1. Participant characteristics***

Major characteristics of the participants have been described in chapter I. In short, among the 20 parent caregivers 19 were mothers, whereas non-parent caregivers consisted of grandfathers, grandmothers, uncles, aunts and neighbors. Among the children participating in FGDs, all but one were infected through vertical transmission. A

12 year old thalassemic male child received HIV from contaminated blood transfusion. Among FGD participants, 11 (58%) CLH were single parent orphans, while both parents of three (16%) children had either expired or abandoned their family.

### **3.2. Emerging themes**

Findings from content analysis of IDIs and FGDs were organized into two major categories; a) issues shared by caregivers and children, and b) issues mentioned only by caregivers.

#### **3.2.1. Common concerns shared by caregivers and children**

Common themes that emerged from content analysis of the interview and group discussion transcripts were; i) concerns associated with being sick, ii) essentiality of taking medications, iii) HIV-related discrimination, iv) health as a state of mind, and v) available health services – satisfaction and grievances.

##### **3.2.1.1. Concerns associated with 'being sick'**

Perceptions and experiences related to living with a 'grave' disease were captured under two subthemes – a) suffering from a chronic/debilitating disease, and b) death or disability related concerns.

##### *Suffering from a chronic/debilitating disease*

Many caregivers and CLH categorized HIV as a serious health concern, and many considered that the children (and sometimes the infected caregiver) might never lead a 'normal' life again. Although the participants admitted that they might not always have symptoms, in general, they understood the chronic nature of the disease and

considered their health to be inferior to those without HIV. Participants also felt that HIV would take away one's ability to work.

*"In terms of health, I can give them (his sons) up to 6-7 (out of 10). I'm saying this as I have seen my kids. We say that we are okay, but we can never say we are healthy. We are good at this moment but can become sick any moment. Even a slight mistake can make us sick.".....* **[HIV +ve father of 11 year old and 14 year old single parent orphan boys, IDI-1]**

*"If you ask about her health..... she is completely healthy, barring a few minor things. Still I would give her 7 out of 10 (on health), I would take 3 away as she has this disease, she has the virus! I can't say she is absolutely healthy. She can be down with illness any moment. As she has this disease, she cannot be as healthy as others.".....* **[HIV -ve uncle of 11 year old both parent orphan girl, IDI-31]**

*"If an adult gets it, he can't work any longer. This disease can also cause so many other types of damages....."* ..... **[HIV +ve 14 year old single parent orphan boy, FGD-3]**

The concerns were more pronounced for caregivers whose children had been suffering from another serious illness along with HIV. They shared their experiences of caring for a CLH who suffered from opportunistic infection like TB, or a blood disorder such as thalassemia.

*"(Narrating the ordeal faced by the child) The thing I dread most.... only HIV was still okay.... but when he (the boy) got TB, too..... Oh...such terrible memories!*



*It was so painful. He had to take so many drugs.... visits to TB center. There can't be anything worse than glandular TB! Doctors would insert a big needle to take sample! I felt so afraid about it. Normally, if you get sick you can get cured quickly by medicines, but if it's TB.....".....* **[HIV +ve neighbor taking care of a 14 year old both parent orphan boy, IDI-27]**

*"Then (following repeated blood transfusion) the doctor advised for HIV blood test.... he got HIV. It was so shocking! He was already receiving blood for thalassemia, and now this! How can even God save him? How will he survive with so much pain?".....* **[HIV –ve mother of a 14 year old thalassemic boy, IDI-16]**

On the other hand there were others who had an optimistic outlook about HIV, and said that they didn't worry about their children being infected with HIV. These respondents felt that being diagnosed with HIV should not be emphasized more than it deserved, and one's HIV status should not deter them from carrying out their regular activities. There was also a rare viewpoint from a caregiver living with HIV that the disease could not be considered the worst possible one. This particular caregiver opined that her condition could have been worse had she been diabetic.

*"Once you are born, you have to die someday. The drug (ART) has really helped us have a healthy life... so what's the worry? Others are dying from cancer, sugar (diabetes). If you have sugar (diabetes), there are so many restrictions.... can't eat this, can't eat that! This HIV disease ..... other than this thing between husband and wife, we don't have to worry about anything else. Just take your*

*daily medications, and you're fine! Keep eating whatever you like.... even deep fried snacks, samosas... everything. Those suffering from sugar (diabetes) can't eat things like sweets, potatoes and so many other things. They crave for those foods, still can't eat. We are much better."..... [HIV +ve mother of 8 year old girl, IDI-17]*

*"Health means having an active mind..... (like) having funny chat with others. We have come so far only because we are healthy..... you got to have a sound mind to be healthy, so we keep stress away! See, we have this disease (HIV) ..... all 3 of us (parents and son) .... we never think that we are ill by any means. We have never thought about being ill for past two years.... since our diagnosis."..... [HIV +ve mother of 11 year old boy, IDI-6]*

Respondents also shared their experiences and perceptions about coping with HIV. They mentioned several internal and external supports that they felt had helped them deal with their condition better. While some replied only God's grace could see them through the crisis, others mentioned about various external assistance – emotional and financial - that they considered vital.

*"I wish that she (daughter) leads a healthy life.... happy life. Whatever happened.... happened. I leave it to God to give us a beautiful future"..... [HIV +ve mother of single parent orphan 9 year old girl, IDI-14]*

*"It's essential to have faith in God. I have a very strong faith. I have left it to the almighty.... let him decide what happens to rest of our life. He will show the path*

*to live, and also to death!”..... [HIV +ve mother, separated from husband, of an 8 year old boy, IDI-15]*

*“I’m very satisfied (about the service received from NGO). They should keep it up so that others also get benefitted. People with the disease need to be assured. They should be told what is right or wrong. Organizations (NGO) like this need to do it more”..... [HIV –ve grandfather of 8 year old boy, IDI-11]*

*“They (NGO volunteers) discuss about our disease... what should we do, how to cope with it, what will help us etc. I have received a lot of help from them (NGO). They even gave us rice (nutritional/financial support). We attended meetings where they talked about how to cope with HIV better”..... [HIV +ve mother of single parent orphan 8 year old girl, IDI-3]*

*“SPARSHA (NGO) is the name of an organization for people with HIV. They are a group for HIV people. They tell us about what is this disease, how this disease happens, how this does not happen (prevention), how to live with it... they give us good advices.”..... [HIV +ve 14 year old single parent orphan boy, FGD-3]*

#### *Death related concerns*

Threat to life due to HIV was a recurring theme as many participants considered HIV as a fatal disease. The issues surrounding death came up in two contexts; the knowledge that HIV/AIDS is a fatal disease and the prospect of death of under care child.

Participants expressed their fear perceptions about the risk of death posed by HIV in various ways,

*“The thing that I fear most is that ..... it (HIV) will slowly drain out all the life energy from you. It’ll eat away everything in your body. Then you’ll be so sick that nothing will save you. This is what I’m very much afraid of.”.....* **[HIV +ve mother of 15 year old girl, IDI-12]**

*“I used to be so afraid (of nephew’s death). It was because my elder brother and sister-in-law (parents of the CLH) died from this disease. It’s very difficult for a person who has this disease to survive.”.....* **[HIV -ve uncle of 14 year old both parent orphan boy, IDI-29]**

*“If anyone gets this disease (HIV), he dies. This disease causes your health to go bad. Then dangers come.”.....* **[HIV +ve 8 year old single parent orphan girl, FGD-2]**

Negative emotions such as sorrow, anxiety, and anger accompanied the caregivers’ description of the possibility that they might lose their child. The fact that their under care children had HIV affected the caregivers very much. Some felt hopeless about the condition of their child. They said health of their children was their foremost concern and nothing could compensate their loss. In the agony of hopeless grief, they blamed the person responsible for giving them the infection and said they would trade anything for the life of their children. Further, parents who were living with HIV revealed that impending death is a concept shared by parents and children alike.

*“(While describing her daughter’s illness) sometimes I feel like there is no point living for those having this disease. How can one live with such a grave disease*

*inside her body? It's such a bad disease. I feel so bad sometimes."..... [HIV +ve mother of 8 year old girl, IDI-8]*

*"I have no hope! What hope.....? My kids..... I have nothing else left. He (her husband) had destroyed our lives [Crying]. I would have accepted my condition, if only my kids were healthy! Every mother has so many dreams about her kids..... that they will grow up, marry, have kids. But I have no hope (about their lives)."..... [HIV +ve mother of 9 year old single parent orphan girl, IDI-14]*

*"One day she (her daughter) was saying 'My parents have it (HIV), I have it, too. Why should we bother about taking drugs? We'll all go (die) together.' "..... [HIV +ve mother of 15 year old girl, IDI-12]*

### **3.2.1.2. Essentiality of taking medications**

Most caregivers and children who had been on anti-retroviral therapy (ART) mentioned that they considered the drugs essential for keeping the disease under control. Many viewed it as the only way to leading a 'healthy' life. Perspectives related to ART were captured under two sub-themes; a) perceived benefits of taking medicines and b) problems associated with adherence.

#### *Perceived benefits of taking medicines*

Many participants compared pre- and post-ART health scenarios from their own experience. They reported a marked improvement in health following initiation of ART. Respondents further revealed that, with intake of ART, they no longer felt weak and could carry out daily activities. Some also had the knowledge that ART protected them

from having opportunistic infections. Moreover, with improving health, respondents seemed to have gotten over the fear associated with HIV. Some children had the impression that medicines could cure the condition that they had.

*“When we (he and his children) got diagnosed, we weren’t doing very well. Then when the medicines (ART) started, we felt like we didn’t have it (HIV). It was like we returned to what we were before. Now, we take it (ART) regularly, and thanks to it we have the strength to work.”.....* **[HIV +ve father of 11 year old and 14 year old single parent orphan boys, IDI-1]**

*“We (parents and son) are taking medicines (ART) and we are doing good. We are not afraid any more. If we were not treated, we would have become weak. Had we not been taking these medicines, we could have been infected with many other diseases. As we are being treated, we feel good. We are like normal people... no lack of energy at all.”.....* **[HIV +ve mother of 11 year old girl, IDI-6]**

*“I take the medicines so that my disease gets cured.... so that this HIV disease gets cured quickly.”.....* **[HIV +ve 10 year old both parent orphan boy, FGD-1]**

*“Yes, it is (important)..... (I take it) because it can cure my disease.”.....* **[HIV +ve 14 year old single parent orphan girl, FGD-3]**

ART seemed to not only improve the health of HIV-infected individuals, but also apparently prevented their condition from deteriorating. Some caregivers rued the fact they were almost on the brink of death when they started taking ART, but were happy

that their children were receiving it from an early stage and, as a result, maintained better health. Negative repercussions following stoppage of ART intake appeared to have convinced the respondents that ART was crucial to staying healthy. There were also comments about the kind of symptoms one would get if the medicines were stopped.

*“Talking about benefits, she (daughter) is healthy because of ART. I mean, she has not become so weak like me..... like I was before it got diagnosed. I was almost dead (before starting ART). Compared to that she is doing quite well. So, I feel as she was on ART, she never fell so sick.”.....* **[HIV +ve mother of 8 year old girl, IDI-8]**

*“Healthy means..... my son is taking the drugs (ART). We visit the doctor regularly and he has been keeping healthy. Whenever the drug is stopped, he falls ill. He is healthy only because of the drugs. He will remain healthy if he keeps taking the drugs.”.....* **[HIV -ve mother of 14 year old thalassemic boy, IDI-10]**

*“I get fever, headache, cough & cold, pain in the limbs (without ART).... sometimes I can't even visit the hospital. The drug they bring me every month (monthly supply of ART) keeps me healthy.”.....* **[HIV +ve 15 year old both parent orphan boy, FGD-3]**

There was also widespread knowledge that HIV affected the immune system, and ART could restore immunity. Participants who underwent regular blood tests for CD4 level

understood that CD4 was a marker of their immunity. Thus, they often described the benefits offered by ART in terms of improvement in CD4 count and vice versa.

*“The timely intake of medicines (ART) should be maintained. He is much better now. Previously, his CD4 had gone down, it was about 100. Currently, it has become more than 200... 295. That means he is more or less healthy!”.....*

**[HIV -ve mother of 8 year old thalassemic boy, IDI-22]**

*“If the medicines (ART) are given meticulously then they (CLH) will stay healthy. If CD4 is good, then there is no need to take medicines. If not, then start the medicines. Give the medicines timely, condition will improve.”.....*

**[HIV -ve grandmother of 9 year old girl, IDI-25]**

*“It is important to take medicines to cure the disease. ART medicines are good for health. Blood test results (CD4) will come out good if one takes it.”.....*

**[HIV +ve 13 year old single parent orphan boy, FGD-3]**

However, not everyone was convinced about the benefits provided by ART. Few caregivers complained that, despite taking ART, there was no noticeable betterment in health parameters unless supported by measures such as nutritious diet.

*“She has not got any benefits (from ART). There hasn't been any improvements (in health). Had there been any benefits, she would have been healthier. I don't know if her diet lacks anything. Probably, if she had more nutritious food, her condition would have been better.”.....*

**[HIV +ve mother of 15 year old girl, IDI-12]**



*“(On benefits of ART) Not yet..... he is not very healthy even after starting the medicines (ART). I mean look at other 14-15 year olds who don’t have this disease. Compare their health with that of my son’s! Since, he has been diagnosed, even after starting the medicines, his health has not changed at all. He is still so skinny! Even after taking the drugs for more than a year, his health has not improved. He eats so little. He doesn’t prefer eating different things.”..... [HIV +ve mother of 14 year old boy, IDI-23]*

#### *Problems with ART adherence*

Most commonly cited barrier to adherence was being frustrated by the rigors of medication regimen. It was difficult for the caregivers to persuade the children to continue taking medicines, especially following realization that the drugs had to be taken for an indefinite period. Caregivers also mentioned that children had to be kept under constant monitoring to make them take the drugs. The number of different drugs, ART and others, which needed to be taken was also revealed as a barrier. Some CLH participants admitted that they did not like taking the medicines, but complained that often they were forced to do so.

*“Regarding health, he (her son) is doing quite well. The only thing is he hates taking those drugs at the designated hours. He does take them occasionally ....at other times his frustration shows up and he refuses.”..... [HIV -ve mother of 12 year old thalassemic boy, IDI-7]*

*“If I went to work, or just say I had to go outside.... before leaving I asked him (grandson) to take the medicine on time. After returning I would find out he had*

*not taken it. If I inquire, 'Have you taken it?' He would answer in affirmative. I have to keep an eye on him always!".....* **[HIV -ve grandmother of 10 year old both parent orphan boy, IDI-20]**

*"The doctor here (at the new treatment center) says that he (son) has become weak because of getting wrong dosage (of ART). To get over this problem the doctor has prescribed many vitamins. How can I keep track of so many medicines? I'm at my wit's end.".....* **[HIV -ve mother of 8 year old thalassemic son, IDI-22]**

*"I don't like taking medicines. They force me to take those. I feel really bad about it.".....* **[HIV +ve 13 year old single parent orphan boy, FGD-4]**

Participants described issues with side effects of the prescribed drugs. Participants usually referred to the problems as 'drugs did not suit the body'. Some commonly reported adverse effects were vomiting, diarrhea, skin rash, anemia, weakness etc. However, it also came up that the side effects were often temporary and diminished with time or change of drugs. Besides the relevant adverse effects, caregivers also mentioned that children gave excuse of side effect in order to avoid taking the drugs.

*"There were difficulties at the beginning (of ART intake)..... he had to be given blood, had bouts of vomiting. Then his medicines were changed. He did not have any problems thereafter. (At that time) His hemoglobin got very low... about 3.".....* **[HIV +ve mother of 14 year old single parent orphan boy, IDI-2]**

*"When her drugs started, she would wet her bed..... there would be diarrhea. When the drugs starts, it takes away all energy from the body*

*(weakness).”.....* **[HIV -ve aunt of 13 year old both parent orphan girl, IDI-18]**

*“When she started taking the medicines, there were problems. I don’t know exactly (the girl was with her parents at that time)..... but from what I heard she had terrible headache. The medicines didn’t suit her. Then the doctor changed medicines, gave different ones. Since then she is doing okay, other than having occasional mouth ulcers.”.....* **[HIV -ve uncle of 11 year old both parent orphan girl, IDI-31]**

*“When the drugs don’t suit your body, the health becomes bad.”.....* **[HIV +ve 14 year old boy, FGD-4]**

*“She (daughter) says that it (ART drugs) gives rise to foul body odor. (She) says, ‘I hate taking the medicines. Stop this nonsense.’ ”.....* **[HIV +ve mother of 15 year old girl, IDI-12]**

### **3.2.1.3. HIV-related stigma and discrimination**

Most participants reported experiencing some form of discrimination because of their (or their children’s) disease status. Discriminating behaviors were experienced in varied settings; a) immediate environment i.e. within family, b) extended environment i.e. in the community and c) health care settings.

#### *Immediate environment/within family*

Participants revealed that they faced discrimination from the persons they considered close. The relatives and family members, possibly due to lack of awareness, resorted to

several uncalled for behaviors such as refusing to touch or share food with infected individuals. Such family members did not only misbehave, they spread their misgivings to others, too. Even uninfected children from extended families were reported to exhibit discriminatory behaviors against CLH of similar age group.

*“The day her father died....she (daughter) did not take a bath or even go to the bathroom....she was crying so much...but no one from the family even touched her or talked to her. They said that they would get infected if they touched her.”.....* **[HIV +ve mother of single parent orphan 8 year old girl, IDI-3]**

*“When my younger daughter was born, the hospital refused to admit us... they told me to go to Medical College (Tertiary care center). That time my mother in law had gone with me and she instructed others, ‘Wherever she goes...all the things used by her should be thrown away’. My husband did not say anything to me, but my mother in law did!.....* **[HIV +ve mother of 8 year old girl, IDI-5]**

*“I have two grandsons - one each from two sons (one of them was HIV +ve and died). But the cousins don’t mingle freely. (The uninfected grandson says) ‘You are not allowed (to play).... get lost’. Then he beats him (the HIV +ve grandson). He becomes upset. He comes to me and complains, ‘Granny, they won’t let me play’.....* **[HIV -ve grandmother of both parent orphan 10 year old boy, IDI-20]**

The form of discrimination within family might not always be overt, as experienced by some respondents. However, even the subtle form of discrimination such as avoidance caused mental trauma to the victims.

*“As we have this disease, some family members (extended family) hate us. They may speak to us, but as we can feel, they harbor hate within. You know from their body language ....and the way they behave. We feel bad about their behavior. We feel bad because they behave this way for our disease. Our mind becomes weak. But we have to live .... we have to fight and live.’..... [HIV +ve mother of 8 year old girl, IDI-8]*

*“Others..... talking about in-laws..... they have it (discrimination) in their mind but don't express it. Apparently, they talk to us, sometimes they give us few things to eat.... they don't refuse any gifts from us. It's alright from that respect. They don't behave that way (discriminatory behavior) in front of us.’..... [HIV +ve mother of 9 year old girl, IDI-13]*

#### *Extended environment/in the community*

Most participants reported that they did not want to share their diagnosis outside their immediate family and friends. They were apprehensive that disclosure of their diagnosis might lead them to be subjected to discrimination in the community. Caregivers expressed their worry that if people came to know about the diagnosis, their children might have to live the rest of their lives in isolation. They blamed the lack of awareness for such a scenario. Further, caregivers reportedly warned the children to be careful so that they did not inadvertently disclose their disease status to people in the community. There were also concerns that a person with HIV might be labelled as having a 'bad' character.

