Secondary Disclosure of Parental HIV Status Among Children Affected by AIDS in Henan, China

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Abstract

For children affected by AIDS, one psychological challenge is whether or how to disclose their parents' HIV status to others (secondary disclosure). The current study, utilizing data from 962 rural children affected by AIDS in central China, examines children's perceptions regarding secondary disclosure (intention of disclosure, openness, and negative feelings) and their association with children's demographic and psychosocial factors. The findings indicated that a high proportion of children preferred not to disclose parental HIV status to others, would not like to tell the truth to others in the situations of having to talk about parental HIV, and also had strong negative feelings about the disclosure. The study findings confirmed that keeping secrecy of parental HIV infection was associated with higher level of negative psychological outcomes (e.g., depression, loneliness, perceived stigma, and enacted stigma), and children's age was strongly associated with both their perceptions of secondary disclosure and psychological measures.

Introduction

WORLDWIDE there was an estimate of more than 16 million children under the age of 18 who had lost one or both parents to AIDS in 2009.¹ Meanwhile, millions of children are living with HIV-positive parents. AIDS orphans (i.e., children who lost one or both of their parents to AIDS) and vulnerable children (i.e., children who lived with HIV-positive, alive parents) often suffer a variety of psychological reactions to parental illness and death related to HIV/AIDS, and are at great risk of mental health problems due to change of caregivers and family composition, and potential emotional deprivation in their development.²⁻⁵ One of the psychological challenges for children affected by AIDS (both AIDS orphans and vulnerable children) is to decide whether or how to disclose their parents' HIV status to others (i.e., secondary disclosure).^{6,7}

Several qualitative studies suggested that children, particularly adolescents living with HIV-positive parents, were struggling about whether, when and to whom to talk about their parents' infection when they became aware of the fact.^{8,9} In the context of prevalent stigma against persons living with HIV (PLHIV) adolescents might feel guilt, shame, and anger when they disclosed their parents' HIV status to others.⁷ In a qualitative study of 59 adolescents living with HIV-positive parents, none of the adolescents who reported having a best friend had told that friend of their parents' HIV infection to that friend.¹⁰

Common reasons for children's disclosing to others included wanting friends to know, needing to get it off their chest, not being able to keep the secret any longer, and wanting others to understand their situation, while the reasons behind nondisclosure included fear of others' ignorance, potential stigmatization, rejection, and further unintended disclosure (i.e., the target of disclosure tells information to others).⁹ Existing studies indicated that the decision of children's disclosure was also influenced by the ways in which HIV-positive parents had disclosed to their children. Some HIV-positive parents explicitly instructed their children not to disclose parental HIV status to other people⁸; some HIV-positive parents also gave their children specific instructions about whom to tell and whom not to tell about parental disease.¹¹ In one study, approximately one-fourth of the HIV-positive mothers identified "safe people" (e.g., family members, health care providers) to whom their children could discuss their mothers' HIV status, but the majority of children had been requested to keep the mothers' HIV status a secrecy in order to maintain family privacy, and to protect themselves and their family members from stigmatization.⁸

Both qualitative and quantitative studies suggested that maintaining the secrecy of their parents' HIV infection might cause stress to the children.⁸ A number of children who had not disclosed to others expressed concerns about their friends finding out the fact from other channels.⁸ Children who were requested to keep the secret were

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found to have more internalizing problems and lower levels of social competence,¹² and tend to display more behavior problems than children who were not asked to do so.¹³ Reyland and colleagues⁷ reported that the more secrets adolescents chose or were requested to hold, the more distance they felt from their peers. In addition, the fear of secrecy breaching and the effort to protect the secrets might affect the development of a healthy sense of intimacy with their peers.⁷

Although disclosing parental HIV status to others may be a significant challenge for many children to cope with parents' HIV-related illness and death, few studies have examined the experiences and perceptions of children regarding the secondary disclosure and relationship of such experiences and perceptions with children's psychosocial well-being. The potential effects of children's secondary disclosure (or nondisclosure) have been hypothesized but not empirically supported. The lack of data about children's secondary disclosure practice and its effects on children's psychological well-being highlights the urgent need for research on issues related to children's secondary disclosure.

At the end of 2009, it was estimated that 740,000 people were infected HIV in China, of whom 105,000 were living with AIDS.¹⁴ The HIV epidemic in China has been affecting not only HIV/AIDS patients but also their families including their children. One of great challenges for parents living with HIV is to disclose their status to their children. Generally, the rates of parental HIV disclosure were low in China based on several qualitative studies, although perception and practice of parental disclosure vary across HIV transmission modes.^{15,16} Most PLHIV did not disclose their HIV serostatus to children due to fear of secondary disclosure, which may result in HIV-related discrimination and stigma.¹⁶

Although some researchers have shed light on HIV disclosure issues in China,¹⁵⁻¹⁹ no study has examined the issue of children's secondary disclosure in China. The current study, utilizing data from 962 children affected by AIDS in rural Henan, China, was aimed to explore children's perceptions of secondary disclosure and their association with children's demographic and psychosocial factors. Henan, is an agricultural province in central China with a population of 96.7 million.²⁰ It was estimated that at least 100,000 AIDS orphans lived in China by the end of 2004, and many of identified AIDS orphans live in rural Henan.²¹ It is important to understand the situation of these children and their families in rural area, who have not yet attracted as much attention as the ones in China's developed areas.¹⁷ In this study, we tried to answer the following questions. First, what are the perceptions among children affected by AIDS about disclosing parental HIV status to others in rural China regarding intention (e.g., willingness of disclosure), openness (e.g., tell truth to others), and feelings (e.g., feel sad, nervous, and negative) of secondary disclosure? Second, are there any differences in the perceptions of secondary disclosure across different groups of children (e.g., orphans in orphanages, orphans in family care, and vulnerable children)? Third, are there any associations between children's perceptions of secondary disclosure and children's demographic characteristics? Fourth, are children's perceptions of secondary disclosure significantly associated with their psychosocial well-being?

