# **Original Article**

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# Fertility desire among HIV-positive individuals in the Chinese sociocultural context: A qualitative study

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# Abstract:

**BACKGROUND:** China's recent change from a one-child policy to a two-child policy has urged many couples/families to consider having a child or an additional child. However, little is known about such fertility desire among heterosexual couples with at least one human immunodeficiency virus (HIV)-positive partner. The objective of this qualitative study was to describe fertility desire and its motivating factors and barriers among people living with HIV (PLHIV).

**MATERIALS AND METHODS:** We conducted in-depth semi-structured interviews in 31 patients at an antiretroviral therapy (ART) clinic in Kunming, China, from October to December 2020. We included only patients in a sexually active heterosexual relationship with no more than one child. Participants gave verbal informed consent before participation. Interview recordings were transcribed verbatim, translated into English, and then analyzed using thematic analysis.

**RESULTS:** Participants who reported fertility desire were mostly male, while participants who reported no fertility desire were mostly female. Study participants reported motivating factors and barriers that were identical to HIV-negative persons such as 1) social norms, 2) Chinese sociocultural factors, 3) the government's two-child policy, and 4) the financial burden of having children. However, study participants also reported motivating factors and barriers unique to human immunodeficiency virus (HIV)-positive individuals that included 1) the availability of ART and prevention of mother-to-child HIV transmission services, 2) health-related concerns, 3) stigma and discrimination against PLHIV, and 4) the additional cost of child-rearing when HIV-positive.

**CONCLUSIONS:** The study findings highlighted major areas of concern for relevant stakeholders. The development of PLHIV-specific health policy should consider the PLHIV-specific motivating factors and barriers reported in this study. However, social desirability and lack of generalizability should also be considered in the interpretation of this study's findings.

# Keywords:

East Asians, fertility desire, people living with HIV, qualitative study, social norm

# Introduction

Fertility desire is defined as the desire to have a child through natural or artificial conception and childbirth. Globally, there are 37.7 million people living with HIV (PLHIV). PLHIV also have fertility desire similar to their HIV-negative counterparts.<sup>[1]</sup> Approximately 42% of PLHIV worldwide wish to have children<sup>[2]</sup>; however, there are

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variations between countries. Fertility desire also varies by a number of characteristics such as age, education level, and current number of children.<sup>[2]</sup>

There are approximately 9.6 million PLHIV in China<sup>[3]</sup> who are entitled to the comprehensive HIV intervention program provided by the Chinese government.<sup>[4–7]</sup> Raising a family is an important part of Chinese culture and is influenced by sociocultural characteristics,

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traditions, and religious beliefs. In 2016, the Chinese government started to replace the one-child policy with a two-child policy and allowed people of childbearing age to have two children. This change could have further increased sociocultural pressures for PLHIV to have a child or an additional child.

However, knowledge gaps exist on this matter. Most studies on fertility desire among PLHIV were conducted in sub-Saharan Africa, which has a very different socioeconomic context compared to China.<sup>[2]</sup> A study conducted in Guangxi Autonomous Region reported that fertility desire existed among PLHIV but did not include information on how HIV positivity affected or complicated fertility desire.<sup>[8]</sup> A study in the Guangzhou showed that PLHIV were concerned about vertical transmission of HIV,<sup>[9]</sup> but such assessment was made in the context of a hypothetical cure being in existence and fully accessible and did not provide information on the interaction between social pressure and HIV status on fertility desire. A study conducted in Beijing and Shanghai showed that PLHIV self-isolated partly from the influence of familial factors (e.g., sense of responsibility to the family and possible reactions from family members to their HIV status)<sup>[10]</sup> but did not assess the extent that such factors also influenced childbearing decisions. Information on the interaction of how the social environment of PLHIV interacts with Chinese sociocultural contexts and co-influence fertility desire can be considered a novelty and potentially contribute useful basic information for stakeholders in HIV prevention and control. This study aimed to describe fertility desire, motivating factors, and barriers to fertility desire among Chinese HIV patients in a stable heterosexual relationship after the implementation of the two-child policy.

