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Formation and psychometric evaluation of a health-related quality of life instrument for children living with HIV in India

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Abstract

In-depth interviews and focus group discussions were conducted to inform the development of an instrument to measure the health-related quality of life of children living with HIV. The QOL-CHAI instrument consists of four generic core scales of the "Pediatric Quality of Life Inventory" and two HIV-targeted scales—"symptoms" and "discrimination." A piloting exercise involving groups of children living with HIV and HIV-negative children born to HIV-infected parents provided evidence for the acceptable psychometric properties and usability of the instrument. It is expected that the QOL-CHAI can serve well as a brief, standardized, and culturally appropriate instrument for assessing health-related quality of life of Indian children living with HIV.

Keywords

children; HIV; quality of life; reliability; validation study

Introduction

Health-related quality of life (HRQoL) distinguishes itself from more general quality of life measures in that its purview is limited to factors related to health or health care. The scope of HRQoL evaluation tools reaches beyond conventional assessments of health, and are therefore considered more appropriate in the context of clinical and public health research (Guyatt et al., 1993).

Antiretroviral therapy (ART) has reduced the incidence of opportunistic infections and other AIDS-defining illnesses. This has led to delayed progression to AIDS and has prolonged the life spans of the infected. However, since complete cure is not possible with current therapies (Stevenson, 2003), helping HIV-infected individuals to attain optimum quality of life remains a key goal of treatment. Assessment of HRQoL of HIV-infected persons not

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only reveals the status of the patient but can also be useful for evaluation of treatment measures (Testa and Lenderking, 1995). For these reasons and the fact that HIV is recognized as a major global health emergency (Beaglehole et al., 2003), there has been a growing interest in development of HIV-targeted HRQoL tools (Franchi and Wenzel, 1998). However, these instruments are developed mostly for high-income country settings, and few target the pediatric population (Punpanich et al., 2011). It has been hypothesized that many such tools designed for high-income countries may be unsuitable for resource-poor settings (Punpanich et al., 2011; Skevington and O'Connell, 2003).

In India, where even normal uninfected children are often deprived of basic amenities and social support, ensuring quality of life for children living with HIV (CLH) is an especially arduous task. Widespread discrimination associated with HIV and lack of parental care (for orphans) compound the problem even further (Das, 2015; Turan and Nyblade, 2013).Therefore, a culturally appropriate tool to assess HRQoL will be helpful in identifying the areas of concern among the pediatric HIV population and to formulate interventions to address their specific needs.

Methods

This study had two phases, a qualitative study with in-depth interviews (IDI) and focus group discussions (FGD) to inform tool development, and a quantitative study to assess the applicability of the developed tool and to evaluate its psychometric properties. The participants for this study were recruited with the help of SPARSHA - a local community-based organization (CBO), which runs care and support programs for people living with HIV (PLH). Eligibility criteria for study participants are presented in Supplementary Material S1 (available at: http://hpq.sagepub.com/).

Qualitative study

Data collection—Participants for the qualitative study were recruited through a convenience sample of CLH and their caregivers residing in the Paschim and Purba Medinipur districts of West Bengal (Das, 2015). Principal caregivers of CLH were requested to participate in IDIs, while CLH took part in FGDs with other CLH in their age group.

In total, 34 IDIs (20 biological parents and 14 non-parent caregivers) and 4 FGDs were conducted between July and September 2014. Among the four FGDs, two each involved CLH aged 8–12 and 13–15 years.

Instrument development—In addition to identifying HIV-targeted items from the formative qualitative research, we performed a literature review (Bozzette et al., 1994; Cleary et al., 1993; Justice et al., 2001; Lenderking et al., 1997; Whalen et al., 1994) and consulted experts regarding selection of items for the scales. The two new scales developed using the above methodology, namely, "symptoms" and "discrimination," were incorporated with 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 (Varni et al., 1999). Thus, the newly created 'quality of life (health-related) of children living with HIV/AIDS in India (QOL-CHAI)' instrument contained 47

items, including 18 items in the symptoms domain and 6 in the discrimination domain, in addition to 23 items from the four domains of the PedsQL. Scoring principles for the two new scales were similar to those of the PedsQL generic core to facilitate interpretation and maintain consistency. Linguistic validation guidelines were followed for translation of PedsQL items to Bengali (Mapi Research Institute, 2002). To assess applicability and detect problems with comprehension of items, cognitive interviews were conducted with 10 children, including five each from the 8–12 and 13–15-year-old age groups (Juniper et al., 1996; Young et al., 1996).

Quantitative study

Data collection—The quantitative phase recruited 8- to 15-year-old CLH from three districts of West Bengal, Paschim Medinipur, Purba Medinipur, and Kolkata. Additionally, children of the 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. The QOL-CHAI instrument was administered to 199 CLH and 194 HIV-affected children between November 2014 and February 2015.

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, and so on. Cronbach's α was calculated for each domain to determine internal consistency reliability. Convergent validity of the symptoms and discrimination scales were assessed by estimating correlation with last reported CD4 cell count and the social functioning scale score, respectively (Elkin, 2012). To assess known group validity, we used the *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 used to determine whether scale scores differed based on infection status.

