Influences in fertility decisions among HIV-infected individuals in Lilongwe, Malawi: a qualitative study

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ABSTRACT

Background The motivation to have a child may be complex with numerous influencing factors, particularly among individuals living with HIV. This study sought to understand factors influencing fertility decision-making for HIV-infected men and women in Lilongwe, Malawi.

Methods Thirteen focus groups were conducted among HIV-infected individuals enrolled in antiretroviral treatment services.

Results Participants identified a hierarchy of influences in fertility decisions including the importance of childbearing, patriarchal influence, family influences and concern regarding HIV transmission.

Conclusions Addressing fertility conversations beyond the confines of a relationship may be important, as family plays a significant role in fertility choices. Childbearing remains a fundamental desire among many individuals with HIV; however, concerns regarding transmission risk need to be addressed with efforts made to overcome misconception and assist individuals in balancing what may be competing influences.

Key message points

- Childbearing is a fundamental desire for many individuals living with HIV.
- Competing influences on fertility decisions include male partners, family and concerns about HIV transmission.
- Education to overcome misconceptions regarding HIV transmission is needed to support those individuals who wish to have children.

INTRODUCTION

The total fertility rate for Malawi has decreased from 6.7 in 1992 to 5.7 in 2010. This decrease coincides with an increase in knowledge of and use of modern contraception.[1 2] There remains, however, a high unmet need for family planning, with only 64% of married women who desire to space or limit childbearing having their contraceptive needs met.[2]

There are approximately 1.1 million people living with HIV in Malawi.[3] According to recent data, the prevalence among individuals aged 15–49 years is 10.8%.[3] In the 1990s, HIV testing was not widespread and many HIV-infected patients were diagnosed in the later stages of the disease.[4] In the early stages of the HIV epidemic in Malawi, researchers concluded that health complications coupled with behavioural influences resulted in lower or limited fertility among women living with HIV.[5] In recent years, with the increased availability of HIV testing and access to antiretroviral treatment (ART), the context of fertility decisions has changed in a short period of time.[6 7] Patients who are HIV-infected and adhering to ART can have improved overall health and longer life expectancies, even in low-resource settings.[8] Further, the availability of ART and programmes reducing mother-to-child transmission increases the possibility of having a healthy, HIV-negative child.[9] Studies indicate that in low-resource settings, fertility rates among women living

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with HIV are now returning to rates similar to those in uninfected women.[10 11]

Discussions about fertility within a marriage or relationship can be challenging in settings where status and identity may be defined by fertility and the number of children.[12–14] Additionally, in couples where childbearing does not occur, the man or woman could potentially be identified as infertile by their communities and ostracised. Women, in particular, face the strongest criticism and judgment in childless relationships.[15] Given the recognised complexity of decision-making regarding childbearing, coupled with the poorly understood influences that living with HIV may have on these decision, this study aimed to explore the factors influencing fertility decisions among HIV-infected individuals in Lilongwe, Malawi.

METHODS

Qualitative methods were used to assess current reproductive health knowledge, attitudes and practices in two clinics in the Lilongwe District of Malawi operated by the Lighthouse Trust in collaboration with Kamuzu Central Hospital and Lilongwe District Health Office, namely Lighthouse Clinic and Martin Preuss Center. All the study participants were HIV-infected and receiving care and health messages through the study clinics.

The study ran from May 2012 to July 2012. The Malawian organisation, Research for Equity and Community Health Trust (REACH Trust), an organisation with several senior researchers with a community and equity focus and expertise in qualitative research methods, conducted male and female focus groups at both clinics. A convenience sample of clients was recruited for participation at these clinics, with 6–8 participants per focus group. Individuals were eligible for study participation if they were clients at one of the Lighthouse clinics, aged between 18 and 45 years old, sexually active within the last 6 months, and on ART for at least 6 months. Individuals were recruited in the waiting rooms of these clinics and taken to a separate area where eligibility was confirmed and informed consent obtained. One or two trained Malawian qualitative facilitators with REACH Trust of the same gender as the focus group conducted the focus groups in Chichewa, the local language, with a note-taker additionally present and interviews audiotaped. The focus groups covered domains including living with HIV, concerns about (vertical and horizontal) transmission, fertility goals and family planning. A focus group guide was developed in English, translated to Chichewa, with questions piloted for clarity and intent prior to study initiation.

