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Practice and Perception of Parental HIV Disclosure to Children in Beijing, China

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Abstract

To explore parental disclosure practices and perceptions among HIV-positive parents in urban China, we conducted in-depth interviews with 29 HIV-positive parents in Beijing in 2011. The disclosure rate was low (17%), and unplanned disclosure was common. Most parents chose not to disclose because of concerns regarding their children's young age, concerns about potentially negative psychological impacts on the children, potential secondary disclosure by the children to others, and perceived stigma associated with HIV infection and the causes of such infection (e.g., homosexual behaviors). Parents considered that an appropriate disclosure should be well-planned, cautious, and a gradual process conducted in a comfortable and relaxed environment when both parents and children were calm. We concluded that it was important to (a) provide professional guidance and services about disclosure to children for HIV-positive parents in China, (b) reduce or eliminate HIV-related stigma, (c) set up support groups among HIV-positive parents, and (d) tailor disclosure strategies for different populations of various demographic and socioeconomic characteristics.

Keywords

caregivers / caregiving; children; China; Chinese culture; disclosure; HIV/AIDS

Increasing availability of antiretroviral therapy (ART) has improved the health and longevity of HIV-positive parents, which means that they are likely to raise their children for many years after the initial diagnosis (Enger et al., 1996). Disclosure of parental HIV infection to children has become an important issue related to physical and psychological health, along with medical adherence among HIV-positive parents and the psychological adjustment of their children (Dematteo et al., 2002; Qiao, Li, & Stanton, 2013;Thorne, Newell, & Peckham, 2000).

Some parents have revealed their HIV infection to their children to protect their children from also becoming infected, to prepare them for parental death (Hawk, 2007; Pilowsky, Sohler, & Susser, 2000), and/or to obtain support from them (Rwemisisi, Wolff, Coutinho,

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Grosskurth, & Whitworth, 2008; Thomas, Nyamathi, & Swaminathan, 2009). Some parents have decided to conceal their HIV infection from their children because of concerns regarding the children's immaturity, secondary disclosure (i.e., the children might inadvertently disclose their parents' HIV serostatus to others), and the potential psychological burden and stigma resulting from disclosure (Armistead, Klein, Forehand, & Wierson, 1997).

Findings regarding the impacts of parental disclosure are mixed, but generally, well-planned and developmentally appropriate parental disclosure appears to have a long-term positive impact on the well-being of children, parents, and the family (Qiao et al., 2013). Children might show strong emotional reactions to the disclosure (Kennedy et al., 2010; Vallerand, Hough, Pittiglio, & Marvicsin, 2005), and some experience impaired emotional and social functioning (Xu, Wu, Rou, Duan, & Wang, 2010), more externalizing symptoms (Palin et al., 2009), or a higher depression score (Murphy, Marelich, & Hoffman, 2002). However, most children, particularly younger children, can adjust to parental HIV disclosure over time, despite initial negative emotional reactions (Lee & Rotheram-Borus, 2002; Murphy et al., 2002; Nöstlinger, Bartoli, Gordillo, Roberfroid, & Colebunders, 2006).

Disclosing HIV status to children is a stressful and challenging task for most HIV-positive parents. Many such parents struggle with the decisions as to whether, when, and how to disclose HIV status to their children. The disclosure rates are low in both the United States and other countries (Corona et al., 2006; Delaney, Serovich, & Lim, 2008; Shaffer et al., 2001). Many children might learn of parental HIV infection accidentally (unintentional disclosure; Delaney et al.; Palin et al., 2009; Woodring, Cancelli, Ponterotto, & Keitel, 2005). These unintentional disclosures commonly result in negative reactions (Vallerand et al., 2005). The emerging issue regarding parental disclosure has transformed from whether to disclose to how to disclose (Wiener, Mellins, Marhefka, & Battles, 2007). Development of evidence-informed interventions to help HIV-positive parents conduct developmentally appropriate and well-planned disclosure will greatly benefit the well-being of parents, children, and families (Qiao et al., 2013).

To design and implement such an intervention, it is necessary to understand the specific needs of these parents by learning their reasons for disclosure and nondisclosure, their approach to acting on disclosure, and their perceptions and suggestions regarding parental disclosure. It is important to understand how practices and perceptions of parental HIV disclosure are shaped by parenting style, family relationship, and social norms rooted in certain cultural contexts.