Methods

Study site

The sample in the current study were participants in the second annual assessment of a longitudinal study of psychosocial needs of children affected by AIDS in China.²² The larger study was conducted in 2005–2009 in two rural counties in central China where many residents were infected with HIV through unhygienic blood collection in the late 1980s and early 1990s. While the unhygienic blood collection was banned in 1998, HIV infection continues to spread from the former plasma donors to other populations through unprotected sex, injection drug use, and mother-to-child transmission.²³

Participants

The participants in the current study included 579 AIDS orphans and 383 vulnerable children. Of all the orphans, 153 were living in orphanages and 426 were living with family members (e.g., surviving parent, older sibling, grandparents). Children 6–18 years of age at baseline were eligible to participate in the study. Age eligibility was verified through the local community leaders, school records, or caregivers.

Sampling procedure

The sampling and consenting procedure for the larger study was described in detail elsewhere.²² Briefly, the AIDS orphans living in orphanages were recruited from four government-funded orphanages in the two counties (two orphanages in each county). To recruit AIDS orphans and vulnerable children from the family or kinship, we worked with the village leaders to generate lists of families caring for orphans or with confirmed diagnosis of parental HIV. We approached the families on the lists and recruited one child per family to participate in the assessment. The research protocol, including consenting procedure, was approved by the Institutional Review Boards at Wayne State University in the United States and Beijing Normal University in China.

Survey procedure

Each child participating in the study completed a confidential assessment inventory in Chinese. During the survey, necessary clarification or instruction was provided promptly when needed. The interviewers were trained education and psychology graduate students and faculty members from the local universities. The entire assessment inventory took about 75–90 min depending on the age of the children. Each child received a gift worth \$2.5 at completion of the assessment as a token of appreciation.

Measures

Demographic characteristics. Children were asked to provide information regarding their age, gender, primary caregivers, and number of HIV infections in the family. Children were also asked about parental education (elementary school or less, middle school, high school or higher), and the main occupational activities in which their parents were currently engaged or had been engaged before their death (farming, migrant worker, or other). In addition, children were asked to report the health status of their parents (e.g.,

healthy, HIV/AIDS, other illness) and their perceived causes of parental death (e.g., AIDS, other illness).

Perceptions of secondary disclosure of parental HIV status. Children's perceptions of secondary disclosure was measured using 10 items in terms of intention (2 items), openness (4 items), and feelings about the disclosure (4 items). Because not all the children were aware of their parents' HIV infection or the real cause of their parental death, children were asked about their experiences and perceptions of secondary disclosure in a general term of parental "illness" or "death" rather than HIV specific. Two intention items ("I would never talk about it with others" and "I would avoid talking about it with others") were used to assess whether children intended to disclose parental illness/death to others (Cronbach $\alpha=0.72$). The openness items ("I would not tell others the truth," "I would not tell others the details about it," "If under the situation that I have to talk about it, I would skip many details about it," and "If under the situation that I have to talk about it, I would not tell the truth") were used to assess whether children intended to be open in the disclosure (Cronbach $\alpha=0.77$). The feelings items ("I felt sad when I talked about it with others," "I felt nervous when I talked about it with others," "I felt tired after talked about it with others," and "I had a low mood after talked about it with others") were applied to assess whether children who had experienced secondary disclosure had strong negative feelings during the disclosure process (Cronbach $\alpha=.78$). All the items have a four-point response option (1=not true at all, 2=sometimes not true, 3=sometimes true, 4=always true). The responses to the items of each secondary disclosure scale (intention, openness, and feelings) were summed up and formed continuous variables (with appropriate reverse recoding). Higher scores indicated higher levels of perception the scale was designed to measure. For the purpose of data analysis, we dichotomized intention scale into "weak" and "strong" using a 25/75 percentile split (scale score ≤ 2 versus scale score > 2). Similarly, openness scale and negative feelings scale were also dichotomized into "weak" and "strong" using a 25/75 percentile split (scale score ≤ 4 versus scale score > 4).

Depression. Children's depressive symptoms were measured using the Center for Epidemiological Studies Depression Scale for Children (CES-DC).²⁴ The CES-DC is a 20-item self-report depression measure with a 4-point response option (0=not at all, 1=a little, 2=some, 3=a lot). The CES-DC was translated into Chinese in the early 1990s and was validated with various Chinese populations.²⁵ Cronbach α of the scale was .81 for the current study sample.

Loneliness. The Chinese version of the Children's Loneliness Scale (CLS)^{25,26} was administered to the children in the current study. The CLS consists of 16 items that assessed children's perceived loneliness and social dissatisfaction. The CLS items have a five-point response option ranging from "strongly disagree" to "strongly agree." The 16 loneliness items have a good internal consistency (Cronbach $\alpha=0.84$) for the current study sample.

Perceived social support (PSS). The PSS was measured in the current study using a 25-item scale,²⁷ which was a

cultural modification of the Medical Outcome Study (MOS) Social Support Survey developed by Sherbourne and Stewart.²⁸ The modified version consists of four subscales: informational/emotional support (8 items), material/tangible support (5 items), affectionate support (8 items), and positive social interaction (4 items). All the items have a five-point response option ranging from "never" to "all the time." The Cronbach α for the four subscales were 0.86, 0.83, 0.87, and 0.86, respectively, in the current study.

Self-esteem. The participants were also asked about their global feelings of self-worth or self-acceptance using the 10-item Self-Esteem Scale with a four-point response option (i.e., strongly disagree to strongly agree).²⁹ The Self-Esteem Scale was introduced into China in the early 1990s.²⁵ This scale demonstrated a good internal consistency for the current study sample (Cronbach $\alpha=0.78$).

