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## Quality of life of children living in HIV/AIDS-affected families in rural areas in Yunnan, China

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### Abstract

The aim of this study was to explore the main influencing factors of the health related quality of life (HRQL) of children living in HIV/AIDS-affected families in rural areas in Yunnan, China. The HRQL of 116 children aged 8 to 17 from HIV/AIDS-affected families and of 109 children from unaffected families was evaluated by the Chinese Version of PedsQL TM 4.0. Some potential influencing factors were investigated, such as demographic characteristics, the families' social and economic status, foster models, children's self-esteem etc. The HRQL of the children's caregivers may also have been among the influencing factors, as measured by the SF-36. Multiple regression analysis was used to explore the influence of independent variables on children's HRQL. Results showed that lower scores of children's self-esteem and caregivers' SF 36 reduced the majority of the PedsQL domains. Results showed children from HIV/AIDS-affected families reported lower scores of HRQL than those from unaffected families, especially in the psychosocial functioning, emotional functioning and school functioning domains. Children living with grandparents reported higher PedsQL scores in psychosocial health, social functioning and school functioning. Disclosure of parental HIV/AIDS status reduced children's PedsQL scores in emotional functioning and social functioning. Caregivers spending more hours accompanying the children appeared to increase the PedsQL scores in psychosocial health and school functioning. The findings indicate the child's self-esteem, the caregiver's perceived quality of life, the child's foster pattern, the average hours of company provided by the caregiver, and whether the child was informed of the parent's HIV/AIDS status are important factors influencing HRQL. Interventions aiming at these factors should be developed to improve the QL of children affected by HIV/AIDS.

### Keywords

Child; Quality of life; PedsQL; HIV/AIDS; Influencing factors

### Introduction

Attention has been given to the spectrum of the impact of HIV/AIDS on children worldwide (China MOH/UNAIDS/WHO, 2007; Enger et al., 1996; Yang et al., 2006). A recent review

has documented the disadvantages faced by children with regard to economic impact, child labor, education, health and nutrition, psychological impact, and long-term developmental impact (Richter, 2004). Given the multidimensional impact of HIV/AIDS on children, it is necessary to employ an appropriate instrument to capture and evaluate the comprehensive nature of the health status of affected children. Pediatric health-related quality of life (HRQL) is increasingly acknowledged as an important health outcome measure in clinical trials and health services' research and evaluation. As a multidimensional assessment of physical, psychological and social functioning status, the HRQL measurement is believed to be a good outcome variable when studying health status (Garretsen et al., 1991).

PedsQL™ is one of the more promising HRQL measures for children. Developed in the US, the advantages of PedsQL™ include brevity, the availability of age-appropriate versions and parallel forms for child and parent (Eiser & Morse, 2001; Varni et al., 1999). Recent reports confirm that PedsQL™ perform well in distinguishing healthy children from pediatric patients with either acute or chronic conditions if those conditions impact significantly on the child's general HRQL (Varni et al., 2001; Varni et al., 2003; Varni et al., 2006).

The most recent estimates indicate that as of the end of 2007, there were approximately 700,000 people living with HIV/AIDS in China (China MOH/UNAIDS/WHO, 2007). The epidemic of children with HIV-infected parents, including children orphaned by AIDS, has emerged as an important issue in HIV-affected areas of China (Yang et al., 2006). Research has explored the social, psychological and economic effects HIV/AIDS on children in China (West & Wedgwood, 2004; UNCEF, 2005), but limited information is available to understand the HRQL of children living in HIV/AIDS-affected families. Understanding the factors influencing the HRQL of these children is important for developing appropriate policies and child support programs. The aim of our study was to learn about factors influencing the HRQL of children living in HIV/AIDS-affected families in rural China.

## Methods

### Participants

This cross-sectional study was carried out in four townships of Longchuan County in Yunnan Province. Longchuan County is one of the regions most affected by HIV/AIDS in Yunnan, and in China as a whole. In 2006, there were 2,718 known cases of HIV in Longchuan, 75% of which were infected via intravenous drug injection. These four townships account for most (70%) of the registered HIV cases in Longchuan County, and have approximately 80% of all children orphaned by HIV/AIDS in the county.

