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Measuring health-related quality of life in children living in HIV/AIDS-affected families in rural areas in Yunnan, China: preliminary reliability and validity of the Chinese version of PedsQL™ 4.0 Generic Core Scales

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Abstract

Objectives—To investigate the preliminary reliability and validity of the Chinese Mandarin version of the Pediatric Quality of Life Inventory (PedsQL)™ 4.0 Generic Core Scales in a sample of general children and children living in HIV/AIDS-affected families.

Methods—The PedsQL™ 4.0 was administered to 116 children aged 8 to 18 from HIV/AIDS-affected families and 115 of their caregivers. The questionnaire was also administered to a control group of 109 children and 107 of their caregivers.

Results—Most of the self and proxy-report scales in both groups exceeded the reliability standard of 0.70, while the self-report Emotional Functioning and School Functioning subscales were slightly less than 0.70. On average, children living in HIV/AIDS-affected families scored significantly lower than the control group. The level of agreement between self and proxy-reports was low. Correlations were higher on average for the younger age group than for the older age group.

Conclusion—The Chinese Mandarin version of PedsQL™ 4.0 is a valid and reliable instrument for use with children living in HIV families. The HRQoL for children living in HIV families is lower than children from ordinary families.

Keywords

Health Related Quality of Life; PedsQL™; HIV/AIDS; Health; Children

INTRODUCTION

An estimated 33 million adults globally, most of them parents, are now living with HIV [1], and more than 15 million children have been orphaned by AIDS [2]. Attention has been given to the spectrum of the impact of HIV/AIDS on children worldwide [3–5]. There is

documentation of the disadvantages faced by these children with respect to economic impact, child labor, education, health and nutrition, psychological impact, and long-term developmental impact [6]. Given the multidimensional impact HIV/AIDS has on children, it is necessary to develop an appropriate instrument to capture and evaluate the comprehensive nature of the health status of affect children. The health related quality of life (HRQoL) is increasingly acknowledged as an important health outcome measure in clinical trials and health services research and evaluation. As a multidimensional assessment of the physical, psychological and social functioning status, HRQoL is believed to be a good measure of studying health status [7].

The Pediatric Quality of Life Inventory (PedsQL)[™] is one of the more promising HRQoL measures for children. Developed in the United States, the advantages of PedsQL[™] include brevity, availability of age-appropriate versions and parallel forms for child and parent [8,9]. Recent reports confirm that PedsQL[™] performs well in distinguishing healthy children from pediatric patients with either acute or chronic conditions if those conditions impact on the child's general HRQoL significantly [10–12].

The most recent estimate indicates that as of the end of 2007, there were approximately 700,000 people living with HIV/AIDS in China [4]. The epidemic of children with HIV infected parents, including children orphaned by AIDS, has emerged as an important issue [5]. However, limited information is available to understand the HRQoL of children living in HIV/AIDS-affected families. The aim of our study was to investigate the preliminary reliability and validity of the Chinese version of PedsQL[™] 4.0 Generic Core Scales in a sample of general children and children living in HIV/AIDS-affected families.

METHODS

Participants

The study was conducted in four townships of Longchuan County, Yunnan Province, China. Institutional ethics approval to conduct the study was obtained from the Institutional Review Boards at National Center for AIDS/STD Control and Prevention, Chinese Center for Disease Control and Prevention (NCAIDS, China CDC). Both HIV/AIDS affected and unaffected families were selected to participate in the study. Within each household, one child aged 8 to 18 and one caregiver (one that is actively involved with the child's day-to-day care) were interviewed. During August to September 2006, 126 affected families and 130 control families with eligible participants were approached. A sample of 116 affected families and 109 control families were recruited for the interviews. No adult was present at home for 8 affected and 16 control families during three contact attempts; the remaining 7 families refused to participate in the study.

Measurements

The 23-item PedsQL 4.0 Generic Core Scales encompasses the essential core domains for pediatric HRQoL measurement: 1) Physical Functioning (8 items), 2) Emotional Functioning (5 items), 3) Social Functioning (5 items) and 4) School Functioning (5 items). It consists of parallel Child Self-Report and Parent Proxy-Report format for ages 2–4, 5–7, 8–12 and 13–18 years. The items for each of the forms are essentially identical, differing in developmentally appropriate languages, or first or third person tense. A 5-point response scale is utilized across Child Self-Report for ages 8–18 and Parent Proxy-Report.

