



Factors underlying the fertility intentions of people living with HIV/AIDS in Karnataka

This report is the result of a collaborative study between Samraksha, Bangalore and the Population Council, New Delhi with support from the Department for International Development, U.K. The study aimed to better understand the fertility intentions of people living with HIV/AIDS, the extent to which their positive status led them to modify their fertility intentions and the factors that impeded or facilitated the realization of their reproductive choices and intentions.

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## Executive summary

The National AIDS Control Organisation (NACO) estimates that there are over 5.1 million people living with HIV/AIDS (PLHA) in India (NACO, 2006). Of these, more than 35 percent are young and likely to be in the reproductive age group (15–49 years). In light of the recent advances in anti-retroviral therapy (ARV), the availability of highly effective treatment regimens for the prevention of parent-to-child transmission (PPTCT) and of assisted reproductive techniques that allow sero-discordant couples to bear children without infecting the uninfected partner, it is becoming increasingly important to address the fertility preferences of PLHA. Thus far, research on the effect of HIV/AIDS on reproductive health has been largely clinical, focusing almost exclusively on the ability of HIV-positive women to conceive and on pregnancy outcomes. Little is known about the fertility preferences of PLHA in India, about their pregnancy and abortion related decision-making or about the ways in which infection may lead PLHA to change their fertility intentions. The few available studies on the fertility intentions of PLHA indicate that PLHA do modify their fertility desires once their status is revealed to them.

In order to ensure that reproductive health services are responsive to the needs of PLHA, it is critical to develop an understanding of the factors that shape their fertility desires and intentions, and the obstacles they face when making informed choices about childbearing. The need for such exploration is timely in India in view of the recent scale up of the PPTCT programme and the roll out of the ARV programme by NACO, with the objective of decreasing the risk of vertical transmission and improving the long-term prognosis of PLHA. In response to this need, the Population Council, New Delhi and Samraksha, Bangalore undertook a study among PLHA to better understand their fertility intentions, examine the extent to which their sero-status modified their fertility intentions, and explore the barriers to and facilitators of their reproductive choices and intentions.

This report describes the findings of a study undertaken in one rural setting, Kushtagi block in Koppal district in north Karnataka and one urban setting, Bangalore city in South Karnataka. In order to understand the factors underlying the fertility intentions of PLHA and fertility related decision-making, in-depth interviews were conducted with currently married HIV-positive women and men from rural and urban sites and key influencing persons, including health care providers, community leaders and panchayat leaders (local elected officials). In order to capture the experiences of a wide range of PLHA, the respondents were divided into two main groups: those who wanted or had a pregnancy/birth following notification of their HIV status and those who did not want a child after learning their status and were purposively selected using quota sampling. The respondents' categories included women and men who had at least one living child as well as those who did not at the time of the interview.



The findings of this study describe the fertility intentions of PLHA and reveal the rich and complex nature of reproductive decision-making. While many women and men had modified downwards the number of children they had intended to have before they were notified about their status, what was notable was that some study participants had decided to limit childbearing altogether once they learnt about their sero-positive status while others opted to go ahead and have at least one child following disclosure. Four sets of factors appear to shape fertility intentions: health concerns, family and social pressures and support, family size and composition desires, and service-related experiences and confidence in counselling.

While all of these issues were pertinent in the decision to have or not have children following disclosure of their HIV status, it was clear that each group, that is, those who wanted a child and those who did not, emphasised a somewhat different combination of factors. Key factors preventing PLHA from modifying their pre-disclosure family size desire downward were health related: the fear of their own failing health, the fear of transmitting infection to the child, and the fear and trauma of losing yet another pregnancy or infant (in the case of those who had experienced this). Also important were social factors, notably the lack of support from extended kin as well as limited awareness of and access to PPTCT and ARV. On the other hand, PLHA who opted to have a child following disclosure of their status highlighted a different set of issues. Paramount among the factors shaping the intentions of this group were the need for a child or children, and more particularly, at least one son, to carry on the family name or to have someone to look after them in old age. Also important were family related issues: the pressure to bear children on the one hand, and confidence in family support of children in the event of parental death on the other. Health related concerns were less often stated and where discussed, were countered by awareness of available therapies and confidence in the services and counselling received.

Stakeholders supported the right of HIV-positive people to have children if they so desired. While agreeing that the decision to bear children was solely that of the couple, stakeholders argued that certain conditions were essential to enable HIV-positive people to have children, in particular, a supportive family environment on the one hand, and access to services on the other.

It is clear from the study findings that as women and men with HIV live longer and healthier lives, there is a need to enable them to make informed choices about having children and pursue their childbearing intentions in a supportive family and social environment. Two clear programme directions emerge that will enable PLHA to arrive at fertility related decisions that are truly informed and desired. First, there is a need to address the family and social environment; to counter stigma and discrimination on the one hand, and ensure greater support and acceptance of the reproductive intentions of PLHA on the other. Second, there is a need to adapt services to cater to the specific health related needs and apprehensions of PLHA. Efforts need to be made to ensure that awareness of HIV is universal and

misconceptions about HIV are reversed; counselling needs to be tailored to address the specific needs of PLHA sensitively, including fears of death and failing health, of bearing infected children and of experiencing the loss of yet another pregnancy or infant (for those with this experience); PPTCT services need to be expanded to ensure that PLHA have easy access to these services; and awareness needs to be created among PLHA about the availability of these services. Findings also call for more evidence-based research that explores the fertility intentions, and the factors shaping these intentions, among larger and more representative samples of HIV-positive women and men; that addresses the ways in which quality of care received and the extent of perceived and experienced stigma and discrimination influence fertility intentions; and that explores provider perspectives on enabling HIV-positive individuals to arrive at informed fertility decisions.

## Introduction

Recent advances in anti-retroviral therapy (ARV), the availability of highly effective treatment regimens for the prevention of parent to child transmission (PPTCT) and assisted reproductive techniques that allow people living with HIV/AIDS (PLHA), including sero-discordant couples, to bear children without infecting the uninfected partner have radically changed the fertility options available to PLHA. While a few studies on fertility intentions of PLHA have been carried out in some other countries (see for example Chen et al., 2001; Gray et al., 1998; Panozzo et al., 2003; Ross et al., 2004; Rutenberg, Biddlecom and Koana, 2000; Sherr and Barry, 2004; Stephenson and Griffioen, 1996; Thackway et al., 1997), unfortunately, little is known about the fertility preferences of PLHA in India, about their pregnancy and abortion related decision-making or about the ways in which infection has led PLHA to compromise their fertility intentions.

At a time when some 35 percent of India's 5.1 million PLHA are young (15–24 years) and likely to be in the prime reproductive ages ([www.unaids.org.in](http://www.unaids.org.in)), it is increasingly important to understand and address the fertility preferences of PLHA, particularly in view of the increasing proportion of the HIV-positive population that is female.

This report presents findings from a study conducted by the Population Council, in partnership with Samraksha, among women and men living with HIV/AIDS on their fertility

intentions, the extent to which their positive status led them to modify their fertility intentions and the factors that impeded or facilitated the realisation of their reproductive choices and intentions. The objective of the report is to provide insights that will inform the design of programmes and interventions, and promote reproductive health services that support PLHA to meet their reproductive goals and realise their reproductive rights.