# **Materials and Methods**

## Study design and setting

We conducted a qualitative study in the antiretroviral therapy (ART) clinic of a tertiary hospital in Kunming City, Yunnan Province, China. The ART clinic provides HIV antiretroviral treatment and associated care to HIV patients. Yunnan Province is located in southwestern China with a large cross-border population.<sup>[11]</sup> Yunnan was the location of nearly 25% of all new HIV diagnoses in China between January and October 2020. Among the local patients who were asked about possible routes of transmission, 89.5% reported heterosexual transmission, 6.5% reported same-sex transmission, and 4.0% reported either injection drug use or unknown route.<sup>[3]</sup>

### **Study participants**

Our study participants included reproductive age PLHIV in a stable and sexually active heterosexual relationship

with no more than one child. Each participant had received ART for more than one year at the ART clinic. Our exclusion criteria were as follows: 1) being unable to communicate fluently in Chinese, 2) having a debilitating disease that precluded their participation, and 3) being unable to conceive for any reason (e.g., history of hysterectomy, oophorectomy, and vasectomy). We decided to recruit participants until we reached data saturation. Therefore, we did not perform a sample size calculation.

#### Study instrument

A question guideline [Supplementary Material 1] was developed by the researchers according to traits-desire-intention-behavior (TDIB) and theory planned behavior (TPB) to explore fertility desire and intention among PLHIV and associated factors.<sup>[12,13]</sup> The questions were reviewed and critiqued by experts in epidemiology, HIV, and nursing. The question guideline included three main issues related to fertility desire: a) perspectives regarding fertility desire (e.g., "Can you talk about your desire to have a child?"), b) internal contributing factors and barriers to fertility desire (e.g., "What made you decide to have or not to have a child?"), and c) external contributing factors and barriers to fertility desire to have a child?").

#### **Data collection**

We identified potential participants from the database of ART patients who agreed to be contacted by the study hospital for research studies. We recruited participants from the study site from October 2020 to December 2020. Designated staff of an affiliated nongovernment organization helped inform potential eligible participants on the purpose of the study. Patients who expressed interest in participation were invited to a private room to be briefed about the study. Eligible participants were told that the interview was voluntary and confidential and would not affect the participant's access to routine clinical care. Eligible participants were then asked for consent to participate and had an option to reschedule the interview at a time convenient for them.

The first author conducted this interview in the local dialect of Mandarin used by the study participants. Participants were interviewed without their partner present to avoid any potential unintended disclosure of HIV status to an uninformed partner. During the first 10–20 minutes of the interview, the interviewer conducted a light conversation with the participant to build rapport and collect basic demographic information, after which the actual recorded in-depth interview would begin. The order of questions and responses in each semi-structured interview varied based on the flow of the conversation. Each interview lasted approximately

30–60 minutes in total duration. If a participant exhibited sign(s) of distress during the interview, the interviewer would console the participant, attempt to deactivate the participant, and either immediately stop the interview or request a recess to assess the psychological state of the participant and conclude the interview at the earliest convenience. Interview recordings were later transcribed verbatim in Chinese. The recordings were stored as electronic files by pseudonyms with password protection. Hard copies of the interview transcripts were kept in a locked storage space.

#### Data management and analysis

The transcribed texts were double-checked for accuracy and then translated from Chinese into English. The Chinese text data were initially manually analyzed using thematic analysis. Investigators then developed a codebook using the three key domains in the interview guide as the initial coding framework. The Chinese coding was carried out independently by Yingwu Guo and a team of research assistants. Yingwu Guo and research assistants were also allowed to add new codes when new concepts were identified during the analysis. Differences between the two codes were resolved through discussions until a consensus was reached.

Yingwu Guo coded the English translations using ATLAS.ti. 9, whereas the research assistants coded the original transcripts in Chinese manually. The revised English-based codes were then summarized, and Yingwu Guo selected quotations to present as examples of the identified themes and subthemes. After the first batch of transcripts, the investigators met to discuss the preliminary coding and narrow down the broader topics initially included in the framework to more specific themes. The English domains, themes, subthemes, and codes were combined with the outputs of the Chinese version analyses to obtain the results.

