

UCLA

UCLA Previously Published Works

Title

Concerns of Parental HIV Disclosure in China

Permalink

<https://escholarship.org/uc/item/6pq843hf>

Journal

Clinical Nursing Research, 30(6)

ISSN

1054-7738

Authors

Sun, Meiyang
Chen, Wei-Ti
Yang, Joyce P
[et al.](#)

Publication Date

2021-07-01

DOI

10.1177/1054773820932725

Peer reviewed

Concerns of Parental HIV Disclosure in China

Clinical Nursing Research
1–10
© The Author(s) 2020
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/1054773820932725
journals.sagepub.com/home/cnr



Meiyan Sun, RN, MSN¹, Wei-Ti Chen, RN, CNM, PhD, FAAN² ,
Joyce P. Yang, PhD³, Shuyuan Huang, RN, MPH⁴, Lin Zhang, RN, MPH¹,
Mingfeng Shi, RN¹, Wei Li, RN¹, Ye Li, RN¹, Meijuan Bao, RN¹,
and Hongzhou Lu, MD, PhD¹

Abstract

Although parental HIV disclosure has benefits for parents and children, the disclosure rate among parents remains low. This study aims to qualitatively examine parental concerns regarding disclosure of their HIV status to their children. Eighty parents were enrolled in a randomized controlled trial of a three-session disclosure-support intervention, with forty receiving the intervention and forty receiving treatment as usual. Intervention sessions were audio recorded, and transcriptions were qualitatively coded for content related to concerns of disclosure. Four themes emerged: Intention to disclose, disclosure approach, indicators for disclosure, and fears about disclosure. These themes reveal struggles that parents experience when considering HIV disclosure suggesting that an effective disclosure intervention must help parents assess pros and cons, discuss the emotions of the children after the disclosure, and monitor the impact on children's lives after disclosure over time. Future research is needed to implement interventions supporting HIV-positive parents' disclosure decision-making and actions.

Keywords

China, disclosure, HIV, parents, qualitative study

In recent decades, antiretroviral therapy (ART) has decreased the prevalence of HIV and the morbidity and mortality of people living with HIV (PLWH) (World Health Organization, 2016). With the increasing accessibility of ART, more PLWH are living longer and experiencing a great likelihood of raising HIV-negative children. One of the most common dilemmas with which HIV-infected parents are confronted is when and how to disclose their HIV serostatus to their children (Murphy et al., 2013). There is growing evidence suggesting that parental HIV disclosure to children is beneficial and that it increases mutual support within the nuclear family (Zhang et al., 2017).

Background

Well-planned parental HIV disclosure has been found to promote psychological and social well-being among parents and children who are affected by HIV (Qiao et al., 2013a). In addition, parental HIV disclosure to children is related to lower levels of depression and anxiety (Simoni et al., 2015), higher social support (Mkwanazi et al., 2017), and better adherence to clinic appointments and HIV medication (Henrickson et al., 2013; Kyaddondo et al., 2013). Furthermore, the benefits of disclosure for parents may also include relief from the stress caused by maintaining

the secrecy (Qiao et al., 2013b) and relief from worrying about unintentional or poorly prepared disclosure (Qiao et al., 2013b).

However, studies also presented that HIV-infected parents are reluctant to disclose their serostatus (Conserve et al., 2017; Rochat et al., 2017). The differences may be attributable to research settings (high-income countries vs. middle- and low-income countries), research samples (maternal disclosure vs. more broadly, parental disclosure), and/or research types (cross-sectional study vs. longitudinal

¹Shanghai Public Health Clinical Center, Fudan University, Shanghai, China

²University of California Los Angeles, Los Angeles, CA, USA

³University of San Francisco, San Francisco, CA, USA

⁴Yale University, Orange, CT, USA

Corresponding Authors:

Hongzhou Lu, Shanghai Public Health Clinical Center, Fudan University, Shanghai, China.

Email: luhongzhou@fudan.edu.cn

Lin Zhang, Shanghai Public Health Clinical Center, Fudan University, Shanghai, China.

Email: zhanglin@shphc.org.cn

Meijuan Bao, Shanghai Public Health Clinical Center, Fudan University, Shanghai, China.

Email: baomeijuan@shphc.org.cn

study). Typically, HIV-infected parents weigh many pros and cons when deciding on disclosure to their children (Gachanja et al., 2014). The most common factors parents take into consideration are their own ages, disease progression, age and maturity of the children, risks and benefits to the children, impact on the parent-child relationship, and the children's level of support within the family (Abdulrahman et al., 2017).

For children, knowing a parent's status can reduce the level of anxiety, depression, fear, and uncertainty about the future (Rochat et al., 2017). Parental HIV disclosure has also been associated with lower levels of aggression and negative self-esteem (Zhou et al., 2013), enhanced self-efficacy, reduced risky behaviors (Mkwanazi et al., 2017), and improved academic performance (Zhang et al., 2017) in children. Parent disclosure can also promote self-confidence, social competence (Rochat et al., 2017), and quality of life (Chen & Barbour, 2017). Parental HIV disclosure can strengthen parent-child relationships (Chaudhury et al., 2016; Murphy et al., 2013), improve cohesion of the family (Qiao et al., 2013a), allow parents to better educate children about HIV and sex, and help parents plan for care and custody of the children should the disease worsen considerably (Liamputtong & Haritavorn, 2016). Furthermore, parental HIV disclosure can have an impact at the community level, by decreasing general misunderstanding about HIV, reducing HIV-related stigma and prejudice, and promoting HIV risk-reduction behaviors, such as HIV counseling and testing, and increasing the use of condoms and other safe sex practices (Rochat et al., 2017). Despite the numerous potential benefits of parental HIV disclosure, the rate of HIV-infected parents disclosing to their children remains low in resource-constrained settings relative to resource-rich ones (Loutfy et al., 2016). According to a review, parental HIV serostatus disclosure rates range from 20% to 97% in high-income countries compared to 11–44% in resource-limited ones (Clifford et al., 2013).