*“(About not disclosing their diagnosis to others) The reason could be... you know people have so many different opinions. You can ask them about their opinion. (If others knew) It could happen that someone insults you in the middle of the street... you can't stop people from saying things.’.....* **[HIV +ve father of 11 year old and 14 year old single parent orphan boys, IDI-1]**

*“The villagers don't know or understand much about our disease. Leave the villagers, even the hospital people are scared of HIV (infected) people. So if I tell others about this .... they would terrorize her, even other kids may terrorize her. I don't think my child would be able to survive that..... that's why I haven't shared anything yet..’.....* **[HIV +ve mother of 9 year old single parent orphan girl, IDI-14]**

*“My son's CD4 count report became low and he was keen to tell that to others. I stopped him. There is chance that people may misinterpret (about diagnosis). I asked him not to speak about it to anyone. I told him, ‘Don't say these things... people will hate you.’.....* **[HIV +ve mother, separated from husband, of an 8 year old boy, IDI-15]**

*“I haven't told our neighbors about HIV. They may think that I am a bad girl. I got this disease as I didn't have a clean character. That's what I think. So, I haven't told anyone.’.....* **[HIV +ve mother of 15 year old single parent orphan girl, IDI-19]**

Sharing their experiences about discrimination from the members of the community, respondents revealed the nature of hardships children (and their caregivers) living with

HIV had to face. The threat of social isolation loomed over their life and stigmatizing behaviors often left a mark on children's psyche.

*"Nobody has this disease (HIV) in our neighborhood. After everyone came to know....no one comes to our place anymore. They are scared that they may get it from touch."..... [HIV +ve mother of 11 year old boy, IDI-9]*

*"My daughter was playing with other kids... someone said, 'She has a disease, and we don't want to mix with her.'" (Afterwards) She became sad and lonely. She would come home and tell me that no one wanted to play with her. She was distressed about the fact that her parents had this disease, and (as a result) nobody would mix or play with her."..... [HIV +ve mother of 15 year old girl, IDI-12]*

*"There are some mothers who don't allow their children to play with HIV-infected children."..... [HIV +ve 14 year old single parent orphan boy, FGD-3]*

Denial of right to education to CLH featured prominently during the interviews. Schools, which were supposed to educate and improve social awareness refused to take in CLH, often under the pressure from parents of other students. Even the private tutors refused to teach such children. Another common mode of ostracization was not allowing infected people to bathe in the community pond.

*".....That private tutor refused to teach him (nephew). One of my sister-in-law informed the tutor about his HIV. Her children were also tutored by the same guy. So she told the teacher that this boy had this disease and nobody should mingle with him or play with him..... that if he (nephew) continues to be tutored she*

*(sister-in-law) would not allow her children to take lessons from him.”..... [HIV -ve uncle of 14 year old both parent orphan boy, IDI-29]*

*“When his mother was still alive, people didn’t allow her to take bath in the neighborhood pond. After she expired, her son was barred from going to school or taking tuition from special tutor (tutor for speech impaired) ..... because he had this disease. Also, he was not allowed to use the pond or play with other kids.”..... [HIV -ve grandmother of 15 year old both parent orphan deaf boy, IDI-30]*

#### *In health care settings*

Compared to discrimination faced from the general community, stigmatizing behaviors from health care providers were less commonly mentioned. Still, such instances were not rare in the study region, as evidenced from experiences shared by the respondents. Even the basic health services were sometimes denied to people living with HIV. Instances of such behaviors were not restricted to any particular group of health care providers.

*“(Narrating the experience of her niece’s hospital stay) The doctor would refuse to see her. In fact, I had to inject her myself. Did I have any other option? Her life was at risk.... what could I do? Mithu, Shyamal (NGO volunteers) they know about it. Because of this disease her teeth turned bad...they (NGO volunteers) confronted the doctor, ‘Did she tell you about her teeth?’ The doctor said, ‘yes’. They asked for explanation, ‘Then why didn’t you pay attention?’ .... the doctor*



*just said, 'I forgot.'* ”..... **[HIV -ve aunt of 13 year old both parent orphan girl, IDI-18]**

*“When my son needed a surgery, I requested so many doctors (to operate). But no one wanted to operate my child because he had HIV. They told me blatantly that he would die anyway, there is no point operating him. He started bleeding profusely ..... no matter how much (blood) we transfused. Still, the doctors kept on refusing.....”*..... **[HIV -ve mother of 14 year old thalassemic boy, IDI-16]**

*“(Following doctor’s advice) So, I admitted her to hospital. They kept her in a corner. The doctors would come and see her. The nurses were forever rude... the cleaners would sometimes refuse to clean her place. The ayahs (nurse maids) would come up with all sorts of excuses, because they didn't want to take care of a HIV patient. Then I had to take care of everything on my own. What could I do? I couldn't abandon her, so I wore gloves and decided to do everything myself.”*..... **[HIV -ve grandmother of 8 year old both parent orphan girl, IDI-26]**

Such fear of discrimination even made a respondent hide her (and daughter’s) HIV status from the doctor they went to see for some common ailments.

*“See... if we tell the local doctor about this disease (HIV)..... that is if I tell the doctor that she (daughter) is HIV positive, she has these complications .... that should be the right thing. But what can we do? We keep it (diagnosis) secret. We just tell the doctor she has fever or diarrhea..... but we don't say she has HIV! We know she is having diarrhea because of HIV, still we hide it. Had he been an*

*ideal doctor we would have said it... that would have been good for my daughter's treatment."..... [HIV +ve mother of 9 year old girl, IDI-13]*

#### **3.2.1.4. Health as a state of mind**

Responses from participants, on the topic of health, were not restricted to illness appraisal only but the issues like 'being happy' and having a 'healthy mind' also came up. We classified the comments made on this topic under two sub-themes – a) importance of having a 'healthy mind', and b) source of happiness.

##### *Importance of having a 'healthy mind'*

Participants recognized that having a positive view of life is important for living a healthy life, especially for those having a disease like HIV. Caregivers said they tried to cheer themselves up by giving example of other 'healthy' people living with HIV. Such examples, some caregivers thought, would likely improve access to care for children. Participants felt that stress could be an important determinant of health and physical health was not everything. Children also understood that it was important to be 'happy' for being 'healthy'.

*"(Narrating what he would say to his nephew during visits to health center) 'Look at these people (other PLH) ..... do they look depressed? Everyone looks happy. Do you know why? The Government is distributing free medications for all. So, don't worry, eat well, relax! Be cheerful! Your health will definitely improve.' I tell him (nephew) bluntly, 'Live like a living being.... don't give much importance to the disease'."..... [HIV -ve uncle of 14 year old both parent orphan boy, IDI-29]*

*“Only good foods don’t make you healthy! She (daughter) needs to have a healthy mind, too. You’ve got to keep her having fun..... we need to find out ways to keep her happy so that she stays healthy. Even after having proper food, one can be down from depression..... to keep her healthy we have to keep her cheerful!”.....* **[HIV +ve mother of 8 year old girl, IDI-8]**

*“The healthy persons are..... those who play regularly, have fun in life are healthy!”.....* **[HIV +ve 14 year old single parent orphan girl, FGD-3]**

### *Source of happiness*

Adults and children living with HIV shared their ideas of ‘being happy’. The idea of happiness for caregivers were often centered on the health of their under care child. Caregivers felt that a ‘normal’ life for their children would bring them happiness. Most respondents, caregivers and children alike, opined that the key to happiness (and health) lay in everyday matters such as interacting or playing with friends, not taking too much stress, moving around etc.

*“If she gets to play with other children ..... mingle with kids, be joyful, get about.... These things are essential for happiness..... and when she is happy, she is healthy. When she doesn’t get these, she gets sick. Her quality of life improves with happiness, her symptoms lessen, too.”.....* **[HIV +ve mother of 8 year old girl, IDI-8]**

*“To be happy, you need to get rid of this disease (HIV). When someone gets this disease, she can no longer enjoy life. She will be burdened by stress.”.....*

**[HIV +ve mother of 8 year old girl, IDI-5]**

*“(On happiness) I think if she can eat, wear or play like a normal kid... that is if she has a normal lifestyle..... that’s happiness! What else do you expect for a kid? ..... Getting to wear nice clothes, eating good food, playing with others, so and so.”.....* **[HIV -ve uncle of both parent orphan 11 year old girl, IDI-31]**

*“If you are cheerful, always smiling ..... you are happy. If you keep thinking about things or get stressed then you become sad.”.....* **[HIV +ve 14 year old single parent orphan boy, FGD-4]**

Importance of having a ‘happy’ family was emphasized by some respondents. However, for orphans, absence of one or both parents often came in the way of ‘happiness’.

*“If everyone in the family is disease-free, if they are having fun ..... that makes a perfectly happy family. Look at us... we are a family of 4. I would say we are good. Although he (son) has a disease, we hope he will be better.... We are good!”.....* **[HIV -ve mother of 14 year old thalassemic boy, IDI-10]**

*“She (daughter) always thinks of her father. Say, she is watching a movie on TV and it shows someone’s father has died..... and she starts to cry. She cries whenever she remembers her father. She thinks about him every day. Her father used to be here till she was five. He used to love her very much. (Her father’s death) It has left a big impact on her. She sometimes tells fellow students that her father died, and starts to cry.”.....* **[HIV +ve mother of 8 year old single parent orphan boy, IDI-3]**

*“We can think she is normal.... but she is not! She doesn’t have a father .... however hard we try to keep her in good mood, you can’t compensate for the*

*loss (death of father).”..... [HIV -ve aunt of single parent orphan 14 year old single parent orphan girl, IDI-28]*

### **3.2.1.5. Available health services – satisfaction and grievances**

Participants discussed about the positive and negative aspects of available health care services. While complaints about services failing to meet expectation were common among service recipients, there were others who opined that services had improved with time and they were quite content about some of the services.

#### *Satisfaction with available services*

Respondents, especially those aware of the ART expenses, seemed content with the fact that they had been getting HIV medications for free. Speaking from their experiences they said that they would have found it difficult to continue the treatment if they had to buy the drugs. Few participants also expressed satisfaction with the proactive approach of testing (CD4 and diagnostic tests) adopted by government health system.

*“About services..... I see everyone is getting the medicines. That’s the best service..... people can take the medicines because they are getting it. We have the ability to buy food as we are getting the medicines (for her son) for free. I am very happy about it.”..... [HIV -ve mother of 14 year old thalassemic boy, IDI-10]*

*“I am happy (about the services). I mean if you get diagnosed (with HIV) and receive the medicines for free, you should be happy. We cannot afford to buy*

*medicines. If I had to buy my own medicines, it would have been impossible for me. I would have died long time back (if free medicines were not given). Although I have to bear the transportation cost, as the medicines are given free from hospitals, it's still manageable. Given the cost, if I had to buy it.... I don't think I could (buy the drugs).”.....* **[HIV +ve mother of 15 year old single parent orphan girl, IDI-19]**

*“They tested her (granddaughter) immediately after she was born (for HIV). They (doctors) didn't tell me but told my daughter-in-law. The people at hospital spoke to my son and asked them to come back on a particular date. But he didn't care about going back. But the hospital didn't lose track.... when she was one and a half years old, some people from Nilratan hospital (a tertiary care hospital) came to our house for inquiry. They took them to the hospital for testing.”.....* **[HIV -ve grandmother of 9 year old both parent orphan girl, IDI-25]**

*“We have Calcutta Medical College and Medinipur Medical College in our state. For those who can't buy the medicines..... the state government and Indian government give free medicines to these people from these Medical Colleges. HIV patients get many kinds of help from these places. I have heard the government bears a lot cost for HIV patients.”.....* **[HIV +ve 14 year old single parent orphan boy, FGD-3]**

There were also praises about the services offered by CBOs. Respondents complimented the efforts of these organizations in spreading awareness about HIV and providing helpful advices. It was also revealed that these organizations ran various

nutritional and other support programs which improved the living conditions of children (and their families) living with HIV. Some attributed their recuperating health condition to the help provided by such organization.

*"I am happy about the help they give us (talking about NGO volunteers)... these efforts should continue and the government should also co-operate. There should also be efforts towards creating awareness for everyone..... about the do's and don'ts of this disease.".....* **[HIV -ve grandfather of 8 year old boy, IDI-11]**

*"About the benefits.... the kind of nutritious foods they (NGOs) provided was quite helpful. They paid the school fees (for the boy), even provided for books and supplies. We had to spend a lot on transportation to fetch the medicines.... (now) they pay for the transportation cost, too. These are the real need! We could do without wearing fashionable shoes and new clothes everyday.... those are not very important. The most important thing is nutrition. (Advices on) Maintaining cleanliness and hygiene..... that is important, too.".....* **[HIV +ve neighbor taking care of 14 year old both parent orphan boy, IDI-27]**

#### *Grievances with available services*

A commonly cited complaint, among the residents of rural areas, were the great amount of distance (and time) they had to travel to receive various health services. Cost of transportation to reach health centers was also quoted as a hurdle by the service recipients. Inconsistent supply of several HIV-related services especially irregular availability of medicines was another major grievance. Respondents depicted their initial

struggle to obtain regular supply of ART. Besides ART, there were also complaints about lack of other basic medications including antibiotics.

*“Treatment facilities..... had the (ART) centers been nearer. If they could open more centers, in small towns, suburbs....then we didn’t have to go to Kolkata (capital city). I understand that it might not be possible to provide the CD4 machine everywhere, that’s fine with me. I can make a single trip every six months ....but if we can get the medicines at a nearby place, then we can save time, energy..... food and transport related expenses. (To go to ART center) See, I have to get up at three in the morning, take a train..... then take a bus. No way can I return home before 10 at night.”.....* **[HIV +ve father of 11 and 14 year old single parent orphan boys, IDI-1]**

*“The most important thing is medicines. Sometimes there is dearth of medicines. They (ART center staff) say, ‘there is no supply’. Drugs are the basic requirement (for survival). They (CLH) need it to live. If these (ART) are not available at the hospital, how can we save them?”.....* **[HIV -ve mother of 11 year old thalassemic boy, IDI-22]**

*“(Complaining about available services) What else do you want to hear? They (ART center staff) sometimes don’t even give us Septran (Co-trimoxazole). She (granddaughter) had a skin lesion and I took her to the center. They didn’t provide anything. I had to buy the ointments twice. What’s the point of going to the hospital if they can’t provide us medicines?”.....* **[HIV -ve grandmother of 9 year old both parent orphan girl, IDI-25]**



Discourteous services at the health facilities often left negative impressions on service recipients. Misbehaviors from ART center staff, especially in response to missed drug dosage, were common occurrence. Such unpleasant experiences might have had a bearing on adherence as some respondents said they considered stopping ART to avoid such experiences.

*“(Sharing her experience at ART center) Sometimes it turns really bad..... if some pills from previous month were left in the container... they would use all sort of filthy language ..... those people who dispense medicines. I feel humiliated..... (I ask myself) why do I need to face this for the girl (niece). They use such nasty words ..... I feel like not going back there again. But what can I do? Can I kill my child? I can't do that! They (ART center staff) would say ‘If you can't remember giving medicines to her regularly, why don't you give away your child to someone else? We would not give you medicine. Go home’.”..... [HIV +ve aunt of 13 year old both parent orphan girl, IDI-18]*

*“(Sharing her experience at ART center) The problems are numerous, sometimes we feel like discontinuing the medicines. They (staff at the ART centers) keep talking among themselves for hours but shout at us if we get little late in collecting our medicines. If we delay our visit by even a single day they behave pretty rudely and tell us, ‘We can't give you medicines, don't come again’..... as if we are not human. We have to face so much pain and suffering....on top of that...they behave in such a manner. Sometimes, we feel that it may be better to stop taking medicines and die.”..... [HIV +ve mother of 8 year old girl, IDI-5]*

*“(On how to improve services for PLH) If the doctors and other staff at hospitals stop shouting and quarreling..... it will be better.”..... [HIV +ve 14 year old single parent orphan boy, FGD-3]*

Lack of basic amenities and poor quality of services at the health facilities were mentioned as deterrents for accessing health care. Especially for children, the unclean environment made them not want to visit hospitals.

*“(About health facility visit) It stinks so bad! The smell is really awful. It is so bad that you don’t feel like talking to people.”..... [HIV +ve 11 year old single parent orphan boy, FGD-1]*

*“(About his hospital stay) When I was admitted there (hospital), I didn’t like it at all. I didn’t feel like eating. The water quality was so bad. The place was so dirty [covering his nose with hands]..... smelt very bad!”..... [HIV +ve 9 year old single parent orphan girl, FGD-2]*

*“(On local health centers) The health center closest to our home is somewhat okay.... for treatment purpose. But it is so filthy..... trash is strewn around, dirty water flowing everywhere. Mosquitoes grow in those dirty water. The place is full of weeds, you can even find animal carcasses. You know .... these mosquitoes can lead to malaria in the surrounding villages. There are other problems, too. The doctors sometimes don’t come on time.”..... [HIV +ve 14 year old single parent orphan boy, FGD-3]*

The above grievances notwithstanding, there was a rare but more grievous concern expressed by caregiver of a thalassemic child. The child's mother, justly, blamed the prevailing blood transfusion system for her son's HIV.

*"My son didn't have any symptoms. He was prescribed blood transfusion ..... and HIV strikes. They have this poster at the hospital which says check for HIV every three months. Because he (son) received blood for thalassemia, we went for the (HIV) test..... and out of ten kids my son was the only one to get infected! People who had regular blood transfusion did not get infected.... and only we got unlucky! They also tested our blood for HIV immediately ... me and my husband... we were found negative. I hate the blood banks..... what sort of checking mechanism do they have? They (blood banks) are highly irresponsible."..... [HIV -ve mother of 8 year old thalassemic boy, IDI-22]*

### **3.2.2. Issues exclusive to caregivers**

The themes identified exclusively from caregivers of CLH were related mostly to their experiences of raising a CLH. Two issues that emerged from content analysis of the in-depth interviews were; i) caregiving challenges, and ii) concerns about child's future.

#### **3.2.2.1. Caregiving challenges**

Financial constraint was cited as the most common caregiving obstacle. Caregivers who were living with HIV revealed that the disease worsened their economic situation or made them unable to work. They rued the fact that they often failed to provide for the basic necessities to the children.

*“We no longer have the energy to work. We get tired easily if we try to do some heavy work. So we have to live like this (in poverty). We used to get help from this place (NGO), but that has stopped, too.”.....* **[HIV +ve mother of 11 year old boy, IDI-6]**

*“Financially, we are almost ruined. We had to sell whatever land, property that we had.... to pay for my husband's treatment. Then she (daughter) had an accident and the little that was left was gone too [crying]. Now, I have to work really hard for survival of myself and two kids. My son (elder) passed Madhyamik (school board exam) this year and wanted to continue his education.... but I couldn't afford.... my daughter is still studying. I don't know for how long I can continue to bear this burden!”.....* **[HIV +ve mother of 9 year old single parent orphan girl, IDI-14]**

*“How would she (daughter) be healthy? Taking medicine is not enough..... you have to arrange for nutrition, too. We are poor... among three of us (family), I'm the only earning member. We have to buy everything other than water..... how can I manage on my own? I think, I have to stop her (daughter's) education and make her do some job.... otherwise we can't survive. My husband (HIV +ve) is bedridden ..... it's not possible for me to earn enough to meet every requirement.”.....* **[HIV +ve mother of 15 year old girl, IDI-12]**

Non-parent caregivers shared the difficulties of raising a child under foster care. They acknowledged that even their best effort at parenting might not be sufficiently good for the children.

*“You know, both her parents are not alive.... considering that, I would say she is doing well. On her quality of life, on a scale of 10 I can give her 9 at most. She would always have this vacuum in life.... her parents aren’t there. We cannot do much about that... grandparents and uncles cannot fill up that space....she will always have something missing in her life.”..... [HIV -ve uncle of 11 year old both parent orphan girl, IDI-31]*

*“Sometimes he (nephew) misses his parents... and he starts behaving differently! When my own kids call me daddy.... it’s not that he doesn’t talk to me..... but, you know, it’s different!”..... [HIV -ve uncle of 14 year old both parent orphan boy, IDI-29]*

### **3.2.2.2. Concern about child’s future**

Caregivers expressed various concerns about the future living condition of their children. Many respondents, especially those living with HIV had apprehensions about the time when they would not be present to care for the children.