Thus far, research on the impact of HIV/AIDS on pregnancy and abortion has been largely clinical, focusing almost exclusively on the ability of HIV-positive women to conceive and on pregnancy outcomes (de Bruyn et al., 2002; Thornton, Romanelli and Collins, 2004). An exception is an exploratory study undertaken by the Population Council that sought to better understand the situation and reproductive intentions of women living with HIV/AIDS (WLHA) in Nammakal district, Tamil Nadu, an area reporting high levels of HIV prevalence (over 1% among women attending antenatal facilities) (TNSACS, 2003). Findings indicate that among women who had modified their reproductive intentions following disclosure of their HIV status, a crucial factor preventing them from fulfilling their desire to bear a first child or another child was the fear of transmitting infection to the child; this fear persisted even among those who received counselling or information about PPTCT services from a health care provider. Also reported were



apprehensions of facing stigma and of leaving behind an orphaned child with no one to look after her or him. On the other hand, among women who decided to have a child or planned to have a child following disclosure of their HIV status, a key factor underlying this choice was their confidence in receiving support from their husband; indeed, close ties with the husband was a key feature distinguishing the narratives of those who opted to have a child following disclosure and those who did not. In addition, important underlying motives among this group were the desire to have someone to live for or pressure from the family to bear a son to carry on the family name (Kanniappan, Jeyapaul and Kalyanwala, 2007). Another study located in Pune and Pimpri, Maharashtra noted substantial pressure, particularly from mothers-in-law, on HIV-positive couples living in joint families to have children, especially a son (Sastry, Suryavanshi and Underwood, 2007). Yet another study undertaken in urban settings in the states of Andhra Pradesh, Karnataka and Manipur concluded that while 40 percent of HIV-positive pregnant women had considered ending their pregnancy, close to three-fourths of them had not done so as their HIV status was diagnosed too late in their pregnancy (Mahendra et al., 2007).

### Study objectives

The objectives of the study were to:

- examine the fertility desires, intentions and fertility-related decision-making in diverse groups of women and men living with HIV/AIDS;
- explore the barriers that PLHA face in fulfilling their fertility desires and intentions; and
- understand the perceptions of key influencing persons, including health care providers, about meeting the fertility intentions of PLHA and assess the extent to which these perceptions may influence reproductive decision-making among PLHA.

### Study setting

The study was conducted in Karnataka, one of six states identified as high HIV prevalence by National AIDS Control Organisation (NACO, 2006). Over the past 10 years, the number of HIV-infected cases has shown a steady increase in the state. According to the sentinel surveillance round of 2002, areas of high HIV prevalence were situated in both rural and urban parts of the state; for example, such districts as Bagalkot, Belgaum, Bangalore urban, Bellary, Bijapur, Dakshin Kannada, Davangere, Dharwad, Gulbarga, Kodagu, Koppal, Mysore Raichur, Shimoga and Udupi were found to areas with a high incidence of HIV infection (NACO, 2006).

Our study is located in one rural setting, Kushtagi block in Koppal district in north Karnataka, and in one urban setting, Bangalore city in South Karnataka. Table 1 highlights the demographic characteristics of these two study areas. As expected, the situation varies widely. Literacy rates are higher in Bangalore than in Koppal district, and the sexual and reproductive



health scenario is better: for example, there is greater awareness and practise of contraception, and more use of services for pregnancy and delivery related care in Bangalore as compared to Koppal district. In the context of HIV too, significant disparities are observed: women in Bangalore are much more likely to be aware of HIV/AIDS than those in Koppal district. Both areas are high prevalence settings, with HIV prevalence rates exceeding 1 percent in Koppal and 0.5 percent in Bangalore among women seeking antenatal care.

Samraksha is a leading NGO that has been working in the study settings to prevent the spread of HIV/AIDS in the community, and to reduce the impact of HIV/AIDS on those already affected. The

organisation is engaged in a range of prevention-to-care interventions including the provision of services related to rural and urban Continuum of Care. The care stream provided includes outreach and facility-based counselling and medical consultation; treatment of opportunistic infections; PPTCT and ARV services; prescription, clinical monitoring and adherence support and in-patient care. Other services include treatment related initiatives such as treatment education and building treatment-preparedness among PLHA, their families and community members; training and capacity building for professional and lay counsellors, medical personnel, and other caregivers; and advocacy.

**Table 1:**  
Profile of the study area

Characteristics	Bangalore city <sup>a</sup>	Koppal district
Total population <sup>1</sup>	6,537,124	1,196,089
Overall sex ratio <sup>*.1</sup>	90.8	98.3
Child (0-6) sex ratio <sup>1</sup>	94.3	95.3
Male literacy (6+) <sup>1</sup> (%)	87.9	46.9
Female literacy (6+) <sup>1</sup> (%)	77.5	19.0
Women's knowledge of any modern contraceptive method <sup>2</sup> (%)	99.7	98.5
Women's knowledge of any modern spacing method <sup>2</sup> (%)	95.1	33.7
Women currently using any family planning method <sup>2</sup> (%)	60.7	43.0
Unmet need for contraception (total) <sup>2</sup> (%)	17.8	15.7
Full antenatal care <sup>**2</sup> (%)	49.6	24.7
Institutional delivery <sup>2</sup> (%)	92.4	20.6
Women aware of HIV/AIDS <sup>2</sup> (%)	83.2	41.4
HIV prevalence among women seeking antenatal care <sup>3</sup> (%)	0.5	2.8

\* Number of females per 1,000 males.

\*\* Full antenatal care includes at least three antenatal check-ups, at least one tetanus toxoid injection and iron and folic acid supplements.

<sup>a</sup> Includes 11% of rural area in Bangalore district.

Sources: <sup>1</sup> RGI, 2001; <sup>2</sup> IIPS, 2006; <sup>3</sup> KSACS, 2005.

## Methods

Given the sensitive nature of this research, an entirely qualitative study design was employed. The study thus comprised in-depth interviews with currently married women, aged 18–40<sup>1</sup> who are HIV-positive. Of these, 40 women had living children and 37 women did not have a child at the time of interview. In-depth interviews were also held with currently married men aged 20–45 years who were HIV-positive. Of these, 16 men had living children and seven had no living children. Finally, we interviewed 20 key informants (10 in each site) to understand their perspectives and experiences. Women were recruited through the outreach clinics run by Samraksha that provide services for PPTCT and ARV. An initial screening questionnaire was used to classify PLHA according to their childbearing experiences. In order that in-depth interviews captured the experiences of a wide range of PLHA, the following groups of individuals were purposively selected, using quota sampling (the distribution of PLHA study participants by fertility intention and status is provided in Table 2).

- (i) Women who wanted or had a pregnancy/birth following disclosure of their HIV status: This group included currently married women who had living children and

those who had no living children at the time of interview, who: (a) had a child after their HIV status was disclosed (N=8); (b) were pregnant at the time of interview (including seven who had a living child and nine who did not)<sup>2</sup>; or (c) wanted a child after their HIV status was disclosed (including 10 who had a living child and eight who did not)

- (ii) Women who did not want a child following disclosure of HIV status: This group included currently married women who had living children and those who had no living children at the time of interview, who: (a) did not want an additional child (for those who had one or more living children, N=15); or (b) did not want a child (for those who had no children, N=20).
- (iii) Currently married men with and without living children who wanted or did not want a child following disclosure of their HIV status (N=23);
- (iv) Key influential persons, namely individuals who play a key role in influencing fertility decision-making including health care providers, councillors, women community leaders, NGO representatives and panchayat leaders (local elected officials) (N=20).

<sup>1</sup> The median age of women at first birth in India is 19.3 years and 80 percent of women have had their last birth by 35 years (IIPS and ORC Macro, 2000). Thus, our selected age range for study participants, i.e. 18–40 years, will cover the reproductive age span of the majority of women in India.

<sup>2</sup> Women who had a child after their HIV status was revealed to them and those who were currently pregnant are included in this category as they continued with their pregnancy and did not access abortion services.



