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Denise Umpierrez Date

Fertility Intentions among HIV-positive women in Atlanta - A Qualitative Study

By

Denise Umpierrez
Master of Public Health

Hubert Department of Global Health

_____
Karen L. Andes, Ph.D.
Committee Chair

_____
Lisa Haddad, M.D.
Committee Member

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By

Denise Umpierrez

Bachelor of Arts
Washington University in St. Louis
2007

Thesis Committee Chair: Karen L. Andes, Ph.D.

Thesis Committee Member: Lisa Haddad, M.D.,

An abstract of
A thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University
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Abstract

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By Denise Umpierrez

With the changing landscape of survival and HIV treatment options, there is an increasing need to address reproductive health and fertility desires of HIV-positive women. This thesis explores the factors influencing fertility desires of African American HIV-positive women in Atlanta, GA. Four focus group discussions and nine in-depth interviews were conducted with 27 women.

HIV-positive women faced issues that women without HIV consider when making pregnancy decisions as well as concerns related to having HIV. The main positive force driving pregnancy was the value of and desire for motherhood. The biggest deterrent to childbearing was vertical HIV transmission. Knowledge of antiretroviral treatment (ART) and the perception of being able to have a baby born without HIV was also a key influencer of fertility intentions for women, especially if the woman had not achieved her fertility intentions when she was diagnosed with HIV. Other factors that modify the women's fertility desires and behaviors included age, parity, money, and religiosity, and perceptions about condoms and family planning methods. Partners had a moderate influence on fertility; however, decisions were often made irrespective of partner considerations. Partners enabled women to achieve their fertility desires by agreeing to unprotected sex; in fact, they often requested unprotected sex and it was the women who pushed for condom use. Although less important than vertical transmission, partner transmission of HIV was also considered when making fertility decisions. Families had little influence on the women's fertility desires and plans.

The findings highlighted that HIV modified pregnancy desires but it far from removed them and that providers were not optimally addressing fertility desires, pre-conception counseling, safe practices, or contraception. The study also underscored how improved understanding of and treatments for HIV have led to increased desires for fertility among HIV-positive women but that many misconceptions still exist and need to be better addressed by healthcare providers and health education support groups.

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CHAPTER 1: INTRODUCTION

The first CDC account of HIV was 1981, the virus was identified in 1984, and the first test to identify the virus was developed in 1985. The initial epidemic arose among gay men in California, however within ten years, the number of infections among women rose until it peaked in 1990. Today, women account for one in four of the more than 1.1 million people living with HIV in the United States.[1] In 2011, women were 25% of new HIV infections; 7,949 women were diagnosed that year. Black women are more likely to be affected than women of other races. Black women are 20 times as likely as white women to be infected with HIV. Of new HIV infections in women in 2010, 64% were in black women, and the Centers for Disease estimating that one in 32 black women today will be diagnosed with HIV at some time in their lives. The epidemic is also one that affects women at the prime of their lives, with the 25-44 year age group accounting for the majority of new HIV infections in women.[2] In the earlier years of the epidemic, women infected with HIV acquired the virus mainly via intravenous drug use (IVDU), however, heterosexual contact has become the main transmission mode in women over time, with 84% of transmission in women coming from heterosexual intercourse in 2010.[1]

In the early years of the HIV epidemic, the diagnosis was devastating for patients, with the average survival after diagnosis being days to months whereas survival for a young person diagnosed with HIV in the current era of highly active antiretroviral therapy (HAART) is 35 years.[3] Along with longevity since the advent of HAART, quality of life of patients affected with HIV has also improved dramatically. The presence of HIV medications has also led to decreased perinatal transmission of HIV. HAART therapy, modified obstetric practices, and replacement feeding have reduced mother-to-child transmission of HIV to 1-2%.[4, 5] Thus, HIV has changed from being a deadly, quick killer to a chronic disease that people can live with for years.

