

**CHILDBEARING DESIRES AND EXPERIENCES OF  
PEOPLE LIVING WITH HIV AND SAFER CONCEPTION  
IN IRINGA, TANZANIA**

by  
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## **ABSTRACT**

**Background:** Many people living with HIV (PLHIV) continue to desire and have children after being diagnosed with HIV. Yet they often lack information on safer conception and face barriers accessing quality reproductive health services.

**Objectives:** The overall objective of this dissertation was to explore childbearing desires and experiences of women and men living with HIV and safer conception in Iringa, Tanzania. Manuscript one examines fertility desires of women and men living with HIV. Manuscript two describes key features of the lived experience of having a child post-HIV diagnosis. Manuscript three explores whether and how international best practices and national childbearing and safer conception guidelines for PLHIV are implemented within HIV care and treatment facilities. Finally, manuscript four examines potential barriers to the adoption of safer conception strategies by HIV-affected couples using an ecological framework.

**Methods:** Data were collected between June and October 2013 in two districts in the Iringa region of Tanzania. In-depth interviews were conducted with 30 HIV-infected women, 30 HIV-infected men, and 30 health care providers engaged in delivering HIV-related care. Direct observations were conducted at five health facilities.

**Results:** Social and structural factors influenced fertility desires and childbearing experiences of women and men living with HIV. There are many factors unique to the experience of living with HIV that motivate and militate against PLHIV wanting more

children. Significant gaps exist between Tanzania's national HIV guidelines, recommendations for safer conception, and actual practices by health providers in delivering reproductive health care to PLHIV. There was limited patient-provider communication on childbearing and safer conception. Multiple barriers to safer conception for HIV-affected couples exist that operate at the individual, relational, environmental, structural, and superstructural levels.

**Conclusions:** Integrating HIV and sexual and reproductive health services is critical to addressing the unique challenges encountered by PLHIV as they make decisions about reproduction. Health care providers can play an important role in assisting their HIV-infected patients safely conceive and deliver uninfected children by regularly assessing their fertility desires and providing safer conception counseling for couples. Findings highlight the need for updated national guidance on safer conception counseling for HIV-infected patients and training for health providers to prepare them for delivering high quality preconception counseling and safer conception services for their HIV-infected patients. Multi-level interventions are needed to ensure adoption of safer conception strategies and reduce the risk of HIV transmission between partners within HIV-affected couples.

**Thesis Committee:** Caitlin Kennedy, PhD, MPH (advisor), Deanna Kerrigan, PhD, MPH, Pamela Surkan, ScD, PhD, and Heena Brahmabhatt, PhD, MPH

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## **LIST OF ACRONYMS**

AIDS	Acquired immunodeficiency syndrome
ART	Antiretroviral therapy
CD4	Cluster of differentiation 4
CTC	HIV care and treatment center
HIV	Human immunodeficiency virus infection
MoHSW	Ministry of Health and Social Welfare
PEP	Post-exposure prophylaxis
PLHIV	People living with HIV
PMTCT	Prevention of mother-to-child transmission of HIV
PrEP	Pre-exposure prophylaxis
RCH	Reproductive and child health
SRH	Sexual and reproductive health
UNAIDS	United Nations Programme on HIV/AIDS
VCT	Voluntary counseling and testing
WHO	World Health Organization



# INTRODUCTION

## BACKGROUND

### HIV and Fertility in Tanzania

An estimated 1.5 million women and men in Tanzania are living with HIV ((TACAIDS), (ZAC), (NBS), (OCGS), & International, 2013). National HIV prevalence is 5.1% with higher prevalence among women compared to men (6.2% versus 3.8%) ((TACAIDS), et al., 2013). There are geographic disparities in the burden of HIV in Tanzania (see Figure 1). The Iringa region has the second highest rate of HIV in Tanzania—9.1% of people between the ages of 15 and 49 years are infected with HIV in the region ((TACAIDS), et al., 2013). In generalized epidemic settings like Tanzania, a large proportion of new

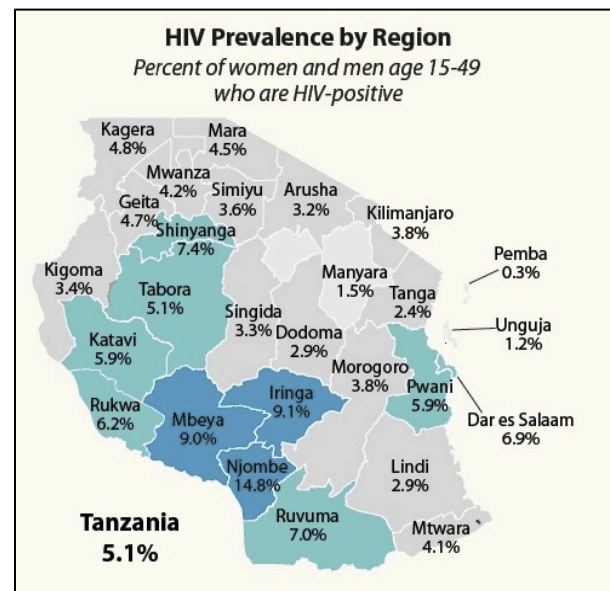


Figure 1. HIV prevalence by region in Tanzania.  
Source: Tanzania HIV/AIDS and Malaria Indicator Survey 2011-12.

HIV infections occur between couples in established relationships, resulting in HIV discordancy within such partnerships serving as a major driver of HIV spread (Rispel, Metcalf, Moody, Cloete, & Caswell, 2011). Among all cohabitating HIV-affected couples in Tanzania – that is, when at least one partner is infected with HIV – almost three quarters are discordant ((TACAIDS), et al., 2013). It is more common among HIV-discordant couples in Tanzania for the man to be infected while the woman

is not than vice versa ((TACAIDS), et al., 2013). According to the 2010 Tanzania Demographic and Health Survey, although the main mode of HIV transmission is through heterosexual contact, mother-to-child transmission is the second most common mode of HIV transmission ((NBS) & Macro, 2011).

Although there has been progress in expanding the availability of antiretroviral therapy (ART) in Tanzania over the past few years, access and uptake of treatment remain limited. According to the most recent UNAIDS Report on the Global AIDS Epidemic (UNAIDS, 2013), in 2012 68% of adults eligible for treatment were receiving ART and 77% of pregnant women living with HIV received ART to reduce the risk of mother-to-child transmission of HIV.

Tanzania has one of the highest fertility rates in sub-Saharan Africa. The 2010 Tanzania Demographic and Health Survey ((NBS) & Macro, 2011) reports the total fertility rate at 5.4 children per women. The mean ideal number of children in Tanzania is 4.9 for all women and 4.8 for all men. The desire for children is related to the number of living children in Tanzania. Among currently married women with no children, 90.9% wanted a child soon and 3.2% wanted a child later. The desire for more children decreases to 33.5% of currently married women with one child wanting a child soon and to 58.9% wanting a child later. This pattern is similar among currently married men. ((NBS) & Macro, 2011)

### **The Impact of HIV on Fertility**

HIV influences fertility trends in sub-Saharan Africa at the population and individual levels (Taulo et al., 2009). The relationship between HIV and fertility is

complex. Though HIV is not a proximate determinant of fertility, it may contribute to several proximate determinants, including sexual exposure within and outside marriage, contraceptive use and effectiveness, induced abortion, breastfeeding, and infecundity resulting from HIV disease progression (Bongaarts, 1982; Chuwa, 2011). A study conducted in the Kyela district of Tanzania found that HIV-infected women had a lower fertility rate compared to uninfected women (Chuwa, 2011). In Malawi, contraceptive use has been reported as being higher among HIV-infected individuals compared to uninfected individuals (Taulo, et al., 2009). However, there is some evidence of the potential risk of interactions between some hormonal contraceptives and antiretroviral therapy resulting in decreased efficacy of hormonal contraception (Leticee, Viard, Yamgnane, Karmochkine, & Benachi, 2012; Makumbi et al., 2011). The prevalence of induced abortion has been found to be high among women living with HIV in multiple settings (Chi, Hanh, Rasch, & Gammeltoft, 2010; Orner, de Bruyn, & Cooper, 2011). HIV-infected women might limit breastfeeding to reduce mother-to-child-transmission of HIV, resulting in a diminished duration of postpartum infecundity.

The growing availability of antiretroviral therapy and the expansion of prevention of mother-to-child transmission (PMTCT) services throughout sub-Saharan Africa also have important implications for fertility trends of people living with HIV (PLHIV). A study conducted in Malawi found that HIV-infected women were more likely to change to not wanting any more children over time compared to uninfected women; however, it should be noted that this study was carried out at a time when highly active antiretroviral therapy was not widely available (Taulo, et al., 2009). Antiretroviral therapy is associated with higher pregnancy rates among HIV-infected women in sub-Saharan Africa. In a

cohort study conducted in seven African countries examining the impact of ART initiation on the incidence of pregnancy, the rates of new pregnancies increased continuously with increasing duration of follow-up in HIV-infected women on ART (Myer et al., 2010). Nearly one-third of the women who initiated ART experienced a new pregnancy during the four-year study follow-up. Though the authors did not have specific data on sexual activity and fertility intentions to elucidate why ART initiation increased the incidence of pregnancy in the study population, they do suggest several factors that may have contributed to this increase in fertility: 1) improvement in health and overall quality of life leading to increased sexual activity, 2) increased fertility desires through increased hopefulness about the future, including new partners, and 3) improvement in immunological functioning with ART resulting in increased female fecundity (Myer, et al., 2010). Makumbi et al. (2011) also reported an association between ART and increased pregnancy rates among HIV-infected women in Uganda, particularly among those women with higher CD4 counts and good immunologic response to therapy (Makumbi, et al., 2011). Smith et al. describes how individuals on ART begin to reconstruct a 'life project,' looking to marry but struggling with whether or how to reveal one's HIV status (Smith & Mbakwem, 2007).

The availability of PMTCT enables HIV-infected women to continue to have children while reducing the risk of transmitting HIV to their children (Hoffman et al., 2008). The Government of Tanzania has been accelerating efforts to eliminate mother-to-child transmission of HIV and improve women, infant, and child survival (PEPFAR/Tanzania, 2011). The PMTCT Program was launched in Tanzania in 2000 as a pilot program and has been rolled out to over 4,300 facilities, which represents 91% of all

reproductive and child health facilities in Tanzania. The 2012 PMTCT acceleration plan seeks to reach 80% of all pregnant women with HIV with counseling and testing services, to reach 85% of those who test positive for HIV with PMTCT interventions, and to reduce the rate of mother-to-child transmission to less than 5 percent (PEPFAR/Tanzania, 2011). Tanzania is moving toward implementing revised national guidelines that promote the use of more efficacious ART and the use of ART for the HIV-infected mother's own health. Tanzania recently adopted PMTCT option B+, in which all HIV-infected women are offered life-long ART regardless of CD4 cell count (WHO, 2013). This shift in PMTCT guidelines offers new opportunities for not only reducing mother-to-child transmission of HIV, but also for improving the health of mothers and reducing HIV transmission to uninfected partners. However, there are also challenges with option B+, as many women—especially those who are just learning about their HIV status during pregnancy—may not be ready for lifelong treatment. This national scale-up of PMTCT interventions has important implications for fertility since advances in HIV management and treatment, and particularly PMTCT interventions, have been shown to increase fertility intentions of people living with HIV (Cliffe, Townsend, Cortina-Borja, & Newell, 2011; Ezeanolue, Stumpf, Soliman, Fernandez, & Jack, 2011).

### **Sociocultural Context of Fertility Desires and Experiences of People living with HIV**

There has been limited research exploring the complex sociocultural context in which fertility desires and childbearing experiences of PLHIV are situated. Previous research suggests that fertility desires of PLHIV are influenced by strong desires to experience parenthood motivated by social and cultural norms encouraging childbearing

(Cooper et al., 2009), having no children (Finocchario-Kessler, Sweat, et al., 2010; Nattabi, Li, Thompson, Orach, & Earnest, 2009; Todd et al., 2011), having lost a child (Nduna & Farlane, 2009), a partner's desire for a child, particularly among women (Cooper, et al., 2009; Finocchario-Kessler, Sweat, et al., 2010; King et al., 2011; Nattabi, et al., 2009), having a new partner with the expectation of a child to 'validate' the relationship (King, et al., 2011), and being aware that mother-to-child transmission of HIV can be reduced by taking antiretroviral therapy (Ezeanolue, et al., 2011). A systematic review of factors influencing fertility desires of PLHIV concluded that a common limitation of the studies reviewed was the 'lack of consideration for and understanding of culture and its impact on fertility desires of PLHIV' (Nattabi, et al., 2009). Furthermore, most of the studies reviewed were quantitative and, according to the authors, did not fully describe the contextual factors that influence fertility decisions or the constraints that PLHIV experience in accessing reproductive health services, suggesting a gap in our understanding within the scientific literature.

Sociocultural norms and expectations of having children influence one's sense of self, the value one places on parenthood, and the risks that one is willing to take in order to realize desires for having children. In the context of fertility and HIV, the perceptions of a partner or family's desire for a child may influence the meanings that a person living with HIV associates with parenthood.

Social and cultural expectations of parenthood may strongly impact one's decision to have children despite the risk of transmitting HIV to a child or partner.

Anthropologist Meyer Fortes stated that, in Africa, parenthood is a means to the "attainment of the full development of the complete person to which all aspire" (p. 125)

(Fortes, 1978). Researchers further suggest that having children is not only a means to individual personhood in many sub-Saharan African settings, but also a fulfillment of one's obligations to kin and community (Smith & Mbakwem, 2007). The Swahili proverb, "Kukosa watoto kwafanya mtu adharauliwe," which can be translated into English as "Having no children makes a person despised," illustrates the importance placed on having children in the Tanzanian context. The status of barren women among many ethnic groups in Tanzania is so low that the first priority in marriage is to bear children and couples are often not able to make independent decisions over their own fertility because of the strong influence of kin (Omari, 1995). In their seminal work, The Endangered Self: Managing the Social Risks of HIV, Green and Sobo (2000) state:

The links between risk and identity are fundamental to an understanding of risk behaviour and each individual's risk behaviour has to be set within the context of the constraints, restrictions and priorities related to who s/he is. (Green & Sobo, 2000)(p. 37)

The social risk of being ostracized for not having children in a context where parenthood and having children are highly valued may override any biological risks of HIV transmission. Fertility aspirations of PLHIV often supersede clinical and public health priorities (Smith & Mbakwem, 2007).

Parenthood is a key identity influenced by social roles and expectations in society. This identity may be fundamentally disrupted by an HIV diagnosis. Bury (1982) described the concept of biographical disruption as an assault of chronic illness on often cherished conceptions of self and life course, resulting in a fundamental rethinking of one's biography and self-concept in light of the illness (Bury, 1982). Wilson has

described biographical disruption among HIV-infected women in the United Kingdom (Wilson, 2007). She found that the narratives of the HIV-infected women in her study were permeated by a sense of threat to their identities as mothers, both from HIV-related stigma and their potential mortality.

Perceiving oneself as having a tainted identity is a hallmark of possessing a stigma as originally defined by Erving Goffman (Goffman, 1963). HIV stigma in Tanzania is high (Amuri, Mitchell, Cockcroft, & Andersson, 2011). Multiple domains of HIV-related stigma have been widely recognized. The Policy Project described how different components of HIV-related stigma manifest as a cyclical continuum: HIV-related stigma leads to discrimination against PLHIV; discrimination leads to internal stigma among PLHIV; and internalized stigma reinforces other forms of stigma. Internalized stigma may cause PLHIV to adopt different means of self-protective actions and to reevaluate important identities (Morrison & POLICY-Project, 2006).

Having a child after an HIV diagnosis may serve as a source of renewed self-worth and social status among women and men living with HIV, i.e. biographical reinforcement. Having children may be a strategy employed by PLHIV to restore a sense of “normality” in the face of possessing a highly stigmatized illness. This phenomenon has been reported in a study conducted among PLHIV in Uganda that showed that greater internalized stigma was associated with fertility intentions (Wagner, Linnemayr, Kityo, & Mugenyi, 2012). Investigators speculated that this might be due to attempts of people who are not comfortable with their HIV status to conform to normative behaviors and relationship patterns as much as possible, including having children, so as not to provoke speculation about their HIV status. Wilson remarked that, “in the context of illness, when



other sources of identity, such as work, may have been undermined, [these findings] suggest that the importance of maintaining such key identities [like motherhood] may be accentuated (p. 622)” (Wilson, 2007).

There are other examples of the reinforcement of key identities following an HIV diagnosis in the literature. Baumgartner and David found that the incorporation of the HIV identity caused a reevaluation of and change in salience of other identities, including relationship and spiritual identities among men and women diagnosed with HIV in the United States (Baumgartner & David, 2009). A study conducted in Kenya found that HIV-infected women became pregnant by actively planning and strategizing to get pregnant and have children (Awiti Ujiji, Ekstrom, Ilako, Indalo, & Rubenson, 2010). The investigators of this study found that regaining status through motherhood was a motivation for pregnancy among the women interviewed. Sherr and Barry found that HIV-infected men in London felt that children gave meaning to life and a reason to live, emphasizing the importance of fatherhood as a source of identity for some men living with HIV (Sherr & Barry, 2004).

Given the strong sociocultural influences on having children in the Tanzanian context and the stigma associated with not having children, it is not surprising that pregnancy rates among HIV-infected women in Tanzania have been shown to be relatively high (Mmbaga, Leyna, Ezekiel, & Kakoko, 2013) and many women and men living with HIV express strong desires for having children (Odutola et al., 2012). Yet there has been a dearth of research exploring the sociocultural influences on fertility desires of PLHIV in Tanzania (Keogh et al., 2012; Mmbaga, et al., 2013).

## **Structural Context of Reproductive Decision-making and Behaviors of People**

### **Living with HIV**

Researchers have called for further research on the place of health care institutions in the connections between HIV, particularly PMTCT and ART, and fertility (Agadjanian, Yabiku, & Cau, 2011). Structural institutional factors may play a key role in the ability of PLHIV to make informed decisions about conception and childbearing.

Structural factors that influence fertility decision-making of PLHIV include: reproductive health policies and guidelines for PLHIV; availability of and access to ART and PMTCT services to reduce vertical and horizontal transmission of HIV (Anglemyer, Rutherford, Baggaley, Egger, & Siegfried, 2011; Brocklehurst & Volmink, 2002); access to quality preconception services for individuals and couples by trained health care providers; and client-provider communication and interactions.

Client-provider communication about fertility desires and intentions is a necessary component of effective HIV treatment and prevention (Schwartz et al., 2012). Client-provider communication about fertility desires and intentions among HIV-infected women and men can lead to reduced risk of horizontal and vertical HIV transmission and reduced risk of super-infection through safer sexual practices (Schwartz, et al., 2012). High- and low-resource strategies to minimize horizontal HIV transmission during conception are being explored by researchers making it even more important for providers to discuss with their HIV-infected clients the available range of options for safer conception. Some of the emerging safer conception strategies include sperm washing when the male is infected, intrauterine insemination when the female is infected,

use of ART to reduce infectiousness, and strategically timed unprotected sex (Finocchiaro-Kessler et al., 2012).

Despite their desire to have children, many HIV-infected people do not discuss future childbearing with their health care providers. A study conducted in Uganda found 35% of HIV-infected clients with fertility intentions reported difficulty in discussing their fertility intentions with their health provider (Wagner, et al., 2012). In this study, higher internalized stigma was a strong predictor of HIV-infected clients having difficulty communicating their intentions to conceive to health care providers. In a study examining factors associated with desires and intentions of childbearing and HIV provider communication with women of reproductive age living with HIV in Brazil and the United States, Finocchiaro-Kessler et al. (2012) found that there was inadequate communication between providers and female HIV-infected clients about childbearing resulting in high unmet need for reproductive counseling among clients who intended to have a child (Finocchiaro-Kessler, et al., 2012). The authors indicated that there is no established overarching health policy on preconception counseling in either setting for HIV-infected clients who intend to have a child or guidance on how PLHIV can safely plan for a future pregnancy. They argue that it is essential that providers assess fertility desires and intentions of all HIV-infected clients of childbearing capacity; be knowledgeable of safer conception options for HIV-discordant couples; and provide referrals to more specialized preconception counseling when needed (Finocchiaro-Kessler, et al., 2012). A study conducted in Brazil found that reproductive health issues were neglected by multiple cadres of HIV care providers and concluded that communication on reproductive health

issues, including conception, remains fragmented and potentially contradictory (Malta et al., 2010).

Though the evidence presented suggests health providers are not having discussions with their HIV-infected clients about future childbearing, there are some situations in which providers and their clients do have these conversations. Many HIV-infected female and male clients in a study conducted in South Africa reported having received advice about childbearing from healthcare providers or suggested that health providers might serve as helpful resources in reproductive decision-making (Matthews et al., 2012). When these conversations do occur between HIV-infected clients and their health care providers, some of the topics discussed include reducing the risk of mother-to-child transmission of HIV, preventing HIV transmission to an uninfected partner, medications during pregnancy, and challenges with conceiving (Finocchiaro-Kessler, Dariotis, et al., 2010).

Discussions between providers and HIV-infected clients are an early step in reducing HIV transmission by providing women and men living with HIV the information and tools essential to planning for PMTCT and reducing HIV transmission within HIV-affected couples.

### **Safer Conception Intervention Strategies for HIV-affected Couples**

There are multiple ways to reduce the risk of HIV transmission among HIV-affected couples that want to have children (see Table 1). ART-based safer conception strategies include ART for the HIV-infected partner to suppress HIV viral load to undetectable levels, periconception pre-exposure prophylaxis (PrEP) for the uninfected

partner, and post-exposure prophylaxis (PEP) for the uninfected partner. Non-ART, behavioral safer conception options for resource-constrained settings include unprotected sex timed at the most fertile period of the woman's menstrual cycle and vaginal insemination with sperm from an HIV-uninfected partner or donated sperm. There are also high-technology assisted reproduction interventions for HIV-affected couples, particularly when the man is HIV infected and his partner is uninfected, that are often unattainable for people living with HIV in resource-constrained settings. These interventions include sperm washing with intrauterine insemination and intracytoplasmic sperm injection.

Table 1. Safer conception intervention strategies for HIV-affected couples.

Low technology interventions	Preconception screening and counseling
	Antiretroviral therapy for infected partner to suppress HIV viral load
	Pre-exposure prophylaxis (PrEP) for uninfected partner
	Post-exposure prophylaxis (PEP) for uninfected partner
	Timed unprotected sex during most fertile period of woman's menstrual cycle
High technology interventions	Vaginal insemination with uninfected partner's sperm or donor sperm
	Sperm washing with intrauterine insemination
	Intracytoplasmic sperm injection

The development of these safer conception technologies has led to international and national guidelines addressing the childbearing needs of women living with HIV, with little focus on men living with HIV as key actors in reproductive decision-making. In 2006 the World Health Organization (WHO) published sexual and reproductive health guidelines for women living with HIV in resource-constrained settings (WHO, 2012).

The WHO recommends that special counseling and support be provided to HIV-infected women planning a pregnancy, whether their partners are infected with HIV or not. The WHO guidelines fall short of making official recommendations for safer conception strategies for serodiscordant couples, but they do discuss various options. These options include timed unprotected sex, artificial insemination, ART for prevention, and PEP for uninfected women in serodiscordant relationships.

