

## Research article

# Between a rock and a hard place: stigma and the desire to have children among people living with HIV in northern Uganda

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### Abstract

**Background:** HIV-related stigma, among other factors, has been shown to have an impact on the desire to have children among people living with HIV (PLHIV). Our objective was to explore the experiences of HIV-related stigma among PLHIV in post-conflict northern Uganda, a region of high HIV prevalence, high infant and child mortality and low contraception use, and to describe how stigma affected the desires of PLHIV to have children in the future.

**Methods:** Semi-structured interviews were conducted with 26 PLHIV in Gulu district, northern Uganda. The interviews, conducted in Luo, the local language, were audio recorded, transcribed and then translated into English. Thematic data analysis was undertaken using NVivo8 and was underpinned by the “Conceptual Model of HIV/AIDS Stigma”.

**Results:** HIV-related stigma continues to affect the quality of life of PLHIV in Gulu district, northern Uganda, and also influences PLHIV’s desire to have children. PLHIV in northern Uganda continue to experience stigma in various forms, including internal stigma and verbal abuse from community members. While many PLHIV desire to have children and are strongly influenced by several factors including societal and cultural obligations, stigma and discrimination also affect this desire. Several dimensions of stigma, such as types of stigma (received, internal and associated stigma), stigmatizing behaviours (abusing and desertion) and agents of stigmatization (families, communities and health systems), either directly, or indirectly, enhanced or reduced PLHIV’s desire to have more children.

**Conclusions:** The social-cultural context within which PLHIV continue to desire to have children must be better understood by all health professionals who hope to improve the quality of PLHIV’s lives. By delineating the stigma process, the paper proposes interventions for reducing stigmatization of PLHIV in northern Uganda in order to improve the quality of life and health outcomes for PLHIV and their children.

**Keywords:** HIV; stigma; fertility desire; northern Uganda.

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### Background

Desire to have children among people living with HIV (PLHIV) continues to have medical and public health implications, particularly in countries with low coverage of prevention of mother-to-child transmission (PMTCT) and highly active antiretroviral therapy (HAART) services [1]. Low coverage of these services and high fertility among PLHIV means that a significant number of infants are at risk of contracting HIV via mother-to-child transmission (MTCT). Several studies have reported that there are a substantial number of PLHIV who desire to have children and that there are several factors that influence this desire [2]. These factors include individual level factors (age, sex, relationship status, number of children, prospective motherhood and fatherhood, subjective health, experience of death of a child due to HIV/AIDS, concerns about orphan-hood for the children, ethnicity, health-related concerns and feelings of internal stigma), interpersonal factors (spousal, family and health workers influences) and community factors (community expressions of stigma and cultural norms and

expectations). Structural influences on the desire to have children include the availability of and access to PMTCT and HAART programmes [2].

HIV-related stigma also affects the desire to have children among PLHIV [3–7], albeit in various ways. Erving Goffman’s [8] first defined stigma as a “discrediting attribute”, constituting a “discrepancy between *virtual* and *actual* social identity” [8, p. 3]. HIV-related stigma was defined by Herek and Glunt [9] as “all stigma directed at persons perceived to be infected with HIV, regardless of whether they are actually infected and of whether they manifest symptoms of AIDS or AIDS-related complex (ARC)” [9, p. 886]. Their definition of stigma included both individual and societal expressions of stigma towards PLHIV.

Stigma has a complex relationship with the desire to have children among PLHIV, as it can increase or decrease the desire to have children depending on the form of stigma and the context. In Cote d’Ivoire and the United States, HIV-positive women who had previously experienced stigma, those who feared rejection or had high levels of internal

stigma were more likely to continue to have children [3,5]. In the United States, stigma enhanced the probability of getting pregnant in those women with higher levels of personalized stigma and negative self-image where having more children would conceal their infected status, thus avoiding stigmatization while at the same time improving their feelings of self-worth [5]. Similarly, in Cote d'Ivoire and South Africa, HIV-positive women reported that in order to avoid stigmatization by the community they continued to have children in order to conceal their serostatus [3,4].

In contrast, stigma reduced the probability of having children among PLHIV in the United States who had disclosed their HIV status and those who wanted to avoid their society's criticism of having a child when infected with HIV and knowing the risks of transmission [5]. In South Africa, it was considered unacceptable for PLHIV to have more children [4], and similarly in Vietnam, PLHIV were concerned about stigma directed towards their children [6]. Health workers' negative attitudes [4] and perceived community disapproval [7] were also factors that deterred PLHIV from having children.

