

A Mixed-Methods Study Supporting a Model of Chinese Parental HIV Disclosure

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Published online: 16 April 2015

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Abstract Parents who are HIV-positive confront difficult decisions regarding whether, when, and how to disclose their HIV status to their children. In China, a setting of acute HIV stigma where family harmony is culturally valued, limited research has been conducted on parental disclosure. We aimed to develop a model of parental disclosure that accounts for the cultural context in China based on a mixed-methods study. In our individual, in-depth interviews ($N = 24$) as well as survey data ($N = 84$) collected from parents living with HIV in Shanghai and Beijing, we found the primary barriers to disclosure were stigma, fear of exposing the mode by which they acquired HIV, psychologically burdening the child, rejection by the child, and negative social consequences for the family. Parents concurrently cited many motivations for disclosure, such as disease progression, ensuring safety of the child, gaining assistance, and fulfilling their parental responsibility. Most parents had not actively disclosed their HIV status (68 %);

many parents reported some form of partial disclosure (e.g., sharing they have a blood disease but not labeling it HIV), unplanned disclosure, or unintentional disclosure to their children by other people. Findings informed the development of a Chinese Parental HIV Disclosure Model, with primary components accounting for distal cultural factors, decision-making (balancing approach and avoid motivations), the disclosure event, and outcomes resulting from the disclosure. This model highlights the cultural context of the Chinese parental disclosure process, and may be useful in guiding future observational research and intervention work.

Keywords HIV/AIDS · Disclosure · Parents · Children · China

Introduction

Parents who are HIV-positive face a difficult decision-making process regarding whether, when, and how to disclose their status to their children. The increasing availability and efficacy of antiretroviral therapy has improved the life expectancy and health for HIV-positive individuals, thereby allowing HIV-positive parents a lifetime to raise their children. The issue of parental HIV disclosure therefore increases in complexity, as parents must balance a wide range of reasons for and against disclosure, including considering its impact on the physical and psychological health of parents themselves, their children, and the rest of their family [1]. Understandably, disclosure to children is one of HIV-positive parents' primary concerns [2, 3]. Indeed, HIV-positive parents experience more distress than parents with other illnesses do [4].

In the United States, backed by the American Academy of Pediatrics [5], clinicians generally encourage serostatus disclosure. Reasons cited in the literature supporting

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disclosure include: acknowledging that keeping family secrets can be destructive [6], providing information to protect children from also becoming infected [7], obtaining social support from children [8], and preparing children for possible parental death [9].

However, the research is inconclusive about the impact of disclosure on child, parental, and family well-being. Findings range from negative, such as more adolescent externalizing behaviors and increased family stressors [10], to neutral or no psychological impact [11, 12], to positive, such as improved maternal wellbeing, adherence to HIV medication, and child mood [3]. Furthermore, the impact of nondisclosure is similarly complex. On the surface, nondisclosure may seem like an easier option that bypasses the possible negative consequences of disclosure. However, quantitative studies have found associations between nondisclosure and increased fear and anxiety in children [13], as well as increased anxiety and psychological pressure and decreased quality of life in the person living with HIV [14]. Furthermore, qualitative studies with AIDS orphans have reported their regret over losing the opportunity to support their parents and spend quality time with them [15]. These findings suggest that nondisclosure is also not a harmless alternative across the board.

While impact of disclosure is ambiguous as of yet in the literature, several patterns have emerged regarding rates of actual parental disclosure. HIV-positive parents in low mental health resource settings tend to disclose at a lower rate than in the United States. Additionally, forced, unplanned, or unintentional disclosures are common, which are likely to lead to greater negative consequences [7, 16].

China is a low mental health resource setting with increasing numbers of parents living with HIV [17]. The limited research conducted in China on parental HIV disclosure indicates that engaging in serostatus disclosure to family members is generally associated with significant psychological distress [18]. Research is needed in China on the issue of parental HIV disclosure to understand the levels of parental distress about disclosure, their culturally specific barriers and facilitators to disclosure, and their current decision-making considerations, in order to better support their experience through this process.

In the present mixed-methods study, we collected qualitative and quantitative data on parental disclosure of HIV in China. Given the lack of a specific parental HIV disclosure model, we sought to understand the disclosure process in order to inform a theoretical model of disclosure that would be culturally applicable for China.

