Published in final edited form as:
AIDS Care. 2010 ; 22(5): 545–555. doi:10.1080/09540120903253999.

Perceived HIV stigma among children in a high HIV-prevalence area in central China: Beyond the parental HIV-related illness and death

Xiuyun Lin, Ph.D.[1], **Guoxiang Zhao, Ph.D.**[2], **Xiaoming Li, Ph.D.**[2,3], **Bonita Stanton, M.D.**[3], **Liying Zhang, Ph.D.**[3], **Yan Hong, Ph.D.**[4], **Junfeng Zhao, Ph.D.**[2], and **Xiaoyi Fang, Ph.D.**[5]

[1] School of Psychology, Beijing Normal University, China

[2] Department of Psychology, Henan University, China

[3] Carman and Ann Adams Department of Pediatrics Prevention Research Center, Wayne State University School of Medicine, USA

[4] Department of Social and Behavioral Health, Texas A&M Health Science Center, USA

[5] Institute of Developmental Psychology, Beijing Normal University, China

Abstract

Objectives—(1) examine the psychometric properties of two parallel measures of HIV-related stigma (i.e., perceived public stigma and children's personal stigma against PLWHA) among these children; (2) examine whether expressions of stigma measures differ by child's sex, developmental stage, family SES, or orphanhood status (i.e., AIDS orphans, vulnerable children, and comparison children); and (3) examine the association between HIV-related stigma and children's psychosocial adjustments among these children.

Methods—Cross-sectional data were collected from 755 AIDS orphans (children who had lost one or both their parents to AIDS), 466 vulnerable children who lived with HIV-infected parents, and 404 comparison children who did not experience HIV-related illness and death in their families. The measures included perceived public stigma, personal stigma, depressive symptoms, loneliness, self-esteem, future expectations, hopefulness about the future, and perceived control over the future.

Results—Both stigma scales were positively associated with psychopathological symptoms (e.g., depression, loneliness) and negatively associated with psychosocial wellbeing (e.g., self-stigma, positive future expectation, hopefulness about future, and perceived control over the future). Both stigma measures contribute to children's psychosocial problems independent of their orphanhood status and other key demographic factors.

Conclusion—Community-wide stigma reduction and psychological support should be part of the care efforts for children affected by AIDS. Stigma reduction efforts should not only target the stigma against PLWHA but also possible stigma against the entire community (e.g., villages) with a high prevalence of HIV/AIDS. The stigma reduction efforts also needs to be appropriate for children's age, gender, family SES and AIDS experience in the family. Future research should explore individual and contextual factors such as social support, coping and attachment in mitigating the negative effect of stigma among these children.

Corresponding author: Xiaoming Li, Ph.D., The Carman and Ann Adams Department of Pediatrics Prevention Research Center, Wayne State University School of Medicine, 4201 St. Antoine Street, UHC 6-D, Detroit, MI 48201, Tel: 313-745-8663, Fax: 313-745-4993, xiaoli@med.wayne.edu.

Introduction

The global AIDS epidemic has been accompanied by a second epidemic of stigma against people living with HIV/AIDS (PLWHA) and their families (Mahajan et al., 2008). HIV-related stigma refers to "the prejudice, discounting, and discrediting directed at PLWHA and groups and communities with which they are associated" (Parker & Aggleton, 2003). Stigmatizing attitudes towards PLWHA have been shown to have negative impacts on timely and proper testing, treatment and care (Chesney & Smith, 1999), health seeking (Lieber, Li, Wu, Rotheram-Borus & Guan, 2006), social support (Lee, Kochman & Sikkema, 2002; Varas-Díaz, Serrano-García & Toro-Alfonso, 2005), preventive behaviors (Bond, Chaseb & Aggleton, 2002; Duffy, 2005; Letamo, 2003; Reidpath, Brijnath & Chan, 2005), and psychosocial well-being (Varas-Díaz, et al., 2005; Zhao et al., 2009).

To date, the body of evidence regarding the negative impact of stigma has focused on the experience of adult populations including individuals with or at-risk of HIV infection and health care workers who provide services to PLWHA. Few studies have examined HIV-related stigma among children who are affected (i.e., either orphaned or made vulnerable) by HIV/AIDS, although limited data from Sub-Saharan Africa suggests that children are not spared from the effect of stigma (Bicego, Rutstein & Johnson, 2003). Children orphaned or made vulnerable by AIDS may encounter hostility from their extended families and community, and may be rejected, denied access to schooling and health care (Bauman, Camacho, Silver, Hudis & Draimin, 2002; Ntozi & Mukiza-Gapere, 1995). Based on a review of global literature on care of children affected by AIDS, Li and colleagues proposed a developmental psychopathological framework of psychosocial needs of children affected by AIDS in China (Li et al., 2008). In their framework (Figure 1), a number of individual and environmental factors were identified as potential correlates or determinants of psychopathological symptoms. One of these factors is HIV-related stigma.