Perceived public stigma against PLHIV and their family (Perceived stigma against PLHIV). Public stigma toward PLHIV and their family was assessed using a 10-item scale (e.g., "People will think someone with HIV is unclean," "People will look down at a family if someone in the family has HIV"). All the 10 items have a 5-point response option ranging from 1="strongly disagree" to 5="strongly agree". The Cronbach α for the 10 items was 0.89 for the current study sample.

Perceived public stigma against children affected by AIDS (Perceived stigma against children). This perceived public stigma was measured by the Stigma Against Children Affected by AIDS (SACAA) scale,³⁰ which consists of 10 items regarding stigmatizing attitudes and actions against children affected by AIDS, including social sanction or exclusion (e.g., "People think children of PLHIV should leave their villages", "People think children of PLHIV should quit school or never go to school"), purposeful avoidance (e.g., "People are unwilling to take care of children of PLHIV," "People do not want their children to play with children of PLHIV"), and perceptions that children affected by AIDS are inferior to children of uninfected parents (e.g., "People think children of PLHIV are unclean," "People do not think children of PLHIV can be as good as other children"). All the items have a five-point response option ranging from 1="strongly disagree" to 5="strongly agree." The Cronbach α for this scale was 0.93 for the current study sample.

Enacted stigma. Children affected by HIV were asked to indicate, on a 14-item list, whether they had experienced some stigmatization because of parental HIV/AIDS. The sample stigmatizing experience included "being beaten by other kids," "being called bad names," "being teased or picked on by other kids," "kids did not play with me anymore," "relatives stopped visiting when parents got sick or died," and "my family lost land or other property." The response option ranged from 1="never happened" to 5="always happened." The Cronbach α of the 14 items was 0.84 for the current study sample.

Hopelessness. Children's perception of hopelessness for the future was assessed using the Hopelessness Scale for Children (HSC) developed by Kazdin and colleagues.³¹ The HSC consists of 17 items and children were asked to indicate if they agree or disagree with each of them. The sample items of

TABLE 1. DEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS

	<i>Overall</i>	<i>Boys</i>	<i>Girls</i>
<i>N</i> (%)	962 (100%)	484 (50.3%)	468 (48.6%) ^a
Orphans in orphanage	153 (15.9%)	94 (19.4%)	57 (12.2%) ^b
Orphans in family	426 (44.3%)	210 (43.4%)	212 (45.3%)
Vulnerable children	383 (39.8%)	180 (37.2%)	199 (42.5%) ^b
Child age	12.41 (2.14)	12.43 (2.10)	12.40 (2.18)
No. of siblings live together	1.07 (1.07)	0.92 (.97)	1.24 (1.15) ^c
No. of HIV infection in family	1.46 (0.76)	1.42 (0.72)	1.51 (0.81)
Primary caregivers			
Father	501 (62.5%)	242 (62.1%)	259 (63.0%)
Mother	519 (64.8%)	262 (67.2%)	257 (62.5%)
Paternal grandparents	286 (35.7%)	134 (34.4%)	152 (37.0%)
Maternal grandparents	40 (5%)	15 (3.8%)	25 (6.1%)
Paternal relatives	41 (5.1%)	15 (3.8%)	26 (6.3%)
Maternal relatives	21 (2.6%)	10 (2.6%)	11 (2.7%)
Other nonrelative	107 (13.4%)	54 (13.8%)	53 (12.9%)
Father's education^d			
≤ Elementary school	333 (35.8%)	173 (36.7%)	160 (34.8%)
Middle school	330 (35.5%)	165 (35.0%)	165 (35.9%)
≥ High school	66 (7.1%)	31 (7.4%)	35 (6.8%)
Mother's education^d			
≤ Elementary school	434 (47.8%)	208 (45.0%)	226 (50.8%)
Middle school	220 (24.3%)	119 (25.8%)	101 (22.7%)
≥ High school	38 (4.2%)	25 (5.4%)	13 (2.9%)
Father's occupation			
Farming work	535 (60.5%)	272 (60.2%)	263 (60.9%)
Working in the city	222 (25.1%)	112 (24.8%)	110 (25.5%)
Others	127 (14.4%)	68 (15%)	59 (13.6%)
Mother's occupation			
Farming work	669 (76.4%)	337 (74.1%)	332 (78.9%)
Working in the city	109 (12.4%)	64 (10.7%)	45 (14.1%)
Others	98 (11.2%)	44 (15.2%)	54 (7%)
Perceived father's health^e			
Healthy	139 (26.8%)	72 (28.7%)	67 (25.0%)
HIV/AIDS	286 (55.1%)	144 (57.4%)	142 (53.0%)
Other illness	30 (5.8%)	13 (5.2%)	17 (6.3%)
I don't know	64 (12.3%)	22 (8.8%)	42 (15.7%)
Perceived mother's health^e			
Healthy	152 (31.0%)	72 (30.5%)	80 (31.4%)
HIV/AIDS	260 (53.0%)	134 (56.8%)	126 (49.4%)
Other illness	36 (7.3%)	12 (5.1%)	24 (9.4%)
I don't know	43 (8.8%)	18 (7.6%)	25 (9.8%)
Perceived father's death cause^e			
AIDS	129 (65.2%)	65 (65.0%)	64 (65.3%)
Other illness	12 (6.1%)	4 (4%)	8 (8.2%)
I don't know	57 (28.8%)	31 (31%)	26 (26.5%)
Perceived mother's death cause^e			
AIDS	141 (73.8%)	73 (73%)	68 (74.7%)
Other illness	11 (5.8%)	7 (7%)	4 (4.4%)
I don't know	39 (20.4%)	20 (20%)	19 (20.9%)

^aThe number in genders did not add up to the total number due to missing values.