Items are reverse-scored and linearly transformed to a 0–100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0), so that higher scores indicate better HRQoL. Scale scores are computed as the sum of the items divided by the number of items answered (this accounts for missing data). In

addition to the four subscales, two summary scores were computed. Physical Health Summary score (8 items) is the same as the Physical Functioning subscale, and Psychosocial Health Summary score (15 items) is computed as the sum of the items divided by the number of items answered in the Emotional, Social, and School Functioning subscales. User agreement was signed with Mapi Research Trust, Lyon, France prior to using the questionnaires. The Chinese Mandarin version of the questionnaires was translated and validated by the research group from the Department of Statistics and Epidemiology, School of Public Health, Sun Yat-sen University, following the PedsQL Linguistic Validation Guidelines [13].

Parents or caregivers of all children filled out an additional questionnaire on family sociodemographic characteristics, including caregiver's age, gender, education, marital status, ethnic group, and child's orphan status.

Procedures

Study participants were recruited through the help of local health service providers who treat HIV-positive patients in the community. Local health service providers approached eligible families and asked the parents or caregivers if they would like to participate in the study. The nearest neighbor households with no HIV-positive patients were also approached as the control families. If they agreed, potential participants were approached by interviewers and enrolled in the study.

The questionnaire interviews were conducted in the health service providers' or the participants' own houses, according to the participants' request. Informed consent was obtained before the interview. Caregivers were interviewed first, after which they were asked whether they would agree to their children participating in the study. If the caregiver agreed, the interviewer talked with the child about the study. The child's verbal consent was obtained and audio-recorded after it was determined that the child understood what he/she was consenting to.

Data Analysis

For categorical variables, data were compiled as frequency and percent and the differences between affected and control groups were compared by Chi-square test. The exception is when one of the categories in the contingency tables is ordinal (e.g., child's education level), in which case, the Wilcoxon Rank-Sum test was employed. For continuous variables (i.e., PedsQL 4.0 score), data were calculated as mean \pm standard deviation (SD) and the two groups were compared by independent t-test. Internal consistency reliability for each scale was determined by calculation Cronbach's α coefficients. Scales with reliability coefficients equal to or greater than 0.70 were considered satisfactory. The validity was determined by comparing scale scores across groups. We anticipated that children in the control group would report higher PedsQL 4.0 scores than children living in HIV/AIDS-affected families. The consistency between Child Self-Report and Parent Proxy-Report was determined through intra-class correlation [14].

RESULTS

Sample characteristics

Of the 109 control families, 107 caregivers and 109 children completed enough items on the parent-proxy or Child Self-Report measure to derive at least one subscale score and/or summary score. Of the 116 affected families, 115 caregivers and 116 children completed enough items to derive at least one subscale score and/or summary score to be included in the data tables. For the School Functioning subscale, data was missing for those children who dropped out of school.

Table 1 summarizes the demographic variables of the caregivers and children in two groups. No statistically significant differences were found with respect to age, gender, education, marital status and household income. In the control group, the average age of caregivers was 39.53 (SD = 9.5) and average age of children was 12.17 (SD = 2.7). In the affected group, the average age of caregivers was 41.17 (SD = 11.5) and the average age of children was 12.09 (SD = 2.6). About 60% of caregivers were females and over 50% of children were boys in both groups. Most children (80.7% in the control group and 84.5% in the affected group) were currently attending school. In terms of ethnic backgrounds, more affected families came from Jingpo but this was not statistically significant ($P = 0.051$).

Internal consistency reliability

Internal consistency reliability alpha coefficients by age group are presented in Table 2. The majority of the Child Self-Report scales and Parent Proxy-Report scales in both groups exceeded the minimum reliability standard of 0.70 required for group comparisons, while the Child Self-Report Emotional Functioning and School Functioning subscales were slightly less than 0.70.

Discriminante validity

Table 3 contains the PedsQL 4.0 scores for children from the affected and control families. For Child Self-Report, affected children scored significantly lower on Total score ($t = 2.530$, $P = 0.006$), Psychosocial Functioning ($t = 2.430$, $P = 0.008$), Emotional Functioning ($t = 2.140$, $P = 0.017$), and School Functioning ($t = 1.687$, $P = 0.047$) than children from the control group. For Parent Proxy-Report, caregivers of children from affected families reported lower scores on Total score ($t = 2.760$, $P = 0.003$), Psychosocial Functioning ($t = 2.286$, $P = 0.012$), Emotional Functioning ($t = 2.953$, $P = 0.002$), and Social Functioning ($t = 2.205$, $P = 0.014$) than those from the control families.

Child/caregiver concordance

Table 4 shows the correlational consistency between self and proxy-report. The level of agreement between self and proxy-reports was low. Correlations were higher on average for the younger age group than for the older age group, especially on psychosocial health. Correlations were higher for the control group than for the affected group.