Undisclosed HIV-infected parents often struggle with the timing, approach, and content of disclosure. Parents may worry that their children are too young to understand HIV or that children do not know how to keep the family's secret (Liamputtong & Haritavorn, 2016; Zhou et al., 2013). In Chinese culture, family is the core social unit in an individual's healthcare journey, including one's experience with HIV (Qiao et al., 2015c). Family ties are among the most important relationships in supporting HIV care (Mao et al., 2018). Therefore, parents are concerned about how to approach the issue of disclosure and may be unsure if they can answer the questions their children may raise (Conserve et al., 2017), especially regarding the parents' transmission route which may disrupt family harmony. Naturally, parents do not want to cause their children mental distress (Conserve et al., 2017). Another barrier that makes parents hesitant to disclose is potential stigma and discrimination from their children (Zhou et al., 2013).

Parents worry about the potential of losing the respect of children or being perceived differently following disclosure (Yang et al., 2016).

China is a setting where HIV-infected individuals are stigmatized (Mao et al., 2018). Therefore, HIV disclosure rate remains very low (Zhou et al., 2013). Influenced by traditional Confucian ideology and culture, HIV-infected parents struggle with whether, when, and how to disclose their HIV status to their children (Ho & Goh, 2017). Under the guidance of Confucian principles, guilt and shame may be linked with particular disease transmission routes, such as extramarital sexual transmission (Tan et al., 2013). In this culture, contracting HIV may imply that the person with HIV has damaged his/her social circle and cannot fulfill their assigned role in the collective society. Thus, revelation of one's disease is difficult.

In response to the needs of Chinese parents living with HIV, we developed a three-session disclosure-support intervention described below, and the results of the randomized controlled trial (RCT) of the intervention were previously reported (Simoni et al., 2015). Each intervention session was audio-recorded and transcribed. This study describes an in-depth qualitative exploration of parents' responses and concerns reported during the intervention, in order to better understand their experience of disclosure decision making.

Statement of the Problem

In this paper, we focus on concerns and responses of Chinese parents living with HIV undergoing a disclosure-support intervention to better understand their decision-making process and inform future interventions that may be more acceptable and feasible. The aim of the study is to describe the disclosure experiences and concerns of parents in China undergoing decision making about disclosing their HIV to their children.

Methods

The intervention was conducted from December 2014 to December 2016 at Shanghai Public Health Clinic Center (SPHCC) in China. SPHCC is a HIV diagnosis and treatment center in the Shanghai metropolitan area. The HIV-infected patients treated at this hospital come from all over China to receive treatment, and approximately 10,000 HIV-infected individuals are being treated regularly there.

Individuals eligible for the intervention study were Mandarin-speaking parents who receive care at the SPHCC. The inclusion criteria were (a) confirmed HIV-positive, (b) having at least one child aged from 13 to 25 years old, (c) the target child did not know his/her parent's HIV status at the beginning of the study, and (d) parents were physically and cognitively capable of attending three nursing intervention sessions. Currently, the HIV

male-to-female ratio in the Shanghai metropolitan area is 9:1; therefore, we aimed to recruit at least four mothers in the current study. We approached all HIV-positive individuals seeking care at SPHCC during the study period. If they met the inclusion criteria, were interested in the study, and could provide the informed consent, these HIV-infected parents were included in this study. Several of them declined to participate due to anticipated emotional distress, not having time, and/or were not living with their children currently. For those who agreed to participate, a research nurse went over the study, answered questions, and obtained informed consent. After securing written consent, the research nurse began the first session immediately or scheduled an appointment at a later date, depending on which was more suitable to study participants.

In this pilot intervention study, we recruited 80 participants, with 40 in the intervention group and 40 in the TAU group. From previous experience with this population and disclosure decision-making phenomenon, we anticipated that an intervention condition sample size of 40 was a feasible number to recruit to achieve data saturation after three counseling sessions. As the goal of qualitative studies is to explore a range of experiences among HIV-positive parents, although “saturation” and “a priori-determined sample size” have stimulated debate in the literature (Sauders et al., 2018), it is generally agreed that a sample size of 16–20 participants should be able to capture a sufficient range of experiences (Sauders et al., 2018). Our sample size of 40 in the intervention group indicates a sample sufficient for data saturation among HIV-positive parents.

Participants were randomly assigned to one of two groups, either the intervention group or the treatment as usual (TAU) group, using a computer-generated randomly assigned number. A block randomization procedure ensured an equal chance of a participant being assigned to either group. The current qualitative study involves the intervention transcripts from the 40 participants in the intervention group.

The intervention was based on the Chinese Parental HIV Disclosure Model (Yang et al., 2016), which was adapted using the Disclosure Process Model (Chaudoir et al., 2011) and the maternal HIV disclosure model (Murphy et al., 2011). This disclosure intervention included three components: decision-making (balancing the pros and cons of parental HIV disclosure), the disclosure event (scope and approach of disclosure and the child’s potential reaction), and related outcomes (such as the long-term influence of disclosure on family dynamics and parent-child relationships). Intervention details and randomized clinical trial (RCT) results have been discussed in related publications (Simoni et al., 2015; Zhang et al., 2017).

The intervention trial was an international collaboration to test an intervention for HIV-positive parents disclosing their serostatus to their children. Prior to the beginning of the RCT, the U.S.-based research team provided a week-long training for four senior nurses at SPHCC who served

as the research nurses and supervised the intervention delivery. This manuscript focuses only on the qualitative analysis of the three sessions of the intervention. Psychologists who are experts in HIV mental health and child development, nurses, and social workers comprised the U.S.-based team. After each intervention session, the research nurse completed a content checklist and a progress note and sent it to the U.S.-based team to ensure research quality, fidelity, and efficiency.

