Published in final edited form as:

J Acquir Immune Defic Syndr. 2010 February ; 53(Suppl 1): S104. doi:10.1097/QAI.0b013e3181c7df8b.

The situation of children affected by HIV/AIDS in Southwest China: schooling, physical health and interpersonal relationships

Tao Xu, MD, PhD^{*,†}, Zunyou Wu, MD, PhD^{*}, Song Duan[‡], Wenxiang Han[§], and Keming Rou[†]

^{*}National Centre for AIDS/STD Control and Prevention, Chinese Center for Disease Control and Prevention, Beijing 100050, China

[†]National Centre for Women's and Children's Health, Chinese Center for Disease Control and Prevention, Beijing 10007, China

[‡]Division of HIV/AIDS, Dehong Center for Disease Control and Prevention, Yunnan, China

[§]Longchuan County Center for Disease Control and Prevention, Yunnan, China

Abstract

Objective—To investigate the schooling, physical health and interpersonal relationships of children affected by HIV/AIDS in rural areas of southwest China.

Methods—Using a structured survey, quantitative data were collected on a total of 116 children and 114 of their caregivers.

Results—Parental illness or death adversely affected children's school attendance as well as school performance. Over one-third (36.2%) of children reported being ill for more than 3 days during the previous 6 months; more orphans were hospitalized during the latest illness than non-orphans although the difference was not statistically significant. One-third (33.6%) of children were aware that their parents were HIV positive. Ten percent of orphans reported their relationships with peers became worse after parental illness or death, which was significantly higher than non-orphans. Twenty-five percent of orphans reported they were teased by others compared to 1.9% of non-orphans.

Conclusion—HIV infection has impacted negatively on the children in terms of education, health and peer association. These findings can be used as preliminary data supporting intervention strategies and activities to improve the general welfare of children affected by HIV/AIDS in China.

Keywords

HIV/AIDS; Child health; Parent; Schooling; Interpersonal relations; China

INTRODUCTION

Approximately 33 million adults, most of them parents, are now living with HIV worldwide,¹ and more than 15 million children have been orphaned by AIDS.² As improved treatment strategies continue to prolong the lives of parents with HIV, more children will live with a chronically ill parent.³ 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 Although HIV prevalence

Correspondence to: Zunyou Wu, National Centre for AIDS/STD Control and Prevention, Chinese Centre for Disease Control and Prevention, 27 Nanwei Road, Xuanwu District, Beijing 100050, China. Tel: 86-10-63165758. Fax: 86-10-63165865. wuzy@263.net.

among the general population is still relatively low in China, high prevalence rates have been reported in certain locations and populations.⁴ Consequently, the situation of children with HIV-infected parents and children orphaned by AIDS, has emerged as a serious issue in high-prevalence areas.⁵

Previous studies from Africa have shown that when a family member has AIDS, expenditure on health care quadruples, food consumption may drop by as much as 41%, savings are depleted and families often go into debt to care for sick individuals.⁶ The amount of resources available for a child's education decreases when parents are infected with HIV or die. As a result, children are more likely to drop out of school as tuition fees become unaffordable.⁷ In addition, HIV/AIDS-related stigma in the classroom may also cause children to stop going to school, decreasing the quality and consistency of school attendance.⁸ Children affected by HIV/AIDS may receive poorer care and supervision, may suffer from malnutrition and may not have access to available health services, although there are conflicting data on the associations between nutrition and family HIV/AIDS status.^{9–11} Affected and orphaned children tend to be traumatized and suffer a variety of psychological reactions to parental illness and death.^{12, 13}

The studies described above were largely conducted in African countries and limited data are available from other developing countries, such as China. Unlike Africa, in China, the HIV/AIDS epidemic has been largely driven by intravenous drug users (IDUs). There are approximately 288,000 drug users living with HIV/AIDS in China, accounting for 44.3% of the country's total number of estimated HIV cases.⁴ In provinces located along drug trafficking routes, drug use accounts for around 90% of HIV/AIDS cases.⁴