DISCUSSION

This article describes the psychometric properties of the Chinese Mandarin version of the PedsQL 4.0 Generic Core Scales (age 8–18 years) in a comparison of children living in HIV/AIDS-affected families to general controls. The performance of the scales was found to be similar to that reported for the original PedsQL 4.0. The Chinese PedsQL 4.0 Total Score for both self- and proxy-reports approached or exceeded an alpha of 0.90, indicating the suitability of the total scale scores for the primary analysis of HRQoL outcome in this population. The Physical Functioning and Psychological Health Summary Scores exceeded 0.70, making them acceptable for group comparisons. The Child Self-Report Emotional Functioning and School Functioning scores did not achieve the standard of 0.70. As discussed in the original PedsQL 4.0 articles [12], these subscales should be used for descriptive or exploratory analysis until further testing is conducted.

The PedsQoL 4.0 performed as hypothesized using the know-groups method. There were differences in HRQoL between HIV/AIDS affected children and those from the control families for both self and proxy-report, with the former significantly lower than the latter. However, our results show that the PedsQoL 4.0 is not sensitive enough to detect the difference of Physical Health between two groups of the present sample. The negative influence of family

HIV/AIDS status on children is embodied mainly in their psychological health, which is consistent with related studies investigating the impacts of HIV/AIDS on children [15,16]. One possibility of this finding may be that families with children affected by HIV/AIDS, especially those with AIDS orphans, tended to receive more assistance from neighbors [5]. Many of these assistances include providing money, food, clothes, medicine, and helping with housework [17]. This contributes partially to the equality in household economic status between the affected and control group, with the impact of household economic status mostly embodied in the physical health of children. An additional explanation may be due to the small sample size that was not powerful enough to detect a difference between the two groups. This finding suggests that children's psychological health be made a priority when developing and conducting intervention programs.

Consistent with previous studies, the caregiver-child agreement on the PedsQL 4.0 was low [14,18], which confirms the need to measure both child and caregiver perspectives when evaluation pediatric HRQoL. Lack of agreement between caregivers and children may result from differences in perception of the same situation, and also differences in interpretation of different items [19]. Differences in levels of caregiver-child correlation were found when analysis were performed separately by age group, domain type and participating group. Across both control and affected groups, caregiver-child correlation for the younger age group was higher on Psychosocial Health but lower on Physical Health than for the older age group. This result is contrary to the findings of another study, which found that parent-child agreement for the younger age group was higher on Physical Health and lower on Psychosocial Health than for the older age group [14]. One explanation may be the 'psychological reactance' that children in the stage of adolescence are less likely to communicate with their caregivers about their problems, especially psychological and emotional problems. Differences in levels of caregiver-child correlations were also found between affected and control group. Correlations were good for the control group on most subscales than those for the affected group. One possibility of this finding may be that children from HIV/AIDS affected families are less likely to communicate with their caregivers than those from the ordinary families [20]. Many children silently bear the grief of parental loss and do not tell their caregivers; some hold it as their responsibility to avoid mentioning it and making the family members sad [21]. Studies have shown that children who are able to communicate freely with their parents about HIV/AIDS issues view their family positively and report fewer psychological problems [22]. Therefore, stronger effort has to be made to increase communication between affected children and their caregivers.

The present study has several potential limitations. Test-retest reliability and responsiveness are not reported. However, it can be argued that test-retest reliability may be less useful than internal consistency reliability in HRQoL instrument development. In addition, the number of cases was limited by availability of children living in HIV/AIDS-affected families as some eligible families refused to have their children participate in the study. Generalizability issues include lack of information on non-participants and participants from communities with intense exposure to drug use and ethnic minorities. Despite the disparities, the findings are still applicable and can inform the development of future interventions that promote care and support of children living in HIV/AIDS-affected families.

CONCLUSION

The study demonstrates the preliminary reliability and validity of the Chinese Mandarin version of PedsQL 4.0 for the first time with a HIV/AIDS affected population. The findings suggests that the PedsQL 4.0 is generally a valid and reliable instrument, replicating some of the earlier findings for the originally version. This is the first study of its kind to provide evidence that

the HRQoL of children living in HIV/AIDS-affected families is lower than the HRQoL of children from ordinary families.