Areas of inquiry among PLHA included desires and intentions related to childbearing and parenthood; attitudes and beliefs related to HIV transmission and prevention; attitudes and practices related to contraception; inter-spousal relationship and communication; decision-making processes at the household level; power dynamics within the household; influence of the family and spouse in pregnancy and abortion intentions and in fulfilling these intentions; perceptions of access to and quality of health care services, and attitudes of health care providers; the impact of HIV diagnosis on fertility-related desires and decision-making; the effect of personal and spouse's current health status

on fertility choices; and the effect of the availability of ARV and PPTCT services on fertility intentions.

Key influential people were probed about their perceptions of PLHAs' fertility intentions and the acceptability of pregnancy among the infected, including: perceptions of appropriate sexual behaviour and reproductive intentions of PLHA; the kinds of messages they conveyed to PLHA regarding pregnancy, fertility, contraception and other reproductive health matters; the extent to which their messages appear to influence decision-making of PLHA; and the kinds of reproductive health service options they believed were available to PLHA.

**Table 2:**  
Distribution of PLHA study participants by fertility intention and status

Fertility intentions following disclosure of HIV status	Currently married women (N=77)					Currently married men (N=23)				
	With living child/children (N=40)		With no living children (N=37)		Total	With living child/children (N=16)		With no living children (N=7)		Total
	Rural	Urban	Rural	Urban		Rural	Urban	Rural	Urban	
Had or want a child										
Had a child after HIV status was disclosed	4	4	NA	NA	8	*	*	NA	NA	NA
Currently pregnant	4	3	4	5	16	NA	NA	NA	NA	NA
Want a child	6	4	4	4	18	2	2	2	0	6
Sub Total	14	11	8	9	42	2	2	2	0	6
Do not want a child	7	8	11	9	35	4	8	2	3	17
Total of those who wanted and did not want a child	21	19	19	18	77	6	10	4	3	23

\* Information on whether men had a child after status was disclosed not available.

NA: not applicable.

Investigators were trained in qualitative research methods and techniques of conducting in-depth interviews. Consenting PLHA were interviewed in Kannada, and if permitted interviews were tape-recorded. Interviews were transcribed and translated into English. Data were analysed using Atlas Ti 5.

Before we present the findings, we begin with an acknowledgement of the limitations of this study. Foremost is that the study is small and findings therefore may not be representative of PLHA in general. Second, we acknowledge that although we have captured reproductive intentions at a single point in time, intentions may well change if there are changes in context, for example, the spread of PPTCT regimens or a change in the extent of family support available. Third, this is a qualitative study using quota sampling and, as a result, is not equipped to suggest the percentages of

women or men who may have modified their reproductive intentions on disclosure of HIV status. Hence, the findings need to be interpreted with caution.

### Structure of the report

The report is structured as follows. The study findings are presented in Chapter 2. We begin with a summary of the socio-demographic profile of the study participants and follow this with a discussion of the context of their lives after disclosure. We then present the fertility intentions of PLHA and the factors shaping these intentions. In Chapter 3, we discuss the perspectives of key stakeholders on meeting the fertility intentions of PLHA. Finally, in Chapter 4, we summarise findings pertaining to the reproductive intentions of PLHA and highlight the kinds of measures that will need to be taken to enable them to meet their reproductive goals.



## Study findings

The study objectives were to examine fertility intentions and decision-making among women and men living with HIV and to explore the barriers they face in fulfilling their fertility desires. This chapter describes the socio-demographic profile of PLHA study participants, the context of their lives once their status was disclosed to them, their fertility intentions following disclosure of their status and the factors shaping these intentions.

### Profile of PLHA study participants

Table 3 presents a socio-demographic profile of the study participants by rural-urban residence, fertility intention following disclosure of HIV status and gender. Noticeable differences are observed by rural-urban residence: urban residents are somewhat older than rural residents, as expected, because of differences in marital age patterns. They are also better educated, and women are less likely to be working. The majority of both rural and urban study participants wanted two children prior to disclosure of their status.

Differences with regard to fertility intentions were observed across the two groups. However, both groups—those who changed and did not change their fertility intentions after disclosure—desired two or more children prior to disclosure of HIV status, and their age, economic activity profiles and education are relatively similar.

Finally, disclosure of status differed considerably among men and women. All men became aware of their HIV status in the course of

consultations with health care providers as a result of experience of such symptoms as vomiting, diarrhoea or fever. In contrast, women were far more likely to have become aware through check-ups following disclosure of their husbands' status or, less often, in the course of antenatal check-ups.

### Context of PLHAs' lives following disclosure

As noted earlier, women reported that their HIV status was disclosed either during pregnancy, or when they had themselves tested after their husbands were diagnosed as HIV-positive; men reported that they were informed of their status following a routine check-up. All study participants were informed by a doctor or counsellor about their status. As expected, typical reactions of both men and women on disclosure included shock, distress, feelings of helplessness and anxiety about the future, about children and imminent death. For example:

*What a punishment God has given me at such a young age. I was scared and cried a lot, thinking that nobody will be there to look after us. (Female, 24 years, rural site, one living child, wants more)*

*I felt depressed in the beginning; I thought my life was completely ruined and nothing was left. People say there is no treatment for this disease, death is ultimate. Who will care for us? We have neither children nor family support. (Female, 22 years, rural site, no living children, currently pregnant)*

**Table 3:**  
Socio-demographic profile of study participants by residence and fertility intention status

	Currently married women who after status disclosed:				Currently married men who after status disclosed:			
	Want a child, including had a child or currently pregnant (N=42)		Do not want a child, including ever aborted (N=35)		Want a child or had a child (N=6)		Do not want a child (N=17)	
	Rural (N=22)	Urban (N=20)	Rural (N=18)	Urban (N=17)	Rural (N=4)	Urban (N=2)	Rural (N=6)	Urban (11)
<b>Age</b>								
19-21	3	3	2	2	—	—	—	—
22-25	13	4	8	5	1	—	—	—
26-29	3	8	3	5	2	—	2	1
30 and above	3	2	4	3	1	2	4	10
Not asked	—	3	1	2	—	—	—	—
Median age	25	26	25	26	27	—	33	35
<b>Education</b>								
Illiterate/no schooling	12	—	5	—	2	1	2	—
Primary (Class 1-5)	2	3	6	1	—	—	1	—
Middle (Class 6-8)	3	4	4	2	1	—	—	3
Secondary (Class 9-12)	3	10	2	11	—	1	3	6
Graduate and above	—	3	1	3	1	—	—	1
Not asked	2	—	—	—	—	—	—	1
Median years of schooling	0	12	4	11	0	—	10	12
<b>Family type</b>								
Joint	13	9	6	11	4	—	5	6
Nuclear	9	11	12	6	—	2	1	5
<b>Working status</b>								
Working	12	5	10	4	4	2	6	11
Not working	8	15	8	13	—	—	—	—
Not asked	2	—	—	—	—	—	—	—
<b>Number of children desired before status known</b>								
No children	—	—	1	2	—	—	—	—
1	2	4	2	2	1	—	—	—
2	13	11	12	8	4	1	4	9
More than 2	1	—	2	—	1	1	1	1
Not planned	6	5	1	4	—	—	1	1
<b>Status disclosed at</b>								
Antenatal check-up	9	6	3	2	NA	NA	NA	NA
Consultation (in case of diarrhoea, vomiting, fever)	3	4	5	5	4	2	6	11
After husband tested HIV-positive	10	10	10	10	NA	NA	NA	NA

NA: not applicable.