To date, there have been few studies conducted to explore the lives of children affected by HIV/AIDS in China. In a cross-sectional survey of 251 AIDS orphans conducted in 5 provinces, 61% of children lived with surviving parents and over 15% of children had lost both parents. One-quarter of the orphans did not attend school.¹⁴ Another study conducted in Yunnan Province indicated that in 266 randomly selected households with registered HIV-infected drug users, forty percent of these children had lost at least one parent. Most of the children resided in a household with a low economic status and a high dependency ratio. Compared to orphans, non-orphans and their families in this study were less likely to receive social support from the community. Orphans and older children were less likely to attend school and more likely to be truant if enrolled in school.⁵

To address this knowledge gap and provide a basis for intervention planning, a cross-sectional study was undertaken to examine the quality of life of children affected by HIV/AIDS from August 2005 to September 2006 in Longchuan County, Yunnan Province, China, one of the regions most affected by HIV/AIDS.¹⁷ In 2006, there were 2,718 known cases of HIV, 75% of which were infected via intravenous drug injection. Four townships were selected to participate in the study. These four townships account for most (70%) of the registered HIV cases, and have approximately 80% of all children orphaned by HIV/AIDS in the county. This paper presents quantitative results on the schooling, physical health and interpersonal relationships of these children.

METHODS

Both qualitative and quantitative methods were employed to investigate various aspects of the quality of life of children living in HIV/AIDS affected families. Results of the qualitative studies have been published elsewhere.^{15, 16} This study was approved by the Institutional Review Board at the National Centre for AIDS/STD Control and Prevention, Chinese Centre for Disease Control and Prevention.

HIV/AIDS-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; and 3) the child had at least one HIV-positive parent or had lost one or both parents to AIDS. Within each household, one child aged 8–18 and one caregiver (the person actively involved with the child's daily care) were interviewed.

Measurements

Two sets of questionnaires were developed to collect information from children and caregivers respectively.^{15, 16} Except for family socio-demographic characteristics, most questions were comprised of parallel child self-report and caregiver proxy-report formats, with the questions essentially identical and differing only in appropriate language.

Socio-demographic characteristic variables measured included caregiver's age, gender, education, marital status, ethnic group, and child's age and gender. The child's orphan status was identified using terms adopted from UNAIDS/UNICEF/USAID.¹⁸ Orphans were defined as children under the age of 18 who had lost one or both biological parents. Children whose parents were both alive at the time of the survey were non-orphans.

Four variables assessed the children's physical health and illness. These included: status of child's health during the previous six months (very good/good/fair/poor); incidences of illness longer than 3 days in the previous six months; duration of any illness in the previous six months; and severity of the last illness.

The status of the child's schooling was assessed by investigating school attendance, whether or not the family received external financial support for education from the government or other sources, and perceived changes in school performance after parental illness or death (became worse/became better/did not change/not sure).

The quality of the child's relationship with the caregiver was measured using five questions assessing whether caregivers knew about their child's school performance (yes/no); whether caregivers knew their child's friends (yes/no); whether the child had been informed about their parent's HIV/AIDS status (yes/no); average time caregivers spent with their child; and frequency of child-caregiver communication (always/often/sometimes/never). The peer relationship was measured by two questions assessing: 1) whether the child was teased by other children (yes/no); and 2) the change in their relationships with their peers after parental illness (i.e., onset of AIDS) or death (became worse/became better/did not change/not sure).

Procedures

Study participants were recruited with the help of local health care workers who treat HIV-positive patients in the community. Eligible families who agreed to participate in the study met with an interviewer. Informed consent was obtained before the interview and potential participants were advised they could decide to quit the interview at any time if they wanted. For caregivers, written informed consent was obtained, and for children, caregivers provided consent. To ensure confidentiality, no identifiable personal information was collected and only research staff had access to the data.

The questionnaire was administered by a qualified interviewer in the health care worker's clinic or in the participant's own house, depending on the participant's request. For illiterate participants, the questionnaires were administered under the supervision of a research assistant. Caregivers were interviewed first, after which they were asked for permission to their children being interviewed. 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. Children were given verbal information before completing questionnaires on their own under the supervision of a research assistant.