Using backward elimination regression analysis, we determined whether the two newly incorporated scales, symptoms and discrimination, yielded additional information on clinical status of CLH beyond that captured by the PedsQL. This was assessed by regressing scale scores on last measured CD4 cell count and by checking whether the scores from the 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 using discriminant analysis. We performed stepwise discriminant analysis on infection status with summary scores of each scale to determine which scales discriminated significantly between CLH and HIV-affected children.

Exploratory factor analysis with principal component extraction (orthogonal rotation) was conducted to determine whether the factor loadings were consistent with the constructs being measured. The numbers of factors to be extracted were determined by setting a cut-off of 75 percent of the initial communality estimate.

Results

Socio-economic and demographic characteristics of the study population are presented in Table 1.

Among the QOL-CHAI scales, Cronbach's α was found to be highest for the social functioning scale (0.85) and lowest for the discrimination scale (0.62) (Table 2). We observed that two items in the discrimination scale ("the staff at hospital/health facilities were rude to me" and "doctors were rude to me") showed very weak correlation with the scale score, and there were marked increases in α with deletion of these items from the scale. These two items were therefore deleted (Hof, 2012), bringing the number of items in the discrimination scale down to four and the total number of items in the QOL-CHAI to 45. The rest of the analysis was performed on this modified instrument (Supplementary Material S2 [available at: http://hpq.sagepub.com/]). In terms of known group validity, we found that CLH performed significantly poorer ($p < 0.01$) than HIV-affected children on all but the discrimination scale (Table 3).

Regarding convergent validity, the symptoms scale score showed significant negative correlation with last measured CD4 cell count (Pearson correlation coefficient (r) = −0.23, $p < 0.01$). The symptoms scale also showed a significant positive correlation with all other scale scores. The discrimination scale score was significantly correlated with the social function score ($r = 0.4$, $p < 0.01$) (Table 4).

Backward elimination regression analysis on the last measured CD4 cell count with all six scale scores as independent variables revealed that the optimal model consisted of the 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 the core scales of the PedsQL (Table 5).

Seven factors were extracted from factor analysis of scale scores among CLH (Supplementary Material S3 available at: http://hpq.sagepub.com/). Except for the symptoms scale, all items belonging to a single scale had maximum loading on the same (but discrete from others) factor. Stepwise discriminant analysis (Supplementary Material S4 available at: http://hpq.sagepub.com/) identified that among the QOL-CHAI scales, physical functioning, school functioning, and symptoms significantly discriminated between CLH and HIV-affected children, adjusting for other scales.

Discussion

The objective of this study was to develop and evaluate the psychometric properties of an instrument for assessing HRQoL among Indian CLH. The QOL-CHAI instrument incorporates four generic core scales of the PedsQL, a widely used disease-independent HRQoL tool, along with two scales measuring symptom- and discrimination-related constructs that were identified from qualitative inquiry.

Internal consistency reliability was high for all scales. Except for the symptoms scale, which had an α of 0.69, the rest of the scales showed an α value higher than the recommended 0.7

(Nunnally, 1978). Distribution of scores on all scales but school functioning was right skewed. We observed that many responses had the lowest possible value (floor effect), especially for the discrimination and social functioning scales. Similar findings were reported from a Thai study (Punpanich et al., 2011). This can be attributed to the fact that we recruited participants from community settings rather than 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 (Das et al., 2016; Panda et al., 2014), most caregivers made a conscious effort to conceal their (and their child's) HIV status to avoid being stigmatized. We hypothesize that the families of most children reporting no experience of discrimination or no decline in social functioning had not revealed their own or their family members' disease status in the community. 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 might be considered less sensitive at the better spectrum of the construct being measured (Streiner et al., 2014). However, instruments that exhibit such floor effects are likely to be more perceptive in detecting any decline in the measured construct, which is an important quality for an HIV-targeted HRQoL scale, as overall health and HRQoL of PLH are expected to worsen with time (Punpanich et al., 2011).

Regarding known group validity, scores on all scales except discrimination showed statistically significant differences, based on the HIV infection status of children. As per our *a priori* hypothesis, CLH had significantly poorer physical, emotional, social, school, and symptoms 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 is often directed towards the entire family, even if only one member of that family is infected. As reported by a previous Indian study (Panda et al., 2014), even the healthy children of parents living with HIV were often subjected to discrimination in school and community settings. Also, as mentioned before, most participants did not report experiencing any discriminatory behavior during the past year, possibly because they and their family members concealed the HIV diagnosis. Thus, the low mean scores obtained on the "discrimination" scale 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 lymphocyte count, indicating that CD4 count was likely to decline with worsening of HIV symptoms and vice versa. The hypothesis that improved/worsened disease symptoms should be associated with respective improvement/decline in HRQoL was confirmed by a positive correlation of the symptoms score with the 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. The significant positive correlation of the physical functioning scale with the rest of the scales was also not surprising, given the psychosomatic nature of infection (Leserman, 2008). Thus, in accordance with our hypothesis, we found a 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 the 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 the symptoms scale had maximum loading on two factors independent from the rest of the factors suggested that unique information was captured by the symptoms scale.