Nineteen focus groups were conducted. Thirteen focus groups (eight male and five female) were included in this analysis due to technical issues with the recording devices used for some of the focus groups (Table 1). Transcripts were not reviewed with participants.

Focus groups were transcribed and translated into English. Translations were reviewed to ensure accuracy, and any verbiage in Chichewa that did not have an English translation was left in Chichewa. Upon completion of translation and transcription, all the focus group files were uploaded into MAXqda V.10 (Verbi GMBH, Berlin, Germany) for analysis.

REACH Trust completed an initial coding of the data for general reproductive health themes. Additional codes were then applied for this analysis of influences in fertility decisions by a second coder. Themes were derived from the data. Coded segments were then reviewed by theme to identify patterns and variations within each theme. We identify core themes that influence men and women in deciding their fertility.

RESULTS

Four themes emerged as central factors influencing fertility for both men and women: importance of childbearing, patriarchal influence, family influences, and concern regarding HIV transmission.

Fundamental importance of having a child

In all discussions, participants agreed that childbearing was fundamental to their identities as men and women. For the participants in this study, to be a mother or father outweighed health concerns and transmitting HIV to uninfected partners or to their unborn children. This belief was shaped by their feelings about motherhood and fatherhood as well as societal expectations and judgments about men and women who do not have children.

For couples who had children with their current partner before knowing their HIV-infected status, the decision to limit having children in the future seemed to be an obvious choice.

> *"When I and my husband were diagnosed with HIV, we had four children…. He said the children we have now are enough because if I continue having children we will end up having an HIV-positive child and it won't be that good for us to be on treatment together with the child."* [Female, Lighthouse Clinic]

> *"From what I think, I feel if you are HIV-positive and you have one or two children, it is better not to*

Table 1 Focus group participants

Location	Male	Female	Total
Martin Preuss Center	31 participants	18 participants	49 participants
	5 groups	3 groups	8 groups
Lighthouse Clinic	18 participants	12 participants	30 participants
	3 groups	2 groups	5 groups
Total (both locations)	49 participants	30 participants	79 participants
	8 groups	5 groups	13 groups

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continue having children because if the doctor encourages us to be using condoms it is obvious that they prevent us from having other children." [Female, Lighthouse Clinic]

At the same time, participants in childless relationships indicated that the desire for children outweighed the health risks relating to their HIV status. This was also true in relationships where one or both of the partners had children from previous relationships; the couple felt that each union should produce children.

"So despite having this problem of HIV, the second wife might demand that she wants a child as it is a new marriage, when you try to refuse and tell her that you should just be supporting one another." [Male, Lighthouse Clinic]

This desire to have children in each relationship was seen as a way to validate or solidify the union. Concerns about being childless seemed more fundamental than HIV-related concerns, such as fears about worsening health status or HIV transmission. Both men and women stated that they found a sense of identity from childbearing, specifically within each union. Consequently in partnerships where one or both of the partners were childless, remaining without a child was a fundamental concern.

Patriarchal influences

Men and women indicated that it was primarily the male partner's desires for children that would be a strong influence on their decision to continue to have children or use contraception. Both men and women said that conversations about fertility occur between a man and woman, however the fertility desires of the man outweighed those of the woman.

"When there is a decision in the house that we should have children mostly it is the man who plays a greater role in making that decision. I have seen many families breaking because the man wants a woman who can have children." [Male, Martin Preuss Center]

The repercussions of refusing to have additional children were discussed in the majority of the focus groups. The threat of a man ending a partnership or finding another more willing partner to continue childbearing strongly impacted the fertility conversation.

"…and what also happens is that a woman can decide to have children for her partner if the man tells you if you don't want to bear me a child, then I will go out to someone else who will give me a child. So for you to meet his desire you bear him a child." [Female, Martin Preuss Center]

Joint discussions about fertility desires appeared to be relatively uncommon. Only a few male and female focus group participants mentioned that in some relationships fertility goals and planning are discussed together. A few participants mentioned consulting the health facility because of their HIV status but the majority spoke solely of their male partner's desires.

Family influences

Family members were also a strong influence in the decision to have additional children. HIV status complicated discussions with family members because many individuals choose not to disclose their status to their families for fear of being ostracised. Even for those family members who do know the couple's HIV status, they may not understand all the additional health considerations for HIV-infected couples beyond the use of condoms to prevent transmission.

Participants, regardless of HIV status, feel pressure from families to produce children within a union. This pressure can seem amplified if the families are unaware of the couple's HIV status.

