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Quality of life and psychosocial well-being among children living with HIV at a care home in Southern India

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Abstract

This study was designed to evaluate the quality of life (QOL) of children living with HIV at an institutional care home in Bangalore, India. The Sneha Care Home is a unique residence that provides educational and community support with a focus on physical, nutritional, medical, and psychological care for orphans and vulnerable children. Cross-sectional health measures and interview data were collected from 97 residents including 52 boys and 45 girls between 5 and 12 years of age (mean age = 9). QOL was measured with the Pediatric Quality of Life 4.0 (PedsQL) Inventory. Caregivers perceived children to have an overall higher QOL than was self-reported by children (total score 83 vs. 78). Our findings indicated self-reported QOL decreased with age of the child, while caregiver-reported QOL increased with age, suggesting a need to ensure greater psychological support for older children. Physical measures showed the children's clinical severity of disease remained well controlled living in this residential, values-based care home.

Keywords

children; orphans; India; HIV; quality of life

Introduction

India has an estimated 112,385 children living with HIV (CLHIV) (NACO, 2013), many of whom are orphans or “vulnerable children” i.e., children whose survival, well-being, or development are threatened by HIV/AIDS (UNAIDS, 2011). Orphaned and vulnerable CLHIV are more likely to be of low socioeconomic status, malnourished, uneducated, and lacking access to basic health care (Mellins & Malee, 2013; Shah, Tullu, & Kamat, 2005; Shet et al., 2009). Mental health problems among CLHIV include attention deficit, hyperactivity, anxiety, and depression (Malee et al., 2011).

Limited research exists on the quality of life (QOL) among orphaned CLHIV in India (Das, Mukherjee, Lodha, & Vatsa, 2010) and on the role of their care environment in QOL. Environments that provide antiretroviral therapy (ART) medication, HIV information, and

future orientation minimize distress, while caregiver involvement and communication are associated with fewer emotional and behavioral problems among CLHIV (Mellins & Malee, 2013; Petersen et al., 2010).

Some studies showed that care of CLHIV by relatives or family friends provides psychosocial security for orphaned CLHIV, yet place a burden on the child and caregivers (Acharya et al., 2013; Wakhweya, Dirks, & Yeboah, 2008). Other studies found better outcomes among children in institutionalized care than in family care (Whetten et al., 2009). Studies in Asia showed that institutions that preserve a family-style care with community support resulted in better QOL than family care (Banerjee, Pensi, & Banerjee, 2010; Hong et al., 2011).

Although there are strengths to each environment for CLHIV, few studies have reported a blended model, i.e., care in an institutional setting that supports the regular involvement of the family in the children's development. This study reports on one institution that applies such a model, Sneha Care Home (SCH), in Bangalore, India. Our first aim was to evaluate QOL among the CLHIV at SCH. Our second aim was to assess physical developmental milestones and HIV severity and determine whether correlations existed between their demographics or clinical measures and QOL. We hypothesized the children would have relatively good health and QOL despite being HIV positive given their stable environment with physical and psychosocial support. We also hypothesized severity of disease and demographic variables such as age of joining SCH and parental status would correlate with behavior and psychosocial QOL.

Methods

Setting

SCH is a Catholic residential care facility for orphaned or vulnerable CLHIV aged between 5 and 12 years. Using a holistic approach to care for the entire person, SCH blends community with family involvement. Housing, nutrition, medical care, a values-based education, and vocational preparation aligned with children's interests and needs are provided. SCH encourages existing family to routinely call and participate in activities and cultural celebrations.

Study design and subjects

Cross-sectional interview data were collected during March 2012. All 100 CLHIV residing at SCH were considered for the study. Participants were required to be 5–12 years old and assent to be in the study. Two children did not qualify because they were too young. Another child chose not to participate, for unknown reasons. We also gathered information about each child from a caregiver, who had to spend more than 15 hours/week with the children. Two on-site caregivers participated. Each caregiver is assigned to a child by the institution and completed a QOL questionnaire for those children with whom they spent the most time.

Procedures

Informed consent was obtained from the guardian of the children and the director of SCH. In addition, participants 8–12 years of age gave written consent, and those aged 5–7 years gave verbal assent. All questionnaires were administered face-to-face, in English or Kannada, the local language, depending on the child's preference. All children received a toy of nominal cost. Caregivers provided written consent to fill out written questionnaire forms, in English or Kannada, depending on their preference. They received a thank-you gift of nominal cost after participation. This study received clearance by the Committee for Human Research at the University of California San Francisco and the Institutional Ethical Review Board at St. John's Medical College Hospital.

