

Quality of life and psychosocial wellbeing among children living with HIV at a Care Home in Southern India

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This study was designed to evaluate the quality of life 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 between 5 and 12 years of age. The Strengths and Difficulties Questionnaire, SDQ, was used to measure levels of caregiver concern about emotional or behavioral difficulties. SDQ scores showed 53% of children scored in the “borderline range”, 47% were in the “abnormal range”, and peer problems were most frequently reported. The Quality of Life (QOL) of each child was measured with the Pediatric Quality of Life (PedsQL) Inventory. Caregivers perceived children to have an overall higher QOL than was self-reported by children (Total Score 83 vs. 78). Emotion and School functioning means were higher according to child self-report than caregiver proxy-report (Emotion 72 vs. 65; School 79 vs. 76, resp.). PedsQL subcategory scores that were indicative of potentially impaired QOL were in social functioning (21%), according to child-report, and school functioning (26%), according to caregiver-report. Our findings indicated maternal orphans to be six times more likely to have psychological difficulties compared to children whose parents were living but unable to care for their child. The age of the child and age of joining the care home were found to be significantly negatively associated with quality of life reported by children and positively associated by caregiver-proxy reports. Physical measures showed the children’s clinical severity of disease remained well-controlled living in a residential, values-based care home.

Keywords: children; orphans; HIV; quality of life;

Introduction:

In India, it is estimated that there are 202,000 children living with HIV (CLHIV) and there are about 56,700 new HIV infected infants annually (NACO 2009). The UNAIDS defined the term ‘vulnerable children’ as children whose survival, well-being, or development is threatened by HIV/AIDS (UNAIDS 2004). Commonly, one or both of their parents die of HIV, and the children become single or double orphans respectively (Nyberg et al., 2012). Orphaned and vulnerable CLHIV often live in households of low socioeconomic status, and are more likely to be malnourished, uneducated, and lacking access to basic health care (Brackis-Cott 2008, Shet 2009, Shilpa 2005). Double orphans are more disadvantaged than single orphans, showing a lower probability of being at the proper education level and developing higher levels of depression (Andrews, Skinner, & Zuma, 2006; Rousseau, 2009). The majority of orphaned CLHIV are cared for by extended family, and due to socioeconomic hardship, many of these children assume adult responsibilities to create income and care for family members (Kumar 2012).

There is limited research on the quality of life (QOL) among orphaned CLHIV in India and a scarcity of anticipatory resources to support mental wellbeing (Das, Mukherjee, Lodha, & Vatsa, 2010). The World Health Organization defines QOL as “individuals’ perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, standards, expectations and concerns.” (Kuyken et al., 1995) Mental health problems previously described among CLHIV include attention deficit, hyperactivity, anxiety, and depression (Malee et al.,

2011). Studies have also explored what environments can provide care that supports resiliency and minimizes distress. ART medication, HIV information, future orientation, and social support are important for coping and general wellbeing while caregiver involvement and communication are associated with fewer emotional and behavioral problems among CLHIV(Mellins & Malee, 2013; Petersen et al., 2010).

Family-focused care such as kinship care models refer to the care of children by relatives or close family friends and has been advocated for internationally despite the burden it can place on the child and caregivers(Wakhweya, Dirks, & Yeboah, 2008). Kinship care models have been shown to provide psychosocial security for HIV positive orphans(Acharya et al., 2013). However, studies in China have shown that orphanages that preserve a family-style care with appropriate government and community support can result in better psychosocial wellbeing than kinship care models(Hong et al., 2011). In resource-poor regions and areas hardest hit by the HIV epidemic, positive outcomes have been cited to support institutionalized care(Whetten et al., 2009). In India, a study also found children who were living at home with their caregivers showed worse QOL compared with children who were living in care homes(Banerjee, Pensi, & Banerjee, 2010). Within institutions, orphans have been found to show less emotional distress when the entire staff participates in decisions affecting the children and the children are encouraged to become self-reliant through personal interactions with staff members than in institutions where the director made the decisions with explicit rules, and with impersonal interactions between staff and children (Wolff & Fesseha, 1998).