Data Analysis

For categorical variables, data were compiled as frequency and percent and the differences between orphans and non-orphans were compared using Chi-square test. When one of the categories is ordinal, Wilcoxon rank-sum test was employed. For continuous variables, data were calculated as mean $\pm$ standard deviation (SD) and the two groups were compared by independent t-test. The agreement between child self-report and caregiver proxy-report was determined through intra-class correlation coefficient (ICC).

RESULTS

Sample Characteristics

During August to September, 2006, 126 families with eligible participants were approached. No adult was present at home for 8 families during 3 contact attempts and the remaining 2 families refused to participate in the study, resulting in a final sample of 116 families. One hundred and fourteen caregivers and 116 children completed all items in the questionnaires. One caregiver agreed for her child to participate but did not answer the questions herself. Another caregiver was sick at home and could not be interviewed. Among the 116 children, 52 (44.8%) were non-orphans. Twenty-five (39.1%) orphans were living with their parents, 35 (54.7%) with their grandparents, two (3.1%) with their uncles and aunts, and two (3.1%) by themselves.

Table 1 summarizes the demographic variables of the caregivers and children. No statistically significant differences were found with respect to ethnic group, caregiver's education, child's age, and gender. Caregivers in the orphan group were significantly older (mean = 44.85 years; SD = 13.87) than those in the non-orphan group (mean = 36.94 years; SD = 5.32). Over 60.0% of caregivers in the orphan group were females while 61.5% of caregivers in the non-orphan group were males. Around 40.0% of caregivers of orphans were widowed, which was significantly higher than caregivers of non-orphans (1.9%) ($P < 0.001$).

Schooling and School Performance

Three-quarters (75.0%) of children were currently attending school (Table 1). This rate is lower than the provincial (96.2% in 2004) and national (98.7% in 2005) level. No significant difference was found for school attendance rates between orphan groups. Further analysis showed that the school attendance rate was 93.3% (56/60) among children eligible to receive primary school education, and 53.6% (30/56) among children eligible to receive junior middle school education. In terms of school performance, 12% percent of children reported a drop of school performance after parental illness or death. More orphans received schooling support from the governments or other organizations (63.8%) than non-orphans (50.0%), but the difference was not statistically significant ($P = 0.74$).

Health and Illness

Table 2 reports the health and illness of children by orphan status, both for child self-report and caregiver proxy-report results. No statistically significant differences were found for health and illness between the two groups. Approximately 60% of children reported their health was very good during the previous 6 months. Over one-third (36.2%) of children reported they had been ill for more than 3 days in the previous 6 month, with an average of one episode of illness. Among those children who had been ill in the previous 6 months, 47.6% reported they had to take medication and stay at home. Orphans reported less serious illnesses than non-orphans but this was not statistically significant. Caregivers of non-orphans reported more frequent illnesses than orphans and more orphans were hospitalized during the latest illness than non-orphans, but the differences were not statistically significant.

Family and Peer Relationships

One-third (33.6%) of children reported they had been informed about their parent's HIV/AIDS status. Twice as many orphans (43.8%) as non-orphans (21.2%) were informed. Approximately 60.0% of children believed their caregivers knew about their school performance and three-quarters of children believed their caregivers knew their friends. No significant difference was found between orphans and non-orphans. However, more non-orphans' caregivers reported knowing about their child's school performance than orphan caregivers. In terms of child-caregiver communication, orphans reported communicating less with their caregivers than non-orphans ($P = 0.04$), while no significant difference was found for the caregiver proxy-report result ($P = 0.76$) (Table 3).

Eleven percent of orphans reported that their relationships with peers became worse after the illness or death of their parents, while 14% of orphan's caregivers reported their child's peer relationships became worse after parental illness or death. One-quarter of orphans reported they were teased by others, which was significantly higher than non-orphans ($P < 0.01$). Caregivers of orphans also reported significantly more teasing than those of non-orphans. It should also be noticed that caregivers tended to report more teasing occurrences than the children did.

