

Infection with the Human Immunodeficiency Virus and Fertility Desires: Results from a Qualitative Study in Rural Uganda

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Abstract

The rationale of this qualitative study was to determine how a positive HIV diagnosis influenced fertility desires and reproductive decisions for women and men living in western Uganda and what the reasons were behind these fertility desires. The qualitative study was undertaken as part of a larger study on the same topic in order to better understand the quantitative findings. Five focus groups with a total of 35 participants, 20 women and 15 men were conducted. Eighteen participants were HIV positive. Almost all HIV-positive participants reported that they did not wish to have more children. The most important reasons given were the devastating impact of HIV on the health of the mother and the high risk of HIV transmission to the child. Most participants were not aware of the benefits of highly active antiretroviral therapy on reducing the risk of mother-to-child transmission of HIV. Some HIV-negative

participants viewed ongoing childbearing by HIV-positive individuals as the result of a lack of education regarding the risks of childbearing while HIV-positive and also as contrary to the current expectations of lifestyle practice. They also emphasized that the community's perceptions of having children when mothers are HIV-infected was unfavorable and that fertility norms for all persons in the study area have now changed due to economic concerns and desire to educate all children in the family. The study findings have to be incorporated in the counselling curriculum for programs directed at HIV prevention and care and family planning. Specific recommendations are provided to improve the districts' primary healthcare programs for HIV care/prevention and family planning.

Introduction

The possibility of passing HIV from mother to child and the likelihood that one or both parents could die prior to the child reaching adulthood are crucial issues for HIV-positive couples to consider in deciding whether they want to have more children or not (Newell et al. 2004). In spite of these concerns, many couples still decide for various personal, cultural and economic reasons to have children after receiving a positive HIV diagnosis (Gregson et al. 1998). In most places in Africa a common expectation of marriage is that the couple will have children. This is an especially important expectation in Uganda, as children become members of the paternal clan (Feldman and Maposhere 2003; Lutalo et al. 2000). Women are valued for their ability to bear children, and a high societal value is placed on fertility. Because of these expectations and social pressures, women and couples may continue childbearing when they are HIV-infected, and they may ignore the risks for the health of the mother and the child. The desire to avoid social stigma and isolation is still strong.

Though there is evidence that HIV/AIDS reduces women's fertility, the relative contributions of social, biological and behavioural factors have not been fully elucidated (Fabiani et al. 2006; Ross et al. 2004). Some studies have shown that an HIV diagnosis causes people to choose to have fewer children (Allen et al. 1993; Feldman and Maposhere 2003; Grieser et al. 2001). Other research has shown that HIV/AIDS does not have a marked impact on fertility decisions, particularly for those who show no signs or symptoms of disease (Baylies 2000; Gregson et al. 1998; Rutenberg and Baek 2004). In Uganda, few studies have investigated the effect of an HIV diagnosis on reproductive decision making. Given its extremely high fertility rate, Uganda may differ from other countries in sub-Saharan Africa (Wakabi 2006). One study from eastern Uganda with HIV-positive participants on highly active antiretroviral therapy (HAART) from a home-based care program indicated that few participants wanted more children (Homsy et al. 2009). A second study from western Uganda showed similar results (Nakayiwa et al. 2006). Overall, the literature revealed the shortage of published material in regard to HIV infection and childbearing decisions.

To further investigate the relationship between HIV status and desire for children, we undertook a study that utilized qualitative methods. The two purposes of the study were (1) to examine if and how a negative or positive HIV diagnosis influences reproductive desires, behaviour and the decision-making processes in individuals living in rural districts in western Uganda, and (2) to investigate why HIV-positive individuals stop childbearing. Another justification for this study was to better explain the findings from our quantitative study on the same topic, which also showed that HIV-positive couples have less desire for future children than HIV-negative ones (Heys et al. 2009).

This study was conducted from September to December 2006 in the districts of Kabarole and Kamwenge in western Uganda.