Previous empirical studies on parental disclosure have been concentrated in Western countries. Limited data are available regarding the practices and perceptions of parental disclosure in low- and middle-income countries, including China, where the HIV epidemic has been steadily expanding. Although the overall prevalence for the general population was 0.058% in China by 2011, the prevalence has been rapidly increasing among some most-at-risk populations; for example, men who have sex with men (MSM). HIV prevalence among MSM reached 6.3% by 2011 (China Ministry of Health, 2012).

To the best of our knowledge, two qualitative studies have addressed the issues of parental HIV disclosure in China. Xu and colleagues (2007) reported a child awareness rate of 18.8% based on data from rural Yunnan. They suggested that most HIV-positive parents did not disclose their HIV serostatus to children because of fear of HIV-related stigma and lack of knowledge and skills needed for disclosure. Zhou, Zhang, Li, and Kaljee (2013) reported a disclosure rate of 23% based on a study in rural Guangxi. They argued that older people were more likely to disclose to their adult children, for the purpose of having both emotional and financial support. However, the participants of both studies were living in rural areas in southwest China, with a relatively low education level, and might not be representative of other HIV-positive parents in urban or suburban areas of big cities. The HIV epidemic in China is diverse by geography and population. Some subpopulations, such as MSM, might have different concerns and needs about disclosing HIV serostatus to their children.

Utilizing data from 29 parents living with HIV in Beijing, China, we explored the practices, intentions, and perceptions of parental disclosure to address the following questions: First, among parents who have disclosed their serostatus to children, what are the reasons for disclosure and what are the common patterns of the disclosure practice? Second, among parents who have not yet disclosed to children, what are reasons for nondisclosure and what is their intention regarding future disclosure? Third, among parents living with HIV, what are their perceptions of an appropriate disclosure?

Methods

Research Site

We conducted this study in Chaoyang District in Beijing, the capital city of China. Beijing has a resident population of 19.61 million (Beijing Statistics Bureau, 2011). Chaoyang District is the largest urban district in Beijing, with a population of 3.55 million (Beijing Statistics Bureau). The number of HIV /AIDS cases in Beijing increased at an annual rate of 17% between 2007 and 2012. According to the Beijing Health Bureau, 2,031 new cases were reported from January to October 2012, and about 94% of those individuals were infected through sexual transmission (Mi, 2013). HIV infection through homosexual behavior is also increasing in Beijing. The HIV prevalence was 4.5% according to one study conducted among 550 MSM in Beijing in 2008 (Zhou et al., 2010).

Participants

We recruited and interviewed a convenience sample of 29 parents living with HIV from HIV clinics of the Centers for Disease Control and Prevention (CDC) in Chaoyang District in Beijing from February to May 2011. We invited HIV patients who visited the clinics to participate in the study if they were at least 18 years of age, the parent of at least one child aged 6 to 18 years, and willing to provide informed consent for an individual interview.

We summarize basic characteristics of the participants and their children in Supplemental Table S1 and Supplemental Table S2, respectively (available online at qhr.sagepub.com/supplemental). Among the 29 participants, 25 (86%) were men. About 48% were in the age group of 35 to 39 years, and 31% were in the age group of 40 to 44 years. Most participants

(66%) had at least a high school education. Nearly 60% of participants were married. Twelve participants (41%) lived in an urban residence and 17 participants (59%) lived in a suburban residence within the jurisdiction of Chaoyang District. Among the 25 men, 18 self-identified as MSM, and these had married at least once (10 were currently married, 6 divorced, 2 separated). About 62% of participants (n = 18 men) reported becoming infected through homosexual behaviors, whereas 14% of the participants (2 men, 2 women) became infected through heterosexual behaviors. Two (7%) participants were infected through blood transfusion and 3 (10%) participants did not know exactly how they were infected.

The 29 participants had a total of 38 children, including 17 boys and 18 girls (genders of three children were not reported). One half of the children were 6 to 11 years of age, and 34% of the children were in adolescence (12 to17 years old). One child was younger than 6 years, and 5 children (13%) were at least 18 years old. Based on their parents' reports, all of the children were HIV-free, although only eight children had taken an HIV test.