#### **Ethical considerations**

This study was approved by the Ethics Committee of Prince Songkhla University (approval number: REC-63-208-18-1) and the Research Ethics Review Committee of the Third People's Hospital (approval number: 2020072001). Investigators used pseudonyms to protect the identity of the participants.

# Results

### **Study participants**

There were 31 study participants: 19 women aged 20–60 years and 12 men aged 20–50 years. Among the female participants, 13 had one living child and six had no children. Among the male participants, seven had one living child and five had no children. There were 23

participants in an HIV serodiscordant relationship and eight participants in an HIV seroconcordant relationship. All participants had been receiving ART for at least 12 months and had undetectable viral loads. Table 1 shows the study domains (rows) and themes, subthemes, and codes (columns). The study domains included 1) perception of fertility desire, 2) motivating factors for fertility desire, and 3) barriers against fertility desire, whereas Table 2 provides details of the expressions of individual participants.

# Self-reported fertility desire

### *Differences in fertility desire by sex*

Self-reported fertility desire among our participants differed by sex. The majority of female participants said that they did not wish to have a child or another child due to concerns about HIV transmission (either to their partner during conception, or from mother to child), their own physical health, and the psychosocial impact of HIV and the responsibilities of childcare:

"Having children is a responsibility. I need to raise the child or at least give birth. But how long can I live with this? That is the first point, and the second point is there are character defects in all of us who are infected. In life, some people cannot even get married. Is this the right situation to have a child? The psychological impact of the disease will make people selfish. Under these conditions, it is impossible to have children." (Cui Yun, 37 years old)

The majority of male participants said that they wished to have children, as they deemed fulfillment of traditional values on parenthood to be an important aspect of their lives, and that having children would ensure they did not experience loneliness in the future:

"I want to be a father because I do not want to be alone. My wife and I have been thinking about it [A child of one's own birth] for a long time." (Li Jun, 40 years old)

"My parents believe that we have a child for the purpose of passing on the lineage. Traditional Chinese think like this; the elderly will be looked after properly only by their own children." (Zhang Ming, 32 years old)

# Generic motivating factors and barriers to fertility desire

# *Generic motivating factors*

PLHIV reported a number of motivating factors that were similar to the non-HIV population, in particular the social norms and socialcultural factors that are particular to the Chinese culture. Sociocultural factors vary widely and include subjective norms on continuing parent's lineage, sex preference, siblinghood, and broader societal values. In addition, the Chinese government's recent change from a one-child to a two-child policy was also reported to be a motivating factor.

Domains	Theme	Subtheme	Codes
Perception of	Differences in	Men's fertility desire	Negative fertility desire
fertility desire	fertility desire by sex	Women's fertility desire	Positive fertility desire
Generic motivating	Generic motivating	Subjective norm	Pressure from parents, partners, siblings
factors and barriers	factors	Chinese sociocultural	Sex preference
		factors	The need to continue the male partner's bloodline
			Siblinghood
		Government's two-child policy	Two-child policy
	Generic barriers	Economic issues	The cost of raising children
PLHIV-specific motivating factors	PLHIV-specific motivating factors	Health service availability	Availability of ART/PMTCT services
and barriers	PLHIV-specific	Health-related	Concern regarding horizontal transmission (infecting the partner)
	barriers	concerns	Concern regarding vertical transmission (infecting the child)
			Lack of awareness of PMTCT
			Participants' own physical health
		Concerns related to	Stigma and discrimination from the community and healthcare providers
		social problems	The hidden cost of HIV-positive infant rearing

#### Table 1: Summary of themes, subthemes, and codes regarding fertility desire among HIV-positive participants

PLHIV=People living with HIV, ART=Antiretroviral therapy, PMTCT=Prevention of mother-to-child HIV transmission