Each intervention session took from 1 to 2 hr. We tape-recorded all the intervention sessions and then transcribed and analyzed contents of each session. Interventions were delivered in a private room at the SPHCC.

Ethical Considerations

The research was approved by the Institutional Review Boards from all the involved institutions. IRB approval numbers are University of Washington 45339G, Yale University HIC1311013017 and SPHCC-2013-021. Study consent was obtained before the intervention started. After completing each intervention, every study participant was given a small reimbursement for their time and effort. Study participants were informed that they could terminate or withdraw from the study at any time.

Data Analysis

In this paper, we analyzed transcripts from all three intervention sessions of 40 participants randomly assigned to the intervention group, resulting in a total of 120 transcripts. Atlas.ti 7 qualitative analysis software was used to code the data and conducted qualitative content analysis (Hsieh & Shannon, 2005) (COREQ checklist in Supplemental material). First, a team of three researchers looked for concept categories/code trees related to disclosure and children. Second, the research staff inspected the transcripts individually and assigned codes from the code list to match with themes that arose from the transcriptions. Third, ambiguous quotes were discussed and resolved by the team members. Last, quotes were translated into English for publication purposes.

For analytic rigor, the interpretation of the transcription were validated with a subset of interviewees to confirm the interpretation of the analysis via member checks to ensure the credibility (Sandelowski, 2008). For the first 10 counseling sessions, we randomly chose three interviews to show a summary of findings and to ensure the transcriptions’ accuracy. In the event of lack of consensus between researchers and participants, we deferred to the participants. In addition to member checks, the team continually consulted with onsite colleagues who work with this population to ensure the trustworthiness of the data. To ensure dependability, the study team strictly followed the intervention protocol ensuring that all participants underwent the same study procedures (Graneheim & Lundman, 2004).

Results

Socio-Demographic Characteristics of Participants

The majority of study participants were fathers. The mean age of these parents was 45 years old, and the average age of the targeted children was 19 years old. Detailed demographic data are presented in Table 1.

Themes

Four primary themes emerged from this study: intention to disclose, approach to disclosure, indicators for disclosure, and fears about disclosure, with several permutations under each theme.

Intention to disclose

Never disclose to children. Many parents expressed that they would not disclose their status in the near future. Some of them had decided not to disclose at all. Upon completion of the intervention, many parents still insisted that they would never disclose their HIV status:

I will never let my child know I have this (HIV), and I can take medicine and visit doctors by myself, so what's the difference if I tell him?" (Father of a 14-year-old boy)

It's my own business. They are them and I am me. They have their own lives. There is no good reason to tell them." (Father of two sons, one is 21 and the other is 25 years old)

These parents, however, also recognized that there could be some situations in which their children might accidentally learn about their HIV diagnosis. For instance, children could discover a parent's ART medication in the medicine cabinet or overhear conversations relating to the parent's disease:

I will never tell [my daughter] unless my physical condition gets worse. When I am hospitalized, she will know. Then I will tell her, because I have no choice. But I won't tell her proactively. (Divorced father of a 14-year-old girl)

I won't tell her right now, but if I have some complications from HIV or if there is no way to hide it, then I will be honest and tell her the truth. (Divorced father of a 15-year-old girl)

Disclose at an appropriate time. Parents had different responses on timing affecting disclosure decisions. In particular, parents did not want to put more stress on adolescent children who were already under enormous pressure to prepare for their college entrance exam:

When she gets in to a college, she may have less study stress. It is better to tell her at that time. (Father of a 17-year-old girl)

A couple parents revealed that it would be better to disclose their HIV status after their children started a career:

Table 1. Demographic Characteristics.

Variables	Mean (SD) or number (%)
Age (years)	44.68 (4.38)
Gender	
Female	5 (12.5%)
Male	35 (87.5%)
Number of children	
1	29 (72.5%)
2	11 (27.5%)
Age of the targeted child	18.65 (3.68)
Gender of the targeted child	
Female	7 (17.5%)
Male	33 (82.5%)
Employment/occupation	
Full-time job	31 (77.5%)
Retired	4 (10%)
Not working	5 (12.5%)
Household registration	
Shanghai	23 (57.5%)
Not Shanghai	17 (42.5%)
Ethnicity	
Han	39 (97.5%)
Other	1 (2.5%)
Education	
Less than 6th grade	3 (7.5%)
Less than 9th grade	27 (67.5%)
≥college	10 (25%)
Marital status	
Married	27 (67.5%)
Divorced or widowed	13 (32.5%)
Sexual orientation	
Homosexual	16 (40%)
Bisexual	6 (15%)
Heterosexual	13 (32.5%)
Declined to answer	5 (12.5%)
Monthly income	
Below average (6,000 RMB)	33 (82.5%)
Above average (6,000 RMB)	7 (17.5%)
Family members are HIV+	
None	33 (82.5%)
≥1	4 (10%)
Unknown	3 (7.5%)
Parents who disclosed HIV status to family members	
None	19 (47.5%)
≥1	21 (52.5%)
Currently on ART	21 (52.5%)
Yes	30 (75%)
No	10 (25%)
The most recent CD4 count	60–885 (451)

I think by the time [my son] graduates from college, he will have more knowledge about the world and will be more sensible. When he gets into society and has a job, he will have more social experience. Then I will tell him directly, 'Your father is HIV positive.' (Father of a 14-year-old-boy)

Other parents felt that since starting their own family was a significant life stage for young people, that would be the best time to disclose:

When my son gets married and has his own children, I will take care of the grandchildren. Then I will find an appropriate chance to let him know. At that time, I will tell him about my disease. (Father of a 21-year-old boy)

Approach to disclosure

Disclosing HIV serostatus to children by themselves. Parents in our study preferred to disclose to their children by themselves:

I communicate well with my son, and my wife may not necessarily understand this disease. I will tell my HIV status to my son by myself. (Father of a 14-year-old boy)