In order to benefit from advancements in safer conception for HIV-affected couples, PLHIV require access to safer conception interventions, including preconception counseling. Yet few HIV programs specifically address fertility desires and safer conception for women and men living with HIV.

In Tanzania, national policies and guidelines on childbearing and safer conception for people living with HIV are limited. Tanzania's *National Guidelines for the Management of HIV and AIDS* (2012) state that people living with HIV have the right to have children like anyone else in Tanzania. The guidelines instruct HIV care and treatment providers to assess fertility desires of HIV-infected clients at every visit and provide appropriate advice and services. The guidelines stipulate that the safest time for having a child for the mother and baby is when the woman's CD4 count is higher than 200 cells/mm<sup>3</sup> or HIV viral load is low, there are no signs of tuberculosis, and the woman is on ART or antiretroviral prophylaxis. They instruct HIV care and treatment providers to assess and modify the woman's drug regimen to avoid adverse health effects, such as potential birth defects associated with efavirenz. They also state that before getting pregnant, HIV-serodiscordant and seroconcordant couples should consider the health of

each partner, desires of each partner to have a child, and the long-term wellbeing of the child.

## **STUDY SETTING**

Iringa is located in the Southern Highlands approximate 500 kilometers southwest of Dar es Salaam, the commercial capital of Tanzania, and is one of 27 administrative regions in the country. The Tanzam highway, which serves as the major thoroughfare between Dar es Salaam and Zambia, runs through the region making Iringa a minor transport hub. The region is largely rural with a population of 941,239 according to the 2012 national census ((NBS) & Macro, 2011). It has one of the lowest population densities in the country with only 27 persons per square kilometer; however, there are differences in population density by districts within the region ((NBS) & Macro, 2011). The region is comprised of five districts. This research was conducted in two districts within the region: Iringa Municipal and Iringa Rural districts.

The Hehe people are the main ethnic group in the region. Among the Hehe marriage is considered a normal state of all adults and confers on both men and women high social status within their families and communities through respect and honor, or “heshima” in Swahili (Brown, 1935). As Otiso (2013) explains:

Good social standing in one’s family and clan are highly valued because in communal societies, where collective rights often surpass individual ones, individual misdeed can easily hurt the reputation of entire clans. Rejection by one’s family is the most severe form of social punishment. (Otiso, 2013)(p. 147)

The Hehe highly value children. Traditionally among the Hehe if pregnancy does not immediately follow marriage, or if it does not follow soon after the weaning of the last child, it is the duty of the husband to seek fertility medicine (Brown, 1935). Childless marriages are considered unstable and may result in divorce with the blame often falling on the woman when a couple has not been able to produce children.

Given the high importance placed on having children, it is not surprising that fertility rates in Iringa are high. The total fertility rate in the Southern Highlands zone, where Iringa is located, is 5.4 children per women ((NBS) & Macro, 2011). The mean ideal number of children is between four and five children for both women and men in the zone ((NBS) & Macro, 2011). Iringa has the second highest HIV prevalence by region—9.1% of women and men age 15 to 49 years are HIV-infected ((TACAIDS), et al., 2013). HIV prevalence in Iringa is higher among women than men (10.9% compared to 6.9%, respectively) ((TACAIDS), et al., 2013). And though there is limited data from the Iringa region specifically on fertility desires and rates of people living with HIV, evidence shows that in Tanzania, more broadly, pregnancy rates among HIV-infected women are high (Odutola, et al., 2012) and many HIV-infected individuals express strong desires for having children (Mmbaga, et al., 2013).

Research participants were recruited through health facilities at different levels of the health care delivery system, including dispensaries, health centers, a district hospital and the regional hospital. The structure of the Tanzanian health care system is based on a tiered system by catchment area. There are six levels to the health care system. The first level includes village health posts comprised of two village health workers chosen by the village council. For this study, we interviewed three home-based care providers based in



the community who provided basic health educational and medical services for people living with HIV in their homes. The second level includes dispensaries followed by health centers. The lower levels of the health care system, particularly village posts and dispensaries, tend to be more accessible geographically than more specialized hospitals. The accessibility of health services at the village level is a remnant of Tanzania's villagization program ("Operation *Sogeza*"), a mandatory resettlement program aimed at improving the standard of living of rural populations by creating communal farms and providing basic infrastructure and services in village settlements, such as schools, clean water and health dispensaries (Osafo-Kwaako, 2012). The third level of the health care system includes health centers. The fourth level of the health care system includes district hospitals, while regional hospitals make up the fifth level. In addition to higher-level health services offered at district hospitals, regional hospitals have specialists in different medical fields. Referral/consultant hospitals are at the top of the tiered health care system. They offer specialized services not offered at regional hospitals. The Mbeya Hospital serves as the referral hospital for the Southern Highlands zone, including Iringa.

HIV-related services are offered through facilities at all levels of the health care system. However, the types of HIV-related services vary by their level within the system and by health facility. HIV care and treatment is sometimes not offered through dispensaries, which means PLHIV who would normally receive health care through dispensaries must seek HIV care and ART at a neighboring health center or hospital. PMTCT services are offered at all levels of the health care system through reproductive and child health (RCH) clinics. In an effort to expand access to PMTCT services in Tanzania, all pregnant women are offered HIV testing and counseling during their

antenatal visits and those who test positive for HIV receive antiretroviral prophylaxis during pregnancy and, in some cases, while breastfeeding.



Image 1. Waiting room at the HIV care and treatment clinic at Iringa Regional Hospital, Iringa municipal district, Tanzania.





Image 2. Nzihi health dispensary, Iringa rural district, Tanzania.



Image 3. Delivery room at Isimani Health Center, Iringa rural district, Tanzania.

## **STUDY DESIGN AND METHODS**

### **The role of the author**

As the author of this dissertation, I conceptualized, designed, and served as lead investigator for the research. Between April and December 2013, I lived in Iringa, Tanzania to conduct fieldwork for this dissertation. I recruited, hired and trained a local team of four research assistants to help implement the research. The weeklong training oriented the research team to the study goals and objectives. The training also focused on qualitative research methods and research ethics. As the lead investigator, I oversaw all data collection activities and provided guidance to research assistants who conducted all interviews. Throughout the data collection period, I conducted routine quality control assessment of the collected data, which included reading through transcripts, providing feedback to research assistants on areas to further probe, and leading weekly debriefing meetings. In addition, I had informal conversations with staff at health facilities and conducted direct observations at select participating health facilities.

### **Study design and methods**

The study used qualitative methods to explore fertility desires, childbearing experiences, and safer conception among women and men living with HIV. Data were collected between June and October 2013 at seven purposively selected health facilities providing HIV care and treatment and/or reproductive and child health (RCH)/PMTCT services in the Iringa region of Tanzania. The health facilities were located in two districts within the region, Iringa Municipal and Iringa Rural, and represented different

levels of the health care delivery system, including the regional hospital, a district hospital, three health centers, and two health dispensaries.

Semi-structured in-depth interviews were conducted with health providers and HIV-infected women and men attending HIV care and treatment services. Thirty health providers engaged in delivering HIV care and treatment and/or RCH/PMTCT services were recruited at the seven health facilities selected as study sites. Trained interviewers explained that their decision to participate or not participate in the study would not affect their job and that all information disclosed during the interview would be kept confidential. Interviews with health providers covered relevant aspects of their clinical practice and training, knowledge of safer conception strategies and guidelines for HIV-infected clients, provider-client communication about childbearing, attitudes towards childbearing among HIV-affected couples, and challenges to addressing the childbearing needs of their HIV-infected clients.

To recruit HIV-infected women and men, the head of the HIV care and treatment clinic provided a brief description of the research to clients waiting to receive HIV care and treatment services. The head of the HIV care and treatment clinic explained that the research was not part of the care being given at the health facility. A member of the research team then approached potential participants to further explain the research and assess interest and eligibility. Clients were eligible to participate in the study if they had been diagnosed with HIV, were between the ages of 18 and 49 years, resided in the Iringa region, and were able to provide consent. HIV-infected participants were purposively sampled based on gender, age and number of children. In-depth interviews were conducted with a total of 60 HIV-infected clients (30 women and 30 men). Interviews

covered experiences living with HIV, HIV-related stigma, previous pregnancy and birth experiences, perceptions of marriage and childbearing, fertility desires, and communication with health providers about having children. Follow-up interviews were conducted with seven HIV-infected participants theoretically sampled based on their reported experience of having children post-HIV diagnosis.

Interviewers trained in qualitative research methodologies and who were fluent in Swahili and English conducted, transcribed, and translated all interviews. There was one female interviewer and three male interviewers. Two interviewers had background training in community development, one was trained in counseling, and the fourth had a background in law. Prior to data collection, interviewers received a one-week training in qualitative research methods and research ethics. To protect privacy and maintain confidentiality, interviews were held in a private location within the health facility, or within participants' homes in two cases. All interviews were audio-recorded with the consent of the participant. No identifying information was linked to any audio files or transcripts. Informed oral consent was obtained from all research participants before conducting interviews.

In addition to in-depth interviews, direct observations were carried out in five health facilities offering HIV care and treatment and PMTCT services. Health facilities were selected to provide representation of different levels of the health care system and included one regional hospital, a district hospital, two health centers, and one dispensary. Permission to observe in the health facilities was obtained from the Regional and District Medical Officers and the head of each health facility. The research team obtained official letters of approval for conducting the research from the Regional and appropriate District



Medical Officers in advance. Two representatives from the research team, including the principal investigator, approached the head of the health facility to explain the purpose of the observation, presented the letters from the Regional and District Medical Officers, and obtained approval for the observation. The observation was then conducted that same day. Two members of the research team, including the author of this dissertation thesis, conducted observations that lasted two to three hours at the HIV care and treatment clinic at each facility and the reproductive and child health clinic at one of the selected health facilities. Observations focused on the physical environment in and surrounding the facility; client navigation processes through the HIV care and treatment clinic and RCH clinic, including waiting times and treatment by staff, available sexual and reproductive health resources, any group educational session offered the day of the observation, and interactions between health care providers and clients in waiting areas. Confidential provider-client interactions, such as HIV counseling and clinic visits, were not observed. Field notes were taken during the observation and expanded following the observational period. Detailed expanded field notes included both descriptive and reflexive notes and were written by the end of the day following the observation period. These observations helped to elucidate structural factors within the health care system that affect the reproductive health and decisions of PLHIV.

This study received ethical approval from the institutional review boards of the Johns Hopkins Bloomberg School of Public Health, Muhimbili University of Health and Allied Sciences, and the Tanzanian National Institute for Medical Research.



## STUDY PARTICIPANTS

### Health Care Providers

Table 2 presents selected characteristics of the thirty health care providers interviewed for the study. Most of the providers were female. Providers represented four levels of the Tanzanian health care system. About a third of providers had a primary affiliation with an HIV care and treatment clinic while approximately half provided PMTCT services within a reproductive and child health (RCH) clinic. Three HIV home-based care providers were also interviewed and one provider worked in a voluntary HIV counseling and testing (VCT) clinic.

Table 2. Characteristics of health providers interviewed (N=30).

Sex	n (%)
Female	25 (83.3)
Male	5 (16.7)
Health facility level	
Dispensary	8 (26.7)
Health center	12 (40.0)
District hospital	4 (13.3)
Regional hospital	6 (20.0)
Primary affiliation	
HIV care and treatment	10 (33.3)
RCH/PMTCT	16 (53.3)
VCT	1 (0.03)
Home-based care	3 (10.0)

### Women and Men Living with HIV

Thirty women living with HIV and 30 men living with HIV who were receiving HIV care and treatment services from seven health facilities in the Iringa region of Tanzania participated in the research. Table 3 presents demographic characteristics of

these HIV-infected participants. About half of the women interviewed were younger than 30 years old while most men were at least 30 years old. Educational levels were low among both women and men interviewed—26 women and 26 men had only a primary education or below. Six women and one man reported not having completed primary school at all. Most participants were married at the time of the interview. Five women and six men had never been married and six women and six men were widowed or divorced. Most participants had at least one child with nine women and eleven men reporting have only one child. Four women and three men had no children at the time of the interview. Most participants had been diagnosed with HIV for over a year. A large majority of participants had disclosed their HIV status to their partners. About half of the participants reported having an HIV-infected partner (31 out of 60), 11 out of 60 reported having an HIV-uninfected partner, and the rest were either not aware of the status of their partner or not in a relationship at the time of the interview. A higher proportion of men compared to women reported being in an HIV-discordant relationship.

Approximately half of all of the women and men living with HIV desired having children or more children in the future—14 out of 30 women and 17 out of 30 men desired more children (see Table 4). Despite high fertility desires among these women and men living with HIV, less than a third had ever talked to a health provider about having children with twice as many men than women reporting having had a conversation with a health provider about have children. Only a quarter (15 out of 60) had some knowledge of safer conception strategies. Among all of the women and men living with HIV interviewed, 10 out of 30 women and 11 out of 30 men revealed that

they had experienced getting pregnant or their partner getting pregnant and having children after being diagnosed with HIV.

Table 3. Demographic characteristics of HIV-infected women and men interviewed (N=60).

	Male, n (%)	Female, n (%)	Total, n (%)
Age			
< 30 years	4 (13.3)	16 (53.3)	20 (33.3)
30 - 39 years	20 (66.7)	12 (40.0)	32 (53.3)
≥ 40 years	6 (20.0)	2 (6.7)	8 (13.3)
Educational level			
Completed primary school	25 (83.3)	20 (66.7)	45 (75.0)
Some secondary school and higher	4 (13.3)	4 (13.3)	8 (13.3)
Did not complete primary school	1 (3.3)	6 (20.0)	7 (11.7)
Marital status			
Married	18 (60.0)	19 (63.3)	37 (61.7)
Never married	6 (20.0)	5 (16.7)	11 (18.3)
Widowed/divorced	6 (20.0)	6 (20.0)	12 (20.0)
Number of children			
No children	3 (10.0)	3 (10.0)	7 (10.0)
1 child	11 (36.7)	9 (30.0)	20 (33.3)
2 to 3 children	10 (33.3)	12 (40.0)	22 (36.7)
4+ children	6 (20.0)	6 (20.0)	12 (20.0)
Recruitment facility level			
Dispensary	5 (16.7)	11 (36.7)	16 (26.7)
Health center	18 (60.0)	10 (33.3)	28 (46.7)
Hospital	7 (23.3)	9 (30.0)	16 (26.7)
Time since HIV diagnosis			
< 1 year	4 (13.3)	5 (16.7)	9 (15.0)
1 to 2 years	7 (23.3)	10 (33.3)	17 (28.3)
3 to 4 years	8 (26.7)	4 (13.3)	12 (20.0)
4 to 5 years	5 (16.7)	4 (13.3)	9 (15.0)
6+ years	6 (20.0)	7 (23.3)	13 (21.7)
Disclosed HIV status to partner			
Disclosed HIV status	24 (80.0)	24 (80.0)	48 (80.0)
Has not disclosed HIV status	3 (10.0)	5 (16.7)	8 (13.3)
No partner	3 (10.0)	1 (3.3)	4 (6.7)
Knowledge of partner's status			
Aware of partner's HIV status	21 (70.0)	20 (66.7)	41 (68.3)
Not aware of partner's HIV status	6 (20.0)	9 (30.0)	15 (25.0)
No partner	3 (10.0)	1 (3.3)	4 (6.7)
Partner's HIV status			
HIV-negative	7 (23.3)	4 (13.3)	11 (18.3)
HIV-positive	15 (50.0)	16 (53.3)	31 (51.7)
Unknown	8 (26.7)	10 (33.3)	18 (30.0)
Currently on ART	25 (83.3)	24 (80.0)	49 (81.7)

Table 4. Childbearing-related indicators for HIV-infected participants (N=60).

	Male, n (%)	Female, n (%)	Total, n (%)
Desires (more) children	17 (56.7)	15 (50.0)	32 (53.3)
Ever talked to health provider about having children	12 (40.0)	6 (20.0)	18 (30.0)
Knowledge of safer conception methods	8 (26.7)	7 (23.3)	15 (25.0)
Had child post-HIV diagnosis	11 (36.7)	10 (33.3)	21 (35.0)

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## **MANUSCRIPT ONE:**

**‘If I don’t have children, they will know that I’m sick’:  
Understanding fertility desires of women and men living with  
HIV in Iringa, Tanzania**



## **ABSTRACT**

Many people living with HIV (PLHIV) want to have children but often lack information on safer conception and face barriers accessing quality reproductive health services. An understanding of the sociocultural and structural forces that shape fertility desires would allow policy makers, program planners, and health care providers to develop culturally sensitive preconception counseling for PLHIV. Yet there is only limited research that has explored the complex cultural and social context of fertility desires of both women and men living with HIV. This study used in-depth interviews with 30 HIV-infected women, 30 HIV-infected men, and 30 health care providers to examine fertility desires of women and men living with HIV in the Iringa region of Tanzania. Respondents reported several factors that motivate PLHIV to have children: knowledge of prophylactic ART to prevent mother-to-child HIV transmission, compensating for the potential loss of a child in order to reach an ideal family size, wanting to be and be perceived as ‘normal,’ receiving help and assistance from their children, and preferring a child of a specific sex. The perceived inability to care for one’s children in the future and health-related concerns were cited by HIV-infected respondents as deterring them from wanting more children. There is a need for the integration of HIV and sexual and reproductive health services to address the unique challenges encountered by PLHIV as they make decisions about reproduction. Health care providers can play an important role in assisting their HIV-infected patients safely conceive and deliver uninfected children by regularly assessing their fertility desires and providing counseling on family planning, safer conception, and the prevention of mother-to-child HIV transmission.

## INTRODUCTION

Many people living with HIV (PLHIV) who are aware of their HIV status still desire children (Nattabi, Li, Thompson, Orach, & Earnest, 2009). With the increasing availability of antiretroviral therapy (ART), PLHIV are living longer and healthier lives and hence more optimistic about having children. Antiretroviral drugs and new reproductive techniques and technologies are reducing the risks of mother-to-child HIV transmission and transmission of HIV to an uninfected partner in serodiscordant couples (Chadwick et al., 2011; Matthews, Smit, Cu-Uvin, & Cohan, 2012). These new technologies offer expanded options for PLHIV who desire children. However, many PLHIV often lack information on safe conception and childbearing and face barriers accessing quality reproductive health services (Kanniappan, Jeyapaul, & Kalyanwala, 2008; King et al., 2011b; Nduna & Farlane, 2009). Policy makers, programmers, and health care providers need to understand the complexities of fertility desires and factors that play into decisions of PLHIV in order to develop culturally appropriate preconception interventions, including preconception counseling.

Previous research suggests that fertility desires of PLHIV are influenced by strong desires to experience parenthood motivated by social and cultural norms encouraging childbearing (Cooper et al., 2009), having no children (Finocchiaro-Kessler et al., 2010; Nattabi, et al., 2009; Todd et al., 2011), having lost a child (Nduna & Farlane, 2009), a partner's desire for a child, particularly among women (Cooper, et al., 2009; Finocchiaro-Kessler, et al., 2010; King et al., 2011a; Nattabi, et al., 2009), having a new partner with the expectation of a child to 'validate' the relationship (King, et al., 2011a), and being aware that mother-to-child transmission of HIV can be reduced by taking ART

(Ezeanolue, Stumpf, Soliman, Fernandez, & Jack, 2011). A systematic review of factors influencing fertility desires of PLHIV concluded that a common limitation of the studies reviewed was the ‘lack of consideration for and understanding of culture and its impact on fertility desires of PLHIV’ (Nattabi, et al., 2009). Furthermore, most of the studies reviewed were quantitative and, according to the authors, did not fully describe the contextual factors that influence fertility decisions or the constraints that PLHIV experience in accessing reproductive health services (Nattabi, et al., 2009). This suggests a gap in the scientific literature on research exploring the complex cultural and social context in which fertility desires of PLHIV are constructed. In addition, there has been limited research exploring the fertility desires of HIV-infected men.

In this study we examined fertility desires of women and men living with HIV in the Iringa region of Tanzania. We used a qualitative approach to better understand the sociocultural and structural context that shapes these fertility desires.

## **METHODS**

We conducted in-depth interviews with 30 HIV-infected women and 30 HIV-infected men between the ages of 18 and 49 years, and 30 health providers engaged in delivering HIV-related services. A sample of 20 to 30 individuals has been recommended to achieve saturation of themes (Creswell, 2007). Participants were recruited through health facilities with HIV care and treatment clinics (CTC) and/or reproductive and child health (RCH) clinics offering prevention of mother-to-child transmission (PMTCT) services in the Iringa municipality and Iringa rural districts. Interviews lasted between 30 minutes and one hour. Interviews with HIV-infected women and men covered

participants' experience living with HIV; HIV-related stigma; previous pregnancy experiences; perceptions of marriage; perceptions of, attitudes toward, and desire of having children; and communication with health care providers about reproductive health. Interviews with health providers included their perceptions and attitudes toward childbearing among HIV-infected clients, fertility desires of PLHIV, and patient-provider communication on childbearing.

We received ethical approval to conduct the research from the institutional review boards of the Johns Hopkins Bloomberg School of Public Health, Muhimbili University of Health and Allied Sciences, and the Tanzanian National Institute for Medical Research. All interviews were conducted in Swahili, digitally recorded with the consent of participants, transcribed in Swahili, and translated into English by local field interviewers. Field interviewers met weekly with the first author throughout the data collection period to discuss emergent themes and refine the interview guide to facilitate a more iterative research process. Thematic analysis was used to analyze data from the interviews (Boyatzis, 1998). Transcripts were read through several times and a subset of transcripts was coded initially to determine emergent themes. A coding scheme was developed based on themes that emerged from the data and a priori themes based on the interview guide. All transcripts were then coded using the coding scheme with additional codes added as they emerged and were deemed important to addressing the study objectives. We coded text related to the reasons provided by participants for desiring or not desiring children. We then conducted line-by-line coding followed by focused coding to identify themes on desiring or not desiring more children (Charmaz, 2006). All coding

was conducted using QSR NVivo Version 9 (QSR International, Doncaster, Victoria, Australia).

## **FINDINGS**

Among participants in our study, 15 out of 30 HIV-infected women and 17 out of 30 HIV-infected men desired having (more) children in the future. Participants described different reasons why they did or did not want more children. Some factors influencing fertility desires were found to be unique to the experience of living with HIV and considering whether to have children. These fell under five key themes: knowing one could prevent mother-to-child transmission, compensating for the potential loss of a child due to mortality, wanting to be and be perceived as ‘normal,’ ability to care for children, and HIV-related health concerns. Other factors that motivated PLHIV to desire more children included wanting to feel complete, receiving future help from children, preferring a certain sex, and emotional factors.

### **Knowing one could prevent mother-to-child transmission of HIV**

Some HIV positive participants expressed desire for more children due to the knowledge that ART prophylaxis can prevent mother-to-child transmission of HIV. As one participant said,

I don't think my problem could inhibit me from having another child because I know how treatments are and what to adhere to. So my plans are to have two or three children. (28-year old married HIV-infected man with one child; MALE12)



These participants did not perceive being infected with HIV as the end of their reproductive lives. Most participants were aware of PMTCT services available through health facilities. Many of the HIV-infected women who we interviewed had been diagnosed with HIV during pregnancy and thus had experience with having HIV-negative children by following PMTCT procedures. Having children escape vertical transmission of HIV motivated some of these participants to want to have more children.