Procedures

A team of trained interviewers conducted individual, indepth interviews using a semistructured interview guide. We developed the initial interview guide based on existing literature on parental disclosure; we then revised the guide according to information from informal discussions on parental disclosure with HIV-positive parents, health care providers, and research staff in the Chaoyang CDC. The resulting guide consisted of open-ended questions and supporting probes covering several topics, including (a) demographic information; (b) medical history (HIV transmission mode, medical therapy, and health status); (c) reasons for disclosure or nondisclosure; (d) experience of disclosure (context, procedure, reactions from children, and impacts); (e) intention to disclose in the future; and (f) general opinions about parental disclosure.

We conducted individual interviews in separate rooms or private spaces at the CDC to ensure confidentiality of the responses. The interviewers were research staff in the Chaoyang CDC who had received prior extensive training on qualitative methodology, research ethics, general skills of conducting in-depth interviews, and special skills of interviewing people living with HIV/AIDS. The interviewers invited potential participants by describing the study protocol and assuring their confidentiality during the study. Each participant provided written informed consent before the interview. The interview took about 60 minutes on average. The study protocal received ethics approval from the institutional review board at the Chaoyang CDC in Beijing, China.

Data Analysis

All 29 interviews were digitally recorded. They were transcribed in Chinese and then translated into English. We managed and analyzed the translated interview transcripts using ATLAS.ti v5.0 (Muhr, 1997). We started preliminary coding by reading and rereading six interview transcripts. We then developed a codebook to cover the codes drawn from the interview guide and the new codes emerging during the interview and coding process. Based on this codebook, two authors independently coded all transcripts and further identified themes by using inductive codes. All the coding disagreements were successfully resolved

through discussion among the research team. We also stored coding memos to facilitate further discussion and elaboration. Quote excerpts and coding memos were categorized according to their themes and further compared and reviewed. We finally selected representative quotes to illustrate key findings.

Results

Experience of Disclosure

Five of the 29 participants had disclosed their HIV serostatus to their children, including two partial disclosures and two full disclosures by the parents themselves, as well as one disclosure by other family members. The disclosure rate was 17% in total. Four fathers (MSM) and one mother reported the disclosures. Among the children who had been fully and/or partially informed of their parents' HIV infection, five were boys and five were girls, ranging in age from 5 to 13 at the time of disclosure. The participants described their reasons for disclosing, the process of disclosure, the reactions from their children to the disclosure, and the impact of the disclosure on their children—based on their observations. Finally, they were invited to share their perceptions and suggestions about disclosure.

Reasons for disclosure.—Almost all of the participants who had disclosed their HIV serostatus to their children mentioned that they did so to ensure that their children would be prepared for their parents' death in the near future. These parents hoped that the disclosure could help their children become independent and mature. One father, who told his 10-year-old daughter of his HIV infection, shared his thinking with the interviewer:

> I would like to educate my child by informing her. She was naughty, and I was quite worried about it and anxious about it. If I pass away one day, no one would take care of her. I had to educate her and warn her, making sure she grew up and had a good performance in school. She thought that the parents would always be there for her. What will she do if parents die one day? Thus, I thought it was necessary to teach the child to take care of herself, to do housework, and to be independent.

Parents who had worsening health conditions or were divorced or widowed were especially likely to emphasize their desire for more rapid maturation of their children. A father said,

> My wife and I were separated, and my health was not very good. I needed to let my son gradually adapt to the situation in which I would not be with him. … I felt stressed because of my drug resistance. I was fearful of a potential breakdown. The purpose of my disclosing to him was to let the child know my current situation so he could be psychologically prepared in case of my death one day.

One widowed mother who lost her husband to AIDS in 2003 expressed a similar reason for disclosure:

> I felt that it was not easy for my child to grow up compared to his peers who were cared for by both parents. His father passed away when he was young, and I might also die one day in the near future. Nobody will take care of him when he grows up.

> I disclosed to him so that he was able to mature earlier, to study hard, and find a good job in the future. I hoped he could have a good life.

A father claimed that he disclosed to his daughter to release his own pressure:

> One month after knowing the diagnosis, a psychological pressure overwhelmed me. I was not able to face it. … If she [the daughter] was not living with me, I might not tell her; that would be okay. But she was living with me. Telling her would benefit me by releasing my pressure. Telling her would be good for me. There is a difference between concealing a thing and disclosing it.