I won't let others to tell my son about my illness. I will tell him by myself, because it will be easier for him to accept it if I tell him. If he learns it from others, he may think I hid the truth from him. He may not forgive me. (Father of a 16-year-old boy)

Concealing the route of transmission. Parents who had decided to disclose had difficulty discussing their potential transmission routes. Parents who had decided to disclose said they would likely cite surgery or a blood transfusion as transmission route:

I won't tell my son that I got HIV through MSM. That would be a huge mental trauma for him, and he would never forgive me. I will tell him that I got infected from an appendectomy several years ago. (Father of a 14-year-old boy)

A few fathers reported that they planned to say they acquired HIV by having sex with female sex workers, as they believed that casual sex with sex workers would be seen as more acceptable than having sex with other men:

I could never tell my daughter that I got HIV from MSM. I cannot say that. I will say I got HIV by buying sex with women. That is normal, because I have been divorced for many years. I believe my daughter will understand my [sexual] needs and will forgive me. (Divorced father of a 15-year-old girl)

One father was worried that if his son learned that he had sex with other men, it would affect his son's behavior. He said:

I can't say MSM to my son. He doesn't know about MSM and I can't teach him about that. When he asks me how I got infected, I will say I acquired HIV by a blood transfusion or even by having sex with other women. I will never reveal the truth. (Father of a 16-year-old boy)

Requiring the children to keep the secret. Most parents said they would ask their children to keep it as a family secret and never talk about it with others:

When I disclose to my son, I will ask him not to tell anyone. I will say "People will laugh at you and look down on you if this secret is revealed." (Mother of a 22-year-old boy)

It's ok for our own family members to know [the HIV status], but you shouldn't talk about it with anyone else. I will definitely tell him that. (Father of a 19-year-old boy)

I will say, "Your mother and grandmother know and you can talk to them about my disease. But you cannot talk to others about it, including your classmates and good friends. Just because you can accept [HIV] does not mean that others can accept it. (Father of a 19-year-old boy).

Indicators for disclosure

Social support. In this study, parents said that they might disclose their disease to their children to secure their ability to receive future financial and other support from their children. They feared that as they aged and their physical condition worsened, they would lose their ability to work and therefore lose their financial resources. They wanted to disclose to their children with ample time so that their children could anticipate providing financial support for them:

When I am old, I won't have enough money to cover my hospital bills. I'll have to ask my son to support me. Then he will ask about my disease, and I will have no choice but to disclose to him. (Mother of a 16-year-old boy)

Other study participants determined that they would be able to take care of themselves and wouldn't need any support from their children:

I don't need the support from my son. I can take care of myself, and I have enough money to cover the costs, even when I have to be hospitalized. My son has his own life. (Father of a 25-year-old boy).

If I have to be hospitalized, my brother and sister-in-law can take care of me. For now, I can work normally, and I can take care of myself. I don't need his support. (Father of a 17-year-old boy)

Custody planning. In this study, none of the participants identified child custody planning as a must when they were asked to list the advantages of HIV disclosure to children and whether they have any custody plan:

My son is a very independent guy and he is more mature than his peers. He is strong-minded and he runs his own business. He usually doesn't need opinions from others. (Father of a 23-year-old boy)

If I am critically ill or if I am not alive, my parents will take care of my children. I don't need to make specific arrangements. My daughter and son get along well with their grandparents. Besides, my sister can also take care of them. (Divorced father of a 14-year-old girl and a 10-year-old boy)

Sexual education and HIV prevention. Most of the parents attested that their children could learn about HIV and sexual education on their own. Parents felt that since the Internet is so easily accessible their children might have already learned about sex and HIV from that source:

Why do we have to teach them [HIV and sexual education]? They have learned it from school already. Besides, even if I teach [my teenage son], can you guarantee that he won't get an HIV infection? (Father of 17-year-old boy)

Children are so smart now. They know more current stuff than you can imagine. They can learn from the Internet. They know things that the adults don't. Who would talk about sex and HIV with children in China? (Father of a 16-year-old boy)

However, one father who was infected with HIV through intravenous drug use wanted to disclose his HIV status to his 16-year-old son to prevent his son from getting an HIV infection. This man came from a small village and noted that there are many drug users in his village. He decided to disclose to his son and educate his son to stay away from substances. He said:

I want to tell my son about the potential transmission routes and let him know about the consequences of intravenous drug use (Father of a 16-year-old boy)

Fears about disclosure

Stigma. Many parents expressed their fears even after a series of disclosure-support sessions. The major concern of these parents was stigma. Parents were concerned about potential discrimination and alienation from their children after disclosure:

Once you mention the word HIV, people will connect it with dishonorable things. I don't want my son to have a bad impression of me. That would be terrible. (Father of a 20-year-old boy)

My daughter respects me and has a positive impression of me. Once she knows I am HIV positive, she may feel ashamed and she might not talk to me anymore. She might even insult me. (A widowed father of a 17-year-old girl)

Some parents revealed that they don't want to put additional pressure on their children because of their disease and would like their children to be able to have a peaceful life. Others felt that their children would not even be able to understand what HIV is:

When you mention HIV, people will get a mental image of critically ill and emaciated patients lying in bed, dying. My daughter would be scared if I told her I have HIV. I don't want my daughter to think of me like that and worry about me. (Father of a 19-year-old daughter)

How to disclose. Among those parents who intended to disclose, many had not decided on the best approach. Parents stated that they didn't have a strategy for disclosure. They therefore needed help from the professionals on whether, when, and how to disclose:

I know it's beneficial to disclose to my son, but I don't know how I can [disclose to him]. Will he understand what I'm trying to say? Could you please teach me the steps of disclosure? I want my son to understand and forgive me. (Mother of a 17-year-old boy)

I don't know whether to disclose to my child. What do you think? You should have some specialized training and steps for disclosure using various approaches. We need your help to let our children know about this and to accept the truth that their parents are infected with HIV. We want for it to happen in a calm and peaceful way. (Father of a 16-year-old boy)

In summary, in the present study, HIV-infected parents discuss several concerns for disclosing their serostatus to their children.