# Subjective norm from parents, spouse, sibling, and significant others

The participants reported that their parents had a strong influence on their own desire to have children. However, most participants decided to hide their HIV status from their family due to fear of stigma and discrimination, while their parents continued to pressure them to have children. When the participants said they did not want to have children, the refusal appeared to be unreasonably disobedient to the elders, which further worsened the tension within the family:

"My parents do not know I am infected with HIV. They keep asking why we have been married for so long and do not want any child. They have been arguing about this till now." (Sun Qing, 30 years old)

In addition to the parents, participants also reported that siblings and extended family members, such as grandparents, were additional sources of pressure to have children. Participants from a more conservative background, and participants who passed a certain age, might have experienced a higher level of such pressure than others.

"My brother is also urging me to get married and have children as soon as possible. After all, I am not too young anymore. My grandfather and grandpa are both civil servants and think like my brother. So now I also feel that I am a bit rushed." (Fan Zeng, Male, 33 year old, childless)

Some interviewees also mentioned subtle pressure from relatives, friends, and colleagues during work and social interactions:

"Classmates, relatives, and friends often talk about the benefits of having children. To tell you the truth, if it were not for this disease, my wife and I would have had a baby now." (Chu Hui, 31 years old)

# Sex preference

The patriarchal structure of Chinese society meant that sons and grandsons were favored over daughters and granddaughters, particularly in conservative families. Sons were also expected to care for their parents during old age, which also provided further motivation to have a male offspring. Participants who already had one female child would be encouraged to try again in hope that the next child would be a male to fulfill the need for a male heir. However, if the family already had a son, then having a daughter as the second child would be regarded as a way to complement the family:

"I have a girl. Now I want a son. If the first child were a son, then I would like to have a girl." (Wang Xiong, 36 years old)

"It is better to have a son because I have a daughter now. But these circumstances are beyond my control, so it does not matter." (Ma Yun, 46 years old)

# Need to continue the male partner's bloodline

Chinese families are patrilineal, and the wealth and power of each family are often tied to the number of persons sharing the same last name, commonly referred to as "bloodline" or "family incense." Participants with parents from rural areas reported greater pressure from parents and society to produce grandchildren to "continue the family bloodline" than participants with parents from urban areas. Having children to continue the patriarchal lineage would be considered an act of filial piety on the part of the man, and the term "continuing the family's incense" was used as a metaphor for this act:

Demographics	Participants	Perception	ption		Motivating factors	actors			Barriers		
Gender/number of children	Pseudonym	Negative	Positive	Subjective norm	Chinese culture	Health service (two-child policy)	HIV transmission	Stigma and discrimination	Physical condition	Health service and policy	Economic issues
Male											
Childless	He Jiong	-		-	2		4	3 (1)		3 (1)	-
Childless	Sun Qing	ო		3 (1)			0		0	0	7
Childless	Li Jun		3 (1)	5				-	0		
Childless	Si Ma		-	က				4 (1)	-	ო	
Childless	Jiang Huai		÷	0			4	1 (1)		-	
1 child	Zhang Ming		1 (1)	0	2 (1)	-	+			-	۲
1 child	Wang Xiong		÷	۲	4 (1)		0	-		ო	-
1 child	Chu Hui		-	1 (1)	4	-	+	1 (1)	-	-	N
1 child	Ma Yun		÷	0	1 (1)				ო	2	ო
1 child	Fan Zeng	-		2 (1)	-		ო		-	-	4
1 child	Ye Zi	-		က		-	ო		ო	2	1 (1)
1 child	Lv Wei		-		4	1 (1)	+			-	2 (1)
Female											
Childless	Cui Yun	5 (1)		Ť.	1 (1)		0	14 (1)	Ŋ	S	Ŋ
Childless	Guo Mu Dan	-		N			+				
Childless	Song Cai	ი			2		4	9	5	4	N
Childless	Su Cui	-			-		2 (1)		N	2 (1)	N
Childless	Tao Hua		2	N	-	1 (1)	-	2 (1)		4	-
Childless	Zhu Cui		-	-							
1 child	Ma Li	-					-			0	
1 child	Ma Cui		-	-	-	-	0	-		-	
1 child	Kung Sha		ი	0	4		0	-	-	0	
1 child	Liu Ying	N		5	-		2	2	6 (2)	1 (2)	
1 child	Zheng Li	N				-	1 (1)	-	4 (1)		N
1 child	Wu Xiu Ying		2	N	2	0	-	4	3 (1)	ю	0
1 child	Luo Yan	N		4	-	2	2			2	ო
1 child	Liu Yun	-		-	N		ი	3 (1)	-		1 (1)
1 child	Liu Si Si			6	5 (1)			4	-	S	4 (1)
1 child	Wu Hua		÷	-	-			ი	1 (1)	-	۲
1 child	Lu Hui		-		-					0	
1 child	Xun Xun		-				-	0		c	N
1 child	Zou Liu	N					4	2			-