Child/caregiver Agreement

Table 4 shows the correlation between child self-report and caregiver proxy-report for some variables. Agreements are better on average for physical and illness items than personal association items. Orphans and their caregivers showed better agreements on most items than non-orphans and their caregivers.

DISCUSSION

In this study, the overall school attendance rate among school-aged children was lower than the provincial and national levels, similar with findings from previous studies.^{5, 14} However, no difference was noted for school attendance rate between orphans and non-orphans and is inconsistent with previous studies conducted in other countries.^{19–21} One possible explanation for this finding is that after the implementation of the Regulations of AIDS Prevention and Treatment (Decree of the State Council of the PRC No. 457, issued in 2006), families with children orphaned by HIV/AIDS were more likely to receive free schooling from the local government or other organizations. Another may be due to the increased community empathy, especially in some minority communities in China, for families with AIDS orphans.⁵ Neighbors may provide assistance to AIDS-affected families, including small amounts of money, food, clothes, medicine, and help with housework.¹⁶ This may partially contribute to the equality seen in the economic status between orphan and non-orphan households.¹³

Although there is a lack of direct empirical data on the impact of being orphaned or made vulnerable on the performance of children in school, it has been suggested that these children might perform poorly in school.²² AIDS-affected children face barriers to education over and above the effects of poverty.²³ These barriers include their need to care for sick parents;²⁴ emotional scarring related to parental death;²⁵ and discrimination within classrooms and the community.⁸ For orphaned children, school-work is most likely supervised by an older sibling, or to be unsupervised, or less likely to be supervised by a caregiver,²⁶ which can also contribute to poorer school performance. Our findings indicated a 12% drop in self-reported school performance after parental illness or death. Appropriate interventions should be developed to promote the school performance of these children.

Regarding the association between family HIV/AIDS status and children's physical health, participants reported no significant differences in terms of severity or frequency of illness between orphans and non-orphans. One possibility may be that the data we collected were based on the participant's self-report of the general health, and no health indicators were measured. From our research, it was clear that most orphans were living with their grandparents and had heavier burdens of housework and farm chores than non-orphans. Orphans, compared to non-orphans, may feel greater responsibility to their families to do well at school and to do their household chores. Therefore, orphans might be less likely to report minor illness than non-orphans. An additional explanation may be that the small sample size was not powerful enough to detect a difference between the two groups. More research is therefore needed to explore the impact of a family HIV/AIDS status on children's physical health.

When HIV/AIDS begins to affect a household, family relationships provide the most immediate source of support. Consistent with findings from other countries,^{27, 28} the vast majority of children orphaned by HIV/AIDS in China continue to live with the surviving parent or their extended family. As our study shows, caregivers were well aware of their children's school performance and friends. However, both children and caregivers reported a low frequency of child-caregiver communication. Non-orphans reported more communication with caregivers than orphans. One explanation may be that many orphans silently bear the grief of parental loss and do not tell their caregivers; some believe that it is their responsibility to avoid mentioning it and making the family members sad.¹⁶ Children who are able to communicate freely with their parents may be more likely to view their family positively and report fewer psychological problems.²⁵ Research has also shown that a strong positive relationship between parents and children is significantly related to lower rates of risk behaviours, including those associated with HIV infection.^{29, 30} Therefore, strategies to increase communication between affected children and their caregivers are needed.

According to the transactional theories of child development, peers play an important role in influencing children's cognition, behaviour and general personality characteristics.³¹ Parents' influence tend to decrease as children enter middle childhood and adolescence.³² The current study found that parental illness or death negatively affected children's relationships with their peers. It could be that children may suffer from discrimination or feel self-stigmatized due to parental HIV/AIDS, which results in self-isolation and impairs their relationships with their peers. Also, children who dropped out of school might feel lonely and isolated because the number of friends and the frequency of contact decreases. Peer support should therefore be incorporated in intervention programs.