^b $p < 0.01$.

^c $p < 0.0001$.

^dCases in this measure did not add up to 100% because some children did not know their parents' education level.

^eThese data were based on baseline report.

hopelessness included "I want to grow up because I think things will be better," "I might as well give up because I can't make things better for myself," and "All I can see ahead of me are bad things, not good things." The Cronbach α for the 17 items was 0.69 in the current study.

Statistical analysis

We performed several analyses to answer our research questions. First, descriptive statistics were used to generate a demographic profile of the study sample. χ^2 or analysis of

variance (ANOVA) was used to compare children's individual characteristics between boys and girls. Second, frequency distribution and associated χ^2 were used to compare children's perceptions of disclosure by orphanhood status (orphans in orphanage, orphans in family care, and vulnerable children). Third, χ^2 or ANOVA was used to compare children's demographic characteristics and psychosocial factors by intention (strong versus weak), openness (strong versus weak), and negative feelings (strong versus weak) of secondary disclosure. A mean score (with appropriate reverse recoding) was used as scale score for each of the psychosocial measures with higher scores indicating higher levels of perception/attribute that the scale was designed to measure.

Finally, multivariate analyses using general linear model (GLM) procedure were performed to test the effect of the children's intention of secondary disclosure (Model 1), openness of secondary disclosure (Model 2), and negative feelings about disclosure (Model 3) on children's psychosocial measures. All psychosocial measures were used as the dependent variables in the GLM analysis. Because of the potential association of children's gender, orphan status, and age with their psychosocial well-being, these variables were controlled in the GLM analysis. Children's gender and orphan status (categorical variables) were used as additional factor variables in the GLM analysis. Children's age was included in the GLM model as a covariate. All analyses were conducted using SPSS for Windows V.16 (SPSS Inc., Chicago, IL).

Results

Sample characteristics

As shown in Table 1, the current sample consisted of 153 (15.9%) orphans in orphanage, 426 (44.3%) orphans living in families, and 383 (39.8%) vulnerable children. Overall the number of boys ($n=484$) and girls ($n=468$) was approximately equal. The average age of participants was 12.41 years (standard deviation [SD]=2.14). The sample had 1.07 (SD=1.07) siblings living together on average. The average number of HIV infections in the family was 1.46 (SD=0.76). Over 60% of the children lived with at least one of their parents (62.5% with father and 64.8% with mother). The primary caregivers also included paternal grandparents (35.7%), maternal grandparents (5.0%), paternal relatives (5.1%), maternal

relatives (2.6%), and other nonrelatives (13.4%). The majority of the participants reported that their father or mother had no more than middle school education (71.3% for father and 72.1% for mother). The majority of parents (85.6% fathers and 88.8% mothers) worked in farming or worked in cities as migrant workers. More than one half of the children had known paternal or maternal HIV infection (55.1% for father and 53.0% for mother). Among children who had lost their fathers, 65.2% thought that their fathers died from AIDS. Similarly, 73.8% of children who had lost their mothers perceived that their mothers died from AIDS. Boys and girls were similar in most demographic characteristics with only a few exceptions: compared with girls, a higher proportion of boys were living in an orphanage (19.4% versus 12.2%, $p<0.01$), while a lower proportion of boys were living with HIV-positive parents (37.2% versus 42.5%, $p<0.01$). In addition, girls reported having more siblings living together than did boys (1.24 versus 0.92, $p<0.001$).

Perceptions of secondary disclosure

Among the 962 participants of this study, 943 provided valid responses to the intention of disclosure, 953 provided data on openness of disclosure, and 950 answered questions about negative feelings about disclosure. Table 2 depicts the perceptions of secondary disclosure among three different groups of children (orphans in orphanage, orphans in families, and vulnerable children).

Intention of disclosure. Based on children's reports, 58 (38.2%) of the orphans in orphanages had a strong intention to disclose their parental HIV status to others. Likewise, 84 (20.5%) of the orphans in families and 130 (34%) of the vulnerable children expressed a strong intention to do so. A χ^2 test indicated a significant difference across the groups ($p<0.0001$) with fewer orphans in families strongly wanting to talk about their parental HIV infection with others compared to children in the other two groups.

Openness of disclosure. Less than one third of children reported a strong intention to tell the truth if they have to disclose their parental HIV status to others. According to their reports, 28.2% of orphans in orphanages, 23.9% orphans in families, and 28.9% vulnerable children would like to talk

TABLE 2. CHILDREN'S PERCEPTIONS OF SECONDARY DISCLOSURE OF PARENTAL HIV INFECTION

	Orphans in orphanage	Orphans in family	Vulnerable children	Total
N (%)	153 (15.9%)	426 (44.3%)	383 (39.8%)	962 (100%)
Intention of disclosure ($p<0.0001$)^a				
Strong	58 (38.2%)	84 (20.5%)	130 (34.0%)	272 (28.8%)
Weak	94 (61.8%)	325 (79.5%)	252 (66.0%)	671 (71.2%)
Openness^a				
Strong	42 (28.2%)	101 (23.9%)	110 (28.9%)	253 (26.6%)
Weak	107 (71.8%)	322 (76.1%)	271 (71.1%)	700 (73.5%)
Negative feelings ($p=0.006$)^a				
Strong	110 (72.8%)	336 (80.4%)	270 (70.9%)	716 (75.4%)
Weak	41 (27.2%)	82 (19.6%)	111 (29.1%)	234 (24.6%)

^aThe number in various measures may not add up to the total number in each group due to missing values.