Nevertheless, the desire to have children among PLHIV must be understood within the context of cultural norms and what parenthood means for many people, including PLHIV. Ko and Muecke's [10] ethnographic study in Taiwan, Smith and Mbakwem's [11] study in Nigeria, Aka's [3] study in Cote d'Ivoire and Oosterhoff's [6] study in Vietnam all showed the strong influence of culture on PLHIV's desire to have children. An ethnographic study that examined the marriage and fertility desires of PLHIV in Nigeria showed the importance of marriage and parenthood in their life aspirations, regardless of their HIV status [11]. Getting married and having children were ways to live normal lives and to mitigate stigma and dissociate from the negativity associated with having HIV [12]. In the United States, the potential for motherhood was shown to be more influential for reproductive decision-making than health risks to mother and child [13]. In Hanoi, Vietnam, HIV-positive women were enthused about having their own children and were further encouraged by those who had given birth to HIV-negative children [6]. According to PLHIV, having children made them look forward to the future and provided them with a reason for living [4,7,14], allowing them to "feel complete and happy" [13,15].

Furthermore, parenthood in sub-Saharan Africa meets important cultural and societal obligations, the importance of which should not be underestimated [16]. The consequences of childlessness for women, in particular, have severe social and personal ramifications for those who cannot meet their obligations in this regard [16]. In sub-Saharan African cultures, early marriages, bridewealth and arranged marriages, polygyny, a strong emphasis on the preservation of the lineage, preference for male children as well as the low status of women and reliance on human labour for agricultural activities all put pressure on individuals and societies to produce as many children as possible [17]. Inhorn and van Balen [18] found that children in some parts of Africa are important because they secure their parent's and family's survival; they support ageing parents in a context of no formal

support for the elderly through pensions, nursing homes, etc.; they serve as a valuable power source for their mothers especially in polygamous families; they continue the group structure into the future and may also serve as a political investment especially in societies where there are strong ethnic and cultural liaisons. Exchange of women for bride-wealth in many African societies takes the reproduction decisions out of a woman's hands and into those of her husband and his family. This means that the husband and his family have the rights to the children, and are entitled to receive the bridewealth back if the woman does not "produce the goods" for which she was paid [16]. Therefore, infertile women are at risk of being divorced, shunned, stigmatized and harassed.

Low education levels of women and strong patrilineal systems in Africa further disable women to make decisions about their reproductive lives, and thus for many poor, uneducated women, their livelihood is tied to their ability to have children. As Fortes [19] argued, fertility "was and still is valued above all other human endowments, in all strata and among all types of African society...and its value primarily was the indispensable condition for the achievement of parenthood" [19]. Parenthood is not just about individual fulfilment but is also a "fulfilment of fundamental kinship, religious and political obligations and represents a commitment by parents to transmit the cultural heritage of the community" [19]. A child is not only born to its parents but also into a lineage, a clan and community, the survival of which depends on the birth of children and it is from these connections, therefore, that "each individual derives his/her place in society" [19]. As Inhorn and van Balen put it: "not having children is seldom viewed as a choice or lifestyle option" [18], this holding true regardless of education or attainments in other spheres of life [16].

Despite a considerable amount of quantitative research on fertility desires of PLHIV, there is limited qualitative research in Africa examining fertility desires among PLHIV. Even fewer studies have examined the effect of HIV-related stigma on childbearing desires [2]. Particularly, no study, to our knowledge, has been conducted among any PLHIV in any post-conflict region, including northern Uganda. It is against this background that we decided to explore the desire to have children among PLHIV in Gulu, northern Uganda, a region of high HIV prevalence [20], high infant and child mortality [21], and very low contraceptive use and coverage [22]. In particular we were interested in how HIV-related stigma influences this desire.

This paper is framed within the "Conceptual Model of HIV/AIDS Stigma" [23] which allows us to understand the process and context of experiences of HIV-related stigma in northern Uganda. This model, developed in conjunction with PLHIV in several African countries, conceptualizes HIV-related stigma as a dynamic and evolving process that exists within the context of the social environment, healthcare system and agents (person, family, workplace and community). In the model, the stigma process includes factors that trigger the process of stigmatization (e.g. HIV-positive diagnosis, disclosure), stigmatizing behaviours (e.g. blaming, insulting), types of stigma (received, internal and associated stigma)

and outcomes of being stigmatized (e.g. poorer health and decreased quality of life) [23]. Underpinned by the Conceptual Model of HIV/AIDS Stigma, this paper describes how each dimension of the stigma process and environment influenced the desire to have children among PLHIV in Gulu, northern Uganda.

## Method

### Setting

The HIV epidemic in Uganda is a generalized epidemic [24], and HIV is predominantly transmitted via heterosexual sex and MTCT [25]. About 21% of HIV cases in Uganda are believed to result from MTCT [25]. In 2009, Uganda had an estimated HIV prevalence of 6.5% [5.9% to 6.9%] with about 1,200,000 PLHIV in Uganda of which an estimated 150,000 were children below the age of 15 years [26]. The majority of HIV-infected children below the age of 15 years in sub-Saharan Africa contract the infection via MTCT which occurs in utero, during delivery or during breastfeeding [27]. Gulu district, northern Uganda, where the study was conducted, had an estimated population of 581,740 in 2010 [28] and a significantly higher HIV prevalence of 10.3% [20]. This region experienced a 20-year long civil conflict between 1987 and 2007, with displacement of 90% of its population at the height of the insurgency. The massive displacement of populations, chronic food insecurity, increase in transactional and survival sex, and rape by combatants were thought to be the key drivers of the high prevalence of HIV in northern Uganda [25].

