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HIV-negative children's experiences and opinions towards parental HIV disclosure: a qualitative study in China

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Abstract

In HIV/AIDS research, few studies to date have evaluated ways to improve parental HIV disclosure practices using feedback from HIV negative children who have recently experienced this event. We conducted semi-structured in-depth interviews with 20 children (aged 6–15) who were partially to fully aware of their parents' HIV status in rural Guangxi, China. Of the 20 children, eight children who were of older age (11.38 years in average) endorsed parental HIV disclosure, five discouraged it, and seven expressed uncertainty. Children's different experiences and attitudes towards disclosure were seen to be associated with their family dynamics (especially the parent-child relationship), social support and care, experiences of stigma and discrimination, psychosocial suffering, comprehension of the disease, and the children's age. Our study contributes to building a child centered comprehensive understanding for Chinese parental HIV disclosure. It is imperative that counsellors and community advocates assess and help parents achieve optimal readiness preceding disclosure of their illness to their HIV negative children.

Keywords

HIV disclosure; experience; parents; children; rural China

Introduction

A recent systematic review reported that problem behaviors and negative family life events decreased over time among adolescents who had experienced parental HIV disclosure and increased among adolescents who had not experienced disclosure (Qiao, Li, & Stanton, 2013). The nature and condition for parental HIV disclosure are different globally (Kennedy et al., 2010; Tiendrebeogo et al., 2013). Commonly parental disclosure is unplanned

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(Kennedy et al., 2010; Nostlinger, Bartoli, Gordillo, Roberfroid, & Colebunders, 2006). Even though a pilot study in rural South Africa supported intervention of maternal HIV disclosure to HIV-uninfected children, very few studies, however, have evaluated how HIV negative children process and adjust to parental HIV disclosure (Rochat, Mkwanazi, & Bland, 2013).

In China, parental HIV disclosure rates have varied from 18.8 to 46 percent (Xu et al., 2007; Ding, Li, & Ji, 2011). Most children have not been explicitly informed of their parents' serostatus, rather discovering parental illness through observation, or from sources outside the family (Xu et al., 2007; Zhang et al., 2013). These children have been found to experience detrimental effects such as fear, anxiety, and rejection from peers (Xu et al., 2009). Furthermore, parental non-disclosure has been associated with a lower quality of emotional and social functioning in children (Xu, Wu, Rou, Duan, & Wang, 2010). Drawing on social influence theory (Stenger, 1996; Zea, Reisen, Poppen, Bianchi & Echeverry, 2007), our qualitative study aimed to explore the individual and contextual factors that may influence childhood adjustment to parental HIV disclosure.

Methods

We received IRB ethics approval from Wayne State University in the United States and Guangxi Center for Disease Control and Prevention (CDC) in China. We employed purposive sampling to conduct semi-structured in-depth interviews with 20 previously tested HIV-negative children who were referred by the local CDC. The inclusion criteria included having at least one HIV-positive parent, being identified by parents as having received partial or full disclosure, being between 6 to 17 years old, and living in rural Guangxi. We obtained written informed consent from parents and oral assent from children. Social influence theory was used as a guidance to evaluate data saturation.

We conducted thematic content analysis (Green & Thorogood, 2009). Using a coding directory, each transcript was first coded independently by two researchers. Coding differences were then discussed and reconciled. We used Dedoose (Version 5.0.11) for coding. We identified three substantial themes in children's opinions. We then conducted cross-case analysis (Hult, Wrubel, Branstrom, Acree, Moskowitz, 2012). Relevant and illustrative quotes were grouped together and synthesized, allowing us to develop interpretive memos (Saldana, 2009).

Results

Of the 20 HIV negative children recruited, eight (aged 8–15 years, 11.38 years in average) endorsed parental HIV disclosure, five (aged 9–14 years, 11 years in average) discouraged disclosure, and seven (aged 6–14 years, 7.29 years in average) expressed uncertainty (see Table 1 for participant descriptions). Some children even provided their suggestions for improving parental HIV disclosure.

Endorsement of parental HIV disclosure

Children who endorsed parental HIV disclosure provided multiple reasons, such as allowing them to better care for their parents, enabling them to more directly communicate with their parents, and improving their knowledge of the illness (or the cause of death).

“Father is my father. I should know about this thing [HIV/AIDS]. . . .Because when parents get sick, I might also give them encouragement.” (Girl, aged 13)

These children also reported gaining more support from their families, peers and friends for their sadness, fear, and anxiety after parental HIV disclosure.