Honestly, after we saw that the first child was not infected, I wanted to have another child. I wanted to try again if God would help me, so that he would be negative as well. (36-year old married HIV-infected woman with four children; FEMALE16)

### **Compensating for potential child mortality to reach ideal family size**

Many participants said they wanted children in the future because they had not yet reached their ideal family size. An HIV-infected woman with two children said, “I have already planned, if I bear children I wish to have three children.” (35-year old married HIV-infected woman with two children; FEMALE17) Having no children or only one child was viewed as risky, likely due to the high risk of infant and child mortality in Tanzania. As a female participant explained,

I would like to have other children in the future because to have one child is a risk. Some say...maybe in the future the child might face problems. Or there is talk in the streets that even the devil is pointing his eye on him; he might take him over for you. So at least it is better to have two children or more than that. (21-year old single HIV-infected women pregnant with her first child; FEMALE04)

This desire to have many children may be even more pronounced in the context of HIV, where there is a risk of transmitting HIV to one's child. When asked why PLHIV desire more children, an HIV care provider described what she encountered in her practice:

If you say he is only supposed to have two or three [children], he would not understand you on that issue. 'If I have two children and they die, it means that I will die without children. So I [must] have more children and if they die, I would still have some of them.' (Nurse, CTC, Health center; HCW20)

The perception that children of PLHIV are less likely to survive into adulthood influenced some PLHIV to have more children in order to reach their ideal family size.

### **Wanting to be and be perceived as 'normal'**

Not being perceived as infected with HIV was identified as motivation for some people living with HIV, particularly HIV-infected women, to desire (more) children. Children are highly valued in Tanzania as they confer high social status on women and men through respect and honor, *heshima* (Otiso, 2013). Many participants described the importance of having children as gaining respect within their families and within the community. Most Tanzanians view bearing children as a key aspect of transitioning into adulthood. The Swahili word for adult is *mtu mzima*, which literally translates to a *complete person* or *whole person*. Children are viewed an extension of one's self and those who do not have children are perceived as being incomplete. Some of the PLHIV interviewed described how their relatives and other people in their communities believe that PLHIV are unable to have children. So, as a way of keeping their HIV status a secret from the community, HIV-infected people may continue to have children to avoid the

stigma associated with being HIV positive. As one HIV-infected woman said when asked how people think about her having children,

*Participant:* They feel good [about me having children].

*Interviewer:* Why do you think they feel good?

*Participant:* Because if I don't have children, they will know that I'm sick.

But if they see that I have a child, they will think that this person is okay; she doesn't have a problem at all. (21-year old married HIV-infected woman with one child; FEMALE25)

A health provider further explained how some PLHIV have children to avoid disclosing their HIV status.

First of all, many are hiding their HIV status. So she expects that when she gets pregnant and has a child that her HIV status is a secret. She knows that if she stays without having children, many would know that she is infected. (Assistant nurse officer, CTC, District hospital; HCW26)

Another health provider described how PLHIV may desire having children in order to return to some sense of normalcy after their HIV diagnosis.

If [a man] is HIV-infected, he may think it's possible that even his sperm have been ruined. So he gets someone pregnant and thinks that his body works as normal, like a man who doesn't have this disease. (Assistant registered nurse, RCH clinic, District hospital; HCW22)

Many HIV-infected women and men interviewed described how they saw HIV as a normal condition because they were 'not alone' or because their health had been restored.

This may have influenced their desire to bear children like anyone else because having children is culturally expected, particularly when one is married.

They desire to have children like any other woman. It could be maybe she is married and has been diagnosed with HIV. But according to our country's culture, I don't think she would not want to have a child even if she is HIV positive. She would desire children because she is married and has a husband. (Nurse, RCH clinic, Health center; HCW17)

### **Ability to care for children**

The desire for children was less among some participants due to economic constraints due to poverty, which would affect their ability to care for their children.

What makes me not to want to have any more children is financial difficulty. Life is too tough to handle more children in the future. So I don't expect to have any more children. (33-year old married HIV-infected woman with five children; FEMALE13)

Many HIV-infected participants described how their ability to work had been diminished since being infected with HIV. It should be noted that only those participants with at least two living children tended to report this as a reason for not desiring more children. These economic constraints appeared to have been outweighed by a strong desire for children among participants with no children or only one child. Many participants were concerned with their ability to provide for and take care of more children. Education was viewed as particularly important for children and not being able to pay school fees was a deterrent for some participants from having more children.

Life is very hard. Children need good education and all children have to study. They need to be cared for well in food and clothes. All of these are their needs. So it will be difficult. (34-year old married HIV-infected woman with four children; FEMALE29)

A few participants reported other financial challenges that were unique to the experience of living with HIV and having children. Although medication to prevent mother-to-child HIV transmission is provided free-of-charge, early cessation of breastfeeding, as recommended by Tanzanian national guidelines, was perceived to require additional expenditures that were viewed as an additional financial burden on HIV-affected couples. HIV-infected male participants were particularly likely to cite financial concerns as a disincentive to having more children. As one male participant explained,

I don't know where this problem will end up. Really it's because of this child who was born. There is work because that child stopped breastfeeding when she was six months. So you see that there are costs. Because she was supposed to breastfeed for six months and for the remaining months I bought milk from outside. (38-year old married HIV-infected man with six children; MALE09)

### **HIV-related health concerns**

Health-related concerns deterred many participants from desiring more children. Some participants felt that having HIV and their current health condition would not allow them to have more children. A few participants expressed that it was important for them to take care of their own health instead of having children, which they felt could have adverse effects on their health.

[More children] would disturb me. They would be infected and I would get new infections. So I would have problems because my condition would get worse and I'd have to go back to my previous condition, like I'd cause it myself because we are given lessons that we should not do that [continue having children]. (45-year old widowed HIV-infected woman with one child; FEMALE19)

The negative effect of having children on one's health was particularly disconcerting for HIV-infected women. There were also concerns among some participants that if they were to have more children, those children would be born infected with HIV.

Because I have this disease, when I have a child the child will be born already infected [with HIV]. (32-year old married HIV-infected man with two children; MALE20)

The thought of becoming ill or dying and leaving her family was a particular concern for one female participant and influenced her desire to not have any more children.

I don't want to have another child because if I were to get a husband I would start to have [other children] and I have this problem. I think in the future I would get a big problem. And those I'm taking care of, I'm afraid to be apart from them...even when I am working. (25-year old divorced HIV-infected woman with three children; FEMALE09)

### **Other factors influencing fertility desires**

Other factors identified by participants as influencing the desire of PLHIV to have children were not related to their HIV status. These included receiving help and

assistance, feeling complete, wanting a child of a certain gender, and the emotional value attached to having children.

Some participants (all with just one child) described their motivation for wanting to have more children as a way of receiving help, particularly later in life when they are older. Children were perceived as a safety net in a country where there is no social security system available to assist the elderly.

When asked what she thought were reasons that a woman living with HIV would want to have children, a health provider emphasized the importance of childbearing for HIV-infected women and men who were diagnosed before having children:

If she doesn't have a child at all, because us as Africans you see that if you don't have any children she will see that she's not complete, even if you convince her to stay alone without a child. (Midwife nurse, RCH clinic, District hospital; HCW21)

Only three participants reported a desire to have more children in order to have both male and female children. These participants explained that children of different genders serve different functions within the family based on existing gender roles. Finally, some participants suggested that their desire to have more children was influenced by the emotional value that they attached to having children. They described children as being a source of happiness and comfort.

## **DISCUSSION**

In this study we explored fertility desires of both women and men living with HIV in Iringa, Tanzania through qualitative interviews with both PLHIV and healthcare

providers. We identified five key themes related to fertility desires of PLHIV that were unique to the experience of living with HIV: knowing one could prevent mother-to-child transmission, compensating for potential child loss, wanting to be and be perceived as 'normal,' the ability to care for children, and HIV-related health concerns.

Knowledge that mother-to-child transmission of HIV can be prevented motivated some participants to desire more children. This is consistent with previous research demonstrating an increase in fertility intentions with advances in HIV management and treatment, particularly PMTCT (Nattabi, et al., 2009). The availability of ART for PMTCT enables HIV-infected women to continue to have children while reducing the risk of transmitting HIV to their children. The Government of Tanzania has been accelerating efforts to eliminate mother-to-child transmission of HIV and improve the survival of women, infants, and children (PEPFAR/Tanzania, 2011). As more people become aware of the availability and effectiveness of PMTCT services, fertility desires among HIV-affected couples may increase. We also found that previously having an uninfected child by following PMTCT guidelines, including ARV prophylaxis and breastfeeding practices, influenced some participants to desire more children. Thus even within individuals, fertility desires may change over time with increasing knowledge of and experiences with PMTCT.

Having no children or not having reached their desired family size also motivated many participants to desire children. Previous research has shown that the fertility desires of people living with HIV are strongly influenced by having no children (Finocchiaro-Kessler, et al., 2010; Nattabi, et al., 2009; Todd, et al., 2011). The mean ideal number of children in Tanzania is 4.9 for women and 4.8 for men ((NBS) & Macro, 2011). In our



study we found that some HIV-infected participants desired more than 1 child to compensate for the potential loss of a child to early mortality and to reach their ideal family size. These fears may be well founded, as HIV-infected infants have been found to have higher mortality compared with uninfected infants in other parts of sub-Saharan Africa (Landes et al., 2012).

In some cases, fertility desires were underpinned by a desire to be and be perceived as ‘normal,’ or HIV-negative. Bury described the concept of biographical disruption as an assault of chronic illness on important conceptions of the self and life course, resulting in a fundamental rethinking of one’s biography and self-concept in light of the illness (Bury, 1982). Biographical disruption has been described in a study among HIV-infected women in the United Kingdom, in which women’s narratives were permeated by a sense of threat to their identities as mothers, both from HIV-related stigma and their potential mortality (Wilson, 2007). The author of this study remarked, “In the context of illness, when other sources of identity [...] may have been undermined, [...] the importance of maintaining such key identities [such as motherhood] may be accentuated;” this phenomenon was labeled ‘biographical reinforcement’ (Wilson, 2007). Having children was a strategy employed by some HIV-infected participants to restore or maintain a sense of “normality” and form of biographical reinforcement of one’s identity as a parent in the face of possessing a highly stigmatized illness. In Uganda researchers found that greater internalized stigma among PLHIV was associated with increased fertility intentions (Wagner, Linnemayr, Kityo, & Mugenyi, 2012). They speculated that this might be due to attempts of people who are not comfortable with their HIV status to conform to normative behaviors and relationship patterns as much as possible, including

having children, so as not to provoke speculation about their HIV status (Wagner, et al., 2012). Likewise, a study conducted in Kenya found that HIV-infected women became pregnant by actively planning and strategizing to get pregnant and have children to regain their social status through motherhood (Awiti Ujiji, Ekstrom, Ilako, Indalo, & Rubenson, 2010).

The perceived future ability to care for one's children deterred some participants from desiring more children, with economic constraints being the most commonly cited reason. Previous research has reported that many PLHIV face financial hardships as a result of being infected with HIV (Bila, Kouanda, & Desclaux, 2008). Financial difficulties resulting from decreased work capacity and extra HIV-related expenses, both current and future, have been shown to discourage PLHIV from desiring more children (Harrington et al., 2012; Withers et al., 2013). Some participants in our study also cited the fear of deteriorating health as deterring them from desiring more children. This is consistent with previous research reporting health concerns as a disincentive among women living with HIV to desire children (Kanniappan, et al., 2008; Nattabi, et al., 2009). Participants also reported the impact of pregnancy on the woman's health as discouraging them from having more children. Although pregnancy has been demonstrated as having no lasting impact on HIV disease progression (Heffron et al., 2014), many still believe that the physiological changes caused by pregnancy adversely affect HIV disease progression (Yeatman, 2011).

This study was limited by interviewing only HIV-infected women and men who were currently engaged in the formal public HIV care system. Fertility desires of the participants included in our study may be different from those of women and men living

with HIV who are not engaged in the HIV care system. For example, knowledge of PMTCT may be lower among PLHIV not receiving HIV care and treatment or PMTCT services. Despite this limitation, our study contributes to the limited body of research exploring fertility desires of both women and men living with HIV. We used data from multiple sources to explore motivations and deterrents for having more children that are specific to the experience of being HIV-infected and making decisions regarding reproduction. Our findings highlight the need for the integration of HIV and sexual and reproductive health services, which should include culturally-appropriate fertility goal-based counseling for HIV-infected women and men that addresses the unique challenges encountered by PLHIV as they make decisions about reproduction. Furthermore, HIV care providers can play an important role in assisting their HIV-infected patients to safely conceive and deliver uninfected children by regularly assessing their fertility desires and providing counseling on family planning, safer conception, and PMTCT.

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## **MANUSCRIPT TWO:**

**‘My problem does not mean the end of bearing children’:  
Experiences of having children following an HIV diagnosis in  
Iringa, Tanzania**

## **ABSTRACT**

Data from sub-Saharan Africa show that people living with HIV continue to have children after being diagnosed with HIV. Most research to date has focused on fertility desires of HIV-infected women and biomedical interventions to reduce HIV transmission associated with pregnancy among HIV-affected couples. Little attention has been paid to the actual lived childbearing experiences of people living with HIV following an HIV diagnosis situated within the broader social and structural context. This paper uses interviews with 10 HIV-infected women and 11 HIV-infected men to describe key features of the experience of having a child post-HIV diagnosis. Participants' experiences were shaped by social and institutional factors. Social pressures to bear children by partners and relatives affected the decision to have children. Some respondents received negative reactions from relatives and friends concerning their pregnancies. Most respondents had not discussed having children with a health provider before attempting to conceive. A small number of respondents reported being reprimanded by health providers for getting pregnant without seeking their advice. Consideration of support systems and challenges surrounding the childbearing experience of people living with HIV is warranted to help develop facility- and community-based reproductive health interventions for those who wish to have children.



## INTRODUCTION

In Tanzania an estimated 1.5 million people are living with HIV, nearly half of whom are women of childbearing age ((TACAIDS), (ZAC), (NBS), (OCGS), & International, 2013). With expanded access to antiretroviral therapy (ART), many are living longer and healthier lives and desire children (Mmbaga, Leyna, Ezekiel, & Kakoko, 2013; Nattabi, Li, Thompson, Orach, & Earnest, 2009). The impact of pregnancy on HIV-infected women is not yet fully understood, but evidence suggests that pregnancy has no sustained effect on HIV disease progression (Heffron et al., 2014), or immunological and virological outcomes (Mayanja et al., 2012). Furthermore, data show that in many settings in sub-Saharan Africa HIV-infected women continue to get pregnant after being diagnosed with HIV (Kaida et al., 2013; Myer et al., 2010; Schwartz et al., 2012).

Though considerable research has examined ways to reduce HIV transmission associated with pregnancy among HIV-affected couples in which at least one partner is infected with HIV (Aaron and Cohan 2013; Matthews et al. 2012; Mmeje, Cohen, and Cohan 2012; Cohen et al. 2011; Chadwick et al. 2011; Matthews et al. 2010) and childbearing desires of people living with HIV (Nattabi et al. 2009), there has been a dearth of research exploring actual lived experiences of people living with HIV having children following an HIV diagnosis. There has also been limited research on the complex social and institutional context in which people living with HIV bear children and even less research looking at having children post-HIV diagnosis from the perspective of HIV-infected men. The reproductive health needs of men, including HIV-infected men, have been historically underemphasized, often to the detriment of both men

and women (Ringheim, 2002). Numerous researchers have called for greater attention to incorporating men into reproductive health programs and policies through adopting a gendered perspective in research (Doyal, 2000; Dudgeon & Inhorn, 2004). This requires research aimed at understanding how reproductive health issues are experienced by both men and women on a local level (Dudgeon & Inhorn, 2004). The purpose of this paper is to describe the experiences of having children following an HIV diagnosis among a sample of women and men living with HIV in Iringa, Tanzania. Understanding the complexity of post-HIV diagnosis experiences of having children of both women and men is important for developing culturally appropriate interventions and policies that address the sociocultural and institutional factors that inhibit optimal reproductive health among women and men living with HIV. These include preconception counseling for HIV-affected couples, safer conception policies that takes into consideration the life space of people living with HIV, and community-based interventions that attempt to overcome sociocultural constraints to safer childbearing.

### **The sociocultural and institutional landscape of childbearing among people living with HIV in Iringa, Tanzania**

The experiences of women and men who have children following an HIV diagnosis are situated within a broader sociocultural and institutional context. Like most groups in Tanzania, the Hehe people—the dominant ethnic group in the Iringa region—highly value children. Even stronger than marriage (since a marriage can be dissolved), having children bestows on women and men high social status through respect and honor, or *heshima* in Swahili, and qualifies them to serve important leadership roles (Otiso,

2013). The bond between parent and child is stronger than any other social relationship. Parenthood is considered a means to the 'attainment of the full development of the complete person to which all aspire (p.125)' (Fortes, 1978). Having children is not only a means to individual personhood and social status, but also a fulfillment of one's obligations to kin and community (D. J. Smith & Mbakwem, 2007). Children are viewed as important for building the clan and society more broadly (Otiso, 2013). In the absence of a national social security system in Tanzania to assist the elderly, children are also perceived as a safety net for the future. Traditionally, among the Hehe, if pregnancy does not immediately follow marriage, or if it does not follow soon after the weaning of the last child, the marriage is considered unstable and may result in divorce with the blame often falling on the woman when a couple has not been able to produce children (Brown, 1935). Given the high importance placed on having children and the stigma associated with not being able to produce children, it is not surprising that pregnancy rates among HIV-infected women have been shown to be relatively high in Tanzania (Odutola et al., 2012) and many people living with HIV express strong desires for having children (Mmbaga, et al., 2013).

The landscape of childbearing among people living with HIV includes not only biomedical risks of HIV transmission to a child or partner but also social risks and structural constraints. Green and Sobo have argued that people living with HIV navigate their own personal 'landscape of risk,' which is multidimensional and situational (Green & Sobo, 2000). Because of the stigma associated with being HIV-infected, weighing biomedical and social risks can be particularly challenging for those women and men who have children following an HIV diagnosis. The social risk of being ostracized for not

having children or for not reaching a socially desirable family size may override any real or perceived biomedical risks (D. J. Smith & Mbakwem, 2007). The landscape of childbearing is also shaped by the institutional context that influences the childbearing experiences of women and men living with HIV. This institutional context of childbearing among people living with HIV includes elements of the HIV care and reproductive health care systems, such as encounters with health providers concerning childbearing and safer conception as well as reproductive health policies and guidelines for HIV-infected patients. The lived experience of having children after an HIV diagnosis is situated within this sociocultural and institutional context where parenthood often defines one's sense of self and one's social position.

## **METHODS**

This research draws on data collected for a qualitative study exploring childbearing desires and experiences of women and men living with HIV in Iringa, Tanzania. We focus on data from in-depth interviews conducted with 10 women and 11 men living with HIV who reported having children after being diagnosed with HIV.

### **Study procedures**

Research participants were recruited through health facilities providing HIV care and treatment and prevention of mother-to-child transmission (PMTCT) services in the Iringa region of Tanzania. After obtaining permission from the clinic director, patients were informed of the study aims. Health care providers referred patients who were interested in participating to the research team. Individuals were eligible to participate if

they were HIV-infected, between the ages of 18 and 49 years, residents of the Iringa region, able to provide consent, and willing to participate in up to two interviews.

Interviews covered experiences living with HIV, HIV-related stigma, pregnancy experiences, perceptions of marriage and childbearing, desires for (more) children, and communication with health care providers about childbearing and safer conception.

Interviews lasted from 30 minutes to over an hour. Through these interviews, other issues emerged, including experiences of having children after being diagnosed with HIV. Of 60 total participants, 21 revealed during their first interview that they had children after being diagnosed with HIV. Interviewers probed to learn more about different aspects of their experience of having children following their HIV diagnosis. To gather more information on this specific phenomenon, we then conducted follow-up interviews with seven participants that covered a range of pregnancy-related topics specific to pregnancies conceived by the participant or by the participant's partner following the HIV diagnosis, including pregnancy intentions, issues surrounding conception, conversations with others about having children as a person living with HIV, and any complications during or after the pregnancy.

To ensure high data quality, interviewers completed a one-week training in qualitative interviewing, data collection procedures, and research ethics. The principal investigator and interviewers held weekly debriefing meetings to discuss emergent themes and refine interview guides to ensure an iterative research process. During the initial stages of data collection, the principal investigator reviewed at least two interview transcripts by each interviewer for completeness and quality, and provided detailed feedback to the interviewers.

To maintain confidentiality, all interviews were conducted in a private location in the health facility. In two cases, the interview took place in the participant's home. We obtained informed consent from all research participants before conducting interviews. All forms and transcripts were labeled with a unique code instead of the participant's name. Identifying information was removed from all interview transcripts. Audio files of the interviews were stored on a password-protected computer. Pseudonyms are used to present our findings. This research received ethical approval from the institutional review boards of the Johns Hopkins Bloomberg School of Public Health, Muhimbili University of Health and Allied Sciences, and the Tanzanian National Institute for Medical Research.

### **Data analysis**

All interviews were digitally recorded with the permission of the participant, transcribed verbatim in Swahili, and translated into English by the original interviewer. A subset of six transcripts was coded initially to determine emergent themes. A coding scheme was developed based on themes that emerged from the subset of transcripts and a priori themes. All transcripts were then coded using the coding scheme with additional codes added as they emerged. Coding was conducted using QSR NVivo Version 9 (QSR International, Doncaster, Victoria, Australia). A second round of coding was conducted using follow-up interview transcripts and transcripts from the first round of interviews. In this round line-by-line coding was conducted on each follow-up interviews and on relevant excerpts from the first round of interviews on previous childbearing experiences (Charmaz, 2006). Themes that emerged from the line-by-line coding process were listed and compared across participants for convergence and divergence (J. A. Smith, 2009).

These themes were then clustered into five key overarching themes that were consistently present across participants: intending vs. not intending to conceive, adopting safer conception strategies, reactions of relatives and friends to the pregnancy, reactions of health providers to the pregnancy, and desire for more children. Memos were written to summarize these overarching themes based on the relevant coded text. The first author then reconstructed childbearing narratives for the seven participants who were interviewed twice to illustrate the experience of having children following an HIV diagnosis from pre-conception to post-delivery using information provided in both interviews.

## **FINDINGS**

Table 1 outlines demographic characteristics of the 21 participants who reported having had a child after being diagnosed with HIV. Most participants were married, had disclosed their HIV status to their partner, and had at least two children. Six out of the 21 participants reported having an HIV-negative partner. Almost all (19 out of 21 participants) were on ART at the time of the interviews.

Table 1. Background characteristics of participants who reported having a child post-HIV diagnosis by gender (N=21).

	HIV-positive women (n=10)	HIV-positive men (n=11)
Age		
< 30 years	2	2
30 - 39 years	8	8
≥ 40 years	1	0
Marital status		
Married	10	8
Never married	0	1
Widowed/divorced	1	1
Disclosed HIV status to partner		
Has not disclosed HIV status	0	2
Disclosed HIV status	11	8
Partner's HIV status		
HIV-negative	5	1
HIV-positive	6	6
Unknown	0	3
Number of living children		
1 child	2	0
2 to 3 children	5	5
4+ children	4	5
Time on ART		
Not on ART	1	1
Less than 1 year	1	0
1 to 2 years	2	0
2 to 3 years	1	4
More than 3 years	6	5

Below we present case narratives of two participants whose experiences reflect some of the recurrent themes observed across our study sample. These narratives are meant to contextualize the experience of having a child after being diagnosed with HIV and to illustrate how these themes are integrated within the life experiences of the women and men interviewed.