Methods

The intent for our qualitative study was exploratory in nature, with content analysis using ethnographic principles of qualitative research. The framework for conducting the study was based on the recognition that cultural and social factors play a significant role in fertility desires and decisions, as this has been reported and highlighted in the literature (Nattabi et al. 2009). In his model for fertility intentions, Airhihenbuwa focuses on "enabling factors," the endogenous factors that may facilitate or hinder childbearing, and "nurturers," factors external to the family that influence and motivate

health behaviour and action (e.g., extended family, peers) (Airhihenbuwa 1995). This study was a component of a larger one on this topic, including quantitative and qualitative study components. The results from the quantitative study are already published (Heys et al. 2009).

Study Area

An estimated 22,400 persons living with HIV reside in Kabarole district in southwestern Uganda which corresponds to an HIV prevalence in the district is 11.6% (Together Against AIDS, 2012). This is substantially above the national average of 6.4% (Ministry of Health [MOH; Uganda] and ORC Macro 2006). Fertility is high, with a total fertility rate of 7.1, also much higher than the national average. Participants were recruited from three health centres in the Rwimi and Kibiito sub-counties in the Kabarole District and the Bigodi sub-county in the Kamwenge District. The health centres are located along two major roads and are government-run. They offer clinical and public health services, as well as voluntary counselling and testing (VCT) and prevention counselling for mother-to-child transmission of HIV/AIDS.

Study Participants

Participants were a convenience sample of the 421 HIV-positive and -negative individuals who participated in the cross-sectional quantitative study mentioned above (Heys et al. 2009). Study inclusion criteria for the original cross-sectional sample were age 18 to 44 years, married or cohabitating with a partner, and having an HIV test result and a known village address. HIV-positive and -negative persons were selected from two health centres and one HIV support group. HIV-positive and -negative persons were selected from the VCT registries from two health centres (Rwimi and Kibiito), wherein all consecutive persons who had been HIV tested to date were included. To increase the sample size, all HIV-positive individuals of an HIV patient support group in the Bigodi sub-county were also included in the study. Spouses of an HIV-positive participant who met the eligibility criteria were invited to participate. Thirty-five participants from this sample were interviewed in five focus group discussions (FGDs) (for details see Table 1). The participants in one FGD reported that they became pregnant after receiving their HIV diagnosis.

Focus Group Discussion Question Guide

An FGD question guide was developed with input from the research team and local health providers involved in HIV care/prevention and family planning programs. FGDs were held separately for men and women. Cultural appropriateness of the questions was discussed with the local health providers. In addition to the question guide, probing questions were asked at any time during the sessions if more information about a particular topic was sought. At the end of each focus group, participants were invited to ask questions or provide comments about any aspect of health to the researcher or the focus group facilitator, who was a trained Clinical Officer but not employed at the same healthcare facility where participants received services.

The duration of each FGD session varied from 40 minutes to two hours, depending on the amount of discussion and the willingness of participants to donate their time to the project. All sessions were conducted in the local language (Rutooro) by an experienced FGD facilitator fluent in both Rutooro and English. The local health centres were chosen as the discussion sites since they were private, neutral and easily accessible for all participants. All FGDs were recorded with two audio recorders, after consent for recording was obtained from all participants. Notes were written by the principle author during and immediately following these sessions to summarize the discussions and capture the tenor and mood of the participants and the dynamics of the group.

Data Analysis

Surface readings of all transcripts were first conducted to obtain a general impression of the data. The five FGDs were then analyzed using thematic analysis in the manner described by Roth (Roth 2000). This entailed organizing the data into categories and then extrapolating overarching themes. Session

content was first coded into four main categories: childbearing in general, family planning, HIV/AIDS in general, and HIV/AIDS and childbearing. The main categories were further subdivided into two to four subcategories. These subcategories were sometimes separated into sections when they contained a large amount of information. Overarching themes were derived by assimilating information from multiple categories supporting the same general concept.