Although some causes of HIV-related stigma may be universal (e.g., fear of AIDS contagion), their manifestations or expressions may vary considerably from culture to culture, and from population to population (Hong et al., 2008). This variation across culture and population is shaped in each society bymultiple factors, including societal values, local HIV epidemic and preexisting prejudice within the local culture or subculture (Parker & Aggleton, 2003). For example, one of the unique features of the AIDS epidemic in China is the clustering of individuals infected with HIV as a result of unhygienic blood collection in rural central China (Zhao et al., 2007).

During the late 1980s and middle 1990s, some governmental and commercial blood stations/centers collected blood in rural areas of central China. The farmers, who were not tested for HIV or other blood-borne infections, sold blood to collection centers as a source of income. The collection centers pooled the blood of several donors of the same blood type, separated the plasma, and injected the remaining red-blood cells back into individual donors to prevent anemia. Such procedures, plus the reuse of needles and contaminated equipment enabled rapid spread of the virus through the local population. Many HIV-infected farmers have progressed to AIDS and thousands have died (Rosenthal, 2002). Similar to the observations in many other countries, HIV infection in China is a highly stigmatized disease; HIV-related stigma is considered as one of the significant barriers in combating the HIV epidemic in China (Chen, Choe, Chen & Zhang, 2005).

However, it is not clear to what extent HIV-related stigma in these local communities has impacted children's psychosocial development. On one hand, because of the high prevalence of infection in the local area and unique cause of the epidemic (e.g., poverty-driven blood selling), it is possible that HIV is viewed as a common thing within the local communities

and therefore has less stigma attached to it (in comparison with HIV infection through sex or intravenous drug use). Families and children might feel less stigmatized and as a result be less isolated or distressed. On the other hand, it is also possible that an entire village or local community that has a high rate of HIV-related illness and death is stigmatized; therefore being from such a village or community could put the children at great risk of distress. In addition, it is not clear whether the negative effect of stigma on children affected by AIDS will be additive to the effect of parental HIV-related illness and death.

These postulations regarding the relationship between culture and HIV-related stigma have highlighted the importance of examining HIV-related stigma among children in this specific cultural setting. Visser and colleagues (2008) have described two forms of stigma: *public stigma* (or attributed stigma) which refers to the general perception of how people in a society or community feel and respond toward PLWHA, and *personal stigma* which refers to the personal beliefs and feelings that individuals hold toward PLWHA. Therefore, in this study, we study both perceived public stigma and personal stigma among three groups of children in a high HIV prevalence area in central China: children who lost one or both of their parents to AIDS (AIDS orphans), children living with HIV-infected parents (vulnerable children), and children who did not experience HIV-related illness and death in their families (comparison children).

This study has the following objectives: (1) examine the psychometric properties of two parallel measures of HIV-related stigma (i.e., perceived public stigma and children's personal stigma against PLWHA) among these children; (2) examine whether expressions of stigma measures differ by child's sex, developmental stage, family SES, or orphanhood status (i.e., AIDS orphans, vulnerable children, and comparison children); and (3) examine the association between HIV-related stigma and children's psychosocial adjustments among these children. Because a previous study has documented that AIDS orphans or vulnerable children had a poorer level of psychosocial adjustment than comparison children (Fang et al., 2009), we will examine the unique contribution of HIV-related stigma to children's poor psychosocial adjustment above and beyond the impact of parental HIV/AIDS.

We hypothesized that children affected by AIDS (AIDS orphans and vulnerable children) would perceive a higher level of public stigma and have a lower level of personal stigma than comparison children. In addition, we hypothesized that both perceived public stigma and personal stigma would differ by children's developmental stages with level of stigma decreasing by age. We further hypothesized that the effect of HIV-stigma on children's psychosocial functioning would be above and beyond the effect of parental HIV-related illness and death.

Method

Study Site

The current study was conducted in 2006–2007 in two rural counties in central China where many residents had been infected with HIV through unhygienic blood collection (Li et al., 2009). The two counties had similar demographic and economic profiles (e.g., both were designated by the central government as "national poverty county"). Although accurate epidemiological data are lacking, both counties are generally believed to have the highest prevalence of HIV infection in central China (Agence France Presse, 2004). We obtained village-level HIV surveillance data from the counties' anti-epidemic stations to identify the villages with the highest number of HIV/AIDS-related death or confirmed HIV infection. The children in the current study were recruited from five administrative villages (rural administrative units under the county) that had jurisdiction over 111 natural villages.