The school functioning, symptoms, and discrimination scale scores emerged as significant predictors of clinical outcome (CD4) of CLH. Thus, both of the newly incorporated scales, symptoms and discrimination, provided additional unique information on clinical status of CLH beyond that captured by the PedsQL. From stepwise discriminant analysis, we observed that the symptoms scale, along with the school and physical functioning scales, successfully distinguished between CLH and HIV-affected children, establishing the symptoms scale as an important component of the QOL-CHAI when comparing HIV-infected to uninfected.

This study had some important limitations. 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. Similar to other HIV-specific CBOs in India, most members of the collaborating CBO belonged to the lower socio-economic strata. Thus, results presented here are neither necessarily representative nor generalizable to HIV-infected and HIV-affected children from all socio-economic classes. Second, although plasma viral load (PVL) is considered a better indicator of clinical conditions 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 PVL measurement. Thus, it was not possible to utilize PVL in analyses related to clinical outcome. 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 socio-economic 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 causing variation in 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 independently 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 (Mahendra et al., 2007). As the participants were 8- to 15-year-old children, it was important to ensure that they understood the meaning of each item in the instrument. Keeping that in mind, we conducted cognitive interviews to linguistically

validate the translated version of the PedsQL generic core and to fine-tune the items in the QOL-CHAI.

The results of this study demonstrate that the QOL-CHAI, administered by trained health workers, can serve well as a brief, standardized, and culturally appropriate instrument to measure HRQoL of Indian children and adolescents living with HIV. With acceptable psychometric properties, wide-scale implementation of the QOL-CHAI can help assess overall health status at the individual level and also inform national HIV program policy for improving treatment and support services.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Characteristics of study participants (n = 393).

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

SD: standard deviation.

[a]Values may not sum to 100 percent due to rounding of numbers.

Table 2

Internal consistency reliability estimates of the QOL-CHAI instrument for children living with HIV (n = 199).[a]

Scale	Items	Cronbach's α	Correlation of item with total scale score	Cronbach's α 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 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 body 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 keep 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 keeping 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 stools		0.33	0.67
	Pain in the limbs		0.21	0.68
	Headache		0.24	0.68
	Skin rash, itchy lesions, sores/ulcers		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 eyes		0.10	0.69
	Dizziness		0.19	0.68
	Throat swelling, sore throat		0.33	0.67

Scale	Items	Cronbach's α	Correlation of item with total scale score	Cronbach's α following deletion of item
Discrimination	Abdominal distension	0.62[c]	0.24	0.68
	Shortness of breath, wheezing		0.30	0.67
	Tingling sensation/numbness in limbs		0.25	0.67
	Oral ulcer		0.42	0.66
	The staff at hospital/health facilities were rude to me[b]		0.03	0.70
	Doctors were rude to me		0.04	0.69
	I was not allowed admission to school/private tutorial institution[b]		0.60	0.48
	I was made to sit separately in school/private tutorial institution		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

QOL-CHAI: quality of life (health-related) of children living with HIV/AIDS in India.

[a]Observations with missing values excluded as applicable.

[b]These two items were deleted from the scale.

[c]Cronbach's α 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[a]
For children living with HIV									
Physical functioning (range 0–32)	8	6.1	5.9	0	31	4	13.6	0	<0.01
Emotional functioning (range 0–20)	5	5.4	4	0	17	5	10.6	0	<0.01
Social functioning (range 0–20)	5	2.4	3.9	0	16	0	56.3	0	<0.01
School functioning (range 0–20)[b]	5	5	3.6	0	15	5	7.5	0	<0.01
Symptoms (range 0–72)	18	9.8	6.1	0	39	9	3.5	0	<0.01
Discrimination (range 0–16)[a]	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)[c]	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)[c]	4	0.3	1	0	8	0	88.7	0	–

QOL-CHAI: quality of life (health-related) of children living with HIV/AIDS in India.

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

[b] 11 missing values excluded.

[c] 7 missing values excluded.

Table 4

Pearson correlation coefficient among scale scores for children living with HIV (n = 199).[a]

	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[b]	1				
Social functioning	0.003	0.444[b]	0.172[b]	1			
School functioning	0.088	0.261[b]	0.121	0.216[b]	1		
Symptoms	−0.160*	0.472[b]	0.215[b]	0.327[b]	0.269[b]	1	
Discrimination	0.060	0.149[b]	0.134	0.409[b]	0.024	0.172[b]	1

[a]Observations with missing values excluded as applicable.

[b]$p \leq 0.05$.

Table 5

Backward elimination regression analysis on last measured CD4 cell count of children living with HIV (n = 188).[a]

Scale	Parameter estimate	Standard error	*t* statistic	*p* value	R^2
Constant	732.1	57.9	12.7	<0.01	0.04
School functioning	14.8	7.6	1.9	0.05	
Symptoms	–14.4	5.1	–2.8	<0.01	
Discrimination	20.2	15.9	1.3	0.21	

[a]Observations with missing values excluded.

p value cut-off for selection = 0.3.