Ethical Considerations

The study was approved by the University of Alberta Health Research Ethics Board in Edmonton. Upon our arrival in Uganda, the study was also approved by the Uganda National Council for Science and Technology in Kampala, and the Ugandan Ministry of Health via the Kabarole District Health Officer. An information letter about the study was read to all participants, and informed consent was obtained from all participants by their signing the consent form.

Results

Participants' characteristics are shown in Table 1. The majority were subsistence farmers with a primary level of education and living in metal-roofed mud huts. Participants had a wide range of tribal and religious affiliations.

Table 1. Characteristics of FGD participants (n = 35)

Participants	Number	Age in years Mean (range)
HIV-negative		
Men	9	29 (19–37)
Women	8	29 (23–28)
HIV-positive		
Men	6	32 (26–42)
Women	6	27 (20–37)
Women who became pregnant following their HIV diagnosis	6	31 (25–35)

Three main themes emerged from the transcripts: (1) the negative impact of an HIV diagnosis on the desire to have more children, (2) women's lack of control over their fertility, and (3) changing norms in fertility desires (see Table 2).

Table 2. Summary of thematic analysis by gender and HIV status

Theme 1: HIV/AIDS has a negative impact on the desire for future children	
Group	Quotation
HIV– woman	<i>I think that if you are HIV+ and you continue giving birth you die so fast.</i>
	<i>I think if you continue giving birth, when you die the children might die or you yourself; you die and leave the children when they are still young.</i>
	<i>It is up to your life – you should care about your life as a woman because if you die the man can get other women – me I won't give birth and the man finds other women.</i>
	<i>I say that I don't get married, I just stay alone because even the baby I want to have, I may die and leave him/her – I don't get married.</i>

Group	Quotation
HIV- man	<i>If I tested and found I am HIV+, definitely my decision of giving birth will change. I will stop because of this reason – the woman will weaken if she is sick and she continues giving birth, and the child born is on the risk of getting this disease.</i>
	<i>... after you test and you are HIV+, that forces you to stop giving birth because you'll have many children, and when you die they start suffering, or maybe they are also infected – you never know.</i>
	<i>... it is better to have few children you can afford to take care of so that you don't have many who will start suffering after you have died.</i>
	<i>... some of us have tested and we have AIDS, so you see that when you continue giving birth you will die very fast so you decide to stop giving birth.</i>
	<i>... if I tested and found am sick – the issue of giving birth, I limit it because you can give birth and in the end you have children who are HIV+.</i>
HIV+ woman	<i>For example, when you don't know your status you can say, I will have my six children, but then after testing positive you give birth and maybe the child dies or you yourself will die and leave the child suffering; that will force you to limit your births.</i>
	<i>... giving birth in villages, it affects us as AIDS patients, when you keep on producing that means too much bleeding whenever you give birth, and you lose a lot of blood and you die very fast, so I came to an understanding with my husband and we decided to stop producing.</i>
	<i>... now that we have tested and we know our status, you can give birth to a baby and he/she is also sick – you die and the baby also dies – me, I say it is better we stop giving birth instead of leaving our children to suffer.</i>
	<i>... now that we know we are HIV+, because now it is useless to have many children whom we will not be able to look after – we are weak and the income is too little.</i>
	<i>If you both test and you are both positive before giving birth – I think you can stay without children.</i>
HIV+ man	<i>... since now we know our status, we should stop on the children we already have, look after them and plan for their future.</i>
	<i>Yes, I would have even six, but now since I know my status why should I have all those children? I can have more than three? No.</i>
	<i>I know I am sick, so if possible, I wouldn't like to have more children – the ones I already have would be enough.</i>
	<i>After knowing our status we decided the children we have are enough and now we have to plan for their future.</i>
	<i>Weakness – this makes you sexually weak; how will you then give birth when you cannot have sex?</i>
	<i>... after testing HIV+ then you decide to stop giving birth so at least you can live longer, because the more children you have the more problems.</i>
Theme 2: Women lack of control of their fertility	
Group	Quotation
HIV- woman	<i>It is the man who decides that now we have two children or one or ten.</i>
	<i>The man wins because he is the head of the family; he is the one who plans for the family and he knows his income.</i>
	<i>The man is the one who wins.</i>
	<i>Some men tell us that let us stop giving birth, but the woman insists that she still wants to give birth – some men talk about it.</i>

Table 2. Continued.