“Grandma explained to me that my father always hung out with some bad guys who took drug when he was young; he then took drug as well. . . . After I grow up, I will not be a drug user.” (Girl, aged 11)

This girl further identified once she was aware of her father’s HIV status she found formal support through her school curriculum, which enabled her to positively face this issue:

“I told them that my father has AIDS. I told them not be afraid. They would not be infected. . . . Our textbooks talked about children who infected HIV fighting doggedly [This girl was encouraged by the stories of HIV-infected children], not being afraid of AIDS. I saw some counseling books talking about HIV infection, such as sexual transmission and needles sharing. . . . Hugging and shaking hands is not contagious.”

From the process of gaining more factual knowledge the same girl was then able to cope and engage in improved self-care and caretaking her father:

“Just think about the good things. . . . Since it [HIV/AIDS] is controllable, we should be happier, not too sad. . . . Dad, don’t be so sad. Let’s go walk the dog.”

Discouragement of parental HIV disclosure

Some children experienced inappropriate, unintended disclosure and reported not wanting to have known about their parents’ HIV status and tended to report fear, grief, and refusing to learn more about HIV/AIDS following disclosure.

“I feel it’s better for her [Grandma] not to tell me about AIDS. . . .Because after she told me, I felt scared and sad.” (Girl, aged 9)

These children commonly testified to having had poor relationships with their parents before disclosure. They reported feelings of isolation, stigma and discrimination, fewer instances of feeling cared for, combined with less access to social and psychological support than did the children who had endorsed disclosure. These children reported considerable sleeplessness and appetite loss, feelings of stress in their studies and daily life, and adopting avoidant coping strategies.

“She [mother] is very sad. . . . they quarreled. . . . I feel very sad. . . . People in the village all discriminate against him [father]. . . . My aunty told me not to use the same dishes or cookers that my father used, and not to touch his clothes. . . . The burden is too heavy.” (Boy, aged 14)

Uncertainty about parental HIV disclosure

The third group of children (mostly aged between 6–8 years) expressed uncertainty and ambivalence about their parental HIV disclosure. They generally knew that their parents were sick, but had few details about the disease, or had been told their parents suffered from cancer or influenza. They reported feeling unhappy, fearing death, experiencing parents' emotions, not talking about things, feeling uncertain, crying, and sleeplessness.

A six-year old boy expressed (as he drew pictures):

“Unhappy. Her father got sick and she worried, worried father would die. And father took medicine. . . . afraid of death. . . . All [families] die.”

Similarly, an eight-year old girl who never discussed the event with her mother tried to make sense of her observations:

“I was surprised. . . . my mother got sick. . . . My mum was surfing online, and I saw there was an AIDS [patient] on the website. . . . If they did not go to hospital [for treatment], it would result in death.”

Children's suggestions for improving parental HIV disclosure

Despite having divergent opinions about parental HIV disclosure, children had similar ideas about improving disclosure practices. Their suggestions included that the most appropriate age of children for disclosure was between 10 and 20 years, taking place in an appropriate place (e.g., private room), with clear communication facilitated by play.

“When they are older, it's okay to disclose. Like me, a middle school student. . . . Those parents should understand their children's mood.” (Boy, aged 12)

Discussion

Our study explored HIV negative children's reasons for supporting, discouraging, and feeling unsure about parental HIV disclosure in rural China. We found that the children who reported experiencing positive family functioning testified to fare better with parental HIV disclosure. However, children who felt they had not benefitted from parental HIV disclosure reported negative consequences (e.g., fear, sadness, resistance), which were not only related to inappropriate, unintended disclosure, but also related to the broader context of family dynamics before HIV disclosure. These family dynamics included poor relationships with their parents, feeling of burden, lack of parental care and support, and parental concealments. These problems prompted these children to adopt avoidant strategies, resulting in poor adjustment (e.g., negative emotional reactions or psychological suffering) as reported in the literature (Cluver & Gardner, 2006).