"Especially in villages when you have one child people laugh at you. They ask you to say, why are you having only one child? For example, relatives on the male side, they go to their relative secretly to ask him why he is having only one child but the thing is they don't know the importance of not having children when you are HIV-positive." [Female, FGD, Martin Preuss Center Clinic]

"Sometimes even your mother, she would say your husband would leave you because you did not bear him children and that's why you force yourself to have a child." [Female, Martin Preuss Center]

Both men and women agreed that familial pressure was usually stronger for people residing in rural areas than in more urban areas. Many spoke of pressures from their family in villages to keep having children.

Men and women feel pressure to bear children soon after marriage or formalising a union, and, in many cases, are expected to have large families.

"You might decide not to have a child to avoid infecting him but the husband comes to say I want a child. At the same time you start to think should I stay without a child and you see your friends laughing at you. Then you decide to have a child because a person cannot stay without having a child." [Female, Lighthouse Clinic]

Women, in particular, were extremely concerned about the perceptions of their peers. Many mentioned that friends would mock them for remaining childless or only having a few children. Women in many of the focus groups agreed that peer pressure could be a strong factor in their desire to have more children.

Concerns regarding HIV transmission

Participants' primary concern about childbearing was the potential of HIV transmission to the unborn child and to their partner. The risk of vertical transmission had a notable impact on their desire to limit or cease childbearing.

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"If you're HIV-positive it's not good to get pregnant because a child can be born with the virus. Hence the child will be sick and sick again, this will in turn bring more worries to the mother and the mother's health will not be good because of worries." [Female, Lighthouse Clinic]

"To prevent from transmitting this [HIV] to the child they say it is better to make a decision of not having children unlike someone who is not HIV-positive…. But to us who are positive we do that in order to protect the one to be born and protect our future." [Male, Martin Preuss Center]

Women and men understood the extra precautions required to decrease the likelihood of mother-to-child transmission during pregnancy and birth. When ART was discussed as a means of reducing the risk of HIV transmission to the child, it was primarily discussed as an approach after the woman finds out she is pregnant, not as a factor influencing the decision to get pregnant. They also understood the positive impact that ART has on boosting the mother's immunity and reducing the risk of mother-to-child transmission; however, the majority of participants indicated that not becoming pregnant was the best option for HIV-infected women.

Participants who were not currently in a relationship said they were concerned about transmission to their future HIV-negative partners, while men and women in a serodiscordant relationship expressed concerns about the health of their partner. If the couple decided to continue bearing children, there was concern about transmission to the HIV-negative partner during attempts to conceive.

"Sometimes it happens that you are HIV-positive and your husband is negative … if you happened to be pregnant … they caution the man that he too will be HIV-positive." [Female, Martin Preuss Center]

The difficult balance of the health of their partner and unborn child against the desires to fulfil the wants and needs of their partners was felt by both men and women. Although in several focus groups participants discussed ART leading to improved health status and reducing the risk of HIV transmission to partners, the use of ART or alternative methods for safe conception was not discussed in any of the focus groups as a strategy for fulfilling fertility desires.

DISCUSSION

This study uncovers several key influences that both men and women face when making fertility decisions, both within and outside the context of HIV. Many of the main influencing factors related to fertility goals are similar to those among uninfected individuals. However, within the context of HIV, there is a need to address fertility concerns and family planning options for HIV-infected individuals as HIV status may itself complicate fertility decision-making. Family planning should not only be discussed within the confines of ART or family planning services at clinics or health centres. Family size and child spacing are issues that need to be addressed on a broader scale, as childbearing and a larger family size was considered a crucial part of an individual's identity for both men and women. Other countries in Africa have successfully used health messages/messaging about the benefits of smaller families and the importance of contraceptives to address fertility issues. Use of health messages/messaging is a strategy that could easily be applied to the Malawian context.[16]

Notably, concerns about how pregnancy may impact on women's health or how HIV may impact on pregnancy were not discussed by focus group participants. The absence of these themes highlights the fact that individuals with HIV may be less concerned with the medical aspects of their disease when it comes to fertility, where social and interpersonal factors are essential factors in their decision-making. Future research may benefit from exploring the association between perception of health consequences from pregnancy and desire for children. Our results additionally highlight the importance that the partner plays in childbearing decisions. Involving men in the family planning discussion not only allows for more education but also gives the couple an opportunity to discuss their fertility goals. Programmes should encourage couples to jointly attend healthcare appointments which offer opportunities for couples' family planning counselling. For serodiscordant couples, efforts may lead to expansion of couples' voluntary counselling and testing programmes to integrate in couples' family planning counselling and provision. For seroconcordant couples, encouraging couples to attend routine HIV/ART care appointments together could enable the couple to jointly engage in family planning care while also building strategies within the couple to encourage ART adherence. Additionally, studies have indicated that men typically have limited knowledge as regards family planning and available options.[17] Utilisation of health messages/messaging that specifically targets men may be an important strategy to address this gap.