Discussion

Disclosing HIV status to children is a challenging and stressful process for parents living with HIV. Currently, the worldwide parental HIV disclosure rate remains low (Clifford et al., 2013). A parent's decision to disclose to their child is associated with a variety of factors such as age of the child, socioeconomic status, disease progression, perceived developmental maturity and intellectual capacity of the child, the overall parent-child relationship, and social discrimination (Abdulrahman et al., 2017).

Recent publications have focused on difficulties experienced by HIV-positive parents (Rochat et al., 2017). With assistance from culturally sensitive interventions, the rate of parental HIV disclosure should be increased, and the mental stress levels of parents and children should decrease accordingly (Qiao et al., 2013a). In this study, after a series of disclosure intervention sessions, many of the parents moved several steps toward willingness to disclose; however, none of them had disclosed fully by the end of the study (Zhang et al., 2017). Many parents believed that HIV infection was their private business and the disease had nothing to do with their children. Societal stigma strongly affects disclosure processes. HIV-infected parents condemned misconceptions and stigmatization spread by social media against PLWH (Dwivedi et al., 2015), often portraying PLWH as drug users, prostitutes, and sexual deviants (e.g., MSM) who deserve to be infected with a disease or have somehow brought it on themselves (Dwivedi et al., 2015). Indeed, HIV disclosure is intrinsically associated with stigma (Liamputtong & Haritavorn, 2016).

One consensus that parents had in our study is that children's reactions must be considered during the disclosure

process. Parents feared that they would lose the respect of their children, and this is especially significant in Chinese culture, where parents are perceived to have great authority and are admired accordingly. In addition, the Chinese social norm emphasizes harmony and hierarchy in structure of the family (Yang et al., 2016). Particularly, Confucianism stresses the social values of “country before community and community before self” (Ho & Goh, 2017). Parents are expected to create a respectful impression on the family, and they cannot be involved with what are perceived as dishonorable things such as HIV, promiscuity, and MSM. Therefore, guilt and forgiveness were mentioned several times in this study. Parents’ self-identities in the family and society are all influenced by Confucianism. Thus, the possibility of being stigmatized by their children is a serious concern for parents considering disclosure. Also, potentially divisive or hurtful topics are usually not discussed within the family in order to maintain family harmony (Conserve et al., 2017). Topics like HIV, sex, or death are taboo in China (Qiao, Li, et al., 2015a); therefore, parents are not prepared for the task of communicating on these topics. However, previous findings have encouraged a family-centered approach to enhance the well-being of HIV-infected parents, and increase connections with extended family can empower parents to rebuild family bounds (Qiao et al., 2015c). Therefore, an effective intervention should educate the general population on HIV to decrease the stigma of HIV.

Various studies have shown that parents disclose their HIV status to help educate their teenage children about sex and HIV and prevent them from contracting sexually transmitted diseases including HIV (Gachanja et al., 2014; Zhou et al., 2013). Parents feel that since the Internet is so easily accessible their children might have already learned about sex and HIV from that source. Moreover, many Chinese parents still feel that open discussion of sex is taboo and are very embarrassed to discuss their own sexuality with family members (Simoni et al., 2015). However, studies have shown that HIV disclosure can provide opportunities for HIV prevention among teenagers (Rochat et al., 2017). They also suggested that children are often able to understand the link among HIV, sex, and death at an earlier age than parents assume (Rochat et al., 2017). This suggests that a possible implications of this study is that parents should educate children about sex education at an early age to prevent them from being exposed to sexually transmitted diseases, including HIV. Therefore, a well-prepared disclosure intervention should assess pros and cons of disclosure, discuss the emotions of the children after the disclosure, and monitor the impact of the disclosure on the children over time.

In addition, children’s maturity is another concern. Some parents preferred to disclose after their children accomplished major life milestones that were associated with stress or required significant preparation, for example, passing a college entrance exam, getting a job, getting married or having a child. Parents stressed that waiting for

appropriate time to disclose was very important. A few parents indicated that it would be a good time to disclose when their children were in college. They believed that after getting into a college, their children would be mature enough to accept the truth at that time. Others believed that after getting married their children would be able to forgive them for contracting HIV.

Parental HIV disclosure is not a simple task, and HIV-infected parents need to consider their options thoughtfully (Chaudhury et al., 2016). Previous research has reported that HIV-infected parents prefer to disclose while other family members were also present (Rochat et al., 2017); however, in this study, parents preferred to disclose to their children by themselves. They did not want any other people to be involved, even family members. Parents believed that they thoroughly understood the disease, so they were the ones best equipped to explain it to their children. Parents also suspected that their children would have a harder time with acceptance if the HIV-positive parent did not disclose to children personally and discreetly. However, studies have shown that HIV-infected Chinese still need to improve their HIV-related knowledge (Mu et al., 2015).

Many of those who decide to disclose stated that they would not tell the truth about their route of transmission, especially those who were men and acquired HIV having sex with other men. Indeed, previous research has found that sexuality is a taboo topic in Chinese society, and it is hard for parents to discuss this topic with their children (Chen et al., 2016). Fathers in particular reported feeling shame about telling their children how they were infected by HIV. As healthcare providers (HCP), good relationships with HIV-infected parents can assist parents’ decision to consider disclosure (Simoni et al., 2015), and later, enhance their antiretroviral therapy (ART) adherence (Chen et al., 2018; Ma et al., 2016). In addition, encouraging disclosure parents’ serostatus, HIV-parents presented with less stress and anxiety (Qiao, Li, et al., 2015b). Therefore, HCP should assist parents to come up with acceptable explanations for when they decide to disclose.