While many counselors encourage appropriate disclosure concordant with children's cognitive development (Lesch et al., 2007; WHO 2011), our Chinese participants suggested that parents should wait until children reach 10 years of age before attempting full disclosure. Appropriate and timely disclosure of parental HIV status has been shown to facilitate positive childhood coping (Chaudoin, Fisher, & Simoni, 2011; Simoni, Davis, Drossman, & Weinberg, 2000). These children also suggested the importance of

idiosyncratic coping mechanisms such as sharing responsibilities in the caretaking of their parents as supported by the international literature (Nam et al., 2009; Rwemisis, Wolff, Coutinho, Grosskurth, Whitworth, 2008).

Recommendations

It is recommended that family assessments and interventions focus on assessing family dynamics, the cognitive state of readiness of the child, the potential coping abilities of the child and the manner in which the information (HIV disclosure) is able to be delivered. We recommend that in rural China specially trained counselors evaluate the extent to which children already display avoidant coping activities and have the potential to suffer other negative consequences of parental disclosure or concealments. This should be done predisclosure. Some children have reported being disclosed inappropriately. Therefore, parents who are unable to communicate disclosure need direct support from health care providers.

The current study's limitations include firstly, that the themes emerging from data analysis after finishing interviews may not have achieved saturation due to an absence of repeated confirmatory interviews. Secondly, our sample size was small and limited to parental contacts of HIV negative children at local groups of people living with HIV. We would contend however that the study has identified in-depth contextual family factors that impacted Chinese children's opinions towards parental HIV disclosure. We advocate that health professionals assess family dynamics, children's cognitive development, and age related coping abilities to help support decision-making for parental HIV disclosure.

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Table 1

Description of Participants (N = 20)

	age	sex	Parent with HIV positive	Age at disclosure	Type of disclosure	Who disclosed
Group 1(endorse parental disclosure)						
A	13	male	Mother	10	Full, direct disclosure ¹	Mother
B	13	female	Mother	13	Using hint, indirect disclosure ²	Mother, and Self-observed
C	15	female	Both parents	14	Full ³ , direct disclosure	Mother
D	13	female	Father	9	Partial ⁴ , third party ⁵ , alternative disclosure ⁶ (lung cancer)	Grandmother, and self-hearing adults' communication
E	15	Male	Mother	13	Using hint, indirect disclosure	Mother, and Self-observed
F	15	Female	Both parents	15	Full, direct disclosure	Mother
G	9	Male	Mother	9	Using hint, partial, indirect disclosure	Mother, and self-observed
H	11	Female	Father	8	Full, third party disclosure	Grandmother
Group 2(discourage parental disclosure)						
I	13	Male	Mother	12	Full, third party disclosure	First, brother, and then mother
J	14	Male	Father	14	Full, third party disclosure	Aunt
K	11	Female	Father	9	Unintended ⁷ , third party disclosure	Policemen
L	9	Female	Mother	9	Full, third party disclosure	First, grandmother, and then mother
M	12	Male	Mother	11	Unintended, inaccurate ⁸ disclosure	Hearing parents quarreling about AIDS
Group 3(uncertain about parental disclosure)						
N	10	female	Mother	10	Indirect, alternative disclosure (brain tumor)	Mother
O	6	Male	Father	6	Indirect, alternative disclosure (influenza)	Mother
P	8	Female	Father	7	Indirect, alternative disclosure (cancer)	Self-observed, and then mother
Q	14	Female	Father	10	Unintended, third party disclosure (drug user and sick)	Classmate
R	8	Male	Both parents	7	Inaccurate disclosure (crying)	Mother
S	6	Male	Both parents	6	Alternative disclosure (get sick and take medicine)	Mother and father
T	6	Male	Father	5	Alternative disclosure (get sick and toothache)	Mother and father

¹ Direct disclosure means parents (mother, father, or both) disclosed their seropositivity to their children directly.

² Indirect disclosure means parents (mother, father, or both) disclosed their seropositivity to their children indirectly, such as using hint.

³ Full disclosure means children were informed fully of their parents' seropositivity.

⁴ Partial disclosure means children were not fully informed of their parents' seropositivity. For example, children were informed parents getting sick, but had no idea of HIV.

⁵ Third party disclosure means children were disclosed by a third person, other than their parents.

⁶ Alternative disclosure means children were informed parents getting illnesses or diseases (e.g., cancer, brain tumor, influenza), other than HIV.

⁷Unintended disclosure means the parental HIV disclosure to their children was not planned or well prepared, such as being heard or observed by children accidentally.

⁸Inaccurate disclosure means parents disclosed their seropositivity to their children in an inaccurate way, such as quarreling about AIDS or crying in from of their children.

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