Northern Uganda also has the poorest health and social indicators of all the regions in Uganda [22,29]. Chronic food shortages, high levels of disease and low levels of education mean that many people in Gulu are living below the poverty line. Gulu district has the highest percentage of its population (58.1%) in the lowest quintile of wealth in Uganda, with 69.2% of IDPs in the lowest quintile and only 0.9% of females and 3.0% of males completing secondary education [22]. Efforts made by international, national and local agencies have led to a significant increase in the number of PLHIV on HAART: from 1228 people in 2004 to 9994 people by the end of 2007, though this is still a very small proportion of those in need of HAART. In addition, the number of health facilities providing HAART in northern Uganda increased from 5 to 35 during this period [30]. Uganda also has one of the highest fertility rates in the world: on average, each Ugandan woman has 6.7 children, with even higher fertility rates in northern Uganda, at 7.5 children per woman [22]. Having children in Uganda is highly regarded, with a woman's identity particularly tied to her ability to have children [31].

### Study participants

Twenty-six participants, 12 male and 14 female participants, were selected for this study using purposive sampling techniques. Participants were identified with the assistance of three interviewers, one woman and two men, all senior community-based HIV counsellors from Comboni Samaritans of Gulu. Comboni Samaritans is a community-based AIDS organization and its counsellors have extensive experience in providing PLHIV with psychosocial support, community-based

care and adherence support for HAART. The interviewers confidentially approached HIV-positive clients from villages surrounding Gulu town who were receiving ongoing psychosocial support from Comboni Samaritans. The participants were HIV-positive, lived in Gulu district or the surrounds and were willing to participate in the study. A wide range of participants were selected to ensure representation from various ages between 15 and 49 years, sex, residence, number of children and time since HIV diagnosis. Overall we aimed for equal sex breakdown and included HIV-positive men who had fathered children and HIV-positive women who had had children and/or pregnancies since their HIV diagnosis. We also selected a few participants who had not had children since their HIV status was diagnosed.

The mean age of the participants was 35 years, with an age range of 20 to 42 years. Nineteen of the participants were married: two were single, two widowed and one separated. All but two participants had children (number of children ranged from 0 to 7), and five participants had children who had died due to AIDS and other infectious diseases. Five male participants had fathered children and three female participants had given birth to children since their HIV diagnosis. Twenty participants lived in the Gulu Municipality area while six lived in Opit sub-county, one of the sub-counties of Gulu District. Only eight participants had some secondary school education. Nineteen participants were Catholic.

The participants had known their HIV status for between 2 and 20 years and just over half of them (16/26) were on HAART. All participants were attending the HIV clinic at St. Mary's Hospital, Lacor and Comboni Samaritan supported them with food supplements, school fees for education of their children and psychosocial support. Most of the participants lived in simple brick houses or mud huts with grass-thatched roofs, as is typical for the population in this area. Some of the participants were peasant farmers eking out a living from the land, but a few others had small businesses that brought in extra money to support the family.

### Data collection and analysis

Semi-structured interviews were conducted between February and May 2009 after the study received ethical approval from the Human Research Ethics Committee of Curtin University (Western Australia), the Makerere University School of Public Health Institutional Review Board, Kampala, Uganda and the Uganda National Council for Science and Technology. The participants were informed about the objectives, procedures and implications of the study. They were informed that their participation in the study was voluntary, and they were free to withdraw at any stage of the study without any negative consequences in terms of access to care and support. Using an interview guide with 38 open-ended questions, the interviewers explored factors influencing reproductive decision-making, experiences of HIV stigma, influence of family, friends and community, and health workers' perceptions towards PLHIV's desires to have children. The interviews were conducted in person in the privacy of participants' homes or in a community setting of the participants' choice, and out of the hearing range of

other family members and neighbours to ensure that they were not privy to the reasons and content of the interview. All participants provided consent. The interviews lasted between 1 and 2 hours and were conducted in Luo (a dialect widely spoken in northern Uganda), audio-recorded, then transcribed and translated into English.

Interview transcripts were imported into Nvivo8 (QSR International Pty Ltd) and were systematically read and initially coded using an open coding method [32]. The process of analysis drew inspiration from thematic content analysis and was guided by the Framework Approach to Analysis [33,34]. The aim of the analysis was to produce a succinct and reliable matrix of key themes [35] and to develop concepts from the data rooted in the reality of the participants' experiences [36]. The first author reviewed the themes with the interviewers in order to increase authenticity. The inductively developed coding themes and sub-themes were then compared and refined against the "Conceptual Model of HIV/AIDS Stigma" [23], to identify dominant themes and sub-themes relating to experiences of stigma particularly around triggers, behaviours, types, outcomes and agents of stigmatization. Transcripts were read repeatedly and cases and quotations that illustrated the themes were selected [37].