Participants and Sampling

The participants include 755 AIDS orphans, 466 vulnerable children, and 404 comparison children. Children 6 to 18 years of age were eligible to participate in the study. Both the recruitment process and consenting procedure for the current study have been described in detail elsewhere (Fang et al., 2009). Briefly, the orphanage sample was recruited from four government-funded AIDS orphanages (n=176) and eight small group homes that had enrolled children at the time of this baseline survey (n=30). The remaining orphans (n=549) and vulnerable children (n=466) were recruited from the family or kinship care settings. The comparison group was recruited from the same villages where the orphans and vulnerable children were recruited. The research protocol, including consenting procedure, was approved by the Institutional Review Boards at both Wayne State University in the United States and Beijing Normal University in China.

Survey Procedure

An assessment inventory was administered to each participating child by trained interviewers (e.g., education and psychology faculty members and graduate students from local universities). The assessment was conducted at AIDS orphanage, home, or school where children were recruited. For children who were too young or had limited literacy, interviewers read each question to them, and the children gave oral responses to the interviewers who recorded the responses in the survey instrument. During the survey, necessary clarification or instruction was provided promptly as needed. The entire assessment inventory took about 75 to 90 minutes, depending on the age of the children. Younger children (e.g., those ages ≤ 8 years) were offered a 10–15 minute break after every 30 minutes of assessment. Each child received a gift at completion of the assessment as a token of appreciation.

Measures

Demographic characteristics—Children were asked to report on individual and family characteristics during the survey. These characteristics include age, sex, ethnicity, perceived health status (i.e., very good, good, fair, and poor), parental education (no schooling, elementary school, middle school, ≥ high school), and the main occupational activities in which their parents were currently engaged or had engaged before their death (i.e., farmer, migrant worker, local small merchant, or other). To facilitate the group comparison by age, children were divided into three developmental groups: pre-adolescents (<12 years of age), early adolescents (12 through 14 years of age), and middle adolescents (>14 years of age). A composite score was created to estimate family socioeconomic status (SES) of the child by indexing those children whose parents (father and mother) had more than elementary school education and engaged in non-farming occupational activities. The SES score had a range of 0 to 4 with a higher score indicating a better family SES.

Stigma and psychosocial measures—Two HIV-related stigma measures (i.e., “perceived public stigma” and “personal stigma”) were developed based on existing measures of HIV-related stigma in the literature (Berger, Ferrans, & Lashley, 2001; Kalichman et al., 2005; Wright, Naar-King, Lam, Templin, & Frey, 2007). In addition, six psychosocial scales were employed in this study to measure a wide spectrum of psychosocial adjustment of participating children. These scales include the Center for Epidemiological Studies Depression Scale for Children (Fendrich, Weissman, & Warner, 1990), the Children’s Loneliness Scale (Asher, Hymel, & Renshaw, 1984), the Self-Esteem Scale (Rosenberg, 1965), a modified version of the Children Future Expectation Scale (Bryan, Rocheleau, Robbins, & Hutchison, 2005), the Hopefulness about Future, and the Perceived Control over Future scales (Whitaker, Miller, & Clark, 2000). A list of all the

scales and their internal consistency estimates (Cronbach alpha), accompanied by brief descriptions of the content of measurement and/or sample questions is provided in Table 1. A composite score (e.g., mean score with appropriate reverse coding) was obtained for each of the scales with a higher score indicating a higher level of the perception/behavior the scale intends to measure.

Statistical Analysis

First, Cronbach alpha was employed as the internal consistency estimate for the stigma scales among the entire sample, as well as among various subgroups. Second, analysis of variance (ANOVA) was employed to assess the association of stigma with key demographic characteristics (e.g., sex, age, family SES), orphanhood status, and psychosocial adjustment. To assess the association between stigma measures and psychosocial adjustment using ANOVA, a categorical score was created for each of the stigma scales as a between-subjects factor by dividing the children into three groups (i.e., approximately bottom 25%, middle 50%, and top 25%) based on their scores on the scale.

Third, multivariate analysis using general linear model (GLM) was employed to assess the unique effect of stigma on children's psychosocial adjustment while controlling for children's orphanhood status, sex, age, and family SES. Two GLM analyses were conducted corresponding to the two stigma scales. Categorical score of stigma measures, orphanhood status, and sex were employed as between-subjects factor variables in GLM analyses. Age and family SES (both as continuous variables) were employed in GLM as covariates. Effects of all interaction terms among the three factor variables were also assessed simultaneously in the GLM analyses. All statistical analyses were performed using SPSS for window v15.0.