Disclosure process.—Among the five cases of disclosure, one was an indirect disclosure described by a father. He suspected that his wife had disclosed to the child during a period of his absence from home in 2006. He recalled that he turned off his cell phone for nearly 3 months waiting for his death all alone because of fear and despair. He said,

> My family could not find me and had no idea what was going on. All the family members were very worried about me when I left home. I disclosed to my wife on the phone, and thus everyone in the family knew it too. I think it was at that time that the child knew my serostatus.

However, he did not know the specific process of the disclosure. He said, “I don’t know how she [his wife] disclosed to the child. I have never asked about this. In fact, we avoid talking about such a topic.”

Among the four direct disclosures, two were planned and two were unplanned. One father reported that he disclosed his HIV infection to his son on their way to the cinema. Another father disclosed to his daughter when she was calm. Both of the two unplanned disclosures happened when the parents were upset during the process of disciplining their children. One father described his disclosure to his 10-year-old daughter:

> It happened after my returning home from work. I had told her to cook rice for dinner, but that day she did not come back home. After a long time I finished cooking. I went to the school to look for her, and found out that she had played with her classmates in a park. In addition, she did not perform well in school in terms of test scores. I let her stand in the corner as punishment, and then I couldn’t help telling her [my health situation]. I said, “I am telling you that I just had a test and found out I had a very serious disease, and maybe I could live for ten years at maximum.” My words probably scared her. I said, “Don’t tell me you do not believe this. It is what the doctor told me. If you don’t change yourself, don’t work hard, you will be knocked out from society one day. Don’t think you will always have parents to count on.”

Similarly, one mother disclosed to her 13-year-old son after punishing him because he was not obedient; she recalled,

> The disclosure happened one day after the spring festival of two thousand eleven, perhaps on the seventh or eighth of February. It was time for him to go back to school, but he had not finished most of his homework. He played [computer] games

> every day and did not listen to my words. He said, “I will stop playing it in half an hour.” However, one hour passed and he still kept playing it. Then I hit him for punishment. Actually, each time after punishing him I felt very sad. He did not live with me before and was not able to feel much love from me. Moreover, I hit him for his naughtiness. I thought I hit him because I was anxious for his growing up. When it was time to go to bed, I said to my son, “Do you know why I punished you? Mum [Mother] just wishes you can have a better life than others in the future. You are different from other children. Others can depend on their parents and thus have an easier life, but who you can count on? Grandparents are old. Me? I have a serious disease. If you don’t work hard yourself, no one can help you. Do you know what disease Mum has? I have the HIV infection.”

The scope of disclosures varied among the participants. Some parents simply told their children, “I have got a serious disease,” or “Dad’s health condition is not good.” Some parents explicitly mentioned HIV or AIDS when they disclosed to their children, but did not tell children how they had become infected. A father said, “I explicitly told the child it is HIV, but did not talk much about it. I just told the child about the symptoms of this disease and [that] some medicine could control the disease.” During the disclosure, all of the participants indicated their potential death because of AIDS. One father described his disclosure to his son as follows:

> I gradually told him that my current health status was not good, I had a deadly infection. If something happened to me one day, maybe he had to grow up without me. It was not because I didn’t love him, but because of the problems related to this disease.

Reaction and impact.—Children’s reactions to disclosure varied according to the different approaches to disclosure. A 9-year-old boy and a 5-year-old girl were reported as not having much of a reaction in two planned parental disclosures; however, a 10-year-old girl and a 13-year-old boy reacted emotionally after two unplanned disclosures. According to her father, the girl was scared, and then cried and was very fearful. The boy’s mother recalled his reaction:

> When my child heard that I had HIV infection, he looked at me helplessly. Then he held my hands and said, “Mum, don’t worry. I will study hard and I will take care of you when you are ill. Please take it easy, Mum! I will take care of you because I am grown up.” On the night of disclosure, I felt that the child did not go to sleep the whole night, just tossing and turning. Several days later, he spent less time on the Internet but more time on his homework. He would ask me if he had some questions or problems about homework, and he completed all the homework before the new term at school.

The participants talked about changes in their children after disclosure. The positive impacts of disclosure on children included having more communication with parents, studying harder at school, showing more obedience to parents, and providing support such as reminding parents to take medicine and comforting parents with words. The mother of the 13-year-old boy reported,

> The teacher told me that he performed well this term and was able to finish homework on time. In all, the teacher thought he performed well and improved somewhat. … I suddenly felt that he was grown up, and was mature.