*“We (parents) always think about it... that when we are no longer there. Nothing can be done about us .... but that girl (daughter).... she also has this infection. What will happen to her? We are not worried about us. We got this disease and we may die. But she is just 13, and has this disease..... how will she manage (without us)?”..... [HIV +ve mother of 15 year old girl, IDI-12]*

*“We (parents) feel concerned about him (son). He is still so young. He has to live like this for the rest of his life.... how will he survive? Anything (death) can*

*happen to us. If something happens to us, will he be able to live? I pray that he gets cured.”..... [HIV +ve mother of 14 year old boy, IDI-23]*

*“I worry about his (grandson) future. Presently we (grandparents) are both alive... but what would happen if one or both of us die? His parents haven't left behind a penny for him.... or any property ... how will the poor child survive? If he was not sick then it might have been possible for him to earn a living and live his own life... but how can he do that when he is sick with a disease (HIV) like this? His grandfather is doing all he can ... but if someday he is no more.... who will be taking him to the treatment center? Being a woman, it will be very difficult for me to take care of everything alone. Also, my age may not permit me. I am always concerned about these things.”..... [HIV -ve grandmother of both parent orphan 10 year old boy, IDI-20]*

Marriage of their children was a major source of distress for participants. They shared their ideas about finding a suitable mate for their child and also the difficulties associated with such marriage. Respondents often felt that their children, especially girls, needed someone for support when the caregivers won't be around. The caregivers also expressed disappointment that their children had little chance of becoming parents in future and the family bloodline might end soon.

*“As per my knowledge... whoever becomes my son in law ... he has to be someone having the same disease. I want her (daughter) to be happy and self-reliant. If her condition (illness) ever becomes like me.... she should be able to survive on her own. I have my father to look after me... but she does not have*

*anybody like that in my absence. I am sick, too.....I don't know for how long will I survive. I'll be gone someday. After I'm gone, her husband needs to look after her..... and if that's not the case she needs to survive independently. This is what I want.".....* **[HIV +ve mother of 8 year old single parent orphan girl, IDI-3]**

*"See, there is no way I can marry her (daughter) off. Once people come to about her disease, she can't get married. She has to live with me... as long as possible.".....* **[HIV +ve mother of 15 year old girl, IDI-12]**

There was also a rare viewpoint from a mother who was so desperate to get her daughter married that she was willing to hide her daughter's HIV status.

*"See.... it's not possible to arrange her (daughter) marriage if people come to know (about her disease). Now, if I can find a boy who is different (immature)..... I'll request him to marry my daughter and stay with us. I'll somehow make him understand! I have this plan for my daughter. If it fails she'll continue to live with me.".....* **[HIV +ve mother of 15 year old single parent orphan girl, IDI-19]**

#### **4. DISCUSSION**

Living with HIV/AIDS can have a great impact on childhood.(8, 12) Published literature reveal that children belonging to families affected by HIV have to face various challenges towards having a normal upbringing.(12, 14) These challenges are not limited only to physical and psychological stress but such children also have to deal with different forms of stigmatizing behavior, economic hardships, sick caregivers and inferior standard of caregiving etc.

This qualitative study conducted in two districts of West Bengal, India revealed several experiences, concerns and perceptions associated with caregiving of 8 to 15 year old CLH. We tried to infer the potential impact that organizational, structural and resource issues might have on quality of caregiving based on the narratives of participating caregivers and care recipients (CLH).

Coping with HIV was identified as a significant psychological challenge faced by the CLH and their caregivers. This underscored the emotional stress associated with HIV diagnosis of self and/or cared for children. A feeling of gloom, at the possibility that those living with HIV might never be able to lead a 'normal' life again, was evident from the narratives of most respondents. 'Fear of impending death' was another anxiety that the caregivers and children had to cope with. As had been reported in other studies from developing country settings, distress and bereavement owing to HIV diagnosis of a family member could affect psychological health of rest of the family.(11, 15) In India, organizational measures such as counseling is limited to post-test and adherence counselling sessions. In order to address the above issues, interventions targeted towards informal caregivers e.g. counselling on caregiving aspects and disease coping mechanisms should be emphasized in newer iterations of India's HIV program.

Most caregivers and children acknowledged the role HIV medications had played in keeping them healthy. However, respondents, mostly caregivers, also narrated their ordeals in making the children take ART pills on a regular basis. Adverse reactions and difficulty of regimen were identified as key impediments for ART adherence for children. Further, the difficulty of ensuring adherence among children who were yet to be disclosed about disease status also came up. These findings were similar to prior



qualitative studies conducted in India and rest of the world.(16) Implementing widely recommended measures for improving adherence among CLH such as simplifying regimens and educating the caregivers on benefits of adherence and childhood disclosure could bring about significant advances in this area.(16, 17)

One of the major challenges faced by caregivers and CLH was HIV-related perceived stigma and discrimination. It has been reported that despite an emphasis on awareness interventions aimed at reducing stigma associated with HIV, discrimination against PLH continues to exist in India.(18) Researchers have also highlighted intense stigma in low HIV prevalence setting within India where adults and children living with HIV stay in relative isolation.(19) Forming and maintaining support groups in such areas have proven difficult and ignorance among masses about HIV have further compounded the hurdle. The respondents in this study experienced discriminating behavior not only in the community environment, but also, appallingly, in health care settings. It is well established that HIV-related stigma, in its various forms, can hinder both provision and uptake of care and support services among children and adults living with HIV.(20) Besides discrimination, respondents reported several other grievances with available health services such as irregular supply of medications, remoteness of health facilities, discourteous behavior by healthcare workers, lack of basic amenities etc. Such barriers put the CLH and their caregivers, an already marginalized and vulnerable population, at a greater difficulty in accessing essential health care. Therefore, India's HIV program, besides improving access to medications and other services, also needs to consider (vide Paranthaman et al(16)) the perceptions and expectations of caregivers and ensure

that disbursement of health care services are confidential, devoid of discriminating behaviors and comprehensive.

For caregivers, raising a child living with a chronic illness involved some familiar and some unique aspects. Responding caregivers expressed everyday concerns such as apprehension about their children's health, financial constraints and foster care challenges. On the other hand, caregivers who themselves were living with HIV narrated how their own condition was hampering quality of caregiving at present and putting their child's future in uncertainty. Misgivings about the possibility of child's marriage and the ominous prospect that family line might end due to absence of heir, were distinctive concerns affecting caregivers of CLH. There were also expectation on the part of caregivers that governmental or non-governmental agencies would assume caregiving responsibilities in case informal caregivers became incapable to carry out their duties. Thus, our findings suggest presence of an institutional gap in several aspects of caregiving for CLH.

The generalizability of findings in this study may be hampered by several limitations. The total number of in-depth interviews (34, 20 parents and 14 non-parents) may appear adequate in terms of broader categorization,(21) but perspectives from some demographic categories were probably under-represented. All responding parent caregivers but one were mothers, which most likely made mothers' views dominant in our findings. Moreover, responding non-parent caregivers had lots of heterogeneity in terms of their relation to CLH. Such caregivers comprised of grandparents, uncles, aunts, and even neighbors. As number of interviews from each group were small, it could not be assessed whether opinions varied among different groups of non-parent

caregivers. Participants in FGDs were categorized according to age and ART intake. We admit the possibility that the focus group participants might have been heterogeneous in terms of other socio-demographic parameters. All participants in this study were recruited through a local CBO. Thus, our study failed to capture the viewpoints of caregivers and CLH who were not recipients of services offered by such organizations.

Despite the above limitations, capturing the perception of varied group of caregivers and triangulating them with views expressed by CLH was a major strength of this study. We understand that a caregiver's own health condition can affect his/her perspectives about the care received by cared for child. Recording perceptions of different groups of caregivers (biological parents and non-parents) helped us explore differing concerns from diseased and non-diseased caregivers. In case of children, too, perceptions of clinically well-off (non-ART) and poorer (taking ART) were recorded. Furthermore, participant recruitment and interview/FGD conduction were done in an informal setting, away from the treatment facilities. We believe above measures might have allowed respondents to communicate without inhibitions about potential negative consequences such as discrimination or impact on treatment.

Most researches on CLH in India has focused on clinical outcomes. The different qualitative methods used in this study allowed us to expand our scope beyond physical wellbeing to holistically assess the issues related to caregiving from the perspectives of caregivers and their under care children. It is clearly evident from our findings that caregiving needs for CLH in a resource limited setting like India is a complex problem. The CLH and their caregivers face a plethora of challenges on an everyday basis and

there are many unmet but relevant expectations. The issue of caregiving goes beyond the child-caregiver dynamic, and is intertwined with prevailing community, health care and support system structures. Our findings further underscore the need for comprehensive care programs focusing on improving support to both CLH and caregivers. Facilitating access and removing barriers associated with health services, as well as provision of economic and psychosocial support (e.g. counselling, educational measures etc.) for children and caregivers are the need of the hour. Involving various non-governmental support groups for implementing such interventions is recommended.

## **5. REFERENCES**

1. National AIDS Control Organisation Annual Report 2012-2013. Department of AIDS Control, Ministry of Health and Family Welfare, Government of India, 2013 5th January, 2015. Report No.
2. Prachakul W, Grant JS. Informal caregivers of persons with HIV/AIDS: a review and analysis. *The Journal of the Association of Nurses in AIDS Care : JANAC*. 2003;14(3):55-71. Epub 2003/06/13. PubMed PMID: 12800812.
3. Decarlo P, Folkman S. Are informal caregivers important in AIDS care? Positive outlook : the newsletter of the AIDS Alternative Health Project. 1997;4(2):26-7. Epub 1997/01/01. PubMed PMID: 12293155.
4. Yeap AD, Hamilton R, Charalambous S, Dwadwa T, Churchyard GJ, Geissler PW, et al. Factors influencing uptake of HIV care and treatment among children in South Africa - a qualitative study of caregivers and clinic staff. *AIDS care*. 2010;22(9):1101-7. Epub 2010/09/09. doi: 10.1080/09540121003602218. PubMed PMID: 20824563.

5. King M. Psychosocial problems in patients with HIV infection. *Practitioner*. 1988;232(1453):841-2. Epub 1988/08/01. PubMed PMID: 3256827.
6. Ferrand RA, Luethy R, Bwakura F, Mujuru H, Miller RF, Corbett EL. HIV infection presenting in older children and adolescents: a case series from Harare, Zimbabwe. *Clinical infectious diseases*. 2007;44(6):874-8.
7. Pridmore P. Access to conventional schooling for children and young people affected by HIV and AIDS in sub-Saharan Africa: A cross-national review of recent research evidence: SOFIE, Institute of Education, University of London; 2008.
8. Punpanich W, Detels R, Gorbach PM, Leowsrisook P. Understanding the psychosocial needs of HIV-infected children and families: a qualitative study. *JMed Assoc Thai*. 2008;91(Suppl 3):S76.
9. USAID U, UNICEF. Children on the brink 2004: a joint report on orphan estimates and program strategies. Washington, DC: USAID Available from: [da ta unaids org/publications//unicef\\_childrenonthebrink2004\\_en pdf](http://data.unaids.org/publications//unicef_childrenonthebrink2004_en.pdf) [cited 10 June 2011]. 2004.
10. Rose MA, Clark-Alexander B. Caregivers of children with HIV/AIDS: quality of life and coping styles. *The Journal of the Association of Nurses in AIDS Care : JANAC*. 1998;9(1):58-65. Epub 1998/01/22. PubMed PMID: 9436168.
11. Punpanich W, Gorbach PM, Detels R. Impact of paediatric human immunodeficiency virus infection on children's and caregivers' daily functioning and well-being: a qualitative study. *Child: care, health and development*. 2012;38(5):714-22. Epub 2011/08/20. doi: 10.1111/j.1365-2214.2011.01301.x. PubMed PMID: 21851376; PubMed Central PMCID: PMC3392445.
12. Ji G, Li L, Lin C, Sun S. The impact of HIV/AIDS on families and children--a study in China. *AIDS (London, England)*. 2007;21 Suppl 8:S157-61. Epub 2008/01/10. doi: 10.1097/01.aids.0000304712.87164.42. PubMed PMID: 18172385; PubMed Central PMCID: PMC2822872.

13. Nyamathi A, Thomas B, Greengold B, Swaminathan S. Perceptions and health care needs of HIV-Positive mothers in India. *Progress in community health partnerships : research, education, and action*. 2009;3(2):99-108. Epub 2009/01/01. doi: 10.1353/cpr.0.0067. PubMed PMID: 20208256.
14. Forehand R, Steele R, Armistead L, Morse E, Simon P, Clark L. The Family Health Project: psychosocial adjustment of children whose mothers are HIV infected. *J Consult Clin Psychol*. 1998;66(3):513-20. Epub 1998/06/27. PubMed PMID: 9642890.
15. Petersen I, Bhana A, Myeza N, Alicea S, John S, Holst H, et al. Psychosocial challenges and protective influences for socio-emotional coping of HIV+ adolescents in South Africa: a qualitative investigation. *AIDS care*. 2010;22(8):970-8.
16. Paranthaman K, Kumarasamy N, Bella D, Webster P. Factors influencing adherence to anti-retroviral treatment in children with human immunodeficiency virus in South India--a qualitative study. *AIDS care*. 2009;21(8):1025-31. Epub 2009/12/22. doi: 10.1080/09540120802612857. PubMed PMID: 20024759.
17. Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection. Panel on Antiretroviral Therapy and Medical Management of HIV-Infected Children, 2014 16th February, 2015. Report No.
18. Unnikrishnan B, Mithra PP, T R, B R. Awareness and Attitude of the General Public Toward HIV/AIDS in Coastal Karnataka. *Indian journal of community medicine : official publication of Indian Association of Preventive & Social Medicine*. 2010;35(1):142-6. Epub 2010/07/08. doi: 10.4103/0970-0218.62580. PubMed PMID: 20606940; PubMed Central PMCID: PMC2888345.
19. Panda S, Das RS, Maruf SKA, Pahari S. Exploring Stigma in Low HIV Prevalence Settings in Rural West Bengal, India: Identification of Intervention Considerations. *Journal of Mixed Methods Research*. 2014. doi: 10.1177/1558689814535843.

20. Turan JM, Nyblade L. HIV-related stigma as a barrier to achievement of global PMTCT and maternal health goals: a review of the evidence. *AIDS and behavior*. 2013;17(7):2528-39. Epub 2013/03/12. doi: 10.1007/s10461-013-0446-8. PubMed PMID: 23474643.
21. Green J, Thorogood N. *Qualitative methods for health research*: Sage; 2013.

# **Chapter V: Formation and psychometric evaluation of a health-related quality of life instrument for children living with HIV in India**

## **1. INTRODUCTION**

Assessment of change in quality of life (QoL), besides being useful in health research and economic impact appraisals, has been suggested as a fundamental step for evaluating effectiveness of developmental programs including public health interventions, in both developed and developing economies.(1, 2) Health-related quality of life (HRQoL) distinguishes itself from the more general quality of life by the fact that its purview is limited to factors related to health or healthcare. HRQoL is a construct specific to health and refers to assessment of an individual's current level of health-related functioning and well-being. Therefore, tools for assessing HRQoL are more appropriate in the context of clinical and public health research. The factors or predictors related to HRQoL are broadly classified into two categories - individual level and community level factors. Individual level predictors comprise perceptions about health, both physical and mental, and related domains such as health risks, functional status, social support, and socioeconomic status.(3) On the community level, HRQoL determinants include the existing health policies and conditions, resources available at the community level, and various health behaviors and practices that can shape the overall health status of a community.(3) Therefore, HRQoL is a multi-dimensional entity dealing with health status and healthcare, but whose scope reaches beyond conventional assessments of health.(4)



Availability of highly active antiretroviral therapy (HAART) has reduced the incidence of opportunistic infections and other AIDS defining illnesses. This has led to delayed, often for an indefinite period, progression to AIDS and, in turn, has prolonged lifespan of the infected. However, the current therapies fail to eliminate latently infected T-cells and, therefore, are not successful in complete elimination of the virus and cure of the patient.(5) As complete cure is not possible, helping the HIV infected to attain an optimum quality of life remains a key goal of treatment. Assessment of HRQoL for HIV infected persons not only indicates the status of the patient, but also helps in evaluation of the treatment measures. It can help in identifying treatment regimens that are not only efficacious but also produce fewer and less severe side effects, both physiological and psychological. HRQoL measures enable policy-makers to take into account efficacy, safety, tolerance, and cost (both direct and indirect) while estimating the effectiveness of a particular treatment regimen or other intervention.(6) HRQoL assessment can be helpful in selecting the best alternative among interventions of apparently equal efficacy (such as similar levels of viral load suppression or increase in CD4 T-cells) by identifying the one that exhibits a superior score in one or more HRQoL domain such as loss of work/school days.(6) Therefore, a better evaluation of health status of individuals and families affected by HIV/AIDS can be achieved by integrating functioning and well-being with clinical parameters.

The aforementioned reasons and the fact that HIV is recognized as a major global health emergency,(7) have led to a growing interest in development of tools specifically aimed at assessment of HRQoL among people living with HIV (PLH).(8) However, these instruments are developed mostly for industrialized country settings and few target the

pediatric population.(9) It has been hypothesized that many such tools, designed for high-income countries, may be unsuitable for resource-poor settings.(9, 10) For the south Asian countries, the recently formulated Thai Quality of Life for HIV-infected Children (ThQLHC) is the only known HIV-targeted HRQoL instrument targeting the pediatric population.(9)

In India, where even perfectly healthy children are often deprived of basic amenities and social support, ensuring quality of life for children living with HIV (CLH) is an arduous task. Widespread discrimination associated with HIV and lack of parental care (for orphans), compound the problem even further.(11) (Reference chapter 4) As with the other resource-poor nations facing an HIV epidemic, a culturally appropriate tool to assess HRQoL is crucial for India where under-15 children account for about 7% of the approximately 2.1 million PLH.(12) Such a tool would be helpful for illness appraisal at an individual level, and, on the other hand, can assist policy-makers in identifying the areas of concern among the pediatric HIV population and, in turn, devising interventions to address their specific needs. As the proportion of Indian CLH living till adulthood increases with access to effective HIV related care, understanding how these children, facing an uncertain future, negotiate the ramifications of everyday life becomes essential.

## **2. METHODS**

The current study was conducted in two phases. In the initial phase, 1) qualitative study methods including in-depth interviews (IDI) and focus group discussions (FGD) with CLH and their caregivers were employed in order to inform instrument development; 2)

followed by a quantitative study involving administration of the instrument to assess its applicability in the Indian context and to evaluate its psychometric properties.

In order to gain access to the study population investigators collaborated with a local community based organization (CBO) named 'Society for Positive Atmosphere and Related Support to HIV/AIDS' (SPARSHA), which have been conducting various care and support programs for children and adults living with HIV since 2000. SPARSHA's registry of CLH and their principal caregivers were accessed to identify potential participants who were then contacted by the outreach workers.

Ethical approval for this study was obtained from the institutional review board (IRB) of the University of California, Los Angeles and the institutional ethics committee (IEC) of the National Institute of Cholera and Enteric Diseases (under the Indian Council of Medical Research), the collaborating research institute located in Kolkata, West Bengal.

## **2. 1. Qualitative study**

### *2. 1. 1. Participant recruitment*

Participants for the qualitative study were obtained through a convenience sample of CLH and their caregivers residing in Paschim and Purba Medinipur districts of West Bengal, recruited with the assistance of the aforementioned SPARSHA registry.

Principal caregivers of CLH were requested to participate in IDIs, while CLH took part in FGD with other CLH in their age group. Eligibility criteria for principal caregivers were: i) being the primary person (caregiver) looking after the needs of (one or more) CLH aged 8-15 years, ii) adult ( $\geq 18$  years old), iii) living in the same household as the concerned child, iv) being a native language speaker, and v) willing to provide informed consent.

Caregivers of institutionalized children, or children who spent  $\geq 2$  weeks/month or  $\geq 6$  months/year away from the caregiver, were not considered. Previous work by SPARSHA documented presence of single parent and both parent orphans living with HIV in the study area. We recruited both - caregivers who were biological parents and those who were not. For FGDs, eligibility of participating children was assessed using the following criteria: i) being diagnosed with HIV at a center approved by the West Bengal State AIDS Prevention & Control Society (WBSAPCS), ii) 8 -15 years age, iii) not previously diagnosed with a disorder that would prevent the participating child from responding rationally to the questionnaire (such as psychiatric, neurologic or developmental disorders, but not limited to them), iv) consent from the accompanying caregiver to participate, v) verbal assent from the child. No gender specific criteria were used to determine eligibility - either for the caregivers or children.

