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## Factors influencing the decision-making of parental HIV disclosure: a socio-ecological approach

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### Abstract

**Objectives**—Using the socio-ecological approach, the current study aims to identify facilitators and barriers to decision-making regarding parental HIV disclosure or nondisclosure at intrapersonal, interpersonal, and sociocultural levels; and examine the unique contribution of factors at different level of influences to the decision of disclosure or nondisclosure.

**Design**—A cross-sectional survey was conducted among people living with HIV in Guangxi, China. A sub-sample of 1254 participants, who had children aged 5–16 years, was included in the data analysis in the current study.

**Methods**—Multivariate models using hierarchical logistic regression were employed to assess the association of parental decision regarding HIV disclosure to children with various factors at intrapersonal, interpersonal, and sociocultural levels controlling background characteristics, and detect the level-specific influence on disclosure decision.

**Results**—Positive coping with HIV infection and a good parent–child relationship facilitated parental HIV disclosure; whereas high level of resilience and fears of parental HIV disclosure impeded their decisions to talk about HIV status to their children. In addition, the current study recognized specific contribution of multiple ecological levels to parental decisions regarding disclosure to children.

**Conclusion**—The socio-ecological model is a promising theoretical framework to guide further studies and interventions related to parental HIV disclosure. Directions for further studies using socio-ecological approach were also discussed.

### Keywords

decision-making; factors; HIV disclosure; parents; socio-ecological approach

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#### Conflicts of interest

The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institute of Child and Human Development. None of the authors has a conflict of interest of any type.

## Introduction

Disclosure of HIV status has been considered as an important component in HIV prevention and treatment due to its complex relationship with secondary prevention, healthcare access, treatment adherence, psychosocial adjustment, and family function [1]. However, disclosing HIV status to family members, particularly to children, is still a big challenge for people living with HIV (PLHIV) [2]. An increasing number of empirical studies have focused on parental HIV disclosure (i.e. parents tell their HIV status to their infected or uninfected children), with respect to reasons for disclosure/nondisclosure, patterns of disclosure, and consequences resulted from disclosure [3]. Increasing interventions to encourage culturally and developmentally appropriate parental disclosure have recently grown in resource-limited settings, including China [4]. However, there is still a theoretical gap in understanding the dynamics of the decision-making regarding parental HIV disclosure [3,5].

Existing theoretical models on HIV disclosure have posited that the decision-making of HIV disclosure is a process of assessing and calculating perceived benefits and risks related to the disclosure [6]. Parents intend to tell their HIV status to children when they feel the benefits of disclosure outweigh potential risks for their children, family, and/or themselves [5]. Perceived benefits include obtaining social support, emancipating stress caused by keeping secrets, and protecting children from HIV infection by teaching them HIV knowledge [2]. Common risks parents worry about are related to stigma and discrimination, secondary disclosure (children tell parental HIV status to others), and negative psychosocial impacts on children [3]. In addition to the rational calculation, some other individual characteristics such as knowledge of HIV, emotions, communication skills, and self-efficacy of performing a disclosure may also influence the decision-making of parental HIV disclosure [3].

In addition to demonstrating the importance of perceived consequences of disclosure (individual-level factors), recent studies have called for a multidimensional perspective to explore HIV disclosure [1]. The practice of disclosure is not just a single individual event [7], but is embedded in certain social relationships and a specific sociocultural context [8]. Hardon *et al.* [8] have argued that HIV disclosure occurred at the intersection of five social spaces: international norms, national legislation, and public health recommendations; household and family settings; couples' relationships; parental relationship; and relationship between health workers and PLHIV. Moses and Tomlinson [7] have pointed out that the meanings and behaviors related to disclosure are changeable along with the changes in the internal and interpersonal worlds of PLHIV over time. Existing studies on disclosure of sexually transmitted diseases (STDs) have shown that perceived risks regarding disclosure vary by cultural and social context [9].

All these arguments suggest the application of a socioecological approach to incorporate broader social factors into the model of decision-making of parental HIV disclosure. Socioecological models recognize individuals in larger social systems and emphasize interactions between individuals and environment that underlie behaviors and health outcomes [10]. The socioecological approach for health promotion identifies factors at various key levels that interventions can target: intra-personal, interpersonal, organizational, community, and public policy [11]. This approach also highlights that the factors at multiple levels are interactive

and reinforcing [12]. The socio-ecological approach has been widely used in public health, especially in health-promotion fields such as smoking [13], physical activity and nutrition [14], and sexual activity [15].

In the present study, we adapted an ecological model of sexual health disclosure [9] to conceptualize the parental HIV disclosure. As depicted in Fig. 1, the decision-making of parental HIV disclosure is nested within multiple levels of influences (intrapersonal, interpersonal, and sociocultural levels). At intrapersonal level, background characteristics (demographic and HIV-related characteristics) and other individual factors (emotions and psychosocial characteristics) affect disclosure decision. The intrapersonal factors are situated within a relationship context (family relationship and parent–child relationship), and the relationship is, in turn, shaped by sociocultural environment (e.g. HIV-related stigma). Thus, factors at interpersonal and sociocultural levels also influence the dynamics of disclosure decision-making.

Utilizing data from China, the current study aims to provide support for this ecological model of parental HIV disclosure through identifying facilitators and barriers to decision-making regarding parental HIV disclosure or nondisclosure at intrapersonal, interpersonal, and sociocultural levels; and examining the unique contribution of factors at different level of influences to the decision of disclosure or nondisclosure.