"My parents said that they want me have a child and pass on the bloodline." (Zhang Ming, 32 years old)

"He may think that I am going to die because I am infected with HIV. [But he also said that] he needs to carry on the family bloodline [despite the risk of HIV transmission]. He does not think about what will happen to the unborn child." (Cui Yun, 37 years old)

In addition to intra-family pressure, participants also reported that having children also functioned as a way to shield the family from social sanctions by their community:

"My mother-in-law wants us have a second child. Both of my husband's two brothers have two sons. The neighbors in the village will look down on us if we do not." (Liu Si Si, Female, 36 years old)

## Siblinghood

Respondents, including those born during the one-child policy era, reported concern of having only one child would mean the child would end up without sibling familial support, particularly during adulthood. This concern became an additional motivating factor to have an additional child:

"He is our only child, and when we are old, he will be too lonely. If you have a brother or sister, you can take care of each other when you grow up. If you do not, no one would come to help when difficulties happen in the future, right?" (Wang Xiong, 36 years old)

#### Government's two-child policy

Participants reported that their family planning decision was influenced by the overall government's one-child versus two-child policy when they made the decision.

"After the implementation of the second-child policy, I want to have another child." (Lv Wei, 35 years old)

# *Generic barriers*

## Economic barriers

Participants reported that the financial burden of having children created a barrier against having children, which was similar to their HIV-negative counterparts. Participants who already had a child reported that the burden of raising one child was already considerable and did not wish to have another child.

"In fact, I have never wanted children, and I have always insisted on this idea until now. I consider the financial pressure. But my husband has insisted on having children, so we have already gotten into a quarrel. Then I told him that everyone is under great financial pressure. We are part-time workers and have low incomes, and the economic conditions are not very good. Anyway, he was arguing about having children. We are arguing just now, and he goes back home alone when he is angry." (Liu Si Si, 36 years old, one child).

"I am paying off a mortgage. Having a child will stress me out." (Su Cui, 25 years old)

"Financial difficulties are also a problem." (Liu Yun, 33 years old)

"If I am all by myself, I may have better quality of life in the future." (Ye Zi, 28 years old)

#### **PLHIV-specific motivating factors and barriers** *PLHIV-specific motivating factors* Availability of ART and PMTCT

Some participants reported that increased access to ART and prevention of mother-to-child transmission (PMTCT) services had strengthened their fertility desire. Successful PMTCT service during the first pregnancy enabled the participants to be confident in the decision to have another child:

"When I had just started receiving antiviral treatment, my doctor told me if you and your boyfriend want to get married and have children, it is recommended to accept this prevention of mother-to-child transmission intervention. I have been thinking about having children ever since." (Tao Hua, 25 years old)

#### PLHIV-specific barriers

Barriers to fertility desire specific to PLHIV could be categorized into two subthemes: 1) health-related concerns (horizontal and vertical HIV transmissions, limited awareness of PMTCT/ART, and physical health) and 2) social problems such as stigma and discrimination from the community and healthcare providers, employment-related stigma and discrimination, socioeconomic issues including the government's child policy, and additional costs of child-rearing.