One father said, “I used to feel my child was not obedient, but I feel he has changed a lot since knowing my HIV serostatus. Now he is well behaved, and cares much more. I am always moved by his sweet words.”

The participants also reported negative psychological impacts of disclosures on their children. Children became depressed, had low self-esteem, did not like communicating with others, or became disruptive and rebellious against parents after knowing of the parental HIV infection. One father of a 5-year-old girl reported that the girl felt depressed after the disclosure and spent her spare time watching TV, doing homework, or doing housework rather than playing with others as she had before. He said, “Before the disclosure, she had a bright character and was carefree. After the disclosure, she became introverted, a little bit depressed.” A divorced father described the change in his daughter since his disclosure 3 years previously:

> She had a feeling of inferiority, sadness, and depression. She was ten years old at that time, and was in the third grade. It seems that she has never been carefree or bright since then. She is thirteen years old now, and she has become disruptive and rebellious. She fights with others, and sometimes cuts her own arms. She always hangs out with another girl whose parents are divorced when I do not have enough time to keep an eye on her. They stay at the Internet bar all day and do not come back home on time. She has probably stolen a bicycle. She told a lie to me, saying she would go to visit her mother but actually she just hung out with her friends.

Experience of Nondisclosure

The majority of the participants reported that they had not disclosed their HIV serostatus to their children, and explained why they had made such a decision. They also assessed whether their children were aware of their HIV infection, described how the children responded to cues of parental illness (e.g., doctor visit), and talked about their intention of disclosure.

Reasons for nondisclosure.—The participants had not disclosed to the children mainly because of concerns regarding the children’s young age, potential negative psychological impacts on the children, potential secondary disclosure, or HIV-related stigma. One mother said,

> The child is too young. I am worried that she will feel stressed after knowing this. In addition, it is not good that many people know it [my HIV serostatus]. This disease is not acceptable in China. The child is too young to know the stigma and will tell this to others.

A father expressed his desire to protect his children from psychological harm:

> Now the children are having a carefree life. If you suddenly tell them that your father is in such a situation, gets this disease, how can they accept the fact? I am

> worried about bringing pressure to my children. I don't want them to feel worried. I hope they can live a better life. I myself will bear the pains I have produced.

For some parents who were also MSM, the reasons for nondisclosure included the fear of stigma against MSM. One participant said, "This disease is related to sex. People always make a moral judgment, and people can't understand homosexual behavior." One father who contracted the HIV infection through homosexual behaviors expressed his worries that the disclosure of his HIV serostatus to his child would result in disclosure of his homosexuality:

> There are many reasons for stigma against [people with] AIDS. First of all, in China, particularly in rural China, more than half of the people are very conservative. Second, China does not allow same-sex marriage. If I disclose to the child, [the child] will find out that the transmission route of my infection is homosexual behavior, because I have no history of using drugs or visiting a prostitute. That will add a lot of pressure to the child. I think my identity as a homosexual person with HIV infection will shock the child a lot.

Some participants had decided not to disclose to their children or other family members because of the desire and perceived responsibility to protect the family. They did not feel that children or family members might really provide needed support, and they thought it would be selfish to disclose their HIV infection to the family because such information would probably cause family conflicts and add a psychological burden to family members. Some typical views are demonstrated by the following statements: "The fewer people know of my HIV serostatus, the better. My whole family will be ruined if others outside of my family know my disease." "I don't dare to tell my wife because of a concern for triggering family conflicts. I will conceal my HIV serostatus as long as I can." "They will also suspect that my family members have it [HIV infection] too." "I think I have already accepted the fact [HIV infection], and I am able to bear it myself. Thus, I don't need to involve them in trouble and let them bear the pain."

Intention of disclosure.—Among 24 participants who talked about their intention to disclose in the future, 7 thought they would not disclose their HIV infection to their children in the foreseeable future or ever. One participant stated that his decision regarding disclosure would depend on whether his daughter continued asking about his medication and disease; he would tell her if she insisted on knowing the truth. The rest of the participants claimed that they would disclose to their children in the future. Specifically, these parents would wait until their children were old enough to understand HIV/AIDS and were able to bear psychological pressure, when their health condition became worse and they became symptomatic, or when their children discovered the fact by themselves one day.