As changes have occurred in the field of HIV/AIDS, women living with the virus are choosing to become pregnant.[6-8] The number of births to HIV-positive women has been increasing, with an approximately 30% increase in births between the year 2000 and 2006.[9] It is imperative to gain a better understanding of what a woman considers prior to becoming pregnant, including her fears, and her support networks in order to provide better counseling, expectant management, and perinatal care in order to have the healthiest mothers and babies possible. This thesis will examine the fertility desires of HIV-positive African American women in Atlanta, GA.

CHAPTER 2: COMPREHENSIVE LITERATURE REVIEW

With the changing landscape of survival and HIV treatment options, there is an increasing need to address reproductive health for HIV-positive women, in particular, issues surrounding fertility desires. In the US, having or desiring children is generally accepted as the norm for women. A study in low-income women reported that American women are expected to finish high school and often even college, marry in their early 20s, and then have children in their mid to late 20s.[10] The importance of motherhood is also seen in HIV-positive women, with a Canadian study showing that 91% of HIV-positive women of reproductive age indicated that motherhood was important to them.[11] These social norms particularly affect the HIV-positive female population since most women with HIV are of childbearing age, with an estimate from the CDC in 2007 being that about 80% are of childbearing age.[8] Thus, knowing that HIV-positive women are navigating these social expectations and personal desires for motherhood, their fertility desires need greater consideration and understanding.

Publications have shown that, since their HIV diagnoses, 30% of women in Ohio[6] and 55% of women in Louisiana[7] have been pregnant and 26-40% of women in the US having had a baby.[8] The number of births to HIV-positive women has been increasing, with an estimated 8,700 births occurring in this population, which is an approximately 30% increase in births between the year 2000 and 2006.[9] Younger women, in particular those under 40 years, immigrants, and black women are more likely to desire pregnancy than older women.[11-15] As with most life decisions, a myriad of factors influence reproductive choices.

Studies have shown that HIV-positive women have a variety of factors that they consider when making pregnancy decisions. The factors that a woman considers vary by geography, income, and ethnicity. A qualitative study published in 2004 that looked at

women in four US cities, including Los Angeles, Milwaukee, San Francisco, and New York, noted that key considerations included vertical transmission risk assessment, risk reduction strategies, outcomes of previous births, desire for motherhood, partner and healthcare worker opinions, religious values, and capacity to parent.[14] A review looking at AIDS in poor women in the US reveals other issues that complicate the dilemma of fertility desires in HIV-positive women include stigma associated with poverty, ethnic minority status, public assistance, substance abuse and single motherhood.[16] Finally, HIV-related stigma influences fertility desires. The Women Living Positive Survey showed that although 61% of HIV-positive women believed that they could safely have children, 59% believed that society strongly urges them not to, and this stigma leads to both positive and negative pregnancy desires. Some women use having children as a way of concealing their HIV status or increasing feelings of self-worth, whereas other women avoid pregnancy to avoid being judged.[17, 18]

Table 1

Factors associated with fertility desires and intentions in women living with HIV[18]

Positive influences	*Negative influences*
Younger age	Personal health concerns
No children	Already having one or more children
Antiretroviral therapy	Concerns about infecting partner
Interventions for PMTCT*	Concerns about infecting child
Partners'/family members' wish for children	Negative or judgmental attitudes of healthcare workers, family, or community
HIV-related stigma	HIV-related stigma

*PMTCT = prevention of mother-to-child transmission

International studies reflect global variations. In the United Kingdom, a multivariate analysis only found number of previous children and years since diagnosis as being associated with desire to have children.[19] A study in Kenya found that children are perceived as requisites for having a fulfilled and happy life and that control of the domain of childbearing played a role in pregnancy-related decisions.[20] This study found that the

biggest barriers to pregnancy were disclosing their HIV status and discussing pregnancy intentions with their partners.[20]