TABLE 3. CHILDREN'S DEMOGRAPHIC CORRELATES OF THEIR DISCLOSURE PERCEPTIONS

	<i>Intention of disclosure</i>		<i>Openness</i>		<i>Negative feelings</i>	
	<i>Strong</i>	<i>Weak</i>	<i>Strong</i>	<i>Weak</i>	<i>Strong</i>	<i>Weak</i>
N (%)	272 (28.8%)	671 (71.2%)	253 (26.6%)	700 (73.5%)	716 (75.4%)	234 (24.6%)
Child gender (male)	146 (54.5%)	325 (48.9%)	132 (53.2%)	345 (49.6%)	343 (48.4%)	137 (59.3%) ^a
Child age	11.69 (2.12)	12.72 (2.07) ^b	11.99 (1.88)	12.59 (2.19) ^b	12.64 (2.17)	11.77 (1.87) ^b
No. of siblings live together	1.15 (1.12)	1.03 (1.05)	1.16 (1.13)	1.05 (1.05)	1.03 (1.04)	1.19 (1.15)
No. of HIV infections in family	1.43 (0.75)	1.49 (0.78)	1.46 (0.77)	1.47 (0.77)	1.48 (0.79)	1.41 (0.71)
Primary caregivers						
Father	155 (72.4%)	345 (59.8%) ^a	141 (66.8%)	361 (60.9%)	358 (59.1%)	143 (74.1%) ^b
Mother	159 (74.3%)	361 (62.6%) ^a	142 (67.3%)	381 (64.2%)	386 (63.7%)	134 (69.4%)
Paternal grandparents	74 (34.6%)	201 (34.8%)	71 (33.6%)	212 (35.8%)	218 (36.0%)	65 (33.7%)
Maternal grandparents	15 (7.0%)	26 (4.5%)	11 (5.2%)	30 (5.1%)	28 (4.6%)	11 (5.7%)
Paternal relatives	9 (4.2%)	32 (5.5%)	7 (3.3%)	34 (5.7%)	31 (5.1%)	9 (4.7%)
Maternal relatives	8 (3.7%)	13 (2.3%)	7 (3.3%)	14 (2.4%)	13 (2.1%)	8 (4.1%)
Other non-relative	28 (13.1%)	75 (13.0%)	24 (11.4%)	83 (14.0%)	84 (13.9%)	24 (12.4%)
Father's education						
≤ Elementary school	95 (36.8%)	233 (35.7%)	77 (32.1%)	251 (36.8%)	259 (37.2%)	70 (31.6%)
Middle school	84 (32.6%)	243 (37.2%)	90 (37.5%)	238 (34.9%)	244 (35.1%)	82 (36.9%)
≥ High school	17 (6.6%)	45 (6.9%)	14 (30.4%)	51 (29.3%)	51 (7.3%)	15 (6.8%)
Mother's education						
≤ Elementary school	120 (47.4%)	310 (48.6%)	118 (50.2%)	314 (47.4%)	321 (47.6%)	108 (48.6%)
Middle school	53 (20.9%)	164 (25.7%)	43 (18.3%)	173 (26.1%)	176 (26.1%)	42 (18.9%)
≥ High school	17 (6.7%)	18 (2.8%)	13 (5.5%)	25 (3.8%)	26 (3.9%)	12 (5.5%)
Father's occupation						
Farming work	137 (55.9%)	393 (63.1%)	133 (57.6%)	398 (61.6%)	409 (61.9%)	121 (56.8%)
Working in the city	72 (29.4%)	141 (22.6%)	65 (28.1%)	154 (23.8%)	156 (23.6%)	63 (29.6%)
Others	36 (14.7%)	89 (14.3%)	33 (14.3%)	94 (14.6%)	96 (14.5%)	29 (13.6%)
Mother's occupation	(<i>p</i> = 0.001)				(<i>p</i> = 0.001)	
Farming work	173 (70%)	489 (79.6%)	166 (72.2%)	499 (78.2%)	513 (78.9%)	148 (68.8%)
Working in the city	45 (18.2%)	60 (9.8%)	38 (16.5%)	68 (10.7%)	64 (9.8%)	43 (20.0%)
Others	29 (14.8%)	65 (10.6%)	26 (11.5%)	71 (11.1%)	73 (11.3%)	24 (11.2%)
Perceived paternal health						
Healthy	41 (28.5%)	94 (25.8%)	37 (28.5%)	100 (25.9%)	101 (26.4%)	38 (28.8%)
HIV/AIDS	79 (54.9%)	202 (55.3%)	76 (58.5%)	209 (54.1%)	206 (53.9%)	76 (57.6%)
Other illness	5 (3.5%)	25 (6.8%)	3 (2.3%)	27 (7.0%)	25 (6.5%)	5 (3.8%)
I don't know	19 (13.2%)	44 (12.1%)	14 (10.8%)	50 (13.0%)	50 (13.1%)	13 (9.8%)
Perceived maternal health						
Healthy	38 (28.6%)	112 (32.1%)	32 (26.2%)	118 (32.3%)	110 (30.7%)	40 (31.3%)
HIV/AIDS	72 (54.1%)	181 (51.9%)	75 (61.5%)	183 (50.1%)	190 (53.1%)	67 (52.3%)
Other illness	9 (6.8%)	27 (7.7%)	6 (4.9%)	30 (8.2%)	28 (7.8%)	8 (6.3%)
I don't know	14 (10.5%)	29 (8.3%)	9 (7.4%)	34 (9.3%)	30 (8.4%)	13 (10.2%)
Perceived paternal death cause						
AIDS	29 (74.4%)	96 (63.2%)	31 (68.9%)	97 (63.8%)	101 (64.7%)	25 (67.6%)
Other illness	2 (5.1%)	9 (5.9%)	2 (4.4%)	10 (6.6%)	10 (6.4%)	2 (5.4%)
I don't know	8 (20.5%)	47 (30.9%)	12 (26.7%)	45 (29.6%)	45 (28.8%)	10 (27.0%)
Perceived maternal death cause						
AIDS	25 (71.4%)	110 (74.8%)	39 (78.0%)	102 (72.9%)	109 (74.7%)	30 (73.2%)
Other illness	3 (8.6%)	7 (4.8%)	2 (4.0%)	9 (6.4%)	9 (6.2%)	2 (4.9%)
I don't know	7 (20.0%)	30 (20.4%)	9 (18.0%)	29 (20.7%)	28 (19.2%)	9 (22.0%)

^a*p* < 0.01.^b*p* < 0.0001.

about truth during the disclosure. No significant difference was detected by orphan status.