Group	Quotation
HIV- man	<i>... it is the man to decide because he is the household head – he can decide and tell the wife “those children are enough; let us now start using family planning,” and the wife will follow what the man has told her.</i>
	<i>It is the man who decides; being the household head he knows his income and therefore knows how many children he can be able to take good care of.</i>
	<i>You see I the man; I am the household head, am the one who looks for the money. I know how much money I have so I will tell the woman to continue giving birth according to my income, and if she refuses I divorce her and marry another woman.</i>
	<i>... if my wife wants to have many children and I don't want – I am the man; I will just keep quiet and monitor her; if she is not in her safe period then I will not have sex with her – she has to obey me as the man and head of the family.</i>
HIV+ woman	<i>... after finding out that I am HIV+ I had not wanted to produce again, but the man refused and he forced me to get pregnant again. I have one boy child and he said he cannot stop, thought I would deliver another boy but then I gave birth to a boy again but then me, I want to stop.</i>
	<i>It is not easy – if you the woman accepts but the man refuses you cannot use family planning.</i>
	<i>... if a woman starts saying we should have these children – three or any number – the man will ask you, “where do you work; it is you to provide for them?”</i>
	<i>... we have little assistance; you find you are married to a man but you have nothing, not even a piece of land that you can build a house, no source of income, no job that will earn anything – you rent and have to look for money; even getting what to eat is hard – at least if we could get capital to at least start up something, that will raise you something.</i>
	<i>... after finding out that I am HIV+ I had not wanted to produce again, but the man refused and he forced me to get pregnant again. I have one boy child and he said he cannot stop; thought I would deliver another boy but then I gave birth to a boy again but then me, I want to stop.</i>
	<i>If you tell the man that let's have maybe three children whom we can manage to look after, he tells you he still wants to have more, and as a woman you are weakening but the man does not weaken.</i>
	<i>Helping especially us women – we don't have even a certificate. The man will abandon you in the house, and he will go and marry another woman, and some men will leave you and go for prostitutes. He will take the little money you have and you the woman will remain suffering with the children – it is you feeding the children, feeding them; it is you who has to dig[meaning to do the farm work] – make sure you get them beddings, blankets – really a woman suffers a lot.</i>
HIV+ man	<i>It is the man who mostly forces the woman that they should have children because he wants to expand his family and clan.</i>
	<i>It is me to decide – If I decide that we stop then we stop, and if I decide that we have more children then we go ahead and have more children.</i>
Theme 3: Fertility norms are changing	
Group	Quotation
HIV- woman	<i>... you want to give birth but then you should give birth and plan – have children that you can afford to look after, educate, look after them in all ways, medical care.</i>
	<i>Now with this generation now we know that we should have few children.</i>
	<i>What makes me stop giving birth is poverty – it needs you give birth to children you can afford to look after not to have many and they suffer.</i>
	<i>I see that nowadays people get families which they don't desire because, for example, you find a person having about 10 or 8 children and cannot afford looking after them, no education; there is no food; the children start suffering, and even you see the parents are not okay – they have no income at all; that is why they say that big families are a problem.</i>