Results

Sample Characteristics

As shown in Table 2, the sample in the current study consisted of 826 boys and 799 girls (49%). The mean age was 12.85 years and did not differ between boys and girls (12.89 vs. 12.82). Ninety-nine percent of the children were of Han ethnicity. Two-thirds of the sample considered themselves as being "very good" or "good" in health. The majority of the sample (>70%) reported that their father or mother had no more than middle school education. About one-fifth of children did not know the educational attainment of their parents. The majority of the parents (66% fathers and 81% mothers) worked mainly in farming or as rural migrant workers. There were a number of significant differences in demographic characteristics among the three groups. Orphans were older (13.16) than either vulnerable children (12.36) or the comparison children (12.83, $p<.0001$). The proportion of children who did not know their parental education attainment was significantly higher among AIDS orphans (24% for father and 29% for mother) than vulnerable children (14% for both parents) or comparison children (6% for father and 13% for mother) ($p<.0001$ for both father and mother). More orphans or vulnerable children reported that their parents mainly engaged in farming than comparison children (i.e., 80% and 75% vs. 67%, $p<.0001$ for mother; 65% and 58% vs. 41%, $p<.0001$ for father).

Group Difference of Stigma Measures

As shown in Table 3, perceived public stigma was similar between boys and girls (2.20 vs. 2.17), but differed by age group with both pre-adolescents (2.27) and middle adolescents (2.23) reporting a higher level of perceived public stigma than did early adolescents (2.11, $p<.0001$). Children's personal stigma differed significantly by gender with boys reporting a higher level of personal stigma than girls (2.40 vs. 2.24, $p<.0001$). Likewise, the personal stigma differed significantly by age groups with pre-adolescents reporting the highest score

of personal stigma (2.64), followed by early adolescents (2.26) and middle adolescents (2.10) in a linear fashion ($p<.0001$). Family SES was positively associated with children's personal stigma ($p=.002$), but not with perceived public stigma.

Perceived public stigma also differed significantly among the three groups of children, with AIDS orphans and vulnerable children perceiving a higher level of stigma than comparison children (2.28, 2.18, and 2.01, respectively, $p<.0001$). There was no statistical difference among three groups of children in terms of their personal stigma, although group differences in personal stigma showed a similar trend as the public stigma.

Association between Stigma and Psychosocial Adjustment

As shown in Table 4, both perceived public stigma and personal stigma were significantly associated with all six psychosocial measures ($p<.0001$). Both stigma scales were positively associated with psychopathological symptoms (e.g., depression, loneliness) and negatively associated with psychosocial wellbeing (e.g., self-stigma, positive future expectation, hopefulness about future, and perceived control over the future).

The association between stigma measures and psychosocial adjustment were confirmed by the GLM analyses (Table 5). In the model with perceived public stigma (Model One), level of stigma was significant in multivariate test ($p<.0001$) and each of the univariate tests. The children's orphanhood status was significant in multivariate test ($p<.0001$) and all but one ("Future") of the univariate tests. Gender was significant for neither multivariate test nor univariate tests. Age was a significant covariant in multivariate test ($p<.0001$) and all univariate tests except depression. Family SES was a significant covariate in multivariate test ($p<.01$) and univariate test for hopefulness about future ($p<.05$). None of the 2-way or 3-way interaction terms among factor variables were significant in either multivariate test or univariate tests.

Similar patterns were observed for the GLM model with personal stigma (Model Two). Level of stigma was significant in multivariate test and univariate tests for all psychosocial measures ($p<.0001$). The children's orphanhood status was significant in multivariate test ($p<.0001$) and each of the univariate tests. Children's gender was significant in multivariate test ($p<.05$) and univariate tests for future expectation and hopefulness about future. Age was a significant covariate in multivariate test ($p<.0001$) and univariate tests for all psychosocial measures except self-esteem and hopefulness about future. Family SES was significant in multivariate test ($p<.01$) and univariate test for future expectation ($p<.05$). None of the 2-way or 3-way interaction terms among factor variables were significant in either multivariate test or univariate tests in Model Two.

Discussion

The current study revealed a significant difference in perceived public stigma by AIDS orphanhood status, with children affected by AIDS perceiving a higher level of perceived public stigma against PLWHA. The higher level of perceived public stigma among these children might be a result of their personal experience associated with HIV in their families. Although the children who lost their parents to AIDS or had the potential of losing a parent to AIDS have suffered elevated psychological problems, this finding suggests that perceived public stigma against PLWHA might put these children at additional risk for psychological problems. In contrast to our hypothesis, there were no differences in personal stigma among three groups of children. Our measures of personal stigma may have lacked sufficient sensitivity to detect differences between children affected by AIDS and comparison children. Alternatively, AIDS experience in the family may not impact a child's attitudes toward PLWHA, especially in communities with a high HIV prevalence.