Both HIV/AIDS affected and unaffected families were approached to invite to participate in the study. The affected families were eligible if they: 1) had at least one child aged between 8 and 18 years old; 2) the child was HIV-negative or not tested for HIV; and 3) the child had at least one HIV-positive parent or had lost one or both parents to AIDS. A convenience sampling method was used to recruit a minimum sample size of 100 affected families, with a statistical power level of 0.85. The control families were eligible if they: 1) had at least one child aged between 8 and 18 years old; and 2) had no confirmed HIV positive patients. The control family should be the nearest neighboring family of the selected affected family. If the nearest eligible neighboring family refused to participate in the study or had nobody present at home during three contact attempts, the second-nearest family was then approached. Within each household, one child aged 8 to 18 and one caregiver (the person actively involved with the child's day to day care) were interviewed. If more than one eligible child, the one with birthday close to the day conducting the interview was chosen. If more than one caregivers in a family, the one who provides most daily care activity was chosen.

## Measurements

The quality of life of the children was measured using the 23-item PedsQL 4.0 Generic Core Scale. This scale encompasses the essential core domains for pediatric HRQL measurements, including physical, emotional, social and school functioning. It consists of a parallel child self-report and parent proxy-report format. The Mandarin Chinese version of the scale was translated and validated by a research group from the Department of Statistics and Epidemiology, School of Public Health, Sun Yat-sen University, following the PedsQL Linguistic Validation Guidelines (Mapi Research Institute, 2002).

Potential independent variables such as the caregiver's quality of life, the child's self-esteem and sociodemographic characteristics were collected from study participants. The quality of life of the caregiver was assessed using the self-administered short-form health survey with 36 questions (SF-36). The SF-36 consists of 36 items which are categorized into 8 domains: physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional and mental health, ranging from 0 to 100 with higher scores reflecting better a perception of health. The child's self-esteem was assessed using the Rosenberg Self-Esteem Scale (RSE). The RSE is a 10-item self-report measure of global self-esteem. It consists of 10 statements related to overall feelings of self-worth or self-acceptance. The items were answered on a four-point scale ranging from strongly agree to strongly disagree. Socio-demographic characteristics were measured, including caregiver's age, gender, education, marital status, ethnic group, child's orphan status and whether the child was aware of their parent's HIV/AIDS status. The child's physical health and illness, schooling and inter-personal relationships were also assessed in the questionnaire.

## Procedures

Institutional ethics approval to conduct the study was obtained from the Institutional Review Boards (IRB) at the National Center for AIDS/STD Control and Prevention, Chinese Center for Disease Control and Prevention (NCAIDS, China CDC). Study participants were recruited with 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 neighboring household with no HIV-positive patients were also approached as control families. If they agreed, potential participants were approached by interviewers and enrolled in the study. Informed consent was obtained before interview directly from caregivers. Caregivers provided consent on behalf of the children.

According to the participants' request, the questionnaire interviews were conducted in the health service providers' offices or in the participants' own home. Caregivers were interviewed first, after which they were asked whether they would agree to have their children to participate 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.

## Analysis

For categorical variables (i.e., gender), data were compiled as frequency and percentage and the differences between groups were compared by Chi-square test, except for contingency tables, where one of the categories is ordinal (i.e., caregiver's education level) and the Wilcoxon Rank-Sum test was then employed. For continuous variables (i.e., PedsQL 4.0 score), data were calculated as mean  $\pm$  standard deviation (SD) and the statistical analysis was performed with independent t-test or one-way Anova. Stepwise multiple regression analysis was used to study the influence of independent variables on the PedsQL while

controlling the effect of other variables. *P* value less than 0.05 was considered statistically significant.