Negative feelings about disclosure. Over 70% of the children reported strong negative feelings associated with the secondary disclosure. About 72.8% of orphans in orphanages and 70.9% of vulnerable children said they experienced strong negative feelings during the disclosure. A significantly higher

proportion of orphans in families (80.4%) experienced strong negative emotions about disclosure to others (*p* < 0.01).

Demographic correlates of children's secondary disclosure

The children's demographic characteristics were similar by intention of disclosure, openness of disclosure, and negative

TABLE 4. ASSOCIATION BETWEEN CHILDREN'S DISCLOSURE PERCEPTIONS AND CHILDREN'S PSYCHOLOGICAL WELL-BEING

	Intention of disclosure		Openness		Negative feelings	
	Strong	Weak	Strong	Weak	Strong	Weak
N (%)	272 (28.3%)	671 (69.8%)	253 (26.3%)	700 (72.8%)	716 (74.4%)	234 (24.3%)
Depression	12.59	13.89 ^a	11.45	14.27 ^b	14.06	11.78 ^b
Loneliness	34.37	33.89	32.21	34.67 ^b	34.29	33.09 ^b
Information/emotional support	14.74	18.05 ^b	15.04	17.80 ^b	17.87	14.67 ^b
Material/tangible support	11.29	13.68 ^b	11.57	13.46 ^b	13.48	11.20 ^b
Affectionate support	15.12	18.57 ^b	15.32	18.35 ^b	18.29	15.11 ^b
Positive social interaction	8.53	10.41 ^b	8.69	10.29 ^b	10.23	8.66 ^b
Perceived stigma against PLHIV	17.74	18.72	17.07	18.95 ^b	18.90	17.10 ^a
Perceived stigma against children	17.25	18.34 ^c	16.64	18.53 ^a	18.52	16.54 ^a
Enacted stigma	17.38	18.98 ^b	16.78	19.16 ^b	19.01	16.91 ^b
Hopelessness	22.80	21.45 ^b	22.41	21.68 ^a	22.86	21.53 ^b
Self-esteem	27.85	29.56 ^b	28.09	29.32 ^b	29.44	28.01 ^b

^a $p < 0.01$.^b $p < 0.0001$.^c $p < 0.05$.

PLHIV, persons living with HIV.

feelings about disclosure (Table 3). Specifically, the children's older age was significantly associated with weak intention to disclosure to others, weak intention to tell the truth in the disclosure, and strong negative emotions about the disclosure ($p < 0.0001$ for all three measures). Living with their father or mother was significantly associated with a strong intention to disclose to others ($p < 0.01$ for both variables). In addition, living without their father or mother was associated with more negative feeling about the disclosure although only the association between living with their father and negative feeling reached statistical significance ($p < 0.0001$). Maternal occupation was also significantly associated with both the intention of disclosure and negative emotions about disclosure. Specifically, children whose mothers were engaged in farming activities were less likely to have a strong intention to disclose to others, while children whose mothers were migrant workers were more likely to have a strong intention to do so ($p < 0.01$). Compared to children whose mothers were migrant workers, children whose mothers were farmers were more likely to report strong negative feelings about the disclosure ($p < 0.01$).

Psychosocial correlates of children's secondary disclosure

As shown in Table 4, most of the children's psychological measures were associated with children's experiences and perceptions of secondary disclosure. Weak intention to disclosure was significantly associated with higher level of negative psychological outcomes including depression score ($p < 0.01$), perceived stigma against children affected by AIDS ($p < 0.05$), and enacted stigma ($p < 0.0001$). However, weak intention to disclosure was also associated with higher scores on all perceived social support scales ($p < 0.0001$), lower hopelessness ($p < 0.0001$), and higher self-esteem ($p < 0.0001$). Likewise, weak intention to be open during the disclosure was significantly associated with higher depression, loneliness, perceived stigma (both against PLHIV and against children affected by AIDS), and enacted stigma ($p < 0.0001$ for each variable, except $p < 0.01$ for stigma against children affected by AIDS), while this weak intention was also significantly asso-

ciated with a higher level of all measures of perceived social support ($p < 0.0001$), lower hopelessness ($p < 0.01$), and higher self-esteem ($p < 0.0001$). In terms of negative feelings about the disclosure, children who reported strong negative emotions about the disclosure were more likely to report a high level of negative psychological outcomes including depression, loneliness, perceived stigma (both towards PLHIV family and children affected by AIDS), enacted stigma, and hopelessness ($p < 0.0001$ for each variable, except $p < 0.01$ for the two perceived stigma variables). The children reporting strong negative feelings about the disclosure were also more likely to report high scores on all perceived social support scales and self-esteem ($p < 0.0001$ for each variable).