Methods

In this two-stage study, we first conducted in-depth qualitative interviews (in 2010–2011) to understand the experiences of mental health and HIV disclosure among

Chinese individuals living with HIV/AIDS. A quantitative survey was later conducted (in 2012) to obtain descriptive information about a larger sample of people living with HIV/AIDS (PLWHA), with questions on disclosure derived from the qualitative interviews. Qualitative data were collected in China from the HIV/AIDS clinic at the Shanghai Public Health Clinical Center (SPHCC; affiliated with Fudan University) and from the AIDS ward at Beijing Ditan Hospital (affiliated with Capital Medical University). Quantitative data were collected from Ditan Hospital only. The Institutional Review Boards (IRB) at University of Washington, SPHCC, and Ditan Hospital approved study procedures.

Potential study participants at both sites were approached directly by clinic staff and informed about the study. Interested patients were then referred to research staff who explained in greater detail the purpose, procedures, and potential risks and benefits of the study and obtained written informed consent. Convenience samples of participants were recruited separately for the qualitative ($n = 19$ from SPHCC and $n = 12$ from Ditan Hospital) and quantitative ($N = 200$ from Ditan Hospital) stages of the study. Eligible individuals were HIV-positive patients who were 18 years of age or older, Mandarin-speaking, and receiving HIV-related care at Ditan Hospital or SPHCC. Exclusion criteria were psychological or cognitive impairment that would affect study participation, as informally assessed by medical providers. Participants were recruited as part of a larger study aimed at understanding mental health and well-being of people living with HIV/AIDS. Only participants who were parents were included in the present analysis of serostatus disclosure to children, yielding a qualitative sample of $N = 24$ and a quantitative sample of $N = 84$. Compared to non-parent survey participants, the parents were older, had lower incomes and education levels, were less likely to be working full time, and more likely to be married and self-identify as heterosexual (data not shown).

Qualitative Study

Semi-structured, in-depth qualitative interviews were conducted in Mandarin by the first, fourth, and fifth authors at Ditan Hospital and SPHCC. Participants received 100 RMB (~USD\$15) for their participation in audio-recorded 1–1.5 h-long interviews. Interviewers used an interview guide designed to collect exploratory data on participants' psychological experiences living with HIV/AIDS, including open-ended questions about receiving their diagnosis, disclosure, HIV-related discrimination, family functioning, social support, and mental health. Specific prompts around disclosure experiences included: *Who knows about your HIV status? How did they learn*

about it? How did you decide whether or not to tell them about your HIV status? What impact did the disclosure have on you and those involved? Responses referring to experiences with children are the focus of the current analyses.

Participants

Of the $N = 24$ participants, 9 were male and 15 were female. Age ranged from 32 to 66 years, with a median of 46. Of the 9 male participants, 7 acquired HIV through sex with other men and 2 did not know their transmission route. Of the 15 female participants, 6 acquired HIV through heterosexual sex; 1 each were infected through plasma blood selling, needle use, and medical procedures; and 6 did not know how they were infected. Participants were heterogeneous in many regards. In terms of education, participants ranged from completing middle school to obtaining graduate degrees. Some were unemployed, others employed full time. Participants also ranged in the length of time they were parents, with some having toddler-aged children and others having adult-aged children. Some participants were diagnosed with HIV within the last year, whereas others had been HIV-positive for over a decade. Nine of the participants had children who knew about their HIV-diagnosis; of these participants, 4 experienced unintentional disclosure in which the children were either informed by other people or by accident, and 5 participants intentionally made efforts to disclose to their children (ranging from direct conversation to indirect methods such as leaving medication out until there is mutual, unspoken understanding).

Data Analysis

Audio recordings of the interviews were transcribed verbatim in Chinese. Each transcript was reviewed for accuracy to the audio recording by at least one additional research staff member. Data were independently coded in Atlas.ti 5.2 [19] using a constant comparison analysis framework [20] by three teams of research assistants, each of whom were Mandarin-speaking Chinese individuals. Discrepancies in codes were reconciled by group consensus.

Quantitative Study

The 84 participants who were parents living with HIV and included in this data analysis completed an hour-long paper-and-pencil survey of demographics, mental health symptomatology, and disclosure practices, and received RMB 100 (~USD \$15) for their participation.