The disclosure experience of other people living with HIV influenced the participants' intentions regarding disclosure. Other people's negative experiences surrounding disclosure to children or family members might have aggravated their concerns and fear of disclosing to their children. One man mentioned the experience of one AIDS patient he knew: "After the disclosure, he lost all the family relatives. His wife and children kicked him out of his house. His parents did not allow him to go back to their home. It was so pathetic." One

woman did not dare to disclose to her sons because of their witnessing other HIV patients' experiences related to stigma:

> When my sons were young they once lived with their aunts in a village where a couple had this disease. My children said to me after they came back, "Two people have a kind of illness. Their faces are dark yellow, and no one wants to talk with them. They get AIDS. No one dares to be close to them." My sons also told me not to get close to them, not to touch them. Thus, I dare not disclose my serostatus to them. My sons had seen the experience of other HIV patients. I feel the children cannot accept the fact [that their mother has HIV]. I would not tell them till my death.

Children's knowledge of parents' health condition.—Among 24 parents who had not disclosed to their children, 21 (88%) were definitely sure that their children did not know their HIV serostatus; the other 3 suspected that their children had guessed about their HIV infection. A mother with two children (16 and 12 years of age) said, "I feel that the older child might suspect a little bit about my disease. The younger one doesn't know." A father told us that he suspected his wife had disclosed his HIV serostatus to their daughter. Another father thought his 17-year-old son had probably known of his HIV infection, "because he saw me taking my medicine." He elaborated further:

> In addition, all other family members have known my situation, thus my son might know it too. He has not yet asked me about this because he would like to save face. I have stayed in [hospital] and the child has visited me in the hospital. Everyone knows what kind of hospital it is. [The hospital is known for treating HIV patients in Beijing.]

The majority of parents concealed their disease and medication through deception. One participant mentioned that his children suspected about his disease because he did not share the same eating utensils with other family members. He described the dialogue between the mother and son in his family: "My son asked, 'What is going on? Why are you using different utensils?' His mother explained, 'Dad had a disease in his eyes; thus he is worried about transmitting the infection to you.'" One mother described the interaction between her and her child about her medication:

> When the child saw me taking my medication I told him that the medicine was for hepatitis. He knew that my health was not good because I always took medicine. … He asked, "Mum, you always take medicine. If your health is not good and you don't feel well, why not go to see a doctor?" Then I answered, "I get hepatitis." "It can be cured. Don't worry about it," he said. And then he always looked for information about hepatitis on the Web. He said, "You should see a doctor. Then you will be okay when you are cured of the disease. Don't always take medicine."

Perceptions of Disclosure

Twenty-seven participants (both those who had disclosed and those who had not) talked about their general perceptions of parental HIV disclosure. Parents expressed many common views in terms of when, where, and how to disclose HIV serostatus to children. It is notable

that there were discrepancies between perceptions and actual practices among participants who had disclosed HIV serostatus to their children, especially the ones who had unplanned disclosure. All 5 participants who had disclosed their HIV status to their children suggested that parents should not disclose to children until the children were at least 15 to 16 years of age, although they disclosed when their children were much younger (from 5 to 13 years old). Four of them who disclosed in unplanned or unintended circumstances also offered their views on ideal disclosure approaches.

Appropriate time and setting.—Children's age was a key factor that parents considered when they made a decision about when to disclose. Most of the participants thought it was appropriate to tell children when they were grown up, able to understand HIV/AIDS, and able to bear the psychological pressure of knowing of a parent's HIV infection. Some parents emphasized that parents would be better not to disclose during children's puberty, when they might be more likely to encounter psychological problems. Generally the participants thought that the ideal age of children for parental disclosure was at least 18 years. Some parents thought their children would not be mature enough until they were 20 to 30 years old, went to college, found a job, or got married and had their own family. Therefore, they felt that parents should conceal their HIV serostatus as long as they could, or until their children became independent.

In addition to the concerns about children's age, parents also intended to carefully select appropriate occasions to make a disclosure to children. Some suggested disclosing on World AIDS Day, or when there would be a program related to HIV/AIDS on TV so they were able to naturally lead discussion to the topic of HIV/AIDS. Others suggested disclosing during summer or winter vacations, to reduce any negative influence on children's school performance. Still others suggested disclosing when children were sexually mature, to protect them from high-risk sexual behaviors. Most of the participants emphasized disclosing to children when parents were stable emotionally and children were calm and in a good mood.