Multivariate analysis

Multivariate analysis (Table 5) confirmed the overall difference in psychological measures by intention of disclosure (Model 1), openness of disclosure (Model 2), and negative feelings about disclosure (Model 3). The multivariate tests in all the models indicated significant associations between the three aspects of secondary disclosure (i.e., intention of disclosure, openness of disclosure, and negative feelings about disclosure) and the psychological measures. Univariate tests for Model 1 suggested that intention of disclosure was significantly associated with all measures of perceived social support, perceived stigma against children affected by AIDS, hopelessness, and self-esteem. Univariate tests for Model 2 showed that openness of disclosure was significantly associated with all the psychological measures. Similarly, negative feeling about the disclosure was also significantly associated with all the psychological measures in univariate tests for Model 3. Child gender was significantly associated with psychological measures based on multivariate tests for Model 1 and Model 2. It was also significantly related to all measures of perceived social support in Model 1 and Model 2. Child group (i.e., orphan status) was significantly associated with psychological measures in all the models according to multivariate test. The results of univariate tests for child group indicated that child group was significantly related to informational/emotional

TABLE 5. RESULTS OF GENERAL LINEAR MODEL ANALYSIS

	Main effect			Interaction ^a D by G	Covariates Child age
	Disclosure Perception (D)	Child Gender (G)	Child Group (P)		
Model 1 Intention of disclosure^b					
Multivariate test	5.762 ^c	2.527 ^d	2.202 ^d	1.919 ^e	12.030 ^c
Depression	2.316	<1	<1	<1	5.868 ^e
Loneliness	<1	6.408 ^c	2.409	2.911	2.576
Information/emotional support	16.789 ^c	19.878 ^c	11.330 ^c	1.446	36.245 ^c
Material/tangible support	8.534 ^d	12.801 ^c	<1	<1	13.612 ^c
Affectionate support	11.687 ^d	8.289 ^d	6.891 ^d	<1	35.485 ^c
Positive social interaction	18.035 ^c	8.100 ^d	7.967 ^c	<1	11.075 ^d
Perceived stigma against PLHIV	3.673	<1	<1	1.625	1.701
Perceived stigma against children	5.830 ^e	<1	<1	3.294	<1
Enacted stigma	7.432 ^d	<1	<1	3.858	4.558 ^e
Hopelessness	25.711 ^c	1.586	<1	<1	56.254 ^c
Self-esteem	14.226 ^c	3.061	1.635	3.280	5.828 ^e
Model 2 Openness^b					
Multivariate test	9.735 ^c	2.591 ^d	1.647 ^e	<1	13.398 ^c
Depression	28.345 ^c	<1	<1	<1	4.538 ^e
Loneliness	11.786 ^d	4.255 ^e	3.909 ^e	<1	4.684 ^e
Information/emotional support	18.502 ^c	21.770 ^c	7.143 ^d	<1	44.309 ^c
Material/tangible support	6.761 ^e	14.339 ^c	1.076	<1	15.599 ^c
Affectionate support	14.089 ^c	11.009 ^d	3.879 ^e	1.734	42.126 ^c
Positive social interaction	17.866 ^c	12.136 ^d	3.957 ^e	<1	16.454 ^c
Perceived stigma against PLHIV	9.000 ^d	<1	1.507	1.171	2.136
Perceived stigma against children	8.125 ^d	<1	1.100	1.425	<1
Enacted stigma	25.358 ^c	<1	<1	<1	5.453 ^e
Hopelessness	10.841 ^d	2.896	<1	<1	67.445 ^c
Self-esteem	6.542 ^e	2.374	2.176	1.130	8.999 ^d
Model 3 Negative feelings^b					
Multivariate test	6.830 ^c	1.431	1.823 ^e	1.178	12.218 ^c
Depression	11.087 ^d	<1	<1	1.462	4.289 ^e
Loneliness	3.923 ^e	<1	2.344	4.075 ^e	4.014 ^e
Information/emotional support	19.720 ^c	10.507 ^d	8.085 ^c	<1	37.303 ^c
Material/tangible support	17.791 ^c	3.919 ^e	<1	2.833	12.333 ^c
Affectionate support	16.028 ^c	2.647	3.773 ^e	1.350	35.050 ^c
Positive social interaction	15.855 ^c	2.614	4.885 ^d	4.278 ^e	12.265 ^c
Perceived stigma against PLHIV	5.503 ^e	<1	<1	2.205	1.785
Perceived stigma against children	5.718 ^e	<1	<1	4.100 ^e	<1
Enacted stigma	16.035 ^c	<1	<1	3.505	5.871 ^e
Hopelessness	14.006 ^c	<1	<1	2.219	60.611 ^c
Self-esteem	5.493	<1	1.170	1.248	7.616 ^d

PLHIV, persons living with HIV.

^aInteraction variables included Disclosure Perception (D)×Child Gender (G), Disclosure Perception (D)×Child Group (P), and Disclosure Perception (D)×Child Gender (G)×Child Group (P). All the statistics for D×P and D×G×P in the multivariate tests and univariate tests of all the models were not significant, thus they were not presented in the table.

^bPillai's Trace F statistics were presented in the table for multivariate test and conventional F statistics (based on Type III Sum of Square) were presented for univariate tests.

^c $p < 0.0001$.

^d $p < 0.01$.

^e $p < 0.05$.

support, affectionate support and positive social interaction in all the three models; and in Model 2, it was also associated with loneliness. Children's age was significantly related to psychological measures in multivariate tests for all the three models. In addition, children's age was significantly related to depression, all measures of perceived social support, enacted stigma, hopelessness, and self-esteem in univariate tests for all the three models.

There was a significant interaction term between children's intention of disclosure and child gender in Model 1 for multivariate test. Likewise, there was a significant interaction be-

tween children's negative feelings about disclosure and child gender in univariate test for loneliness, positive social interaction, and perceived stigma toward children affected by AIDS in Model 3. Further examination of the cell means indicated that the significant interaction term was largely a result of uneven gender difference by the intention of disclosure. For instance, among children who had a strong intention of disclosure, average score of enacted stigma were similar between boys and girls (17.12 versus 17.79), while among the children with weak intention, boys' average score of enacted stigma was higher than that of girls (19.43 versus 18.52).

