

Secrets, shame and guilt:

HIV disclosure in rural Chinese families

Running title: Caregivers and HIV-born Adolescents in Rural China

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Word Count: 3862 words (OVER 862)

Acknowledgements

We would like to thank all parents and adolescents who gave their time to take part in our study, as well as staff from the Dali People's No. 2 Hospital for their assistance and support during data collection. We also thank Ms Skye Wong, Ms Emilie Wong, Ms Bonnie Wong and Mr Sam Galler for their assistance in the interviews and Mr Sam Galler for his advice to improve on the manuscript.

Funding

This work was supported by Dr Zeng's Research Centre.

Competing Interests

Dr. Jianbo Zhang runs the HIV care and treatment unit at Dali No 2 Hospital, Yunnan.

Ethics

Ethical approval for this study was granted by the Institutional Review Board of the University of Hong Kong/Hospital Authority Hong Kong West Cluster (Reference Number: UW15-008).

Contributory Statement

WW and JBZ were responsible for overseeing the whole study while EH made considerable contributions to the methodology and designing of the interview tools. JBZ liaised with the informants. YPZ and CSW conducted the transcription and some analysis. HM was responsible for cleaning the interview materials as well as analysis and interpretation of the results which was also overseen by EH and WW. HM and EH were mainly responsible for drafting the manuscript, with help from YPZ and CSW. All authors have helped to review, finalize and approve the manuscript before submission.

Data sharing statement

No additional data are available.

Abstract

This in-depth ethnographic study examines the processes, barriers and impacts experienced by Mainland Chinese caregivers residing in rural Yunnan for disclosing HIV status to their adolescents born with the infection and other community members, highlighting their associated personal, social, relational and cultural vulnerabilities. A purposeful sample of 13 pairs of HIV-born adolescents between the ages of 11-19 years and their accompanying caregivers were recruited in December 2014. An adapted version of Sexual Health Disclosure model was used to explore different aspects of the adolescents and caregiver's relationships. All interviews were audiotaped, transcribed verbatim and then translated into English. A grounded theory approach using Conceptual Model of Sexual Health Disclosure was adopted to guide the data analysis.

Complex sociocultural interactions emerging in these dyadic interviews included guilt, shame, unintended disclosure, the need for secrecy, perceived stigma, "loss of face", protection of parents, inability to support their families, and deep concerns over lineage and future marriage prospects amongst the parents, which has significant psychosocial and even physical impacts on HIV-born adolescents and families. Frontline healthcare workers and HIV peer support programs are recommended to counteract the current top-down biomedical disease-related approach. It is crucial to provide instrumental avenues of confidential psychosocial support for caregivers of HIV positive adolescents allowed within a uniquely Chinese cultural context.

Word Count: 213 words

Key Words: HIV, Disclosure, Parent-child relationship, China, Stigma, Culture

Introduction

The landscape of HIV infection has changed significantly in recent years with fewer people living with HIV (PLHIV) dying as a result of increased access to antiretroviral therapy (ART).(China, 2015) Despite the increased options for termination of pregnancy, access to ART, and caesarean deliveries which have helped to reduce its vertical transmission, many children in China are still born with HIV (incidence of 6.2% per month in 2014) and survive into adolescence.(China, 2015; UNAIDs, 2015) They face unique challenges to maintain their health amidst the associated social stigma(UNAIDs, 2015) which are significant and well-recognized health barriers.(Duffy, 2005; Grossman & Stangl, 2013; Jain et al., 2013; Mburu et al., 2013; Zhang et al., 2016)

In China, the stigma associated with HIV is underpinned by specific cultural beliefs, which espouse the notion that HIV is contracted from socially deviant and outcast behaviors such as promiscuity and drug use.(Steward, Miège, & Choi, 2013; Zhao et al., 2015) Community rhetoric of blame exacerbates the stigma for vulnerable groups such as sex workers and men-who-have-sex-with-men (MSM) and drug addicts; creating negative perceptions and victimization.(Steward et al., 2013) Stigma surrounding HIV not only inhibits disclosure of HIV status, but is also associated with negative mental health outcomes(Hua et al., 2014) and hindering of treatment-seeking behaviour and compliance to ART.(Langebeek et al., 2014)