## Findings

In the first part of the findings, we present a summary of the findings pertaining to the desire to have children among PLHIV as this sets the context for understanding the desire to have children in this strongly patriarchal society. Then we present the findings on experiences of stigma and how the process of, and dimensions of stigma, directly or indirectly influence the desire to have children among PLHIV in northern Uganda. Finally, we present how PLHIV manage both internal and external expressions of stigma in order to meet their own reproductive needs.

### Desire to have children among PLHIV

The interviews revealed that there was a marked difference in desire to have children by sex and there was a range of factors that influenced these desires. Nine of the 26 participants (35%), all male, said they would still like to have children in the future while 15 participants, 13 of them female and only two male, said they did not want any more children. One male participant was not sure whether he wanted more children. Hence more men (9/12) than women wanted to have children. However, regardless of the differences in desire to have children, almost all of the PLHIV had made a reassessment of their ability to have more children and generally accepted that they could not have as many as they wanted. There was generally high level of knowledge around HIV transmission, particularly MTCT of HIV. Thus the decision-making process around having children was complex: the men and women interviewed knew the implications of having children, given their HIV status and the possibility of infecting their children. The themes around the desire to have children among the 26 participants included decision making (reassessment of reproductive career, male dominance and fatalism), external influences (spouses, family and health workers, and access to HAART and PMTCT services), cultural

influences (heirs and inheritance), health concerns (personal health concerns and concerns for children's health), stigma and attitudes to children (as sources of joy, utilitarian roles, strengthening marriages).

Children were seen as sources of joy and blessings by most of the participants. The participants who had delivered children after their HIV diagnosis were pleased that they could have children and were particularly happy when they had HIV-negative children. Other participants spoke about the utilitarian function of children and how they would be a help in the future. A widow and mother of five children encapsulated the utilitarian function of children when she said:

If they grow up they will also help you when you are now helpless. They will take you to hospital if you are very sick, dig for you, feed you and give you other help.

Several female participants emphasized the role of children in strengthening marriages. A 20-year-old female participant, said:

I think in marriage it means a lot to have children, because it makes a happy marriage, increase love among the two people.

However, it was not just women who felt that children were essential for cementing relationships. Although several male participants had children with former spouses, they wanted to have children with their current partners. One male participant said that people would mock and query their inability to have children and this would lead to the wife deserting him:

To my wife the issue is even more important because if you don't have children with a woman she will not agree to live with you... The reason why I want to have a child is if you have a woman and don't bear children with her your relationship will not be strong or good. Even other people will be insulting her that you are living with him without having a child maybe he is barren that's why you are not having a child with him.

Most of the female participants were worried about their own health, and what future pregnancies could do to their health. They were mainly concerned with looking after the children they had. Furthermore, they were concerned about potential infection of their infants. Several participants had given birth to HIV-infected infants and did not want to repeat the experience. Others were waiting on HIV results for their newly born infants and were distressed at the thought that they could be infected. Though some of the male participants shared these health concerns, they were further influenced by the desire to have heirs and meet social and cultural obligations. It was important to individual PLHIV, as well as their close blood relatives, that PLHIV also have children of their own to carry on their name and inherit their property and lands. Their ability to have children was also closely tied to the respect they would have from other community members and a number of participants indicated that having

children guaranteed them respect from other family and community members. It also proved that they were not infertile, a state which was equated by some participants to being “useless”. One male participant said:

Fatherhood is good also because if since your childhood you never had a child here in our clan, elders see you as a child, they may think because you maybe impotent. So if you have a child you are respected because you are now an adult and that gives you respect.

Although 15 participants said they wanted no more children, the data indicate that having children met several personal and societal expectations. All the participants had a good understanding of MTCT and the potential risks of infecting their infants; however, they were all under extreme internal and external pressure to have more children. The availability of HAART and PMTCT programmes made it possible for many to consider having children and some were actively accessing these services in order to both reduce the possibility of infecting their infants and improve their own health.

#### **Dimensions of stigma that affected desire to have children** *Types of stigma*

The themes around the dimensions of stigma that affect the desire to have children are summarized in Table 1. The “Conceptual Model of HIV/AIDS Stigma” recognizes three major types of stigma namely, received, internal and associated stigma [23]. Received stigma refers to behaviours targeted towards PLHIV as experienced by them or explained by others and includes neglecting, avoiding and abusing. Internal stigma refers to negative thoughts and behaviours stemming from negative perceptions due to the presence of HIV. Associated stigma results from a person’s association with someone living with HIV [23].

Most of the participants (22/26) had experienced some form of stigma, the most common being internal stigma (14/26), with decreased self-esteem and pessimistic thoughts (being worthless and useless and thoughts of death). This form of stigma affected the desire to have children among some participants. When asked whether having HIV had changed their minds about having children, the response of some participants implied that they did not see themselves as “normal” although they wanted to maintain the semblance of normality. One female participant, a 30-year-old mother of three, said:

No, of course I would behave like other people with normal life and bear as many children as I want. Because children help a lot, in the family, the workload is shared and makes a person feel responsible.