Measures

Participants responded to a measure of demographics assessing age, gender, number and age of children, marital status, sex of sexual partners, education, income, and occupation. Participants also responded to items, derived from the qualitative data, on their disclosure behaviors (ranging from engaging in full disclosure to engaging in no disclosure) and their cognitions around disclosure, including what they perceived were motivators and barriers to disclosure to children.

Participants

Demographic characteristics are presented in Table 1. Among the total sample of 84 parents, 70.2 % were male, with a mean age of 41.7 years (SD 9.0; range 25–78). The majority of participants (60.7 %) were currently married or with a steady partner, 36.8 % were divorced, widowed, or separated. Interestingly, likely because participants were all parents in China, only 1 participant had never been married.

Data Analysis

Independent samples t tests and χ^2 tests were used to examine differences in disclosure practices between fathers and mothers of different demographics. Descriptive analyses were also conducted for disclosure practices.

Results

Qualitative Findings

Our analyses of participants' responses to prompts around disclosure yielded three primary themes: barriers to disclosure, motivators for disclosure, and experiences with disclosure.

Theme 1: Barriers to Disclosure

Parents reported five primary barriers to wanting to or being able to disclose their HIV status to their children: stigma, fear of exposing the mode by which they acquired HIV, psychologically burdening the child, rejection by the child, and negative social consequences for the family.

Parents discussed the prevalence of HIV-related stigma in China, ranging from experiencing derogatory messages from official governmental campaigns for HIV prevention, to the stigmatizing tone in stories related to HIV in popular media.

Table 1 Socio-demographic characteristics of parents living with HIV/AIDS in Beijing and Shanghai, China ($N = 84$)

Characteristic	n (%)
Sex	
Female	25 (29.8)
Male	59 (70.2)
Age in years; M (SD)	41.7 (9.0)
Marital status	
Married or steady partner	51 (60.7)
Single, never married	1 (1.2)
Other (divorced, widowed, separated)	31 (36.8)
Sexual partner	
Same sex	19 (22.6)
Opposite sex	42 (50.0)
Both	7 (8.3)
Refuse to answer	11 (13.1)
Missing data	5 (6.0)
Education	
Primary or lower	7 (8.4)
Middle school graduation	17 (20.2)
High school graduation	21 (25.0)
Professional/vocational training school	10 (11.9)
Above high school (college & post-college)	28 (33.4)
Employment	
Full time	29 (34.5)
Part time	9 (10.7)
Unemployed	44 (52.4)
Annual household income (RMB)	
≤ 2000	40 (47.6)
2001–5000	29 (34.6)
≥ 5000	10 (11.9)

There is too much stigma. The government puts up media campaigns titled, ‘Stay away from AIDS’. It’s supposed to keep people safe from STDs, but if they tell you to stay away, it’s also like saying stay away from people with AIDS.—Father, 53 years old (yo)

Fathers, who acquired HIV through sexual transmission, whether via commercial sex or having sex with other men, reported that a major barrier to disclosure was *fear that their mode of acquiring HIV would be exposed*.

I can’t tell my son about my HIV because then he will ask how I got this disease, and of course I cannot tell him that I got it through having sexual relationships with other men.—Father, age N/A

Parents repeatedly stated being worried that disclosure would *create unnecessary or unbearable psychological burden* for their children. They were particularly concerned about avoiding disclosure during “critical periods”, such as

prior to sitting for high school or college entrance exams, during stressful times at school or work, or if children were in the beginning of a romantic relationship, in order to not adversely affect the relationship, or cause the child to have to keep a secret from his or her romantic partner.

If I told my child, I would have to choose a better time to do it...I would want him ... to be able to enjoy a normal young person’s life. After a decade or two, maybe when he is an adult and married and has his own family. Maybe then I will tell him.—Father, 48 yo

I cannot tell my son right now. He is close to getting married. If I tell him, it will put him in a difficult position with his girlfriend and maybe her family will not accept us, or maybe it will ruin the relationship.—Mother, 50 yo

Parents had some fear about *rejection by their children*, primarily framed as children possibly losing respect for their parents.

What if my child cannot respect me anymore? Children are supposed to respect their parents.—Mother, 33 yo

Parents feared *possible negative social or practical consequences for the child and family*, primarily due to worry that children would not be able to keep the disclosure a secret. Parents reported knowing other families whose children had revealed their parent’s HIV status to others. Some of these families subsequently were ostracized by neighbors, were forced out of their village of residence, lost their jobs, or were asked to remove their children from school.