## Methods

### Study site and participants

Data used in the current study were derived from a cross-sectional survey, which was conducted from October 2012 to August 2013, in the Guangxi Autonomous Region (Guangxi) of China. Guangxi has been experiencing the fastest growth of the HIV epidemic and is ranked second among Chinese provinces in terms of HIV-seropositive cases [16]. Heterosexual transmission has become the dominate transmission route in Guangxi [16]. With the assistance and collaboration of the Guangxi Center for Disease Prevention and Control (CDC), we ranked all 17 cities and 75 rural counties in Guangxi in terms of cumulated number of reported HIV and AIDS cases, and selected the top 12 sites (2 cities and 10 counties) with the largest cumulated number. In all, 29 606 persons with HIV/AIDS (i.e. 43% of all the reported cases in Guangxi by 2011) were selected as the sampling frame. The project coordinator at each site was instructed to randomly recruit 10% of the total number of infected persons to participate in the survey.

People selected in the sampling frame were invited to participate in the study by the staff from the local CDC along with the healthcare workers from health centers in town (in certain counties) or community health service centers (in cities). Outreach workers made at least three attempts (including telephone contact and/or house visitation) within 2 months to contact a potential participant. About 90% of those contacted agreed to participate in the survey. The main reasons for refusing participation included migration outside of the province and transportation problems. We finally recruited 3002 HIV patients to participate in the survey and 2987 of them completed the survey. As the main focus of the current study

was on parental HIV disclosure, a sample of 1254 participants who had children aged 5–16 years was included in the data analysis.

### Survey procedure

Participants completed an assessment inventory including demographic characteristics and HIV-related measures, HIV disclosure, mental health, and interpersonal relationship. The survey was conducted in offices of local CDC or HIV clinics where the participants received their medical care. About 20% of the participants completed the questionnaire on their own. For the rest of the sample, the interviewers read the items to the participants and recorded the response on the questionnaire. The interviewers were local CDC staff or healthcare workers in the HIV clinics who had received intensive training on research ethics and interview skills with PLHIV prior to the field data collection. The most recent CD4<sup>+</sup> cell counts, if available, were taken from participants' medical records with appropriate consent. The survey protocol including consenting process was approved by the Institutional Review Boards at the Wayne State University in the United States and Guangxi CDC in China.

### Measures

**Background characteristics**—Participants were asked about individual and family characteristics including gender, age, ethnicity, religion, marital status, place of original residence, education attainment, work status, number of people in the family, number of children, and monthly household income. Participants were also asked to provide HIV-related information, including duration since their HIV diagnosis, whether or not they received antiretroviral therapy (ART), and HIV infections among other family members and current sexual partners. For data analysis in the current study, we dichotomized ethnicity into Han and non-Han, work status into work (full time or part-time) and not work.

**Parental HIV disclosure decision**—Two variables (decision to disclose HIV status to children and decision to conceal it from children) were employed to assess the participants' plans or intention to disclose or not to disclose their HIV infections to their children. For the decision to disclose, the participants were asked to check all individuals 'To whom have you planned to tell about your HIV status?' A positive response to 'children under the age of 18' was viewed as making a decision to disclose to children. In a similar way, the participants were also asked to check all individuals 'To whom will you never tell about your HIV status?' Selecting the response 'children under the age of 18' was viewed as making a decision not to disclose to children.

**Other measures**—In the survey, we also asked the participants to report their emotions (fears) related to general HIV disclosure (to disclose HIV-positive status to others including partners, family, friends, community members, and children) and parental HIV disclosure (to disclose HIV-positive status to children). To assess the fears associated with the general HIV disclosure, the participants were asked how much they agreed with the descriptions of a number of possible feelings in relation to HIV disclosure. These feelings include 'fear of being stigmatized', 'fear of being rejected', 'fear of violence harms', 'fear of blame', and 'fear of gossips'. Potential answers to these questions were 4-point responses ('don't agree at all' = 0, 'don't agree' = 1, 'agree' = 2, and 'agree a lot' = 3). Similarly, the fears related to

parental HIV disclosure were measured by four items with the same 4-point responses. These feelings associated with parental HIV disclosure include ‘fear of facing my children’s reactions to parental disclosure’, ‘fear of children’s rejection after knowing my HIV status’, ‘fear of losing children’s respect’, and ‘fear of children’s telling my HIV status to others’. The responses to items related to each type of disclosure were summed to create a composite score, with a higher score indicating a higher level of psychological fears associated with each type of disclosure. The Cronback’s  $\alpha$  was 0.83 for the fear of general HIV disclosure and 0.89 for the fear of parental HIV disclosure among the sample. Several other psychosocial scales were modified and utilized in the survey, including stress, depression, positive coping to HIV infection, resilience, family relationship, parent–child relationship, social support, and stigma. A brief description of measures for these scales is presented by Table 1.

## Data analysis

First, for each disclosure decision variable (disclose or conceal), we examined the relationships between factor variables (background characteristics, factors at intrapersonal, interpersonal, and sociocultural levels) and disclosure decision. We employed one-way analysis of variance (ANOVA) (for continuous measures) and chi-square test (for categorical measures) to compare the differences between relevant decision-related groups in terms of factor variables.

Second, for each disclosure decision variable (dependent variable), we constructed four logistic regression models by hierarchically entering background-characteristic variables (model 1), intrapersonal-level variables (model 2), interpersonal-level variables (model 3), and sociocultural-level variables (model 4). Model 1 contained a block of background-characteristic variables including gender, age, marital status, education attainment, and duration since HIV diagnosis. All the independent variables selected into the rest blocks were associated with the dependent variable (disclosure decision variable) at *P* value less than 0.2 in bivariate analysis. Once the independent variables were entered into a model, they were retained in the above models, even though they might no longer be significantly associated with the dependent variable as new models were developed. All statistical analyses were performed using SPSS 16.0 (SPSS Inc, Chicago, Illinois, USA).