Moderate agreement was found for variables between self- and proxy-report. To our knowledge, no such data have been previously reported. Agreement was better for physical health than for interpersonal relationships. One possibility may be that teenaged children are more likely to rebel against adults and are thus less likely to communicate with their caregivers, especially in terms of talking about their friends and any emotional problems they encounter. In addition, our results indicated that agreement was better between orphans and their caregivers than that of non-orphans and their caregivers. An explanation may be that after the tragedy of parental loss, caregivers of orphans may be more concerned about the children in their care compared to caregivers of non-orphans. This suggests the need to measure both the child's and the caregiver's perspectives when evaluating children's health status.

Results of this study may be limited by its generalizability to other families affected by HIV. For instance, the current study may be more applicable to an older population of children due to the literacy requirement. Also, information on non-participants was not available. In addition, all participants came from communities with a high ratio of drug use and some were ethnic minorities, so the findings of this study may not be applicable to other areas of China

where the HIV epidemic and the ethnicity of the general population is different. Despite these disparities, the findings can still apply to most affected children and inform the development of intervention programs that promote care and support of children affected by HIV/AIDS.

Acknowledgments

Authors are grateful to all the children and their caregivers who participated in this study. Our thanks also go to our collaborators at Longchuan County CDC and to Naomi Juniper and Adrian Liao for editorial assistance.

Supported by the International Clinical Operational and Health Services Research and Training Award (ICOHRTA) AIDS/TB, Grant #U2RTW006917 and U2RTW006918, funded by the US National Institutes of Health, the Fogarty International Center, the National Institute of Drug Abuse and the National Institute of Mental Health.

References

1. UNAIDS/WHO. The 2008 Report on Global AIDS epidemic. Geneva: Joint United Nations Programme on HIV/AIDS & World Health Organization; 2008.
2. UNAIDS/UNICEF. A call to action: Children the missing face of AIDS. New York: United Nations Children's Fund; 2005.
3. Enger C, Graham N, Peng Y, et al. Survival from early, intermediate, and late stages of HIV infection. *JAMA* 1996 May 1;275(17):1329–1334. [PubMed: 8614118]
4. MOH/UNAIDS/WHO. A joint assessment of HIV/AIDS prevention, treatment and care in China (2007). Beijing: Chinese Ministry of Health; 2007.
5. Yang H, Wu Z, Duan S, et al. Living environment and school of children with HIV infected parents in Southeast China. *AIDS Care* 2006;18(7):647–655. [PubMed: 16971271]
6. Foster G, Williamson J. A review of current literature on the impact of HIV/AIDS on children in sub-Saharan Africa. *AIDS* 2000;14:S275–S284. [PubMed: 11086871]
7. Nyamukapa C, Gregson S. Extended family's and women's roles in safeguarding orphans' education in AIDS-afflicted rural Zimbabwe. *Soc Sci Med* 2005 May;60(10):2155–2167. [PubMed: 15748665]
8. Cohen J. Southern Africa: AIDS-affected children face systemic discrimination in accessing education. *HIV AIDS Policy Law Rev* 2005 Dec;10(3):24–25. [PubMed: 16544404]
9. Foster G. Today's children--challenges to child health promotion in countries with severe AIDS epidemics. *AIDS Care* 1998 Apr;10:S17–S23. [PubMed: 9625891]
10. Sarker M, Neckermann C, Muller O. Assessing the health status of young AIDS and other orphans in Kampala, Uganda. *Trop Med Int Health* 2005 Mar;10(3):210–215. [PubMed: 15730503]
11. Bridge A, Kipp W, Jhangri GS, Laing L, Konde-Lule J. Nutritional status of young children in AIDS-affected households and controls in Uganda. *Am J Trop Med Hyg* 2006 May;74(5):926–931. [PubMed: 16687705]
12. Sengendo J, Nambi J. The psychological effect of orphanhood: a study of orphans in Rakai district. *Health Transit Rev* 1997;7:105–124. [PubMed: 10169639]
13. Foster G. Beyond education and food: psychosocial well-being of orphans in Africa. *Acta Paediatr* 2002;91(5):502–504. [PubMed: 12113315]
14. Xu W, Ji C, He J, Li H, Zhang K, Wang T. Preliminary analysis of conditions of AIDS related orphans in selected areas of China. *Chin J AIDS STD* 2004;10(6):416–419.
15. Xu T, Yan Z, Rou K, et al. Disclosure of parental HIV/AIDS to children in rural China. *Vulnerable Children and Youth Studies* 2007;2(2):100–105.
16. Xu T, Yan Z, Wang C, et al. A qualitative study of the sociopsychological impact of parental HIV/AIDS on children in rural China. *Chin J AIDS STD* 2007;13(1):17–19.
17. Wu Z, Zhang J, Detels R, et al. Characteristics of risk-taking behaviors, HIV and AIDS knowledge, and risk perception among young males in southwest China. *AIDS Educ Prev* 1997 Apr;9(2):147–160. [PubMed: 9167800]
18. UNAIDS/UNICEF/USAID. Children on the brink 2004: A joint report of new orphan estimates and a framework for action. New York: United Nations Children's Fund; 2004.