Since fear regarding potential HIV transmission consistently emerged as a central theme around fertility, we must further explore what individuals perceive as the risk of transmission. Although our study participants acknowledged the benefits of ART in improving health and reducing HIV transmission risks both to their child and to their partner, they did not specifically discuss ART use influencing their family planning decisions. Further, it is unclear if these individuals have a true understanding of the actual reduced transmission risk with ART since these participants seemed to believe it was preferable for HIV-infected women to avoid having children altogether. As efforts to reduce mother-to-child transmission can effectively

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reduce HIV transmission rates to 2% or less,[18] it is important to direct individuals to appropriate services and education to accurately counsel about the risk of transmission. Similarly, the risk of transmission to a partner can be significantly reduced with viral load suppression on ART.[19] Further information is needed to clarify individuals' true understanding regarding transmission risk with ART and how potential provider biases or stigma may be contributing to the perception that HIV-infected individuals should cease childbearing.

Reducing viral loads with ART should be a central focus within HIV programmes in sub-Saharan Africa. To optimise fertility outcomes and reduce transmission, the World Health Organization supports access to ART for all serodiscordant couples and all pregnant women for life (Option B+).[20] Although Malawi was an early adopter of the Option B+ strategy, adequate adherence to treatment with viral load suppression is not always maintained. As our study highlights, the desire for children can be a strong motivator, irrespective of HIV status and fear of transmission, and thus some couples may choose to have a child without achieving complete virologic suppression. For those serodiscordant couples who do desire conception when virologic suppression has not been achieved, pre-exposure prophylaxis (PrEP) and insemination where the male is seronegative could prove to further reduce transmission risk.[21] Although PrEP may not currently be a viable option for many serodiscordant couples, it is hoped that these types of cost-effective, safe and acceptable options will become available in the future, making their inclusion in fertility discussions a key component of risk reduction. Incorporating appropriate education and strategies into HIV care while regularly providing an opportunity for individuals to discuss their fertility desires and concerns is critical to allow individuals with HIV to meet their fertility goals. Providers are missing important opportunities to reduce periconception HIV transmission by not frequently reassessing childbearing goals and discussing safer conception strategies.[22] Family planning education and counselling should focus on safe contraception with dual protection (condoms plus a more effective hormonal contraception or intrauterine device) until children are desired. At that point, ART adherence and viral load monitoring could be part of the 'fertility management' services at HIV clinics.

Our study allowed for a more in-depth conversation around fertility goals and influencing factors in fertility decisions in relationships in which one or both partners are HIV-infected. Because the study population consisted of HIV-infected individuals enrolled in ART programmes and receiving ART for at least 6 months, our findings may not apply to a wider population. Participants in our study were receiving care on a regular basis at health facilities; consequently these participants may present a biased view on health centre involvement. Furthermore, although trained qualitative facilitators and a structured focus group guide were utilised in the focus group discussions, further probing may have been helpful in understanding more nuanced influences of fertility desires. For example, specific probes could have better elucidated the possible role of partner disclosure, knowledge regarding the role of ART in reducing transmission of HIV, or provider influences on fertility decisions. As some of these topics were not discussed in the focus groups, we are challenged to make conclusions regarding the importance of these factors. Despite these limitations, we believe our findings identify key areas of focus for interventions in fertility discussions within relationships with an HIV-infected partner. Additionally, this study complements other studies conducted in sub-Saharan Africa and their findings on the fertility desires of HIV-infected men and women.[23 24]

As with similar studies conducted in the same geographical region, HIV-infected individuals are seeking to establish a balance between their fertility desires in order to be accepted in their communities and their potential concerns related to their HIV status.[25] In common with men and women worldwide, childbearing can fulfil many emotional, economic and societal needs for men and women in Malawi.[14] For HIV-infected individuals, the additional health considerations make fertility decisions significantly more challenging.

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