## Results

From 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 was recruited for the interviews. No adult was present at home for 8 affected and 16 control families during three contact attempts. The remaining 2 affected families and 5 control families refused to participate in the study. 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 in both groups, 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. About 60% of caregivers were females and over 50% of the children in both groups were boys. 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 the Jingpo ethnic group but this was not statistically significant ( $P=0.051$ ). Around one quarter (22.4%) of children in the HIV/AIDS-affected families were living with their grandparents, while in the control group, the proportion was only 9.2% ( $P=0.020$ )

### The effect of family HIV/AIDS status on HRQL

Table 2. demonstrates that children from HIV/AIDS-affected families showed lower scores (worse HRQL), on average, than those from unaffected families. For child self-report, affected children scored significantly lower on the 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 caregivers' 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.

### Factors influencing HRQL in HIV/AIDS-affected families

Multiple regression analysis of the association of PedsQL domains and multiple independent variables were performed. A lower level of child self-esteem and caregiver's SF-36 score reduced the majority of PedsQL domains, especially in domains that reflect psychological health. Children living with grandparents reported higher PedsQL scores in psychosocial health, social functioning and school functioning. Awareness of parent's HIV/AIDS status reduced children's PedsQL scores in emotional functioning and social functioning. Caregivers spending more hours accompanying the child appeared to increase the PedsQL scores in psychosocial health and school functioning (Table 3).

## Discussion

In this study we found that children from HIV/AIDS-affected families reported worse HRQL than those from unaffected families. The important factors influencing HRQL in

HIV/AIDS-affected children included child's self-esteem, caregiver's subjective quality of life, child's foster pattern, average hours of company provided by the caregiver to the child, and whether the child was aware of the parent's HIV/AIDS status.

Self-esteem is known to be one of the major predictors of subjective quality of life (Marriage & Cummins, 2004). Children in HIV/AIDS-affected families may face additional life burdens, with one study indicating that this may impair their confidence as well as self-esteem (Siegel & Gorey, 1994). Reductions in self-esteem have been consistently shown to be associated with increased psychological problems (Raveis et al., 1999; Sandler et al., 2003; Worden, 1996; Xu et al., 2008). Studies on the HRQL of children with chronic disease (i.e. heart disease, cancer) have indicated that self-esteem was a significant contributor to the explained variance of HRQL (Cohen et al., 2007; Langeveld et al., 2004). Our findings showed that a decrease in self-esteem reduced the child's emotional functioning, school functioning, and psychosocial health, thereby reducing their HRQL. According to motivational theoretical models of children's adaptation to adversity, stressors following parental death (e.g., moving to a new house, dropping out of school) may eliminate contact with esteem-supporting caregivers and peers, and reduce opportunities for esteem-enhancing activities (e.g., sports, social activities) (Wolchik et al., 2006). This finding suggests that appropriate interventions with esteem-supportive activities may help improve children's HRQL.

Older adults are increasingly playing the principal role in caring for children affected by HIV/AIDS. Our findings showed that around one quarter of HIV/AIDS-affected children was fostered by their grandparents. Children living with grandparents tended to report better HRQL than others, especially in psychosocial domains. This was beyond our expectation and inconsistent with previous studies conducted in other countries (Joslin & Harrison, 2002; Juma et al., 2004; Ozuah, 2003). We found that caregivers spending more hours accompanying the child appeared to increase the child's psychosocial health. This was consistent with another study showing that greater hours of childcare with a child aged 5 predicted a higher quality of life score in an adolescent aged 13 (Wilkins et al., 2004). Based on these findings, we give our explanation that after the tragedy of parental illness or loss, older caregivers may be more concerned about the children and spend more time accompanying them. Another important finding was that caregivers' quality of life was positive correlated with children's HRQL. Under most circumstances, older caregivers derive satisfaction from their caregiving roles, yet many are suffering from exhaustion, financial hardship, grief and emotional upheaval, and a lack of knowledge and resources for child care (Mall, 2004). These strains may take their toll on older people's health and as a result impair the health of the children in their care. These findings provide important implications for public health programs that advocate the inclusion of older people in responses to the disease, and illustrate the importance of addressing caregiver education and social and economic support.