*When I consulted the doctor and he told me that I am HIV-positive, I was in tears. I was afraid and said I was going to die. (Female, 25 years, urban site, no living children, wants a child)*

*I was depressed for a while, because whoever is infected will die. [I did not know] what I should do. I have a family and even my wife is infected. (Male, 33 years, one living child, does not want more)*

Some women and men reported harbouring suicidal thoughts. For example:

*I felt very bad. I wanted to die as soon as I reached home. I did not want to continue living. I tried many times to end my life. But poverty and the responsibilities that I had to take on in my family, without brothers to support me, made me continue to live. (Female, 28 years, rural site, two living children, currently pregnant)*

*When I heard that I have HIV, I was very upset. I thought there was no point in living. I wanted to end my life. (Female, 20 years, urban site, one living child, wants another child)*

*Since I became HIV-positive, I have lost interest. I do not even open my shop regularly, nor do I meet my friends. Earlier, I used to spend time with lots of friends but now I am not interested. Sometimes, I feel like committing suicide. (Male, 27 years, rural site, no living children, does not want any)*

*I felt this disease has infected me and when my wife also tested positive, I felt more depressed. I felt bad thinking that she had got the infection from me. For six months, I was very depressed and felt like doing something to myself. Then my wife helped me recover and gave me*

*strength. (Male, 42 years, urban site, one living child, does not want more)*

Disclosure of their status to others was fraught with the fear of facing stigma and discrimination. For example, while the majority of women reported that they had informed their natal families about their status, in some instances, women withheld this information from their marital families because they feared they would be asked to leave the house or be discriminated against in some other way. Indeed, several study participants, both female and male, who disclosed their status to their families, reported facing stigma from relatives, notably from the marital family.

*Everyone knows about my status in the family. All my relatives keep far away from us. They do not talk to us as they used to. They say that being the only son, you have got this infection and destroyed your life. (Male, 37 years, urban site, no living children, does not want any)*

*None of our relatives or in-laws came to help us. (Female, 24 years, rural site, one living child, wants more)*

*They [my in-laws] do not say anything in front of me. But I think my brother's wife tells everyone that I have this disease. (Female, 23 years, rural site, no living children, does not want any)*

*Earlier, before our status was known, they [my relatives] would come to my house, but now [after knowing my status] they do not come to my house and speak to us from far away. (Female, 30 years, rural site, three living children, had a child after status disclosed)*

In contrast, the majority of respondents – both female and male – reported that they had not informed their friends about their status for fear of facing stigma and ostracism. Indeed, several women reported that if asked about their failing health by others, they would respond that they had tuberculosis and hence had a constant cold and cough. Fears of being stigmatised by peers and colleagues were expressed as follows.

*No, my friends don't know [about my status] and I won't inform them about my status in the future either. They would discourage me and tell me to abort the child. So that is why we have not told any of our friends. And, if I tell my neighbours about my infection and my plan to have a child, they will force me to abort the child; that is why I don't want to tell them.*  
(Female, 20 years, rural site, no living children, currently pregnant)

*When I go to work we all sit together and eat; if they find out that I am HIV-positive they won't eat with me.* (Female, 24 years, rural site, one living child, wants more)

*My friends do not know about this [my HIV status] because if I tell them, they will stay away from me.*  
(Female, 37 years, urban site, no living children, does not want any)

*After knowing that I have HIV, I am very worried. If anyone comes to know about it, they will move far from us, and this thought has started bothering me. I also do not feel like going near others since I have this disease. They are healthy and we are infected.*  
(Female, 20 years, rural site, currently pregnant, no living children)

*If people come to know [my status] they will talk about it. I have not experienced such a situation as I have not disclosed my status to anyone. I have seen many people who have been discriminated against because they have disclosed their status, and they have ended their lives early.* (Male, 43 years, rural site, one living child, wants more)

Several narratives also suggest that with time, initial feelings of despair have dissipated and some PLHA appear to have come to terms with their status and gained a cautious optimism about life. For some, family and peer support played a significant role.

*Earlier I was a little angry with my husband but now I understand things. If I worry, the infection will increase; but if we accept it there will not be much problem.* (Female, 20 years, urban site, no living children, wants a child)

*In the beginning, I was very upset; later I became reconciled. Now that it has come [I have the disease], what can we do? We have to enjoy life as long we are living. I do get disturbed when I think of my status.*  
(Female, 26 years, urban site, one living child, wants more)

*All our close friends know. They give us support and courage.* (Female, 33 years, urban site, no living children, does not want any)

For several study participants, and urban women in particular, access to counselling also played a significant role in enabling them and their families to accept their situation, come to terms with their status and carry on with their daily lives.



For example:

*I had suffered a lot because of discrimination. I decided to die. But when I went to KNP+ [positive persons' network], they gave me training and counselling, and also talked to my family members. Only then did they [family members] change their attitude towards me and now they eat with me and touch me. Now, everyone is fine with me. (Female, 23 years, urban site, no living children, does not want any)*

*When I came to the hospital and talked to people, I got to know about this disease [HIV]. This disease cannot be cured by medicine alone; a person has to be happy. We got to know when [the hospital staff] told us, otherwise I would have died worrying about it [the disease]. (Female, 23 years, urban site, no living children, does not want any)*

In short, although all study participants were informed about their status by a health care provider, and despite the fact that in many cases families and spouses were supportive, PLHA experienced periods of extreme depression and anxiety immediately following disclosure. In addition, the fear of being stigmatised by peers, colleagues and even family members was so severe that many PLHA hesitated to disclose their status to others and withdrew from previous social networks. There is some suggestion from the narratives that female study participants obtained more support from families and social networks than men did, but overall, both women and men reported similar feelings of despair and fear of disclosure. Yet there was a note of optimism in some – but not all – narratives: the individual's own strength and resilience, family and peer support and

professional counselling clearly resulted in a greater sense of optimism and self-worth among PLHA.

### Reproductive intentions and decision-making following disclosure of HIV status

As mentioned earlier, women and men were purposively selected to include both those who wanted a child, or in the case of women had a pregnancy or child following disclosure of their status, and those who did not want a child, or in the case of women, had aborted a pregnancy following disclosure of their status.

Of the 42 women who reported that they did not change their fertility intentions once their status was revealed to them, women were roughly equally divided across the rural and urban samples; of the six men, four were from the rural site and two from the urban site. Among women, 25 had one or more living children and 17 had none; among men, four had at least one living child and two did not. Among women, eight (four in each site) had already borne at least one child after their status was revealed to them. All of these women were informed about their status at the time of that pregnancy; five had an infected child while the rest did not yet know their child's status. In addition, 16 women (eight per site) were pregnant at the time of interview, nine without a living child and seven with at least one living child. Finally, 18 women (10 rural and eight urban) who had neither borne a child after their HIV status was revealed to them nor were pregnant at the time of interview

expressed a desire to have a child in the future; these included 10 women who had at least one living child (six rural and four urban) and eight (four in each site) who did not have any living children (see Table 2).

We interviewed 35 women who indicated that they decided not to have a/another child after they were informed about their status; 18 resided in the rural site and 17 were from the urban setting. Of the 17 men who reported that they did not want a child following disclosure, six were from the rural site and 11 were from the urban site. Among women, 15 had one or more living children and 20 had none; among men, correspondingly, 12 had at least one living child and five did not. Those who did not have a living child included those who had never had a live birth, those whose child or children had died and those who had miscarried previous pregnancies (see Table 2).

### Factors influencing PLHAs' intentions to have or not have children following disclosure of HIV status

In this section we explore the factors influencing the fertility intentions of each of the two broad groups of PLHA – those who wanted a child and those who did not want a/another child following disclosure of their HIV positive status - to have or not have a child following disclosure.

#### *PLHA who wanted a child after disclosure*

Narratives suggest five key factors influencing the intentions of this group of 48 individuals (42 women and six men) to bear children following disclosure

of their HIV status. Several study participants in this group did report that they had modified their pre-HIV family size preference downwards, but nevertheless opted to have at least one child post-disclosure. Factors influencing this intention included:

#### *Desire for children, in particular sons*

Like studies of fertility intentions in the general population, fertility intentions of PLHA were significantly influenced by a desire for children, or additional children.