#### *Triggers of stigmatization*

For some PLHIV, an HIV-positive diagnosis and disclosure of HIV status triggered several processes including low self-esteem and self-image, and internal stigma, thereby deterring them from forming new relationships or making decisions about having more children. When asked how he felt about having children after he was diagnosed with HIV, a 34-year-old male participant indicated that he

constantly thought of death and did not even consider having a relationship, let alone children:

The first time when the counsellor told me I am HIV-positive, I felt useless, I thought I would die in less than one week... I thought my whole life was not there, I thought I would not stay with any woman... issues of having children never came in my mind. I thought of death only.

Disclosure of HIV status was another trigger for stigmatization, and sometimes led to conflict and desertion by close family members, including spouses. Both overt disclosure [23] and unintentional disclosure [38] have been reported to trigger the stigmatizing process among PLHIV in Africa. Desertion of PLHIV by spouses is relatively common in northern Uganda and may be a result of fear of contagion (many spouses return when the client improves on medication), shame, fear of associated stigma and because PLHIV are sometimes blamed for having the disease especially if they were known to be promiscuous. A male participant described his wife’s reaction when he informed her about his HIV status:

This brought a lot of tension between me and my wife until we separated. When I told my wife I was positive, we went and tested, she was negative, the counsellor told her to test again after 3 months but she told me she cannot stay with an HIV-positive man. Then she went and got married to another man.

Some PLHIV who had experienced this form of stigmatization had not entered new relationships, while others formed relationships with other HIV-positive people in order to reduce stigmatization.

#### *Stigmatizing behaviours*

Stigmatizing behaviours were those that harmed, isolated, excluded or identified the HIV-positive person in a negative way, and they included blaming, insulting, avoidance and accusation [23]. Nine of the 26 participants reported insults and hostility from the community and one reported insults from health workers. Community members questioned why HIV-positive people continued to have children, calling their children “HIV children”. When asked about the community’s reactions to HIV-positive people having children, one male participant said:

There are those who speak, especially on women. They will say ‘why are you still bearing children when you know that you are HIV-positive and you will die leaving us behind with the burden of children’. Occasionally they are also insulted like that.

The one male participant, who reported verbal abuse from health workers at the health facility where his HIV status was known, said:

When I went to the hospital, when the health workers learnt that my wife was pregnant, some

**Table 1. Coding framework: stigmatizing experiences of PLHIV's in northern Uganda**

Codes	Basic themes identified	Organizing themes <sup>a</sup>	How this impacted on desire to have children
HIV-positive diagnosis starting pessimistic thoughts and feelings of worthlessness Disclosure leading to separation and desertion		Triggers of the stigmatizing process	Reduced desire to start relationships and have more children
Insults from community members	Received stigma	Types of stigma	Reduced self-esteem and self-image, self-isolation and hence reduced desire to start new relationships and have more children. Reluctance to expose children to stigma
Insults from health workers Insults towards children Anticipated discrimination towards children	Associated stigma Anticipated stigma		
Pessimistic thoughts Feelings of worthlessness Decreased self-esteem	Internal stigma		
Calling PLHIV names	Abusing, Insulting	Stigmatizing behaviour	Reduced desire to start relationships and have more children
Desertion by spouses on diagnosis No stigma from family	Avoidance Positive family support	Agents for and against stigma	Improvement in self-image and desire to start new relationships or damage to self-image with resultant reduced desire to have children
Insults from community members Hostility from health workers Support from health workers	Community as enhancer of stigma Health workers are source of stigma Health workers as mitigators of stigma		
HAART reducing physical symptoms and restoring vitality HAART reducing psychological stresses and negative thoughts around death Reduction in negative self image with HAART	HAART reducing stigmatizing symptoms of AIDS HAART reducing internal stigma		
Told all relatives and friends	Disclosure	Management of stigma	Improved self-esteem, improvement in shattered and damaged self-image, increased desire to start new relationships and have more children
Remaining strong in face of stigma Ignoring verbal taunts and obvious stigmatizing behaviour Remaining normal despite disease Going about daily business despite illness Having more children despite disease	Resilience Adjustment Normification		
Keeping to herself to avoid stigma Proposed to by fellow PLHIV	Withdrawal Sero-sorting	Reactions to stigma	Reduced interaction with others Start new relationships and reassessment of ability to have children
Started new relationship with fellow PLHIV after being alone for 3 years			

<sup>a</sup>Themes adapted from the "Conceptual Model of HIV/AIDS Stigma" [23].

were using very abusive language but some were good to us. Some were saying that we are always told about delivery, but we don't listen, we are delivering like pigs. So how can they get time to help us yet we are told not to deliver. But some were good, telling us to take our medications properly. Some were saying HIV-positive persons should not conceive.