## Results

### Background characteristics

The background characteristics for the whole sample and by different decision-related groups are presented in Table 2. About 59% of the parents were men. The average age of the parents was 38.90 years (*SD* = 8.33). Nearly 72% of the participants were of Han ethnicity, less than 7% reported any religion affiliation, and 78% were currently married. The mean education attainment was 7 years (*SD* = 2.70). The majority (87%) of the parents lived in the rural areas, and 22% reported that they did not work. There were on average 4.15 members in each family (*SD* = 2.08) including 1.92 children (*SD* = 0.99). Almost 56% of the parents reported that their monthly household income was less than 1000 yuan (approximately 160 US dollars in 2012). Over 76% of the participants had received ART. The average duration

since their HIV diagnosis was 44 months ( $SD = 29.90$ ). According to the available medical records, 34% of the parents' most recent  $CD4^+$  cell counts were lower than 250. In addition, 48% of the parents reported that at least one of their family members was also infected by HIV, and 58% reported that their current sexual partners were infected by HIV.

Generally, most of background characteristics were similar between the decision-related groups with only a few exceptions. Compared to the parents who had not planned to disclose HIV status to children, a higher proportion of the parents who had decided to do so were of non-Han ethnicity (42 vs. 27%) and were currently unmarried (41 vs. 20%). Compared to the parents who had not planned to conceal HIV status from children, a higher proportion of the parents who had decided to do so were men (62 vs. 54%), had no religion (6 vs. 10%), were currently married (82 vs. 76%), and reported not working (21 vs. 17%). In addition, the parents who decided to conceal had a shorter duration since HIV diagnosis (43.68 vs. 49.40).

### **Intrapersonal, interpersonal, and sociocultural difference across decision-related groups**

As shown in Table 3, participants differed on a number of factors at intrapersonal, interpersonal, and sociocultural levels by relevant decisions. Specifically, parents who decided to disclose their HIV status to children reported a higher level of positive coping, and a lower level of fears of parental HIV disclosure than those deciding not to do so. At interpersonal level, they also reported stronger parent–child relationship. Stigma was negatively related to the decision of disclosing HIV status to children, but the association did not reach the statistical significance ( $P = 0.05$ ).

Parents who decided to conceal the HIV status from their children showed a lower level of stress and depression, more fears of disclosure (both general and parental disclosure), as well as higher level of resilience, compared to those decided not to do so. Decision to conceal HIV infection from children was associated with weaker parent–child relationship, and higher level of stigma.

### **Multivariate analysis**

Results for hierarchical regression analyses of decision to disclose HIV status to children and decision to conceal HIV status from children were summarized in Tables 4 and 5, respectively. For each model, we presented adjusted odds ratio (OR) and 95% confidence intervals (CIs) of each single independent variable. In addition, we presented the  $R^2$  of each model, as well as  $R^2$ -change ( $R^2$ ) for the inclusion of each block of variables to assess the level-specific influence on relevant disclosure decisions.

**Factors associated with decision to disclose**—As shown in Table 4, background characteristics explained 5% of the variance in the decision to disclose HIV status to children (model 1a). Only marital status was significantly associated with decision to perform parental HIV disclosure [adjusted OR (aOR) 0.31, 95% CI 0.17, 0.56], with currently married parents being less likely to decide to tell their HIV infection to their children. Intrapersonal-level factors accounted for about additional 9% of the variance in the dependent variable (model 2a). Specifically, the higher the score of positive coping with



HIV infection the parents reported, the more likely they decided to tell their HIV status to children (aOR 2.32, 95% CI 1.34, 4.00). In addition, fear of parental HIV disclosure was negatively associated with decision to disclose to children (aOR 0.33, 95% CI 0.18, 0.58). About 5% of variance in the dependent variable could be explained by the factors at interpersonal level (model 3a). A better parent–child relationship was proved as a facilitator to HIV parental disclosure (aOR 5.66, 95% CI 2.45, 13.04). Stigma, as a sociocultural factor, contributed to explaining about 1% of the variance (model 4a), although its negative association with decision to disclose to children did not reach statistical significance.

**Factors associated with decision to conceal**—As shown in Table 5, background characteristics explained 5% of the variance in the dependent variable (model 1b). Currently married parents were more likely to decide to conceal their HIV infection from children (aOR 1.45, 95% CI 1.04, 2.02). In addition, parents who reported believing in a religion (aOR 0.57, 95% CI 0.34, 0.95) or for a longer duration since HIV diagnosis (aOR 0.99, 95% CI 0.99, 1.00) were less likely to intend to conceal their HIV status from children. There was about 5% of variance in the dependent variable that attributed to intrapersonal-level factors (model 2b). Parents' higher level in resilience (aOR 1.79, 95% CI 1.01, 3.20) and fears of parental HIV disclosure (aOR 1.72, 95% CI 1.28, 2.31) were positively associated with their decision of concealing the HIV status. Interpersonal-level factors accounted for nearly 5% of the variance in the dependent variable (model 3b). Parents reporting a better parent–child relationship were less likely to conceal their HIV status from their children (aOR 0.30, 95% CI 0.20, 0.45). The sociocultural-level factor, stigma, was positively associated with parental decision to conceal HIV status from children (aOR 1.40, 95% CI 1.04, 1.88). Stigma further explained nearly 1% of the variance in the dependent variable (model 4b).

## Discussion

The current study identified different factors influencing the two decision variables (disclose and conceal). Parents' marital status, positive coping with HIV infection, and fear of parental HIV disclosure were associated with their decision of disclosing HIV status to children, whereas parents' religion, marital status, duration of HIV infection, resilience, and fear of parental HIV disclosure were related with their decision of concealing their HIV infection from children. In addition, the current study recognized specific contribution of multiple ecological levels to parental decisions regarding disclosure to children controlling basic background characteristics. In summary, positive coping with HIV infection and a good parent–child relationship facilitated parental HIV disclosure; whereas high level of resilience and fears of parental HIV disclosure impeded their decisions to talk about HIV status to their children. The findings demonstrated the complexity of the decision-making process of parental HIV disclosure, as well as supported the ecological approach with an emphasis on interpersonal-level and sociocultural-level factors.