My child is too young. If she tells her teacher or classmates, she might get kicked out of school.—Mother, 34 yo

Theme 2: Motivators for Disclosure

Although parents endorsed significant concerns that served as barriers to disclosing their HIV status to their children, they also mentioned four primary circumstances or factors under which they would plan to disclose or be motivated towards disclosure: disease progression, safety of the child, gaining assistance, and fulfilling their parental responsibility.

Parents commonly reported that they anticipated a day in which their *disease would progress* to a point where their HIV status could no longer be hidden.

Anyway, I will have to tell my child one day, because this disease is going to progress to a serious point

where it will show. So when it shows, I will tell.—
Father 50 yo

Parents endorsed wanting to tell their children about their HIV in order to *keep their children safe*. Parents emphasized the importance of providing sex education for their children and highlighted the necessity of safe sex practices to prevent STD transmission, allowing their children to learn from their experiences. Additionally, parents wanted to protect their children from acquiring HIV from them, so were motivated to explain the possible routes of HIV transmission (e.g., warning children to take particular care to avoid contact with blood in the event of an accident).

I plan to tell my son so he doesn't make the same mistakes I did. He's growing older and he has a naughty spirit, like I did, so I want him to know that it's dangerous out there. I want to tell him not to mess around.—Father, 48 yo

Parents also described how they were motivated by the *possibility of assistance* from children upon disclosure. This assistance included children being more considerate of the parent and more motivated to help out with chores, helping parents remember to take their HIV medication, and supporting parents through the experience of being ill. Parents had different expectations of their children based on age. From older children, parents anticipated social support in the form of financial assistance or tangible social support such as transportation to the clinic. From younger children, parents hoped for better behavior, more discipline, and consideration. They were concerned that their children be prepared for a future in which they might not be there to support them.

She has to be a better kid; not get into trouble. If I cannot be around to take care of her, she has to learn now.—Mother, 40 yo

Finally, many parents described a disclosure plan far in the future, potentially on their deathbed. They discussed a desire to fulfill a parental responsibility to tell their children the truth, about a burden that they had held on to for a lifetime.

Before death, I will tell my child. That's the way it should be. That's a parental responsibility.—Father, 50 yo

Theme 3: Experiences of Disclosure

Few parents in our sample had the experience of intentionally engaging in a direct, verbal disclosure with their children. Of the parents who had progressed beyond

contemplating disclosure to children, some form of partial disclosure was much more likely. For example, many parents reported that disclosure had occurred without their planning or intention. This unintentional disclosure often took the form of another person disclosing on their behalf (typically without consent).

The doctor, he just loudly said “You have HIV!” in front of everybody. My daughter, husband, my whole family, everybody. So she [my daughter] knows.—
Mother 33 yo

Other parents reported accidentally disclosing during an emotional discussion with their children; some parents disclosed their spouse's HIV status when angry with the child, in an effort to convey the gravity of the situation.

He [my son] was so disobedient and acting out. I was so angry and said, “Don't you know your mother is already sick!” So I ended up telling him like that.—
Father 48 yo

Parents also reported taking a “test the waters” approach to disclosure, indirectly informing their children of their HIV status. For example, parents left labeled anti-retroviral medications visible around the house, or took their children with them to clinic appointments, where their children sat in the waiting room of a clinic clearly marked as an infectious disease facility.

She [my daughter] should know since I take her to doctor's appointments here all the time, and it says clearly on the windows ‘Infectious Disease Clinic’.—
Mother, 44 yo

Other parents took a direct approach of telling their children that something was wrong with them physically, without informing them about HIV. For example, many parents reported telling children they had a generic blood disease and others told their children they had hepatitis. This method allowed them to teach their children about safeguards or protections (such as being careful to avoid blood contact) without disclosing their HIV.

I told my child I have a blood disease. I didn't say HIV, but she knows it travels in blood.—Mother, 46 yo

We told our child that we have a disease, just like hepatitis. It's not a problem because people live just fine with hepatitis all the time.—Father, 39 yo

Quantitative Findings

Based on themes emerging from the qualitative data, we created a questionnaire on disclosure behaviors with

multiple-choice questions that we used in the quantitative phase of this project. See Table 2 for detailed quantitative findings. Compared to mothers ($n = 25$), fathers ($n = 59$) were older $t(80) = 2.0$, $p < 0.05$; had higher education levels $\chi^2(7, n = 83) = 15.1$, $p < 0.05$; and more likely to identify as gay or bisexual $\chi^2(3, n = 79) = 9.6$, $p < 0.05$. They did not differ in terms of other demographic factors. The likelihood of disclosing to children, the amount of time between diagnosis and disclosure, and likelihood of intentional versus unintentional disclosure did not differ based on demographic factors of parent gender, employment status, education level, and sexual identification.