Group	Quotation
	<i>... the pregnancy I have now I wish it would be the last one, because if I have more children I will not be able to look after them.</i>
HIV- man	<i>You have little or no income at all, and you are not in position to look after many children; that is why we have decided to have few children – those that we can be able to take care of, be able to take them to school, feed and dress them.</i>
	<i>I am also saying it is better to have few children you can afford to take care of so that you don't have many who will start suffering after you have died.</i>
	<i>I also say one should have the children he is able to look after – you can have many children; you fail to feed or cloth them; you are not able to treat them in case of any sicknesses – people should have children they can manage to take care of, and they grow up healthy.</i>
	<i>I want to say that people should have the number of children they are able to look after.</i>
HIV+ woman	<i>Some are poor, and they say if I give birth to many children where will I put them?</i>
	<i>Taking care of the children – like when you have many children you find others are not even going to school because you have no money – others are not healthy; the feeding is poor, but if they are like two at least – though you are poor you can manage to look after them.</i>
	<i>I want three children because I can be able to take care of them – get them what to eat, wear or have treatment in case of sickness, but if you have six you can even fail to take care of them – start begging.</i>
	<i>I say four because I can be able to take care of them, cloth them, educate them. I now have one, but four children are okay for me.</i>
HIV+ man	<i>These days you don't give birth to expand the clan; things have changed and the responsibility is on you.</i>
	<i>Some of us are weak – sickly, not like people of some years back; for them, they used to produce many children because they had enough property and this disease hadn't come – so they had nothing to worry about, but nowadays that is why we have decided to have few children that we can manage to look after.</i>
	<i>In the past people gave birth to many children because they had a lot of property, but nowadays fewer people just give birth even after knowing they are HIV+; they just want to see children fill in the house, not bothering how hard it is to look after them.</i>
	<i>In the past there was no family planning.</i>
	<i>These days we can plan, but in the past you would just hear that so and so's wife is pregnant [laughs].</i>

HIV/AIDS Has a Negative Impact on the Desire for Future Children

Almost all participants stated that an HIV diagnosis did/would impact their reproductive decisions. Most participants agreed that when a couple finds that one of them tests positive for HIV, their best course of action is to stop childbearing.

(HIV+ man): ... since now we know our status, we should stop [at] the children we already have, look after them and plan for their future.

(HIV- man): If I tested and found I am HIV+, definitely my decision of giving birth will change. I will stop because of this reason – the woman will weaken if she is sick and she continues giving birth, and the child born is [at] risk of getting this disease.

If a couple was newly wed and/or did not have any children yet, the situation was perceived differently. While many participants still thought that these individuals should remain without children, some were sympathetic and felt that they could have a small number of children.

(HIV– woman): ... maybe if they are newly married and they test HIV+ before even having a child, if they see they can afford [it] they can maybe give birth to at least one child or two.

(HIV– woman): ... if you have not given birth, you also feel you want to have a child – that of saying you are positive won't work, a person will say I rather give birth and the child dies other than being there without giving birth [laughter]. [This participant wanted to express that the great social pressure to have children may override the concerns HIV-positive couples have towards childbearing].

Thus, rather than stopping childbearing, participants often noted that having smaller family sizes was the best course of action for HIV-positive couples. Participants also reported that another reason why HIV-positive individuals limit childbearing is because they lose their sexual desire. However, it was reported that this desire returns with HAART, which can motivate people to resume childbearing.

Three of the six women who became pregnant following their positive HIV diagnosis reported that their pregnancy was unintentional. Failure to use family planning was mentioned as the reason. It was reported that some HIV-positive individuals have children because either they do not know their status or they have not disclosed it to their partner.

Eighty percent of participants (including those who were HIV-positive) stated that they did not have enough information with respect to childbearing if HIV infected. Often individuals were unsure about what to do in this situation and wanted more information from healthcare providers:

(HIV+ woman): Giving birth, I still want to, but when we tested and found me and my husband were both HIV+ [at] that time there was a training here about reproductive health, so I came and attended to know if I can go on with giving birth or totally stopping – I have not yet decided.

(HIV+ woman who became pregnant): I think we don't have information – the information we have is little, but we beg you as nurses and doctors to teach us so we can know more.