19. Case A, Paxson C, Ableidinger J. Orphans in Africa: parental death, poverty, and school enrollment. *Demography* 2004 Aug;41(3):483–508. [PubMed: 15461011]
20. Monasch R, Boerma JT. Orphanhood and childcare patterns in sub-Saharan Africa: an analysis of national surveys from 40 countries. *AIDS* 2004 Jun;18:S55–S65. [PubMed: 15319744]
21. Muller O, Sen G, Nsubuga A. HIV/AIDS, orphans, and access to school education in a community of Kampala, Uganda. *AIDS* 1999 Jan 14;13(1):146–147. [PubMed: 10207564]
22. PCD. The Partnership for Child Development (PCD). 2nd Edition. [Accessed April 23, 2007]. Ensuring education access for orphans and vulnerable children: A planners' handbook. Available at: <http://www.schoolsandhealth.org/OVC/2nd-edition/OVC-hanbook-second-edition.pdf>
23. Cohen, J.; Epstein, H.; Amon, J. Human rights implications of AIDS-affected children's unequal access to education. Paper presented at: XVI International AIDS Conference; 13–18 August, 2006; Toronto, Canada.
24. van Rensburg GH, et Phil DL, Human SP. Children's rights in the context of HIV/AIDS in Southern Africa. *J Assoc Nurses AIDS Care* 2005 May–Jun;16(3):41–51. [PubMed: 16433116]
25. Woodring LA, Cancelli AA, Ponterotto JG, Keitel MA. A qualitative investigation of adolescents' experiences with parental HIV/AIDS. *Am J Orthopsychiatry* 2005 Oct;75(4):658–675. [PubMed: 16262522]
26. Gray GE, Niekerk RV, Struthers H, et al. The effects of adult morbidity and mortality on household welfare and the well being of children in Soweto. *Vulnerable Children and Youth Studies* 2006;1(1): 15–28.
27. Nostlinger C, Jonckheer T, de Belder E, et al. Families affected by HIV: parents' and children's characteristics and disclosure to the children. *AIDS Care* 2004 Jul;16(5):641–648. [PubMed: 15223533]
28. Safman RM. Assessing the impact of orphanhood on Thai children affected by AIDS and their caregivers. *AIDS Care* 2004 Jan;16(1):11–19. [PubMed: 14660140]
29. McBride DC, Freier MC, Hopkins GL, et al. Quality of parent-child relationship and adolescent HIV risk behaviour in St. Maarten. *AIDS Care* 2005 Jun;17:S45–S54. [PubMed: 16096117]
30. Tinsley BJ, Lees NB, Sumartojo E. Child and adolescent HIV risk: familial and cultural perspectives. *J Fam Psychol* 2004 Mar;18(1):208–224. [PubMed: 14992622]
31. Sameroff AJ, Mackenzie MJ. Research strategies for capturing transactional models of development: the limits of the possible. *Dev Psychopathol* 2003 Summer;15(3):613–640. [PubMed: 14582934]
32. Salmivalli C, Ojanen T, Haanpää J, Peets K. "I'm OK but you're not" and other peer-relational schemas: explaining individual differences in children's social goals. *Dev Psychol* 2005 Mar;41(2): 363–375. [PubMed: 15769192]