Studies have shown that parental HIV disclosure support is necessary and effective (Gachanja et al., 2014). Parental HIV disclosure can facilitate parents’ planning for their children’s future (Rochat et al., 2017). In this study, even during the intervention session, no parents reported custody planning as a benefit. This might due to collectivist cultural norms that emphasize the value of the family identity (Mellor et al., 2014). Everyone is a part of the family unit in China (Hu et al., 2016); therefore, parents feel that there is no need to specify custody roles. Typically, grandparents and uncles/aunts will assume the role of guardians for the parentless children. In this study, parents believed that after their death, their children would either take care of themselves or some family member would step in without them needing to make arrangements for that in advance. In addition, social support can affect the decision to disclose (Zhou

et al., 2013). Ideally, HIV-infected parents would experience higher social support after disclosure, and improved social support would lead to better disclosure rates and outcomes (Qiao et al., 2013b). Given the Chinese social norm that adult children have a duty to support their aging parents (Zhou et al., 2013), these HIV-infected parents would like to get not only financial support but also emotional support from their adult children.

The parental HIV disclosure rate is low in China (Zhang et al., 2017). Therefore, parents were concerned about potential discrimination and alienation from their children after disclosure. Parents believed that if others knew the parents' HIV-positive status, the family would suffer discrimination. In China, there is a cultural norm that "family shame" should not be made public (Zhou et al., 2013). Even when parents disclosed, they would typically ask their children to keep the secret to protect against stigma and isolation from their community. The men especially did not want to lose the respect of their children; they wanted to maintain an "honorable image" as fathers (Zhang et al., 2017). Even had they not cared about their image, they might still have avoided disclosure, since saving face and avoiding conflict are standard practice in Chinese culture (Mellor et al., 2014).

Sometimes, involuntary disclosure happens when parents were under duress. When aging PLWH parents can no longer care for themselves, for example, their adult children become the single resource on which they depend for all kinds of financial and practical support. Compare this to other studies in which PLWH parents choose to disclose while they are in good health (Gachanja et al., 2014). When PLWH parents lose the ability to take care of their children, grandparents, uncles and aunts will then assume the role of caregiver. Therefore, arranging custody or guardianship is not necessarily an urgent matter for Chinese PLWH parents. This contrasts with Western countries, where parents often choose to disclose earlier to aid in arranging for the future custody of their children (Mkwanzazi et al., 2017).

Limitations

There were several limitations in this study. First, many participants were fathers. PLWH mothers may hold different perspectives from fathers, and those perspectives will be somewhat lacking in the current study. Second, the research nurses had varying levels and kinds of experience in our study. There were two senior head nurses who worked on an HIV unit for more than 20 years and two junior nurses who recently graduated from college. The senior nurses earned more trust from PLWH parents compared to junior research nurses, so the quality of the counseling sessions might be different. Third, this study was conducted in Shanghai, a comparatively resource-rich setting, and may not be generalizable to the many resource-limited areas in China. Fourth,

during the intervention, the research nurses' skills were easily influenced by the research nurses' personal biases and idiosyncrasies. Therefore, although the intervention nurses were uniformly trained by the U.S. research team members, there might still have been some individual differences affecting the data. Last, we did not have access to the participants' children; therefore, we were not able to compare direct assessment of their perspectives compared to the responses reported by parents.

In conclusion, parental HIV disclosure is an ongoing process and not a linear path with an end-point (Dwivedi et al., 2015). We presented a unique perspective on the process of parental HIV disclosure in Chinese society. China's collectivistic culture and high level of stigma toward PLWH restrains parental disclosure. The rate of parental HIV disclosure to children is low, and parents are less likely to communicate with their children about sensitive topics, such as HIV and sex. Healthcare providers should consider assisting HIV-infected parents to consider decisions around disclosure when parents seek help. Providing efficient coping strategies, decreasing self-stigma and enhancing social support from family members should be encouraged. Findings from this study provide insights on parental perspectives that will be helpful for future research on implementation and dissemination of disclosure support interventions for HIV-positive parents in China.

Acknowledgments

We gratefully acknowledge the study participants who generously shared their experiences with us. We would also like to thank Dr. Jane M. Simoni and her colleagues who train the nurse interventionists in this study. We want to also acknowledge all staffs at the Shanghai Public Health Clinical Center and BeautifulLife for their assistance and support with this research.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: **This project is supported** by the National Institute of Child Health and Human Development, National Institute of Nursing Research, National Institute of Mental Health of the National Institutes of Health and National Institute of Minority and Health and Health Disparities, under Award Numbers [R21HD074141], [K23NR14107], [R03MD012210] and [R21TW011277]. In addition, the research was also supported by Shanghai Municipal Commission of Health and Family Planning under award numbers [20174Y0066].

ORCID iD

Wei-Ti Chen  <https://orcid.org/0000-0002-2342-045X>

Supplemental Material

Supplemental material for this article is available online.