### *2.1.2. Data collection*

In-depth interviews with caregivers, and FGDs with children were conducted using semi-structured guides with the following agenda themes; general understanding about physical and mental health, issues related to illness perception, key areas affecting quality of life, apprehension(s) and strategies to cope with them, attitude towards available health services etc. Following Green and Thorogood(13), who suggested conducting up to 20 IDIs (or till thematic saturation was reached) for each unique group, we interviewed 20 biological parents and 14 non-parent caregivers. Four FGDs were carried out – two each involving CLH aged 8-12 years and 13-15 years. Within each group, one FGD involved CLH who were on anti-retroviral therapy (ART), whereas the other one had participants who had not started ART. While all the FGDs were held at

the local field offices of SPARSHA, IDIs were conducted either at the participant's home or the field office, depending on the participant's preference. Interviews and FGDs, held from July to September, 2014, were conducted in Bengali, the native language of the area.

### *2.1.3. Data analysis and instrument development*

Audio recordings of interviews and group discussions were transcribed verbatim into *MS Word* in Bengali within 24 hours of completion of the interview/discussion. The notes taken during IDIs/FGDs were used to facilitate the transcription process and to enhance the transcripts by insertion of relevant comments (e.g. mood, emotional status of interviewee etc.). These were also utilized later for content analysis. The transcripts were then imported into the Atlas.ti 7.5 package for the purpose of coding and data analysis.

In addition to identifying HIV-targeted items from the formative qualitative research, we performed a literature review and consulted experts regarding selection/modifications of items for the scale. The methodology employed during development of ThQLHC,(9, 14) a validated HIV-targeted instrument developed in south Asia, was used as a guideline for our work. The two new scales developed using the above methodology, namely 'symptoms' and 'discrimination', were incorporated alongside the Pediatric Quality of Life Inventory (PedsQL) generic core scales (child/teen report). The PedsQL generic core is a widely used and validated, disease-independent instrument for assessing HRQoL which contains 23 items in four domains - physical, emotional, social and school functioning.(15, 16) Thus, the newly created 'Quality of life (health-related) of children

living with HIV/AIDS in India (QOL-CHAI)' contained 47 items (later reduced to 45) – 18 items in the 'symptoms' domain, six in the 'discrimination' domain (later reduced to 4), in addition to 23 items from four domains of the PedsQL. [See appendix] Translation of PedsQL items to the Bengali language involved 'forward translation', 'backward translation', and 'patient testing', as recommended by Mapi Research Institute, France.(17)

In order to assess applicability and detect problems with understanding of intended meaning of items, cognitive interviews were conducted with 10 children (5 each from 8 - 12 years and 13 – 15 year age categories).(18, 19) The instrument was administered in 'assisted self-administered' format i.e. respondents were asked to complete the questionnaire in presence of interviewer.(20) The interviewer helped participants if they had any queries. Following completion of questionnaire, the interviewer probed respondents about individual items and instructions. Probing was done to assess whether the interviewees understood the intended meaning of directions, questions, and answer categories. Any difficulties in understanding, as reported by the participants, were noted by the interviewer and were used to modify the instrument accordingly.(17)

## **2. 2. Quantitative study**

### *2. 2. 1. Participant recruitment*

Quantitative phase involved recruiting 8 to 15 year old CLH from three districts of West Bengal – Paschim Medinipur, Purba Medinipur and Kolkata. Additionally, children of same age group who were 'exposed to but not infected' with HIV were recruited in this phase. These children, referred to as 'HIV-affected children', were born to HIV-infected

mothers but were not HIV-positive themselves. Abovementioned SPARSHA registry was again used for recruitment. In addition, only for Kolkata city, contact lists of patients attending different ART centers were obtained from other CBOs working in tandem with SPARSHA for HIV/AIDS care in the state of West Bengal. We approached the families of 217 CLH and 232 HIV-affected children, out of which we managed to conduct interviews with 199 CLH and 194 affected children. Eligibility criteria for participating CLH were similar to that used for FGD. In case of HIV-affected group, we only considered those children, who were born to HIV infected mother and who had tested negative for HIV antibody at or after 18 months age. Rest of the eligibility criteria for affected children were same as that for CLH. The interviews were conducted between November, 2014 and February, 2015.

### *2.2.2. Data collection*

Following consent, brief demographic information were obtained from the caregivers of participating children. Additionally, CD4 cell counts, only for CLH, were recorded from 'ART card' issued by the treatment center. Each assenting participant was asked to complete the QOL-CHAI instrument with assistance from a trained interviewer. The interviews were conducted in a private room at participants' home or field office of collaborating CBO, as preferred by the participant. Participants were required to answer how much problem they had to face regarding each item in the instrument during the past month, except for the 'discrimination' domain which dealt with problems during the past year. Severity of the problems associated with each item were classified as follows; never (0), almost never (1), sometimes (2), often (3), and almost always (4). Interviews with children took approximately 15 minutes to complete.

### 2.2.3. *Statistical analysis*

Descriptive analyses were performed for items in each scale/domain of the QOL-CHAI instrument to determine parameters such as mean, median, standard deviation, proportion of 'ceiling' and 'floor' values etc. Cronbach's  $\alpha$  was calculated for each domain to determine internal consistency reliability. Additionally, for each item we determined correlation of that item with the scale it belonged to and the resultant change in Cronbach's  $\alpha$  with deletion of each item from the scale. Convergent validity of 'symptoms' and 'discrimination' scales, respectively, were assessed by estimating Pearson correlation coefficients with last reported CD4 cell count and social functioning scale score.(21) To assess known groups validity, we used a priori hypothesis that scores for each HRQoL domain would be significantly lower for CLH, compared to HIV-affected children. Wilcoxon rank sum tests were performed to evaluate if scale scores differed based on infection status.

We sought to ascertain, using 'backward elimination' regression analysis,(22) if the newly incorporated scales, 'symptoms' and 'discrimination', yielded additional information on clinical status of CLH beyond that captured by PedsQL. This was assessed by regressing scale scores on last measured CD4 cell count and by checking if the scores from 'symptoms' and 'discrimination' scales accounted for significant unique variance. We also attempted to determine which scales in the newly developed instrument differentiated between HRQoL status of CLH and HIV-affected children by discriminant analysis. We performed stepwise discriminant analysis on 'infection status' with summary scores for each scale - to determine the scales that discriminated significantly between CLH and HIV-affected children.



We performed exploratory factor analysis with principal component extraction and 'varimax' rotation methods to examine if the factor loadings were consistent with the constructs being measured.(22) The number of factors to be extracted was determined by setting a cut-off of 75% of initial communality estimate(23) i.e. number of extracted factors were increased until the sum of eigenvalues for the retained factors exceeded 75 percent of the common variance.

All statistical analyses were performed using SAS 9.4.

### **3. RESULTS**

Among 199 CLH and 194 HIV-affected children interviewed, 65% and 52%, respectively, were males. The mean age of participating CLH was 11.3 years (SD  $\pm 2.5$  years), while that of HIV-affected children was 11.9 years (SD  $\pm 2.5$  years). Among participating CLH, 149 (75%) were on ART and 62% of them had CD4 count above 500/mm<sup>3</sup> at the time of last measurement. Table 1 provides socio-economic and demographic characteristics of the study population.

Cronbach's  $\alpha$  of QOL-CHAI scales for CLH, correlation of each item in a scale with total scale score, and effect of deletion of individual items on Cronbach's  $\alpha$  of that particular scale are presented in table 2. Cronbach's  $\alpha$  was found to be highest for social functioning scale (0.85) and lowest for discrimination scale (0.62). We observed that there was a marked increase in  $\alpha$  with deletion of first two items in discrimination scale ('the staff at hospital/health facilities misbehaved with me' and 'doctors misbehaved with me'). In case of items belonging to rest of the scales, there was either decrease or minimal increase with deletion of items. In view of such an observation, we decided to

delete those two items from discrimination scale.(24) This brought the number of items in discrimination scale down to four, and total number of items in QOL-CHAI to 45. Rest of the analysis was performed on this modified instrument containing eight items in physical functioning scale; five items each in emotional, social and school functioning scales; 18 items in symptoms scale and four items in discrimination scale. In terms of known groups validity, we found that CLH performed significantly worse ( $p < 0.01$ ) than HIV-affected children on all HRQoL domains except 'discrimination' (table 3).

Regarding convergent validity, symptom scale score showed significant negative correlation with last measured CD4 cell count (Pearson correlation coefficient ( $\rho$ )=-0.23,  $p<0.01$ ) i.e. the CLH with worse health status were likely to have lower CD4 cell count . Symptom scale also showed significant positive correlation with all other scale scores. Discrimination scale score was significantly correlated with social function score ( $\rho=0.4$ ,  $p<0.01$ ) (table 4).

'Backward elimination' regression analysis on last measured CD4 cell count with all six scale scores as independent variables and p-value cut-off of 0.3,(22) revealed that optimal model consisted of 'school functioning', 'symptoms', and 'discrimination' scales. Thus, both the newly incorporated scales, 'symptoms' and 'discrimination' provided additional information on health status of CLH beyond that captured by PedsQL (table 5).

Seven factors accounting for 75% of total variance were extracted from factor analysis of scale scores among children living with HIV. Table 6 shows that except for 'symptoms' scale, all items belonging to a single scale had maximum loading on the

same (but discrete from others) factor. Only for 'symptoms' scale items split into different factors – among them nine items maximally loaded on to factor-6 and four loaded on to factor-7. Stepwise discriminant analysis (table 7) identified that among QOL-CHAI scales, 'physical functioning', 'school functioning', and 'symptoms' scales significantly discriminated between CLH and HIV-affected children, adjusting for other scales.

#### **4. DISCUSSION**

The objective of this study was to develop and evaluate the psychometric properties of an instrument to assess HRQoL of children living with HIV in India. The newly created instrument QOL-CHAI incorporates four generic core scales of the PedsQL, a widely used disease-independent HRQoL tool, along with two scales measuring symptoms and discrimination related constructs that were identified from qualitative inquiry.

Internal consistency reliability, as measured by Cronbach's  $\alpha$  coefficient was high for all scales. Except 'symptoms' scale, which had  $\alpha$  of 0.69, rest of the scales showed  $\alpha$  value more than recommended 0.7,(25) making the scales capable of group comparisons (between CLH and HIV-affected). Distribution of all the scale scores were right skewed, with mean being greater than median for all scales except 'school functioning' (where mean equaled median). We observed that a good amount of responses for all scales exhibited lowest possible value (floor effect), especially 'discrimination' and 'social functioning' scales. Punpanich et al reported a similar finding with ThQLHC.(9) This can be attributed to the fact that we recruited participants, including CLH, from respective community settings and not from health facilities. Thus, the 'floor effect' seen in HRQoL

domains was an indicator that most participants in our study were ambulatory and not severely diseased. Also, as was revealed during qualitative investigation and review of prior studies conducted in the region,(26) (reference chapter 4) most caregivers made a conscious effort to keep their (and their children's) HIV status secret in order to avoid being stigmatized. We hypothesize that families of most children reporting no experience of discrimination or no decline in 'social functioning' were clandestine about their or their family members' disease status. It has been reported in the literature that if a considerable proportion of subjects obtained the best possible score with an instrument, the concerned instrument may be considered less sensitive at the 'better' spectrum of the construct being measured.(27) On the other hand, instruments that exhibit such 'floor effects' are likely to be more perceptive in detecting any decline in the measured construct – an important quality for an HIV-targeted HRQoL scale, as it can be anticipated that the overall health and, in turn, HRQoL of individuals living with HIV may worsen with time.(9, 28)

Regarding known groups validity, scores on all scales, except 'discrimination', showed statistically significant differences based on the HIV infection status of children. As per our priori hypothesis, CLH had significantly poorer 'physical', 'emotional', 'social', 'school' and 'symptoms' status, compared to HIV-affected children. The fact that 'discrimination' scale scores did not differ significantly between these two groups was not entirely surprising as HIV-related stigma, including social ostracization, were often directed towards the entire family, even if only a single member of that family was infected. As recorded in our qualitative inquiries and also during previous work carried out by the collaborating CBO in the same study area,(26) even the healthy children of

parents living with HIV were often subjected to discrimination in school and community settings. Also, as mentioned above, most participants did not report experiencing any discriminatory behavior during the past year, possibly because they and their family members kept their HIV diagnosis a secret. Thus, the low mean scores obtained in 'discrimination' scale, as can be seen from table 3, reduced the statistical power of detecting a difference between groups.

As had been expected, the 'symptoms' scale score showed significant negative correlation with last measured CD4 cell count, indicating that CD4 count was likely to decline with worsening of HIV symptoms and vice versa. The hypothesis that betterment/worsening of disease symptoms should be associated with respective improvement/decline in HRQoL, was confirmed by a positive correlation of 'symptoms' score with the score in rest of the scales. We also anticipated that the 'discrimination' scale score would be positively correlated with 'social functioning', as experiences of discrimination were likely to hamper social interactions. Significant positive correlation of 'physical functioning' scale with rest of the scales was also not surprising given the psychosomatic nature of the infection.(29) Thus, as per our hypothesis, we found satisfactory level of convergent validity of QOL-CHAI scales with measures assessing concepts related to the HRQoL construct being measured.

Factor analysis of the scale scores for CLH revealed that the factor structure of the entire instrument was roughly in agreement with the domain specific categorization of QOL-CHAI. Among the scale scores, only the 'symptoms' scale had cross-loading across different factors. This was not entirely unexpected as a multitude of varying symptoms constituted this scale. Despite the cross-loadings, the fact that most items

(13) of 'symptoms' scale had maximum loading on two factors independent from rest of the factors, suggested that unique information was captured by the 'symptoms' scale.

The backward elimination method for variable selection showed that, adjusting for other parameters, 'school functioning', 'symptoms', and 'discrimination' scale scores were important predictors of clinical outcome (measured by CD4 cell count) of CLH. Thus, both newly incorporated scales, 'symptoms' and 'discrimination, provided additional unique information on clinical status of CLH beyond that captured by PedsQL. Further, from stepwise discriminant analysis we observed that the 'symptoms' scale, along with the 'school functioning' and 'physical functioning' scales, successfully distinguished between CLH and HIV-affected children, establishing 'symptoms' scale as an important component of QOL-CHAI to compare between HIV-infected with uninfected.

Our study suffered from some important limitations that are worth mentioning. First, we cannot claim that the study population was representative. The participants of this study were recruited through convenience sampling from the contact list of a CBO that provided various preventive and awareness services to adults and children living with HIV in the study area. In the Indian context, most recipients of such services belong to the lower socio-economic strata of the society. This characteristics applied to current study participants as well, as substantiated by poor financial condition and low parental literacy level. Hence, results presented here are neither necessarily representative of nor generalizable to HIV-infected and –affected children from all socio-economic classes. Second, test-retest reliability and correlation with parental-proxy report (as performed with PedsQL) were not assessed. While logistical and ethical considerations of re-contacting a vulnerable population prevented us from assessing test-retest

reliability, low numerical literacy among majority of parents was also a hindrance for recording parental-proxy report. Third, although plasma viral load (PVL) is considered a better indicator of clinical condition than CD4 count, it is not offered under the standard treatment protocol in government run HIV centers and most CLH participants in this study never had their PVL measured. Thus, it was not possible to utilize PVL in analyses related to clinical outcome. Fourth, it is possible that some answers from participating children were biased by social desirability, especially for items in 'social functioning', 'school functioning' and 'discrimination' domains. Finally, as discussed above, most participants in this study were ambulatory and/or in good health and reported no or very few problems in most HRQoL domains. Thus, performance of the scales for severely ill HIV-infected children remains to be evaluated.

Notwithstanding the above limitations, the QOL-CHAI, to the best of our knowledge, is the first India specific HIV-targeted HRQoL instrument that has been constructed using triangulation of caregivers' and children's perspectives from qualitative inquiries. A large sample size and an analogous comparison group were major strengths of this study. It can be presumed that characteristics (parental HIV status, similar socioeconomic background, recipients of services from same CBO) of HIV-affected children recruited in this study made them a valid comparison group of CLH, with HIV infection being the single major factor affecting the HRQoL between the groups. Collaborating with a local CBO, despite the methodological limitations, not only enabled us to recruit a large number of participants from a vulnerable population, but also allowed us to conduct interviews independent of hospital or treatment settings. We believe such measures enhanced the quality of interview responses as participants were not apprehensive

about any negative repercussions from their treatment facilities.(30) As the participants were 8 to 15 year old children, it was important to ensure they understood the meaning of each item in the instrument. Keeping that in mind, we conducted cognitive interviews, prior to large scale application, to linguistically validate translated version of PedsQL generic core and to fine-tune the items in QOL-CHAI.

The published literature suggests that HRQoL assessment of individuals living with HIV allows health care providers to obtain patient's perceptions about the disease and its consequences, and, in turn, improves treatment effectiveness and adherence.(31) However, compared to HRQoL assessment of HIV-infected adults, owing to methodological and other challenges, much less progress has been made regarding evaluation of HRQoL among CLH, especially in developing country settings.(2, 31) The results of this study demonstrate that QOL-CHAI, administered by trained health workers, can serve well as a brief, standardized, culturally appropriate instrument to measure HRQoL of Indian children and adolescents living with HIV. With acceptable psychometric properties, wide scale implementation of QOL-CHAI can not only help assess overall health status at the individual level, but can also inform national HIV program policy for improving treatment and support services.