Table 1
Demographic Characteristics of Children and their Caregivers

	Total	Non-orphan	Orphan	P value
Caregivers	(n = 114)	(n = 52)	(n = 62)	
Age (years) #	41.25 (11.50)	36.94 (5.32)	44.85 (13.87)	<0.01
Gender*				<0.01
Male	52 (45.6)	32 (61.5)	20 (32.3)	
Female	62 (54.4)	20 (38.5)	42 (67.7)	
Ethnic group*				0.92
Jingpo	65 (57.0)	29 (55.8)	36 (58.1)	
Dai	21 (18.4)	10 (19.2)	11 (17.7)	
Han	21 (18.4)	9 (17.3)	12 (19.4)	
Others	7 (6.2)	4 (7.7)	3 (4.8)	
Marital status*				<0.01
Unmarried	8 (7.0)	3 (5.8)	5 (8.1)	
Married	73 (64.0)	46 (88.5)	27 (43.5)	
Divorced	8 (7.0)	2 (3.8)	6 (9.7)	
Widowed	25 (22.0)	1 (1.9)	24 (38.7)	
Education*				0.75
Didn't go to school	43 (37.7)	21 (40.4)	22 (35.5)	
Primary	60 (52.6)	27 (51.9)	33 (53.2)	
Junior middle or higher	11 (9.7)	4 (7.7)	7 (11.3)	
Relation with child*				<0.01
Parent	78 (68.4)	50 (96.2)	25 (40.3)	
Grandparent	34 (29.8)	2 (3.8)	35 (56.5)	
Uncle/Aunt	2 (1.8)	0 (0.0)	2 (3.2)	
Children	(n = 116)	(n = 52)	(n = 64)	
Age (years) #	12.09 (2.62)	12.15 (2.67)	12.03 (2.59)	0.80
Gender*				0.94
Male	62 (53.4)	28 (53.8)	34 (53.1)	
Female	54 (46.6)	24 (46.2)	30 (46.9)	
Education*				0.85
Current school attendance	87 (75.0)	39 (75.0)	47 (73.4)	
School dropout	29 (25.0)	13 (25.0)	17 (26.6)	

Data given as Mean (SD).

* Values presented as number (percentage).

Table 2
Physical health and illness of HIV/AIDS affected children by orphan status: child self-report and caregiver proxy report

	Child self-report			Caregiver proxy-report		
	Total (n = 116)	Non-orphan (n = 52)	Orphan (n = 64)	P value	Total (n = 114)	P value
Child's health during the previous 6 months *						
Very good	66 (56.9)	30 (57.7)	36 (56.3)	0.69 ⁺	59 (51.8)	28 (45.2)
Good	42 (36.2)	20 (38.5)	22 (34.4)		43 (37.7)	28 (45.2)
Fair	7 (6.0)	2 (3.8)	5 (7.8)		10 (8.8)	5 (8.1)
Poor	1 (0.9)	0 (0.0)	1 (1.6)		2 (1.8)	1 (1.6)
Child has been ill for $\geq$ days in the previous 6 months? *						
Yes	42 (36.2)	18 (34.6)	24 (37.5)	0.75	35 (30.7)	18 (29.0)
No	74 (63.8)	34 (65.4)	40 (62.5)		79 (69.3)	44 (71.0)
How many times have child been ill for ≥ 3 days in the previous 6 months? #	1.00 (1.00, 2.00)	1.00 (1.00, 3.00)	1.50 (1.00, 2.00)	0.92 ⁺	1.00 (1.00, 3.00)	1.00 (1.00, 3.00)
How severe was the latest illness? *	(n=42)	(n=18)	(n=24)	0.30 ⁺	(n=35)	(n=18)
Did not disturb schooling or normal life	18 (42.9)	6 (33.3)	12 (50.0)		15 (42.9)	8 (44.4)
Took some medicine and stayed at home	20 (47.6)	10 (55.6)	10 (41.7)		15 (42.9)	6 (33.3)
Was in hospital	3 (7.1)	1 (5.6)	2 (8.3)		5 (4.4)	4 (22.2)
Has not got well till now	1 (2.4)	1 (5.6)	0 (0.0)		0 (0.0)	0 (0.0)

Data given as Median (25 percentile, 75 percentile).