## **David's narrative**

In May 2006, David went to the hospital to seek treatment for a persistent fever. After taking medication prescribed to him at the hospital, he became severely ill. He decided to test for HIV. He tested at the Iringa Regional Hospital where he was diagnosed with HIV. For the first year following his diagnosis, David took co-trimoxazole<sup>\*</sup> on a regular basis, but after a year he started taking ART.

In 2010, after his health had improved, David married his second wife who was HIV-negative (he had divorced his first wife in 2003). Before marrying, he disclosed his status to his fiancée. She decided to remain with him. He and his second wife decided not to have an official marriage. They feared that they would be forced to test for HIV and their marriage would be rejected.

When David was initially diagnosed with HIV he did not want to have more children. He already had two children from his previous marriage and feared he would not live long enough to take care of his children and that he might infect any unborn children:

Initially, I did not want to have [more] children, as they would live a hard life, since I would die. You see, I was not confident that I could stay alive.

Since 2006 up to now, I didn't know if I could reach [the year] 2013.

[Not wanting another child] was because of my situation. And at that time

I was not yet educated. I had not yet accepted that problem. So I knew that

I would have an infected child and give him problems. You see? So I

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<sup>\*</sup> Co-trimoxazole is a low-cost antibiotic used to treat opportunistic infections. The WHO recommends that all HIV-infected adults be treated with co-trimoxazole in high HIV prevalence settings.

wanted to convince [my wife], but I failed to convince her [not to have children].

The uncertainty of his own survival and his fear of infecting his children influenced David's desire to not have children. However, his second wife was young and had no children of her own. She felt social pressure from her family and the broader community and persuaded David to reconsider. As David described it:

I had no need for a child because I had children. But my partner was forced into it. She said, 'No matter what, we must have a child. I will not be understood in the community.' Because in our community, I can say even in the Iringa region, for the Hehe, even a mother likes a grandchild. If you get married and stay for one year, two years, three years, no grandchild, words start. You won't live comfortably.

David lacked information on safer conception strategies for HIV-discordant couples. In the absence of this information, David decided on his own to limit the frequency of sexual intercourse with his wife: "I can have sex with my wife once or twice per month. This is what we have arranged for ourselves. No one arranged for us."

David's wife eventually became pregnant. At the time that she became pregnant, David and his wife were not using any form of contraception, including condoms. His wife had at one point used hormonal implants as a form of contraception, but discontinued use at the advice of health providers due to medical complications.

David described how his wife was happy when she became pregnant. However, David worried that he may have infected his wife with HIV. When asked how he felt when his wife became pregnant, David explained:

*David:* Initially, I did not feel so much at peace. But when we came for testing and found out she was okay, I felt a very wonderful happiness.

*Interviewer:* Why didn't you feel at peace initially?

*David:* I thought that my wife was already infected. So I had no peace at that particular time, but she was happy. Sometimes when I came back she would ask me, 'What are you thinking about?' I would tell her that work was bothering me, but I was lying to her. I was thinking that I had already infected my partner.

The anxiety caused by the thought that he may have infected his wife and unborn child with HIV eased once his wife and their child both tested negative for HIV. David described initially believing that it was not possible that he could be in a relationship with his HIV-negative wife and have children without infecting them with HIV. This discouraged him from talking with health providers about having more children.

Initially my mind rejected that I could live with someone who is not infected and I am infected and she is okay [uninfected]. It's not true. You see? So that made us, even we did not want to go to a health provider. We used [our own way of limiting sex unprotected sex]. God himself supervised and directed her. That's all. We came to get a child.

It was not until having a child who tested negative that David began to believe that he could have HIV-negative children without infecting his wife, which he had heard in group counseling sessions at the HIV care and treatment center.

I remember I told you before that education [about having uninfected children with an HIV-negative partner] was not getting in my head. Even

though they taught me, it didn't get in. I only came to believe it after having children and I live with them, their mother is okay and they're okay. Then I came to believe what they said was true.

Though his wife's relatives were unaware of his HIV status, David had disclosed his HIV status to a couple of his relatives, including his uncle, his father's younger brother. David said when his uncle found out that his wife was pregnant, he questioned David's intention and felt that he would spread the infection to his wife and child.

For relatives who know that I am this way, many things happened. You find out they say, 'Ah, he is fathering children while he's infected, so he is fathering infected children.' [My uncle] said, 'I wonder this man is HIV positive, but he impregnates his wife. I don't know what his intention is.'

Although his uncle responded negatively to him having children, David said that his uncle became more accepting after seeing that his wife and children are doing well and are not infected with HIV. David is open to having more children in the future since his wife is still young and may want more children in the future.

### **Stella's narrative**

In 2007 Stella's two-year old daughter fell sick, so she took her to the hospital. At the hospital a health provider asked Stella if she wanted to be tested for HIV. She agreed and they tested her and her child. They were both diagnosed with HIV. Stella later discovered that her husband was also living with HIV. It was unclear whether her husband was aware of his status before Stella and their daughter were diagnosed.

At the time of her HIV diagnosis, Stella had three children: two daughters from her first husband who had passed away and the two-year old daughter with her second

husband. Stella described initially fearing being around others because she felt they might ostracize her based on her HIV status. She found that she did not have energy to do her work. However, after starting ARV medication, her health began to improve and she felt that she had been restored to her 'normal' condition. Though she initially hid her HIV status from others, she no longer felt the need to hide her status.

About a year after being diagnosed with HIV, Stella was pregnant with a fourth child. She and her husband had not planned this pregnancy. Stella said that they had started using condoms to avoid new infections after they were diagnosed with HIV, though it was unclear whether they had been consistently using condoms at the time that she became pregnant. In one interview, Stella described how some of her friends questioned whether it was appropriate for her to have another child.

*Stella:* My friends asked me, 'Why do you get pregnant while you are using medication?'

*Interviewer:* Why do you think they felt that way?

*Stella:* They felt so because they were protecting me, because I might face problems.

Stella felt that her friends reacted in this way because they were concerned about her health deteriorating with getting pregnant while infected with HIV and while on ART. Because this pregnancy was unplanned, Stella had not spoken to a health provider before attempting to conceive. Instead she started attending antenatal care visits at the reproductive and child health clinic at the health center in her village.

I went and explained to [the health providers] that I'm pregnant. They told me to go immediately to the [HIV] clinic for counseling to start

medication. But I was to make sure not to repeat the same the next time...

They told me I was wrong because I was supposed to check my CD4 first.

If I wanted to have children and if my CD4 were high, the health providers at [the district hospital] would have allowed me to get pregnant again.

When she became pregnant with her fourth child, Stella had not received any information from health providers on getting pregnant: 'We only attend to come to the [HIV care and treatment] clinic. They don't teach about getting pregnant.' Health providers warned her of potential adverse effects of having a child as an HIV-positive woman. They told her that she risked having a miscarriage and that she might face medical complications and die as a result of the pregnancy. In light of these warnings, Stella followed through with the PMTCT services provided to her at the health center and delivered an uninfected child without experiencing any medical complications.

A couple of years after giving birth to her fourth child, Stella's husband told her that he wanted to try to have a boy—up to that point all of their children were girls. Stella suggested to her husband that they check their CD4 count before trying to get pregnant.

When my husband asked me, I told him that I should go for CD4 testing.

If they are high, we might be in a position to have children and [health providers] will give us advice. So we went there for CD4 testing and we were given advice... We were told that CD4 are high and we agreed that we might try to get a boy.

The health provider told them that it was okay for them to have a child since both of their CD4 counts were high, but warned them that they should not continue bearing children

because it might affect Stella's health: "The health providers felt bad. They told me that I know that I am sick and I continue to give birth. I will die early."

At the time of our interviews with Stella she was 37 years old with five children. She did not want to have any more children. When asked why she did not desire more children, she said:

For now, I have to take care of my body.... I might face problems. I wouldn't even be able to take care of them because I would continue being sick and would not manage to take care of them and provide for their needs.

Though her husband insisted that she undergo tubal ligation, at the time of our second interview with her she had not yet had the surgery.

### **Intending vs. not intending to conceive**

As illustrated in David's narrative, most participants interviewed described initially not intending to have another child after being diagnosed with HIV. Often the intention not to have more children was due to fears of having an HIV-infected child and of not being able to care for children because of their health.

Participants also feared that having children while HIV-infected would harm a woman's health and possibly lead to death. When discussing how his wife initially hesitated to have more children after being diagnosed with HIV, a male participant explained:

She hesitated because of her health, whether she could bear a child or fail [to bear a child] and during delivery she could die with the child or the

child could die while she survives. (35-year old man with three children; MALE19)

Despite not intending to have children, many participants reported not using any form of contraception, including condoms, at the time that they or their wives became pregnant. A few participants noted that they or their wives discontinued using hormonal contraceptives due to complications.

For some participants fertility desires changed over time as they regained their health and became more knowledgeable of services available to prevent mother-to-child HIV transmission. David's narrative not only demonstrates the phenomenon of changing fertility desires over time, but also illustrates how one's desire to have more children while living with HIV is intertwined with medical consequences, dynamics within a couple's relationship, socio-cultural norms surrounding marriage and childbearing, and financial considerations.

### **Adopting safer conception practices**

Though many pregnancies occurring following an HIV diagnosis were unplanned, some participants described planning to conceive and have more children. The few participants who spoke of planning to have more children sought ways to safely conceive. They described talking with health providers and monitoring their health status, particularly their CD4 counts, before attempting to conceive.

We tried to get advice about if it was possible to have a child according to our health, since it was already known that we were infected [with HIV]. But she said first we should wait to check our CD4. After we checked our



CD4 and it showed that our CD4 had increased, she said now we were ready to have a child. (35-year old man with three children; MALE19)

Some participants also reported timing unprotected sex around the woman's ovulation period as a strategy to reduce the risk of HIV reinfection or HIV transmission to an uninfected partner during conception. A few of the women and men living with HIV that we interviewed had some knowledge of timed unprotected sex that they had obtained from group counseling sessions at an HIV clinic or from individual conversations with health providers.

A female participant described how a health provider at the HIV care and treatment center explained to her what she should do if she wanted to conceive:

For getting pregnant, he told me that it's possible if you don't use [condoms] for a single day, but the following day you have to use condoms... That means so as to get a child. But then after that I have to continue using *Salama* condoms. (30-year old widowed woman with three children; FEMALE11)

The few participants who were aware of the risk reduction strategy of timing unprotected sex when trying to conceive had limited understanding that there is a period of multiple days surrounding ovulation in which a woman is most likely to conceive, not one single day.

### **Reactions of relatives and friends to the pregnancy**

A few participants encountered negative responses to their pregnancies from relatives and friends who were aware of their HIV status. Many of these negative responses stemmed from others not knowing that people living with HIV could have

children, fears that their children would also be infected with HIV, fears that they would not be able to take care of their children because of poor health resulting from HIV infection, and, in the case of HIV-discordant couples, fears that they would infect their partners.

Having a child infected with HIV was often the main concern among one's relatives and friends, according to participants. A female participant described reactions from others when she became pregnant:

They felt so bad because they knew that if you're infected you're not allowed to get pregnant because you might have a child who has the same problem... They said, 'Why did she get pregnant while she has that status?'... I felt bad. (36-year old married woman with four children;

FEMALE16)

Though she had given birth to two children uninfected with HIV after being diagnosed with HIV, her husband still hesitated to have more children because of the uncertainty of the child's HIV status.

[My husband] would feel bad [about having another child] because we are already infected and in the future you can never know if we will continue to have children. You can't know if you will have a negative child.

To avoid negative reactions from others, one male participant described how he and his wife kept their pregnancy a secret from their relatives.

Some people were afraid. They said, 'How will it be possible for the mother to have a child while infected [with HIV], my friend. Why can't they stop since they're infected?' But on our side, we kept it a secret

between the doctor and us. We talked with [the doctor] and she allowed us. (35-year old married man with two children; MALE19)

### **Reactions of health providers to the pregnancy**

Many participants reported receiving support from health providers either before or after conception. A few participants said health providers instructed them on ways to prevent HIV transmission to their children during and after the pregnancy.

Though most participants reported receiving support from health providers, there were some accounts of discouraging responses. A male participant described how health providers reacted to his wife's pregnancy at a health dispensary:

They said, 'Didn't we tell you that you couldn't have a child? How did your wife get pregnant?' Ah, I stayed silent and they said it's okay, no problem. They said your wife should attend and she kept on attending.

When the final days came, they disturbed me so much...Like, I was stigmatized and treated with harsh words. (37-year old married man with three children; MALE21)

He described how he and his wife received poor treatment at the dispensary when she was in labor, which he felt was due to their HIV status. Because of this negative

experience with health providers at that particular dispensary, he decided not to return.

He decided to obtain his HIV care and treatment center from the district hospital, despite the additional distance and expense. Fear of disapproving attitudes from health providers about childbearing prevented some participants from seeking preconception counseling.

*Interviewer:* Why do you think you did not talk with the health provider about getting pregnant?

*Participant:* I knew it was wrong to get pregnant if you have infections.

*Interviewer:* Did they tell you that it is not allowed to have another child?

*Participant:* Yes. They don't allow it. (36-year old married woman with four children; FEMALE16)

### **Desire for more children**

Knowledge of PMTCT services available for HIV-infected pregnant women encouraged some participants to continue to want to bear children.

I believe my problem does not mean the end of bearing children. I don't think my problem could inhibit me from having another child because I know how treatments are and what to adhere to. So my plans are to have two or three children. (28-year old married man with one child; MALE12)

Additionally, a few participants described how having an uninfected child after being diagnosed motivated them to want to have more children.

Honestly, after we saw that the first child was not infected, I wanted to have another child. I wanted to try again if God would help me, so that he would be negative as well. (36-year old married woman with four children; FEMALE16)

Some participants said they desired more children in the future because the number of children they had was not enough. Other participants viewed having no children at all or only one child as a liability, so there were strong desires of having children particularly among those women and men living with HIV who had no children or only one child.

Though six out of the 21 participants expressed the desire to have more children in the future, others said they did not want to have more children. Some of the main

reasons for not desiring more children expressed by women and men who had experienced having children post-HIV diagnosis were having enough children already and being discouraged by others from having more children in the future, as seen in the case of Stella. Health was also a major factor for some participants. Some felt that their HIV status and current health condition would not allow them to have more children. They expressed that it was important for them to take care of their own health instead of having more children, which may hurt their health and ability to care for their children.

## **DISCUSSION**

Our findings suggest that the experience of bearing children following an HIV diagnosis is situated within a complex sociocultural and institutional context in Iringa, Tanzania. The experiences and decision-making processes surrounding childbearing were described by research participants as being shaped by interactions with family and friends, encounters with health providers, and changes in fertility desires over time and life circumstances.

David and Stella's narratives illustrate how social pressures affected childbearing experiences and decision-making of many participants. David described how his current wife, who was HIV-uninfected and childless when they married, demanded that they have children to avoid being stigmatized within their community. In a context where parenthood and having children are highly valued, the social risk of being ostracized for not having children trumped the biomedical risk of David transmitting HIV to his uninfected wife. This weighing of biomedical and social risks has been previously reported in the literature as influencing reproductive decision-making (D. J. Smith &

Mbakwem, 2007). In Stella's case, her husband encouraged her to have another child, despite already having four children, because he wanted a son. Under a patriarchal social system such as that which dominates in Tanzania, bearing no sons may be the social equivalent of a couple being deemed infertile ('mgumba' or 'tasa' in Swahili), which has a damaging impact on one's social position (Inhorn, Balen, & (eds), 2002). This highlights the importance of recognizing suffering that may be experienced due to fertility problems as subjectively experienced by HIV-affected couples (Inhorn, et al., 2002).

We found that some participants reported receiving negative reactions from relatives and friends who were aware of their HIV status about the pregnancy. A study in South Africa found that whether or not an HIV-infected person disclosed his or her HIV-positive status was a key factor in the social pressures they experienced surrounding their reproductive decisions (Cooper, Harries, Myer, Orner, & Bracken, 2007). In that setting, it was considered socially unacceptable for people living with HIV who had disclosed their status to have more children. In our study we found evidence that HIV-infected women and men actively managed the risks of social rejection and stigma by selectively choosing to whom to disclose their HIV status and discuss their childbearing decisions. Participants reported that their relatives and friends' greatest fear was that the child would be born infected with HIV. Although data suggest that knowledge of PMTCT is generally high in the Iringa region ((TACAIDS), et al., 2013), this fear could have stemmed from some uncertainty among relatives and friends surrounding the effectiveness of PMTCT intervention. Some participants also reported that their relatives feared they would not be able to take care of their children due to declining health, which

could create a burden on relatives who would be responsible for caring for their HIV-infected relative and their children (Kanniappan, Jeyapaul, & Kalyanwala, 2008). HIV care providers, home-based care providers, and social service providers can play an important role in helping HIV-infected patients cope with and overcome mental distress caused by social pressures and stigma surrounding childbearing. This could be accomplished through individual, family counseling, and referrals to health facility-based and/or community-based mental health services.

Encounters with health providers also influenced the childbearing experiences and decisions of many participants. Most participants in our study did not seek counseling from health providers before attempting to conceive. Existing literature suggests there is an unmet need for preconception counseling for HIV-infected women (Finocchario-Kessler et al., 2012; Finocchario-Kessler et al., 2010; Malta et al., 2010). The main reasons reported for not seeking preconception counseling were not intending to conceive and fear of disapproving and judgmental attitudes from health providers. Since many pregnancies in the context of HIV may be unintended (Kikuchi, Wakasugi, Poudel, Sakisaka, & Jimba, 2011; King et al., 2011), efforts should be made by HIV care providers to initiate conversations about childbearing with their HIV-infected patients, both women and men. Previous research has reported on HIV-infected women's experiences of stigma and prejudice within the health care setting and the lack of preparedness of health providers in addressing concerns regarding their reproductive health (Malta, et al., 2010). This points to the need for training health providers in non-judgmental, patient-centered preconception counseling. Participants who did report seeking advice from health providers when planning to have children were in some cases

advised to time unprotected sex during the most fertile period of the woman's menstrual cycle. Timed unprotected sex around the woman's ovulation period is recommended by the WHO as a safer conception strategy for HIV-affected couples, both HIV concordant and discordant couples, in low-resource settings (WHO & UNFPA, 2006). This safer conception strategy should be formally adopted in Tanzania's national HIV guidelines along with other safer conception strategies that have been recommended to reduce the risks of mother-to-child and partner transmission of HIV (Chadwick et al., 2011; WHO & UNFPA, 2006).

Our research further revealed that fertility desires changed over time as women and men living with HIV experienced safely conceiving and delivering an HIV-uninfected child without adverse health consequences. Participants were discouraged from desiring more children after first being diagnosed with HIV due to concerns over their ability to take care of their children in the future and fear of infecting their children with HIV. Poor health affecting one's ability to care for current and future children and fear of infecting one's child with HIV have been previously reported in the literature as reasons for not desiring children among HIV-infected women and men (Cooper, et al., 2007; Nattabi, et al., 2009). Some participants in our study also described fears of pregnancy-related health risks as an initial deterrent to having children after being diagnosed with HIV, even though biomedical research suggests that pregnancy has no lasting impact on HIV disease progression (Heffron, et al., 2014; MacCarthy, Laher, Nduna, Farlane, & Kaida, 2009; Mayanja, et al., 2012; Minkoff et al., 2003). This is consistent with research demonstrating local beliefs that pregnancy adversely affects HIV disease progression (Berhan, 2008; Yeatman, 2011). Despite these initial deterrents to



desiring more children following an HIV diagnosis, fertility desires of some participants changed over time. Two factors that seemed to influence this change of fertility desires were safely delivering a child uninfected with HIV in the past and increased knowledge of available PMTCT services. Knowledge of and previous experiences with PMTCT programs have been shown to influence fertility desires (Berhan, 2008; Cooper, et al., 2007). Changes in fertility desires over time may also be influenced by ART use, which has been previously reported as influencing fertility desires in other contexts (Kisakye, Akena, & Kaye, 2010; Nattabi, et al., 2009).

Several limitations to our study should be acknowledged. First, exploring the lived experience of having children *following* an HIV diagnosis was not one of our original study objectives. Thus, we did not explicitly ask a few early participants whether they had children after being diagnosed with HIV. Though we were able to glean this information indirectly based on the content of the interview for some of these participants, we may have missed exploring this topic extensively with those early participants who may have been eligible for inclusion in this analysis. Despite this limitation, we believe that our sample of 21 participants was sufficient for fully exploring key elements of these childbearing experiences and reaching data saturation.

Furthermore, we used follow-up interviews with select participants to focus more in-depth on emerging issues. Second, we only interviewed women and men living with HIV who were, at the time of data collection, currently engaged in the HIV care system. Their experiences may have been different from those women and men who had been diagnosed with HIV but were not attending HIV care and treatment centers. Future research is warranted to explore any potential distinctions of having children following an

HIV diagnosis among HIV-infected individuals who have not been linked to HIV care and treatment or who have been lost to follow-up for HIV care services. Despite these limitations, this study is strengthened by its focus on both women and men. Much of the research in the area of childbearing among people living with HIV has centered on being diagnosed while pregnant. Our study focuses on pregnancies conceived after being diagnosed with HIV. In addition, we adopted a qualitative approach that enabled us to explore in-depth the complexity and diversity of childbearing experiences of women and men living with HIV.

## **CONCLUSION**

The experience of having children following an HIV diagnosis is shaped by sociocultural and institutional factors that also influence decision-making processes surrounding the experience of having children following an HIV diagnosis. Our findings support the need to consider potential facilitators and constraints at the familial, community and institutional levels that may be experienced by people living with HIV when developing health facility-based and community-based interventions for HIV-infected patients who wish to conceive.