## 5. TABLES

**Table 1. Characteristics of study participants (n = 393).**

| <b>Characteristic</b>                           | <b>Children living with HIV (n=199)</b> | <b>HIV-affected children (n=194)</b> |
|---|---|--------------------------------------|
|   | <b>Frequency (%)*</b>                   | <b>Frequency (%)*</b>                |
| Mean age in years (SD)                          | 11.9 (2.5)                              | 11.3 (2.5)                           |
| Male  | 130 (65.3)                              | 101 (52.1)                           |
| Residential district                            |   |                                      |
| <i>Paschim Medinipur</i>                        | 90 (45.2)                               | 133 (68.6)                           |
| <i>Purba Medinipur</i>                          | 24 (12.1)                               | 31 (16)                              |
| <i>Kolkata</i>                                  | 85 (42.7)                               | 30 (15.5)                            |
| Primary caregiver                               |   |                                      |
| <i>Mother</i>                                   | 154 (77.4)                              | 185 (95.4)                           |
| <i>Father</i>                                   | 6 (3)                                   | 1 (0.5)                              |
| <i>Others</i>                                   | 39 (19.6)                               | 8 (4.1)                              |
| Parent status                                   |   |                                      |
| <i>Both parents alive</i>                       | 91 (45.7)                               | 129 (66.5)                           |
| <i>Single parent orphan</i>                     | 86 (43.2)                               | 62 (32)                              |
| <i>Both parent orphan</i>                       | 22 (11.1)                               | 3 (1.6)                              |
| School drop-out                                 | 12 (6)                                  | 7 (3.6)                              |
| Mother's education                              |   |                                      |
| <i>Did not attend school</i>                    | 57 (28.6)                               | 27 (13.9)                            |
| <i>Primary school</i>                           | 27 (13.6)                               | 41 (21.1)                            |
| <i>Middle school</i>                            | 100 (50.3)                              | 122 (62.9)                           |
| <i>High school or above</i>                     | 11 (5.5)                                | 4 (2)                                |
| <i>Not reported</i>                             | 4 (2)                                   | -                                    |
| Father's education                              |   |                                      |
| <i>Did not attend school</i>                    | 37 (18.6)                               | 32 (16.5)                            |
| <i>Primary school</i>                           | 44 (22.1)                               | 60 (30.9)                            |
| <i>Middle school</i>                            | 95 (47.7)                               | 98 (50.5)                            |
| <i>High school or above</i>                     | 11 (5.5)                                | 2 (1)                                |
| <i>Not reported</i>                             | 12 (6)                                  | 2 (1)                                |
| Per-capita family income (in INR/month)         |   |                                      |
| <i>1st quartile (≤375)</i>                      | 52 (26.1)                               | 50 (25.8)                            |
| <i>2nd quartile (≥400 - ≤600)</i>               | 37 (18.6)                               | 65 (33.5)                            |
| <i>3rd quartile (≥625 - ≤1000)</i>              | 60 (30.2)                               | 55 (28.4)                            |
| <i>4th quartile (≥1111)</i>                     | 50 (25.1)                               | 24 (12.4)                            |
| Last measured CD4 cell count(/mm <sup>3</sup> ) |   |                                      |
| <250  | 16 (8)                                  | -                                    |
| ≥250 - <500                                     | 56 (28.1)                               | -                                    |
| ≥500  | 123 (61.8)                              | -                                    |
| <i>Not reported</i>                             | 4 (2)                                   | -                                    |

\*Values may not sum to 100% due to rounded numbers

**Table 2. Internal consistency reliability estimates of the QOL-CHAI instrument for children living with HIV (n=199)\***

| Scale                 | Items   | Cronbach's $\alpha$ | Correlation of item with total scale score | Cronbach's $\alpha$ following deletion of item |
|-----------------------|---|---------------------|--|--|
| Physical functioning  | It was difficult for me to walk 8-10 minutes at a stretch | 0.82                | 0.52                                       | 0.80   |
|                       | I had difficulty running                                  |                     | 0.62                                       | 0.78   |
|                       | I had difficulty playing or exercising                    |                     | 0.69                                       | 0.77   |
|                       | I had difficulty in lifting heavy objects                 |                     | 0.52                                       | 0.80   |
|                       | It was hard for me to bathe by myself                     |                     | 0.44                                       | 0.81   |
|                       | It was hard for me to do housework                        |                     | 0.55                                       | 0.79   |
|                       | I had bodily pain, ache or discomfort                     |                     | 0.46                                       | 0.81   |
| I felt weak           | 0.50  | 0.80                |  |  |
| Emotional functioning | I felt afraid   | 0.79                | 0.53                                       | 0.76   |
|                       | I felt sad or depressed                                   |                     | 0.65                                       | 0.73   |
|                       | I felt angry  |                     | 0.49                                       | 0.78   |
|                       | I had difficulty sleeping                                 |                     | 0.60                                       | 0.74   |
|                       | I felt worried about what would happen to me              |                     | 0.57                                       | 0.75   |
| Social functioning    | I had trouble getting along with friends                  | 0.85                | 0.71                                       | 0.81   |
|                       | Other boys/girls did not want to be friends with me       |                     | 0.68                                       | 0.81   |
|                       | Other boys/girls made fun of me                           |                     | 0.65                                       | 0.82   |
|                       | I could not do things that my friends could do            |                     | 0.62                                       | 0.83   |
|                       | I could not catch up with friends while playing           |                     | 0.64                                       | 0.83   |
| School functioning    | I could not pay attention in class                        | 0.76                | 0.67                                       | 0.67   |
|                       | I forgot many things                                      |                     | 0.54                                       | 0.72   |
|                       | I had difficulty in catching up with my studies           |                     | 0.49                                       | 0.74   |
|                       | I missed school because of being sick                     |                     | 0.49                                       | 0.74   |
|                       | I missed school in order to visit doctor/hospital         |                     | 0.48                                       | 0.74   |
| Symptoms              | Fever   | 0.69                | 0.46                                       | 0.65   |
|                       | Common cold   |                     | 0.34                                       | 0.66   |
|                       | Weight loss, emaciation                                   |                     | 0.41                                       | 0.66   |
|                       | Diarrhea, loose stool                                     |                     | 0.33                                       | 0.67   |

|                |  |        |      |      |
|----------------|--|--------|------|------|
|                | Pain in the limbs  |        | 0.21 | 0.68 |
|                | Headache   |        | 0.24 | 0.68 |
|                | Skin rash, itchy lesions, sore/ulcer   |        | 0.17 | 0.68 |
|                | Vomiting, nausea   |        | 0.33 | 0.67 |
|                | Ear discharge, hearing difficulties  |        | 0.04 | 0.70 |
|                | Loss of appetite   |        | 0.18 | 0.68 |
|                | Abdominal pain   |        | 0.32 | 0.67 |
|                | Jaundice, yellowish discoloration of eye   |        | 0.10 | 0.69 |
|                | Dizziness  |        | 0.19 | 0.68 |
|                | Throat swelling, sore throat   |        | 0.33 | 0.67 |
|                | Abdominal distension   |        | 0.24 | 0.68 |
|                | Shortness of breath, wheezing  |        | 0.30 | 0.67 |
|                | Tingling sensation/numbness in the limbs   |        | 0.25 | 0.67 |
|                | Oral ulcer   |        | 0.42 | 0.66 |
|                | The staff at hospital/health facilities misbehaved with me <sup>#</sup>          |        | 0.03 | 0.70 |
|                | Doctors misbehaved with me   |        | 0.04 | 0.69 |
|                | I was not allowed admission in school/ private tutorial institution <sup>#</sup> |        | 0.60 | 0.48 |
| Discrimination | I was made to sit separately in school/ private tutorial institution             | 0.62** | 0.54 | 0.50 |
|                | Other boys/girls refused to play with me   |        | 0.53 | 0.50 |
|                | People in the neighborhood did not allow their kids to play with me              |        | 0.48 | 0.52 |

\*Observations with missing values excluded as applicable.

<sup>#</sup>These two items were deleted from the scale. \*\*Cronbach's  $\alpha$  of discrimination scale following deletion of two items = 0.8.

**Table 3. Descriptive statistics of the QOL-CHAI instrument for children living with HIV (n=199) and children exposed to but not infected with HIV (n=194)**

| Scale                               | No. of items | Mean score | Standard deviation | Minimum score | Maximum score | Median score | % scoring floor | % scoring ceiling | Wilcoxon rank sum p value* |
|-------------------------------------|--------------|------------|--------------------|---------------|---------------|--------------|-----------------|-------------------|----------------------------|
| <i>For children living with HIV</i> |              |            |                    |               |               |              |                 |                   |                            |
| Physical functioning (range 0-32)   | 8            | 6.1        | 5.9                | 0             | 31            | 4            | 13.6            | 0                 | <.01                       |
| Emotional functioning (range 0-20)  | 5            | 5.4        | 4                  | 0             | 17            | 5            | 10.6            | 0                 | <.01                       |
| Social functioning (range 0-20)     | 5            | 2.4        | 3.9                | 0             | 16            | 0            | 56.3            | 0                 | <.01                       |
| School functioning (range 0-20)*    | 5            | 5          | 3.6                | 0             | 15            | 5            | 7.5             | 0                 | <.01                       |

|                              |    |     |     |   |    |   |      |     |      |
|------------------------------|----|-----|-----|---|----|---|------|-----|------|
| Symptoms (range 0-72)        | 18 | 9.8 | 6.1 | 0 | 39 | 9 | 3.5  | 0   | <.01 |
| Discrimination (range 0-16)* | 4  | 0.6 | 1.7 | 0 | 16 | 0 | 79.9 | 0.5 | 0.12 |

*For children exposed to but not infected with HIV*

|                                    |    |     |     |   |    |   |      |   |   |
|------------------------------------|----|-----|-----|---|----|---|------|---|---|
| Physical functioning (range 0-32)  | 8  | 2.4 | 3.1 | 0 | 21 | 2 | 36.6 | 0 | - |
| Emotional functioning (range 0-20) | 5  | 4.1 | 3   | 0 | 16 | 4 | 15.5 | 0 | - |
| Social functioning (range 0-20)    | 5  | 0.7 | 1.9 | 0 | 16 | 0 | 78.9 | 0 | - |
| School functioning (range 0-20)#   | 5  | 2.5 | 2.4 | 0 | 12 | 2 | 28.9 | 0 | - |
| Symptoms (range 0-72)              | 18 | 5.6 | 4.5 | 0 | 22 | 5 | 12.9 | 0 | - |
| Discrimination (range 0-16)#       | 4  | 0.3 | 1   | 0 | 8  | 0 | 88.7 | 0 | - |

\* 11 missing values excluded. #7 missing values excluded.

\*\* *p* value for difference in scale scores between children living with HIV (CLH) and HIV exposed but not infected (HIV-affected) children.

**Table 4. Pearson correlation coefficient among scale scores for children living with HIV (n=199)#**

|                       | CD4 count | Physical functioning | Emotional functioning | Social functioning | School functioning | Symptoms | Discrimination |
|-----------------------|-----------|----------------------|-----------------------|--------------------|--------------------|----------|----------------|
| CD4 count             | 1         |                      |                       |                    |                    |          |                |
| Physical functioning  | -0.020    | 1                    |                       |                    |                    |          |                |
| Emotional functioning | -0.018    | 0.252*               | 1                     |                    |                    |          |                |
| Social functioning    | 0.003     | 0.444*               | 0.172*                | 1                  |                    |          |                |
| School functioning    | 0.088     | 0.261*               | 0.121                 | 0.216*             | 1                  |          |                |
| Symptoms              | 0.160*    | 0.472*               | 0.215*                | 0.327*             | 0.269*             | 1        |                |
| Discrimination        | 0.060     | 0.149*               | 0.134                 | 0.409*             | 0.024              | 0.172*   | 1              |

#Observations with missing values excluded as applicable. \**p*≤0.05.

**Table 5. Backward elimination regression analysis on last measured CD4 cell count of children living with HIV (n=188)\***

| Scale              | Parameter estimate | Standard error | <i>t</i> statistic | <i>p</i> value | <i>R</i> <sup>2</sup> |
|--------------------|--------------------|----------------|--------------------|----------------|-----------------------|
| Constant           | 732.1              | 57.9           | 12.7               | <.01           |                       |
| School functioning | 14.8               | 7.6            | 1.9                | 0.05           | 0.04                  |
| Symptoms           | -14.4              | 5.1            | -2.8               | <.01           |                       |
| Discrimination     | 20.2               | 15.9           | 1.3                | 0.21           |                       |

\*Observations with missing values excluded. *p* value cut-off for selection = 0.3

**Table 6. Factor loadings for QOL-CHAI among children living with HIV (n = 188)\***

| Scale                 | Items   | Factor 1 | Factor 2 | Factor 3 | Factor 4 | Factor 5 | Factor 6 | Factor 7 |
|-----------------------|---|----------|----------|----------|----------|----------|----------|----------|
| Physical functioning  | It was difficult for me to walk 8-10 minutes at a stretch | 0.41     | -0.09    | 0.28     | 0.16     | 0.01     | 0.07     | -0.01    |
|                       | I had difficulty running                                  | 0.66     | 0.17     | 0.10     | 0.02     | 0.10     | 0.11     | -0.01    |
|                       | I had difficulty playing or exercising                    | 0.67     | 0.14     | 0.14     | 0.11     | 0.10     | 0.00     | 0.04     |
|                       | I had difficulty in lifting heavy objects                 | 0.47     | -0.08    | 0.11     | -0.03    | 0.09     | 0.00     | 0.29     |
|                       | It was hard for me to bathe by myself                     | 0.33     | -0.03    | 0.23     | -0.22    | -0.07    | -0.17    | 0.04     |
|                       | It was hard for me to do housework                        | 0.45     | 0.20     | 0.20     | 0.11     | 0.03     | -0.17    | 0.22     |
|                       | I had bodily pain, ache or discomfort                     | 0.52     | 0.01     | 0.20     | 0.25     | 0.17     | 0.11     | -0.06    |
|                       | I felt weak   | 0.52     | 0.07     | 0.02     | 0.20     | 0.02     | 0.27     | 0.06     |
| Emotional functioning | I felt afraid   | 0.11     | 0.12     | 0.10     | 0.56     | 0.18     | 0.06     | -0.07    |
|                       | I felt sad or depressed                                   | 0.09     | 0.04     | 0.09     | 0.72     | -0.04    | -0.07    | 0.08     |
|                       | I felt angry  | 0.05     | 0.12     | 0.01     | 0.58     | -0.03    | -0.07    | -0.05    |
|                       | I had difficulty sleeping                                 | 0.11     | 0.03     | 0.13     | 0.66     | 0.15     | -0.01    | 0.08     |
|                       | I felt worried about what would happen to me              | 0.08     | -0.05    | -0.03    | 0.69     | -0.08    | 0.01     | -0.07    |
| Social functioning    | I had trouble getting along with friends                  | 0.15     | 0.49     | 0.68     | 0.07     | 0.05     | 0.08     | -0.13    |
|                       | Other boys/girls did not want to be friends with me       | 0.06     | 0.47     | 0.65     | 0.03     | 0.16     | 0.19     | -0.05    |
|                       | Other boys/girls made fun of me                           | 0.15     | 0.12     | 0.67     | 0.10     | 0.08     | 0.07     | 0.13     |
|                       | I could not do things that my friends could do            | 0.21     | 0.00     | 0.68     | 0.06     | 0.08     | 0.03     | 0.19     |
|                       | I could not catch up with friends while playing           | 0.28     | 0.10     | 0.64     | 0.05     | 0.03     | 0.03     | 0.24     |
|                       | I could not pay attention in class                        | 0.11     | 0.03     | 0.03     | 0.03     | 0.76     | 0.05     | 0.09     |
| School functioning    | I forgot many things                                      | 0.07     | 0.04     | -0.06    | 0.08     | 0.70     | 0.01     | -0.19    |
|                       | I had difficulty in catching up with my studies           | -0.02    | -0.07    | 0.12     | 0.04     | 0.65     | -0.04    | 0.01     |

|                |  |             |             |       |             |             |             |             |
|----------------|--|-------------|-------------|-------|-------------|-------------|-------------|-------------|
| Symptoms       | I missed school because of being sick                                | 0.21        | 0.06        | 0.18  | 0.11        | <b>0.52</b> | 0.12        | 0.34        |
|                | I missed school in order to visit doctor/hospital                    | 0.13        | 0.01        | 0.11  | -0.05       | <b>0.50</b> | 0.11        | 0.25        |
|                | Fever  | 0.13        | 0.13        | -0.02 | 0.13        | 0.23        | <b>0.44</b> | 0.17        |
|                | Common cold  | 0.20        | 0.01        | 0.07  | -0.04       | 0.17        | <b>0.38</b> | -0.04       |
|                | Weight loss, emaciation  | 0.24        | -0.09       | -0.04 | 0.05        | 0.13        | <b>0.29</b> | 0.13        |
|                | Diarrhea, loose stool  | 0.11        | -0.05       | 0.15  | 0.00        | 0.09        | <b>0.29</b> | 0.12        |
|                | Pain in the limbs  | <b>0.60</b> | -0.03       | 0.07  | 0.14        | 0.12        | 0.15        | -0.20       |
|                | Headache   | 0.07        | -0.08       | 0.01  | <b>0.34</b> | 0.07        | 0.30        | 0.17        |
|                | Skin rash, itchy lesions, sore/ulcer                                 | -0.03       | -0.02       | 0.11  | -0.01       | 0.09        | -0.01       | <b>0.22</b> |
|                | Vomiting, nausea   | -0.07       | 0.03        | 0.07  | 0.09        | 0.07        | <b>0.42</b> | 0.33        |
|                | Ear discharge, hearing difficulties                                  | 0.15        | <b>0.28</b> | 0.08  | 0.15        | 0.06        | -0.02       | -0.08       |
|                | Loss of appetite   | <b>0.18</b> | 0.02        | -0.01 | 0.02        | -0.01       | 0.04        | 0.10        |
|                | Abdominal pain   | 0.12        | -0.02       | 0.06  | 0.01        | -0.03       | <b>0.37</b> | -0.16       |
|                | Jaundice, yellowish discoloration of eye                             | 0.00        | -0.03       | -0.09 | 0.08        | 0.11        | <b>0.13</b> | -0.02       |
|                | Dizziness  | 0.03        | 0.06        | -0.06 | <b>0.34</b> | 0.06        | 0.31        | -0.07       |
|                | Throat swelling, sore throat   | 0.00        | 0.12        | 0.07  | -0.02       | -0.07       | <b>0.50</b> | 0.02        |
|                | Abdominal distension   | -0.08       | 0.02        | -0.04 | -0.16       | -0.14       | <b>0.42</b> | -0.01       |
|                | Shortness of breath, wheezing  | 0.16        | 0.22        | 0.05  | 0.07        | 0.01        | 0.14        | <b>0.29</b> |
|                | Tingling sensation/numbness in the limbs                             | 0.22        | -0.03       | 0.14  | -0.12       | 0.00        | -0.03       | <b>0.34</b> |
|                | Oral ulcer   | 0.16        | 0.07        | -0.09 | -0.09       | -0.02       | 0.09        | <b>0.17</b> |
| Discrimination | I was not allowed admission in school/ private tutorial institution# | 0.13        | <b>0.90</b> | 0.02  | 0.01        | -0.04       | -0.05       | -0.01       |
|                | I was made to sit separately in school/ private tutorial institution | 0.04        | <b>0.86</b> | 0.02  | -0.01       | 0.04        | -0.03       | -0.05       |
|                | Other boys/girls refused to play with me                             | -0.11       | <b>0.57</b> | 0.22  | 0.05        | -0.07       | 0.19        | 0.17        |
|                | People in the neighborhood did not allow their kids to play with me  | -0.01       | <b>0.51</b> | 0.22  | 0.13        | -0.08       | 0.06        | 0.37        |

\*Observations with missing values excluded. Bold numbers indicate maximum factor loading for each item.

**Table 7. Stepwise discriminant analysis to identify scales that discriminated between children living with HIV (n=188)\* and children exposed to but not infected with HIV (n=187)\***

| Retained scales      | Partial $R^2$ | F statistic | $p$ value | Average squared canonic correlation | $p$ value of avg sq canonic correlation |
|----------------------|---------------|-------------|-----------|-------------------------------------|---|
| School functioning   | 0.15          | 63.54       | <.01      | 0.15                                | <.01                                    |
| Physical functioning | 0.07          | 26.62       | <.01      | 0.20                                | <.01                                    |
| Symptoms             | 0.03          | 10.08       | <.01      | 0.22                                | <.01                                    |

Area under curve (AUC) for the full model = 0.791. AUC for the model with 3 selected variables = 0.786.

\*Observations with missing values excluded

## 6. APPENDIX

### QOL-CHAI instrument

(First 4 domains have been adapted from PedsQL - copyright © 1998 JW Varni, PhD.)