Chinese parents diagnosed with HIV are subject to specific culturally stigmatizing processes at familial, community and health service provision levels. Although studies have been undertaken to assess the processes of parental disclosure,(Qiao, Li, et al., 2015a, 2015b; Yang et al., 2016) little has emphasized the processes and barriers faced by Mainland Chinese caregivers when handling their child's HIV status or even disclosing it to the children themselves. This

study aimed to explore the associated social, economic and cultural vulnerabilities faced by Chinese caregivers bringing up HIV-born adolescent in the rural county of Dali in Yunnan province of China. Yunnan is one of the provinces most affected by HIV.(Wu, Wang, Detels, & Bulterys, 2015)

Methods

Framework and study approach

This study employed an adapted version of the Conceptual Model of Sexual Health Disclosure developed by Lo *et al.* (2009)(Lo, Zea, & Poppen, 2009) It was used to guide the semi-structured interviews, providing comprehensive coverage of the different nested components involved with HIV disclosure. They included: a) Individual- examining personal components such as perceptions, attitudes and individual characteristics; b) Relational- exploring closeness and characteristics of the parent-child relationship as well as influences from outside social network; and c) Sociocultural factors- investigating the effects of cultural values and social norms including the stigma and discrimination often associated with HIV/AIDs. A pilot study was also conducted to assess the duration of interviews and to find the ambiguities in the interview guide; consisting of one parent and one adolescent interview independent to the main study. These interviews allowed for brief content analysis and modifications prior to the main interviews.

Recruitment and procedure

Thirteen interviews were conducted with the caregivers of vertically-transmitted HIV-born adolescents during December 2014. Participants consisted of caregivers of male or female adolescents between the ages of 11-19 years who were receiving HIV treatment and management at the Dali No. 2 People's Hospital in Dali, Yunnan. Using purposeful sampling, consulting

doctors would refer potential participants and their caregivers and the interviewers further explained in detail the purpose of the study, the participant's rights of voluntary participation and rights to withdrawal. Interviews took place in private rooms designated for the purpose. Written informed consent for interviews were obtained from each family. Participant families were given RMB200 (approx. \$30 USD) as remuneration for time and transportation costs. Interviews were conducted in Putonghua, lasting about 45 to 90 minutes. Data collection continued concurrently until saturation was reached; where no new themes were identified.(Fusch & Ness, 2015)

Data analysis

All interviews were audiotaped, transcribed, and translated into English. Two reviewers worked independently to code emerging themes. Open coding was done initially to allow capturing of unexpected or newly emerging themes. These were then classified in accordance to the different nested levels of the Conceptual Model of Sexual Health Disclosure.(Lo et al., 2009)

Ethics

Ethics Committee approval was obtained from the Institutional Review Board of the University of Hong Kong/ Hospital Authority Hong Kong West Cluster (UW15-008). Consent to gain the primary physicians' referral was granted by the Dali No. 2 People's Hospital.

Results

Participants

The most caregivers were parents to HIV-born adolescents, apart from cases where both parents had passed away. Two caregivers were single mothers after their husbands had passed away from AIDS. Drug use and sexual transmission were reported to be the main transmission routes for infection in the parents. Caregivers indicated a range of manual labor employment

such as farming, fishing, delivering goods, construction, and services. Only one adolescent was over 15 years of age and all but two reported living in their school dormitory visiting home on weekends. Themes and subthemes are summarised in Table 1.

1. Individual Level Factors

On the individual level, caregivers carry a strong sense that the disease must be kept a secret from their friends and the community, sometimes even family members.