There were also reports of insults towards children born to PLHIV; thus, children of PLHIV were exposed to associated stigma. This form of stigma may also influence PLHIV's desires to have children in the future. When asked about community members' responses to his wife's pregnancy, one male participant said:

Yes, they were saying we should wait and see how HIV-positive children will be born. But even some still call my child 'HIV-positive child'... [They say] 'Bring your HIV-positive child and I carry'.

Another type of stigma which was not elaborated in Holzemer's [23] framework, but was revealed through the interviews, was anticipated stigma. Anticipated stigma is defined as the degree to which PLHIV expect that they will experience prejudice in the future [39]. This form of stigma resulted in self-isolation and sero-sorting, as described in the next section. Some study participants excluded themselves from relationships or confined themselves to HIV sero-concordant relationships for fear of being stigmatized. This form of stigma reduced the desire to have more children in some PLHIV for fear that they would be stigmatized as well. When asked why he didn't desire to have more children, one male participant said:

...so when you die and these children are left in their hands, they mistreat them, saying they are positive. . .

#### **Agents and their impact on desire to have children among PLHIV**

The findings also revealed that the family, community and health system could either support or discourage the desire to have children among PLHIV. Some participants reported receiving family support for their decision to have more children. When asked about how his mother and other immediate family members felt about him having more children after his HIV-positive diagnosis, one male participant said:

They have no objection because they are the one who suggested that I get a child at least and the women that I have now.

Community members could also reinforce stigmatization of PLHIV. Some participants said that they faced verbal abuse and mocking from neighbours, with some of their children being called "HIV-positive children". One male participant said that his neighbours told him that he should stop having children. Another male participant was asked by community members:

You are HIV-positive, why do you want a child?

A female participant expressed the difficulty she experienced:

Yes, they were saying such people should no longer bear children, but nature is very hard to control especially if you have a man, you can only stop bearing children if you separate.

As described earlier, one participant had also experienced stigmatizing comments from health workers. Thus some staff members had judgmental attitudes towards PLHIV who had the desire to have more children. Participants who reported that they did not experience hostility towards them as a result of their decisions to have more children were more likely to have positive attitudes towards participation in health services. Some pregnant women and their partners who were well received at the health facilities said they did not face stigmatization. One male participant said:

They [the health workers at the hospital] welcomed us very warmly when they saw that I accompanied her for ANC. . . . No, there was no difficulties which I experienced at all because they served me eagerly, you know there are some men who are reluctant to accompany their wives to the hospital if their wife asks them and this is very challenging to the health workers.

The health workers' reactions also depended on PLHIV's willingness to disclose their status, according to one male participant:

When she went for ANC she was received well and attended to because she was open to them. . . . There was no problem at all.

This was confirmed by his wife:

The health workers were friendly and after disclosing to them our status they were very supportive and counselled me and also emphasised the need for me to continue with my ANC visits.

Another male participant reiterated this, saying:

The medical staff received us with a lot of hospitality, because they knew that I am HIV-positive, and as I have taken my wife for ANC, they were very pleased because we went together, she did not go un-accompanied.

Health systems and facilities also mitigated HIV-related stigma through their role in reducing disease-related symptoms and overt manifestations of HIV/AIDS. By reducing overt manifestations of HIV/AIDS, HAART restored the health and vitality of PLHIV. As a result, negative thoughts decreased, allowing some participants to feel more positive at the prospect of starting new relationships and having more children. As one male participant said:

It changed and I stayed for a long time without the urge and desire of a woman, but after I started getting improvement [after initiating HAART] I am thinking that, if possible, this new woman, I should

not live with her without getting a child, at least a child should be there.

### Management of stigmatization

There were a range of outcomes amongst the participants and we classified them into two broad categories, namely reactions to stigmatization and management of stigma. Reactions to stigmatization included reduced desire to have children, self-isolation, sero-sorting, internal stigma and delayed access to healthcare and services. Stigma management, defined as the actions people take in order to reduce the effects of stigmatization [40], included disclosure, resilience, adjustment and normification. Normification is a process whereby the stigmatized individual presents him/herself as an ordinary person without necessarily making a secret of his/her undesirable attributes [8]. The outcomes of stigmatization varied according to the level of support that the participants received from their family, community and health system.

#### *Self-isolation and sero-sorting*

Stigmatized persons avoid situations where they may be forced to reveal their previously unknown stigma to others [8]. Stigmatized people are unsure of how they will be treated and they react by “defensive cowering” [8], that is, avoiding situations where they may be stigmatized. PLHIV may self-isolate, remain single and celibate, or they may sero-sort. Sero-sorting, whereby PLHIV choose their partners based on their HIV status [41], relates to a phenomenon called “in-group alignments” where individuals who experience the same stigma, and suffer the same deprivations, develop a “secessionist ideology” [8]. This was illustrated among some participants, who chose other HIV-positive persons as spouses. A male participant was approached by an HIV-positive woman who encouraged him to test for HIV and to form a relationship with her:

A girlfriend who encouraged me that she was also living with HIV and that I should also come out so that we can live together.