The two stigma scales also showed some different patterns in their association with other key demographic characteristics (e.g., children's age, sex, and family SES). Although the differences by age group were significant in both types of stigma ($p<.0001$), the trends of the difference were mixed. While children's personal stigma was linearly decreased with age as we hypothesized, perceived public stigma was higher among pre-adolescents (children <12 years of age) or middle adolescents (children >15 years of age) than early adolescents (children 12–15 years of age). The linear age trend of personal stigma may reflect the relative maturity in cognition and emotion among children as they mature. The nonlinear age trend of perceived public stigma might be confounded by the AIDS orphanhood status as AIDS orphans were older and perceived a higher level of public stigma than other children in the current study. Child sex and family SES show similar patterns in their association with the two stigma scales, although the differences by sex or SES did not reach statistical significance. Generallyboys and children from family with higher SES reported higher level of stigma than their counterparts.

Despite the inconsistent patterns by AIDS orphanhood status and some demographic differences, both perceived public stigma and personal stigma contribute to children's psychosocial problems independent of their orphanhood status and other key demographic factors. However, the two scales were positively correlated ($r=.36$, $p<.0001$). The relatively high correlation suggests that children's own stigmatizing attitudes may be influenced by the perceived public stigma or vice versa. Future study is needed to examine the possible interactions of these two aspects of HIV-related stigma and their unique contribution to children's psychological problems.

There were several potential limitations in the current study. First, the representativeness of our samples may be limited for several reasons. Our samples were recruited from one of the AIDS epicenters in China with a unique cause of parental HIV/AIDS (i.e., unhygienic blood collection) and dominant Han ethnicity composition. The HIV/AIDS epidemic in China also contains several other modes of viral transmission (e.g., sex, intravenous drug use, and mother-to-child). In addition, HIV/AIDS has disproportionally affected ethnic minorities in other areas of China. Therefore, future studies need to involve children from other ethnic backgrounds and also with different causes of parental HIV/AIDS in order to validate the findings in the current study. Second, there might be some selection bias in sampling as convenience sampling rather than random sampling method was used. Third, some psychological scales in the current study had relatively low reliability estimates (e.g., Cronbach $\alpha=.63$ for self-esteem and perceived control over future). Future studies are needed to develop reliable measures that are culturally and developmentally appropriate for rural Chinese children.

Despite these potential limitations, the findings in the current study have several important implications for policy and practice in care of children affected by AIDS. First, stigma reduction should be part of the care efforts for children affected by AIDS. The current study suggests that even in the communities with a high prevalence of HIV, HIV-related stigma could still be wide spread and affecting psychological well-being of PLWHA and their family members including children. Therefore community-wide stigma reduction efforts need to be part of the AIDS care program. Second, the stigma reduction efforts should not only target the stigma against PLWHA but also possible stigma against the entire community (e.g., villages) with a high prevalence of HIV/AIDS. Third, because stigma measures differed by age, gender, and SES, the stigma reduction efforts needs to be appropriate for children's age, gender, family SES and AIDS experience in the family. Finally, psychological support and counseling services should be provided to children affected by AIDS. These children most likely suffer from multiple AIDS-related stressors, including loss of a parent (or facing the potential of losing a parent) to AIDS, stigmatization

for parental HIV, and the emotional and financial challenges of orphanhood. Future research should explore individual and contextual factors such as social support, coping and attachment in mitigating the negative effect of stigma among these children.

Acknowledgments

The study described in this report was supported by NIH Research Grant R01MH76488 by the National Institute of Mental Health and the National Institute of Nursing Research. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institute of Mental Health or the National Institute of Nursing Research. The authors want to thank Joanne Zwemer for assistance with manuscript preparation.

References

Agence France Presse. China agrees to 1st official orphanage for AIDS children. June 16. 2004 Retrieved March 17, 2005 from http://www.aegis.com/NEWS/AFP/2004/AF040661.html

Asher SR, Hymel S, Renshaw PD. Loneliness in Children. Child Development. 1984; 55(4):1456–1464.

Bauman L, Camacho S, Silver E, Hudis J, Draimin B. Behavioral problems in school-aged children of mothers with HIV/AIDS. Clinical Child Psychology and Psychiatry. 2002; 7:39–54.

Berger BE, Ferrans CE, Lashley FR. Measuring stigma in people with HIV: Psychometric assessment of the HIV stigma scale. Research in Nursing & Health. 2001; 24(6):518–529. [PubMed: 11746080]

Bicego G, Rutstein S, Johnson K. Dimensions of the emerging orphan crisis in sub-Saharan Africa. Social Science & Medicine. 2003; 56:1235–1247. [PubMed: 12600361]

Bond V, Chaseb E, Aggleton P. Stigma, HIV/AIDS and prevention of mother-to-child transmission in Zambia. Evaluation and Program Planning. 2002; 25:347–356.