**How much problem** have you faced **during past one month** due to each of the following....

| <b>RELATED TO MY HEALTH AND DAILY ACTIVITIES (problems faced during past one month)</b> | Never | Almost Never | Some-times | Often | Almost Always |
|---|-------|--------------|------------|-------|---------------|
| 1. It was difficult for me to walk 8-10   | 0     | 1            | 2          | 3     | 4             |
| 2. I had difficulty running   | 0     | 1            | 2          | 3     | 4             |
| 3. I had difficulty playing or exercising   | 0     | 1            | 2          | 3     | 4             |
| 4. I had difficulty in lifting heavy objects  | 0     | 1            | 2          | 3     | 4             |
| 5. It was hard for me to bathe by myself  | 0     | 1            | 2          | 3     | 4             |
| 6. It was hard for me to do housework   | 0     | 1            | 2          | 3     | 4             |
| 7. I had bodily pain, ache or discomfort  | 0     | 1            | 2          | 3     | 4             |
| 8. I felt weak  | 0     | 1            | 2          | 3     | 4             |

| <b>RELATED TO MY EMOTIONS (problems faced during past one month)</b> | Never | Almost Never | Some-times | Often | Almost Always |
|--|-------|--------------|------------|-------|---------------|
| 1. I felt afraid   | 0     | 1            | 2          | 3     | 4             |
| 2. I felt sad or depressed   | 0     | 1            | 2          | 3     | 4             |

|  |   |   |   |   |   |
|--|---|---|---|---|---|
| 3. I felt angry                              | 0 | 1 | 2 | 3 | 4 |
| 4. I had difficulty sleeping                 | 0 | 1 | 2 | 3 | 4 |
| 5. I felt worried about what would happen to | 0 | 1 | 2 | 3 | 4 |

| <b>RELATED TO BONDING WITH OTHERS<br/>(problems faced during past one month)</b> | Never | Almost Never | Sometimes | Often | Almost Always |
|--|-------|--------------|-----------|-------|---------------|
| 1. I had trouble getting along with friends                                      | 0     | 1            | 2         | 3     | 4             |
| 2. Other boys/girls did not want to be friends                                   | 0     | 1            | 2         | 3     | 4             |
| 3. Other boys/girls made fun of me   | 0     | 1            | 2         | 3     | 4             |
| 4. I could not do things that my friends could                                   | 0     | 1            | 2         | 3     | 4             |
| 5. I could not catch up with friends while                                       | 0     | 1            | 2         | 3     | 4             |

| <b>RELATED TO SCHOOL (problems faced during past one month)</b> | Never | Almost Never | Sometimes | Often | Almost Always |
|---|-------|--------------|-----------|-------|---------------|
| 1. I could not pay attention in class                           | 0     | 1            | 2         | 3     | 4             |
| 2. I forgot many things   | 0     | 1            | 2         | 3     | 4             |
| 3. I had difficulty in catching up with my                      | 0     | 1            | 2         | 3     | 4             |
| 4. I missed school because of being sick                        | 0     | 1            | 2         | 3     | 4             |
| 5. I missed school in order to visit                            | 0     | 1            | 2         | 3     | 4             |

| <b>RELATED TO SYMPTOMS (problems faced during past one month)</b> | Never | Almost Never | Sometimes | Often | Almost Always |
|---|-------|--------------|-----------|-------|---------------|
| 1. Fever  | 0     | 1            | 2         | 3     | 4             |
| 2. Common cold  | 0     | 1            | 2         | 3     | 4             |
| 3. Weight loss, emaciation  | 0     | 1            | 2         | 3     | 4             |
| 4. Diarrhea, loose stool  | 0     | 1            | 2         | 3     | 4             |
| 5. Pain in the limbs  | 0     | 1            | 2         | 3     | 4             |
| 6. Headache   | 0     | 1            | 2         | 3     | 4             |
| 7. Skin rash, itchy lesions, sore/ulcer                           | 0     | 1            | 2         | 3     | 4             |
| 8. Vomiting, nausea   | 0     | 1            | 2         | 3     | 4             |
| 9. Ear discharge, hearing difficulties                            | 0     | 1            | 2         | 3     | 4             |
| 10. Loss of appetite  | 0     | 1            | 2         | 3     | 4             |
| 11. Abdominal pain  | 0     | 1            | 2         | 3     | 4             |



|  |   |   |   |   |   |
|--|---|---|---|---|---|
| 12. Yellowish discoloration of eye/ jaundice | 0 | 1 | 2 | 3 | 4 |
| 13. Dizziness                                | 0 | 1 | 2 | 3 | 4 |
| 14. Throat swelling, sore throat             | 0 | 1 | 2 | 3 | 4 |
| 15. Abdominal distension                     | 0 | 1 | 2 | 3 | 4 |
| 16. Shortness of breath, wheezing            | 0 | 1 | 2 | 3 | 4 |
| 17. Tingling sensation/numbness in the limbs | 0 | 1 | 2 | 3 | 4 |
| 18. Oral ulcer                               | 0 | 1 | 2 | 3 | 4 |

Please answer the following questions keeping in mind your experiences during **past one year**.

**How much problem** have you faced **during past one year** due to each of the following....

| <b>RELATED TO DISCRIMINATING BEHAVIOR<br/>(problems faced during past one year)</b> | <b>Never</b> | <b>Almost<br/>Never</b> | <b>Some-<br/>times</b> | <b>Often</b> | <b>Almost<br/>Always</b> |
|---|--------------|-------------------------|------------------------|--------------|--------------------------|
| 1. I was not allowed admission in school/<br>private tutorial institution           | 0            | 1                       | 2                      | 3            | 4                        |
| 2. I was made to sit separately in school/<br>private tutorial institution          | 0            | 1                       | 2                      | 3            | 4                        |
| 3. Other boys/girls refused to play with me   | 0            | 1                       | 2                      | 3            | 4                        |
| 4. People in the neighborhood did not allow<br>their kids to play with me           | 0            | 1                       | 2                      | 3            | 4                        |

## 7. REFERENCES

1. Smith KW, Avis NE, Assmann SF. Distinguishing between quality of life and health status in quality of life research: a meta-analysis. Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation. 1999;8(5):447-59. Epub 1999/09/04. PubMed PMID: 10474286.
2. Mabugu T, Revill P, van den Berg B. The Methodological Challenges for the Estimation of Quality of Life in Children for Use in Economic Evaluation in Low-Income Countries. Value in Health Regional Issues. 2013;2(2):231-9.

3. Health-Related Quality of Life (HRQOL) Centers for Disease Control and Prevention [cited 2015 March 2]. Available from: <http://www.cdc.gov/hrqol/concept.htm#six>.
4. Guyatt GH, Feeny DH, Patrick DL. Measuring health-related quality of life. *Annals of internal medicine*. 1993;118(8):622-9. Epub 1993/04/15. PubMed PMID: 8452328.
5. Stevenson M. HIV-1 pathogenesis. *Nature medicine*. 2003;9(7):853-60. Epub 2003/07/02. doi: 10.1038/nm0703-853. PubMed PMID: 12835705.
6. Testa M, Lenderking W. Quality of life considerations in AIDS clinical trials. *AIDS clinical trials*. 1995:150-9.
7. Beaglehole R, Irwin A, Prentice T, Organization WH. *The world health report 2003: shaping the future*: World Health Organization; 2003.
8. Franchi D, Wenzel RP. Measuring health-related quality of life among patients infected with human immunodeficiency virus. *Clinical infectious diseases : an official publication of the Infectious Diseases Society of America*. 1998;26(1):20-6. Epub 1998/02/10. PubMed PMID: 9455505.
9. Punpanich W, Hays RD, Detels R, Chokephaibulkit K, Chantbuddhiwet U, Leowsrisook P, et al. Development of a culturally appropriate health-related quality of life measure for human immunodeficiency virus-infected children in Thailand. *Journal of paediatrics and child health*. 2011;47(1-2):27-33. Epub 2010/10/27. doi: 10.1111/j.1440-1754.2010.01886.x. PubMed PMID: 20973862; PubMed Central PMCID: PMC3033216.
10. Skevington SM, O'Connell KA. Measuring quality of life in HIV and AIDS: A review of the recent literature. *Psychology and health*. 2003;18(3):331-50.
11. Turan JM, Nyblade L. HIV-related stigma as a barrier to achievement of global PMTCT and maternal health goals: a review of the evidence. *AIDS and behavior*. 2013;17(7):2528-39. Epub 2013/03/12. doi: 10.1007/s10461-013-0446-8. PubMed PMID: 23474643.

12. National AIDS Control Organisation Annual Report 2012-2013. Department of AIDS Control, Ministry of Health and Family Welfare, Government of India, 2013 5th January, 2015. Report No.
13. Green J, Thorogood N. Qualitative methods for health research: Sage; 2013.
14. Punpanich W. Development of a Culturally Appropriate Health-related Quality of Life Measure for HIV-infected Children in Thailand: ProQuest; 2009.
15. Varni JW, Seid M, Kurtin PS. PedsQL 4.0: reliability and validity of the Pediatric Quality of Life Inventory version 4.0 generic core scales in healthy and patient populations. Medical Care. 2001;39(8):800-12. Epub 2001/07/27. PubMed PMID: 11468499.
16. Varni JW, Seid M, Rode CA. The PedsQL: measurement model for the pediatric quality of life inventory. Medical Care. 1999;37(2):126-39. Epub 1999/02/19. PubMed PMID: 10024117.
17. The linguistic validation - PedsQL™. Mapi Research Institute, 2002 June 30, 2014. Report No.
18. Young TL, Kirchdoerfer LJ, Osterhaus JT. A Development and Validation Process for a Disease-Specific Quality of Life Instrument\*. Drug Inf J. 1996;30(1):185-93.
19. Juniper EF, Guyatt GH, Jaeschke R. How to develop and validate a new health-related quality of life instrument. Quality of life and pharmacoeconomics in clinical trials. 1996;2:49-56.
20. Harris LR, Brown GT. Mixing interview and questionnaire methods: Practical problems in aligning data. Practical Assessment, Research & Evaluation [Internet]. 2010 May 15, 2015; 15(1). Available from: <http://pareonline.net/pdf/v15n1.pdf>.
21. Elkin E. Are You in Need of Validation? Psychometric Evaluation of Questionnaires Using SAS. SAS Global Forum [Internet]. 2012 March 15, 2015. Available from: <http://support.sas.com/resources/papers/proceedings12/426-2012.pdf>.
22. Afifi A, Clark VA, May S. Practical multivariate analysis: Chapman & Hall; 2011.

23. Pett MA, Lackey NR, Sullivan JJ. Making sense of factor analysis: The use of factor analysis for instrument development in health care research: Sage; 2003.
24. Hof M. Questionnaire Evaluation with Factor Analysis and Cronbach's Alpha: An Example 2012 March 17, 2015. Available from: <http://www.let.rug.nl/nerbonne/teach/rema-stats-meth-seminar/student-papers/MHof-QuestionnaireEvaluation-2012-Cronbach-FactAnalysis.pdf>.
25. Nunnally J. C.(1978). Psychometric theory: New York: McGraw-Hill; 1978.
26. Panda S, Das RS, Maruf SKA, Pahari S. Exploring Stigma in Low HIV Prevalence Settings in Rural West Bengal, India: Identification of Intervention Considerations. Journal of Mixed Methods Research. 2014. doi: 10.1177/1558689814535843.
27. Streiner DL, Norman GR, Cairney J. Health measurement scales: a practical guide to their development and use: Oxford university press; 2014.
28. Bindman AB, Keane D, Lurie N. Measuring health changes among severely ill patients: the floor phenomenon. Medical care. 1990;1142-52.
29. Leserman J. Role of depression, stress, and trauma in HIV disease progression. Psychosom Med. 2008;70(5):539-45.
30. Mahendra VS, Gilborn L, Bharat S, Mudoi R, Gupta I, George B, et al. Understanding and measuring AIDS-related stigma in health care settings: a developing country perspective. SAHARA J : journal of Social Aspects of HIV/AIDS Research Alliance / SAHARA , Human Sciences Research Council. 2007;4(2):616-25. Epub 2007/12/12. PubMed PMID: 18071613.
31. Garvie PA, Lawford J, Banet MS, West RL. Quality of life measurement in paediatric and adolescent populations with HIV: a review of the literature. Child: care, health and development. 2009;35(4):440-53. Epub 2009/07/30. doi: 10.1111/j.1365-2214.2009.00985.x. PubMed PMID: 19638021.

## **Chapter VI: Children living with HIV and children born to parents infected with HIV in West Bengal, India – a comparison from quality of life perspective**

### **1. INTRODUCTION**

Children and adolescents living with HIV are the most affected by the current HIV epidemic globally and constitute the key target population for future epidemic control.(1, 2) Worldwide, in 2013, 3.2 million children and adolescents under 15 years had been living with HIV and about 150,000 of them were in India.(3, 4) Review of published literature reveals that these children, due to chronic nature of their disease, often face biologic, cognitive and social developmental challenges, as well as low self-esteem resulting from HIV-related stigma.(5-7) Moreover, apart from children living with HIV (CLH), the epidemic caused by this infection has also affected the lives of many other children who have been rendered orphans due to parental death from HIV.(8) Thus, the tremendous impact of HIV/AIDS at the family level invariably trickles down to the most susceptible population – children – irrespective of their own disease status.(5)

In developing countries, treatment policies on HIV have primarily depended on biological disease markers such as the CD4 lymphocyte count for assessment of infected individuals and for disbursement of health services. However, in view of the multitude of psychosocial challenges faced by adults and children living with HIV, such clinical markers often fail to provide a complete picture of the disease impact.(9)

Therefore, in order to comprehensively assess the overall impact of HIV infection on the lives people living with HIV (PLH) and to better inform the policy-makers regarding various needs of this population, health-related quality of life (HRQoL) measures are

increasingly being preferred as more efficient alternatives than the traditional clinical assessments of health.(10, 11) Large scale implementation of such measures can also help in monitoring the efficacy of care and support services delivered by various public health agencies.(12, 13) Moreover, with introduction of and increasing access to highly active anti-retroviral therapy (HAART), a great advancement has been made towards improving clinical parameters of HIV-infected and reducing morbidity and mortality associated with the disease.(14) However, there has been no unanimous agreement on the beneficial effects of HAART on HRQoL.(15) Some published studies have reported little change or even decline in HRQoL of patients following initiation of HAART, possibly owing to drug-related adverse events.(16-18) Therefore, it is important to assess the association of HAART with HRQoL in order to inform programmatic interventions targeted towards PLH.

Most research on HRQoL measures related to HIV has focused on the adult population.(12, 19) With increasing recognition of present and future vulnerabilities of CLH, the importance of assessing the perspectives of children regarding their physical and emotional well-being and functional abilities has started to be acknowledged in the field of clinical care and pediatric health research.(12, 20) While the majority of studies on HRQoL of the pediatric HIV population have been conducted in developed country settings,(12) implications of such researches are no less important for resource-constrained nations where basic amenities and social support are often found wanting even for healthy children. Similar to many other developing nations, helping the children suffering from this stigmatizing infection to attain optimum quality of life has not been a

priority for India's national HIV program and HRQoL is yet to be accepted widely as an outcome measure for planned interventions.(4, 21)

Prior Indian studies on determinants of HRQoL among children and adults living with HIV, have mostly recruited patients and control groups from treatment settings.(21-23) Such recruitment strategy probably led to assessment of HRQoL among participants with poorer health status and their responses might have been influenced by treatment-setting associated stigma.(24) The current study enrolled CLH and children exposed to but not infected with HIV (HIV-affected children) from community settings with the help of a community-based organization (CBO) that provided services to families impacted by HIV. The participants were administered the instrument 'Quality of life (health-related) of children living with HIV/AIDS in India (QOL-CHAI)' which is a HIV-targeted HRQoL scale comprising of six domains.(chapter V) The instrument had been validated in the present study setting and showed good internal consistency validity (Cronbach's  $\alpha$  ranging from 0.69 to 0.85 for different domains). The purpose of the present study were three-fold: a) to identify association of HIV infection status with different HRQOL domains through comparison of community-recruited CLH and HIV-affected children; b) to observe how anti-retroviral therapy (ART) affected HRQoL among CLH; and c) to evaluate if the most widely used clinical parameter for HIV in India (CD4 cell count) could predict HRQoL among CLH.

## **2. METHODS**

### *2. 1. Study setting and participant recruitment*

Participants in this study were a convenience sample of eight to fifteen year old CLH and HIV-affected children residing in three districts of West Bengal - Purba Medinipur, Paschim Medinipur and Kolkata. In order to facilitate participant recruitment, we collaborated with a community based organization (CBO) named 'Society for Positive Atmosphere and Related Support to HIV/AIDS' (SPARSHA). Since 2000, SPARSHA, constituted of and managed by people living with HIV and their friends (PLWHAF), has been working for children and adults living with HIV in rural and urban settings of West Bengal. The various services offered by SPARSHA include 'facilitating access to antiretroviral therapy', 'conducting community awareness programs', 'HIV stigma reduction activities' and 'HIV/AIDS counseling services'. As part of its activities SPARSHA had prepared a roster of its service recipients (and their families) residing in the study districts. CLH and HIV-affected children meeting the inclusion criteria were identified from this roster and their parents (or primary caregivers) were contacted by outreach workers from SPARSHA regarding participation of their children.

Parents/caregivers who expressed a preliminary approval about participation of their children in the study were invited to bring their children to the nearby SPARSHA field office for an interview. In case the child or his/her caregiver wanted the interview to be conducted at their home, an interview team visited their home on the scheduled date and time. Each interview was preceded by obtaining an informed consent from the respective parent/caregiver, followed by verbal assent from the child.

Eligibility criteria for participating CLH were as follows: i) being diagnosed with HIV at a center approved by the West Bengal State AIDS Prevention & Control Society (WBSAPCS), ii) 8 -15 years age, iii) not previously diagnosed with a disorder that would



prevent the participating child from responding rationally to the questionnaire (such as psychiatric, neurologic or developmental disorders, but not limited to them), iv) consent from the accompanying caregiver to participate, v) verbal assent from the child. In terms of recruitment to the HIV-affected group, an eligible child had to be born to an HIV-infected mother and must have tested negative for HIV antibody at or after 18 months age. Other than having an HIV-diagnosis, the rest of the eligibility criteria for CLH applied to recruitment of HIV-affected children as well.

HIV-affected children were chosen as comparison group for CLH as these two groups were similar in many socio-demographic aspects such as parental HIV status, socio-economic background, receiving services from the same CBO, geographic location etc. Therefore, we hypothesized that HIV infection status would be the principal reason if any difference was noted in overall HRQoL between these two groups.

## *2.2. Data collection*

Between November, 2014 and February, 2015, caregivers of 217 CLH and 232 HIV-affected children were approached for participation, of whom we managed to conduct interviews with 199 CLH and 194 affected children. Following informed consent from caregivers about interviewing their child and assessing treatment records, some socio-demographic information were obtained from respective caregivers about the children and their families. Treatment related information of respective CLH (CD4 cell count, ART intake etc.) were recorded from their 'ART card' issued by treatment center. Children providing verbal assent were then requested to complete the QOL-CHAI instrument with assistance from a trained interviewer. The QOL-CHAI is a 45 item

instrument comprising of six domains. The first four domains – physical (8 items), emotional (5 items), social (5 items) and school (5 items) functioning were adapted from the ‘Pediatric Quality of Life Inventory (PedsQL)’ generic core scale.(25, 26) The other two domains contain questions related to disease symptoms (18 items) and experiences of discriminating behavior (4 items). Participants were required to answer how much of a problem they had to face regarding each item in the instrument during the past month, except for the ‘discrimination’ domain which dealt with problems during the past year. Severity of the problems associated with each item were classified as follows; never (0), almost never (1), sometimes (2), often (3), and almost always (4). Interviews with children took approximately 15 minutes to complete.

### *2.3. Measures*

Besides recording participants’ responses on the QOL-CHAI scale items, we collected information on participants’ age, gender, study class (attending grade/standard in school), primary caregiver, survival status of parents, parental education, number of family members, family income, ART intake, ART initiation date, CD4 cell count at the time of ART initiation and at last measurement. To estimate prevalence of the reported symptoms during the past month, we dichotomized the ‘symptom’ scale into: i) no symptoms (score 0) and, ii) some occurrence of symptoms (scores 1 – 4). Parental status of children was categorized into – both parents alive, single parent alive and none of the parents alive. Per-capita income of the children’s family was categorized into quartiles. To aid interpretation of and comparison between different domains, we reverse coded each item and they were then linearly transformed to a score ranging 0–100 (higher scores indicated better HRQoL).(25) The summary score for each domain

was computed by adding together the scores on items constituting the domain and dividing by the number of items. The overall summary score was also converted to a scale of 0 to 100, by adding together the scores on all 45 items and dividing by 45.

#### *2.4. Statistical analysis*

Descriptive analysis was carried out to determine the distribution of socio-demographic characteristics of the study participants and to evaluate if any difference existed between CLH and HIV-affected children. Among the CLH, categorical analysis was performed to compare participant characteristics between ART-receiving CLH and those who had not started ART (or were taking it for less than six months). Frequencies, proportions, and corresponding p values (Cochran-Mantel-Haenszel chi-square) of any differences in symptom prevalence between CLH and HIV-affected groups were estimated. In order to evaluate the associations between HIV infection status and QOL-CHAI scale scores, we employed simple and multiple linear regression models. Further, among the CLH, the association of ART regimen and CD4 lymphocyte count with QOL-CHAI scores were determined using separate unadjusted and adjusted linear regression models. All multiple regression models were adjusted for age, gender, parental status (parents alive or not) and per-capita family income. Model fit was assessed by adjusted  $R^2$  statistic and residual plot. All statistical analyses were performed using SAS 9.4.