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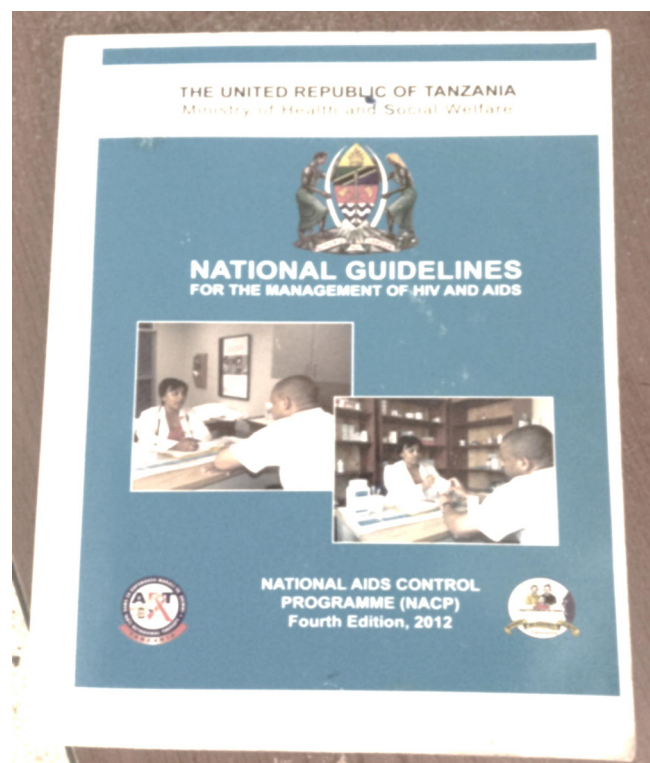
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### **MANUSCRIPT THREE:**

## **Gaps between childbearing and safer conception policies and guidelines for people living with HIV and patient-provider communication in Tanzania**



## **ABSTRACT**

Developments of safer conception technologies have led to international guidelines and recommendations addressing childbearing experiences of people living with HIV (PLHIV). However, national guidelines on childbearing and safer conception for PLHIV in Tanzania are limited. Furthermore it is unclear to what extent guidelines that do exist are implemented on the ground. The aim of this paper is to explore whether and how international best practices and national childbearing and safer conception guidelines for PLHIV are implemented within health facilities offering HIV care and treatment services in Iringa, Tanzania. We conducted in-depth interviews with 30 HIV-infected women and 30 HIV-infected men attending HIV care and treatment clinics and 30 health care providers delivering HIV-related services recruited from seven health facilities. We found significant gaps between Tanzania's national HIV guidelines, recommendations for safer conception, and actual practices by health providers in delivering reproductive health care to PLHIV. There was limited patient-provider communication on childbearing and safer conception. Most health providers interviewed were aware of the national guideline to assess the CD4 count of HIV-infected patients who wish to conceive. However, many patients did not appear to be aware that a CD4 assessment is recommended before attempting to conceive. Though most health providers were knowledgeable of timed unprotected sex during a woman's ovulation period as a safer conception option, few patients were aware of this safer conception strategy. Despite health providers stating that PLHIV have the right bear children, some patients reported being discouraged by health providers from having more children. Findings highlight the need for updated guidance on safer conception counseling for HIV-infected patients and



training for health providers to prepare them for delivering high quality preconception counseling and safer conception services for their HIV-infected patients.

## INTRODUCTION

In Tanzania there has been growing availability of antiretroviral therapy (ART) and prevention of mother-to-child transmission of HIV (PMTCT) services for people living with HIV (UNGASS Reporting for 2010, 2010). Advances in HIV treatment and PMTCT have been shown to increase fertility desires of people living with HIV (Cliffe, Townsend, Cortina-Borja, & Newell, 2011; Ezeanolue, Stumpf, Soliman, Fernandez, & Jack, 2011; Nattabi, Li, Thompson, Orach, & Earnest, 2009). Indeed, many people living with HIV in Tanzania express strong desires to have children (Mmbaga, Leyna, Ezekiel, & Kakoko, 2013). Yet despite their desire to have children, women and men living with HIV often lack information regarding safe conception and childbearing and face barriers accessing quality reproductive health services (Kanniappan, Jeyapaul, & Kalyanwala, 2008; King et al., 2011; Nduna & Farlane, 2009).

Developments of safer conception technologies have led to international and national guidelines addressing the childbearing needs of people living with HIV. In 2006 the World Health Organization (WHO) published sexual and reproductive health guidelines for women living with HIV in resource-constrained settings (WHO & UNFPA, 2006). The WHO recommends that special counseling and support be provided to HIV-infected women planning a pregnancy, whether their partners are infected with HIV or not. The guidelines offer several low-technology safer conception strategies that could reduce the risks of reinfection with a foreign strain of HIV and new HIV infections for seroconcordant and serodiscordant couples, respectively, when attempting to conceive (see Table 1 for language included in the guidelines). For HIV-seroconcordant couples, WHO recommends that couples time unprotected sex at fertile times of the woman's

menstrual cycle to limit exposure to reinfection with HIV. The WHO guidelines fall short of making official recommendations for safer conception strategies for serodiscordant couples, but they do discuss various options. The effectiveness of safer conception strategies for serodiscordant couples depends on whether the HIV-infected partner is the male or female. To prevent female-to-male HIV infection, artificial insemination during the fertile time of the menstrual cycle of the woman is highlighted in the guidelines as an option for safer conception. To reduce the risk of male-to-female HIV transmission, several options are mentioned: lowering the seminal viral load to undetectable levels with ART, timed unprotected sex, and post-exposure prophylaxis (PEP) for the uninfected woman.

In Tanzania, national policies and guidelines on childbearing and safer conception for people living with HIV are limited. Tanzania's 2012 *National Guidelines for the Management of HIV and AIDS* state that people living with HIV have the right to have children like anyone else in Tanzania. The guidelines instruct HIV care and treatment providers to assess fertility desires of HIV-infected patients at every visit and provide appropriate advice and services (see Table 1). The guidelines stipulate that the safest time for having a child for the mother and baby is when the woman's CD4 count is higher than 200 cells/mm<sup>3</sup> or HIV viral load is low, there are no signs of tuberculosis, and the woman is on ART or prophylaxis. They instruct HIV care and treatment providers to assess and modify the woman's drug regimen to avoid adverse health effects, such as birth defects resulting from efavirenz. They also state that before getting pregnant, HIV-serodiscordant and seroconcordant couples should consider the health of each partner, desires of each partner to have a child, and the long-term wellbeing of the child.

Though there are some national guidelines on childbearing and safer conception in Tanzania, it is unclear to what extent these guidelines are implemented on the ground. Research suggests that there may be a gap between reproductive health recommendations for people living with HIV and what is actually implemented at the health facility level during clinical encounters between patients and health providers (Bharat & Mahendra, 2007; Steiner, Finocchiaro-Kessler, & Dariotis, 2013). In the absence of clear guidance on safer conception, it is imperative that key stakeholders, such as policymakers and health officials, are aware of what health providers are communicating to their HIV-infected patients about childbearing and safer conception in order to improve reproductive health services for people living with HIV.

The aim of this paper is to explore whether and how international best practices and national guidelines concerning childbearing and safer conception are implemented within health facilities offering HIV care and treatment services in Iringa, Tanzania. We examine knowledge of HIV care and PMTCT providers on childbearing issues and safer conception for their HIV-infected patients and patient-provider communication on childbearing and safer conception in health facilities in Iringa, Tanzania.

## **METHODS**

### **Study Setting**

The Iringa region is located in the Southern Highlands zone in Tanzania. The region is largely rural with a population of over 940,000. It has one of the lowest population densities in the country with only 27 persons per square kilometer. Iringa has the second highest HIV prevalence by region in Tanzania—9.1% of people between the

ages of 15 and 49 years are infected with HIV ((TACAIDS), (ZAC), (NBS), (OCGS), & International, 2013). HIV prevalence in Iringa, like Tanzania more broadly, is higher among women than men (10.9% compared to 6.9%, respectively).

### **Study Procedures**

This study was conducted between June 2013 and October 2013 at seven purposively selected health facilities providing HIV care and treatment and/or reproductive and child health (RCH)/PMTCT services in the Iringa region of Tanzania. The health facilities were located in two districts within the region, Iringa Municipal and Iringa Rural, and represented different levels of the health care delivery system, including the regional hospital, a district hospital, three health centers, and two health dispensaries.

In-depth interviews were conducted with health providers and HIV-infected women and men attending HIV care and treatment services. Thirty health providers engaged in delivering HIV care and treatment and/or RCH/PMTCT services were interviewed. It was explained that their decision to participate or not participate in the study would not affect their job and that all information disclosed during the interview would be kept confidential. Interviews with health providers covered relevant aspects of their clinical practice and training, knowledge of safer conception strategies and guidelines for HIV-infected patients, provider-patient communication about childbearing, attitudes towards childbearing among HIV-affected couples, and challenges to addressing the childbearing needs of their HIV-infected patients.

To recruit HIV-infected patients, the head of the HIV care and treatment clinic provided a brief description of the research to patients waiting to receive HIV care and treatment services. The head of the HIV care and treatment clinic explained that the

research was part of the care being given at the health facility. A member of the research team then approached potential participants to further explain the research and assess interest and eligibility. Patients were eligible to participate in the study if they had been diagnosed with HIV, were between the ages of 18 and 49 years, resided in the Iringa region, and were able to provide consent. In-depth interviews were conducted with a total of 60 HIV-infected patients (30 women and 30 men) who were purposively recruited based on gender, age, and number of children at the seven health facilities selected as study sites. Interviews covered experiences living with HIV, HIV-related stigma, previous pregnancy and birth experiences, perceptions of marriage and childbearing, fertility desires, and communication with health providers about having children. Follow-up interviews were conducted with 7 patients to further explore the experience of having children post-HIV diagnosis.

Interviewers trained in qualitative research methodologies and who were fluent in Swahili and English conducted, transcribed, and translated all interviews. To protect privacy and maintain confidentiality, interviews were held in a private location within the health facility, or within participants' homes in two cases. All interviews were audio-recorded with the consent of the participant. No identifying information was linked to any audio files or transcripts. Informed consent was obtained from all research participants before conducting interviews. This study received ethical approval from the institutional review boards of the Johns Hopkins Bloomberg School of Public Health, Muhimbili University of Health and Allied Sciences, and the Tanzanian National Institute for Medical Research.

## **Data analysis**

The research team, comprised of the first author and interviewers, met weekly to discuss themes that emerged from interviews conducted in the field the previous week and to make any adjustments to the interview guides. This facilitated a more iterative research process and allowed the research team to further explore topics of particular salience and interest. Data were managed using Nvivo version 9.1 (QSR International, Doncaster, Victoria, Australia). Thematic content analysis was used to analyze interview transcripts (Boyatzis, 1998). The first author read through the transcripts at least twice. A subset of transcripts was initially coded to determine themes and concepts present in the data. A codebook was developed for the different themes and concepts to facilitate consistency in the coding process. All transcripts were then coded using the codebook with additional codes added as they emerged and were deemed important to addressing study objectives. In addition to coding, memos were written to further develop broader categories and to track emerging insights and interpretations (Charmaz, 2006). Relevant text on patient-provider communication on childbearing was compared between health provider and patient transcripts in order to determine similarities and differences between the accounts of these two groups and accounts from female and male patients. Here we present findings focused on health providers' training in and knowledge of issues pertaining to childbearing and safer conception for people living with HIV and patient-provider communication about childbearing in the context of HIV.

## **FINDINGS**

### **Health providers' awareness of childbearing and safer conception strategies for people living with HIV**

Health providers reported limited training in addressing childbearing issues of people living with HIV beyond PMTCT, which affected their ability to provide information to their HIV-infected patients on childbearing and safer conception to help them make an informed choice. As a provider stated:

Honestly, because I have no training, I cannot provide good counseling [on conception and childbearing]. Concerning the guidelines, usually I say the people at CTC [HIV care and treatment center], they can [help]. For me, they come to get reproductive health services. (Nurse/midwife, RCH clinic (PMTCT), Regional hospital; HCW05)

Several health providers mentioned referring HIV-infected patients to other providers considered to be better qualified to address their concerns of childbearing and safer conception. Other times referrals were made to higher-level providers, who were viewed as being more qualified and knowledgeable of childbearing issues for HIV-infected patients. A home-based HIV care provider described how he handles cases in which serodiscordant couples wish to conceive:

To be honest, I refer them to the health center; to the doctor to give them more counseling...I can't help them other than to refer them...because we have our boundaries in providing services. (Home-based care provider, Health center; HCW23)



Health providers reported not being aware of specific childbearing policies and guidelines for people living with HIV. However, most stated that the national policy was that people living with HIV, like all others in the country, have the right to have children. Some health providers noted how this policy differs from what was advised in the past. When asked about childbearing policies and guidelines for people living with HIV, one participant stated:

Mmm...I don't remember well. But it states that HIV patients have the right to bear children. Mmm... She has the right to give birth and she needs to get services like others. Because I remember in the past we used to say, 'You're now HIV positive, so you're not allowed to bear children,' without knowing we were infringing on their rights. They can have children but under supervision and frequent counseling. (Nurse, RCH clinic (PMTCT), Regional hospital; HCW10)

When asked about their knowledge of safer conception strategies for HIV-affected couples, nearly all health providers interviewed (26 out of 30) stressed that it is important for the HIV-infected partner to 'check their health' before attempting to conceive. In this context, checking their health status involved assessing the HIV-infected partner's CD4 cell count to ensure that it was above a certain level and treating any opportunistic infections, such as tuberculosis, or other sexually transmitted infections.

I think after having good health with enough CD4 then she can get pregnant because her body's immunity is high. We know that pregnancy also reduces immunity, so when she has enough good nutrition and her

CD4 are high then she can get pregnant and is able to deliver safely.

(Health officer, RCH clinic (PMTCT), Health center; HCW18)

There was some inconsistency among health providers concerning the specific CD4 cell count deemed 'safe' for an HIV-affected couple to conceive. Most health providers did not specifically quantify what they deemed a 'safe' CD4 cell count. However, many reported they would only advise HIV-infected patients that they could conceive if their CD4 cell counts were 350 cells/mm<sup>3</sup> or above, while two health providers reported even higher CD4 cell counts that ranged from 500 to 700 cells/mm<sup>3</sup> for safer conception.

In addition to checking the health of the woman, some health providers also felt it was important for HIV-infected men to have a CD4 test before attempting to impregnate their partners. As one health provider stated:

[A] man needs to have a CD4 count in the hundreds. Also we check his clinical staging. If he is at about stage four, I don't think it's important for him to have child. I don't think he would have even enough *nguvu za kiume* [male strength] that would allow him to produce sperm for fertilization. But if he is healthier and has enough CD4, he would have adequate energy to produce sperm that would allow him to have a child.

(Nurse, RCH clinic (PMTCT), Health center; HCW17)

Twenty-two of the 30 health providers interviewed were aware of timed, unprotected sex as a risk-reduction strategy for HIV-affected couples who wish to conceive. Timed, unprotected sex was considered by health providers as a strategy not only to reduce the risk of new infections among serodiscordant couples, but also as a way to reduce HIV reinfection among seroconcordant couples.

If she needs a baby, when having sex she has to check her menstrual cycle. She should stop using condoms if found to be in her ovulation period. And if discovered to conceive, they should return to using condoms to prevent new infections. (Nurse, RCH clinic (PMTCT), Regional hospital; HCW08)

### **Provider-patient communication about childbearing: Providers' perspectives**

All health providers interviewed reported that they had at some point discussed reproductive health issues with their HIV-infected patients. However, the topics discussed varied. Some health providers reported informing their HIV-infected patients that they are still capable of conceiving and having HIV-uninfected children in order to alleviate fears expressed patients. As one health provider said:

These days, we see girls who are 18 years old but already infected. So she starts to ask, 'Can I conceive and have a baby?' I tell her don't worry, you will conceive and have a baby. But when you need to have a child, you will come and we will give you education... From the woman's perspective, what they think is that after being infected she can't have a family anymore. So as health providers, it's our task to provide knowledge and to remove fear and tell her that despite her condition, she could still have a family. (Laboratory officer, HIV and RCH clinics, Dispensary; HCW02)

A majority of health providers reported that they talked with their HIV-infected patients about seeking advice and checking their health, including their CD4 cell count, when they were ready to have more children. Some providers also reported discussing

timing unprotected sex around the woman's fertile period with their patients as a safer conception strategy for HIV-affected couples.

Though many health providers described telling their HIV-infected patients that they have the right to have children and that no one can prevent them from having children, a few providers said they encouraged some of their HIV-infected female patients to discontinue bearing children.

Like when she comes for the first time and I test her and I find that she is positive, I start to explain to her the importance of stopping to continue to have children. So I counsel her so that when she leaves here she already understands by saying that, 'Aha, if I continue to have children it would affect me more because pregnancy itself causes low immunity and I already have low immunity.' For people who understand you, they go into family planning. (Nurse/midwife, RCH clinic (PMTCT), District hospital; HCW21)

Like the participant quoted above, these health providers told their HIV-infected patients that pregnancy could have adverse effects on the health of HIV-infected women. A female home-based care provider said: "We advise them that the more you continue having children, the weaker you become." [Home-based care provider, Health center; HCW24]

Some health providers revealed they were more likely to counsel their HIV-infected patients with no children on safer conception strategies than their HIV-infected patients with more than one or two children. For their HIV-infected patients who already

have multiple living children, a few health providers reported that they tend to recommend contraceptive use to prevent pregnancy.

The situation that [allows a woman to have children when she is infected with HIV] is for those who do not have children at all, even one child. It is for those whom we counsel. So this situation is good for them to have [children]. But if she is living with HIV and she has two or three children, most of the time, a situation like this is not good for her. So we counsel them that it is best for them to stop [having children]. But if she doesn't have any children at all and her CD4 count is high, we allow her to get pregnant. (Nurse, HIV care and treatment clinic, District hospital; HCW25)

#### **Provider-patient communication about childbearing: Patients' perspectives**

Less than a third of the HIV-infected patients interviewed (18 out of 60) reported ever having discussed having a child with a health provider post-HIV diagnosis. More male patients reported having discussed childbearing than female patients (12 out of 30 compared to 6 out of 30). Some of the reasons patients provided in interviews for not talking with a health provider about childbearing included not intending to have (more) children yet, not being in a relationship, feeling in poor health, and not having a health provider initiate the conversation. When asked why she had never had a conversation with a health provider about childbearing, one female patient who became pregnant after being diagnosed with HIV stated:

Because if they don't ask us, we keep quiet. One must ask you first and then you start to talk. You can't talk without being asked. (35-year old married female patient with three children; FEMALE24)

Another reason why some patients had not talked to a health provider was because they were uncertain about whether people living with HIV were allowed to continue having children.

I don't know if people infected with HIV can continue to bear children or... there I don't know well, because if I knew I would ask. (21-year old married female patient with one child; FEMALE25)

Some patients anticipated a negative response from their health providers, which deterred them from discussing their desires for more children.

Interviewer: Why do you think you did not talk with the health provider about getting pregnant?

Participant: I knew it was wrong to get pregnant if you are infected.

Interviewer: Did they tell you that it's not allowed to have another child?

Participant: Yes. They don't allow it. (36-year old married female patient with five children; FEMALE16)

Some patients reported being asked by health providers whether they would like to have children. Patients described health providers explaining to them that it is possible to have children despite their HIV status. Some of the advice that patients reported receiving from their health providers included coming to the health facility to seek counseling from health providers when they are ready to have children and getting their health checked, including assessing their CD4 cell count, to determine whether they are

healthy enough to have children. Only female patients reported being advised to check their CD4 cell count before attempting to conceive.

Our health providers instruct us that if we plan to have another child we have to tell them and they will give us the instructions to use up until we have the child. And they will have to check our health and see if you are be able to have a child or you don't have the ability to have a child. (29-year old married female patient with two children; FEMALE08)

Some female and male patients reported being advised by health providers against continuing to have children, which was also reported by a few health providers in our study. A married 32-year old female patient with four children described a conversation she had with a health provider after conceiving and giving birth to a child post-HIV diagnosis. She stated:

They said according to these problems you had because of that child, return again to [the hospital]. You should tie your tubes [*ukafunge kizazi*] and you should not repeat because it wants to destroy you and you will die. You will leave your child and it will be responsibility of the government... Now even the government has too many orphans. (32-year old married female patient with four children; FEMALE27)

An HIV-infected male patient recounted his encounters with health providers when he desired to have more children:

Okay, one day I came here to our dispensary and I talked to a woman over there, a nurse midwife. I told her that I'm getting older and what about children because my first child has finished standard seven and the other

one is in standard three. I'd like to have another child. She said it's completely not possible. For an [HIV-infected] patient, it's not possible. I asked, 'Are you joking with me...?' She said, 'It's not possible. If you see it has happened, it's God.' But there was a man who came, as you have come here; they were nursing students... He said, 'No, just come to the hospital and you will find a woman called Mrs. Esther<sup>†</sup>. Just ask her, 'Me, with my status, can I have a child?' She will tell you what to do.' Really, I went there to talk with her and she told me what to do. (37-year old male patient with three children; MALE21)

The quote above illustrates the diversity of patient-provider communications on childbearing experienced by HIV-infected patients who we interviewed, ranging from discouraging conversations to supportive conversations that provided patients with concrete strategies for reducing risks during conception.

Another commonly cited strategy for safer conception that patients reported learning from health providers was 'preparing before sex:'

The [health provider] told me that you should completely prepare her. When you prepare her well, make sure that you eat well and your CD4 are high, then you can have a child. However, before having a child, you need to test your health. Since I would want to have a child, I wouldn't need to use condoms. I would have to prepare the woman very well by touching her until she becomes [aroused] and after she conceives, it's over. (37-year old male patient with three children; MALE21)

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<sup>†</sup> This name has been changed to protect the individual's identity.



More male patients than female patients reported being aware of preparing before sex as a safer conception strategy. As described by participants, preparing before sex involved engaging in foreplay for the purposes of sexual arousal and increasing vaginal lubrication to reduce friction and avoid *michubuko*, ‘abrasions.’

Patients also described being informed by health providers about timing unprotected sex as a safer conception strategy. However, they seemed to be unclear on how to determine the fertile period or were told that they should see a health provider to be informed of when to attempt to conceive.

They advise you that there is a certain day that you should stop using condoms so that you...so that those sperm are able to... You are able to get pregnant. [(26-year old married female participant with three children; FEMALE14)

[Health providers] at the [HIV care and treatment center] here told us if you want to have a child, there is a date that you will be told to try to have a child. You would be directed to have [unprotected sex] just one time and not repeat it for a second time. And after that you should start using condoms again. (35-year old married man with three children; MALE07)

## **DISCUSSION**

This study examined how health providers in Iringa, Tanzania have adopted childbearing and safer conception guidelines for HIV-infected patients receiving HIV care and treatment services. Drawing from the experiences of both health providers and HIV-infected patients receiving HIV care and treatment, our findings suggest some

patients had knowledge of safer conception strategies for HIV-affected couples, which they had learned through discussions with health providers. However, there were gaps between Tanzania's national guidelines for the management of HIV/AIDS, best practices for preconception counseling and safer conception for people living with HIV, and actual practices by health providers in delivering services for HIV-infected patients within HIV care and treatment centers in the Iringa region of Tanzania.

In our study we found limited patient-provider communication on childbearing and safer conception from the patient's perspective that, at times, did not reflect national guidelines. Though Tanzania's *Guidelines for the Management of HIV and AIDS* instruct health providers in HIV care and treatment centers to assess fertility desires of patients at each visit and provide appropriate advice and services, less than a third of the patients who we interviewed had ever discussed having children with a health provider after being diagnosed with HIV. Other studies have found a similar lack of communication between health providers and their HIV-infected patients about childbearing (Finocchiaro-Kessler et al., 2012; Finocchiaro-Kessler et al., 2010; Malta et al., 2010). In one study conducted in Brazil and the United States, researchers found low rates of communication about childbearing between providers and HIV-infected women who intended to have a child (Finocchiaro-Kessler, et al., 2012). They speculated that this was due to the absence of an established overarching health policy on preconception counseling in either setting for HIV-infected patients who intend to have a child and guidance on how people living with HIV can safely plan for a future pregnancy. In Tanzania there is a lack of clear guidance for health providers in counseling women and men living with HIV on childbearing, including safer conception. Most health providers in our study reported only limited

training in addressing the childbearing concerns of their HIV-infected patients. Also in Ghana, lack of training in childbearing and safer conception for people living with HIV has been previously reported by health providers engaged in delivering HIV care and PMTCT services (Laar, 2013).