Bryan A, Rocheleau CA, Robbins RN, Hutchison KE. Condom use among high-risk adolescents: testing the influence of alcohol use on the relationship of cognitive correlates of behavior. Health Psychology. 2005; 24:133–142. [PubMed: 15755227]

Chen J, Choe MK, Chen S, Zhang S. Community environment and HIV/AIDS-related stigma in China. AIDS Education and Prevention. 2005; 17:1–11. [PubMed: 15843106]

Chesney MA, Smith AW. Critical delays in HIV testing and care. American Behavioral Scientist. 1999; 42:1162–1174.

Duffy L. Suffering, shame, and silence: the stigma of HIV/AIDS. Journal of the Association of Nurses in AIDS Care. 2005; 16:13–20. [PubMed: 15903274]

Fang X, Li X, Stanton B, Zhao G, Lin D, Lin X, Zhao J, Hong Y, Zhang L. Parental HIV/AIDS on psychosocial adjustment of rural Chinese children. Journal of Pediatric Psychology. 2009 Advance Access published February 10, 2009. 10.1093/jpepsy/jsp006

Fendrich M, Weissman MM, Warner V. Screening for depressive disorder in children and adolescents: validating the center for epidemiologic studies depression scale for children. American Journal of Epidemiology. 1990; 131:538–551. [PubMed: 2301363]

Hong Y, Li X, Stanton B, Fang X, Lin D, Wang J, Mao R, Yang H. Expressions of HIV-related stigma among rural-to-urban migrants in China. AIDS Patient Care STDS. 2008; 22:823–831. [PubMed: 18847389]

Kalichman S, Simbayi L, Jooste S, Toefy Y, Cain D, Cherry C, Kagee A. Development of a brief scale to measure AIDS-related stigma in South Africa. AIDS and Behavior. 2005; 9:135–143. [PubMed: 15933833]

Lee RS, Kochman A, Sikkema KJ. Internalized stigma among people living with HIV/AIDS. AIDS and Behavior. 2002; 6:309–319.

Letamo G. Prevalence of, and factors associated with, HIV/AIDS-related stigma and discriminatory attitudes in Botswana. Journal of Health, Population and Nutrition. 2003; 21:347–357.

Li X, Fang X, Stanton B, Zhao G, Lin X, Zhao J, Zhang L, Hong Y, Chen X. Psychometric evaluation of the trauma symptoms checklist for children (TSCC) among children affected by HIV/AIDS in China. AIDS Care. 2009; 21:261–270. [PubMed: 19280403]

Li X, Naar-King S, Barnett D, Stanton B, Fang X, Thurston C. A developmental psychopathology framework of the psychosocial needs of children orphaned by HIV. The Journal of the Association of Nurses in AIDS Care. 2008; 19:147–157. [PubMed: 18328965]

Lieber E, Li L, Wu Z, Rotheram-Borus MJ, Guan J. HIV/STD stigmatization fears as health-seeking barriers in China. AIDS and Behavior. 2006; 10:463–471. [PubMed: 16374668]

Mahajan AP, Sayles JN, Patel VA, Remien RH, Sawires SR, Ortiz DJ, Szekeres G, Coates TJ. Stigma in the HIV/AIDS epidemic: a review of the literature and recommendations for the way forward. AIDS. 2008; 22:S67–S79. [PubMed: 18641472]

Ntozi JPM, Mukiza-Gapere J. Care for AIDS orphans in Uganda: findings from focus group discussions. Health Transition Review. 1995; 5:245–252. [PubMed: 10159892]

Parker R, Aggleton P. HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. Social Science & Medicine. 2003; 57:13–24. [PubMed: 12753813]

Reidpath DD, Brijnath B, Chan KY. An Asia Pacific six-country study on HIV-related discrimination: introduction. AIDS Care. 2005; 17:S117–S127. [PubMed: 16174623]

Rosenberg, M. Society and the adolescent self-image. Princeton, New Jersey: Princeton University Press; 1965.

Rosenthal E. AIDS scourge in rural China leaves villages of orphans. New York Times. 2002 August 25.