As for the setting of disclosure, most parents thought an appropriate location would be someplace familiar to the children with good privacy and a relaxing atmosphere. Some parents would choose a bar or a restaurant; some would disclose to children during entertainment or other family activities; and some planned to make a disclosure during their stay in the hospital.

Appropriate disclosers.—Twenty-one participants talked about who would be the most appropriate disclosers. The majority of them believed that they should disclose to the children themselves, for various reasons: They were afraid that other disclosers might not have as strong a desire to protect the children as parents do; they thought that being informed by others rather than parents would hurt children's feelings and ruin trust between parents and children; they assumed that a disclosure by parents would be easier to accept because children often had a closer relationship with parents than with other family members; they felt that parents living with HIV were able to better explain their own disease and health condition than others; and they perceived that it was the responsibility of parents living with HIV to tell the facts to their children because it was no one else's business.

Two men expressed their preference for their wife to be the discloser; 2 others thought all family members (including parents and grandparents) would be fine as potential disclosers. One participant expressed that he did not care who would disclose to the child, and another thought the best discloser would be a psychologist or a professional working in the field of HIV prevention and treatment.

Appropriate approach.—One participant highlighted applying different approaches for children of different ages: “For adolescents or school-age children, you can’t tell them explicitly. If children are adults or get married, then you can tell them directly and openly.” However, the participants generally agreed that an appropriate disclosure should be a well-planned and gradual one no matter how old their children were. The following comments describe typical views of an ideal process of disclosure:

> It is better to talk frankly with children alone about this issue [HIV infection], step by step. First you lead to the topic, then talk about it indirectly, then talk about it through the perspectives of international and national policies, then try to ask them [what they will do] if their parents get the HIV infection. First you need to let them be prepared through teaching them knowledge about prevention and risks of HIV, then disclose to them.

The participants perceived that parents should be cautious during the whole process. They should assess children’s ability to understand and bear the fact of parental HIV infection, and consider children’s emotions before making a disclosure. They should also observe children’s reaction to partial disclosure and stop if they feel children are not able to accept the fact during a disclosure. A father said,

> I might tell the children that I have an incurable disease and might die soon. I will disclose gradually and observe the extent to which they accept this news. If the children are strong and able to accept it, I will tell them completely.

In addition, an appropriate disclosure should be guided by professionals. The father of a 5-year-old girl regretted his disclosure without professional guidance, and suggested seeking support from psychologists. He explained his rationale for such a suggestion:

> A psychologist is a professional, and will do better in terms of approach, manner, tones, and he or she will know more about child psychology, know more comprehensive issues about children. … He or she can communicate with my child, understand her needs and set up a close relationship first, then indirectly and gradually tell her what we would like to disclose. In this way, we can let the child understand the whole thing without damaging her psychological well-being.

Discussion

We conducted qualitative analysis of parental disclosure practices and perceptions among parents living with HIV in Beijing, China. The patterns of disclosure practice were generally consistent with the existing literature. The disclosure rate was low. Parents disclosed to children to ensure that the children were prepared for parents’ potential death. Most parents chose not to disclose because of concerns regarding children’s young age, potential negative

psychological impacts on children, potential secondary disclosure, and perceived stigma associated with both HIV and sources of the HIV infection (e.g., homosexual behaviors). Unplanned disclosures resulted in children's strong emotional reactions. The scope of disclosure varied and parents might not have clearly or completely explained HIV infection and transmission; however, almost all the disclosers mentioned the parent's potential death. The impacts of disclosure on children were mixed, although the data were limited in this regard.

The majority of participants in this study were men who contracted HIV through homosexual behaviors, which might reflect the trend of the recent HIV epidemic in Beijing, where a large number of new HIV cases were among young MSM (China Ministry of Health, Joint United Nations Program on HIV/AIDS, & World Health Organization, 2009). Estimations on the size of the MSM population in China range from 10 to 20 million (Guo, Li, & Stanton, 2011). The stigmatization against MSM is so common in China that they frequently conceal and/or deny their homosexual preference by getting married and having children in the context of traditional Chinese culture, which values the continuation of the family name (Choi, Gibson, Han, & Guo, 2004; Li, 2002; Liu, Liu, Cai, Rhodes, & Hong, 2009). MSM living in big cities, with relatively higher educational attainment, might view the issues of parental disclosure differently from other populations. Only 4 (20%) of 18 MSM in the current study disclosed their HIV infection to their children. Many participants chose nondisclosure mainly because of fears of revealing their sexual orientation and the possible stigmatization that might result.