Generally speaking, the effects of intrapersonal-level factors on parental decision regarding HIV disclosure were consistent with the existing literature. However, stress and depression were not found to be significantly related to decision of disclosing to children. One possible interpretation is the complicated role of stress and depression. On one hand, stress and depression caused by concealing secrets in front of children may facilitate decision to

disclose HIV status to children to get some relief [27]; on the other hand, the stress and depression may reduce their self-efficacy of planning and performing a disclosure [28], and thus these psychological situations may become barriers to disclose intention. These two directions opposed to each other, resulting in no significant association of disclosure decision with stress and depression.

It is notable that high level of resilience was significantly associated with decision to conceal HIV infection from children. Resilience in dealing with HIV infection itself may not directly improve the motivation to tell HIV status to children. However, parents with high level of resilience may not have urgent demand of social support from their children and they may develop confidence of dealing with disease by their own or keeping HIV status as a secret in front of their children. The relationships between resilience, motivation to disclose, and decision-making need to be further explored.

Fears of parental HIV disclosure played a prominent role in the decision-making process. This finding indicated that emotions and feelings, as irrational factors, may also influence the decision-making process (which is always viewed as reasoned behavior). We need to pay attention to parents' feelings during their decision-making, respect their fears, and provide necessary assistance to help them overcome their fears. Emotions may also influence the disclosure practice. A high proportion of unplanned disclosures occur under the circumstances when parents were not able to control their emotions [3]. Emotion control and management may be a helpful component in parental HIV disclosure intervention.

The multivariate analysis results suggested that the interpersonal-level factors influenced the parental decision regarding HIV disclosure, almost in the same magnitude as the intrapersonal-level factors did. Particularly, the findings indicated that parent–child relationship is a key interpersonal factor. There could be many domains of parent–child relationship, and the current study focused on parent–child communication style. Parents who were able to openly communicate with children about important issues and parents' feelings were more likely to decide to disclose their HIV status to children. This finding could have important implications in disclosure interventions in rural China where parents may not develop an open communication style with their children, even though they may perceive a good quality of relation with their children [29]. Disclosure is also a type of communication [30]. A positive and open communication style between parents and children will facilitate not only a decision to tell children the parental HIV status but also an appropriate disclosure practice [31–35].

Sociocultural-level factors may vary with specific social contexts. However, stigma related to HIV is a prominent and persistent cross-culturally relevant barrier to HIV disclosure [3]. Stigma renders communication regarding HIV potentially embarrassing and negative [36]. In addition, the negative consequences of disclosure due to stigma increase the uncertainty and vulnerability of the communication [9]. Consistent with the existing literature, stigma was confirmed to be a big barrier to parental HIV disclosure among our sample. Further studies need to explore the interactions between stigma and factors at other levels.



The current study was subject to several limitations: First, due to the scope of the study design, we did not include several important factors in our conceptual model, for example, the relationship between parents and healthcare workers (interpersonal level), social norms about parental HIV disclosure, and policy and regulations regarding HIV disclosure (sociocultural level). Second, there was only a single factor variable (stigma) at the sociocultural level in the data analysis, which might result in a small contribution of sociocultural-level factors to the disclosure decision. Third, on the basis of the cross-sectional data, we were not able to examine the causal relationship between the factor variables and the parental decisions regarding HIV disclosure. Fourth, the majority of sample was recruited from the rural areas in China. The findings therefore need to be validated among parents living with HIV in other regions or countries.

Despite these limitations, this study provided empirical evidence to support socio-ecological model as a promising theoretical framework to guide further studies and interventions related to parental HIV disclosure. Guided by the socio-ecological model, advanced analytic approaches (e.g. mediation analysis) can be used to investigate mechanism through which factors at different levels influence the parental decisions on disclosure. We also need to collect longitudinal data to perform causal analysis, thus exploring the complexity and fluidity of parental HIV disclosure. Parental HIV disclosure may be affected by background characteristics, as well as physical and psychosocial well beings of their children. Studies based on parent–child dyads will be important to elaborate how variables related to children interplay with decision and practice of parental HIV disclosure. In addition, the research and practice on parental HIV disclosure could be informed by other relevant theories from the fields of communication, resilience, and child development.

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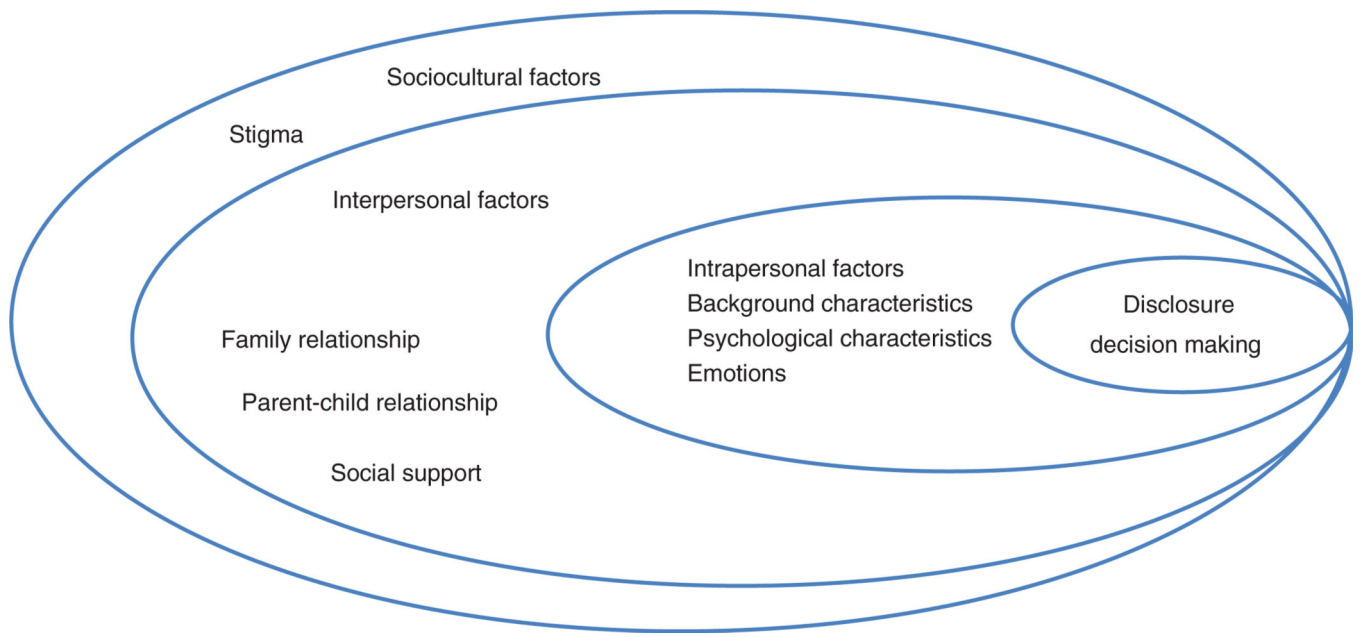
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## References