One male participant who had been deserted by his wife after his diagnosis lived for 3 years without a companion, but he later found an HIV-positive partner following encouragement from his doctor. His story shows how effectively sero-sorting can overcome stigma and the limitations it places upon the options of those who suffer from it:

It took such a long time, for about three years that I was single... I then went to my doctor and told him, now I feel healthy, and need someone to stay with. I was told if I can get someone who is also HIV-positive, I should come with her to him. Later I got a lady and went to him, as I talk now, I have a wife... The current one was requesting me if I could also have a child with her since she has never had a child in her life. My doctor talked to both of us and as I talk now my wife has a baby. When my wife was pregnant I was very happy because I thought I would not get any other child again.

#### *Disclosure*

Though disclosure can lead to further stigmatization of PLHIV, it is also a form of stigma management as it has been shown to ease further disclosure, enhance healing and feelings of accomplishment, pride and self-understanding, and empower PLHIV among other positive effects [40]. The participants who had fully disclosed their infection appeared to have adapted better to their illness. One male participant, who had been previously very ill but had now recovered after being on HAART for 4 years, told his whole family, clan and the rest of the community:

My wife is aware and we went for HIV test together... Everyone at home even people of my clan know it.

By disclosing his HIV status, this participant was able to garner help and support from family, the community and the health system. He was open about both his desire to have more children and his willingness to work with the health system to prevent possible transmission of HIV infection to his children. After his HIV diagnosis 4 years previously, he and his two wives had started HAART, and both wives had conceived and delivered HIV-negative babies. When asked about whether he cared about the health of his HIV-positive pregnant wife, he said:

Yes I care about her health because when she is pregnant I take her to the health centre for ANC [antenatal] and she gets ANC card so that the doctor takes good care of her.

#### *Adjustment and resilience*

In regard to resilience and adjustment, some participants had coped with their illness and the stigmatization that they experienced. These PLHIV generally ignored people who stigmatized them. When asked about whether people talked ill of him when he wanted to have another child, one male participant said:

Yes there were some people who like stigmatising HIV-positive people and they were the ones talking ill of me, but I did not mind because I considered that to be idle talk, because a person can't say I am healthy (HIV-negative) without going for blood test, you can only know your HIV status after a test, but they don't know theirs now.

The availability of HAART, which made them healthier and capable of looking after themselves and their children, also made them more resilient. When asked what advice he would give to HIV-positive pregnant women, another participant said:

What would I say is this if you are HIV-positive just adhere to your drugs only and don't mind what others say and you will be in a very good state of health even better than some of the people stigmatising you.

### Discussion

The purpose of this qualitative study was to explore the experiences of stigma and delineate its effect on the desire



to have children among PLHIV in northern Uganda. The “Conceptual Model of HIV/AIDS Stigma” [23] was the most useful framework since it allowed the exploration of both the process and context of HIV-related stigma in this population and how these elements influence the desire to have children in this region. HIV-related stigma continues to affect the lives of PLHIV in northern Uganda, where an HIV diagnosis and disclosure of HIV status are the main triggers of stigma, while received stigma and internal stigma are the main forms of stigma experienced. Outcomes of the stigma process include self-isolation and sero-sorting, but also resilience, adjustment and normification. Deacon [42] argued that to only consider the negative outcomes of the stigmatization process has limited the understanding of stigma and the range of effects it has on stigmatized people. Stigmatization of PLHIV does not necessarily lead to disadvantage or discrimination [42]. Some PLHIV challenge those who stigmatize them and refuse to accept the dominant perspective that they are “deviant” [43]. Stigmatized people will not always suffer low esteem and many continue to perform at high levels, are happy and resilient and have a range of coping strategies [44]. Many PLHIV maintain positive attitudes, and constructively engage with their communities to reduce stigma and increase knowledge about HIV [45]. Positive activism by stigmatized people challenges stereotyping and discrimination and it can lead to improvement in the status and overall physical and psychological health of the stigmatized population [42].

Positive support from family, community and health systems can help PLHIV maintain the desire to have children. Participants who did not experience overt stigma continued to desire children and utilized health services to achieve better health outcomes for their children through adopting strategies for reducing MTCT. However, the same agents can have a negative influence on the desire to have more children through verbal abuse from health workers or neighbours or via desertion by spouses. In fact, childbearing and pregnancy among PLHIV triggered further stigmatization in the form of insults and mocking from the community and health professionals. The combination of insults, mocking and overt hostility from community members, coupled with feelings of worthlessness and isolation from friends and family, reduced the desire to have children among some PLHIV. Other PLHIV sought new relationships with other HIV-positive people. Keeping a physical or emotional distance from “normal” (uninfected) individuals was a form of stigma management, and it also facilitated remarriage and rekindled a desire to have children among some PLHIV.