Most health providers in our study were aware of the need to assess the CD4 count of HIV-infected patients who wish to conceive, which is recommended by Tanzania's HIV/AIDS management guidelines (National guidelines for the management of HIV/AIDS, 2012). Some patients reported being advised by health providers to evaluate their health status, including their CD4 count, before attempting to conceive, suggesting that some health providers are following this national guideline. However, given the low proportion of patients aware of this advice in our study, the implementation of this guideline appears to be inconsistent. This recommendation was included in Tanzania's national guidelines to protect the health of HIV-infected women and to reduce the risk of mother-to-child transmission of HIV during pregnancy. However, it may also reduce transmission of HIV within serodiscordant couples trying to conceive. Immediate antiretroviral therapy initiation leading to increased CD4 count has been found to reduce the risk of HIV transmission in serodiscordant couples by 96% (Cohen et al., 2011). Recent WHO guidelines recommend early ART initiation for HIV-infected partners in serodiscordant relationships irrespective of CD4 count, yet this has not yet been adopted in Tanzania's national guidelines (WHO, 2013).

We also found that few patients received information from health providers about timed unprotected sex. Health providers appeared to obtain information on timed unprotected sex through channels other than the national guidelines. For example, a

workshop organized by Tanzania's *National Council of People Living with HIV and AIDS* disseminated further guidance on conception and pregnancy for people living with HIV. The workshop used a guidance package published by the Global Network of People Living with HIV/AIDS (GNP+) to present safer conception guidance to attendants, which included timed unprotected sex, artificial insemination, and lowering seminal viral load through ART to reduce male-to-female HIV transmission in serodiscordant couples (Advancing the sexual and reproductive health and human rights of people living with HIV, 2009).

Sexual arousal of the woman through foreplay to stimulate vaginal lubrication to avoid *michubuko*, or vaginal or penile abrasions, was also advised by health providers to HIV-infected patients, particularly HIV-infected male patients, as a strategy to reduce HIV transmission when attempting to conceive. Previously research conducted in Tanzania has found that people perceive *michubuko* resulting from rough or 'dry' sex and lack of foreplay as increasing the risk of HIV transmission (Layer, Beckham, Momburi, & Kennedy, 2013). There is no mention of increasing vaginal lubrication through foreplay as a safer conception strategy in Tanzania's national guidelines or the WHO guidelines. And though a few past studies have suggested that 'dry sex' may increase HIV transmission risks through vaginal or penile abrasions, the evidence for such a relationship is inconclusive (Kun, 1998). More research from a social science perspective might provide insight on why health providers are recommending foreplay to induce vaginal lubrication as a safer conception strategy for their HIV-infected patients.

Despite most health providers stating that the policy in Tanzania is that people living with HIV have the right to have children, some patients reported being discouraged

by health providers from having more children. Health providers advising their HIV-infected female patients against becoming pregnant has been previously reported in the literature, including within the Tanzanian context (Finocchiaro-Kessler, et al., 2012; Keogh et al., 2012). These negative responses from health providers deterred some patients in our study from seeking counseling on safer conception and childbearing. Some patients also reported not discussing childbearing with a health provider because providers did not initiate the conversation and they did not feel empowered to bring up the topic; this points to the need for non-judgmental provider-initiated preconception counseling (Finocchiaro-Kessler, et al., 2012; Steiner, et al., 2013). Some PMTCT and HIV home-based care providers in our study felt unequipped to advise their HIV-infected patients on safer conception and instead referred patients to the HIV care and treatment center. These represented missed opportunities for counseling HIV-infected patients about childbearing and safer conception.

Our findings have implications for policy and practice. First, Tanzania's guidelines for the management of HIV and AIDS and for the prevention of mother-to-child transmission of HIV should be updated to provide clear guidance on preconception counseling for HIV-infected patients. These guidelines should include a broad spectrum of feasible and locally appropriate safer conception strategies for HIV-infected patients, including those patients in HIV serodiscordant relationships. Second, health providers engaged in delivering HIV care and treatment and PMTCT services, including HIV home-based care providers, should be trained in these updated guidelines for preconception counseling and safer conception. Job aids and safer conception decision-making tools could also be developed to assist health providers when discussing

childbearing issues with their HIV-infected patients. Job aids and decision-making tools have been shown to improve the quality of provider communication with patients and patients' knowledge of health information (Jennings, Yebadokpo, Affo, & Agbogbe, 2010; Kim, Davila, Tellez, & Kols, 2007). Lastly, given evidence that fertility desires change over time in response to changes in life circumstances (Sennott & Yeatman, 2012), it is important that HIV care providers assess fertility desires at each patient visit and initiate preconception counseling when implicated.

We acknowledge several limitations of our study. First, we only interviewed HIV-infected patients attending HIV care and treatment centers. The experiences of patients currently receiving HIV care and treatment services likely differ from HIV-infected individuals who are not engaged in care. Research has shown that many people diagnosed with HIV are not linked to HIV care and treatment or disengage from care (Govindasamy, Ford, & Kranzer, 2012; Rosen et al., 2011; Tomori et al., 2014). Second, we did not observe actual conversations between HIV-infected patients and health providers during consultations, but instead relied on self-reported accounts of the content of these conversations from health providers and HIV-infected patients, increasing the risk of social desirability bias. Health providers in our study may have misreported topics covered in actual interactions with their patients and patients may have been less likely to report negative encounters with health providers. We attempted to minimize social desirability by explaining during the informed consent process that responses would not affect providers' jobs or patients' care. Patients were also informed that the interviewers were not affiliated with the health facility. Furthermore, credibility of our findings was enhanced and our study strengthened through triangulating data from HIV care and

PMTCT service providers and HIV-infected patients attending HIV care and treatment clinics. Another strength of our study is that it drew from the experiences of both HIV-infected female and male patients.

## **CONCLUSION**

This study used patient and providers' accounts to better understand patient-provider communication on childbearing and safer conception in relation to current national and international guideline recommendations for people living with HIV. Findings from this study highlight the need for broadened integration of HIV and sexual and reproductive health services in Tanzania. The WHO is in the process of updating its sexual and reproductive health guidelines for women living with HIV. This would be an ideal opportunity for the Tanzanian government to update its guidelines for the management of HIV/AIDS to provide health providers engaged in HIV care and treatment with the needed guidance to consistently deliver comprehensive preconception counseling to women and men living with HIV.

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Table 1. WHO and Tanzanian national guidelines on childbearing and low-technology safer conception.

Safer conception strategy	WHO guideline statement <sup>1</sup>	Tanzania's national guideline statement <sup>2</sup>
<b>Preconception counseling and screening</b>	Recommendation: 'Women living with HIV/AIDS should be aware of additional risks that HIV-positive women may encounter in carrying a pregnancy when considering whether to have children and planning a family. Special counseling and support should therefore be provided to HIV-positive women planning a pregnancy, whether their partner is HIV-positive (seroconcordant) or HIV-negative (serodiscordant).'	Recommendation: 'Women and men living with HIV should be provided family planning and safer conception counseling within the CTC (care and treatment center) following an integrated model of service provision. To ensure that women and men living with HIV receive these services, HIV care and treatment providers need to assess fertility desires and unmet need for contraception at every visit, and provide advice and services as appropriate.'
	Recommendation: 'As a consequence of either her own reduced fertility or that of her partner, women living with HIV/AIDS may be more likely to have difficulty in getting pregnant and to request assistance. These women should be given full support and counseling and advised of their options, including adoption and assisted reproduction, if available.'	Recommendation: 'HIV care and treatment providers should frequently assess their patients' desires for childbearing so that they can provide appropriate information, counseling support and services needed for patients to make informed decisions that protect their own health, their partner's health, and ensure the highest likelihood of a healthy pregnancy and uninfected child.'
		Recommendation: 'If an HIV-positive woman's illness is advanced, she is at higher risk for transmitting HIV to her child. If the woman, man, or both are ill, caring for a child could be more burdensome. Clinicians should encourage the woman to continue using contraceptives and condoms until she is healthy enough to become pregnant.'
		Recommendation: 'For the mother and baby, the safest time for having a child is when the woman's CD4 count is not low (<200) or viral load is low; there are no signs of TB; and the woman is on ART or prophylaxis according to

		guidelines.'
<b>Timed unprotected sex</b>	Recommendation for seroconcordant couples: 'Seroconcordant couples should be counseled to use condoms to prevention reinfection with another strain of the virus. When planning a pregnancy, they should be advised to attempt conception at fertile times of the menstrual cycle to limit exposure.'	No recommendation
	Option only for serodiscordant couples: 'Ways to help reduce risk of male-to-female HIV transmission include...timing conception at the fertile time of the menstrual cycle to limit exposure.'	No recommendation
<b>Vaginal insemination with uninfected male sperm</b>	Option only: 'To prevent female-to-male HIV transmission among discordant couples, artificial insemination can be used. Simple techniques to introduce sperm into the woman's vagina using a syringe or other clean receptacle during the fertile time of the menstrual cycle can provide a means to conceive that prevents the male sexual partner from becoming infected.'	No recommendation
<b>Antiretroviral therapy for infected partner to reduce HIV viral load</b>	Option only: 'Ways to reduce risk of male-to-female HIV transmission include lowering the seminal plasma viral load to undetectable levels with ART [antiretroviral therapy].'	No recommendation
<b>Post-exposure prophylaxis (PEP)</b>	Option only: 'Ways to help reduce risk of male-to-female HIV transmission include...using post-exposure prophylaxis for the women.'	No recommendation
<b>Peri-conception pre-exposure prophylaxis (PrEP)</b>	No recommendation	No recommendation

<sup>1</sup> Source: *Sexual and reproductive health of women living with HIV: Guidelines on care, treatment and support for women living with HIV/AIDS and their children in resource-constrained settings* (WHO, 2006)

<sup>2</sup> Source: *National guidelines for the management of HIV and AIDS* (Tanzania National AIDS Control Programme and Ministry of Health and Social Welfare, 2012)

## **MANUSCRIPT FOUR:**

**Using an ecological framework to examine barriers to the  
adoption of safer conception strategies by HIV-affected couples  
in Tanzania**

## **ABSTRACT**

The World Health Organization is currently in the process of updating its sexual and reproductive health guidelines for women living with HIV. Prior to implementing safer conception interventions, it is essential to understand potential barriers to their adoption so that strategies can be developed to overcome these barriers. This paper examines potential barriers to the adoption of safer conception strategies by HIV-affected couples in Iringa, Tanzania using an ecological framework. We used in-depth interviews with 30 HIV-infected women, 30 HIV-infected men and 30 health providers engaged in delivering HIV-related services, as well as direct observations at five health facilities. Findings suggest there are multiple barriers to safer conception that operate at the individual, relational, environmental, structural, and superstructural levels. The barriers to safer conception identified are complex and interact across these levels. Barriers at the individual level included antiretroviral adherence, knowledge of HIV status, knowledge and acceptability of safer conception strategies, and poor nutrition. At the relational level, unplanned pregnancies, non-disclosure of status, gendered power dynamics within relationships, and patient-provider interactions posed a threat to safer conception. HIV stigma and distance to health facilities were environmental barriers to safer conception. At the structural level there were multiple barriers to safer conception, including but not limited to limited safer conception policies and guidelines for PLHIV; lack of health provider training in safer conception strategies and preconception counseling for PLHIV; limited resources; and lack of integration of HIV and sexual and reproductive health services. Poverty and gender norms and ideals influenced and reinforced barriers to safer conception operating at different levels of the framework. Multi-level interventions are

needed to ensure adoption of safer conception strategies and reduce the risk of HIV transmission between partners within HIV-affected couples.

## INTRODUCTION

Worldwide there are an estimated 35.3 million people living with HIV (PLHIV), most of whom are of reproductive age (UNAIDS, 2013). With the growing availability of antiretroviral therapy (ART), people living with HIV are living longer and healthier lives. Data suggest that many of those living with HIV want to have children (Nattabi, Li, Thompson, Orach, & Earnest, 2009). Expanded access to ART for the prevention of mother-to-child HIV transmission (PMTCT) has made it possible for PLHIV to have uninfected children. However, despite their desires to have children, they often lack information regarding safe conception and childbearing, and face barriers accessing quality reproductive health services (Kanniappan, Jeyapaul, & Kalyanwala, 2008; King et al., 2011a; Nduna & Farlane, 2009).

There are multiple ways to reduce the risk of new HIV infections within HIV discordant couples and reinfection in HIV concordant couples that want to have children. ART-based safer conception strategies include ART for the HIV-infected partner to suppress HIV viral load to undetectable levels (Cohen et al., 2011; Matthews, Smit, Cu-Uvin, & Cohan, 2012), periconception pre-exposure prophylaxis (PrEP) for the uninfected partner (Aaron & Cohan, 2013; Kaida et al., 2013; Matthews, Baeten, Celum, & Bangsberg, 2010; Matthews, et al., 2012), and post-exposure prophylaxis (PEP) for the uninfected partner (WHO & UNFPA, 2006) (see Table 1). Non-ART, behavioral safer conception options for resource-constrained settings include unprotected sex timed at the most fertile period of the woman's menstrual cycle and vaginal insemination with sperm from an HIV-uninfected partner or donated sperm (Chadwick et al., 2011; Mmeje, Cohen, & Cohan, 2012). There are also high-technology assisted reproduction



interventions for HIV-affected couples, particularly when the man is HIV infected and his partner is uninfected, that are often unattainable for PLHIV in resource-constrained settings (Chadwick, et al., 2011). These interventions include sperm washing with intrauterine insemination (Eke & Oragwu, 2011) and intracytoplasmic sperm injection (Sauer et al., 2009). In order to benefit from these advancements in safer conception for HIV-affected couples, people living with HIV require access to safer conception intervention strategies, including preconception counseling. Yet few HIV programs specifically address fertility desires and safer conception.

Table 1. Safer conception intervention strategies for HIV-affected couples.

Low technology interventions	Antiretroviral therapy for infected partner to suppress HIV viral load
	Pre-exposure prophylaxis (PrEP) for uninfected partner
	Post-exposure prophylaxis (PEP) for uninfected partner
	Timed unprotected sex during woman's ovulation period
	Vaginal insemination with uninfected partner's sperm or donor sperm
High technology interventions	Sperm washing with intrauterine insemination
	Intracytoplasmic sperm injection

The World Health Organization is currently in the process of updating its sexual and reproductive health guidelines for women living with HIV. Prior to implementing safer conception interventions, it is essential to understand potential barriers to their adoption so that strategies can be developed to overcome these barriers. This paper examines potential barriers to the adoption of safer conception strategies by HIV-affected couples using qualitative data collected in the Iringa region of Tanzania, including in-depth interviews with HIV-infected women and men and health providers engaged in

delivering HIV-related services as well as direct observations in health facilities. Though there has been some research exploring challenges to safer conception among HIV-affected couples (Crankshaw et al., 2012; Crankshaw, Mindry, Munthre, Letsoalo, & Maharaj, 2014; Gombachika et al., 2012), this is the first to explore this issue in Tanzania.

## **METHODS**

Qualitative data were collected between June and October 2013. Semi-structured in-depth interviews were conducted with 30 purposively selected health care providers engaged in delivering HIV-related services and 60 purposively selected HIV-infected individuals attending HIV care and treatment services (30 HIV-infected women and 30 HIV-infected men) in the Iringa region. Topics covered during interviews with health care providers included knowledge of childbearing and safer conception policies for PLHIV, communication about childbearing, including safer conception, with HIV-infected clients, their attitudes toward PLHIV having children, and barriers to providing reproductive health services to HIV-infected clients. Interviews with HIV-infected women and men covered the experience of living with HIV, HIV-related stigma, previous childbearing experiences, fertility desires, communication with health care providers about reproductive health, and acceptability of safer conception strategies.

In addition to in-depth interviews, direct observations were conducted in five health facilities offering HIV care and treatment and PMTCT services. Health facilities were selected to provide representation of different levels of the health care system and included one regional hospital, a district hospital, two health centers, and one dispensary.

Observations were conducted by two research team members per facility and lasted two to three hours. Observations focused on the physical environment in and surrounding the facility; client navigation processes through the health facility, including waiting times and interactions with health care providers and other clients; and the availability of sexual and reproductive health resources. Field notes were taken during the observation period and expanded by the end of the day following the observation period.

All interviews were conducted in Swahili, digitally recorded with the consent of participants, transcribed in Swahili, and translated into English by local field interviewers. Field interviewers met weekly with the first author throughout the data collection period to discuss emergent themes and refine the interview guide to facilitate an iterative research process. Thematic analysis was used to analyze the interview transcripts and field notes. Transcripts and field notes were read through several times and a subset of transcripts was coded initially to determine emergent themes. A coding scheme was developed based on themes that emerged from the data and a priori themes based on the interview guide. All data were then coded using the coding scheme with additional codes added as they emerged and were deemed important to addressing the study objectives. All coding was conducted using QSR NVivo Version 9 (QSR International, Doncaster, Victoria, Australia). We employed the Sweat-Denison ecological model during a second round of coding as a framework for organizing themes with implications for barriers to the adoption of safer conception strategies by women and men living with HIV (Sweat & Denison, 1995).

## RESULTS

Potential barriers to safer conception for people living with HIV in Tanzania were identified across the multiple levels of the Sweat-Denison ecological model. These barriers are presented at the individual, relational, environmental, structural and superstructural levels. Below, we describe barriers in each of these levels, while supporting quotes for each are presented in Table 2.

### **Individual barriers**

Health providers reported inconsistent ART use among their HIV-infected clients was one barrier to safer conception. ART-based safer conception strategies, including reducing the HIV viral load of the HIV-infected partner to an undetectable level using ART, periconception PrEP for the uninfected partner, and PEP for the uninfected partner, require proper adherence to ART to be effective in reducing the risk of new HIV infections in HIV-affected couples.

Lack of knowledge of HIV status was also identified as a potential barrier to safer conception. Some participants felt that this was particularly an issue for men who were perceived as less likely to test for HIV compared to women. Knowledge of safer conception strategies was particularly low among HIV-infected participants with only 7 out of 30 women and 8 out of 30 men reporting knowledge of a safer conception strategy, predominately preconception screening and timed unprotected sex around the woman's ovulation period.

Participants stated that another challenge to adopting certain safer conception strategies for PLHIV was the acceptability of these strategies, particularly self-insemination. Some participants perceived self-insemination as going against cultural

standards surrounding conception. For example, some participants reported that men might question whether the sperm used for vaginal insemination actually belongs to them.

Additionally, many health providers viewed nutrition as an important component of improving the health of HIV-infected women before they attempt to conceive. Yet poor nutrition resulting from the inability to buy nutritious food was reported by many of the HIV-infected women and men interviewed.

### **Relational barriers**

Many safer conception strategies recommended by HIV providers in this study require advanced planning and HIV status disclosure between coupled partners. Many PLHIV described having unplanned pregnancies after being diagnosed with HIV. Some HIV-infected participants reported difficulties in disclosing their HIV status to others, including their partners. Unequal power dynamics within relationships also posed a challenge to HIV-affected couples adopting safer conception strategies. We found reports of discordance in pregnancy intentions, often with men pressuring their wives to have more children.

Interactions between PLHIV and their providers also presented barriers at the relational level. Power imbalance between clients and providers may have prevented some HIV-infected participants from discussing safer conception and childbearing with their health providers. In addition, some HIV-infected participants feared discussing childbearing with health providers because of previous negative responses of health providers to their pregnancies. Observations in health facilities revealed that HIV care providers spend very little time consulting with their HIV clients, often less than three

minutes. It was therefore not surprising that most HIV-infected participants said they had never discussed childbearing with a health provider and that their knowledge of safer conception strategies was low. Only 18 out of 60 HIV-infected participants had ever discussed having children with a health provider. A lower proportion of women than men reported having discussed childbearing with a health provider (6 out of 30 compared to 12 out of 30, respectively).

### **Environmental barriers**

Environmental barriers to safer conception included HIV-related stigma and discrimination and were found to influence other factors previously mentioned including HIV testing, HIV status disclosure, ART adherence, and health care seeking behaviors. Distance to health facilities offering HIV-related services was also found to be a barrier to accessing reproductive health services, including preconception counseling and access to ART.

### **Structural barriers**

We identified many structural barriers to the adoption of safer conception strategies by women and men living with HIV at the health systems level. These structural barriers included: limited safer conception policies and guidelines for PLHIV; lack of health provider training in safer conception strategies and preconception counseling for PLHIV; limited resources, including antiretroviral (ARV) drugs and CD4 reagents required for CD4 testing; health workforce shortages that limit the quality of counseling provided to clients; stigma within the health care system toward PLHIV having children; poor linkages to HIV care and treatment; lack of integration of HIV and sexual and reproductive and health services; and inconsistent availability of family

planning methods to prevent unintended pregnancies. Two of the health facilities included in our study were religiously affiliated and did not offer modern family planning methods, including condoms, to their HIV-infected clients.

### **Superstructural barriers**

We identified two superstructural barriers, poverty and gender, which influenced and were reinforced by factors operating at the different levels of the ecological model. Poverty was found to reduce access of PLHIV to HIV-related and reproductive health services and proper nutrition. Poverty and lack of resources also meant that the health care system was unable to consistently have the resources and personnel capacity needed to deliver safer conception services. Gender imbalances influenced power dynamics within relationships, where men's desire for children sometimes trumped the desires of their wives, even at the expense of their wives' health. We also found evidence of gender discrimination within the health care system, where traditional gender norms led some clients and health providers to perceive reproductive health as a woman's issue. These gender norms impeded the engagement of men in discussions about reproduction within the health care system.

Table 2. An ecological framework of barriers to safer conception for people living with HIV in Tanzania.