Our quantitative findings supported themes from our qualitative data. Specifically, a majority of parents (70 %) reported that their children did not know about their HIV status. Of the remaining parents who reported that their children did know about their HIV status, less than half had directly informed their children. Parents ranged in the amount of time between diagnosis and disclosure, with half of those who disclosed doing so within 1 year of finding out about the diagnosis. Of parents who had disclosed directly, their primary reasons for disclosure were that their children saw their medication around the house, the disease had progressed to a point that it could not be hidden, or they were worried about their children's safety. When given forced-choice questions of how disclosure affected their relationship with their children, parents were more likely to report that the immediate response of their children was positive (87 %; e.g., demonstrating willingness to help parents) compared to negative (13 %; e.g., rejecting the parents). However, regarding longer-term impact, 59 % indicated the impact was positive, while 41 % indicated that the impact was negative.

Parents were given the opportunity to endorse all the consequences they experienced as a result of the disclosure. The three most commonly were: experiencing general social stigma about HIV/AIDS, losing face and feeling shame, and being rejected by their neighbors. They were also given the opportunity to endorse all the consequences they thought their children experienced as a result of the disclosure. The most commonly reported consequences were: children worrying about parental health, children having increased psychological burden, and children being concerned for the family's financial situation.

Among parents who had children who were not aware of their HIV, a third reported that they would never tell their children (33 %), while the remaining were unclear about this decision (25 %), or were planning to disclose to their children at a later time (40 %). For these parents, the two most commonly anticipated reasons for disclosure are to educate their children about STDs and associated dangers (37 %) and because their disease has progressed to a point where it can no longer be hidden (21 %).

All parents, regardless of disclosure status, endorsed having concerns about the decision-making process. Barriers to disclosure that parents endorsed most frequently were concerns about general societal stigma about HIV/AIDS (72.4 %), neighbor's opinions about HIV/AIDS (70.1 %), and the possibility of their children being stigmatized by peers or others (63.2 %).

Conceptual Contributions: Chinese Parental HIV Disclosure Model

Based on the qualitative and quantitative data analysis above, we adapted Chaudoir and Fisher's Disclosure Process Model [21] for application to parental disclosure in a Chinese cultural context. The Disclosure Process Model comprises three main components: decision-making (balancing approach and avoid motivations), the disclosure event, and outcomes resulting from the disclosure. Our cultural extension of the model was further informed by input from stakeholders [22, 23] of Community Advisory Board members, HIV healthcare providers, and family caregivers from the clinic communities, who reviewed our themes and conclusions after our data analysis. We made three key conceptual extensions, creating the Chinese Parental HIV Disclosure Model (see Fig. 1). First, we added an entire component of distal factors of the *cultural context* to the model to acknowledge China as a setting with acute societal and community-based HIV stigma and low mental health resources, as well as emphasis on a harmonious family unit with prescribed parental and child roles and responsibilities. Second, we anchored the original decision-making approach and avoid motivations to Chinese-specific concerns as well as parental disclosure-specific concerns. We clarified approach motivations such as wanting to gain social support, educate children about HIV transmission risks, and fulfill parental responsibility, as well as avoid motivations such as fear of exposure of parents' HIV transmission route, potential consequences from the community if the child cannot keep the parent's HIV status a secret, and psychological burden on the child. Third, we broadened the outcomes of the disclosure event to encompass the impact on the parent, child, and family well-being.