*I want to have at least one child whether male or female. Earlier [before my status was disclosed] I wanted to have two children. (Female, 27 years, urban site, no living children, lost two pregnancies, wants a child)*

Gender composition was an additional factor that guided the final decision to have a child. Indeed, the need to have at least one son was an important motivating factor underlying the final decision to have a child or another child. Many spoke, moreover, about the need to have a child for security in old age and to carry on the family name. Several mentioned likewise, a desire to bear a son to “complete” their family. For example:

*Now I have a daughter, I want a son. My husband also wants a son. If I say yes [to having a child], he will also say yes. He even took me to a hospital for tests. (Female, 24 years, rural site, one living child, wants more)*

*Like others, we also want children, so that we can live with them and in future they will support us. So I feel*



*I should have a child.* (Female, 22 years, rural site, currently pregnant, no living children)

*I lost my first child because of this disease [HIV]. But we need children for our survival. If we have children now, we will have someone in our old age; we will have somebody to give us food. I want my property to be in my children's name otherwise somebody else will take away our wealth. I do not want that to happen.* (Female, 24 years, rural site, no living children, lost a previous pregnancy, wants a child)

Male study participants concurred with these views. Indeed, the need for a son was expressed by all men who desired a child following disclosure of their HIV status. For example:

*My first child was a boy but he died. Now I have a daughter. So we are thinking of having a son to look after us in old age.* (Male, 27 years, rural site, one living child, wants more)

*If the second child had been a boy, I would not have bothered. Our desire was to have one daughter and one son, two children are enough. But now we have two daughters so we would like to have a son.* (Male, 28 years, rural site, two living children, wants more)

There was a suggestion, moreover, from the narratives of women, that husbands were sometimes more concerned about having a child or a son following disclosure of HIV status than were women themselves; for example:

*Due to my present situation, I did not want a child but my husband wanted one. I thought maybe because my first child is a girl and he may be interested in a boy. I agreed only because it came from him.*

(Female, 28 years, rural site, one living child, currently pregnant)

*I was ready for sterilisation after my daughter was born but my husband wanted one more child.*

(Female, 28 years, rural site, two living children, had a child after status known)

### *Family or societal pressures*

Also frequently mentioned were family or societal pressures to have at least one child or at least one son. For example, all eight women in the rural area and most of those in the urban area who were pregnant at the time of interview, irrespective of whether they had a living child or not, indicated that their husbands or family members had put pressure on them to continue their pregnancies. For example:

*Yes, he [husband] said that we would have this child. I wanted to undergo an abortion but he said no. He said, "We can have only one or two children due to this infection so let us have this child and not abort it."* (Female, 25 years, rural site, one living child, currently pregnant)

*My family wants the child, but I do not.* (Female, 25 years, rural site, four living children, currently pregnant)

*My husband wants a son because people taunt him and say that he does not have a male child. So I also want a male child.* (Female, 28 years, urban site, three living children, wants more)

Several women, notably pregnant urban women, also reported that they felt societal



pressures to prove their fertility. While they expressed concern about their ability to bear a healthy child, these women reported that they were willing to face any problem to have the child:

*I want a child because people keep asking me why we do not have any children; they do not know our condition. I am ready to face any problems but I want this child. (Female, 20 years, urban site, currently pregnant, no living children)*

*Usually people ask how many children you have and not how much property you have. If you have no children, they ask why there are no children. To avoid these questions, I need to have a child. (Female, 28 years, rural site, currently pregnant, lost earlier two pregnancies, no living children)*

Fewer male study participants reported such pressures; those that did also mentioned issues of family honour and respect. For example:

*I have fear as well as a desire to have another child. We need one more to gain respect from society as they respect people with two children. (Male, 43 years, rural site, one living child, wants more)*

*As my mother wishes to have a grandchild, I will tell my wife that I want a child. (Male, 27 years, rural site, no living children, wants a child)*

#### **Confidence that children would grow up in a supportive environment in the event of parental debility or death**

Families influenced PLHAs' decisions to have children in a different way as well. Narratives

suggest that the availability of extended kin – usually a parent – to care for children in case of study participants' disability or death was a leading reason for PLHA to have children following revelation of their status.

*Both my husband and I are the only child in each of our families. So our parents say that we should have as many children as we want to, and they will take care of them. (Female, 22 years, rural site, currently pregnant, no living children)*

*My husband suggested that we should not have more children. But my mother did not agree. I told her that as long as we are alive, we will look after the child and after us, she would have to do so. My mother has agreed to this; now she is pressurising us to have a child. (Female, 20 years, urban site, no living children, wants a child)*

Accounts of respondents suggest that in the final decision on child bearing, the acceptance of the decision and offer of support from family members played an important role.

*First, my mother-in-law did not accept our decision to have a child but after getting information from the doctor, she agreed that I could have a child. (Female, 20 years, rural site, currently pregnant, no living children)*

*My husband and I decided to have children. My father and mother said the same thing [supported our decision]. Even they feel that we should have children. (Female, 22 years, rural site, currently pregnant, no living children)*

***Having another child so that siblings would support each other in the event of parental death***

PLHA with one living child also highlighted the need to have another child to create support mechanisms and structures among siblings for the future. The reason they cited for wanting another child was the need for a second child to bond with the first so that children would have each other's support in the event of parental death. For example:

*We should have two children so that they can play together and grow up together. We have one child so we decided to have one more. Both children will be together. We should have one more in case one child dies. (Female, 35 years, rural site, one living child, wants more)*

*My husband said that if we have one more child, they would look after one another as he may not live long because of the infection. One child will not be able to face any problems alone. (Female, 23 years, rural site, two living children, had a child after status known)*

***Awareness of PPTCT/ARV and confidence in counselling received***

As compared to those who did not want a child, this group of 22 women in the rural site and 20 in the urban site were far better informed about PPTCT and ARV and the availability of these services, and were much more likely to have confidence that these treatments would enable them and their children to survive. These women underscored the quality of the counselling and information received—not only on PPTCT but

also on pregnancy and post-pregnancy care — as playing an important role in their intention to bear children following disclosure of their status. Indeed, in both sites many women from this group discussed the extent to which the counselling they received enabled them not only to accept their status and “face life” but also to consider childbearing. Women in this group overwhelmingly noted the positive effect of ARV on improving their health, which in turn also changed their attitude towards and confidence in having a healthy child. For example, women who had children or were pregnant at the time of interview reported the following:

*I did not want to have this child but the doctors have assured me that if I take medicines regularly, my child will not get infection. (Female, 26 years, urban site, currently pregnant, one living child)*

*When I got to know that I was pregnant, I consulted a doctor for an abortion. But he suggested that we should not go for an abortion and told us about medicines [ARV]. He said that there are medicines to prevent the infection from mother to child. After delivery again they gave us counselling and told us what to do in future. We followed their advice and are healthy today. (Female, 22 years, rural site, two living children, had a child after status known)*

Men who expressed a desire for another child also depended on the provider's assurance before making the decision to have a child; for example:

*I will tell the doctor about my status and my desire to have a child. I will ask whether the child would be*



*born HIV-negative. If they give me confidence that 100 percent the child will be negative, then we will have a child. Otherwise, we do not want one more.* (Male, 43 years, rural site, one living child, wants more)

So too, study participants without children also noted the critical role that counselling along with a likelihood of availability of drugs played in enabling them to take the final decision about bearing children:

*As they [doctors] have told us that we will get medicines, we feel that we can have a child by taking these.* (Female, 28 years, rural site, currently pregnant, no living children)

*I have decided to have a child based on the information given by the doctor and the counsellor. They have said that with PPTCT treatment, mother to child infection could be stopped. Now I am trying to have a child.* (Female, 20 years, urban site, no living children, wants a child)

*Initially I was afraid but after I spoke to the doctor and the counsellor, I got courage. After the doctor said that the infection will not pass on to my child, my fear has reduced. That is why I changed my decision from not wanting a child to having one.* (Female, 20 years, urban site, currently pregnant, no living children)

*I have heard that they have found a medicine that prevents the child from getting infected and if breast milk is not given to the child then the transmission of infection can be prevented.* (Female, 28 years, urban site, three living children, wants more)

In short, narratives suggest that the intentions of both female and male study participants who had

or wished to have children following revelation of their HIV status were shaped by at least five key factors. Two of these were those that shaped the intentions of women and men more generally: to have a family, in particular to have a son, and to overcome pressures from families and communities. Other factors were directly linked to their HIV status, namely, confidence that a parent or other extended kin would care for their children in case of death or debility, the need for at least two children so that siblings could support each other in the event of parental debility or death, and awareness of PPTCT and ARV and confidence in the quality of counselling received.