#### *2.5. Ethical approval*

Ethical approval for this study was obtained from the institutional review board (IRB) of the University of California, Los Angeles and the institutional ethics committee (IEC) of

the National Institute of Cholera and Enteric Diseases (under the Indian Council of Medical Research), the collaborating research institute located in Kolkata, West Bengal.

### **3. RESULTS**

In total, we interviewed 393 children (199 CLH and 194 HIV-affected) out of whom 59% were males (65% among CLH and 52% among HIV affected). The overall mean age of participants was 11.6 years (Standard deviation  $\pm 2.5$  years), with CLH being slightly younger (11.3 years, SD  $\pm 2.5$  years), than HIV-affected (11.9 years, SD  $\pm 2.5$  years). Mothers assumed the role of primary caregiver for the majority of participants (CLH: 77% & HIV-affected: 95%). A significantly higher proportion of CLH (36%) studied at a school class/standard lower than that recommended for their age compared to HIV-affected children (19%). The proportion of both parent orphans (11%) and single parent orphans (43%) were much higher among CLH compared to HIV-affected group (both parent: 2% & single parent: 32%). One hundred and thirty CLH (65%) had been taking ART for at least six months prior to the date of interview. Among the ART taking CLH 71% had CD4 cell count above  $500/\text{mm}^3$  compared to 45% of non-ART group (including those taking it for less than six months). Table 1 depicts the major socio-demographic and disease-related characteristics of participating children.

Prevalence of symptoms among CLH and HIV-affected children are presented in table 2. The most commonly reported symptom among both study groups was the common cold, with 73% CLH and 55% HIV-affected children reporting at least a single occurrence during the previous month. Other commonly reported symptoms occurring in the past month were pain in the limbs (CLH 56%, HIV-affected 39%), loss of appetite

(CLH 52%, HIV-affected 37%), headache (CLH 45%, HIV-affected 34%), and tingling/numbness in the limbs (CLH 38%, HIV-affected 37%). Compared to HIV-affected children, prevalence of most of these physical symptoms were significantly higher among CLH except for abdominal pain, yellowish discoloration of eye and tingling/numbness in the limbs.

As can be seen from table 3, the overall QOL-CHAI mean score and mean scores in each HRQoL domain were lower among CLH compared to HIV-affected children. In simple linear regression analysis, HIV infection was found to be associated with lower mean scores on all HRQoL domains except 'discrimination'. The overall QOL-CHAI score was also significantly lower for CLH than HIV-affected (parameter estimate ( $\beta$ ): -7.2, 95% confidence interval (CI): -8.6, -5.7). The findings were similar for multiple linear regression models that adjusted for children's age, gender, parental status and per capita family income. With all covariates being equal, it was observed that HIV infection was significantly associated with worsening of HRQoL scores in individual domains (except discrimination) and total score.

Mean HRQoL domain scores for CLH who had been taking ART for at least six months and those who had not started ART (or taking it for <6 months) are depicted in table 4. From findings of unadjusted linear regression we could see that ART intake was associated with significantly poorer score in the discrimination domain ( $\beta$ : -5.6, 95% CI: -9.9, -1.4). Even after adjusting for covariates, ART intake ( $\beta$ : -4.7, 95% CI: -9.1, -0.3) remained a significant negative predictor of discrimination scale score. In other HRQoL domains and in terms of overall score, there were no significant differences between ART and non-ART groups in both unadjusted and adjusted analysis.

Linear regression of HRQoL domain scores on last reported CD4 cell count revealed that CD4 cell count was a significant positive predictor of the 'symptom' scale score (table 5). From unadjusted analysis we could see that every 100 unit increase in CD4 cell count was associated with a mean increase of 0.5 units in symptom scale score ( $\beta$ : 0.5, 95% CI: 0.2, 0.9). In multiple linear regression analysis, every 100 unit rise in CD4 cell count led to a 0.6 unit increase in mean score in symptom scale ( $\beta$ : 0.6, 95% CI: 0.2, 0.9). CD4 cell count did not show significant associations with rest of the HRQoL domains and overall QOL-CHAI score.

#### **4. DISCUSSION**

The current study aimed to provide an insight into an often neglected aspect of HIV care for children – quality of life. In developing countries like India, the HIV program for children is primarily focused on clinical parameters and ensuring optimum HRQoL of children, infected with or affected by the infection, is given little emphasis.(12) In order to attain our study objectives, we used convenience sampling to recruit 8 to 15 year old children residing in the state of West Bengal, India to compare HRQoL between children living with HIV and children exposed to but not infected with HIV and also between CLH on anti-HIV medication and those who were not.

From descriptive analysis of socio-demographic characteristics, we observed that the proportion of single parent and both parent orphans were higher among CLH compared to the HIV-affected group. We hypothesize that married PLH who presented to the health system early and received treatment and/or behavioral interventions were not only more likely to have better survival but also had lesser chance of passing on the

infection (including vertical transmission). Thus, it was possible that, although both groups of children were born to HIV-infected parents, a higher proportion of parents of HIV-affected children received treatment and other associated services for themselves (leading to longer lifespan) and also received pregnancy-related interventions that reduced their likelihood of giving birth to a HIV-positive child.(27) We further observed that a significantly higher proportion of school-going CLH, compared to HIV-affected group, had a study-lag i.e. they attended a class/standard lower than that recommended for their age. This was not surprising as a number of prior studies have documented cognitive difficulties and resultant poor school performance among CLH.(28-30) Interestingly, among the CLH, the ART recipients were not only more likely to have a study-lag but also had higher proportion of school drop-out compared to those who had not started ART. As ART initiation in India depends on immunological status (CD4 cell count), children on ART probably had a poorer overall health status compared to non-ART group and as a result faced more difficulty to keep up with school syllabi or even continue attending school. Furthermore, previous research have suggested that neurocognitive decline due to HIV among school-going children may not be reversed with ART.(31-33)

We found that HIV infection was associated with poorer score in all HRQoL domains except the 'discrimination' domain. This was in accordance with multiple prior publications, which reported that HIV infection significantly compromised HRQoL in children.(22, 34, 35) In the Indian context, HIV-related discrimination is often not limited to the infected individual and social ostracization frequently involves the entire family of PLH.(36) As HIV-infected parents were a common characteristic of both CLH and HIV-

affected children, it was likely that any discrimination directed at their parents/family members might have affected the children, too. Also, a low proportion of participants reported experiencing any discriminatory behavior during the previous year, as evidenced from very high mean scores for the 'discrimination' domain. This might have reduced the statistical power of finding a significant difference in the 'discrimination' score between the two study groups. Lower discrimination experiences might have been an offshoot of the fact that participating children and their family members were likely to keep their HIV-diagnosis a secret in order to avoid stigmatizing behavior.(36) (chapter IV)

Among the CLH, we found that ART intake was not associated with any of the HRQoL domains except 'discrimination'. This finding was in contrast to that reported from prior studies conducted in India(21) and developed countries(35, 37). As discussed before, the probable poorer immunological status of ART recipients at baseline, compared to those who had not started taking ART, negated any potential benefits provided by ART. Because of our cross-sectional study design, we could not assess whether ART intake led to improvements in HRQoL over time among the recipients. Being on ART was found to be associated with poorer score in the 'discrimination' domain. A possible explanation could be that the ART recipients and their family members found it difficult to keep their HIV diagnosis secret, because of poorer overall health status and frequent visits to health facilities/ART centers, which might have resulted in experiencing discriminatory behavior. Adverse effects associated with anti-retroviral medications, perhaps, also have contributed to HIV-status disclosure and increased the likelihood of facing discrimination for children taking ART.



Interestingly, an increase in CD4 cell count, the most commonly used disease marker in Indian context, was not found to be associated with improvement in HRQoL score in any of the domains other than the 'symptoms'. As reported by Punpanich et al., clinical parameters related to disease progression may not always successfully capture an individual's perception about his/her well-being and overall quality of life.(19) Previous researches on HRQoL of patients with HIV and other chronic diseases have also noted that clinical indices did not always consistently predict performance on self-reported HRQoL parameters.(38-40)

Being an observational study, our results suffered from a few limitations. First, because of our cross-sectional design, lack of temporality prevented us from drawing any causal inferences. The time sequences of predictors were often unclear such as whether ART intake affected perception about health status or already poor health status led to initiation of ART. Second, we employed convenience sampling to recruit participants from the contact list of a CBO which catered mostly to low- and lower-middle income families. The fact that most study participants belonged to lower socio-economic strata was evident from the low family income and poor parental educational level of study participants. Therefore, generalizability of our study findings to different socio-economic groups and populations may be inappropriate. Third, the fact that most of our data was self-reported raises concern about social desirability bias, which could potentially introduce outcome misclassification in our analysis especially for the 'social functioning', 'school functioning' and 'discrimination' domains. Fourth, as we recruited children from community settings and not from treatment facilities, participants in this study were mostly ambulatory and not severely ill. This was reflected by the fact that a major

proportion of study participants reported none or very few problems in most HRQoL domains. Therefore, our findings could differ if the QOL-CHAI was administered to HIV-infected or -affected children with poorer general health. Moreover, although HIV-affected children constituted a valid comparison group to CLH, differences in HRQoL parameters for CLH possibly had been more pronounced against a general population control group (as opposed to HIV-affected children). Finally, in the current study, we relied on CD4 lymphocyte count as a marker of disease progression. Plasma viral load (PVL), alone or in combination with other markers, is generally considered superior to CD4 count in predicting clinical outcome of individuals living with HIV.(41, 42) However, in India, owing to cost considerations, PVL assessment is not offered routinely under the national HIV program. As all CLH participants in this study attended state-run HIV clinics which did not have facility for PVL measurement and/or did not recommend it as part of standard treatment protocol, almost none of the participants ever had his/her PVL measured. Therefore, despite recognizing its relevance, we could not assess whether PVL status had an important bearing on HRQoL of participating CLH.

Nationwide scale-up of ART program has made it possible for an increasing number of pediatric HIV patients in India to survive into adolescence and adulthood. However, as the presently available treatments are unsuccessful in completely eliminating the virus,(43) the patients have to continue medications for an indefinite period and suffer from associated drug-related adverse effects. Therefore, as with other chronic diseases, ensuring an adequate level of quality of life for CLH remains a challenge for policy-makers and health care providers. Poor HRQoL status of Indian CLH highlighted in the current study calls for culturally and developmentally appropriate psychosocial support

measures to address the multitude of challenges faced by these children. As recommended by Amzel et al,(44) in order to be comprehensive, such support measures should involve individual, family and community level components and utilize existing support networks in community/schools/treatment facilities. Further insights into the problems faced by this population might be gained through follow-up studies designed to monitor changes in HRQoL with disease course. Such studies could also help in assessing effectiveness and feasibility of planned medical and/or socio-behavioral interventions targeted to CLH and children affected by HIV.

## 5. TABLES

**Table 1. Socio-demographic and disease related characteristics of study participants (n = 393).**

| Characteristic              | Children living with HIV (n=199) |                            |                            | Total      | HIV-affected children (n=194) | P-value <sup>3</sup> |
|-----------------------------|----------------------------------|----------------------------|----------------------------|------------|-------------------------------|----------------------|
|                             | On ART <sup>2</sup> (n=130)      | Not on ART (n=69)          | P-value <sup>4</sup>       |            | Frequency (%) <sup>1</sup>    |                      |
|                             | Frequency (%) <sup>1</sup>       | Frequency (%) <sup>1</sup> | Frequency (%) <sup>1</sup> |            | Frequency (%) <sup>1</sup>    |                      |
| Mean age in years (SD)      | 11.8 (2.5)                       | 10.6 (2.4)                 | <0.01*                     | 11.3 (2.5) | 11.9 (2.5)                    | 0.02*                |
| Gender                      |                                  |                            |                            |            |                               |                      |
| <i>Male</i>                 | 88 (67.7)                        | 42 (60.9)                  | 0.34                       | 130 (65.3) | 101 (52.1)                    | <0.01*               |
| <i>Female</i>               | 42 (32.3)                        | 27 (39.1)                  |                            | 69 (34.7)  | 93 (47.9)                     |                      |
| Residential district        |                                  |                            |                            |            |                               |                      |
| <i>Paschim Medinipur</i>    | 58 (44.6)                        | 32 (46.4)                  | 0.37                       | 90 (45.2)  | 133 (68.6)                    | <0.01*               |
| <i>Purba Medinipur</i>      | 13 (10)                          | 11 (15.9)                  |                            | 24 (12.1)  | 31 (16)                       |                      |
| <i>Kolkata</i>              | 59 (45.4)                        | 26 (37.7)                  |                            | 85 (42.7)  | 30 (15.5)                     |                      |
| Primary caregiver           |                                  |                            |                            |            |                               |                      |
| <i>Mother</i>               | 98 (75.4)                        | 56 (81.2)                  | 0.52                       | 154 (77.4) | 185 (95.4)                    | <0.01*               |
| <i>Father</i>               | 5 (3.9)                          | 1 (1.5)                    |                            | 6 (3)      | 1 (0.5)                       |                      |
| <i>Others</i>               | 27 (20.8)                        | 12 (17.4)                  |                            | 39 (19.6)  | 8 (4.1)                       |                      |
| Parent status               |                                  |                            |                            |            |                               |                      |
| <i>Both parents alive</i>   | 54 (41.5)                        | 37 (53.6)                  | 0.12                       | 91 (45.7)  | 129 (66.5)                    | <0.01*               |
| <i>Single parent orphan</i> | 58 (44.6)                        | 28 (40.6)                  |                            | 86 (43.2)  | 62 (32)                       |                      |
| <i>Both parent orphan</i>   | 18 (13.9)                        | 4 (5.8)                    |                            | 22 (11.1)  | 3 (1.6)                       |                      |
| School drop-out             |                                  |                            |                            |            |                               |                      |
| <i>Yes</i>                  | 11 (8.5)                         | 1 (1.5)                    | 0.04*                      | 12 (6)     | 7 (3.6)                       | 0.26                 |
| <i>No</i>                   | 119 (91.5)                       | 68 (98.6)                  |                            | 187 (94)   | 187 (96.4)                    |                      |

|   |           |           |        |            |            |        |
|---|-----------|-----------|--------|------------|------------|--------|
| Studying at a class/standard lower than recommended for age |           |           |        |            |            |        |
| Yes   | 55 (42.3) | 16 (23.2) | <0.01* | 71 (35.7)  | 36 (18.6)  | <0.01* |
| No  | 75 (57.7) | 53 (76.8) |        | 128 (64.3) | 158 (81.4) |        |
| Mother's education  |           |           |        |            |            |        |
| <i>Did not attend school</i>                                | 34 (26.2) | 23 (33.3) |        | 57 (28.6)  | 27 (13.9)  |        |
| <i>Primary school</i>                                       | 18 (13.9) | 9 (13)    |        | 27 (13.6)  | 41 (21.1)  |        |
| <i>Middle school</i>  | 68 (52.3) | 32 (46.4) | 0.85   | 100 (50.3) | 122 (62.9) | <0.01* |
| <i>High school or above</i>                                 | 7 (5.4)   | 4 (5.8)   |        | 11 (5.5)   | 4 (2)      |        |
| <i>Not reported</i>   | 3 (2.3)   | 1 (1.5)   |        | 4 (2)      | -          |        |
| Father's education  |           |           |        |            |            |        |
| <i>Did not attend school</i>                                | 17 (13.1) | 20 (29)   |        | 37 (18.6)  | 32 (16.5)  |        |
| <i>Primary school</i>                                       | 32 (24.6) | 12 (17.4) |        | 44 (22.1)  | 60 (30.9)  |        |
| <i>Middle school</i>  | 64 (49.2) | 31 (44.9) | 0.09   | 95 (47.7)  | 98 (50.5)  | 0.03*  |
| <i>High school or above</i>                                 | 8 (6.2)   | 3 (4.4)   |        | 11 (5.5)   | 2 (1)      |        |
| <i>Not reported</i>   | 9 (6.9)   | 3 (4.4)   |        | 12 (6)     | 2 (1)      |        |
| Per-capita family income (in INR/month)                     |           |           |        |            |            |        |
| <i>1st quartile (≤375)</i>                                  | 34 (26.2) | 18 (26.1) |        | 52 (26.1)  | 50 (25.8)  |        |
| <i>2nd quartile (≥400 - ≤600)</i>                           | 30 (23.1) | 7 (10.1)  | 0.11   | 37 (18.6)  | 65 (33.5)  | <0.01* |
| <i>3rd quartile (≥625 - ≤1000)</i>                          | 38 (29.2) | 22 (31.9) |        | 60 (30.2)  | 55 (28.4)  |        |
| <i>4th quartile (≥1111)</i>                                 | 28 (21.5) | 22 (31.9) |        | 50 (25.1)  | 24 (12.4)  |        |
|   |           |           |        |            |            |        |
| Last measured CD4 cell count(/mm <sup>3</sup> )             |           |           |        |            |            |        |
| <250  | 12 (9.2)  | 4 (5.8)   |        | 16 (8)     | -          |        |
| ≥250 - <500   | 26 (20)   | 30 (43.5) | <0.01* | 56 (28.1)  | -          | -      |
| ≥500  | 92 (70.7) | 31 (44.9) |        | 123 (61.8) | -          |        |
| <i>Not reported</i>   | -         | 4 (5.8)   |        | 4 (2)      | -          |        |

<sup>1</sup>Values may not sum to 100% due to rounded numbers. <sup>2</sup>Taking ART for at least past 6 months.

<sup>3</sup>P-value of difference between CLH and HIV-affected groups. <sup>4</sup>P-value of difference between ART and non-ART groups.

\*Statistically significant (p≤0.05).

**Table 2. Prevalence of reported symptoms among children living with HIV and children exposed to but not infected with HIV (n=393)**

| Symptoms                | Participants reporting at least a single episode during previous month (%) |                         |                                  | P-value*           |
|-------------------------|--|-------------------------|----------------------------------|--------------------|
|                         | Overall  | Living with HIV (n=199) | Exposed but not infected (n=194) |                    |
| Fever                   | 141 (35.9)   | 82 (41.2)               | 59 (3.4)                         | 0.03 <sup>#</sup>  |
| Common cold             | 252 (64.1)   | 146 (73.4)              | 106 (54.6)                       | <0.01 <sup>#</sup> |
| Weight loss, emaciation | 74 (18.8)  | 45 (22.6)               | 29 (15)                          | 0.05 <sup>#</sup>  |
| Diarrhea, loose stool   | 70 (17.8)  | 46 (23.1)               | 24 (12.4)                        | <0.01 <sup>#</sup> |

|  |            |            |           |        |
|--|------------|------------|-----------|--------|
| Pain in the limbs                        | 187 (47.6) | 111 (55.8) | 76 (39.2) | <0.01# |
| Headache                                 | 155 (39.4) | 90 (45.2)  | 65 (33.5) | 0.02#  |
| Skin rash, itchy lesions, sore/ulcer     | 86 (21.9)  | 63 (31.7)  | 23 (11.9) | <0.01# |
| Vomiting, nausea                         | 100 (25.5) | 63 (31.7)  | 37 (19.1) | <0.01# |
| Ear discharge, hearing difficulties      | 51 (13)    | 42 (21.1)  | 9 (4.6)   | <0.01# |
| Loss of appetite                         | 174 (44.3) | 103 (51.8) | 71 (36.6) | <0.01# |
| Abdominal pain                           | 105 (26.7) | 60 (30.2)  | 45 (23.2) | 0.12   |
| Yellowish discoloration of eye/ jaundice | 7 (1.8)    | 6 (3)      | 1 (0.5)   | 0.06   |
| Dizziness                                | 63 (16)    | 45 (22.6)  | 18 (9.3)  | <0.01# |
| Throat swelling, sore throat             | 73 (18.6)  | 46 (23.1)  | 27 (13.9) | 0.02#  |
| Abdominal distension                     | 14 (3.6)   | 9 (4.5)    | 5 (2.6)   | 0.3    |
| Shortness of breath, wheezing            | 52 (13.2)  | 35 (17.6)  | 17 (8.8)  | <0.01# |
| Tingling sensation/numbness in the limbs | 148 (37.7) | 76 (38.2)  | 72 (37.1) | 0.83   |
| Oral ulcer                               | 32 (8.1)   | 27 (13.6)  | 5 (2.6)   | <0.01# |

\*P-value for difference in scale scores between children living with HIV and HIV exposed but not infected children

#Statistically significant ( $p \leq 0.05$ )

**Table 3. Parameter estimates from unadjusted and adjusted linear regression analyses to evaluate the association of HIV infection status with QOL-CHAI scale scores (n=393)#**

| Scale                 | No. of items | Mean score               |   | Unadjusted analysis |             | Adjusted analysis** |             |
|-----------------------|--------------|--------------------------|---|---------------------|-------------|---------------------|-------------|
|                       |              | Living with HIV (n=199)* | Exposed to but not infected with HIV (n=194)* | Parameter estimate  | 95% CI      | Parameter estimate  | 95% CI      |
| Physical functioning  | 8            | 80.9                     | 92.5  | -10.6*              | -13.3, -7.8 | -11.2*              | -14.1, -8.4 |
| Emotional functioning | 5            | 73.2                     | 79.7  | -5.8*               | -9.4, -2.2  | -6.1*               | -9.9, -2.3  |
| Social functioning    | 5            | 87.9                     | 96.5  | -8.1*               | -11.2, -5.1 | -8*                 | -11.2, -4.8 |
| School functioning    | 5            | 74.9                     | 87.5  | -12.6*              | -15.8, -9.5 | -12.4*              | -15.7, -9.1 |
| Symptoms              | 18           | 86.6                     | 92.2  | -5.6*               | -7, -4.2    | -5.7*               | -7.2, -4.2  |
| Discrimination        | 4            | 94.5                     | 96.6  | -1.2                | -2.9, 0.6   | -0.9                | -2.7, 0.9   |
| Overall               | 45           | 83.1                     | 90.9  | -7.2*               | -8.6, -5.7  | -7.3*               | -8.9, -5.7  |

#Observations with missing values excluded as and where applicable.