References

- Abdulrahman, R., Stuard, E., Vachon, M. E., Nicholas, C., Neugebauer, R., Hagmann, S. H., & Purswani, M. U. (2017). Predictors of disclosure of maternal HIV status by caregivers to their children in an inner-city community in the United States. *AIDS and Behavior, 21*(1), 141–151. <https://doi.org/10.1007/s10461-016-1372-3>
- Chaudhury, S., Kirk, C. M., Ingabire, C., Mukunzi, S., Nyirandagijimana, B., Godfrey, K., Brennan, R. T., & Betancourt, T. S. (2016). HIV status disclosure through family-based intervention supports parenting and child mental health in Rwanda. *Frontiers in Public Health, 4*, 138. <https://doi.org/10.3389/fpubh.2016.00138>
- Chaudoir, S. R., Fisher, J. D., & Simoni, J. M. (2011). Understanding HIV disclosure: A review and application of the Disclosure Processes Model. *Social Science & Medicine, 72*(10), 1618–1629. <https://doi.org/10.1016/j.socscimed.2011.03.028>
- Chen, M., Liao, Y., Liu, J., Fang, W., Hong, N., Ye, X., Li, J., Tang, Q., Pan, W., & Liao, W. (2016). Comparison of sexual knowledge, attitude, and behavior between female Chinese college students from urban areas and rural areas: A hidden challenge for HIV/AIDS control in China. *BioMed Research International, 2016*, 1–10. <https://doi.org/10.1155/2016/8175921>
- Chen, W. T., & Barbour, R. (2017). Life priorities in the HIV-positive Asians: A text-mining analysis in young vs. old generation. *AIDS Care, 29*(4), 507–510. <https://doi.org/10.1080/09540121.2016.1221029>
- Chen, W. T., Shiu, C., Yang, J. P., Chuang, P., Zhang, L., Bao, M., & Lu, H. (2018). A structural equation model of patient-health-care provider relationships and HIV-infected patient outcomes in Chinese populations. *AIDS Care, 30*(3), 383–390. <https://doi.org/10.1080/09540121.2017.1380778>
- Clifford, G., Craig, G. M., McCourt, C., & Barrow, G. (2013). 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 Medical Journal, 62*(4), 357–363. <https://doi.org/10.7727/WIMJ.2013.087>
- Conserve, D. F., Teti, M., Shin, G., Iwelunmor, J., Handler, L., & Maman, S. (2017). A systematic review and narrative synthesis of interventions for Parental Human Immunodeficiency Virus Disclosure. *Frontiers in Public Health, 5*, 187. <https://doi.org/10.3389/fpubh.2017.00187>
- Dwivedi, P., Patkar, P., & Beard, J. (2015). Necessity of systematic HIV disclosure in HIV-infected families: Committed Communities Development trust's approach and intervention. *Indian Pediatrics, 52*(5), 375–378.
- Gachanja, G., Burkholder, G. J., & Ferraro, A. (2014). HIV-positive parents, HIV-positive children, and HIV-negative children's perspectives on disclosure of a parent's and child's illness in Kenya. *PeerJ, 2*, e486. <https://doi.org/10.7717/peerj.486>
- Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today, 24*(2), 105–112.
- Henrickson, M., Brown, D. B., Fouche, C., Poindexter, C. C., & Scott, K. (2013). 'Just talking about it opens your heart': Meaning-making among Black African migrants and refugees living with HIV. *Culture, Health & Sexuality, 15*(8), 910–923. <https://doi.org/10.1080/13691058.2013.790076>
- Ho, L. P., & Goh, E. C. L. (2017). How HIV patients construct liveable identities in a shame based culture: The case of Singapore. *International Journal of Qualitative Studies on Health and Well-being, 12*(1), 1333899. <https://doi.org/10.1080/17482631.2017.1333899>
- Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Quality Health Research, 15*(9), 1277–1288. <https://doi.org/10.1177/1049732305276687>
- Hu, C. S., Ferrari, M., Liu, R. D., Gao, Q., & Weare, E. (2016). Mainland Chinese implicit theory of wisdom: Generational and cultural differences. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 73*(8):1416–1424. <https://doi.org/10.1093/geronb/gbw157>
- Kyaddondo, D., Wanyenze, R. K., Kinsman, J., & Hardon, A. (2013). Disclosure of HIV status between parents and children in Uganda in the context of greater access to treatment. *SAHARA-J: Journal of Social Aspects of HIV/AIDS, 10*(Suppl. 1), S37–S45. <https://doi.org/10.1080/02664763.2012.755323>
- Liamputtong, P., & Haritavorn, N. (2016). To tell or not to tell: Disclosure to children and family amongst Thai women living with HIV/AIDS. *Health Promotion International, 31*(1), 23–32. <https://doi.org/10.1093/heapro/dau057>
- Loutfy, M., Johnson, M., Walmsley, S., Samarina, A., Vasquez, P., Hao-Lan, H., Madihlaba, T., Martinez-Tristani, M., & van Wyk, J. (2016). The Association between HIV disclosure status and perceived barriers to care faced by women living with HIV in Latin America, China, Central/Eastern Europe, and Western Europe/Canada. *AIDS Patient Care STDS, 30*(9), 435–444. <https://doi.org/10.1089/apc.2016.0049>
- Ma, Q., Tso, L. S., Rich, Z. C., Hall, B. J., Beanland, R., Li, H., Lackey, M., Hu, F., Cai, W., Doherty, M., & Tucker, J. D. (2016). Barriers and facilitators of interventions for improving antiretroviral therapy adherence: A systematic review of global qualitative evidence. *Journal of the International AIDS Society, 19*(1), 21166. <https://doi.org/10.7448/IAS.19.1.21166>
- Mao, Y., Li, X., Qiao, S., Zhao, Q., Zhou, Y., & Shen, Z. (2018). Social support, stigma, and HIV disclosure among parents living with HIV in Guangxi, China. *AIDS Care, 30*(2), 168–172. <https://doi.org/10.1080/09540121.2017.1387639>
- Mellor, D., Xu, X., Wong, J., & Richardson, B. (2014). The factor structure of the Chinese family assessment instrument adapted for parent report. *Assessment, 21*(1), 60–66. <https://doi.org/10.1177/107319111425855>
- Mkwanazi, N. B., Roachat, T. J., & Bland, R. M. (2017). The Amagugu intervention: A qualitative investigation into maternal experiences and perspectives of a maternal HIV disclosure support intervention in rural South Africa. *Health Policy and Planning, 32*(9), 1231–1240. <https://doi.org/10.1093/heapol/czx056>
- Mu, W., Zhao, Y., Khoshnood, K., Cheng, Y., Sun, X., Liu, X., Xu, W., Wang, S., Ma, Y., & Zhang, F. (2015). Knowledge and perceptions of sexual and reproductive health and HIV among perinatally HIV-infected adolescents in rural China.