<b>Individual</b>	
ART adherence	"Some are not careful with medication. When you tell them they shouldn't skip any days, you find they skip two or three." (PMTCT provider, regional hospital; HCW07)
Knowledge of HIV status (HIV testing)	"Most men hide themselves and you can't diagnose them unless they come to test with their wife. A pregnant woman you diagnose when she comes to have her HIV test. But for men, it's difficult as they rarely come [to test]." (PMTCT provider, regional hospital; HCW07)
Knowledge of safer conception strategies	[7 out of 30 women and 8 out of 30 men reported knowledge of a safer conception strategy, predominately preconception screening and timed unprotected sex around the woman's ovulation period.]
Acceptability of safer conception strategies	In reference to self-insemination: "That is somewhat difficult. The father can say that those sperm aren't mine." (31-year old married HIV-infected woman with two children; FEMALE21)
Poor nutrition	"You find that meat, milk and fish are expensive. So you find that some people who are infected [with HIV] don't have the means to buy things that they need. So they must be affected in terms of their health." (30-year old divorced HIV-infected man with one child; MALE28)
<b>Relational</b>	
Unplanned pregnancies	In response to a follow-up question about her pregnancy reported as unplanned: "I didn't want to get pregnant at the time because I was already diagnosed with HIV and I thought if I were to get pregnant, I might have a child who is infected as well." (36-year old married HIV-infected woman with four children; FEMALE16)
Non-disclosure of HIV status	"Honestly, I didn't even tell the truth to my partner. He found out after he found this card [HIV clinic card]. He asked why did I start treatment alone and keep it a secret from him. I told him, 'I saw that I was sick and when I saw that you weren't even bothered, I went to test and I was told that I have this [disease].' He was angry with that and he chased me away. He told me to go back to my mother. So I told him okay." (26-year old married HIV-infected woman with one child; FEMALE22)



	"After testing, I was the only one at home to be diagnosed with HIV. So I felt bad and it was a little hard to tell others at home. It was hard to tell the mother of my children. When she found out about [me going to the HIV clinic], it forced me to tell her." (35-year old married HIV-infected man with three children; MALE07)
Gendered power dynamics within relationships	"[Men] are the ones who force their wives to have children, regardless of her CD4 count. You find a man telling his wife, 'You have been using medication for 6 months or one year, so we need to have a child. This child has already gotten older'...And the mother has no say. You find she says [she got pregnant] unintentionally." (PMTCT provider, regional hospital; HCW08)
Patient-provider interactions	In response to why she had not spoken to a health provider about having children: "Because if they don't ask us, we keep quiet. One must ask you first and then you start to talk. You can't talk without being asked." (35-year old HIV-infected woman with three children; FEMALE24)
<b>Environmental</b>	
HIV stigma and discrimination	"[People] said, 'How will it be possible for the mother to have a child while infected [with HIV], my friend. Why can't they stop since they're infected?'" (35-year old HIV-infected man with two children; MALE19)
Distance to health facility offering HIV-related services	"Some people come here come from far villages and they don't have bus fare. Most of the time we give them [bus fare] from our pockets because when she explains her journey to her, you find that it's far and she can't go by foot." (HIV care provider, health center; HCW20)
<b>Structural</b>	
Limited safer conception policies and guidelines for PLHIV	"Guidelines? Honestly, I haven't seen any guidelines. I can't lie, I don't know the guidelines, but what I know is that [people living with HIV] have the right to have children." (PMTCT provider, regional hospital; HCW05)
Lack of health provider training in safer conception strategies and preconception counseling for PLHIV	"Honestly, because I have no training I can't provide good counseling on [conception and childbearing]." (PMTCT provider, regional hospital; HCW05)
Limited resources (e.g. ARVs, CD4 reagents, equipment)	"Sometimes a woman who is infected with HIV should have her CD4 count assessed, but the problem is that there is no CD4 reagent. So you find that you don't give this woman the

	right to know if she can have a child or not." (HIV care provider, health center; HCW13)
Health workforce shortages	"I think one of the barriers is client load. If we have a lot of clients, honestly, we find that we serve them quickly so that we can leave. If you have a lot of clients, then you won't consider the proper counseling." (HIV care provider, regional hospital; HCW09)
Stigma within the health care system toward PLHIV having children	"[Health providers] completely opposed me having children. They said that you might increase infections or you might have an infected child. So it's bad to have a child when you're HIV positive." (48-year old married HIV-infected man with three children; MALE06)
Poor linkages to HIV care and treatment	"You may find that a man is tested [for HIV] and given a referral form. You ask him where he would prefer to go [for HIV treatment] and when he goes, it's closed. You find some are lost [to follow-up]. They are not going [to the HIV clinic]. The referral form is not even returned." (VCT Laboratory officer, dispensary; HCW02)
Lack of integration of HIV and sexual and reproductive health services	"When a client comes to start family planning or she is pregnant, she arrives at the health center and finds that there are no HIV services and she is infected. If you tell her to go to another health center, she has already been lost [to follow-up]. So I think all of these services that are important for the reproductive health of people living with HIV be available in any dispensary or health center." (PMTCT provider, dispensary; HCW01)
Inconsistent availability of family planning methods to prevent unintended pregnancies	"Sometimes we don't have family planning services. Someone who is HIV-positive may come for a certain method, but we don't have it...Sometimes we may not have them for even a whole month. For example, we normally don't have [hormonal] implants. It happens that we don't have implants and an HIV-positive client comes and needs that. So we advise her to use a method that's available and come back next time and we might have it then." (PMTCT provider, health center; HCW17)

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### **Superstructural**

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Poverty	"You find that you tell them a date to return to the clinic, but she doesn't come because of transportation fees...She tells you, 'I didn't come because I didn't have any money.' So [HIV-infected patients] face financial difficulties." (HIV care provider, regional hospital; HCW09)
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Gender norms	<p>"You find that a woman says, once diagnosed, 'I have to have a child.' Her husband also says, 'It's not possible, I must have children. I can't stay without a child.' So she gets pregnant because her husband wants her to. That is, 'My husband has forced me to have a child.'" (PMTCT provider, regional hospital; HCW10)</p> <p>"A large number of fathers don't attend reproductive health services. You find that many of them think that these services are only concerned with women." (PMTCT provider, health center; HCW14)</p>
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## DISCUSSION

Our findings suggest multiple challenges to the adoption of safer conception strategies among HIV-affected couples in Tanzania that operate at the individual, relational, environmental, structural, and superstructural levels. The barriers to safer conception identified in this study are complex and interact across levels.

At the individual level, we found acceptability of safer conception strategies to be an important barrier to their adoption by HIV-affected couples. Some participants reported that men might question whether the sperm used for vaginal insemination actually belongs to them. This finding echoes what was found in South Africa, where certain safer conception strategies, including vaginal insemination, were perceived by men living with HIV as threats to paternity (Taylor, Mantell, Nywagi, Cishe, & Cooper, 2013). Knowledge of and access to ART and ART adherence were also identified as barriers to safer conception interventions, including ART for the HIV-infected partner and PEP and PrEP for the uninfected partner. Though we identified ART adherence as operating at the individual level, there are other factors at higher levels of the ecological framework that influence adherence. We found that poverty and distance to health

facilities offering HIV-related services influenced the ability of people living with HIV to access HIV care and treatment services due to transportation costs. Geographic and transportation barriers have been previously reported in the literature as barriers to ART adherence (Lankowski, Siedner, Bangsberg, & Tsai, 2014).

We identified several barriers to safer conception at the relational level. Participants reported that most pregnancies conceived post-HIV diagnosis were unplanned. Rates of unplanned pregnancies have been found to be high among PLHIV (Kikuchi, Wakasugi, Poudel, Sakisaka, & Jimba, 2011; King et al., 2011b; Schwartz et al., 2012; Wanyenze et al., 2011). Unplanned pregnancies are a barrier to preconception screening and counseling, which are the first components to delivering safer conception interventions. Preconception screening for HIV-affected couples includes determining the HIV-infected partner has a low HIV viral load, high CD4 cell count, and no AIDS-defining symptoms and that both partners are free from sexually transmitted infections (Chadwick, et al., 2011). In our study, participants reported inconsistent availability of family planning methods to prevent unintended pregnancies and a lack of integration of HIV and reproductive health services. These structural forces directly influence HIV-affected couples' ability to prevent unplanned pregnancies and implement safer conception strategies. The integration of HIV and reproductive health services coupled with improved access to contraceptives is critical to allow HIV-affected couples plan their pregnancies and reduce HIV transmission risks (Kennedy et al., 2010). Additionally, the adoption of PMTCT Option B+, in which all HIV-infected women are offered life-long ART regardless of CD4 cell count, offers new opportunities for not only reducing

mother-to-child transmission of HIV, but also for reducing HIV transmission to uninfected partners (WHO, 2013).

Non-disclosure of HIV status is also an important relational barrier for HIV-affected couples to adopting safer conception strategies. Certain safer conception options, particularly timed unprotected sex, vaginal insemination, PrEP, and PEP, require HIV disclosure between partners in order to be effectively implemented. HIV disclosure has been found to have a profound effect on decision-making surrounding pregnancy among HIV-infected women (Zamudio-Haas, Mudekanye-Mahaka, Lambdin, & Dunbar, 2012). The fear of disclosing one's HIV status to a partner is partially influenced by environmental forces, such as HIV-related stigma and discrimination. Participants more often reported that HIV-infected women experienced negative consequences of HIV disclosure to partners, including abandonment. This is consistent with previous research (Rujumba et al., 2012; Zamudio-Haas, et al., 2012). HIV-positive support groups and HIV care providers could play a key role in helping PLHIV navigate the disclosure decision-making process through clinic-based and home-based couples HIV testing and counseling with support for mutual disclosure (Walcott, Hatcher, Kwen, & Turan, 2013).

We further identified gendered power dynamics between partners in HIV-affected couples as a potential barrier to safer conception. Some participants conveyed that men exert control over reproductive decisions within their relationships, which could result in a lack of planning necessary for adopting certain behavioral safer conception strategies. Power relations within couples are influenced by gender norms operating at the superstructural level. Gender norms and ideologies that reinforce reproductive health as a

women's issue were also found to affect HIV-infected men's access to reproductive health services and the care they received once at the health facility. Though it may be challenging to change community norms around gender, HIV and reproductive health policies and guidelines could adopt a broader vision of gender equality that includes male involvement in reproductive health (Ramirez-Ferrero & Lusti-Narasimhan, 2012).

Several structural barriers to the adoption of safer conception strategies by HIV-affected couples were revealed during analysis. Limited policies and guidelines on safer conception for people living with HIV limit the ability of health providers to consistently offer quality safer conception counseling to their HIV-infected clients. The revision underway by the WHO on its sexual and reproductive guidelines for women living with HIV presents Tanzania and other low- and middle-income countries with an ideal opportunity to revisit their national policies and guidelines in order to incorporate evidence-based guidance for safer conception for HIV-affected couples. The lack of health provider training in safer conception strategies and preconception counseling for people living with HIV is a barrier that could be addressed through increased training of health providers engaged in delivering HIV and/or reproductive health services for HIV-infected clients.

Limited resources, including HIV medication and CD4 reagents, and health worker shortages, pose threats to the adoption of safer conception by HIV-affected couples. Improvements in supply chain management, consistent funding of essential resources, and task shifting could help to overcome these barriers. There is evidence that shifting HIV-related tasks from doctors to trained nurses and community health workers reduce costs without reducing quality of care received by HIV clients (Kredo, Adeniyi,

Bateganya, & Pienaar, 2014; Mdege, Chindove, & Ali, 2013). Task shifting certain components of safer conception counseling to community health workers or home-based care providers could help to address health workforce shortages.

Some participants described stigma within the health care system as a challenge to safer conception. Some HIV-infected participants reported being discouraged from having children by health providers. These stigmatizing attitudes sometimes led to negative interactions between clients and providers. This finding is consistent with previous research reporting on HIV-infected women's experiences of stigma and prejudice within the health care setting and the lack of preparedness of health providers in addressing concerns regarding their reproductive health (Malta et al., 2010) Fear of stigma and discrimination by health providers deterred some participants from discussing childbearing issues with their providers. Limited client-provider communication on childbearing and safer conception has been previously reported in the literature (Finocchario-Kessler et al., 2012; Finocchario-Kessler et al., 2010; Malta, et al., 2010). To overcome these challenges, training health providers in non-judgmental, client-centered preconception counseling on safer conception is warranted.

There are limitations to this study that should be considered when interpreting findings. First, HIV-infected women and men were recruited through HIV care and treatment clinics. The challenges that they reported may have been different from PLHIV who are not currently accessing HIV-related care. Yet recruiting through HIV care and treatment clinics allowed us to capture barriers encountered by HIV-infected clients within the health care system in relation to childbearing and safer conception. Second, we

conducted the research in one rural region in Tanzania; other settings may face other barriers to safer conception not represented in our study.

## **CONCLUSION**

As the World Health Organization progresses toward updating its sexual and reproductive health guidelines for women living with HIV, national HIV programs must examine how they will adopt evidence-based guidelines into national policies and guidelines. Prior to developing national guidelines and interventions for safer conception for HIV-affected couples, a broader understanding of potential barriers to safer conception operating at the individual, relational, environmental, structural and superstructural levels will be essential to developing effective safer conception interventions. Multi-level interventions that address barriers across these multiple levels are needed to ensure adoption of safer conception strategies and reduce the risk of HIV transmission between partners within HIV-affected couples.



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# CONCLUSIONS

## Overall Findings

This dissertation qualitatively explored childbearing desires and experiences of women and men living with HIV and safer conception in the Iringa region of Tanzania. The four manuscripts presented each tell part of the larger story of how sociocultural and structural forces, including national HIV policies and guidelines, influence fertility desires and behaviors of PLHIV.

Manuscript one sought to better understand the sociocultural and structural context that shapes fertility desires of PLHIV from the perspectives of HIV-infected women and men and health providers engaged in delivering HIV-related services. Respondents reported several factors that motivate PLHIV to have children. Knowledge of prophylactic ART to prevent mother-to-child HIV transmission was reported by HIV-infected respondents as influencing their desire for more children. Compensating for the potential loss of a child in order to reach an ideal family size, wanting to be and be perceived as ‘normal’, and receiving help and assistance from one’s children motivated some PLHIV to desire more children. The perceived inability to care for one’s children in the future and health-related concerns were cited by HIV-infected respondents as deterring them from wanting more children.

Manuscript two presents two case narratives that highlight recurrent features of the lived experience of having children following and HIV diagnosis that emerged from interviews with 21 HIV-infected women and men who reported having children post-HIV diagnosis. Respondents described their experiences and decision-making processes

surrounding childbearing as being shaped by interactions with family and friends, encounters with health providers, and changes in fertility desires over time and life circumstances. Social pressures to bear children by partners and relatives affected the decision of respondents to have children. Some respondents received negative reactions from their relatives and friends about their pregnancies, specifically when they were aware of the HIV-positive status of the respondent. Most respondents had not discussed having children with a health provider before attempting to conceive. Finally, a few respondents reported being reprimanded by health providers for getting pregnant without seeking their advice.

Manuscript three used HIV-infected patient and providers' accounts to better understand patient-provider communication on childbearing and safer conception in relation to current national and international guideline recommendations for PLHIV. We found significant gaps between Tanzania's national guidelines for the management of HIV/AIDS, best practices for safer conception, and actual practices by health providers in delivering reproductive health services for HIV-infected patients attending HIV care and treatment services. There was limited patient-provider communication on childbearing and safer conception. Most health providers interviewed were aware of the national guideline to assess the CD4 count of HIV-infected patients who wish to conceive. However, many patients did not appear to be aware that a CD4 assessment is recommended before attempting to conceive. Though most health providers were knowledgeable of timed unprotected sex during a woman's ovulation period as a safer conception strategy for HIV-affected couples, few patients were aware of this safer conception strategy. Additionally, though most health providers stated that PLHIV have

the right to have children, some patients reported being discouraged by health providers from having more children.

Finally, manuscript four examined barriers to HIV-affected couples adopting safer conception strategies in Tanzania. Findings presented in the manuscript suggest that there are multiple challenges to safer conception that operate at the individual, relational, environmental, structural, and superstructural levels. The barriers to safer conception identified are complex and interact across these levels.

## **Implications for Programs and Policies**

Findings from the four manuscripts have several key implications for programs and policies, which are summarized below. For a more thorough treatment of programmatic and policy implications, refer to the discussion and conclusion sections of the individual manuscripts.

Manuscripts one and two found that many PLHIV desire and indeed have children following their HIV diagnosis. Many of these pregnancies were reported to be unplanned, which is often the case in the context of HIV similar to the general population (Kikuchi, Wakasugi, Poudel, Sakisaka, & Jimba, 2011; King et al., 2011). High rates of unplanned pregnancies hinder health providers from conducting preconception screening and safer conception counseling for reducing the risk of HIV transmission to an uninfected partner and child. Fertility desires of PLHIV were also found to change over time depending on changes in knowledge of PMTCT, previous experiences and current life circumstances. Efforts should be made by health care providers to regularly initiate conversations about childbearing with their HIV-infected patients, both women and men. Furthermore, these

findings point to the need to integrate HIV and sexual and reproductive health (SRH) programs in Tanzania. The integration of SRH and HIV interventions has been shown to have positive effects on multiple SRH outcomes, including reducing HIV incidence (Kennedy et al., 2010). Despite evidence demonstrating the benefits of SRH and HIV integration, integration has not yet been adequately addressed by implementing partners in Tanzania, though is gathering more momentum now as an important and critical issue (C. Asmani, personal communication, July 16, 2013). Additionally, the Tanzania MoHSW is soon to release national operational guidelines for maternal, neonatal and child health and HIV integration. These guidelines will provide guidance to health care providers at all levels of the health system in delivering integrated services and provide a greater opportunity for PLHIV to make informed decisions about their reproductive health (National operational guidelines for integration of maternal, newborn, child health, and HIV/AIDS services in Tanzania, 2012).

We consistently found in our analyses that many PLHIV face challenges in dealing with relatives and community members surrounding their childbearing decisions and experiences. Social pressures to have children in order to gain and reinforce one's status within family and community are sometimes offset by continued stigma surrounding PLHIV having children. Findings presented in manuscript two showed how relatives and friends of HIV-infected participants feared that any child born to an HIV-infected person would be infected with HIV. Perceived and previously experienced undesirable reactions from family and friends may contribute to mental distress and prevent PLHIV from seeking preconception care. Health care providers, including home-based care providers, and social service providers can play a key role in helping their



HIV-infected patients cope with and overcome mental distress caused by social pressures and stigma surrounding childbearing. Interventions that could help address mental distress surrounding childbearing include individual and family counseling and referrals to health facility-based and/or community-based psychosocial support services.

Manuscript 3 highlighted the gaps between Tanzania's national guidelines concerning childbearing of PLHIV, best practices for safer conception, and actual patient-provider communication on childbearing and safer conception. Tanzania's national guidelines for the management of HIV and AIDS and for PMTCT should be updated to provide clear guidance on preconception counseling for HIV-infected patients. These guidelines should include a broad spectrum of feasible and locally appropriate low-technology safer conception strategies for HIV-affected couples. The upcoming revision of the WHO's *Sexual and Reproductive Health Guidelines for Women Living with HIV* (WHO & UNFPA, 2006), which will include official recommendations for safer conception strategies, will provide the ideal opportunity for the MoHSW to update national HIV guidelines to include safer conception for HIV-affected couples. Once evidence-based safer conception recommendations are adopted, health care providers will need to be trained in delivering preconception and safer conception counseling for HIV-infected patients. Task shifting safer conception counseling to lower level health workers, such as home-based care providers and support group peers, with the assistance of job aids and safer conception decision-making tools, could improve the reach of safer conception services by countering barriers to access.

Findings from manuscript four on barriers to the adoption of safer conception underline the importance of developing multilevel interventions that address barriers at

the individual, relational, environmental, structural, and superstructural levels. Though its focus is on barriers to safer conception, a workgroup of multiple and diverse stakeholders could use the framework presented in the manuscript to develop action plans for ensuring access to safer conception for PLHIV in Tanzania. Couple-based reproductive health services for HIV-affected couples could help mitigate challenges to safer conception at the relational level, including gendered power dynamics within relationships, non-disclosure of HIV status and unplanned pregnancies. Health providers could play a key role in counseling couples on sexual and reproductive health issues, including safer conception and family planning. However, they will require guidelines and training. Job aids could be developed to assist health providers deliver couples based safer conception and family planning counseling by describing low-cost and low technology approaches to safer conception. Job aids could further serve as reminders for health providers to talk to their HIV-infected patients about their fertility desires and safer conception.

## **Future Research Directions**

As our knowledge of fertility desires and childbearing experiences of people living with HIV has expanded, future research attention should focus on parenting behaviors and experiences of PLHIV and the adoption of safer conception interventions. Prior to the future adoption of the WHO safer conception guideline recommendations, formative research is warranted in Tanzania to explore the acceptability of safer conception options by PLHIV and to inform the development of training curricula, job aids, and locally appropriate service delivery approaches. Once safer conception

interventions are introduced, their effectiveness in improving outcomes and cost effectiveness will need to be measured.

## **Concluding Remarks**

The research presented in this dissertation advances our understanding of fertility desires and childbearing experiences of PLHIV. Safer conception interventions have been limited to date in Tanzania and there may be challenges with adopting safer conception among HIV-affected couples. However, there are opportunities for directly addressing these barriers so that women and men living with HIV have access to strategies that allow them to bear children while reducing HIV transmission risks.

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## **APPENDIX**

### **Interview Guide #1 for People Living with HIV**

#### **Introduction**

*Thank you for taking the time to speak with me today. I want to give you the opportunity to tell me your story. Please feel free to let me know if you do not feel comfortable with answering any questions and I will move on to the next question.*

---

#### **Experience Living with HIV**

Can you explain to me how you found out that you were HIV-positive?

How did you feel when you were told that you were HIV-positive?

How did you decide whom you would tell about your HIV status?

How has being HIV-positive affected your life?

[Probe: Relationships with family and neighbors; Romantic relationships]

Is there anything that you do differently now that you have HIV? What do you do differently now that you have HIV?

How do you feel in terms of health?

How do you try to maintain your health?

[Probe: antiretroviral therapy, side effects of medication, compliance]

What are you most hopeful for regarding your future?

What do you fear most about your future?

#### **HIV Stigma**

How do you feel about yourself being HIV-positive?

Do you think people treat you differently when they discover that you are HIV-positive? In what ways do people treat you differently? How does it make you feel when people treat you that way?

## **Marriage and Children**

### **Perceptions of Marriage**

What do people in your community think about marriage?

How important is it for a [woman/man] to get married in your community?

What do people think about [women/men] who do not get married?

What happens to [women/men] who do not get married?

Are you married? If yes, what has it been like being married? If no, would you like to get married in the future?

How important is being married to you?

### **Perceptions of, Attitudes Toward, and Desire to Having Children**

What do people in your community think about having children?

How important is it for a [woman/man] to have children in your community?

What do people think about [women/men] who do not have children?

What happens to [women/men] who do not have children?

Do you have any children? How many children do you have?

How did you feel when you first became a [mother/father]?

How did other people feel when you became a [mother/father]?  
[Probe: parents, family, neighbors]

How important is having children to you? Please explain.

Would you like to have [more] children in the future? What makes you [not] want to have [anymore] children in the future?

How do you think others would feel about you having children in the future?  
[Probe: partner, family, neighbors, health providers]

What challenges do you think you might face with having a[nother] child in the future?  
[Probe: medical/health problems, disapproval from others]

## **Communication with Health Providers**

Have you ever talked to a health provider about having a child? Can you tell me about this conversation?

[Probe: If yes, what did the provider tell you? If no, would you like to discuss having children with your health provider? If no, why not?]

What questions or concerns would you like to ask a provider about having children in the future?

What do you think about the conversation(s) that you have had with the health provider about having children?

[Probe: How did they make you feel? How would you suggest that providers discuss this topic with patients?]

## **Knowledge of Safer Conception Strategies**

Are you aware of any ways to make conception safer for you and your partner?

[Probe: If yes, please describe any steps that can be taken and how they might reduce risk of HIV transmission. How did you become aware of these options?(provider, counselor, peers, other?)]

Are you aware of the strategy of “timed, unprotected sex” to reduce risk during conception?

[Probe: If yes, can you identify the steps involved? Is that a strategy that would be feasible/ acceptable with you and your partner? What parts would seem difficult? Is this something you would want to learn more about?]

If female participant has an HIV- partner: How acceptable would self-insemination be for you and your partner?

[Probe: What part(s) would seem difficult? Is this something you would like to learn more about?]

What else would like to share that you think would be important for me to know?

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*Now I would like to ask you a few questions. You may have already told me some of this information when telling me your story, but I would just like to make sure that I have heard you correctly.*

1. Where do you live?

2. How old are you?

3. What is the highest level of education that you completed?

4. What is your marital status?

Married      Single      Divorced      Widowed      Other:

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5a. Are you currently sexually active?