Varas-Díaz N, Serrano-García I, Toro-Alfonso J. AIDS-related stigma and social interaction: Puerto Ricans living with HIV/AIDS. Qualitative Health Research. 2005; 15:169–187. [PubMed: 15611202]

Visser MJ, Kershaw T, Makin JD, Forsyth BWC. Development of Parallel Scales to Measure HIV-Related Stigma. AIDS Behav. 2008; 12:759–771. [PubMed: 18266101]

Whitaker DJ, Miller KS, Clark LF. Reconceptualizing adolescent sexual behavior: Beyond did they or didn't they? Family Planning Perspectives. 2000; 32:111–117. [PubMed: 10894256]

Wright K, Naar-King S, Lam P, Templin T, Frey M. Stigma scale revised: Reliability and validity of a brief measure of stigma for HIV+ youth. Journal of Adolescent Health. 2007; 40:96–98. [PubMed: 17185215]

Zhao G, Li X, Fang X, Zhao J, Yang H, Stanton B. Care arrangement, grief, and psychological problems among children orphaned by AIDS in China. AIDS Care. 2007; 19:1075–1082. [PubMed: 18058390]

Zhao G, Li X, Kaljee L, Zhang L, Stanton B, Fang X, Zhao J, Lin D, Lin X. Psycho-social consequences for children experiencing parental loss due to HIV/AIDS in Central China. AIDS Care. 2009; 21(6):769–774. [PubMed: 19437169]

Figure 1.
Developmental psychopathology framework of psychosocial needs of children affected by HIV/AIDS, adapted from Li et al. (2008)

Table 1

Description of Measurement Scales Used in the Study

Scale	# of Items	Content/Sample Questions	Response Option
Perceived Public Stigma (α=.86)	10	Number of people in the community/society would have certain stigmatizing attitudes or actions toward PLWHA and their family (e.g., "People will look down at a family if someone in the family has HIV/AIDS")	1=none, 2=few, 3=some, 4=most
Personal Stigma (α=.87)	10	Whether they agreed with each of the statements reflecting either negative perception of PLWHA or social sanctions/ exclusion against PLWHA (e.g., "PLWHA should feel shame of themselves")	5-point scale from 1="strongly disagree" to 5="strongly agree"
Center for Epidemiological Studies Depression Scale for Children (α=.81)	20	Depressive symptoms (e.g., "I was bothered by things that usually don't bother me.")	0=not at all 1=a little 2=some 3=a lot
Children 's Loneliness Scale (α=.81)	16	Perceived loneliness and social dissatisfaction (e.g., "I have nobody to talk to", "it is hard for me to make friends")	5-point scale from 1="not at all true" to 5="always true"
Self-esteem (α=.63)	10	Global feelings of self-worth or self-acceptance (e.g., "I feel that I have a number of good qualities", "I am able to do things as well as most other people")	4-point scale from 1="strongly disagree" to 4="strongly agree"
Children Future Expectation (Future) (α=.84)	6	Expectations about specific future outcomes in life (e.g., handling problems in life, handling school work, having friends, staying out of trouble, having a happy life, having interesting things to do)	5-point scale from 1="not at all" to 5="very much"
Hopefulness about Future (Hope) (α=.78)	4	hopefulness with regard to some concrete outcomes in the future (e.g., graduation from high school)	4-point scale from 1="will not happen" to 4="will definitely happen"
Control over the Future (Control) (α=.63)	7	personality-based/dispositional measure relating to perceived control over the future (e.g., "What happens to me in the future mostly depends on me")	4-point scale from 1="disagree a lot" to 4="agree a lot"

Table 2

Sample Characteristics

	Overall	AIDS Orphans	Vulnerable Children	Comparison Children
N(%)	1625(100%)	755(47%)	466(29%)	404(25%)
Boys	826(51%)	403(53%)	219(47%)	204(51%)
Girls	799(49%)	352(47%)	247(53%)	200(50%)
Mean Age in Years (SD)	12.85(2.21)	13.13(2.20)	12.36(2.24)	12.83(2.11)*
Perceived Health				
Very Good	464(30%)	193(27%)	139(32%)	132(33%)
Good	523(34%)	258(36%)	146(33%)	119(30%)
Fair	499(32%)	234(33%)	132(30%)	133(34%)
Poor	65(4%)	34(5%)	20(5%)	11(3%)
Father Education*				
No School	41(3%)	29(4%)	7(2%)	5(1%)
Elementary School	527(33%)	231(31%)	175(38%)	121(30%)
Middle School	597(38%)	251(34%)	166(36%)	180(45%)
≥High School	467(8%)	49(7%)	44(10%)	41(10%)
Don't Know	294(19%)	177(24%)	65(14%)	52(13%)
Mother Education*				
No School	476(9%)	67(9%)	52(12%)	24(6%)
Elementary School	614(39%)	238(33%)	208(46%)	168(42%)
Middle School	421(21%)	177(25%)	115(25%)	129(32%)
≥High School	70(5%)	28(4%)	16(4%)	26(7%)
Don't Know	318(20%)	206(29%)	61(14%)	51(13%)
Father Occupation*				
Farmer	879(57%)	462(65%)	255(58%)	162(41%)
Migrant	131(9%)	45(6%)	35(8%)	51(13%)
Local Merchant	415(27%)	146(21%)	129(29%)	140(35%)
Other	117(8%)	54(8%)	21(5%)	42(11%)
Mother Occupation*				
Farmer	1141(75%)	540(80%)	335(75%)	266(67%)
Migrant	90(6%)	32(5%)	18(4%)	40(10%)
Local Merchant	193(13%)	60(9%)	73(16%)	60(15%)
Other	95(6%)	47(7%)	19(4%)	29(7%)
Family SES Composite Score (SD)	1.94(1.17)	1.92(1.17)	1.79(1.17)	2.15(1.15)*