Although there are strengths to each of the environments that provide care for children, few studies have reported a blended model. A blended model of care provides an institutional setting that supports the regular involvement of primary and extended

family in the development of children. In this study, we report on one institution that does apply such a blended model, Sneha Care Home (SCH), in Bangalore, India. Our first aim was to evaluate the QOL among the CLHIV at the SCH, and assess the children's mental health and behavior difficulties. Our second aim was to evaluate the physical health among these CLHIV to assess developmental milestones and HIV severity, and to determine whether correlations existed between their demographics or clinical measures and QOL or mental health. We hypothesized that the children would have a relatively high QOL despite being HIV positive because of a stable environment with individualized resources to support physical and psychosocial health. We also hypothesized that severity of disease and demographic variables such as age of joining a care home, and parental status would correlate with a child's behavior and psychosocial QOL.

Methods:

Study Setting

Data were collected at SCH, a Catholic residential care facility for HIV positive orphans and vulnerable children between five and twelve years old. SCH uses a model that blends community with family involvement and is founded on providing a values-based education tailored to the unique needs of each child. The SCH provides housing, nutrition, medical care, education, and vocational preparation. Their long-term goal is for the children to ultimately thrive in the community as well-informed, self-sufficient, and productive adults. An on-site hospital with a medical officer and therapists is available at all times and the children receive medication supervision and monthly health assessments. A holistic approach is taken by all staff to care for the entire person of each child. SCH encourages existing family to call on a weekly or bimonthly basis and be involved in activities and cultural celebrations. Vocational mentorship in line with children's interests and talents is provided.

Study design and Subjects

Cross-sectional interview data were collected during March 2012. All one hundred CLHIV residing at SCH were considered for the study. The study participants were required to be between the ages of 5-12 years and assent to be in the study. Ninety-eight children qualified to be in the study. Two did not because they were younger than five years old. Another child chose not to participate and declined to provide a reason. In addition to interviewing the children, we gathered information about each child from a teacher and a therapist. These caregivers had to spend more than 15 hours/week with the children. Six teachers qualified under these criteria and consented to filling out a caregiver questionnaire about conduct, hyperactivity, emotional and peer problems for children they taught in their classroom. Additionally, two on-site therapists were asked to participate. Each therapist 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. Recruitment of child participants began by describing the study and answering questions in a group setting. Participants 8-12 years of age were asked for written consent, those 5-7 years gave verbal assent. All questionnaires were administered face-to-face, independently and confidentially, by trained interviewers, in either English or Kannada, the local language, depending on the child's preference. All the children regardless of whether they qualified or assented received a small toy of nominal cost. The interviews took approximately 15 minutes. Teachers and therapists provided written consent to fill out written questionnaire forms, in either English or Kannada, depending on the caregiver's preference. All participating caregivers received a thank you gift of nominal cost. This study received clearance by the Committee for Human Research at the University of California San Francisco and by the Institutional Ethical Review Board at St. John's Medical College Hospital.

Measures

Demographic, clinical and immunological information was collected from medical charts. They included age, sex, recent CD4 count and clinical stage (WHO 2006), parental status, ART status, age of starting ART, age of joining SCH, and years of schooling.

The Pediatric Quality of Life Inventory (PedsQL™) measures Health Related Quality of Life (HRQoL) and comprises parallel child self-reports and caregiver proxy-reports. The PedsQL encompasses physical (8 items), emotional (5 items), social (5 items), and school functioning (5 items). There exist developmentally appropriate forms for different ages. This study utilized reports for ages 5 to 7 (young child) and 8 to 12 (child). Items are scored and transformed to a 0 to 100 scale such that high scores indicate better HRQOL. A mean score is computed per subscale, for emotional, social and school functioning combined ('Psychosocial Health Summary'), and for the scale as a whole. The PedsQL has been validated for use among pediatric populations with acute or chronic health conditions (Varni, Seid, & Kurtin, 2001). One standard deviation below the mean has been used as a meaningful cut off point score for an at-risk status for impaired HRQOL in study performed in California (Varni, Burwinkle, Seid, & Skarr, 2003). The PedsQL has also been validated with CLHIV and uninfected children in India, with internal consistency $\alpha > 0.7$ (Banerjee et al., 2010). The PedsQL was validated for use in Hindi (Das et al., 2010) but not Kannada, the native language of our participants. Therefore, experienced interpreters performed translation and back translation of the PedsQL questionnaire to provide Kannada forms.