- AIDS Care*, 27(9), 1137–1142. <https://doi.org/10.1080/09540121.2015.1032206>
- Murphy, D. A., Armistead, L., Marelich, W. D., Payne, D. L., & Herbeck, D. M. (2011). Pilot trial of a disclosure intervention for HIV+ mothers: The TRACK program. *Journal of Consulting and Clinical Psychology*, 79(2), 203–214. <https://doi.org/10.1037/a0022896>
- Murphy, D. A., Roberts, K. J., & Herbeck, D. M. (2013). Adolescent response to having an HIV-infected mother. *AIDS Care*, 25(6), 715–720. <https://doi.org/10.1080/09540121.2013.769495>
- Qiao, S., Li, X., & Stanton, B. (2013a). Disclosure of parental HIV infection to children: A systematic review of global literature. *AIDS and Behavior*, 17(1), 369–389. <https://doi.org/10.1007/s10461-011-0069-x>
- Qiao, S., Li, X., & Stanton, B. (2013b). Theoretical models of parental HIV disclosure: A critical review. *AIDS Care*, 25(3), 326–336. <https://doi.org/10.1080/09540121.2012.712658>
- Qiao, S., Li, X., Zhou, Y., Shen, Z., Tang, Z., & Stanton, B. (2015a). Factors influencing the decision-making of parental HIV disclosure: A socio-ecological approach. *AIDS*, 29(1), S25–S34. <https://doi.org/10.1097/QAD.0000000000000670>
- Qiao, S., Li, X., Zhou, Y., Shen, Z., Tang, Z., & Stanton, B. (2015b). The role of enacted stigma in parental HIV disclosure among HIV-infected parents in China. *AIDS Care*, 27(Suppl. 1), 28–35. <https://doi.org/10.1080/09540121.2015.1034648>
- Qiao, S., Nie, J. B., Tucker, J., Rennie, S., & Li, X. M. (2015c). The role of social relationship in HIV healing and its implications in HIV cure in China. *Health Psychology and Behavioral Medicine*, 3(1), 115–127. <https://doi.org/10.1080/21642850.2015.1040405>
- Rochat, T. J., Mitchell, J., Lubbe, A. M., Stein, A., Tomlinson, M., & Bland, R. M. (2017). Communication about HIV and death: Maternal reports of primary school-aged children's questions after maternal HIV disclosure in rural South Africa. *Social Science & Medicine*, 172, 124–134. <https://doi.org/10.1016/j.socscimed.2016.10.031>
- Sandelowski, M. J. (2008). Justifying qualitative research. *Research in Nursing & Health*, 31(3), 193–195.
- Sauders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B., Burroughs, H., & Jinks, C. (2018). Saturation in qualitative research: Exploring its conceptualization and operationalization. *Qualitative & Quantity*, 52(4), 1893–1907. <https://doi.org/10.1007/s11135-017-0574-8>
- Simoni, J. M., Yang, J. P., Shiu, C. S., Chen, W. T., Udell, W., Bao, M., Zhang, L., & Lu, H. (2015). Nurse-delivered counseling intervention for parental HIV disclosure: Results from a pilot randomized controlled trial in China. *AIDS*, 29(Suppl. 1), S99–S107. <https://doi.org/10.1097/QAD.0000000000000664>
- Tan, C., Chen, W., Wu, Y., & Chen, S. (2013). Chinese medicine for mental disorder and its applications in psychosomatic diseases. *Alternative Therapies in Health and Medicine*, 19(1), 59–69.
- World Health Organization. (2016). Consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations: 2016 update. *World Health Organization*. Retrieved from <http://www.who.int/hiv/pub/guidelines/keypopulations-2016/en/>
- Yang, J. P., Xie, T., Simoni, J. M., Shiu, C. S., Chen, W. T., Zhao, H., & Lu, H. (2016). A mixed-methods study supporting a model of Chinese parental HIV disclosure. *AIDS and Behavior*, 20(1), 165–173. <https://doi.org/10.1007/s10461-015-1070-6>
- Zhang, L., Chen, W. T., Yang, J. P., Simoni, J. M., Shiu, C., Bao, M., Zhang, J., Sun, M., Qiu, Y., & Lu, H. (2017). Disclosing parental HIV status to children in China: Lessons learned through an intervention study. *Journal of the Association of Nurses in AIDS Care*, 28(1), 130–141. <https://doi.org/10.1016/j.jana.2016.09.006>
- Zhou, Y., Zhang, L., Li, X., & Kaljee, L. (2013). Do Chinese parents with HIV tell their children the truth? A qualitative preliminary study of parental HIV disclosure in China. *Child: Care, Health and Development*, 39(6), 816–824. <https://doi.org/10.1111/j.1365-2214.2012.01394.x>

Author biographies

Meiyan Sun, RN, MSN, is a case manager, Department of Nursing, Shanghai Public Health Clinical Center, Fudan University, Shanghai, China.

Wei-Ti Chen, PhD, CNM, RN, FAAN, is an associate professor, School of Nursing, University of California, Los Angeles, CA, USA.

Joyce P. Yang, PhD, is an assistant professor, Department of Psychology, University of San Francisco, San Francisco, CA, USA.

Shuyuan Huang, RN, MPH, is a doctoral student, School of Nursing, Yale University, Orange, CT, USA.

Lin Zhang, RN, MPH, MBA, is the nursing director, Shanghai Public Health Clinical Center, Fudan University, Shanghai, China.

Mingfeng Shi, RN, is a staff nurse, Department of Nursing, Shanghai Public Health Clinical Center, Fudan University, Shanghai, China.

Wei Li, RN, is a staff nurse, Department of Nursing, Shanghai Public Health Clinical Center, Fudan University, Shanghai, China.

Ye Li, RN, is a staff nurse, Department of Nursing, Shanghai Public Health Clinical Center, Fudan University, Shanghai, China.

Meijuan Bao, RN, BS, is the director of Nursing Research, Shanghai Public Health Clinical Center, Fudan University, Shanghai, China.

Hongzhou Lu, MD, PhD, is a professor, the president, Shanghai Public Health Clinical Center, Fudan University, Shanghai, China.