1. Dima AL, Stutterheim SE, Lyimo R, de Bruin M. Advancing methodology in the study of HIV status disclosure: the importance of considering disclosure target and intent. *Soc Sci Med.* 2014; 108:166–174. [PubMed: 24641881]
2. Clifford G, Craig GM, McCourt C, Barrow G. What are the benefits and barriers of communicating parental HIV status to seronegative children and the implications for Jamaica? A narrative review of the literature in low/middle income countries. *West Indian Med J.* 2013; 62:357–363. [PubMed: 24756599]
3. Qiao S, Li X, Stanton B. Disclosure of parental HIV infection to children: a systematic review of global literature. *AIDS Behav.* 2013; 17:369–389. [PubMed: 22016331]
4. Rochat TJ, Arteche AX, Stein A, Mkwanazi N, Bland RM. Maternal HIV disclosure to young HIV-uninfected children: an evaluation of a family-centred intervention in South Africa. *AIDS.* 2014; 28(Suppl 3):S331–S341. [PubMed: 24991906]
5. Qiao S, Li X, Stanton B. Theoretical models of parental HIV disclosure: a critical review. *AIDS Care.* 2013; 25:326–336. [PubMed: 22866903]
6. Chaudoir SR, Fisher JD, Simoni JM. Understanding HIV disclosure: a review and application of the Disclosure Processes Model. *Soc Sci Med.* 2011; 72:1618–1629. [PubMed: 21514708]

7. Moses S, Tomlinson M. The fluidity of disclosure: a longitudinal exploration of women's experience and understanding of HIV disclosure in the context of pregnancy and early motherhood. *AIDS Care*. 2013; 25:667–675. [PubMed: 23110311]
8. Hardon A, Desclaux A, Lugalla J. Disclosure in times of ART: a relational analysis of social practices. *SAHARA J*. 2013; 10(Suppl 1):S1–S4. [PubMed: 23844798]
9. Lo, SC.; Zea, MC.; Poppen, PJ. Information, uncertainty, and sexual disclosures in the era of HIV/AIDS. In: Afifi, TD.; Afifi, WA., editors. *Uncertainty, information management, and disclosure decisions: theories and applications*. New York and London: Taylor & Francis Group; 2009. p. 254–276.
10. Golden SD, Earp JA. Social ecological approaches to individuals and their contexts: twenty years of health education and behavior health promotion interventions. *Health Educ Behav*. 2012; 39:364–372. [PubMed: 22267868]
11. McLeroy KR, Bibeau D, Steckler A, Glanz K. An ecological perspective on health promotion programs. *Health Educ Q*. 1988; 15:351–377. [PubMed: 3068205]
12. Stokols D. Translating social ecological theory into guidelines for community health promotion. *Am J Health Promot*. 1996; 10:282–298. [PubMed: 10159709]
13. de Vries H, Mudde A, Leijts I, Charlton A, Vartiainen E, Buijs G, et al. The European Smoking Prevention Framework Approach (EFSA): an example of integral prevention. *Health Educ Res*. 2003; 18:611–626. [PubMed: 14572020]
14. Elder JP, Lytle L, Sallis JF, Young DR, Steckler A, Simons-Morton D, et al. A description of the social-ecological framework used in the trial of activity for adolescent girls (TAAG). *Health Educ Res*. 2007; 22:155–165. [PubMed: 16855014]
15. Salazar LF, Bradley EL, Younge SN, Daluga NA, Crosby RA, Lang DL, et al. Applying ecological perspectives to adolescent sexual health in the United States: rhetoric or reality? *Health Educ Res*. 2010; 25:552–562. [PubMed: 20007196]
16. Guangxi Center for Disease Control and Prevention (Guangxi CDC). Update on HIV/AIDS epidemic in Guangxi. In NIAAA venue-based HIV and alcohol risk reduction among female sex workers in China. Guilin, Guangxi, China. 2009
17. Sun W, Wu M, Qu P, Lu C, Wang L. Psychological well being of people living with HIV/AIDS under the new epidemic characteristics in China and the risk factors: a population-based study. *Int J Infect Dis*. 2014; 28:147–152. [PubMed: 25281441]
18. Zung WW. A rating instrument for anxiety disorders. *Psychosomatics*. 1971; 12:371–379. [PubMed: 5172928]
19. Radloff LS. The CES-D scale: a self-report depression scale for research in the general population. *Appl Psychol Measurement*. 1977; 1:385–401.
20. Vyavaharkar M, Moneyham L, Tavakoli A, Phillips KD, Murdaugh C, Jackson K, et al. Social support, coping, and medication adherence among HIV-positive women with depression living in rural areas of the southeastern United States. *AIDS Patient Care STDS*. 2007; 21:667–680. [PubMed: 17919094]
21. Campbell-Sills L, Stein MB. Psychometric analysis and refinement of the Connor-davidson Resilience Scale (CD-RISC): validation of a 10-item measure of resilience. *J Trauma Stress*. 2007; 20:1019–1028. [PubMed: 18157881]
22. Olson DH, Gorall DM, Tiesel JW. *Faces IV package*. Minneapolis, MN: Life Innovations. 2004
23. Kerr M, Stattin H, Trost K. To know you is to trust you: parents' trust is rooted in child disclosure of information. *J Adolesc*. 1999; 22:737–752. [PubMed: 10579887]
24. Zimet GD, Dahlem NW, Zimet SG, Farley GK. The multidimensional scale of perceived social support. *J Person Assess*. 1988; 52:30–41.
25. Yu DS, Lee DT, Woo J. Psychometric testing of the Chinese version of the medical outcomes study social support survey (MOS-SSS-C). *Res Nurs Health*. 2004; 27:135–143. [PubMed: 15042639]
26. Berger BE, Ferrans CE, Lashley FR. Measuring stigma in people with HIV: psychometric assessment of the HIV stigma scale. *Res Nurs Health*. 2001; 24:518–529. [PubMed: 11746080]
27. Pilowsky DJ, Sohler N, Susser E. Reasons given for disclosure of maternal HIV status to children. *J Urban Health*. 2000; 77:723–734. [PubMed: 11194312]