* Values presented as number (percentage).

⁺ Rank sum test.

Table 3

Family and peer relationships of HIV/AIDS affected children by orphan status: child self-report and caregiver proxy report

	Child self-report		Caregiver proxy-report					
	Total (n = 116)	Non-orphan (n = 52)	Orphan (n = 64)	P value	Total (n = 114)	Non-orphan (n=52)	Orphan (n=62)	P value
Caregiver knows about child's school performance*	69 (59.5)	31 (59.6)	38 (59.4)	0.98	78 (68.4)	42 (80.8)	36 (61.3)	<0.01
Caregiver knows who child's friends are*	87 (75.0)	39 (75.0)	48 (75.0)	1.00	85 (74.6)	41 (78.8)	44 (71.0)	0.34
Child informed of parental HIV/AIDS status*	39 (33.6)	11 (21.2)	28 (43.8)	0.01	43 (37.7)	18 (34.6)	25 (40.3)	0.53
Child teased by others*	17 (14.7)	1 (1.9)	16 (25.0)	<0.01	52 (45.6)	7 (13.5)	45 (72.6)	<0.01
Average time of caregiver accompanying child (hours per day) #	3.00 (1.00, 4.00)	3.00 (2.00, 4.00)	3.00 (1.00, 4.50)	0.70	3.00 (2.00, 4.00)	3.00 (2.00, 4.75)	3.00 (1.00,4.00)	0.44
Child communicates with caregiver*								
Always	23 (19.8)	12 (23.1)	11 (17.2)	0.04 ⁺	24 (21.1)	13 (25.0)	11 (17.7)	0.76 ⁺
Often	17 (14.7)	3 (5.7)	14 (21.9)		27 (23.6)	9 (17.3)	18 (29.1)	
Sometimes	23 (19.8)	16 (30.8)	7 (10.9)		9 (7.9)	6 (11.5)	3 (4.8)	
Never	53 (45.7)	21 (40.4)	32 (50.0)		54 (47.4)	24 (46.2)	30 (48.4)	
Change of peer relations after parental illness or death*								
Became worse	9 (7.8)	2 (3.8)	7 (10.9)	<0.01 ⁺⁺	9 (7.9)	0 (0.0)	9 (14.5)	<0.01 ⁺⁺
Became better	6 (5.2)	0 (0.0)	6 (9.4)		0 (0.0)	0 (0.0)	0 (0.0)	
Did not change	74 (63.8)	30 (57.7)	44 (68.8)		32 (28.1)	14 (26.9)	18 (29.0)	
Not sure	27 (23.2)	20 (38.5)	7 (10.9)		73 (64.0)	38 (73.1)	35 (56.5)	

Data given as Median (25 percentile, 75 percentile).

* Values presented as number (percentage).

⁺ Rank sum test.⁺⁺ Fisher's exact test.

Table 4

Correlations between child self-report and caregiver proxy-report

	ICC		
	Total	Non-orphan	Orphan
Child's health during the previous 6 months	0.40 [*]	0.44 [*]	0.36
Child ill for ≥ 3 days in the previous 6 months	0.63 ^{**}	0.67 ^{**}	0.59 ^{**}
Severity of the latest illness	0.76 ^{**}	0.54 [*]	0.92 ^{**}
Caregiver knows about child's school performance	0.47 [*]	0.22	0.59 [*]
Caregiver knows about child's friends	0.39	0.39	0.39
Child informed of parental HIV/AIDS status	0.45 [*]	0.38	0.49 [*]
Child teased by others	0.48 [*]	0.36	0.50 [*]
Child communicates with caregiver	0.36	0.29	0.40 [*]
Change of peer relations after parental illness or death	0.35	0.27	0.38

*
p < 0.05;**
p < 0.01.