#### Health-related concerns: HIV transmission

Participants reported that they were worried about horizontal and vertical transmissions of HIV during conception and childbirth, respectively, despite the availability of ART and PMTCT intervention.

"I am worried about infecting my husband when we try to conceive. The pregnancy also could increase the burden on my physical health." (Su Cui, 25 years old)

Another concern was that a HIV-positive child would be in poor health and that it would be difficult to raise the child.

"Because of our situation, you cannot have a baby like a normal person. If the child is born with HIV, I think it will be very stressful to raise a child who is in poor health." (Zheng Li, 34 years old)

# Health-related concerns: Lack of awareness regarding PMTCT

Participants also reported that they were either not informed about PMTCT by their healthcare providers or that they had difficulty understanding the content of PMTCT health promotion materials.

"The doctor mentioned something about prevention of mother-to-child transmission of HIV, but I did not understand [it] clearly...She only talked about mother-to-child transmission, not how to prevent mother-to-child transmission." (He Jiong, 41 years old, childless)

"I have never heard of PMTCT." (Su Cui, 25 years old, childless)

# Health-related concerns: Participants' own physical health

Participants expressed concerns about their own physical health. Participants were concerned that they would not be healthy enough to have a child or that their immune system would preclude them from engaging in active parenting.

"My poor health condition did not allow me to have children, so we gave up on having a second child." (Liu Ying, 36 years old)

"I am afraid that I will not have the time to be with my child or the energy to take care of my child. Every time my child gets sick, and I get sick with him, I will feel as though I have weak resistance. I cannot even take care of myself, so I cannot take care of my kids." (Zheng Li, 34 years old)

"I have been on HIV antivirals for seven or eight years now. Sometimes I feel a bit depressed. I do not think I am going to be by my children's side for very long. I do not have any serious health problems yet. I usually feel fine. I take my medication, I exercise regularly, and I pay attention to [maintaining a] healthy diet. But I still worry that one day, my condition will worsen, and I will not have enough money to treat [HIV]. There may be many complications that take over my body." (Liu Ying, 36 years old)

# Social problems: Stigma and discrimination

Stigma and discrimination from the community and healthcare providers: Participants reported that they were concerned about stigma and discrimination against PLHIV, and this concern made them hesitate to have children. Participants identified three sources of stigma: 1) self-stigmatization, 2) the community, and 3) healthcare providers. Participants presumed that the doctors and nurses would judge them if they consulted them about fertility while HIV-positive, so they decided not to consult or denied having fertility desire when questioned by healthcare workers.

*"Everyone gives me a strange look [because of] this disease. [Everyone discriminates against me because of this* 

disease] even though I cannot infect them. Most people cannot accept the fact that I am HIV-positive." (Tao Hua, 25 years old)

"If my HIV infection information is leaked, [I will be compelled to commit] suicide, and suicide [will be] my only choice. I will not retaliate against society, but [I will] commit suicide promptly. However, I cannot let my child commit suicide with me!" (Cui Yun, 37 years old)

Participants reported that they disclosed their HIV status to their spouse but not to their family members, colleagues, friends, or neighbors, due to fear of shame.

"I am under a lot of pressure because I was infected with HIV. I cannot disclose it to my parents and friends. After all, it is not like other common diseases." (He Jiong, 41 years old)

"I am worried that my children will feel ashamed and not be respected because their parents are HIV carriers when they grow up." (Liu Yun, 33 years old)

"Most people become more miserable after informing their families about their HIV infection. I did not tell my parents about it because they could not help with anything anyway. I did not want to put this burden on them." (Si Ma, 26 years old)

# Social problems: Additional costs of child-rearing among PLHIV

Female participants also reported additional concern regarding the need to purchase infant formula *in lieu* of breastfeeding. The cost of such formulas, along with other related goods and services, could become relatively high and function as a barrier against having children:

"We want to have a child with my wife right now, and you know the economic pressures are tough. It costs a lot of money to raise a child nowadays. I have spent more than 100,000 yuan on my daughter since she was born." (9063, Lv Wei, 35 years old)

# Discussion

In this qualitative study, we explored the motivations and limitations for fertility desire among partnered heterosexual PLHIV in Yunnan, China. Male participants were more likely to report wanting to have children than female participants. Similar to HIV-negative persons, study participants reported the influence of subjective norms and sociocultural factors, such as the wish to continue the male partner's family lineage and the government's two-child policy, whereas economic issues were barriers to having children. However, PLHIV also reported motivating factors unique to the context of living with HIV, such as the availability of health services, in particular PMTCT, as well as unique barriers such as concerns about health, discrimination against

PLHIV, and the additional costs of childbearing among HIV-positive parents.