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Table 1

Demographic Characteristics of Children and their Caregivers

	Control group	Affected group	P value
Caregivers	(n = 107)	(n = 115)	
Age ⁺	39.53 (9.5)	41.17 (11.5)	0.25
Gender [*]			0.64
Male	45 (42.1)	52 (45.2)	
Female	62 (57.9)	63 (54.8)	
Ethnic group [*]			0.05
Jingpo	43 (40.2)	66 (57.4)	
Dai	27 (25.2)	21 (18.3)	
Han	23 (21.5)	21 (18.3)	
Others	14 (13.1)	7 (6.1)	
Marital status [*]			0.10
Unmarried	1 (0.9)	1 (0.9)	
Married	90 (84.1)	81 (70.4)	
Divorced	5 (4.7)	8 (7.0)	
Widowed	11 (10.3)	25 (21.7)	
Education [*]			0.54
Didn't go to school	32 (29.9)	44 (38.3)	
Primary	60 (56.1)	60 (52.2)	
Junior middle	11 (10.3)	9 (7.8)	
Senior middle or higher	4 (3.7)	2 (1.7)	
Household income per year [#]	3000	3000	0.37
Children	(n = 109)	(n = 116)	
Age ⁺	12.17 (2.7)	12.09 (2.6)	0.80
Gender [*]			0.97
Male	58 (53.2)	62 (53.4)	
Female	51 (46.8)	54 (46.6)	
Education [*]			0.55
School dropout	21 (19.3)	18 (15.5)	
Current school attendance	88 (80.7)	98 (84.5)	

* Values are presented as number (percentage).

⁺ Data given as Mean (SD).

[#] Data given as Median

Table 2
Cronbach's α coefficients for PedsQL 4.0 Generic Core Scales Child Self-Report and Parent Proxy-Report for affected and control groups

Scale	Control group			Affected group		
	8-12 years	13-18 years	Total	8-12 years	13-18 years	Total
Child Self-Report						
Total score	0.89	0.86	0.88	0.91	0.88	0.90
Physical Health	0.87	0.89	0.88	0.89	0.84	0.87
Psychosocial Health	0.83	0.70	0.79	0.85	0.81	0.84
Emotional Functioning	0.63	0.56	0.60	0.58	0.71	0.64
Social Functioning	0.74	0.65	0.71	0.81	0.81	0.81
School Functioning	0.68	0.66	0.67	0.58	0.62	0.63
Parent Proxy-Report						
Total score	0.89	0.91	0.91	0.90	0.87	0.89
Physical Health	0.83	0.90	0.86	0.90	0.85	0.88
Psychosocial Health	0.85	0.85	0.85	0.87	0.81	0.85
Emotional Functioning	0.78	0.78	0.78	0.76	0.75	0.75
Social Functioning	0.76	0.82	0.82	0.83	0.83	0.83
School Functioning	0.79	0.85	0.85	0.77	0.75	0.76

Table 3
Scale descriptives for the PedsQL 4.0 Generic Core Scales Child Self-Report and Parent Proxy-Report: affected and control groups

Scale	Control group				Affected group				t score	P Value*
	N	Mean	SD	N	Mean	SD	N	Mean		
Child Self-Report										
Total Score	88	78.15	12.18	98	73.39	13.35			2.530	0.006
Physical Health	109	79.12	17.02	116	80.77	17.07			0.726	0.234
Psychosocial Health	88	77.33	11.90	98	72.78	13.47			2.430	0.008
Emotional Functioning	109	74.62	15.62	116	70.17	15.56			2.140	0.017
Social Functioning	109	80.36	14.98	116	81.64	17.15			0.595	0.276
School Functioning	88	72.44	15.40	98	68.52	16.19			1.687	0.047
Parent Proxy-Report										
Total Score	82	81.62	12.53	88	76.57	11.32			2.760	0.003
Physical Health	107	85.29	14.95	115	84.17	13.75			0.578	0.282
Psychosocial Health	82	80.10	13.36	88	75.67	11.90			2.286	0.012
Emotional Functioning	107	76.95	17.26	115	70.14	16.93			2.953	0.002
Social Functioning	107	84.33	15.93	115	79.89	13.92			2.205	0.014
School Functioning	82	72.43	17.69	88	73.11	17.60			0.251	0.401

* The differences are statistical significant if $P < 0.05$ (one-tailed).

Table 4
 Intra-class correlation between PedsQL 4.0 Generic Core Scales Child Self-Report and Parent Proxy-Report for affected and control groups

Scale	Control group			Affected group		
	8–12 years (n=56)	13–18 years (n=47)	Total (n=103)	8–12 years (n=57)	13–18 years (n=43)	Total (n=100)
Total score	0.58*	0.16	0.48*	0.41*	0.14	0.29
Physical Health	0.36	0.41	0.39	0.22	0.47*	0.29
Psychosocial Health	0.63*	0.09	0.54*	0.38	0.09	0.26
Emotional Functioning	0.54*	0.09	0.35	0.38	0.04	0.24
Social Functioning	0.40	0.39	0.40	0.16	0.46*	0.28
School Functioning	0.75*	0.33	0.65*	0.60*	0.41	0.51*

* Correlations are significant at the $P < 0.05$ level (two-tailed).