Negative parameter estimates indicate that HIV infection is associated with poorer functioning and vice versa.

\*Statistically significant ( $p \leq 0.05$ ).

\*\*Adjusted for child's age, gender, parental status and per capita family income.

**Table 4. Parameter estimates from unadjusted and adjusted linear regression analyses to evaluate the association of ART intake (for at least 6 months) with QOL-CHAI scale scores among children living with HIV (n=199)#**

| Scale                 | Mean score   |                 | Unadjusted analysis |            | Adjusted analysis** |            |
|-----------------------|--------------|-----------------|---------------------|------------|---------------------|------------|
|                       | ART (n=130)* | Non-ART (n=69)* | Parameter estimate  | 95% CI     | Parameter estimate  | 95% CI     |
| Physical functioning  | 79.8         | 82.9            | -3                  | -8.4, 2.3  | -0.9                | -6.4, 4.7  |
| Emotional functioning | 74           | 71.7            | 2.3                 | -3.7, 8.2  | 3.6                 | -2.5, 9.7  |
| Social functioning    | 86.9         | 89.9            | -3                  | -8.7, 2.7  | -2.4                | -8.3, 3.5  |
| School functioning    | 73.1         | 78.1            | -5                  | -10.4, 0.4 | -4.2                | -9.7, 1.3  |
| Symptoms              | 86.3         | 86.5            | -0.2                | -2.7, 2.3  | 0                   | -2.6, 2.6  |
| Discrimination        | 92.5         | 98.2            | -5.6*               | -9.9, -1.4 | -4.7*               | -9.1, -0.3 |
| Overall               | 82.3         | 84.6            | -2.3                | -5.2, 0.7  | -1.2                | -4.2, 1.8  |

#Observations with missing values excluded as and where applicable.

Negative parameter estimates indicate that ART intake is associated with poorer functioning and vice versa.

\*Statistically significant ( $p \leq 0.05$ ).

\*\*Adjusted for child's age, gender, parental status and per capita family income.

**Table 5. Parameter estimates from unadjusted and adjusted linear regression analyses to evaluate the association of CD4 count (for every 100 units change in CD4 cells/mm<sup>3</sup>) with QOL-CHAI scale scores among children living with HIV (n=199)#**

| Scale                 | Unadjusted analysis |           | Adjusted analysis** |           |
|-----------------------|---------------------|-----------|---------------------|-----------|
|                       | Parameter estimate  | 95% CI    | Parameter estimate  | 95% CI    |
| Physical functioning  | -0.1                | -0.8, 0.5 | -0.2                | -0.9, 0.5 |
| Emotional functioning | 0                   | -0.8, 0.8 | 0                   | -0.8, 0.8 |
| Social functioning    | 0                   | -0.8, 0.7 | 0                   | -0.8, 0.7 |
| School functioning    | -0.4                | -1.2, 0.3 | -0.4                | -1.2, 0.3 |
| Symptoms              | 0.5*                | 0.2, 0.9  | 0.6*                | 0.2, 0.9  |
| Discrimination        | -0.2                | -0.6, 0.3 | -0.1                | -0.6, 0.3 |
| Overall               | 0.1                 | -0.2, 0.4 | 0.1                 | -0.2, 0.5 |

#Observations with missing values excluded as and where applicable.

Negative parameter estimates indicate that increase in CD4 cell count is associated with poorer functioning and vice versa

\*Statistically significant ( $p \leq 0.05$ ).

\*\*Adjusted for child's age, gender, parental status and per capita family income.

## 6. REFERENCES

1. Global report: UNAIDS report on the global AIDS epidemic 2013. Joint United Nations Programme on HIV/AIDS (UNAIDS), 2013 April 12, 2015. Report No.
2. Wilson CM, Wright PF, Safrit JT, Rudy B. Epidemiology of HIV infection and risk in adolescents and youth. *Journal of acquired immune deficiency syndromes (1999)*. 2010;54(Suppl 1):S5.
3. The Gap Report. Geneva: Joint United Nations Programme on HIV/AIDS, 2014 April 15, 2015. Report No.
4. National AIDS Control Organisation Annual Report 2012-2013. Department of AIDS Control, Ministry of Health and Family Welfare, Government of India, 2013 5th January, 2015. Report No.
5. Children on the brink 2004: a joint report on orphan estimates and program strategies. Washington D.C.: USAID, UNAIDS, UNICEF, 2004 January 12, 2015. Report No.
6. Remien RH, Mellins CA. Long-term psychosocial challenges for people living with HIV: let's not forget the individual in our global response to the pandemic. *AIDS (London, England)*. 2007;21:S55-S63.
7. Li X, Naar-King S, Barnett D, Stanton B, Fang X, Thurston C. A developmental psychopathology framework of the psychosocial needs of children orphaned by HIV. *J Assoc Nurses AIDS Care*. 2008;19(2):147-57.
8. Towards an AIDS-free generation: children and AIDS: sixth stocktaking report, 2013. New York: UNICEF, 2013 April 15, 2015. Report No.: 9280647237.
9. de Boer JB, van Dam FS, Sprangers MA. Health-related quality-of-life evaluation in HIV-infected patients. *Pharmacoeconomics*. 1995;8(4):291-304.
10. Franchi D, Wenzel RP. Measuring health-related quality of life among patients infected with human immunodeficiency virus. *Clinical infectious diseases : an official publication of the*

Infectious Diseases Society of America. 1998;26(1):20-6. Epub 1998/02/10. PubMed PMID: 9455505.

11. Skevington SM, O'Connell KA. Measuring quality of life in HIV and AIDS: A review of the recent literature. *Psychology and health*. 2003;18(3):331-50.

12. Garvie PA, Lawford J, Banet MS, West RL. Quality of life measurement in paediatric and adolescent populations with HIV: a review of the literature. *Child: care, health and development*. 2009;35(4):440-53. Epub 2009/07/30. doi: 10.1111/j.1365-2214.2009.00985.x. PubMed PMID: 19638021.

13. Igumbor J, Stewart A, Holzemer W. Comparison of the health-related quality of life, CD4 count and viral load of AIDS patients and people with HIV who have been on treatment for 12 months in rural South Africa. *SAHARA-J: Journal of Social Aspects of HIV/AIDS*. 2013;10(1):25-31.

14. Detels R, Muñoz A, McFarlane G, Kingsley LA, Margolick JB, Giorgi J, et al. Effectiveness of potent antiretroviral therapy on time to AIDS and death in men with known HIV infection duration. *JAMA : the journal of the American Medical Association*. 1998;280(17):1497-503.

15. Burgoyne RW, Rourke SB, Behrens DM, Salit IE. Long-term quality-of-life outcomes among adults living with HIV in the HAART era: the interplay of changes in clinical factors and symptom profile. *AIDS and behavior*. 2004;8(2):151-63. Epub 2004/06/10. doi: 10.1023/B:AIBE.0000030246.19577.fb. PubMed PMID: 15187477.

16. Gill CJ, Griffith JL, Jacobson D, Skinner S, Gorbach SL, Wilson IB. Relationship of HIV viral loads, CD4 counts, and HAART use to health-related quality of life. *Journal of acquired immune deficiency syndromes (1999)*. 2002;30(5):485-92.



17. Saunders DS, Burgoyne RW. Evaluating health-related wellbeing outcomes among outpatient adults with human immunodeficiency virus infection in the HAART era. *International journal of STD & AIDS*. 2002;13(10):683-90.
18. Low-Beer S, Chan K, Wood E, Yip B, Montaner J, O'Shaughnessy M, et al. Health related quality of life among persons with HIV after the use of protease inhibitors. *Qual Life Res*. 2000;9(8):941-9.
19. Punpanich W, Hays RD, Detels R, Chokephaibulkit K, Chantbuddhiwet U, Leowsrisook P, et al. Development of a culturally appropriate health-related quality of life measure for human immunodeficiency virus-infected children in Thailand. *Journal of paediatrics and child health*. 2011;47(1-2):27-33. Epub 2010/10/27. doi: 10.1111/j.1440-1754.2010.01886.x. PubMed PMID: 20973862; PubMed Central PMCID: PMC3033216.
20. Cremeens J, Eiser C, Blades M. Characteristics of health-related self-report measures for children aged three to eight years: a review of the literature. *Qual Life Res*. 2006;15(4):739-54.
21. Banerjee T, Pensi T, Banerjee D. HRQoL in HIV-infected children using PedsQL™ 4.0 and comparison with uninfected children. *Qual Life Res*. 2010;19(6):803-12.
22. Das S, Mukherjee A, Lodha R, Vatsa M. Quality of life and psychosocial functioning of HIV infected children. *The Indian Journal of Pediatrics*. 2010;77(6):633-7.
23. Peter E, Kamath R, Andrews T, Hegde BM. Psychosocial determinants of health-related quality of life of people living with HIV/AIDS on antiretroviral therapy at Udupi district, southern India. *International journal of preventive medicine*. 2014;5(2):203.
24. Mahendra VS, Gilborn L, Bharat S, Mudoj R, Gupta I, George B, et al. Understanding and measuring AIDS-related stigma in health care settings: a developing country perspective. *SAHARA J : journal of Social Aspects of HIV/AIDS Research Alliance / SAHARA* , Human Sciences Research Council. 2007;4(2):616-25. Epub 2007/12/12. PubMed PMID: 18071613.

25. Varni JW, Seid M, Kurtin PS. PedsQL 4.0: reliability and validity of the Pediatric Quality of Life Inventory version 4.0 generic core scales in healthy and patient populations. *Medical Care*. 2001;39(8):800-12. Epub 2001/07/27. PubMed PMID: 11468499.
26. Varni JW, Seid M, Rode CA. The PedsQL: measurement model for the pediatric quality of life inventory. *Medical Care*. 1999;37(2):126-39. Epub 1999/02/19. PubMed PMID: 10024117.
27. De Cock KM, Fowler MG, Mercier E, de Vincenzi I, Saba J, Hoff E, et al. Prevention of mother-to-child HIV transmission in resource-poor countries: translating research into policy and practice. *JAMA : the journal of the American Medical Association*. 2000;283(9):1175-82.
28. Koekkoek S, de Sonnevile LM, Wolfs TF, Licht R, Geelen SP. Neurocognitive function profile in HIV-infected school-age children. *European Journal of Paediatric Neurology*. 2008;12(4):290-7.
29. Nozyce ML, Lee SS, Wiznia A, Nachman S, Mofenson LM, Smith ME, et al. A behavioral and cognitive profile of clinically stable HIV-infected children. *Pediatrics*. 2006;117(3):763-70.
30. Souza E, Santos N, Valentini S, Silva G, Falbo A. Long-term follow-up outcomes of perinatally HIV-infected adolescents: infection control but school failure. *J Trop Pediatr*. 2010;56(6):421-6.
31. Puthanakit T, Aurpibul L, Louthrenoo O, Tapanya P, Nadsasarn R, Insee-ard S, et al. Poor cognitive functioning of school-aged children in Thailand with perinatally acquired HIV infection taking antiretroviral therapy. *Aids Patient Care STDS*. 2010;24(3):141-6.
32. Smith L, Adnams C, Eley B. Neurological and neurocognitive function of HIV-infected children commenced on antiretroviral therapy. *South African Journal of Child Health*. 2008;2(3):108-13.
33. Jeremy RJ, Kim S, Nozyce M, Nachman S, McIntosh K, Pelton SI, et al. Neuropsychological functioning and viral load in stable antiretroviral therapy-experienced HIV-infected children. *Pediatrics*. 2005;115(2):380-7.

34. Lee G, Gortmaker S, McIntosh K, Hughes M, Oleske J. Pediatric AIDS Clinical Trials Group Protocol 219C Team. Quality of life for children and adolescents: impact of HIV infection and antiretroviral treatment. *Pediatrics*. 2006;117(2):273-83.
35. Storm DS, Boland MG, Gortmaker SL, He Y, Skurnick J, Howland L, et al. Protease inhibitor combination therapy, severity of illness, and quality of life among children with perinatally acquired HIV-1 infection. *Pediatrics*. 2005;115(2):e173-82. Epub 2005/01/05. doi: 10.1542/peds.2004-1693. PubMed PMID: 15629958.
36. Panda S, Das RS, Maruf SKA, Pahari S. Exploring Stigma in Low HIV Prevalence Settings in Rural West Bengal, India: Identification of Intervention Considerations. *Journal of Mixed Methods Research*. 2014. doi: 10.1177/1558689814535843.
37. Lee GM, Gortmaker SL, McIntosh K, Hughes MD, Oleske JM. Quality of life for children and adolescents: impact of HIV infection and antiretroviral treatment. *Pediatrics*. 2006;117(2):273-83.
38. Globe DR. Associations of clinical parameters with health-related quality of life in hospitalized persons with HIV disease. *AIDS care*. 1999;11(1):71-86.
39. Wachtel T, Piette J, Mor V, Stein M, Fleishman J, Carpenter C. Quality of life in persons with human immunodeficiency virus infection: measurement by the Medical Outcomes Study instrument. *Ann Intern Med*. 1992;116(2):129-37.
40. Kaplan RM, Anderson JP, Wu AW, Mathews WC, Kozin F, Orenstein D. The Quality of Well-being Scale: applications in AIDS, cystic fibrosis, and arthritis. *Medical care*. 1989:S27-S43.
41. Mellors JW, Rinaldo CR, Jr., Gupta P, White RM, Todd JA, Kingsley LA. Prognosis in HIV-1 infection predicted by the quantity of virus in plasma. *Science*. 1996;272(5265):1167-70. Epub 1996/05/24. PubMed PMID: 8638160.

42. Mellors JW, Munoz A, Giorgi JV, Margolick JB, Tassoni CJ, Gupta P, et al. Plasma viral load and CD4+ lymphocytes as prognostic markers of HIV-1 infection. *Annals of internal medicine*. 1997;126(12):946-54. Epub 1997/06/15. PubMed PMID: 9182471.
43. Stevenson M. HIV-1 pathogenesis. *Nature medicine*. 2003;9(7):853-60. Epub 2003/07/02. doi: 10.1038/nm0703-853. PubMed PMID: 12835705.
44. Amzel A, Toska E, Lovich R, Widyono M, Patel T, Foti C, et al. Promoting a combination approach to paediatric HIV psychosocial support. *AIDS (London, England)*. 2013;27 Suppl 2:S147-57. Epub 2013/12/24. doi: 10.1097/qad.000000000000098. PubMed PMID: 24361624.

## Chapter VII: Conclusion

In addition to organic disease, children living with HIV in India face several emotional and societal barriers that hinder them from achieving optimal quality of life. In this context, we aimed to develop a culturally suitable instrument that captured the functional impairments in physical, psychological, and social domains, and therefore could assist in improving fidelity of targeted interventions. In order to achieve our goal we started with qualitative inquiries with CLH and their caregivers to understand the various health-related issues associated with quality of life of these children. We used the findings to formulate a HRQoL instrument, the QOL-CHAI, which incorporated four generic core scales of the PedsQL,(1, 2) a widely used disease-independent HRQoL tool, along with two scales measuring symptoms and discrimination related constructs that were identified from qualitative inquiries.

In addition to helping us formulate the instrument, qualitative interviews also allowed us to gain a perspective of the issues around pediatric disclosure of HIV status and various life experiences of CLH and their caregivers. To the best of our knowledge there has not been any published studies that qualitatively explored the issues around childhood disclosure in India and as yet no specific guidelines have been formulated to help the process. Qualitative findings further highlighted the experiences and concerns of CLH and their caregivers' related to living with a life-threatening disease, HIV-related discrimination, perspectives about available health services and caregiving challenges.

The findings from quantitative phase of the current study showed that the newly developed QOL-CHAI instrument had acceptable psychometric properties to assess

HRQoL of CLH. During this phase, we also compared HRQoL between a group of CLH and uninfected children born to HIV infected parents (HIV-affected) belonging to similar socio-economic strata. This comparison revealed that CLH performed much worse compared to HIV-affected children not only in terms of overall HRQoL score but also in individual domains such as the physical, emotional, social and school functioning and physical symptoms.

We would like to make a few recommendations for India's HIV program on the basis of our literature review and findings from the qualitative and quantitative phases of the current study:

- I. In order to facilitate childhood disclosure of HIV status it is important to develop context-specific interventions that take into account the child's age or developmental maturity and domestic environment, as well as relevant cultural factors
- II. Simplification of regimen and education of informal caregivers regarding benefits to improve ART adherence
- III. Specific interventions targeted at informal caregivers such as counselling on caregiving aspects and disease coping mechanisms need to be implemented
- IV. Measures aimed towards improving the experience at health facilities e.g. establishing newer facilities in remote areas, ensuring availability of ART, behavioral training for health-center staff etc.
- V. Renewed emphasis on information, education and communication (IEC) campaigns to reduce the stigma associated with HIV

- VI. Implementing HRQoL assessment for illness appraisal at individual level and also as a performance indicator for various HIV programs especially those targeted at children
- VII. Design and implementation of psychosocial interventions targeted at CLH with individual, family and community level components that utilize existing support networks in community/schools/treatment facilities

In summary, the findings from this study will fill some of the existing knowledge gaps regarding HRQoL status of children living with HIV in India and behavioral and sociocultural constructs related to the pediatric disclosure among such children. Also, we have highlighted several relevant areas requiring further research in the results section. We expect the findings to inform the design and implementation of suitable and effective interventions targeted at improving the quality of life of Indian children infected or affected by HIV.

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## **REFERENCES**

1. Varni JW, Seid M, Kurtin PS. PedsQL 4.0: reliability and validity of the Pediatric Quality of Life Inventory version 4.0 generic core scales in healthy and patient populations. *Medical Care*. 2001;39(8):800-12. Epub 2001/07/27. PubMed PMID: 11468499.
2. Varni JW, Seid M, Rode CA. The PedsQL: measurement model for the pediatric quality of life inventory. *Medical Care*. 1999;37(2):126-39. Epub 1999/02/19. PubMed PMID: 10024117.