#### **PLHA who did not want a child after disclosure**

All 52 individuals—35 women and 17 men—in this group were quite firm in their decision about not wanting a child. Indeed, all reported that they had modified their fertility intentions once their status was revealed. For example:

*I would like to have another child, but because of this infection, I have decided not to.* (Female, 25 years, rural site, one living child, does not want more)

*Before I knew that I was infected [HIV-positive], I wanted to have two children. After becoming infected, I think one is enough.* (Male, 33 years, rural site, one living child, does not want more)

Motives for modifying fertility intentions were largely similar for women and men, and for those who had and did not have a living child.



**Concern about their own poor and failing health**

Irrespective of previous fertility history, the leading motive for the decision to limit childbearing, expressed by all 35 women and 17 men in this group, was concern about their own poor and failing health and consequent ability to bear and take care of children. Fear of early death and of leaving the children orphaned were reasons repeatedly cited by both women and men, and by both those who had living children and those who did not.

For those with living children, moreover, several reported that they did not have the physical strength to go through with another pregnancy or to care for another child, and preferred to regain their strength so as to provide for their living children. For example, women with living children reported thus:

*There is no need to have children. First, our health should become better. My husband should get good treatment and get better.* (Female, 25 years, rural site, one living child, does not want more)

*I cannot take this decision [to have a child]. All the time I will think of what may happen. Will I die soon, will I die badly?* (Female, 26 years, urban site, experienced spontaneous abortion, one living child, does not want more)

Women with no living children also expressed similar concerns:

*I have problems at home and I have infection [HIV], therefore, I feel it is good if I do not have a child.* (Female, 27 years, urban site, lost previous pregnancy, no living children, does not want any)

*As we are not well, he [husband] says that I should not have a child. And I also think this is right.*

(Female, 23 years, rural site, lost two pregnancies, no living children, does not want any)

Men expressed similar anxieties. They perceived that they should not have a child in the light of their infection; many were, in addition, concerned that pregnancy would affect the health of their wives.

Several study participants reported that their extended kin had also expressed a concern that a pregnancy would have an adverse effect on women's lives, and had supported their decision not to have children, suggesting that they devote available resources to look after the living child and take care of their own health. For example:

*My family said, "As you are facing this problem, why do you want to have children? Look after the children who are there well."* (Male, 35 years, rural site, three living children, does not want more)

*My parents took me for an abortion once my status was known to them. I agreed because I was infected and did not want my child to get HIV.* (Female, 38 years, rural site, two living children, aborted pregnancy after status disclosed)

*My mother and my aunt also told us not to have children. They told us to stay well and not worry about children.* (Female, 37 years, urban site, no living children, does not want any)

**Concerns about bearing an infected child**

Irrespective of whether or not pregnancy or child loss had been experienced, the fear of having an

HIV-infected child and causing the child to suffer as a result of infection was central in the decision not to bear children post-disclosure. This suffering, they felt, would be compounded in event of the death of one or both of the child's parents. This perception was reported by both women who had children and those who did not. For example, among women who had a living child:

*Now that we are infected, we may have problems, and our children will also have problems. As long as we are alive, we can look after them. If they are healthy, they can live anywhere. But if they too are infected, it would be very difficult. The child should not suffer. That is why we [my husband and I] decided not to have any more children.* (Female, 30 years, rural site, experienced miscarriage, three living children, does not want more)

*Tomorrow my child may have problems because of me.... Then the thought of educating children. My main wish is to look after my [living] child well, nothing else.* (Female, 26 years, urban site, one living child, does not want more)

*I thought if I had a son and a daughter, it would be enough. Now, after this infection, I feel I do not want any children. Let whatever has to happen, happen to us but the children should not get HIV. My elder daughter has it [HIV] and she has not eaten or slept for a week.* (Female, age not known, rural site, has experienced miscarriage, one living child, does not want more)

Women without living children also expressed this concern:

*What is the use of having children if we cannot live? I know only one thing, that giving birth to a child, it [HIV] will spread to our children from us.* (Female, 22 years, rural site, ever aborted, no living children, does not want any)

*Earlier [before disclosure] we wanted to have children. But now we are patients. If because of us our children have problems, their future will also be spoilt. So, now we do not feel like having children.* (Female, 25 years, urban site, lost earlier pregnancies, no living children, does not want any)

*If the child is not healthy, we will suffer.* (Female, 22 years, rural site, ever aborted, no living children, does not want any)

*I feel we should not have children because we have this infection and our children may face the same problem. We know that the children we give birth to will also get the same infection and our children will suffer in future.* (Female, 20 years, rural site, lost two pregnancies, no living children, does not want any)

At least two women who expressed these concerns reported that they had deliberately aborted a previous pregnancy as a result:

*I am already infected with HIV; I worry that my child will also get HIV. It will also have problems, so I decided to seek an abortion to avoid all problems.* (Female, 38 years, rural site, two living children, does not want more)

*As both of us have HIV, I am scared that my child may also get it. So I told my husband that I wanted to have an abortion and he agreed.* (Female, 38 years, urban site, lost earlier pregnancies, no living children, does not want any)



*Concern about care-takers for children in case of parental debility or death*

As expected, a leading concern among PLHA was the apprehension that children would not be cared for in case of parental debility or death. Women recognised that they would need to depend on extended family support in case of their own or their husbands' failing health, and they expressed a fear that there was no guarantee that a family member would look after the child after their death, particularly in cases where the family had not accepted or come to terms with their positive status.

*We are not healthy ... who will look after the child? That is why we decided not to have any more children.* (Female, 25 years, rural site, one living child, does not want more)

*Many HIV infected people feel better sometimes, but they fall ill suddenly and die. So I think my child should not have any problems because of me.* (Female, 33 years, urban site, one living child, does not want more)

*If we want to, we can have children, but we should not have children because there may not be anyone to look after them once we die.* (Female, 28 years, urban site, experienced miscarriage, one living child, does not want more)

*He [husband] will never take a decision on his own to have a child. He is already depressed about our life. He says that now we do not have many days to live. Let us not think of having one more child but think of building our [living] children's future. So he will not think of having another child.* (Female, age not known, experienced spontaneous abortion, two living children, does not want more)

This sentiment was also expressed by those without living children:

*I came to know about my infection in the third month of pregnancy. I decided not to have any children because I do not know who will look after them.* (Female, 22 years, rural site, lost earlier pregnancy, no living children, does not want any)

*We do not want any children because if something happens to us, then who will take care of my children?* (Female, 25 years, rural site, lost one child to premature birth, no living children, does not want any)

Men echoed these concerns. For example:

*Why should I have another child just to leave it an orphan? I do not want to desert anyone in my life.* (Male, 33 years, rural site, one living child, does not want more)

*We both are [HIV] positive; if one of us is unwell, then the other person can provide care. But if we have a child, we should be able to look after the child. We decided not to have a child as it is difficult to look after it, and the child may also get infected.* (Male, 37 years, urban site, no living children, does not want any)

Indeed, in this group, extended kin appeared unavailable or unwilling to make a commitment to care for study participants' children in case the health of PLHA and/or their spouses made it impossible for them to do so themselves. Several study participants suggested that their extended families had not accepted their HIV-positive status, and hence may not support children in the future.