Discussion

The data in the current study were consistent with the existing qualitative studies, suggesting that the majority of children affected by AIDS would not like to disclose their parental HIV status to others and even though they have to talk about it they may struggle with how much of the truth or details to tell, and they may experience strong negative feelings during the disclosure.^{8,9} The findings of multivariate analysis also supported the existing notion that keeping secrecy of parental HIV infection (e.g., weak intention to disclose, weak intention to tell truth) was associated with a higher level of negative psychological outcomes.^{12,13,32} Consistent with the global literature, the data in this study also indicated the important role of children's age in several aspects of secondary disclosure. First, existing studies suggests that children's age is significantly related to their understanding of HIV.³² Older children may be able to understand more about HIV infection.³³ Therefore, they may more easily realize the HIV-related stigma and have more fears of disclosing parental HIV status to others and its negative consequences. This may partially explain the results in the current study regarding an older age for children with weak intention to disclose, weak intention to tell the truth to others, and strong negative feelings about the disclosure than younger children. Second, the social network of children may vary across age groups; therefore, children at different age group may choose different people to whom they would like to disclose parental HIV infection and ask for support. In addition, the appropriate persons to whom the children affected by AIDS can safely communicate with about HIV may also vary for children at different age. Third, many studies indicate that children's age affects their psychological adjustment after becoming aware of parental HIV infection.^{6,32} Generally, children at different age may show different level of psychological adjustment in response to parental HIV infection.³⁴⁻³⁶ The current study confirmed that children's age was significantly associated with most of psychological measures.

The data in the current study also suggested negative associations between the intention and openness of disclosure and perceived social support, self-esteem, and hopelessness. One possible reason for children to disclose their parental HIV status may be the needs to get emotional or materials supports from others (e.g., the target of the secondary disclosure). This may partially explain the negative association between intention to disclose and perceived social support. Likewise, if children felt good about the outlook of their future and also felt good about themselves, they would be less likely to disclose or felt pressured to tell the truth to others. While future studies are needed to validate these speculations, these findings indicate the complexity of the relationship between children's perceptions about disclosure and their psychological well-being, and thus underscore the importance of conducting further studies to examine these associations, which may be also moderated or mediated by other factors of social context such as community norms, family relations, and school environment.

There are several potential limitations in the current study. First, given some children might not be aware of their parental HIV status, we asked children about perceptions of disclosing parental illness or death rather than explicitly asking them about disclosing parental HIV status to others. This approach,

while culturally and developmentally appropriate, might result in an overestimation of the intention of disclosure. However, we conducted a subgroup analysis using data from the children who knew their parental HIV infection (based on their responses to related questions in the survey), and found similar results (data not shown). Second, the sample in the current study was relatively young (with a mean age of 12.41). As children's developmental stage might be a critical factor in children's understanding of HIV and their decision about secondary disclosure. Therefore the findings in the current study may not be generalized to older children. Third, the sample was recruited from rural counties with high rate of HIV infection through unhygienic blood collection in central China. The findings may not be generalized to children affected by HIV / AIDS living in other areas of China or children affected by parental HIV that was transmitted via other mode (e.g., sex or drug use).

Despite these limitations, this study is one of the first efforts to examine secondary disclosure of parental HIV from the perspectives of children in China. The findings in this study underscores the needs of examining how children's perceptions of secondary disclosure influenced their psychological adjustment and developing efficacious interventions to assist children affected by AIDS overcome barriers and negative feelings related to the secondary disclosure.

Parental illness or death due to AIDS is traumatic for a child, profoundly affecting the child's psychological well-being.³⁷ Psychosocial problems of these children call for exploration of risk and resilience factors.²⁰ Communication about the illness or death of loved ones is an important step for recovery from grief.³⁸ Open communication with others can provide affected children opportunities of receiving emotional support and coping strategies, therefore, their needs and problems could be heard and addressed appropriately.³⁹ Hiding within "The wall of silence" built around children affected by AIDS could not protect them from discrimination or bullying from their peers, because other children learned situations of the affected children's parents from other persons in the community.³⁹ According to a guideline on HIV disclosure counseling for children by the World Health Organization (WHO), the focus related to HIV disclosure for children has turned from "whether or not to disclose" to "how to disclose appropriately."⁴⁰ Similarly, a key issue related to secondary disclosure among children affected by AIDS may be "how to development-appropriately assist these children to talk about their parental HIV / AIDS to a safe person." Few studies have discussed the criteria of identifying a safe person with whom the children can freely talk about HIV-related issues, but potential ones include family members, health care workers, friends, and school personnel.⁴⁰ The choice of these persons may depend on children's age and other contextual factors, but the choice should be made in the best interest of children.⁴⁰

In addition, a range of protective resources is needed in the process of assisting children affected by AIDS in disclosure process in order to promote their welfare and minimize the risk to their well-being. One qualitative study in Rwanda suggested the protective resources included individual resources, family cohesion and parenting skills, as well as social support.⁴¹ For instance, engaging local community in interventions may improve children's access to stigma-free places to communicate with peers.⁴²

Future studies should engage children of different age groups; particularly adolescents are needed to compare perceptions of children in different development stages. The study of secondary disclosure can be expanded from children's perceptions to children's practice (e.g., rate of disclosure, target of disclosure, settings of disclosure). A validated and standardized scale of secondary disclosure is needed to compare results from numerous studies. Studies with a longitudinal design are needed to explore the causal relationship between children's disclosure and psychological adjustment. In addition, prior to an intervention integrating multiple resources, we need to examine various family, community, and culture factors that may potentially influence children's perceptions and practices of secondary disclosure, and potentially mediate the effect of secondary disclosure on psychological well-being. Children's disclosing parental HIV status to others and its effects on children's psychological adjustment are important aspects of their coping with parental HIV-related infection and death. Further research and intervention efforts are needed to maximize the long term benefit of secondary disclosure to children affected by AIDS.

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