5b. Did you use a condom the last time you had sexual intercourse?

5c. Do you currently use any other form of contraception? If yes, what do you use?

6. Do you have any children? How many children do you have?

7. When were you first diagnosed with HIV?

8. Are you currently on antiretroviral therapy? How long have you been on antiretroviral therapy?

9. Does your partner know your HIV status?

10. Do you know your partner's HIV status? Is your partner HIV positive?

11. Tell me whether you agree or disagree with each of the following statements:

It is difficult to tell people about my HIV infection.	Agree	Disagree	Don't know
Being HIV positive makes me feel dirty.	Agree	Disagree	Don't know
I feel guilty that I am HIV positive.	Agree	Disagree	Don't know
I am ashamed that I am HIV positive.	Agree	Disagree	Don't know
I sometimes feel worthless because I am HIV positive.	Agree	Disagree	Don't know
I hide my HIV status from others.	Agree	Disagree	Don't know

*Thank you for taking the time to talk with me.*



## **Follow-up Interview Guide for Women who Experienced Pregnancy after Knowing Their HIV Status**

### **Introduction**

*Asante kwa kuzungumza tena na mimi leo. Nataka kukupa nafasi ya kunisimulia hadithi yako ya kuwa na mtoto baada ya kugundua kuwa una maambikizi ya VVU. Tafadhali jisikie huru kunijulisha kama hujisikii huru kujibu swali lolote na nitaendelea na swali linalofuata.*

### **PART ONE**

Can you tell me about your experience of getting pregnant after knowing that you are HIV-positive?

GIVE THE RESPONDENT TIME TO ANSWER THIS FIRST QUESTION BEFORE MOVING ON TO PART TWO.

### **PART TWO**

Did your partner know that you were HIV-positive at the time that you got pregnant? Why not?

Was your partner also HIV-positive?

Did you want to get pregnant at that time?

#### ***If NO:***

Why did you not want to get pregnant?

What were you doing to prevent yourself from not getting pregnant?  
[Probe: Contraceptive use; Why were you not using contraceptives?]

#### ***If YES:***

Why did you want to get pregnant?

How did you decide to get pregnant?

Did you do anything special to get pregnant? [If YES: What did you do to get pregnant?]

Who did you talk to about getting pregnant? [Probe: partner, family, and friends]  
[If the respondent did not talk to anyone, ask: Why did you not talk to anyone about getting pregnant?]

Can you describe the conversation you had with [XXX] about getting pregnant?

Probe:

How did [XXX] feel about you getting pregnant?

Did [XXX] know about your HIV status?

What advice did [XXX] give you about getting pregnant?

REPEAT QUESTIONS ABOVE FOR EACH PERSON THE RESPONDENT SAYS SHE TALKED TO ABOUT GETTING PREGNANT.

### **PART THREE**

Did you talk to a health provider about getting pregnant before you became pregnant?

***If YES:***

Can you describe the conversation you had with your health provider?

What did your health provider advise you to do?

How did you feel about what s/he said?

***If NO:***

Why did you not talk to a health provider about getting pregnant before you became pregnant?

Is there any information that you think would have been useful to know before getting pregnant, since you are HIV-positive?

***If YES:***

What information would you had liked to know before getting pregnant?

Are there any services that you think would have been useful to have before getting pregnant, since you are HIV-positive?

***If YES:***

What services would you have liked to have before getting pregnant?

#### **PART FOUR**

How did you feel when you found out that you were pregnant? Why did you feel that way?

How did other people react to you getting pregnant? [Probe: partner, family, friends]

Why do you think they felt that way?

Were you aware of any problems that you might have in getting pregnant?

***If YES:***

What were the problems that you were aware of?

How did you know about these potential problems? [Probe: Who explained this to you?]

***If NO:***

So no one talked to you about possible problems that you might have getting pregnant?

Did you have any problems with getting pregnant?

***If YES:***

What problems did you have with getting pregnant?

How were these problems solved?

***If NO:***

Why do you think you did not have any problems with getting pregnant?

Did you have any problems during or after your pregnancy?

***If YES:***

Can you describe any problems you had during or after your pregnancy?

What did you do for these problems?

Is there anything else that you would like to share with me?

Thank you for speaking with me again today.

## **Follow-up Interview Guide for Men who Experienced Pregnancy after Knowing Their HIV Status**

### **Introduction**

*Asante kwa kuzungumza tena na mimi leo. Nataka kukupa nafasi ya kunisimulia hadithi yako ya kuwa na mtoto baada ya kugundua kuwa una maambikizi ya VVU. Tafadhali jisikie huru kunijulisha kama hujisikii huru kujibu swali lolote na nitaendelea na swali linalofuata.*

### **PART ONE**

Can you tell me about your experience of having a child after knowing that you are HIV-positive?

GIVE THE RESPONDENT TIME TO ANSWER THIS FIRST QUESTION BEFORE MOVING ON TO PART TWO.

### **PART TWO**

Did your partner know that you were HIV-positive at the time that she got pregnant? Why not?

Was your partner also HIV-positive?

Did you want to have a child at that time?

#### ***If NO:***

Why did you not want to have a child?

What were you or your partner doing to prevent yourself from not having a child? [Probe: Contraceptive use; Why were you not using contraceptives?]

#### ***If YES:***

Why did you want to have a child?

How did you decide to have a child?

Did you do anything special so that your partner would get pregnant? [If YES: What did you do to get pregnant?]

Who did you talk to about having a child? [Probe: partner, family, and friends]

*[If the respondent did not talk to anyone, ask: Why did you not talk to anyone about having a child?]*

Can you describe the conversation you had with [XXX] about having a child?

Probe:

How did [XXX] feel about you having a child?

Did [XXX] know about your HIV status?

What advice did [XXX] give you about having a child?

REPEAT QUESTIONS ABOVE FOR EACH PERSON THE RESPONDENT SAYS SHE TALKED TO ABOUT GETTING PREGNANT.

### **PART THREE**

Did you talk to a health provider about having a child before your partner became pregnant?

***If YES:***

Can you describe the conversation you had with your health provider?

What did your health provider advise you to do?

How did you feel about what s/he said?

***If NO:***

Why did you not talk to a health provider having a child before your partner became pregnant?

Is there any information that you think would have been useful to know before having a child, since you are HIV-positive?

***If YES:***

What information would you had liked to know before your partner got pregnant?

Are there any services that you think would have been useful to have before your partner got pregnant, since you are HIV-positive?

***If YES:***

What services would you have liked to have before your partner got pregnant?

#### **PART FOUR**

How did you feel when you found out that your partner was pregnant? Why did you feel that way?

How did other people react to your partner getting pregnant? [Probe: partner, family, friends]

Why do you think they reacted that way?

Were you aware of any problems that you might have in having a child?

***If YES:***

What were the problems that you were aware of?

How did you know about these potential problems? [Probe: Who explained this to you?]

***If NO:***

So no one talked to you about possible problems that you might face with having a child?

Did your partner have any problems with getting pregnant?

***If YES:***

What problems did your partner have with getting pregnant?

How were these problems solved?

***If NO:***

Why do you think you and your partner did not have any problems with getting pregnant?

Did your partner have any problems during or after the pregnancy?

***If YES:***

Can you describe any problems your partner had during or after the pregnancy?

What did you do for these problems?

Is there anything else that you would like to share with me?

Thank you for speaking with me again today.



## **Health Provider Interview Guide**

### **Introduction**

*Thank you for taking the time to speak with me today. I want to give you the opportunity to share your views on the reproductive health of women and men living with HIV. Please feel free to let me know if you do not feel comfortable with answering any questions and I will move on to the next question.*

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### **Clinical Practice**

What is your occupation title?

Can you describe to me a typical day at the health facility for you?

[Probe: Number of clients, working hours and work activities, time spent counseling, time spent filling out paperwork]

How long have you been [treating/counseling] clients?

### **Provide-Patient Communication about Childbearing**

Have you ever talked about reproductive health issues with patients living with HIV?

What reproductive health issues have you discussed with patients living with HIV?

[Probe: pregnancy, childbearing, sexually transmitted infections, infertility, HIV transmission to sexual partners]

Who typically initiated these conversations?

Can you tell me about some of the conversations you have had with patients living with HIV about their reproductive health?

What were some of the questions or concerns brought up by the patient?

What advice did you provide to these patients?

Do you feel you have adequate training/information to respond to patient questions about reproduction?

Are you aware of any guidelines available to HIV providers to assist with such counseling?

### **Perceptions of and Attitudes toward PLHIV having Children**

What do you think are reasons that a [woman/man] living with HIV would want to have children?

How important is it for women and men to have children in this community?

How do you feel about women and men living with HIV having children?  
[Probe for concerns or feelings of ambivalence]

Under what circumstances do you think it would be okay for a woman living with HIV to get pregnant and have a child? Please explain.

Under what circumstances do you think it would be okay for a man living with HIV to have children? Please explain.

What advice would you give a woman living with HIV who wants to have a child?  
[Probe: Have a child with a seroconcordant partner, have a child with a serodiscordant partner]

What advice would you give a man living with HIV who wanted to get married and have a child?  
[Probe: Have a child with a seroconcordant partner, have a child with a serodiscordant partner]

What challenges do you think you a [woman/man] living with HIV might face with having a child in the future?  
[Probe: medical/health problems, disapproval from others]

### **Pre-Conception Resources and Guidelines for PLHIV**

What are the reproductive health needs of women and men living with HIV in this community?

What reproductive health services are available for women and men living with HIV?  
[Probe: In the community, referral services]

What do you think about these services?

What are the guidelines and policies for childbearing among people living with HIV?  
What do you think about these guidelines and policies?

Can you describe any training you have had specific to the reproductive health of people living with HIV?

Would you feel comfortable initiating a conversation with your HIV patients about having children and contraception?

When do you think these conversations about having children should occur?

Do you feel confident that you could counsel patients living with HIV on conception and childbearing? Why or why not?

*How motivated are you to ask patients about their future childbearing goals?*

---

1      2      3      4      5      6      7      8      9      10

How confident do you feel in your ability to provide guidance to patients about their future childbearing goals?

---

1      2      3      4      5      6      7      8      9      10

What barriers do you face in counseling couples with at least one HIV-positive partner about risk reduction strategies for safe conception?

What resources and skills would you need to effectively counsel HIV patients about conception and childbearing?

What else would you like to share that you think is important for me to know?

*Thank you for your participation.*

## Direct Observation Guide

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The purpose of this direct observation is to describe the physical and social settings in health facilities providing HIV care and treatment for people living with HIV in the Iringa region of Tanzania.

Observe the area surrounding the health facility. Draw a map of where the health facility is situated within the community. Describe the geographical location (note buildings surrounding the health facility and road), the people surrounding the facility, and the actual health facility building structure. Enter the health facility and take a seat in the public waiting room. Draw a schematic of the organization of the health facility. Comment on patient-provider interactions, the environment of the health facility, any posters and pamphlets included in the facility, available sexual and reproductive health resources, and the intake process. Note the flow of people in the health facility and describe what people are doing during the observation period.

Spend two to three hours making your observations. Thank the head of the health facility for allowing you to observe for the day. Then leave the health facility.

## **Curriculum Vitae**

### **HANEEFA TASLEEM SALEM**

#### **PERSONAL DATA**

Birthdate and place: February 27, 1982 in Washington, DC USA

Address: 114 West University Parkway, Apt. A3  
Baltimore, Maryland 21210  
USA

Telephone: 202-725-0705

Email: [haneefa.saleem@jhu.edu](mailto:haneefa.saleem@jhu.edu)

Skype: haneefa.saleem

#### **EDUCATION AND TRAINING**

PhD, December 2014. Department of International Health, Social and Behavioral Interventions Program, Bloomberg School of Public Health, Johns Hopkins University, Baltimore, Maryland.

MPH, 2009. Concentration in Social and Behavioral Sciences in Public Health, Bloomberg School of Public Health, Johns Hopkins University, Baltimore, Maryland.

B.A., 2004, Public Health Studies Program, Natural Science Option, Johns Hopkins University, Baltimore, Maryland.

#### **PROFESSIONAL ACTIVITIES**

##### **Society Memberships**

International AIDS Society  
Global Health Council (2009 – 2012)  
American Public Health Association

#### **EDITORIAL ACTIVITIES**

##### **Peer Review**

PLOS One (2014 – present)  
International Journal of Environmental Research and Public Health (2014 – present)

## **HONORS AND AWARDS**

Fulbright-Hays Doctoral Dissertation Research Abroad Grant, Tanzania, April 2013 – December 2013.

Robert and Helen Wright Award in International Health, JHSPH, 2013

Research-to-Prevention Doctoral Student Publication Initiative Award, 2012

Georgeda Buchbinder Award, Department of International Health, JHSPH, 2011

International Maternal and Child Health Training Grant, sponsored through National Institute of Child Health and Human Development, 2010 – 2011

Delta Omega Honorary Public Health Society, inducted in 2009

Milken Scholarship, 2000-2004

## **PEER-REVIEWED PUBLICATIONS**

### **Papers Published**

Saleem, H. & Surkan, P. (2013). Parental pregnancy wantedness and child social-emotional development. *Maternal and Child Health Journal*. 2013, 22:22, doi: 10.1007/s10995-013-1320-z.

Saleem, H., Kyeyagalire, R., & Smith, S. Patient and provider perspectives on improving the linkage of HIV-positive pregnant women to HIV care in Eastern Uganda. *African Journal of AIDS Research*. In press.

### **Manuscripts under Review**

Wenzel, J. A., Mbah, O., Xu, J., Moscou-Jackson, G., Saleem, H., Sakyi, K., & Ford, J. F. A model for clinical trial decisional balance informed by African American cancer patients. *Journal of Racial and Ethnic Health Disparities*.

### **Manuscripts in Preparation**

Saleem, H. & Brahmbhatt, H. Trends in hormonal contraceptive use and the impact of community-wide antiretroviral therapy availability on hormonal contraceptive use in Rakai, Uganda.

## **ABSTRACTS AND CONFERENCE PRESENTATIONS**

Saleem, H., Kennedy, C., Kajula-Maonga, L., Likindikoki, S., Mah, T., & Mbwapbo, J. Community perspectives and recommendations for communication campaigns on concurrent sexual partnerships and sexual networks in urban and rural settings in Tanzania. International AIDS Conference, Washington, DC. July 2012.

Saleem, H., Kennedy, C., Kajula-Maonga, L., Likindikoki, S., Mah, T., & Mbwambo, J. How Tanzanians understand the concepts of sexual networks, concurrent partnerships, and HIV risk: A qualitative study. International AIDS Conference, Washington, DC. July 2012.

Xu, J., Ahmed, S.R., Mbah, O., Wenzel, J., Saleem, H., Phelan, D., Brahmer, J., & Ford, J. Enhancing minority participation in clinical trials (EMPaCT): Preliminary findings of the patient-level needs assessment. American Society of Preventive Oncology Annual Meeting, Washington, DC. March 2012.

Stryker, J., Frazee, J., Saleem, H., & Daniels, B. Formative research to inform the i know campaign. National Conference on Health Communication, Marketing and Media, Atlanta, GA. August 2010.

Kim, A., Kelly, B., Stryker, J., Frazee, J., Saleem, H., Daniels, B., & Ngong, L. Evaluating web 2.0 health campaigns: case study of CDC's i know HIV/AIDS prevention campaign. National Conference on Health Communication, Marketing and Media, Atlanta, GA. August 2010.

Frazee, J., Stryker, J., Saleem, H., Kelly, B., Kim, A., Daniels, B., & Ngong, L. To what extent is the i know campaign promoting dialogue about HIV? A look at preliminary data. National Conference on Health Communication, Marketing and Media, Atlanta, GA. August 2010.

## **RESEARCH GRANT PARTICIPATION**

Title: Experiences of women and men living with HIV in Iringa, Tanzania

Funding Agency: U.S. Department of Education (Fulbright-Hays Doctoral Dissertation Research Abroad Program)

Principal Investigator: Haneefa Saleem

April –December 2013

The goal of this project was to examine fertility desires and behaviors of women and men living with HIV in Iringa, Tanzania.

## **TEACHING EXPERIENCE**

### **Concentration Co-Coordinator**

Social and Behavioral Sciences MPH Concentration, August 2010 – May 2013

Johns Hopkins Bloomberg School of Public Health, Baltimore, MD

### **Teaching Assistant**

Johns Hopkins Bloomberg School of Public Health, Baltimore, MD

Formative Research for Behavioral and Community Interventions, 2011, 2012, 2014

Qualitative Research Theory and Methods, 2012  
Qualitative Data Analysis, 2012  
Health Behavior Change at the Individual, Household and Community Levels, 2010

## **PROFESSIONAL EXPERIENCE**

UNIVERSITY RESEARCH CO.— Bethesda, MD  
Quality and Performance Institute  
Health Care Improvement (HCI) Project  
Intern – Research and Evaluation, April 2012 – January 2013

Provided scientific guidance and support for developing research protocols, study instruments, and data management tools using innovative qualitative and quantitative methodologies. Evaluated health care improvement projects in low- and middle-income countries using quantitative and qualitative research methods. Conducted scientific literature review on quality improvement in low- and middle-income countries, including patient involvement in quality improvement. Wrote USAID technical reports and a manuscript for a peer-reviewed journal.

JOHNS HOPKINS BLOOMBERG SCHOOL OF PUBLIC HEALTH— Baltimore, MD  
Department of Health, Behavior and Society  
Research to Prevention Project  
Graduate Research Assistant, August 2011 – present

Designed the research plan for a process evaluation of HIV-related services in Iringa, Tanzania as part of a USAID-funded project on the evaluation of a combination of prevention interventions to reduce HIV incidence in the Iringa region of Tanzania. Developed study instruments for the process evaluation, including client exit interview guide, provider interview guide, drugs and supplies assessment guide, register review guide, and direct observation guide. Conduct data analyses and report and manuscript writing for various studies under the Research-to-Prevention Project.

Study Coordinator (based in Dar es Salaam, Tanzania), June 2011 – August 2011  
Research Project: *Understandings and Interpretations of Communication Campaign Messages about Concurrent Partnerships, Acute HIV Infection, and Sexual Networks in Tanzania and Botswana*

Managed and coordinated this scientific study from the field. Served as liaison between Muhimbili University of Health and Allied Sciences research team in Dar es Salaam and U.S.-based principal investigator. Developed qualitative study instruments, including interview and focus group discussion guides, and consent forms. Assisted in the submission of study documents for institutional review board approval in the U.S. and Tanzania. Conducted mapping of communication campaigns on concurrent partnerships and sexual networks implemented in Tanzania as one of the study's aims. Carried out site visits with local organizations to discuss and review campaign documents on concurrent



partnerships, acute HIV infections, and sexual networks. Trained interviewers and focus group facilitators in study methods and research ethics. Developed qualitative training curriculum and manual. Coded and analyzed interview and focus group transcripts using NVivo. Collaborated with study team to develop the final report.

JOHNS HOPKINS BLOOMBERG SCHOOL OF PUBLIC HEALTH— Baltimore, MD  
Department of Epidemiology  
Research Project: *Enhancing Minority Participation in Clinical Trials (EMPaCT)*  
Graduate Research Assistant, March 2011 – September 2011

Worked with study team to develop the codebook for the analysis of focus group discussions conducted to explore barriers and facilitators to minority enrollment in therapeutic/treatment clinical trials. Coded and analyzed focus group discussion transcripts using NVivo. Attended periodic data analysis meetings with the principle investigator and fellow data analysts to review emergent themes from the data analysis process.

CENTERS FOR DISEASE CONTROL AND PREVENTION — Atlanta, GA  
Division of HIV/AIDS Prevention, Prevention Communication Branch  
Research and Evaluation Team  
Research Fellow, September 2009 to August 2010

Collaborated with team to develop and implement the scientific evaluation of the *i know* social marketing campaign that encourages conversations about HIV/AIDS among African American youth aged 18 to 24 years through social media, e.g. Facebook, Twitter, YouTube, blogs, etc. Managed the evaluation of the *Act Against AIDS Leadership Initiative*, a \$10 million, five-year partnership with some of the leading organizations serving African Americans and Latino Americans that sought to increase HIV awareness and prevention. Led a team of four evaluators from the contractor. Assisted in the coordination of the development of standard metrics reporting forms for the *Act Against AIDS* campaign. Served as an objective reviewer of applications for a Global AIDS Program review panel on HIV/AIDS prevention and care among rural populations in a sub-Saharan African nation.

ICF MACRO — Calverton, MD  
MEASURE Evaluation Project  
Monitoring and Evaluation Consultant, June 2009 – September 2009

Revised the Malaria Indicator Survey (MIS) questionnaires and training materials based on the most recent Roll Back Malaria guidelines. Revised malaria-specific monitoring and evaluation training curriculum materials. Provided strategic direction to the USAID mission in Mali in the revision of its Performance Monitoring Plan. Conducted a rapid assessment of Mali's multiple indicator cluster survey. Offered recommendations to the USAID mission in Mali on key survey items needed to capture data required to measure key high impact health indicators and provide implementing partners with information to meet program objectives. Developed interviewer and supervisor manuals for an

adolescent sexual health and gender survey study conducted in three countries in sub-Saharan Africa.

JOHNS HOPKINS BLOOMBERG SCHOOL OF PUBLIC HEALTH— Baltimore, MD  
The Lighthouse Studies at Peer Point  
Graduate Research Assistant, October 2008 – May 2009

Examined HIV/STI risk communication and group processing among participants in an HIV peer education program through the qualitative analysis of qualitative group sessions. Conducted literature review on HIV/STI risk communication and group processing.

POPULATION SERVICES INTERNATIONAL (PSI) — Washington, DC  
Asia Region Team  
Senior Program Assistant, April 2007 – June 2008

Communicated with overseas staff and conducted administrative follow-up by liaising with home office support departments on procurement, accounting, personnel, publications, travel, and other project issues. Contributed to the preparation and editing of reports and proposals. Prepared monthly health impact briefs for country programs in the region that highlighted progress on key health and performance indicators. Prepared and monitored operational and donor budgets.

UNITED STATES PEACE CORPS — Cameroon, Africa  
Health Volunteer, September 2004 – November 2006

Wrote a grant that secured funding for a series of hygiene and sanitation training seminars held in five villages in Cameroon. Designed the training curriculum and manual in French for 118 community participants in collaboration with local health officials. Led a team of ten Peace Corps volunteers in the planning and implementation of three youth camps that trained 47 youth in life skills and HIV/STI prevention in three villages in the North province of Cameroon. Organized a three-day women's health fair. Trained nine community members in facilitation skills and reproductive health, nutrition, malaria, and STI issues to conduct workshop sessions in the local language. Facilitated health talks with a local nurse twice a week at the district hospital for prenatal consultations. Health talks were conducted in French and translated into the local language, Fulfulde, by the nurse. Assisted in the revision of the Peace Corps/Cameroon Health Project Plan and the monitoring and evaluation reporting formats as representative of the North province to the health, water and sanitation steering committee.

Volunteer Trainer, October 2006 – November 2006

Developed training sessions and designed training materials for health technical training for Peace Corps trainees based on experiential and participatory teaching methods. Instructed 14 Peace Corps trainees in formal and non-formal education techniques,

interpersonal communication, and counseling skills in preparation for their field assignments.