Similar to previous studies,<sup>[14,15]</sup> we found that participants with fertility desire were predominantly men and participants with no fertility desire were predominantly women. Filial piety, or respect for one's parents, is a virtue in Confucianism that strongly influences society through norms and sanctions for noncompliance.<sup>[16]</sup> To show filial piety, both men and women are expected to take care of their parents, marry, and have children. However, Chinese society is patriarchal and patrilineage. Boys are expected to care for their parents when they become adults and are regarded as "the hope of the family's economic security".[17] Adult sons also have a moral duty to produce biological sons to continue the family's bloodline. Girls, however, are expected to care for their in-laws rather than their own parents. These differences in the level of fertility desire by gender could have been attributed in part to these factors. Yet interestingly, none of the participants reported the wish to perform the sex-selective abortion, which was common during the one-child policy era.<sup>[6]</sup>

Barriers against fertility unique to PLHIV included health-related concerns and concerns regarding social stigma faced by PLHIV and their children. However, some participants did report that the male partner wished to conceive and have children regardless of the risk of horizontal and vertical transmission of the virus. Perhaps the motivating factors (e.g., the need to fulfill social norms) in the perception of these men outweighed the potential risks of transmission or subsequent discrimination that their wives and children might face in the future.<sup>[18]</sup> This situation could have led to conceptions that were not well-planned (e.g., discussions and planning with healthcare providers on safe conception and PMTCT).<sup>[19,20]</sup>

Our findings provided potentially useful basic information for relevant stakeholders, particularly those working on HIV/acquired immunodeficiency syndrome (AIDS)-related services in China, to consider when designing interventions and planning programs to achieve the target of "three zeros" by 2030 (zero new HIV infections, zero AIDS-related deaths, and zero discrimination) under China's National Free Antiretroviral Treatment Program (NFATP). In China, the current policy on providing PMTCT is for healthcare providers to deliver such advice and service when inquired by the client.<sup>[21]</sup> However, given the complex dynamics of social interaction and their effect on the psyche of the clients, PLHIV service programs should consider providing information on safe conception and PMTCT at diagnosis and reinforce the message of accessibility of such services as appropriate. Future

studies should also not preclude the assessment of HIV preventive behaviors.<sup>[22]</sup> The findings of this study can also inform communication-based interventions to help PLHIV manage social pressures to have children so that they do not outweigh the need to carefully plan safe conception and PMTCT.

Despite the success of China's NFATP from 2006 to 2020,<sup>[23,24]</sup> our study participants still expressed concerns about HIV transmissions during conception and childbirth. Fears of stigma and discrimination were also common, which was similar to other studies in PLHIV.<sup>[25,26]</sup> Despite recent progress, it is still not uncommon for couples with at least one person with HIV disease to face opposition on childbearing decisions from their family members and healthcare workers.<sup>[27]</sup> Future studies should explore the reasons for the continuation of such stigma and discrimination toward HIV-positive couples and their children despite the advancement in public health and medicine, to generate much-needed empirical evidence for relevant stakeholders.