*There is no one to look after me, I do not have any support from my marital family. (Female, 27 years, rural site, lost earlier pregnancies, no living children, does not want any)*

#### *Trauma of a previous child's death or pregnancy loss*

The trauma of a previous child's death or the loss of a previous pregnancy was a key factor leading PLHA with no living children to modify their fertility intentions. Indeed, of the 20 women (11 and nine in the rural and urban sites, respectively) and five men (two and three in the rural and urban sites, respectively) who neither had a living child nor wanted one in future, nine women (five and four in the rural and urban sites, respectively) and four men (two in each site) reported their wives' experience of a previous spontaneous abortion or premature delivery, or their experience of the death of a child. In addition, of 15 women who had at least one surviving child, nine women (four and five in the rural and urban sites, respectively) reported a similar experience. All of these study participants indicated that they did not want to undergo the trauma of losing a child again.

*After witnessing the deaths and funerals of my two children, I feel I should not have a child. (Female, 33 years, rural site, lost two children to infection, no living children, does not want any)*

*In the beginning I wanted to have a child. But now after the death of my child, as we are HIV-positive, we feel scared. In case the child is infected then there will be problems in future. That is why we decided*

*not to have a child. (Female, 23 years, urban site, lost a child, no living children, does not want any)*

#### *Limited awareness of and access to PPTCT/ARV*

Narratives indicate that this group of respondents were poorly informed about PPTCT or ARV. In contrast to those who wanted a child, even PLHA who had been informed about these services reported that they did not trust or have confidence in the counselling they received from providers, either about their own survival or about prevention of infection from parent to child and the survival of children. As mentioned earlier, the majority of these study participants had experienced a previous pregnancy or child loss, and this experience appeared to play a major role in their lack of confidence in provider statements/information, or in their ability to go through pregnancy or bear a child who would survive.

*No, we do not know about PPTCT. Even if it is available, we do not want to have a child. Because people say there is no treatment for this infection [HIV]. I do not want my children to suffer because of us. (Female, 25 years, rural site, no living children, does not want any)*

*Yes, the child can be protected from this infection if a regular check-up is done during pregnancy and by delivering the baby in a hospital. But even with the treatment I do not want a child because we are going to die for sure, and then our children will become orphans. (Female, 27 years, rural site, ever aborted, one living child, does not want more)*

*No, I don't know about PPTCT. I have heard that when the child is in the womb this medicine should be taken and that it could prevent the transmission of infection. I learnt about it from the media; I have heard some people talking about it. But I have not still decided [to have a baby] because I am not sure if the child will be HIV-negative or not. (Male, age 35, urban site, two living children, does not want more)*

Narratives suggest then that irrespective of the sex of the study participant, and irrespective of whether they had a living child or not, some PLHA were firm in their decision about not wanting another child. Several key factors appeared to underlie this intention. Some are health related, for

example, fears of their own failing health; apprehensions of bearing an infected child and causing a child to suffer; concerns about taking care of an infected child in case of debility; and, among those who had experienced pregnancy or child loss, the trauma of that experience. Other factors are related to the lack of family or community support; for example, the fear of abandoning a child without appropriate care-takers and the lack of supportive extended kin. And finally, narratives suggest that this group lacked complete information about PPTCT or confidence in the counselling received from health care providers. Indeed, the availability of PPTCT or ARV did not enter into the decision-making process of this group of PLHA.

## Perspectives of stakeholders

Health care providers, counsellors, NGO representatives, women community leaders and panchayat leaders comprised stakeholders addressing the needs of HIV-positive people in the community with whom interviews were held (10 in each site). It is evident that this group supported the right of positive people to achieve their desired family size but also stressed the need for informed decision-making.

*The decision to have a child is theirs [PLHA], we can advise them. It is okay if they want to have a child because everyone has a desire to have a child and enjoy motherhood.* (VCTC counsellor, rural site)

Stakeholders recognised, however, the huge family and societal pressure that HIV-positive people face to bear a child, especially among couples without children. For example:

*Women who do not have children will be more interested in having children otherwise society will call them "banjh" [barren]. Being barren is more difficult for a woman than being HIV-positive. They can conceal their HIV status but the status of a barren woman is difficult to hide and they may want at least one baby. In some cases, the woman may not be interested [in having a baby] but her husband may be interested, and may force her to have a baby.* (Doctor, urban site)

*The pressure [to have a child] may come from the family, the husband or the mother-in-law. The mother-in-law may say, "You do not have a child, especially a male child." In general, women do not*

*have much choice about whether to have a child or to opt for family planning. It is the family that decides whether the woman should have a child or not.*

(Social worker in an NGO, urban site)

In their narratives, stakeholders suggested several essential conditions that would enable HIV-positive couples to have children. The first was the availability of family support. Stakeholders cautioned that if an HIV-positive couple wants to have a child, they must be assured of family support to ensure that the child is cared for in the event of parents' debility or death, for example:

*It is not enough if you tell them about PPTCT. What happens if a child is negative and the parents die? Who will look after the child? Who will follow up with the parents on whether they are taking medicines regularly? One must ensure some security to the parents. There should be some family support so that there is at least one person to look after the child.* (HIV-positive person, working as a counsellor in a PLHA network, urban site)

The second was creating awareness about and ensuring access to appropriate services. Several stakeholders noted that HIV-positive people are not well informed of available services. They underscored the need to raise awareness of available services in the community, for example:

*People have not thought of accessing these services in our taluk [block]. We need more awareness programmes, we need to start people's groups. This is*



*because people do not have adequate knowledge about HIV. (Social worker in an NGO, rural site)*

*We cannot say that the government is not doing anything for them [PLHA] or what they are doing is correct. The government does its work in its own way – distributing pamphlets, brochures or materials on HIV. But how far does it reach uneducated people and the rural masses – that is not monitored. (NGO worker, urban site)*

Stakeholders recognise that PLHA who are aware of available services hesitate to access them for fear of revealing their status and exposing themselves to discrimination. Stakeholders underscored the need to ensure access to appropriate services including both detailed information on PPTCT and pre- and post-delivery care, as well as, more generally, sexual and reproductive health services.

*There are many services available to prevent infection from mother to child. Using these services, they [PLHA] can have HIV-negative children. Earlier these services were not available but today, an HIV-positive person can use these services in the early stages of infection and live for some more years. We give all this information to PLHA who come to us. (Doctor, urban site)*

*If they [PLHA] do not disclose their status, they will not get any services but if they do, they will get all the services that are needed. (Social worker from an NGO, rural site)*

Indeed, several stakeholders argued that the health care environment was not yet suitably

adapted to meet the needs of HIV-positive people. For example:

*Recently, an HIV-infected woman was denied admission at the time of delivery.... This should not happen and everybody should be treated equally. HIV-infected women should also get the same services as other women. Because of this, I have requested for a separate division of the hospital for HIV-infected women, with a separate operation theatre and instruments. (Women's group leader, rural site)*

*The facilities available here are not adequate. We need a gynaecologist. In the government hospitals, the doctors are working on contract. They do not treat patients properly – no services are provided for infected women, especially at the time of delivery. (Woman taluk [block] leader, rural site)*

*The government is not providing sufficient services; those that are currently available are inadequate. (NGO worker, urban site)*

Stakeholders also recognised the need for improved training of counsellors to help HIV-positive people deal better with their status and achieve their reproductive intentions.