1.1 Caregivers

A sense of needing to keep secrets ran through many testimonies fuelled by fear of neighbors finding out. Participants spoke of feeling continually vigilant.

1.1.1. “We must keep this to ourselves”

Throughout the discussions, it was clear that caregivers internalized the associated stress of their HIV status. An aunt of an HIV positive adolescent, who was the primary caregiver described the pressure of living with this secret: *"We certainly have stress. For example, we are nervous at all time... In case someone would recognise me and then all of a sudden spread this out to the public. I am always afraid, for sure."* ~**Aunt #1**

1.1.2. “Shame & guilt that we brought onto them”

Parents commonly expressed feelings of guilt, shame and that of obligation to their adolescent children, seeing them as an innocent victim. One mother expressed that, *“Indeed, innocent. It is really the child who is innocent. It is OK for us, alas, but the child is too innocent.”* ~**Mother #6**

2. Relationship Factors

Within this theme was emotions resulting from disrupted intergenerational relationship. Participants testified to a strong sense of guilt that HIV had been transmitted to a young generation who were essentially blameless. There was the sense that the older generation had damaged the young generation's future, which evoked feelings of obligation. Participants needed to protect the innocence of their adolescent form knowing the grim future they would inherit, testified as being as "*too young to know*".

2.1. Between Caregivers and HIV-born Adolescents

2.1.1. "We should give them all since we owe them"

The guilt the parents felt towards passing the disease onto the adolescents was often reported as a sense of obligation. A mother who was living away from her daughter noted, "*[I would] ask her what she wants to eat and then make some for her to take home ah, that's it. Because we owe her, I feel guilty inside. You owe her, like (sobbing)... [We] brought this on her.*" ~**Mother #6**

2.1.2. "They are too young to know. They can't understand"

Only a few caregivers had disclosed their HIV status to their adolescents. The primary reasons for non-disclosure arose from the perception that the adolescents were too young and not sufficiently mature yet: "*...so definitely (I) have to tell her, but now you see, if you tell her now, she may not be able to understand.*" ~**Mother #5**

Despite this, some parents testified to feeling that their adolescent might already know to a certain extent: "*Now she is fourteen, she sort of vaguely, say, knows it. She is inwardly, let's say, quite sensible....*" ~**Father #1**

2.1.3. "They need to keep this a secret also"

Caregivers taught the adolescents the need to keep their health status (known or unknown to the child) a secret from others, e.g. their friends and even family. As described by a mother, *“I just tell her when other people talk about this disease, or what medicines to take, like this, just tell her, that is to say, even if friends, you do not tell them.”* ~**Mother #4**

This is sometimes even the case with immediate family, *“I’ve also told him not to let his sister know it. I’ve told him that.”* ~**Mother #3**

However, while many did not admit to knowing their HIV status, they alluded to particularities of the disease, which might suggest otherwise. For example, some adolescents expressed knowingly it was infectious or contrasted to diseases such as cancer.

2.1.4. “Be careful and always take your medication”

All caregivers reportedly ensured their adolescents complied with ART regimes and took careful preventative measures, particularly around wound injuries. Caregivers testified to deceiving their adolescents regarding the duration of the treatment, or inventing alternative health benefits and supplements to encourage compliance with addressing the question directly. As noted by one mother, *“The younger son has already taken medicine for several years, but I still did not tell him that he is infected with this disease, only told him that your leg often sore, then you must take the medicine; if you do not take medicine, the leg then will be sore.”* ~**Mother #8**

Indeed, the most interviewed adolescents indicated compliance with their medications. At the same time, they also retained the secrecy enforced by their parents. In conjunction with not knowing their HIV status, as was the case for a

number of adolescents, this secrecy had created a sense of uncertainty and void in the adolescent's awareness. Indeed, some expressed the fear from "*not knowing what was happening*". One adolescent even expressed the fear that they might "*die young if they stopped taking the medication*".