Discussion

In one of the few studies addressing parental HIV disclosure to children in China, we conducted mixed-methods research with Chinese parents living with HIV to describe their experiences undergoing the disclosure decision-making process. Our qualitative and quantitative data converged to reveal motivations, barriers, and experiences of

Table 2 Quantitative data from disclosure behaviors measure ($N = 84$)

Items	<i>n</i> (%)
Does your child know about your HIV status?	
No	57 (67.9)
Yes	23 (27.4)
Maybe	4 (4.8)
For parents whose children likely know about their HIV status	27 (32.2)
When did you disclose to your child?	
Immediately after diagnosis	6 (22.2)
Within 1 month of finding out about the diagnosis	4 (14.8)
Within 1 year of finding out about the diagnosis	4 (14.8)
Many years after finding out about the diagnosis	4 (14.8)
Unable to answer because parent does not know	9 (33.3)
How did your child find out?	
PLWHA told directly	14 (51.9)
Other people told children	8 (29.6)
Indirectly telling them, e.g., leaving medication out	3 (11.1)
What was the primary reason motivating disclosure to your child?	
My child saw my medication	12 (44.4)
Disease progressed to a degree it could not be hidden	6 (22.2)
Worry about child's safety (STI/STD education)	4 (14.8)
What is the longer term impact of disclosure on your child?	
Positive	13 (48.1)
Negative	4 (14.8)
What consequences did you experience as a result of disclosing to your child?	
Receiving general social stigma	8 (29.6)
Losing face and feeling shame	4 (14.8)
Being rejected by neighbors	4 (14.8)
What consequences did your child experience as a result of disclosing to him/her?	
Child worried about parental health	16 (59.3)
Child experienced psychological burden	8 (29.6)
Child concerned about financial situation of the family	6 (22.2)
For parents whose children do not know their HIV status	64 (76.2)
What are your future plans for disclosure?	
I will never tell my child	24 (37.5)
I will tell my child at an appropriate time in the future	19 (29.7)
I am not sure	17 (26.6)
The main reason why I think I will disclose my HIV status is	
To educate my child about STDs and associated dangers	19 (29.7)
Because my disease has progressed to a point where it can no longer be hidden	15 (23.4)
Because they have a right to know	9 (14.1)
The main reason why I do not want to disclose my HIV status is	
General societal stigma about HIV/AIDS	45 (70.3)
Neighbor's opinions about HIV/AIDS	43 (67.2)
My child will experience stigma from peers or society	43 (67.2)

disclosure. Interestingly, although our qualitative and quantitative data revealed similar anticipated motivations for disclosure (i.e., parents who had not yet disclosed in both samples anticipated that they would like to disclose one day in order to educate their children about STDs,

because they had a right to know, and because they anticipated their disease progressing to a point where it could no longer be hidden), parents in the quantitative sample who actually engaged in disclosure did so for different reasons than the anticipated reasons. The most common