28. Qiao S, Li X, Stanton B. Practice and perception of parental HIV disclosure to children in Beijing. *China Qual Health Res.* 2014; 24:1276–1286. [PubMed: 25079498]
29. Xia YR, Xie X, Zhou Z, Defrain J, Combs R. Chinese adolescents' decision-making, parent-adolescent communication and relationships. *Marriage Fam Rev.* 2008; 36:119–145.
30. Eustace RW, Ilagan PR. HIV disclosure among HIV positive individuals: a concept analysis. *J Adv Nurs.* 2010; 66:2094–2103. [PubMed: 20626492]
31. Woodring LA, Cancelli AA, Ponterotto JG, Keitel MA. A qualitative investigation of adolescents' experiences with parental HIV/AIDS. *Am J Orthopsychiatry.* 2005; 75:658–675. [PubMed: 16262522]
32. Vallerand AH, Hough E, Pittiglio L, Marvicsin D. The process of disclosing HIV serostatus between HIV-positive mothers and their HIV-negative children. *AIDS Patient Care STDS.* 2005; 19:100–109. [PubMed: 15716641]
33. Murphy DA, Armistead L, Marelich WD, Payne DL, Herbeck DM. Pilot trial of a disclosure intervention for HIVR mothers: the TRACK program. *J Consult Clin Psychol.* 2011; 79:203–214. [PubMed: 21355637]
34. Dematteo D, Harrison C, Arneson C, Goldie RS, Lefebvre A, Read SE, et al. Disclosing HIV/AIDS to children: the paths families take to truth-telling. *Psychol Health Med.* 2002; 7:339–356.
35. Delaney RO, Serovich JM, Lim JY. Reasons for and against maternal HIV disclosure to children and perceived child reaction. *AIDS Care.* 2008; 20:876–880. [PubMed: 18608085]
36. Herek GM, Capitanio JP, Widaman KF. HIV-related stigma and knowledge in the United States: prevalence and trends, 1991–1999. *Am J Public Health.* 2002; 92:371–377. [PubMed: 11867313]



**Fig. 1. Socio-ecological model for decision-making of parental HIV disclosure**  
Adapted from the Conceptual Model of Sexual Health Disclosure [9].

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**Table 1**

Summary of psychological outcomes scales.

Psychological scales	#Items	$\alpha$	Sample item	Response options
Anxiety Zung Self-Rating Anxiety Scale (SAS) [17,18]	20	0.87	I feared of losing control.	4-point response option ('not at all' to 'a lot')
Depression Shorten version of Center for Epidemiological Studies Depression Scale for Children (CESD-10) [19]	10	0.88	I was bothered by things that usually don't bother me.	4-point response option ('not at all' to 'a lot')
Positive coping with HIV Family Coping Project Coping Scale (FCPCS) [20]	25	0.93	I accept AIDS symptoms (fever, body weakness).	5-point response option ('never' to 'always')
Resilience The 10-item Connor-Davidson Resilience Scale(10-item CD-RISC) [21]	10	0.96	I think of myself as a strong person.	5-point response option ('never' to 'always')
Family relationship Family Communication Scale (FCS) [22]	10	0.95	Family members express their true feelings to each other.	5-point response option ('totally disagree' to 'totally agree')
Parent-child relationship Parental lack of self-disclosure [23]	7	0.85	Do you often talk with your child about things that are personally important to you?	Yes/no
Social support The Multidimensional Scale of Perceived Social Support (MSPSS) [24] The Medical Outcomes Study Social Support Survey (MOS-SSS-C) [25]	28	0.98	Someone will provide me with the advice I need.	5-point response option ('never' to 'always')
Stigma The Berger HIV Stigma Scale [26]	14	0.94	I feel guilty because I have HIV.	4-point response option ('totally disagree' to 'totally agree')

Table 2

Demographic characteristics by disclosure-related groups.