2.2. *Between Core Family and the Outside World*

The fear of having one's capacity for personhood judged based of HIV status was perceived in all sectors of society. These included extended family, friend's neighbours and work colleagues. This perceived fear was the source of considerable stress ongoing

2.2.1. "We cannot let our families know"

Although a few caregivers did inform their family about their status, in some cases many feared rejection from their family as described by a father: "*Once the family members know, the whole family will know. If the family knows, we can no longer live in the family.*" ~**Father #3**

2.2.2. "People will look down on us"

Carers were also fearful that others would look down on them or exclude them if their status was disclosed: "*I was rather worried at that time. [I] had to go to work, afraid of being known by the company, afraid of being known by [my] friends, afraid of being known by [my] family, so the stress was particularly great.*" ~**Mother #5**

2.3. *Between PLHIV and Health Professionals*

2.3.1. "Trust that we can talk about everything"

Caregivers were very secretive about their concerns relating to their HIV status, including to healthcare professionals at facilities outside. However, one source of beneficial social support was from healthcare workers at the Dali hospital where they

received their HIV treatment and management, as well as from other HIV positive parents they meet there. Caregivers revealed discussions ranging from economic support, health advice and problems revolving around marriage. A mother speaks of the discussions she had with other HIV parents at the hospital (CDC): *“Like that time, we did it there, this, there, in the CDC. Well, we were all with this disease and we were gathered together and were discussing this issue.” ~Mother #2*

3. Sociocultural Factors

3.1. Stigma and Discrimination

3.1.1. Perceived Stigma

The secrecy around disclosure which the caregivers created served in some way to protect them from acts of discrimination, however their fears were often fuelled by hearsay or exaggerated news reports. As described by one father, *“A friend told me that he also ran restaurants. But when others got word that his family members had this disease - just within a month, the restaurant business shut down, and the whole family moved away.” ~Father #1*

Other caregivers rationalised the stigma around HIV: *“I hope that the discrimination can be eliminated. It is like that HIV positive is just like any other diseases... [It's] like fierce floods and dreadful monster, it was still so terrible.” ~Mother #5*

3.2. Collectivist Culture

3.2.1. “How can I face my family?”

All caregivers kept their HIV status a secret from their extended family. The notion of ‘face’ and ‘being looked down upon’ is often alluded to.

3.3. Over and Above Responsibility as the Primary Caregiver

3.3.1. “I have to provide for my child”

Many of the respondents were employed in manual labour. It was evident that the disease impacted their ability to carry out their work, however the respondents reported being under extreme pressure to provide for themselves and their families: *“Everything [I] do now is for children, I said. Now my physical strength becomes worse year over year. This year, so far this year I can only work for one week and then cannot work.”* ~**Mother #8**

3.3.2. “It’s safer not to apply for support”

Some caregivers actively held back from accessing any available support due to fear of their status being disclosed or being rejected. As described by one parent: *“...this low Minimum Living Standard insurance is ok to give up, right? Because I was afraid, that people inside the village know, right? Then, it is easier not to get it, that low Minimum Living Standard insurance. For the difficult in rural areas, such as us, we should be getting it, that money, right?”* ~**Father #2**

3.4. *Social Norms of Marriage and Family Lineage*

3.4.1. “How will they find a partner?”

Of particular concern for parents and caregivers was their adolescents’ future dating potential and the possibility of having a marital life. A mother describes the time her 19-year-old HIV positive daughter first started dating: *“In the beginning, when they wanted to date, I did not allow. She was rather young at that time, so I beat up her. Later they still are together, then I do not bother. I just told them to pay more attention.”* ~**Mother #6**

Many caregivers of younger adolescents also worry significantly about their children's future marital prospects: *"We would be delighted if she could find a boy who, to be frank, loves her from his heart. If he could accept my daughter, to be honest, I would treat him with all my heart...I'll see...if she has such luck that she could come across such a good-hearted, understanding man."* ~**Father #1**

Some caregivers considered that the only way for their adolescent to find partners was to find someone also with the disease. As suggested by the following mother: *"...we should gather everyone- those who had disease and introduced [them] to each other."* ~**Mother #2**

Interestingly, although future marriage and procreating were a significant concern for the caregivers, the adolescents interviewed were instead focused on their education and maintaining their relationship with their parents.