Measures and analyses

A description of the measures is provided in Table 1. Frequencies, means, and standard deviation (SD) were calculated to describe the demographic and laboratory characteristics of the participants and their Pediatric Quality of Life 4.0 (PedsQL) scores. Unadjusted linear regression was performed to evaluate associations of demographics, clinical severity, and anthropometric measurements with the continuous PedsQL summary score as the outcome. Analyses were performed using STATA version 11.1.

Results

Demographics

Among the 97 child participants, 46% were girls, and 73% were 8–12 years old. The age of joining SCH was, on average (SD), 6 (2) years. Forty-eight percent of the children had one deceased parent, 12% were double orphans, and the remaining 39% were vulnerable children. See Table 2 for details.

Anthropometry and HIV status

The majority of children were within healthy Z-score ranges based on the WHO criteria for height (71%) and BMI (89%) (Table 2). Three-quarters had CD4+ T-cell levels greater than 500 cells/mm³. Accordingly, 85% were diagnosed as stage 1 or 2. About half of the children were on ART with average (SD) treatment duration of 2 (1) years.

PedsQL

Table 3 shows QOL means and SD from both child self-reports and caregiver proxy reports. The average total score and the physical functioning score reported by caregivers were higher than the corresponding scores reported by children (total score 83 vs. 78; physical functioning 93 vs. 81, respectively). The overall psychosocial functioning means from child and adult reports did not differ (both 77). The proportion of children at risk for impaired QOL was around one-fifth, based on total, physical, or psychosocial functioning scores, and was similar based on child or caregiver report. Table 4 shows that age was significantly associated with child-reported and caregiver-reported PedsQL scores in opposing directions (child $B = -2.7, p < 0.001$; caregiver $B = 2.0, p < 0.001$). QOL was not significantly associated with the remaining covariates.

Discussion

This research provides an important contribution to the study of QOL of orphaned and vulnerable CLHIV in a care home in Southern India. Consistent with our expectation that most children would have a good health and QOL despite being HIV positive given the high level of support, only about 20% of children were at risk for impaired QOL. These CLHIV likely did face stress, poverty, and stigma before joining SCH, which could negatively influence their subsequent psychosocial health. Average total QOL, according to both children and caregivers, was higher for the CLHIV at SCH than among CLHIV living in North India (Banerjee et al., 2010), a study sample with more than half of the children living in an institution. QOL decreased with child's age according to child self-report, but increased with child's age according to caregiver report. This is an unexpected finding because other studies have generally found children to be more optimistic about their well-being than adults even in the context of chronic disease (Britto et al., 2004; Varni et al., 2003). The result may reflect differing caregiver expectations for children of different ages or be due to older children living longer with chronic disease and possessing a deeper understanding of the long-term implications of their condition than younger children. Since child's current age and age when joining SCH were highly correlated, the lower QOL score of older children could also be due to having had less time in the stable environment at SCH and more occasion to experience stigma or abuse before joining SCH. Either way, these findings indicate that older children and those joining SCH at an older age could benefit from even greater psychosocial support and underscore the importance of taking child reports into account to effectively provide such support. This need may have been overlooked previously given that older children were perceived by caregivers to have a higher QOL.

Consistent with our hypothesis, physical health was relatively high, with most children showing a healthy height and BMI. Overall high levels of CD4 counts and low clinical stages of disease also suggest health-care maintenance at SCH was appropriate. This aligns with earlier findings of a longitudinal study at SCH that showed improvement in the nutritional profile of the children irrespective of ART status (Kapavarapu et al., 2012). We may not have found the expected associations of health with QOL because the overall physical health of the children was so high, with minimal variation. Therefore, there may have been a lack of power to detect the expected associations.

There were several limitations to our study. This was a cross-sectional analysis; therefore, no causal conclusions can be drawn. Our study population was relatively small and there was no comparison group. The generalizability may be limited to CLHIV living at a values-based care home setting.

Conclusion

Ours is the first study to our knowledge examining QOL for CLHIV in a blended institutional model. Our findings show that age was negatively associated with child self-reported QOL and positively associated with caregiver-reported QOL. Focus should be placed on ensuring adequate psychological support for older children. Future research

should compare blended models, family, and institutionalized care to identify environments and approaches that allow CLHIV to grow up to contribute to society and experience a fulfilling life.

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Table 1

Overview of measures.