	Whole sample (n = 1254)	Decision to disclose HIV status to children		Decision to conceal HIV status from children	
		Yes	No	Yes	No
Age in years (SD)	38.90 (8.33)	36.66 (4.73)	37.58 (5.92)	37.65 (5.74)	37.32 (6.08)
Gender (male)	742 (59.2%)	29 (49.2%)	618 (59.3%)	423 (61.7%)	223 (53.6%)**
Ethnicity					
Han	899 (71.7%)	34 (57.6%)	759 (72.8%)*	488 (71.2%)	304 (73.1%)
Zhuang	303 (24.2%)	22 (37.3%)	248 (23.8%)	172 (25.1%)	99 (23.8%)
Others	51 (4.1%)	3 (5.1%)	35 (3.4%)	25 (3.6%)	13 (3.1%)
Any religion	85 (6.8%)	3 (5.2%)	78 (7.5%)	39 (5.7%)	42 (10.2%)**
Marital status					
Currently married	950 (78.2%)	35 (59.4%)	819 (81.2%)	543 (82.1%)	310 (76.2%)
Currently unmarried	264 (21.8%)	24 (40.6%)	190 (18.8%)*	118 (17.9%)	97 (23.8%)*
Residence					
Rural residence (Hukou)	1090 (87%)	53 (89.8%)	913 (87.6%)	613 (89.5%)	353 (84.9%)*
Work status					
Full-time	544 (43.6%)	20 (34.5%)	472 (45.4%)	163 (39.5%)	330 (48.2%)
Part-time	429 (34.4%)	23 (39.7%)	380 (36.6%)	165 (40.0%)	237 (34.6%)
Do not work	275 (22.0%)	15 (25.9%)	187 (18.0%)	85 (20.6%)	117 (17.1%)*
Education in years (SD)	7.04 (2.70)	6.86 (2.52)	7.10 (2.63)	7.13 (2.75)	7.03 (2.42)
Household size					
No. of family members:(SD)	4.15 (2.08)	3.78 (1.87)	4.11 (2.12)	4.07 (2.16)	4.11 (2.02)
No. of children	1.92 (0.99)	1.73 (0.83)	1.91 (0.95)	1.94 (0.99)	1.83 (0.88)
Monthly household income					
<1000	694 (55.9%)	32 (54.2%)	582 (56.5%)	371 (54.6%)	242 (59.0%)
1000–1999	366 (29.5%)	20 (33.9%)	287 (27.8%)	199 (29.3%)	108 (26.3%)
2000–2999	119 (9.6%)	6 (10.2%)	106 (10.3%)	70 (10.3%)	43 (10.5%)
>3000	63 (5.1%)	1 (1.7%)	56 (5.4%)	40 (5.9%)	17 (4.1%)
HIV infection					



	Whole sample (n = 1254)	Decision to disclose HIV status to children		Decision to conceal HIV status from children	
		Yes	No	Yes	No
On ART	960 (76.7%)	48 (81.4%)	822 (79.0%)	532 (77.8%)	338 (81.3%)
Duration since HIV diagnosis (monthly)	44.39 (29.90)	47.82 (29.00)	45.75 (29.89)	43.68 (28.90)	49.40 (31.01)**
Infection in family (yes)	607 (48.4%)	28 (47.5%)	525 (50.3%)	336 (49%)	216 (51.9%)
Infected partner (yes)	672 (58.1%)	26 (50%)	562 (58.4%)	221 (57.3%)	367 (58.3%)
Most recent CD4 <sup>+</sup> cell counts					
250	408 (34.1%)	27 (46.6%)	336 (34.0%)	229 (35.2%)	133 (33.6%)
250–500	536 (44.8%)	25 (43.1%)	439 (44.4%)	285 (43.8%)	179 (45.2%)
>500	253 (21.1%)	6 (10.3%)	214 (21.6%)	137 (21.0%)	84 (21.2%)

ART, antiretroviral therapy.

\*  $P < 0.05$ .

\*\*  $P < 0.01$ .

\*\*\*  $P < 0.001$ .

**Table 3**

Comparison of intrapersonal, interpersonal, and sociocultural factors by HIV disclosure decisions.

	Whole sample	Decision to disclose HIV status to children			Decision to conceal HIV status to children			P value
		Yes	No	F	Yes	No	F	
<b>Intrapersonal factors</b>								
Stress	1.710 (0.502)	1.776 (0.622)	1.719 (0.499)	<i>F</i> (1 1098)=0.729	1.692 (0.498)	1.770 (0.517)	<i>F</i> (1 1098) = 6.1 67	0.013
Depression	1.922 (0.610)	2.034 (0.687)	1.923 (0.608)	<i>F</i> (1 1099) = 1.830	1.893 (0.610)	1.986 (0.609)	<i>F</i> (1 1099) = 6.057	0.014
Coping	2.552 (0.669)	2.835 (0.589)	2.569 (0.680)	<i>F</i> (1 1099) = 8.677	2.586 (0.698)	2.577 (0.641)	<i>F</i> (1 1099) = 0.042	0.837
Resilience	3.237 (0.850)	3.234 (0.872)	3.233 (0.858)	<i>F</i> (1 1099) < 0.001	3.295 (0.865)	3.134 (0.837)	<i>F</i> (1 1097) = 9.132	0.003
Fears of general HIV disclosure	2.889 (0.426)	2.790 (0.440)	2.895 (0.425)	<i>F</i> (1 1099) = 3.397	2.923 (0.398)	2.835 (0.462)	<i>F</i> (1 1099) = 11.164	0.001
Fear of parental HIV disclosure	2.804 (0.490)	2.537 (0.536)	2.819 (0.484)	<i>F</i> (1 1093) = 4.453	2.862 (0.452)	2.706 (0.531)	<i>F</i> (1 1093) = 26.582	<0.0001
<b>Interpersonal factors</b>								
Family relationship	3.534 (0.668)	3.477 (0.625)	3.538 (0.668)	<i>F</i> (1946) = 0.342	3.543 (0.673)	3.518 (0.658)	<i>F</i> (1946) = 0.301	0.583
Parent-child relationship	0.370 (0.342)	0.562 (0.325)	0.359 (0.340)	<i>F</i> (1 1098) = 20.074	0.315 (0.321)	0.460 (0.358)	<i>F</i> (1 1098) = 48.38	<0.0001
Social support	2.442 (0.877)	2.679 (0.784)	2.454 (0.894)	<i>F</i> (1 1099) = 3.591	2.458 (0.924)	2.477 (0.832)	<i>F</i> (1 1099) = 0.116	0.733
<b>Sociocultural factors</b>								
Stigma	2.459 (0.510)	2.337 (0.465)	2.469 (0.512)	<i>F</i> (1 1099) = 3.794	2.487	2.421 (0.515)	<i>F</i> (1 1099) = 4.325	0.038

**Table 4**

Multivariate logistic regression of factors (odds ratios and 95% confidence interval) on decision to disclose HIV status to children.