Disclosure of HIV status is mentioned in many papers related to HIV, and is intimately related to the issue of conception. A Kenyan and a Ugandan study found disclosure as a barrier to pregnancy, and the latter explained that fear of disclosure was influenced by gender norms, economic dependency, women's roles as mothers, and young age.[21] In a small US study, fear, stigmatization, and denial were also intertwined in the decision to disclose HIV-status to a partner. In India, repeat pregnancies among HIV-positive women were more likely to occur in women who had not disclosed their statuses to their spouses, and the likelihood of repeat unplanned pregnancies was higher in HIV-positive than HIV-negative women (70% vs. 36%).[22] Issues preventing disclosure in a review of studies from several African countries found the following as barriers to disclosure: fear of accusations of infidelity, abandonment, discrimination, and violence. In this review, between 3.5 and 14.6% of women reported violent reactions from partners following HIV-status disclosure.[23]

Anti-retroviral therapy (ART) appears to play an important role in fertility decisions. Average survival for women if the ART-era is approximately 35 years, which allows women to consider childbearing and motherhood.[3] Increased knowledge about perinatal transmission of HIV, including the role of HAART therapy, modified obstetric practices, and replacement feeding which together can reduce mother-to-child transmission of HIV to 1-2%,[1, 5] have also affected childbearing decisions. Pregnancy rates have increased since the advent of HAART, with birth rates among HIV-positive women increasing 150% from before to after the advent of HAART, as shown when looking at women in the Women's Interagency HIV study in 1994-1995 (pre-HAART era) compared to 2001-2002 (HAART era). This study also found the increased birth rates to be increased in particular among

women over age 35 years (306% increase) and with more than a high school education.[24] The association between HAART and increased fertility intentions can also be seen in Africa, where, in African settings where women have limited access to ARVs, HIV-positive women have lower pregnancy intentions than HIV-negative women,[25, 26] and HAART is associated with increased pregnancy intentions among HIV-positive women. [27, 28] However, there are misunderstandings about how the HAART medications relate to viral transmission. Some women fail to understand the relationship between high CD4 cell counts and low chance of vertical HIV transmission.[20] In a Kenyan study, women believed that feeling well, taking ARVs, and eating nutritious food are sufficient for safe pregnancy,[20] which alludes to the importance of healthcare workers and information dissemination to this population of women.

Despite the importance of discussing fertility desires with HIV-positive patients, many clinicians do not address childbearing and conception with their HIV-positive patients. Patients also do not discuss their fertility intentions with their providers. In a study conducted in Los Angeles, although 39% of patients surveyed reported a desire to have children, two-thirds of clients had not discussed their desires, or methods of safe conception, with providers.[29] Another study conducted in two urban health centers associated with Johns Hopkins, found that only 31% of HIV-infected women had a personalized discussion about childbearing intentions with their providers, although 67% of women did report having had a general discussion about issues and concerns regarding HIV and pregnancy with their providers.[30] Studies in South Africa show similar lack of discussion about childbearing desires as seen in the Los Angeles cohort.[27, 31] A Kenyan study even noted that consulting with healthcare providers was seen as interfering with a woman's decision for pregnancy.[20] Furthermore, when discussions occur, they are more

likely to have been initiated by the patient; in the Hopkins study of the women who had discussions with their providers, 64% initiated the discussion themselves.[30]

Some studies have found that pre-conception planning and risk-reduction information are not readily available to HIV-positive women and couples, and this likely relates to the lack of discussion about fertility desires.[32-34] A study in Los Angeles revealed that there is a knowledge gap about safe ways to conceive among HIV-positive women interested in becoming pregnant. Although 39% of clients in the study reported a desire to have children, most were unaware of methods that are available to increase the safety of conception, and most had not discussed such methods or their desires for children with providers.[29] Given the rising pregnancy rates among women with HIV and the aforementioned barriers to conception including fear of transmission to both partners and offspring, it is interesting that this Los Angeles study showed that only 25% of respondents said that there were methods to ensure that they could conceive a child with limited risk of transmitting HIV to their partner; 69% said they 'did not know.' This lack of communication leads to women becoming pregnant without ever discussing pregnancy with their healthcare providers. Among women who had been or were pregnant at the time of the survey, 57% had not had discussions with their HIV provider prior to conception about HAART or safe methods to conceive.[17]