* p<.0001

Table 3

Cronbach Alpha and Mean Score (SD) of Two Stigma Scales

	Perceived Public Stigma			Personal Stigma		
	Alpha	**M (SD)**	**P-value**	**Alpha**	**M (SD)**	**P-value**
Overall sample	.86	2.18(.68)		.87	2.32(.75)	
Sex			n.s.			<.0001
Boys	.87	2.20(.69)		.87	2.40(.78)	
Girls	.86	2.17(.68)		.85	2.24(.71)	
Age			<.0001			<.0001
<12	.87	2.27(.74)		.86	2.64(.82)	
12–14	.87	2.11(.66)		.88	2.26(.72)	
>15	.85	2.23(.65)		.81	2.10(.61)	
Orphanhood Status			<.0001			n.s.
AIDS Orphans	.87	2.28(.70)		.86	2.31(.74)	
Vulnerable Children	.85	2.18(.69)		.89	2.37(.85)	
Comparison Children	.84	2.01(.61)		.83	2.29(.63)	
Family SES Score			n.s.			.002
0	.88	2.22(.71)		.87	2.31(.80)	
1	.86	2.21(.68)		.88	2.24(.75)	
2	.85	2.15 (.66)		.87	2.29(.73)	
3	.86	2.16(.71)		.86	2.40(.74)	
4	.86	2.26(.70)		.83	2.47(.75)	

AIDS Care. Author manuscript; available in PMC 2011 April 19.

Table 4

Association between stigma and psychosocial adjustment

	Level of HIV-related Stigma		
	Low	**Medium**	**High**
Scale 1: Perceived public stigma			
Depression	.78(.36)	.95(.42)	1.10(.45)****
Loneliness	2.25(.72)	2.43(.69)	2.63(.66)****
Self-Esteem	2.94(.43)	2.87(.41)	2.81(.40)****
Future	3.20(.88)	3.09(.85)	2.83(.98)****
Hope	2.94(.68)	2.87(.67)	2.71(.80)****
Control	3.04(.48)	3.01(.61)	2.86(.51)****
Scale 2: Personal stigma			
Depression	.89(.46)	.92(.41)	1.00(.41)***
Loneliness	2.25(.69)	2.38(.70)	2.73(.66)****
Self-Esteem	2.99(.44)	2.88(.41)	2.73(.66)****
Future	3.25(.82)	3.12(.84)	2.72(1.00)****
Hope	2.99(.62)	2.90(.67)	2.61(.82)****
Control	3.19(.44)	3.02(.59)	2.74(.50)****

**** p<.0001

Table 5

Results of Multivariate Analysis (GLM)[1]

	Main Effect			Covariate	
	Stigma	**Children Status[2]**	**Gender**	**Age**	**SES**
Model One: Perceived public stigma					
Multivariate	11.16****	12.43****	1.81	18.99****	3.26**
Depression	53.89****	26.26****	<1	1.47	<1
Loneliness	22.85****	37.84****	<1	37.99****	<1
Self-Esteem	7.22***	18.68****	<1	13.20****	1.28
Future	15.71****	1.76	3.05	24.69****	2.92
Hope	7.24***	15.00****	1.94	7.58****	4.83*
Control	9.14****	7.94****	1.08	76.66****	2.63
Model Two: Personal stigma					
Multivariate	11.91****	14.43****	2.64*	10.81****	3.03**
Depression	11.23****	33.81****	<1	4.58*	<1
Loneliness	37.41****	45.43****	<1	12.06***	1.45
Self-Esteem	36.72****	19.29****	2.19	1.43	<1
Future	29.37****	3.69*	6.16*	5.57**	4.51*
Hope	24.84****	15.30****	8.67**	<1	3.25
Control	33.88****	8.45****	<1	37.67****	1.43

Note:

[1]Two- and three-ways interaction terms were omitted from the table because of the absence of multivariate significance;

[2]Children status: AIDS orphans, vulnerable children, and comparison children;

*p<.05,

**p<.01,

***p<.001,

**** p<.0001