A major caveat in the interpretation of our study data is we did not probe for in-depth answers as extensively as in other studies. During data collection, the investigators realized that the subject matter of the study questions could induce emotional distress and decided that caring for participants who showed signs of distress would be prioritized over probing the responses. When participants exhibited signs of distress, the interviewer stopped the interview or requested a recess to assess the psychological state of the participant before concluding the interview at the earliest convenience. The information that we obtained from the participants thus had limited depth. Future studies should consider alternatives to in-depth probes during interviews, for example, supplementing the study data with secondary qualitative data from individuals in similar contexts, such as messages on sensitive issues posted online.<sup>[28]</sup>

#### Limitations and suggestions for future studies

The primary strength of this study is the novelty of the study topic, and the ability to reach a hidden and marginalized population to present qualitative data, which was otherwise difficult to obtain. However, several limitations in addition to the ones mentioned in previous paragraphs should be considered in the interpretation of the study findings. First, the responses of the participants were possibly influenced by social desirability. The interviewer did not know most of the participants before the study, and the lack of previous rapport could have affected the extent the participants were willing to share details of events or provide deeper reflections on their psyche and thought processes.<sup>[29,30]</sup> Second, this study was conducted only among PLHIV

in monogamous marriage or cohabitation who did not identify as LGBTQIA+, and thus, the study findings may not be generalizable to those in more casual or less heteronormative relationships.

# Conclusion

We found that the social and cultural contexts of China, pronatalist culture, and sex preference as expressed by family members influenced the fertility desire of HIV patients receiving ART in China. Participants mentioned HIV-related discrimination and HIV prognosis as the most common sources of concern. Limitations regarding selection bias, information bias, and lack of data from spouses of HIV patients and patients not receiving ART should be considered in the interpretation of the study findings.

# Institutional review board statement

This study was conducted in accordance with the Declaration of Helsinki and approved for studies involving humans by the Ethics Committee of Prince Songkhla University (approval number: REC-63-208-18-1) and the Research Ethics Review Committee of the Third People's Hospital (approval number: 2020072001). Investigators used pseudonyms to protect the identity of the participants.

#### Informed consent statement

Informed consent was obtained from all subjects involved in the study.

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# **Conflicts of interest**

There are no conflicts of interest.

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# **Supplementary Material 1**

# In-depth interview guide for reproductive PLHIV on ART

I'm interested in discussing how psychosocial factors have affected your fertility desire and intention and the support you get from the health care.

# **Topic 1: HIV-infected experience**

• Could you talk about how you became infected with HIV?

# Topic 2: Fertility behavior (barriers and facilitators)

- Could you tell me about your fertility experience? (inquire about pregnancy, deliver or abortion, respondent's existing children, any HIV positive children?)
- Could you talk about your desire and intention to have a child?
- What do you see as the barriers of fertility after you learn about two-child policy?
- Probe: (what make you decide to have or not have children within next three years?)

# Topic 3: Psychosocial factors towards having a child

- From your point of view, what is your motivation to have a child?
- What is your attitudes towards having a child?
- Do you think how do they decide your fertility decision?
- What are your partner's thoughts and feelings with regard to having children?
- Have you considered discussing your wishes for having a child with anyone?
- Could you talk about your point of parents pressure their adult child to have a child, or for those who already have one child, pressure them to have another child?
- Can you talk about how external factors determine your reproductive intentions?

# **Topic 4: HIV and Fertility policy**

- How do you know about national policy about HIV?
- What do you see as two-child policy about fertility by PLHIV?
- From your point of view, does Two-child policy affect your fertility decision?
- (Probe: two-child policy).

# Topic 5- Use of the health care service

- Have you used a counselling service regarding safe sex practices? (condom use, avoidance of multiple sex partners, knowing your partner's serostatus etc.) When and why did you use
- In your point of view, do health care providers at this centre support childbearing among HIV positive people?
- Have you ever consulted on safe conception methods? How is it like or affect your fertility desire and plan?
- People may aware of existence of services that can reduce risk of transmission of HIV to partner, unborn child and infants, what is your opinion and why do you think in that particular way?

# Conclusions

- Are there any other comments, concerns, or ideas we haven't mentioned today?
- I'll be analyzing the information you gave me and writing a draft in one month. I'll be happy to send you a copy to review at that time, if you are interested.
- Thank you for your time.

"The interview materials in this study were first transcribed into Chinese, then translated into English. These materials are available from the corresponding author upon request."