The Strengths and Difficulties Questionnaire (SDQ) is an internationally well-validated brief behavioral screening tool for children 3–16 years old, to assess behavioral and emotional difficulties and pro-social behavior. The SDQ has versions for parent, teacher, and self-report. This study utilized only teacher reports. The SDQ is composed of five sub-scales of five items each (emotional symptoms, conduct problems, hyperactivity/inattention, peer relationships, and pro-social behavior). Items are scored on a 3-point scale, from 0 (Not true) to 2 (Certainly true). The Pro-social score is the

sum of its five items. The Total Difficulties summary score is the sum of all items of the other four scales. It ranges from 0 to 40, with higher values signifying more difficulties. Scores are categorized into normal, borderline, and abnormal ranges (Goodman, Meltzer, & Bailey, 1998). It has been validated in Indian populations (Bele, Bodhare, Valsangkar, & Saraf, 2013) and was available in Kannada.

Height and weight were measured at the time of the interview and Z score standard deviations (SD) were calculated based on WHO criteria for anthropometric measurements (WHO 2006). Height-for-age Z-scores between 2 SD around the international average for sex and age are considered healthy (World Health Organization, 2007). Z-scores more than 2 SD below the mean for weight, height, or BMI were defined as underweight, stunted, or wasted respectively.

Analyses

Univariate statistics such as frequencies, means and SD were calculated to describe the demographic and laboratory characteristics of the participants, their PedsQL and SDQ scores. Logistic regression was performed to evaluate associations of demographics, clinical severity, and anthropometric measurements with psychological difficulties as a dichotomous outcome (abnormal vs. other Summary SDQ score). Similar linear regression models were performed with the continuous PedsQL score as the outcome. Analyses were performed using STATA version 11.1.

Results

Study sample: 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, and the children had been in school for a mean (SD) of 4 (2) years at the time of the interview. Forty-eight percent of the children had one deceased parent, 12% were double orphans, and the remaining 39% were vulnerable children (see Table 1).

Anthropometry and HIV status: The majority of children in this study were within healthy Z score ranges based on WHO criteria for height (71%) and BMI (89%) (Table 1). One child qualified as obese. Three-quarters of children had CD4+ T cell levels greater than 500 cells/mm³. Accordingly, the majority of children had been diagnosed as Stage 1 or 2 by a clinician up to six months prior to the study (85%). About half of the children were on ART (54%), with average (SD) treatment duration of 2 (1) years.

SDQ

Table 2 reveals that 45 children (47%) had a total score that placed them in the “abnormal” or “significant concerns” range. A slightly greater proportion (53%) had scores falling in the “borderline range”, denoting caregiver concerns about behavior that are not severe enough to be considered serious or abnormal. None of the children scored within the “normal” range. Peer problems were most frequently reported, followed by emotional and hyperactivity problems. Scores on the Conduct scale generally fell in the “normal” range and Pro-social behaviors were mostly in the normal to borderline range.

PedsQL

Table 3 shows HRQOL means and SD from both child self-reports and caregiver proxy-reports. The average total and physical domain score reported by caregivers was higher than the corresponding score reported by children (Total Score 83 vs. 78; Physical functioning 93 vs. 81, resp.). The overall Psychosocial functioning mean from child and adult reports were not significantly different (both 77). Within Psychosocial functioning, the Social functioning mean self-reported by the children was lower than the caregiver report (80 vs. 90, resp.) but Emotion and School functioning means were higher according to child than caregiver report (Emotion 72 vs. 65; School 79 vs. 76, resp.). The PedsQL subcategory with the highest proportion of scores lower than 1 SD below the mean – indicative of potentially impaired QOL in this domain – was social

functioning (21%) according to child-report and school functioning (26%) according to caregiver-report.

Association of SDQ & PedsQL reports with sample characteristics

Age of the child was significantly associated with child self-reported and caregiver proxy-reported PedsQL scores in opposing directions (child $B=-2.7, P<0.001$; caregiver $B=2.0, P<0.001$). Otherwise, QOL was not significantly associated with the remaining demographic and clinical characteristics (Table 4). Parental status was significantly ($\chi=8.6, P=0.04$) associated with the probability of scoring in the abnormal range for total SDQ score. Specifically, maternal orphans were six times more likely to be in the abnormal range than vulnerable children (unadjusted OR=6.1 [95% CI 1.4-26.6], $p<0.02$). Children on ART were marginally more likely to be in the abnormal range than children not taking ART (OR=2.2 [0.97-5.1], $p<0.06$). Age, sex, age of joining SCH, and physical health measures were not significantly associated with increased odds of behavioral difficulties.