In short, stakeholders strongly supported the right of HIV-positive people to achieve their reproductive goals in an informed way but cautioned that such conditions as family support and access to appropriate services were essential conditions that HIV-positive people need to ensure before making the decision to bear children.

## Summary and recommendations

The study findings describe the fertility intentions of PLHA. Admittedly, given the small sample size, the findings are tentative, nonetheless revealing the rich and complex nature of reproductive decision-making. While many women and men had modified downwards the number of children they had intended to have before their status was disclosed, what was notable was that some study participants had decided to limit childbearing altogether while others opted to go ahead and have at least one child following disclosure. Four broad sets of factors that appear to shape fertility intentions include health concerns; family and social pressures and support; family size and composition desires; and service-related experiences including confidence in counselling. While all of these issues played a role in the decision to have or not have children following disclosure of their HIV status, it was clear that each group emphasised a somewhat different combination of factors.

PLHA who opted to have a child following disclosure of their status highlighted a different set of issues. Paramount among the factors shaping the intentions of this group were the need for a child or children and more particularly, at least one son. Also important were family related issues: the pressure to bear children on the one hand, and confidence in family support for children in the event of parental death on the other. Health related concerns were less often

stated and, where discussed, were countered by awareness of available therapies and confidence in the services and counselling received. Indeed, counselling on available services played a key role in enabling PLHA to fulfil their childbearing intentions or to continue a pregnancy.

Key factors preventing PLHA from fulfilling their pre-disclosure desired family size were health related: the apprehension of their own failing health, the fear of transmitting infection to the child, and the anxiety and trauma of losing yet another pregnancy or infant (in the case of those who had experienced this). Also important were social factors, notably the lack of support from extended kin. There was also a suggestion in the narratives that this group may not have had access to comprehensive information about PPTCT or ARV, or quality counselling on these issues, although some did report that they had no confidence in provider counselling about PPTCT services and the possibility of bearing a child who is not infected.

Stakeholders supported the right of HIV-positive people to have children if they so desired. While agreeing that the decision to bear children should be solely that of the couple, stakeholders suggested that HIV-positive people would be more likely to have children if two essential conditions are met: a supportive family environment on the one hand, and access to services on the other. Both of these were also highlighted in the narratives of study participants who wanted or had children



following disclosure of their status. Indeed, stakeholders suggested that neither of these conditions is available to large numbers of HIV-positive people.

It is clear from the study findings that with the availability of more effective treatment opportunities and transmission reduction programmes, as women and men with HIV live longer and healthier lives, there is a need to enable them to make informed choices about having children and pursue their childbearing intentions in a supportive family and social environment. Two clear programme directions emerge.

First, there is a need to address the family and social environment, to counter stigma and discrimination on the one hand, and ensure greater support and acceptance of the reproductive intentions of PLHA on the other. Parents, families and the larger community must be oriented to support PLHA to arrive at their own decisions about bearing children; at the same time, they must be oriented to support PLHA in that decision – including, for those who opt to have children, assurances that children will be cared for in the event of parental death.

Second, there is a need to adapt services to cater to the health related needs and apprehensions of PLHA. Efforts need to be made to ensure that awareness is universal and misconceptions are reversed. Counselling needs to be sensitive and convincing to PLHA, and tailored to address their fears, for example, of death and failing health, of uncertain survival and quality of life of children, and of experiencing the loss of yet another pregnancy or infant (for those with this experience). Finally, there is a need to expand PPTCT services to ensure easy access to and availability of these services, and PLHA must be better informed about where these services can be obtained.

Findings also call for more research that explores the fertility intentions, and the factors shaping these intentions, among larger and more representative samples of HIV-positive women and men. Amongst others, the issues that need to be explored are the ways in which the quality of care received and the extent of perceived and experienced stigma and discrimination influence fertility intentions; and providers' perspectives on enabling HIV-positive individuals to arrive at informed fertility decisions.



## References

- Chen, J.L., K.A. Philips, D.E. Kanouse et al. 2001. "Fertility desires and intentions of HIV-positive men and women." *Family Planning Perspectives* 33(4): 144–152, 165.
- de Bruyn, M., M. Njoko, D. Odhiambo et al. 2002. *HIV/AIDS, Pregnancy and Abortion Related Care: A Preliminary Inquiry*. Chapel Hill, USA: Ipas.
- Gray, R.H., M.J. Wawer, D. Serwadda et al. 1998. "Population-based study of fertility in women with HIV-1 infection in Uganda." *Lancet* 351(9096): 98–103.
- International Institute for Population Sciences (IIPS). 2006. *Reproductive and Child Health. 2006*. Mumbai: IIPS.
- International Institute for Population Sciences (IIPS) and ORC Macro. 2000. *National Family Health Survey (NFHS-2). 1998–99; India*. Mumbai: IIPS.
- Kanniappan, S., M.J. Jeyapaul and S. Kalyanwala. 2007. "Desire for motherhood: Exploring HIV-positive women's desires, intentions and decision-making in attaining motherhood." *AIDS CARE* (Forthcoming)
- Karnataka State AIDS Prevention and Control Society (KSACS) 2005. *The Sentinel Surveillance Report for HIV in Karnataka, Bangalore*, Bangalore, Government of Karnataka.
- Mahendra, V.S., N. Rutenberg, A. Sarna et al. 2007. "Sexual and reproductive needs of HIV positive women receiving PPTCT services: Findings from a diagnostic study in India." *Programmes and Abstract, International Conference on Actions to Strengthen Linkages between Sexual and Reproductive Health and HIV/AIDS*, Mumbai, February.
- National AIDS Control Organisation (NACO). 2006. *HIV/AIDS epidemiological surveillance and estimation report for the year 2005*. New Delhi: Ministry of Health and Family Welfare, Government of India.
- Panozzo, L., M. Battegay, A. Friedl et al. 2003. "High risk behaviour and fertility desires among heterosexual HIV-positive patients with a serodiscordant partner: Two challenging issues." *Swiss Medical Weekly* 133(7–8):124–127.
- Registrar General, India (RGI). 2001. *Census of India*, New Delhi: Office of Registrar General.
- Ross, A., L. Van der Paal, R. Lubega et al. 2004. "HIV-1 disease progression and fertility: The incidence of recognized pregnancy and pregnancy outcome in Uganda." *AIDS* 18(5):799–804.
- Rutenberg, N., A.E. Biddlecom and F.A.D. Koana. 2000. "Reproductive decision-making." *Family Planning Perspectives* 26(3):124–130.
- Sastry, J., N. Suryavanshi and C. Underwood. 2007. "Fertility desires and family size: Impact of HIV, PPTCT and ART in communities around Pune and Pimpri, India." *Programmes and Abstract, International Conference on Actions to Strengthen Linkages between Sexual and Reproductive Health and HIV/AIDS*, Mumbai, February.
- Sherr, L. and N. Barry. 2004. "Fatherhood and HIV-positive heterosexual men." *HIV Medicine* 5(4): 258–263.

Stephenson, J.M. and A. Griffioen. 1996. "The effect of HIV diagnosis on reproductive experience, Study Group for the Medical Research Council Collaborative Study of Women with HIV." *AIDS* 10(14):1683-1687.

Tamil Nadu State AIDS Control Society (TNSACS). 2003. *The Sentinel Surveillance for HIV in Tamil Nadu*. Chennai: Government of Tamil Nadu.

Thackway, S.V., V. Furner, A. Mijch et al. 1997. "Fertility and reproductive choice in women with HIV-1 infection." *AIDS* 11(5):663-667.

Thornton, A.C., F. Romanelli and J.D. Collins. 2004. "Reproduction decision making for couples affected by HIV: A review of the literature." *Topics in HIV Medicine* 12(2): 61-67.

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