	Decision to disclose HIV status to children			
	Model 1a	Model 2a	Model 3a	Model 4a
Background characteristics				
Gender	1.275 (0.724, 2.246)	1.337 (0.741, 2.413)	1.239 (0.679, 2.260)	1.267 (0.691, 2.323)
Age	0.982 (0.934, 1.032)	0.972 (0.922, 1.024)	0.956 (0.904, 1.010)	0.957 (0.907, 1.011)
Ethnicity	1.530 (0.975, 2.401)	1.477 (0.921, 2.367)	1.342 (0.829, 2.171)	1.321 (0.813, 2.147)
Marital status	0.346 (0.198, 0.606)***	0.330 (0.185, 0.588)***	0.310 (0.171, 0.564)***	0.306 (0.168, 0.557)***
Education	0.949 (0.855, 1.054)	0.936 (0.839, 1.044)	0.941 (0.844, 1.049)	0.933 (0.836, 1.041)
Duration of HIV infection	1.001 (0.992, 1.010)	1.000 (0.991, 1.010)	0.999 (0.990, 1.009)	0.999 (0.990, 1.009)
Intrapersonal factors				
Depression		1.354 (0.888, 2.064)	1.393 (0.894, 2.171)	1.577 (0.991, 2.511)
Coping		2.253 (1.475, 3.442)***	2.159 (1.256, 3.712)***	2.316 (1.342, 3.998)***
Fears of general HIV disclosure		0.884 (0.476, 1.643)	0.957 (0.512, 1.789)	1.075 (0.566, 2.042)
Fears of parental HIV disclosure		0.293 (0.167, 0.512)***	0.303 (0.170, 0.539)***	0.325 (0.181, 0.583)***
Interpersonal factors				
Parent–child relationship			5.641 (2.463, 12.919)***	5.655 (2.452, 13.044)***
Social support			1.087 (0.748, 1.580)	1.046 (0.719, 1.521)
Sociocultural factors				
Stigma				0.581 (0.332, 1.016)
$R^2$	5.4% **	14% ***	18.7% ***	19.6% ***
$R^2$	NA	8.6%	4.7%	0.9%

\*\*  $P < 0.01$ .

\*\*\*  $P < 0.001$ .

**Table 5**

Multivariate logistic regression of factors (odds ratios and 95% confidence interval) on decision to conceal HIV status from children.

	Decision to conceal HIV status from children			
	Model 1b	Model 2b	Model 3b	Model 4b
Background characteristics				
Gender	0.789 (0.600, 1.039)	0.774 (0.583, 1.029)	0.804 (0.602, 1.076)	0.805 (0.601, 1.077)
Age	1.008 (0.985, 1.032)	1.007 (0.983, 1.031)	1.014 (0.990, 1.040)	1.014 (0.989, 1.039)
Ethnicity	1.161 (0.905, 1.489)	1.188 (0.917, 1.539)	1.258 (0.965, 1.639)	1.260 (0.965, 1.644)
Marital status	1.422 (1.036, 1.953)*	1.424 (1.027, 1.972)*	1.432 (1.027, 1.996)*	1.445 (1.035, 2.017)*
Education	1.021 (0.972, 1.074)	1.012 (0.961, 1.066)	1.019 (0.967, 1.075)	1.025 (0.972, 1.080)
Religion	0.466 (0.285, 0.761)**	0.492 (0.297, 0.815)**	0.520 (0.311, 0.871)*	0.565 (0.335, 0.952)*
Work status	0.730 (0.561, 0.951)*	0.798 (0.604, 1.053)	0.850 (0.640, 1.131)	0.848 (0.637, 1.129)
Duration of HIV infection	0.993 (0.989, 0.998)	0.993 (0.989, 0.997)*	0.994 (0.989, 0.998)**	0.993 (0.989, 0.998)**
Intrapersonal factors				
Stress		0.550 (0.124, 2.439)	0.513 (0.113, 2.330)	0.484 (0.106, 2.211)
Depression		2.975 (0.811, 10.921)	2.832 (0.757, 10.587)	2.766 (0.735, 10.403)
Resilience		1.842 (1.043, 3.255)*	1.749 (0.982, 3.115)	1.794 (1.006, 3.198)*
Fear of general HIV disclosure		1.215 (0.874, 1.691)	1.186 (0.847, 1.661)	1.102 (0.783, 1.551)
Fear of parental HIV disclosure		1.782 (1.336, 2.377)***	1.781 (1.329, 2.385)***	1.722 (1.283, 2.310)***
Interpersonal factors				
Parent-child relationship			0.295 (0.197, 0.441)***	0.297 (0.198, 0.445)***
Sociocultural factors				
Stigma				1.400 (1.041, 1.882)*
$R^2$	4.6%***	9.3%***	14.0%***	14.6%***
$R^2$	NA	4.7%	4.7%	0.6%

\*  $P < 0.05$ .

\*\*  $P < 0.01$ .

\*\*\*  $P < 0.001$ .