Discussion

This research provides an important contribution to the study of QOL and mental health of orphaned and vulnerable CLHIV in a unique care home located in Southern India. Perinatally acquired HIV infection is a chronic illness that impacts the physical and psychological health of a child. It is notable that on the children's behavioral assessment by teachers in the SDQ no one's total score fell in the normal range. These findings stand in contrast to our expectation that the children would have a high level of mental health despite being HIV positive due to receiving psychosocial and physical support from healthcare providers, family, teachers, and peers in a future-oriented educational model. This is understandable given that most CLHIV face a substantial amount of stress, poverty, and stigma that can impact their behavior, and another study found worse behavior problems among orphans than non-orphans living with chronic disease (Bhattacharya, Rajeshwari, & Saxena, 2010). Nevertheless, greater than half of

the children had scores that were not severe enough to be considered serious based on caregiver-proxy reports. Peer problems, emotional problems, and hyperactivity problems were consistent with previous studies screening mental health among CLHIV (Mellins & Malee, 2013). Somewhat surprisingly, conduct scores fell mainly within the “normal” range because other studies have typically found them to commonly be a problematic area (Chi & Li, 2012). We speculate this difference could be attributed to the experiential model of learning that provides children with organized activities in line with their own unique interests. The high level of pro-social behaviors among the children could also conceivably be influenced by the educational structure provided at SCH to instill universal values and social interaction. Maternal orphans were six times more likely to be in the abnormal behavior range than vulnerable children, whose mother is still alive. This may be explained by the fact that in the Indian culture children typically rely highly on maternal care, and maternal death can result in more stress for children. The loss of maternal care may result in an extended time receiving less adult support before reaching out for help from other family members or community-based programs. Maternal reliance may also partially explain the finding that double orphans showed the second highest OR, although this result was not significant.

Few studies have assessed QOL among orphaned CLHIV in care homes. Average total HRQOL, according to both children and caregivers, was higher for CLHIV living 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. Self-reported QOL decreased with age of the child, while caregiver-reported QOL increased with age. This is an unexpected finding because QOL studies have generally found children to be more optimistic about their wellbeing 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. These findings may also be due to older children living longer with chronic disease and processing a deeper understanding of the long-term implications of their condition. Since the child’s age at the time of the study

and age at the time of joining SCH were highly correlated ($R=0.85$, $P<0.001$), 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 prior to 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 underscores the importance of taking child-report 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 based on the majority of children being within healthy ranges of height and BMI. Overall high levels of CD4 counts and low clinical stages of disease also suggest that health care maintenance at SCH was appropriate and consistent. This aligns with the findings of a prospective longitudinal study performed at SCH that showed an improvement in the nutritional profile of the children even irrespective of ART status (Kapavarapu et al., 2012). We may not have found the expected associations between physical and psychosocial HRQOL 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.

Limitations

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 is limited to CLHIV living at a Care Home setting. The measurement of mental health via the SDQ included only teacher report, not parent and child report. Given the size and nature of the sample, parent report had a limited value relative to the expense of time and resources involved. Furthermore, in order to minimize the burden on the children and disruption of daily routines, we chose to include only the teacher perspective.

Conclusion

Ours is the first study to our knowledge providing QOL and mental health results for CLHIV in a blended institutional model that provides physical, mental, and emotional support. Our findings show that age was negatively associated with child-self reported QOL and positively associated with caregiver reported QOL. We also found that maternal orphans were more likely to have psychological difficulties compared to vulnerable children. Despite living with on-going disease, the children's clinical severity of disease has remained well controlled. Given that a percentage of children still scored within a concerning range for SDQ, these results also indicate the on-going need to build psychological infrastructure into the social systems of orphaned CLHIV. Focus should be placed on ensuring adequate psychological support for maternal orphans and older children. Future efforts should focus on comparing blended models, family, and kinship care. Given the significant diversity and disparity of resources within India, future work should continue to focus on identifying effective environments and approaches to allow CLHIV to grow up to contribute productively to society and experience a rewarding and fulfilling life.

Acknowledgements

We would like to thank all the children who contributed information and their time. A heartfelt thanks to Sister Mini and Clera Lewis for coordinating interviews at Sneha, Siju Thomas for coordinating at the research site, and the team members in Prerana that were involved in translating: namely Laxmi, Shanthi, Nandini, Sudhamani & Nagesh.

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