Research into the impact of disclosure of parental HIV/AIDS is inconsistent. Some research indicates that children who have been personally informed of their mother's HIV status might exhibit lower levels of aggression and have lower levels of negative self-esteem (Murphy et al., 2001). Among adolescents, however, the immediate effects may be negative, with one study finding that adolescents informed of their parent's illness were more likely to be emotionally distressed and to engage in unprotected sex and substance abuse (Rotheram-Borus et al., 1997). Our findings showed that disclosure of parental HIV/AIDS to the child reduced their HRQL. One possible explanation may be that most caregivers, especially older caregivers, did not have sufficient HIV/AIDS knowledge and could not answer children's questions such as 'Will my parent will die?' and 'Are there any medicines that can cure the disease?'. If the caregiver failed to respond to the child's questions in an appropriate

manner, then misunderstanding and negative emotions (i.e. fear, anxiety) may result and would accordingly impair the psychological health of the child (Xu et al., 2007). Therefore, strategies to increase caregivers' communication skills with children about parental HIV/AIDS are needed.

The present study has several limitations. The regression analysis of the physical health domain was not ideal as the study variables only explained 37.3% of the variance. One possible reason is that many independent variables measured in the study were focused on the subjective feelings of the participants and therefore may not contain enough objective variables associated with physical health. Further research might be necessary to explore contributors to the physical health of these children. Seven of the eligible families refused to have their children participate in the study. Information on non-participants was not available which may also limit generalizability.

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**Table 1**

## Demographic Characteristics of Children and their Caregivers

	Control group	Affected group	P value
<b>Caregivers</b>	(n = 107)	(n = 115)	
Age <sup>+</sup>	39.53 (9.5)	41.17 (11.5)	0.245
Gender <sup>*</sup>			0.635
Male	45 (42.1)	52 (45.2)	
Female	62 (57.9)	63 (54.8)	
Ethnic group <sup>*</sup>			0.051
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 <sup>*</sup>			0.097
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 <sup>*</sup>			0.538
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 <sup>#</sup>	3000	3000	0.373
<b>Children</b>	(n = 109)	(n = 116)	
Age <sup>+</sup>	12.17 (2.7)	12.09 (2.6)	0.804
Gender <sup>*</sup>			0.972
Male	58 (53.2)	62 (53.4)	
Female	51 (46.8)	54 (46.6)	
Education <sup>*</sup>			0.551
School dropout	21 (19.3)	18 (15.5)	
Current school attendance	88 (80.7)	98 (84.5)	
Relationship with caregiver			0.020
Parent	90 (82.6)	79 (68.1)	
Grandparent	10 (9.2)	26 (22.4)	
Other relatives	9 (8.2)	11 (9.5)	

\* Values are presented as number (percentage).

<sup>+</sup> Data given as Mean (SD).

<sup>#</sup> Data given as Median



**Table 2**  
Scores for the PedsQL 4.0 Generic Core Scales child self-report and caregiver proxy-report: affected and control groups

Scale	Control group			Affected group			t score	P Value*
	N	Mean	SD	N	Mean	SD		
<b>Child self-report</b>								
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
<b>Caregiver proxy-report</b>								
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 statistically significant if  $P < 0.05$  (one-tailed).

**Table 3**  
Variables affecting PedsQL child self-report domains in the HIV/AIDS-affected group (standard  $\beta$ -coefficient)

Variables*	Total Score	Physical Health	Psychosocial Health	Emotional Functioning	Social Functioning	School Functioning
Child's RSE	0.139*		0.127*	0.141*		0.122*
Caregiver's SF36	0.209*		0.222*	0.156*		0.111*
Living with parents	0.275				0.330	
Living with grandparents	0.359*		0.367*		0.566*	0.287*
Being double orphan		0.261*		-0.318*		
Being single orphan		0.212		-0.116		
Child's nutrition		0.184*			0.136*	
Child has been ill for $\geq 3$ days in the previous 6 months	0.201	0.105				0.017
Accompany hour			0.125*			0.191*
Disclosure of parental HIV/AIDS status				-0.136*	-0.188*	
Female (child)				0.036		0.131*
Jingpo minority	-0.115					
Caregiver remarried	-0.118					
<i>F</i> -statistic	5.410	4.966	5.574	4.720	6.135	5.768
<i>R</i> <sup>2</sup>	0.518	0.373	0.445	0.603	0.454	0.572

\*  $P < 0.05$