Discussion

This study depicts the complexity of cultural thoughts interwoven with Chinese lineage relationships, prevailing social norms, and individual life circumstances; between parents, caregivers, and their HIV-born adolescents in the Yunnan province in Mainland China. We contend that it contains specific cultural nuances and debates that shape contemporary social norms and changes that are central to what matters in a Chinese family. The study explores the daily challenges faced by these caregivers, specifically highlighting the complex psychological and social issues revolved around informing their adolescents of their HIV status.

Our findings indicate that non-disclosure of HIV status for these families is shaped by considerable fear of how others i.e. neighbors or communities might have reacted; hence underlining the stigma and discrimination associated with HIV infection. This secrecy and

stigma in Mainland China is well-documented(Mo, Lau, Yu, & Gu, 2014) but no previous reports on the tension between the caregivers and the HIV-born adolescents and a family unit as a whole. Our caregiving respondents describe considerable and persistent emotional burden due to their HIV status, manifesting as feelings of guilt and shame. Aligned with this, the literature reports high rates of social stigma, depression and anxiety amongst those positive for HIV in community settings.(Zhang et al., 2016) The emotional burden further serves to prohibit disclosure through the associated stigma and discrimination (direct and indirect) which remain foremost obstacles to HIV prevention, treatment, and support.(Fernet et al., 2011; Nichols, Steinmetz, & Paintsil, 2016) This fear of stigma and discrimination, discourages HIV patients and their caregivers from disclosing their status even to the close family members and partners; thus, undermining their ability and willingness to access and adhere to treatment as well as potentially undermining wider prevention efforts. In addition, it also jeopardizes access of caregivers or their adolescents to other non-health related public and professional services to assist in socio-cultural, economic and health challenges often face by those with HIV positive status.

Disclosure is deemed an important part to HIV prevention;(Qiao, Nie, Tucker, Rennie, & Li, 2015) however, this is particularly the case for adolescents; whereby individuals develop increasing cognitive and emotional stability, maturity, and independence from their caregivers.(Vreeman, Gramelspacher, Gisore, Scanlon, & Nyandiko, 2013) Indeed, adolescents in this study indicate that they live away from their home and caregivers for their schooling. However the adolescent period also represents a time of sexual maturity with youth likely to start engaging in romantic relationships.(Fernet et al., 2011) Despite this, majority of caregivers choose not to disclose the adolescents HIV status to them. Caregivers in this study report

employing strategies such as lying, bargaining and secrecy to help ensure their adolescents to comply with ART regimes and preventative measures amongst non-disclosure. Use of alternative health explanations are also used caregivers to avoid directly disclosing HIV status; such strategies have been seen in other studies such as by Yang *et al* (2016).(Yang et al., 2016)

The caregivers' levels of disclosure vary amongst different families. They express a variety of emotions and concerns against disclosing to the adolescents; vulnerability to negative attitudes, to abuse, or to being judged by their friends, family members, or wider community. These adolescents or their caregivers are at times shunned by their peers and not be able to communicate, marry, work, or have regular social interactions with them. Whilst appropriate timing and delivery of disclosure can promote open communication and more effective prevention; if unplanned, it can also foster anguish and turmoil, as the long-term illness reverses the role of the adulthood in the family. The chronic illness of a child is a powerful personal and cultural force that determines family dynamics and destinies. Unfortunately, there are currently no established guidelines or services in place in China to assist in appropriate disclosure.