One of the major concerns mentioned with respect to childbearing for HIV-positive individuals was their physical well-being, in particular if the mother was HIV-positive. Many participants thought that having a child would cause an HIV-positive woman to weaken and/or lose a lot of blood, which may lead to her death. Many participants were also concerned that having children when HIV positive could lead to infection of the child. Worries that the parents would die and leave the child orphaned were also voiced:

(HIV+ woman): For example, when you don't know your status you can say, I will have my six children, but then after testing positive you give birth and maybe the child dies or you yourself will die and leave the child suffering; that will force you to limit your births.

Some participants were confident that if a mother is on HAART then HIV cannot be transmitted to the child. However, most respondents were unsure what effect HAART has on mother-to-child transmission and asked for more information. The HIV-positive women who became pregnant following their diagnosis mentioned hospital delivery as one of the main interventions they utilized to ensure the safe delivery of their children.

Some participants commented on those HIV-positive people who knowingly became pregnant, as shown in the following responses:

(HIV– man): If I see someone who has tested HIV+ and they have gone ahead to give birth, then I take such people as people who don't reason.

HIV– man): If people came here as husband and wife and tested HIV+, then I think they [should] be given some counselling to show them the problems and dangers of giving birth when you are HIV+; then I think they can also decide on what to do if they show them the danger of AIDS.

Interviewer: Now if they are taught but then go ahead and give birth – what do you think about?

(HIV– man): There I say they don't reason – they are illiterate.

The comments from these participants reflected a belief that those who knowingly become pregnant while HIV-positive are “illiterate” and “uneducated” and do not think about the consequences.

Women Lack Control of Their Fertility

One major theme that emerged from the responses was women's near complete lack of control over their own sexual and reproductive lives. This included their inability to make decisions regarding the number of children they wish to have as well as their inability to use family planning if their husband objects. Thus, women are often unable to avoid becoming pregnant if they are HIV infected and are unable to protect the unborn from HIV transmission through HAART.

(HIV+ woman who became pregnant): ... after finding out that I am HIV+ I had not wanted to produce again, but the man refused and he forced me to get pregnant again. I have one boy child and he said he cannot stop, thought I would deliver another boy but then I gave birth to a boy again but then me, I want to stop (I gave birth to a boy in spite of wanting to stop childbearing because my husband insisted on having more children).

(HIV+ woman): It is not easy – if you the woman accepts but the man refuses you cannot use family planning.

The main reason women were reported to have such a lack of control over decision making is that they lack economic power. Men control all of the money in the relationship, and women fear destitution for themselves and their children if they become divorced. Many women were not officially married to their husband, and felt they would not receive any support if their relationship were to end. Thus, they felt helpless and believed the only way to survive was by following their husband's demands. These challenges are illustrated in the following quotations:

(HIV+ woman): ... if a woman starts saying we should have these children – three or any number – the man will ask you, “where do you work; it is you to provide for them?”

(HIV+ woman): ... we have little assistance; you find you are married to a man but you have nothing, not even a piece of land that you can build a house, no source of income, no job that will earn anything – you rent and have to look for money. Even getting what to eat is hard – at least if we could get capital to at least start up something, that will raise you something.

(HIV+ woman): ... helping especially us women – we don't have even a certificate. The man will abandon you in the house, and he will go and marry another woman, and some men will leave you and go for prostitutes. He will take the little money you have and you the woman will remain suffering with the children – it is you feeding the children, feeding them; it is you who has to dig [meaning to do the farm work] – make sure you get them beddings, blankets – really a woman suffers a lot.

Fertility Norms Are Changing

Participants noted that it is now becoming more common for people to discuss with their partner how many children they desire and to choose smaller family sizes. Some of this change appears to be due to the HIV/AIDS epidemic: participants noted that it is difficult to have many children if you are sick. However, some of these changes are attributed simply to changing attitudes and norms in the community and appear to be independent of HIV/AIDS. For example, land fragmentation was frequently noted as a reason why people are now deciding to have fewer children: large family sizes of the past are now limiting the number of children these participants can have because parents need to ensure their male children each inherit enough land to support a family. The following quotations portray the changing norms with respect to fertility desires:

(HIV+ man): These days you don't give birth to expand the clan; things have changed and the responsibility is on you.