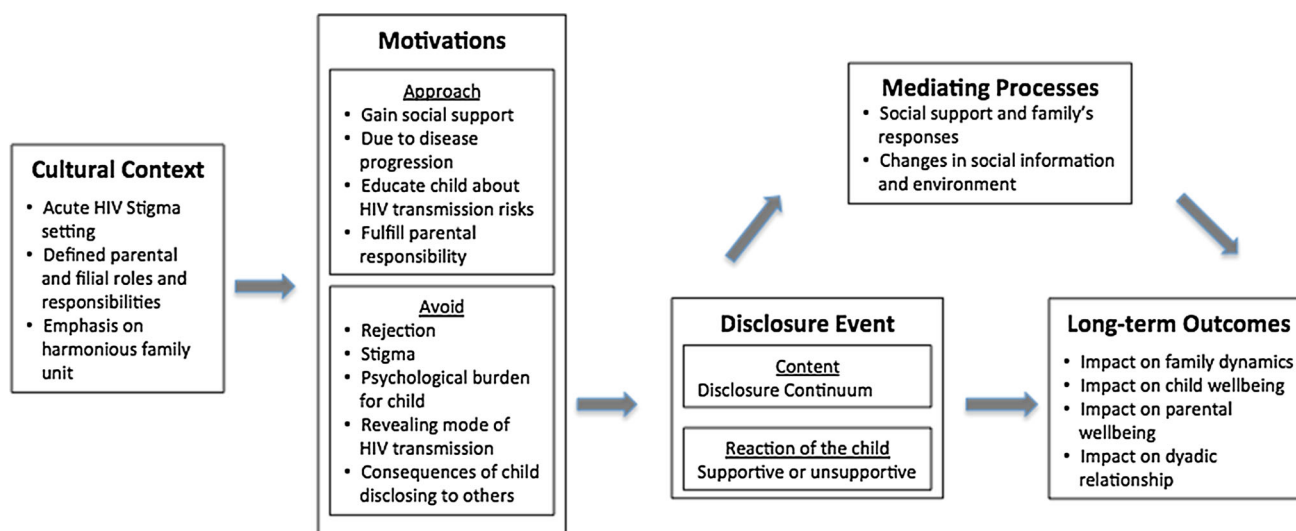


Fig. 1 Chinese Parental HIV Disclosure Model

reason for engaging in disclosure was because their children had already seen their medications around and asked questions. This may suggest that their 'hand was forced' to disclose. Furthermore, in anticipating future disclosure, over a third of parents (37.5 %) endorsed never planning to disclose. At the same time, parents in both samples reported having significant concerns and distress about disclosure. Taken together, these findings demonstrate the importance of understanding contextual factors involved in parental HIV disclosure in China. In particular, these data may highlight the need for providers to not only recommend parental serostatus disclosure, which as noted in the introduction is typically the standard of care in the United States [5]. Rather than focusing only on the outcome of disclosing, it may be most useful to support parents to systematically weigh their unique pros and cons and make the best decision for their families.

Our findings informed a cultural adaptation of the Disclosure Process Model, originally developed for disclosure among people living with stigmatized conditions [21, 24]. As in the original model, we found evidence for approach motivations such as disease progression and social support as well as avoid motivations such as stigma. We further specified the model with factors we found that are unique to the phenomenon of parental HIV disclosure to children, such as approach motivations of wanting to educate children about HIV transmission risks and perceiving disclosure as fulfilment of parental responsibility, and the avoid motivations of fearing additional psychological burden for the child, the consequences if the child cannot keep the secret, and revealing the mode of HIV acquisition. Additionally, we identified cultural factors specific to the Chinese context, such as defined parental and filial roles and responsibilities,

and emphasis on a harmonious family unit that will affect parents' disclosure decision-making process.

There are several limitations to the current study. First, sample sizes were small and participants were recruited from premier HIV treatment centers in Shanghai and Beijing, China. These settings likely have better resources for PLWHA, and participants in our sample may have different demographics (e.g., higher education) from PLWHA in other areas of China, potentially affecting generalizability. Additionally, our quantitative data were collected using a measure we created from our qualitative data which does not have previously established psychometric properties.

Despite the limitations, our findings and subsequent generation of the Chinese Parental HIV Disclosure Model provide a theoretical framework to guide the design of an intervention to support parents living with HIV through the process of disclosure decision-making. The study findings elucidate the specific concerns parents have about disclosing to their children, including primary motivators and barriers. Our data demonstrate that parents are distressed and concerned about the topic of parental disclosure given the cultural context of stigma and strong family values, and need support in going through the process of thinking about disclosure to children. Furthermore, given parents' real and legitimate concerns about the possible negative consequences of parental disclosure (e.g., increased psychological burden on the children and fear of rejection from the community if the child cannot keep the parent's HIV status a secret) [25–27], HIV-positive Chinese parents are in need of culturally competent and relevant support in navigating this process. Specifically, parents need support that does not merely encourage disclosure (as is the often the case in other cultural contexts, such as the United States

[5]), but acknowledges parents' serious concerns. From these results, the authors have created a manualized parental disclosure-support intervention that helps parents systematically consider common motivations and barriers to disclosure, as well as create and practice a mindful plan for their goals regarding disclosure (whether they decide to or not), in order to avoid unintentional disclosure. (Please contact authors for intervention manual; for information on the pilot randomized controlled trial testing this intervention at SPHCC, see Simoni et al. [28] in press at *AIDS*). Future research may seek to validate the model in a larger, more heterogeneous sample. Meanwhile, it may provide a useful framework for future research and other intervention strategies to help alleviate the considerable distress parents experience in planning for their children.

Acknowledgments We gratefully acknowledge our participants, our Community Advisory Board, Red Ribbon Society, Beautiful Life, research assistants at University of Washington, and the clinic staff at Beijing Ditan Hospital and Shanghai Public Health Clinical Center for their support and help with this project. Research reported in this publication was supported by NIMH of the NIH under Award Numbers [F31MH099925-01], [K24MH093243], [K23NR14107]. Additional support was provided by the University of Washington Department of Psychology and University of Washington Center for AIDS Research (CFAR), an NIH-funded program [P30AI27757].

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