Variables	Collected via	Measurement information
Demographics	Medical chart review	Age, sex, parental status (mother/father deceased), age of joining SCH, and years of schooling
Clinical/immunological data	Medical chart review	Height, weight, recent CD4 count, clinical stage, ART status, and age of starting ART Height and weight were measured at the time of the interview and Z-score standard deviations (SD) were calculated based on World Health Organization (WHO) criteria (WHO, 2006) Height-for-age Z-scores between 2 SD around the international average for sex and age are considered healthy (WHO, 2007). Z-scores more than 2 SD below the international average for weight, height, or BMI were defined as underweight, stunted, or wasted, respectively.
Quality of Life (QOL)	Pediatric Quality of Life Inventory 4.0 (PedsQL)	Encompasses physical (eight items), emotional (five items), social (five items), and school functioning (five items) Has developmentally appropriate forms for different ages. This study utilized reports for ages 5–7 (young child) and 8–12 (child) Items are scored and transformed to a 0–100 scale such that high scores indicate better QOL A mean score is computed per subscale, for emotional, social, and school functioning combined (“Psychosocial Health Summary”), and for the scale as a whole One SD below the mean has been used as a meaningful cutoff point for an at-risk status for impaired QOL in a study performed in California (Varni, Burwinkle, Seid, & Skarr, 2003) Has been validated for pediatric populations with acute or chronic health conditions (Varni, Seid, & Kurtin, 2001) including studies with caregivers and institutionalized CLHIV and uninfected children in India (internal consistency $\alpha > 0.7$) (Banerjee et al., 2010) Has been validated in Hindi (Das et al., 2010) but not Kannada, the native language of our participants. Therefore, it was translated and back-translated to provide Kannada forms for this study

Table 2Demographic and clinical characteristics of the sample ($N = 97$).

	Frequency	Percentage
Age		
5–7 years	26	27
8–12 years	71	73
Sex, female	45	46
Parental status		
Maternal orphan	13	13
Paternal orphan	34	35
Double orphan	12	12
Vulnerable child	38	39
BMI ^a		
Obese (Z-score >2.0)	1	1
Healthy (Z-score –2.0 to 2.0)	86	89
Wasting (Z-score <–2.0)	10	10
Height		
Healthy (Z-score –2 to 2.0)	69	71
Stunting (Z-score <–2.0)	28	29
Clinical staging		
Stage 1 or 2	82	85
Stage 3 or 4	15	16
Immunological staging		
>500 cells/mm ³	73	75
350–499 cells/mm ³	16	17
200–349 cells/mm ³	7	7
<200 cells/mm ³	1	1
On ART	52	54
	Mean	SD
Age	9.0	2.0
Age of joining Sneha (years)	6.4	1.8
Education (years in school)	4.3	1.9
Height (cm)	122.0	10.0
Weight (kg)	22.7	5.2
Duration of ART (years)	2.0	1.3

Note:

^aThe WHO Z-scores for weight are unavailable for ages >10 and therefore are not included.

Table 3

PedsQL scores from child self-report and caregiver proxy-report (total $N = 97$).

	Mean	SD	95% CI	At risk status ^a
Child self-report				
Total score	78	14	75–81	21
Physical functioning	81	16	78–84	20
Psychosocial functioning	77	15	74–80	19
Emotional functioning	72	18	68–75	13
Social functioning	80	19	76–83	21
School functioning	79	16	76–82	20
Caregiver proxy report				
Total score	83	10	81–84	22
Physical functioning	93	7	92–95	18
Psychosocial functioning	77	13	74–79	19
Emotional functioning	65	13	62–67	15
Social functioning	90	12	88–92	11
School functioning	76	21	72–80	26

Notes: Higher mean scores indicate better QOL in that domain.

^a% below (mean – 1 SD).

Table 4

Unadjusted linear regression results for PedsQL total score.

Demographics	PedsQL			
	Child self-report		Caregiver proxy report	
	B	SE	B	SE
Age	-2.7***	0.7	2.0***	0.5
Female gender	0.8	2.9	1.3	1.9
Parental status				
Vulnerable child	0.0		0.0	
Maternal orphan	-2.5	4.7	-4.0	3.1
Paternal orphan	-3.3	4.7	-0.5	3.1
Double orphan	-2.1	5.8	0.1	3.8
Physical measures				
Stunted height (Z-score <-2.0)	-2.2	3.2	-2.9	2.1
Wasted BMI (Z-score <-2.0) ^a	-0.6	4.8	-4.4	3.2
Immunological stage				
>500 cells/mm ³	0.0		0.0	
350–499 cells/mm ³	-0.6	4.0	1.4	2.7
200–349 cells/mm ³	-7.1	5.7	3.5	3.8
Clinical Stage 3 or 4	2.9	4.0	-2.5	2.7
On ART	-4.7	2.9	1.2	1.9

Notes:

^a Obese category left out.***
 $p < 0.001$.