(HIV+ man): Some of us are weak – sickly, not like people of some years back; for them, they used to produce many children because they had enough property and this disease hadn't come – so they had nothing to worry about; but nowadays that is why we have decided to have few children that we can manage to look after.

(HIV+ man): In the past people gave birth to many children because they had a lot of property, but nowadays fewer people just give birth even after knowing they are HIV+; they just want to see children fill in the house, not bothering how hard it is to look after them.

(HIV+ man): These days we can plan, but in the past you would just hear that so and so's wife is pregnant [laughs].

Discussion

We conducted a qualitative study on fertility desires in HIV-positive and -negative individuals of reproductive age (18 to 44 years) in western Uganda. One strength of our study was the qualitative study design, which enabled us to probe beyond the simple question= “Do you want more children in future” and to elucidate reasons for the participants' fertility desires. We included both HIV-positive and -negative men and women; thus we are able to make the voices of both HIV-positive and -negative men and women heard. The majority of other studies reviewed included only HIV-positive participants.

One finding of our study was that HIV serostatus had a large impact on the desire for children. HIV-positive participants were less likely to want more children in future compared to HIV-negative participants, according to the statements of HIV-positive and -negative respondents. These results confirmed those from the quantitative component of our study, where the strongest predictor of not wanting more children was HIV positivity, and other significant predictors such as female sex, older age, and higher number of living children had an odds ratio of only 2.5 or less (Heys et al. 2009). The responses of all participants were very consistent in this finding, and even the women who became pregnant after receiving a positive HIV diagnosis stated that their pregnancies were not intentional and were due to lack of access to effective family planning services or their spouse's wish. Our findings are supported by several other studies that reported a positive HIV status caused lower fertility desires (Hoffmann et al. 2008; Baek and Rutenberg 2005).

Most prior studies on the effect of an HIV diagnosis on fertility desires are quantitative in nature and based on the outcome of a single question (i.e., if participants wanted more children or not). The qualitative nature of our study design enabled us to examine the reasons why HIV-positive respondents wanted fewer children. Many participants, both men and women, stated that the devastating impact of HIV on the health of the parents and the possibility of mother-to-child transmission were the primary reasons why HIV-infected individuals desire fewer children. The

most common concern was for the mother's health, as participants stated that if an HIV-infected woman becomes pregnant, her infection will progress more rapidly and lead to earlier death. These responses are probably based on longstanding observations and experiences with HIV infection in this high-HIV-prevalence community.

The study finding that persons who are HIV positive and knowingly conceive children are viewed as "uninformed" or "illiterate" is important to note, as it indicates some stigma against pregnancy in HIV-infected women/couples in the community. This finding was surprising to us, as it was not reported in the literature or in the quantitative portion of our study. It has likely played a role in the strong negative influence of HIV-infection on the desire for future children. It is important to determine to what extent this stigma exists in the community, how severe it is and how much it affects the reproductive decision-making process for HIV-infected persons. This stigma could also be an obstacle to promoting HAART for HIV-positive pregnant/breastfeeding women, a group that has been found to underutilize HIV treatment options within the program for the prevention of mother-to-child transmission of HIV in Uganda (Mbonye et al. 2009; UNAIDS 2010). Another important finding in our study is the evidence that participants do not know about or fully understand the huge beneficial impact of HAART on reducing mother-to-child transmission of HIV. This underlines the critical importance of educating the public that all HIV-positive pregnant/breastfeeding women should receive HAART, which is the policy of the Ugandan Ministry of Health but is not happening for many HIV-positive women.