Caregivers report various reactions when discussing the issue of their adolescents forming romantic relationships; from strong forbidding to apathy and indifference. The study shows Yunnan's collectivism culture centred on the protection of family and its lineage; informed by highly valued social norms of marriage and continuity of blood lines. A diagnosis of HIV interrupts this continuity, posing challenges to regular family life and generational continuity. Caregivers emphasize this in their fear of future marriage and life prospects of their adolescents. For effective reduction of HIV-related stigma and discrimination in rural China the underlying social norms and values need to be scrutinized as these pose deep-seating tensions in the sustainable management of HIV, it is this norms and values which serve to perpetuate fear of

disclosure such powerful and unpredictable consequences as ostracism. Changing such concepts requires high level of awareness at all social and ecological levels then educational campaigns that target these norm being a gradual and arduous process.

Such socio-cultural environment also stops many caregivers from accessing support due to fear of their status being disclosed. They further testify to deceiving their adolescents regarding the duration of the treatment when compliance with ART greatly improves health outcomes of PLHIV(Nijhawan et al., 2015). Preventing adolescent-to-adolescent HIV transmission is an important target area for public health.(Kasedde, Luo, McClure, & Chandan, 2013; WHO, 2013) Amongst fears of public disclosure, stigma and shame, HIV caregivers report that HIV/AIDS community healthcare workers and the current HIV-positive peer-peer support programs at the hospital, improved their daily lives.(Lemos, 2015) In some testimonies attending health services serves to provide normative support as well as a place to meet other HIV-infected people, who could also serve as a point of reference. This support includes economic and health advice, and advice around marriage and relationships. Establishment of peer-peer HIV support programs have been shown to play an important role for HIV positive patients.(Brashers, Basinger, Rintamaki, Caughlin, & Para, 2016) The peer-to-peer programs at Dali No. 2 Hospital provides information on economic and legal support, opportunities for sharing the burden of the disease and associated stigma, sharing HIV-specific health advice and health promotion messages, which makes the hospital an important place to obtain relationship support. These healthcare facilities are the main sites for HIV prevention education and have the potential to use a social model that addresses underling stigma and associated health risk behaviours to target HIV disclosure. Special attention is needed for HIV caregivers and their HIV-positive adolescents in rural Mainland China and elsewhere. In a similar manner to HIV/AIDS

Community Healthcare Workers centres/programs(Kenu et al., 2014; Persson, Newman, & Miller, 2014) these centres have the potential to reduce HIV transmission and increase compliance with ART globally.

Limitations

Despite the richness of the data within the unique context of rural China and the use of the conceptual model of disclosure, this study has a number of inherent limitations. Firstly, it took place on only one setting, in a town in rural China. Thus, transferability to large urban and other rural locations could be restricted due to profound sociocultural and contextual difference. Secondly, the interviews being conducted by five researchers, none of which from the local area, introduces the potential for intersubjective bias but also opportunities and security to open up. Constant comparisons were undertaken each evening in the field to mitigate these effects. Thirdly, the nature of the village location may have added to a hesitancy to talk openly with the research team due to potential associated stigma from other villagers and considerable time was spent to familiarize with the targeted families.

Conclusion

Public health must adapt to the changing face of HIV in China, as many babies who were born HIV-positive, are now adolescents. People with a positive HIV status in China remain highly stigmatized resulting in both perceived and enacted discrimination; hence, parents and caregivers of HIV-positive adolescents face difficulty disclosing their HIV status. This discrimination actively discourages health service attendance and reduces capacity to cope with HIV and disclose their children's status to the children. This has significant implications for public health model based on community and psychosocial support required to prevent future HIV transmission. Underlying social and normative values needed to be examined in the form of

human rights based education at all levels of community. To ensure intergenerational social support compliance with ART. Community Healthcare Workers and peer-peer HIV support programs need to offer instrumental avenues of support for caregivers of HIV-positive adolescents within the unique context of HIV parent-child disclosure in China.

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