What is clear in this study, however, is that PLHIV do have a good understanding of the potential to infect their children, but the social drivers that force them to have more children place them “between a rock and a hard place” because they wish to have children of their own to enhance their social standing among family, clan and tribe members. Both male and female identities are tied to their ability to have children and PLHIV may rather face the consequences of HIV transmission to their partners and children than be labelled “infertile”. Because parenthood in many African societies is the major purpose, and the primary value, of a marriage,

members of those societies are not complete until they have had children of their own [19,46]. It is against this backdrop of a strongly patriarchal society, coupled with high levels of poverty and lack of social support, that PLHIV have to make difficult decisions around having children that they could potentially infect. In societies with low literacy, endemic poverty, high child mortality and lack of social welfare and security programmes, children are considered as a form of insurance to provide support in old age. Having children in Uganda increases a person’s social status [47] and this also applies to couples living with HIV. What is interesting is that the term “useless” was used twice: once when describing the inability to having children, but also when an individual has contracted HIV. So there is a stigma related to not having children, as well as a stigma associated with an HIV-positive person having children.

However, it is also clear that PLHIV are not callous, deliberately having children as they please and putting them at risk of infection. PLHIV are markedly concerned about what their infection means for them and their children and they actively engage with health services to improve their own health outcomes. Many have risen above their illness and actively engage with their families and communities to reduce not only their own personalized stigma but also community stigma. Therefore, it is important that health workers understand the underlying contextual issues that influence their clients behaviour. Ko and Muecke [10] called it “cultural competence”, where health workers recognize and appreciate the significance of specific cultural values of PLHIV that shape their fertility decision making.

By presenting themselves as normal and reducing their own self-stigmatization, PLHIV enhanced their acceptance by family members, community and health systems. Returning to work, building new homes, and having more children were some of the ways in which the participants were re-evaluating their “spoiled” identity or the “dying” identity associated with having HIV [40]. Participants who had adjusted to their condition were more positive about having children in the future. This study revealed that resilience could be a positive outcome of the stigma process, an aspect that may assist PLHIV in coping with their HIV status.

Delineating the influence of stigma on fertility desire and intent is essential for development of interventions aimed at reducing stigmatization of PLHIV and to the improvement in their quality of life. These findings are important for programme managers and other health and social personnel who work with PLHIV. Weiss *et al.* [48] proposed multi-level interventions targeting the individual with the stigmatizing condition, the people who stigmatize, the disease and the community. Similarly, Logie and Gadalla [49], suggested that stigma-reducing interventions should operate on multiple levels and target several populations in order to be effective. Counselling would help PLHIV cope with their illness and enhance resilience in response to stigmatizing encounters. Cognitive behavioural therapy has also been found to reduce internal stigmatization and stress, and improve self-esteem [50]. PLHIV should also be encouraged to join peer groups. In such groups, PLHIV can feel normal and find relief from internalized and overt stigmatization [43]. PLHIV in Uganda

found a lot of support from PLHIV groups, developing feelings of solidarity [51].

Interventions aimed at the disease itself include HAART, which would reduce the signs and symptoms of the disease and improve overall quality of life of PLHIV [51]. HAART has been reported to reduce stigma through its effect on the ability of PLHIV to lead normal and productive lives, and reconstruct their “devalued, shattered identities” [52]. Interventions for the general public, such as community education, could improve the knowledge of HIV, correct misconceptions about risks of transmission and also enhance empathy with PLHIV [48]. Other community-based interventions include social marketing [49]. Health workers also need to understand the role of the health system in stigmatization of PLHIV and how their stigmatizing attitudes negatively affect PLHIV [45]. Identification of the role of the health system in mitigating or enhancing stigma can lead to improvements in services through strengthening the mechanism of protecting confidentiality. Education programmes for health professionals to change their attitudes towards PLHIV, promote competence and non-judgment of PLHIV could help in the reduction of health system-related stigmatization of PLHIV [49].

Though this study is limited to a purposely selected number of participants in northern Uganda, the findings could inform the improvement of services for PLHIV in other regions of Uganda. Individuals, PLHIV, communities, health organizations, government and non-government partners, and other stakeholders could use this information to develop strategies to reduce stigmatization of PLHIV.

## Conclusion

HIV-related stigma continues to affect the quality of life of PLHIV in Gulu district, northern Uganda, and influence their desire to have children. A reduction in the stigmatization of PLHIV may result in an increased willingness among PLHIV to utilize HIV care and prevention services to achieve better health outcomes, through the adoption of strategies for reducing MTCT. Identification of the stigma process and agents illuminates the areas where interventions could be tested to reduce stigmatization of PLHIV and improve the quality of life of both PLHIV and their children.

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### Competing interests

The authors have no competing interests to declare.

### Authors' contributions

BN designed the study, collected and analysed the data, and prepared the initial draft. JL, SCT, CGO and JE assisted with the design of the study, contributed to the interpretation of the results, reviewed the various drafts and assisted with the writing. All authors have read and approved the final manuscript for submission to a peer-reviewed journal.

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