To assist HIV-positive couples who wish to have greater control over their decision to have children and fully understand the available options, both family planning and HIV prevention and care services should be extended to all couples in the study districts. The integration of HIV/AIDS and family planning programs should be accelerated to ensure that counselling about both the prevention of HIV and unwanted pregnancy is the norm. The population should be informed about the benefits of HAART in reducing mother-to-child transmission of HIV, so that HIV-infected couples can make better choices regarding their fertility, based on the entire range of options available to them.

Limitations

(1) As this was a qualitative study with a relatively small sample, the results are not intended to be generalized to the population at large. (2) Social desirability bias cannot be excluded, as the study topic dealt with sensitive issues. This could potentially alter participants' responses, causing them to provide answers that conform to socially accepted norms. To reduce this bias, highly trained interviewers familiar with qualitative interview techniques were used.

Conclusions and recommendations

The most cited reason why HIV-positive women and couples do not desire more children is the devastating impact of HIV on the health of the parents and future children, based on their past experiences or those of others in the community. Women's lack of control over their own fertility emerged as an important finding from this study. Responses from some participants revealed a community sentiment that it is "unacceptable" for HIV-infected women/couples to have children. These perceptions do not take into account the enormous benefits of HAART on reducing the risk of mother-to-child transmission and improving maternal health (Ciaranella et al. 2008; Goetghebuer et al. 2009; Rasmussen et al. 2008).

Based on the study findings we suggest four recommendations for Kabarole's and Kamwenge's healthcare delivery services.

- Managers of the primary healthcare programs, particularly for HIV/AIDS prevention and care programs and family planning services, have to ensure that healthcare workers who deal with reproductive and HIV/AIDS issues know that HIV-positive persons/couples are less likely to want more children. This knowledge would be very important for appropriate client counsel-

ling on HIV/AIDS and reproductive issues. Relevant and updated information could be easily included in the ongoing training programs for healthcare workers in the districts.

- Both men and women have to be informed about the beneficial effect of HAART on HIV transmission from mother to child and on the health of HIV-positive pregnant/postpartum women. This is especially important for HIV-positive persons/couples who want a child but decide not to have one because of the negative health effects of HIV/AIDS on mother and child. This information also needs to be included in the education program for the communities. In addition, HAART services have to be made available to all HIV-positive persons/couples in the reproductive age group, as to date approximately only half of this population group has access to HIV/AIDS treatment in Kabarole district. District guidelines for HIV/AIDS and family planning counselling of HIV-infected persons/couples and community education should be updated to include this recommendation.
- Participants' negative sentiments about HIV/AIDS and childbearing should be counteracted by accurate information on the relationship between HIV/AIDS, HAART and reproduction/family planning. Healthcare workers have to be informed about this, and they should be required to raise the topic in counselling sessions. It would also be important to investigate (a) if healthcare workers express these negative sentiments themselves, and (b) to what extent these negative sentiments are prevalent in the community and how they can be best addressed.
- Healthcare services staff have to be reminded again of the consequences of gender bias in a male-dominated society like in western Uganda. For example, an HIV-positive women who does not want a child can be coerced into becoming pregnant. Addressing the gender gap must include couple counselling in HIV/AIDS and family planning clinics; this is still largely absent in the study area, where mostly women are dealing with the issues and men do not participate. Couple counselling should be offered to all clients, and they should be encouraged to utilize it. It must be included in the counselling guidelines and checklists for reproductive health programs. Couple counselling must be widely marketed and made mandatory at each clinic, and staff competence in the area must be developed promptly.

The study findings can be summarized as follows: HIV-positive couples are seeking to exercise responsible family planning by curbing their desires to have more children as a result of their positive HIV status. These same couples should have more up-to-date counselling to ensure their awareness of the benefits of HAART for improving health outcomes for the mother during pregnancy and childbirth and reducing the risk of mother-to-child HIV transmission. Responsible family planning now allows for couples receiving HAART to realize their desired family size.

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