According to previous studies, parents disclose their HIV infection to children when children become aware of their medication and symptoms (Dematteo et al., 2002; Kennedy et al., 2010; Wiener, Battles, & Heilman, 1998); however, in the current study, the majority of participants concealed their ART medication or deceived their children about their health problems by explaining that they were suffering from diseases other than HIV. In addition, almost all of the parents believed that their children were not aware of their HIV-positive serostatus. Their confidence in successfully concealing this infection in front of their children might be another reason for nondisclosure.

Participants preferred taking a gradual approach to disclose their HIV serostatus to children in a familiar and comfortable setting. They also emphasized paying attention to children's emotions and behavior changes before and after the disclosure. This illustrates their desire to protect the children by reducing potential negative impacts of disclosure. However, only one participant mentioned the need for professional support. Most of the parents might not have known where they could obtain professional support related to parental disclosure.

We need to be cautious in interpreting results of the current study because of several limitations. First, the sample size was relatively small. The small number of disclosure cases might not provide comprehensive information about different disclosure patterns. In addition, it was difficult to compare disclosure patterns by parent gender because of a small number of mothers in the sample, even though we assumed that notions of motherhood or fatherhood might affect parents' practices and perceptions related to disclosure.

Second, the sample, which was recruited from an urban center in China, might not be representative of HIV-positive parents in other areas of China. The relatively large proportion of MSM in the sample, although justified by the local epidemic, might further limit the representativeness of the sample. Third, we did not interview the children of the participants because of ethical concerns (e.g., revealing parental HIV status). The information about children's awareness of parental HIV infection, children's reactions to disclosure, and changes following disclosure was solely based on parents' perceptions and observations. Fourth, the narratives of parents were subject to reporting bias or error of recall.

Despite these limitations, to the best of our knowledge the current study is the first qualitative study about parental HIV disclosure to children conducted among an urban population in China, and thus revealed important insights. The perceptions and experiences of parents who contracted HIV through homosexual behaviors are especially concerning. Most parents interviewed in our study perceived overwhelming stigma associated with homosexuality in society, which was a primary barrier to disclosure. We need more effective efforts to reduce homosexuality-related stigma.

Second, we need to involve both parents and children (as dyads) in future studies, when ethically justified, to obtain a complete picture of parental disclosure. In future research, we need to explore whether children's knowledge of parental HIV infection might differ from the one perceived by parents, and to examine how the interaction between parents and children regarding medications and symptoms might influence intentions and practices of parental disclosure.

Third, professional information and services about parental HIV disclosure should be more accessible for people living with HIV. Most parents with the intention to disclose might not know where they can obtain professional guidelines and support, even though they have a strong desire to protect children from negative psychological impacts of disclosure.

Fourth, we need to explore how social norms (e.g., common attitudes and perceptions of community members) affect the perceptions and practices of parental disclosure. Some HIV patients' experiences related to parental disclosure might influence other patients' general opinions and their decision making about disclosing HIV infection to children; negative consequences of disclosure elaborated in others' cases might aggravate their fears of parental disclosure. It is necessary to set up support groups and provide a professional guide for parents living with HIV who are challenged by disclosure issues.

Fifth, we need to be aware of specific needs among different subpopulations when we design interventions for parental HIV disclosure. We should tailor intervention approaches and strategies for individuals of various demographic characteristics (age, marital status), family relationship, and HIV transmission routes (less stigmatized routes such as blood transfusion vs. more stigmatized routes such as sex and drug behaviors). Sixth, the perceptions and practices of parental disclosure are interwoven with parenting and communication styles between parents and children. We need to integrate interventions for parental disclosure into

efforts toward improving family relationships and quality of family life for people living with HIV.

In summary, based on the findings of this study, we suggest that most parents living with HIV in China are struggling with disclosure to their children. Unplanned parental disclosures cause negative impacts on children. Concealment and deception about HIV medication might damage trust between parents and children, and negatively affect the quality of family relationships and family life. Parents living with HIV need professional assistance with and guidelines for parental disclosure.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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