Talking with providers about pregnancy and conception have to be ongoing, and perhaps because these discussions are not occurring is why a knowledge gap exists related to HAART and pregnancy, safe conception methods, and other fertility related issues such as fecundity. Mindry et al. present data from focus groups with providers, where the providers discuss that, in the early phase of learning about their HIV status, HIV-positive women do not discuss pregnancy and fertility. These providers agree that later discussions about future childbearing are more effective,[29] however, from other research it is clear that these

discussions do not always occur. How information is presented may also contribute to the knowledge gap. Fertility planning and risk-reduction information need to be relevant to the socioeconomic and cultural contexts as well as relationship gender dynamics of patients.[35]

Along with reproductive desires, discussions that should be occurring with HIV-positive women of childbearing age are discussions about contraception and dual protection. Yet studies show that personalized discussions about contraceptive options are not occurring. In Atlanta, one study showed that only about half (50.6%) of sexually active women had spoken with a provider about contraceptive plans in the last year.[36] This also overlaps with the oft seen phenomenon of women not desiring pregnancy but not actively using a contraceptive method to prevent pregnancy. A Canadian study of over 400 HIV-positive women showed that 56% of women identified their last pregnancy as unintended, with no real difference in the last pregnancy being unintended based on the woman's HIV-status at the time (57% before vs. 54% after HIV diagnosis).[11]

The role of HAART on contraceptive use and unintended pregnancy is unclear. Some studies suggest that HAART use has been associated with engagement in unprotected sex. A study looking at participants enrolled in the Women's interagency HIV Study (WHS), a cohort study established in 1993 to look at the natural history of HIV infection in women, found that sexually active women were less likely to report two or more partners in the six month period after HAART initiation compared to before HAART therapy (odds ratio (OR)= 0.79). However, the risk odds of the women having unprotected sex after initiation of HAART was greater, both for women with one partner and those with two or more partners (OR = 1.22 and OR 1.84, respectively).[37] Thus, for these women unprotected sexual intercourse was associated with beginning HAART but not a therapeutic response, and could represent a risk factor for HIV transmission among females. In another study that looked at sero-discordant couples showed undetectable viral load was associated with

having unprotected sex, but HIV-positive participants on protease inhibitors were actually 2.4 times less likely to report unprotected sex than those not on protease inhibitors.[38] Most unprotected sex among serodiscordant couples occurs in primary or long-term relationships.[34, 35, 39] A more recent study suggests that sexually active HAART users may be more likely to practice protected sex and use contraceptives than HIV-positive women not on HAART.[28] Although rates of unprotected sex may not be increased, new treatment options may decrease concerns about HIV transmission, especially among seronegative partners.[38]

CHAPTER 3: PROJECT CONTENT

METHODS

A qualitative research design was used to examine the reproductive desires of HIV-positive women in Atlanta, GA. Corbin and Strauss' method of grounded theory influenced the analysis of the data.[40, 41] The narratives of the women interviewed for this study led to the creation of theoretical categories and informed the understanding of reproductive desires for this population.

For this study, a convenience sample of 28 HIV-positive, pre-menopausal women who admitted to sexual activity (anal, vaginal, or oral) in the last six months was recruited for interviews. Nine in-depth interviews (IDIs) and four focus groups discussions (FGDs) were conducted. The data were collected between June 1 and December 31, 2012, at the Ponce de Leon Center, also known as the Ponce Clinic or IDP, in Atlanta, Georgia. This clinic is a large comprehensive clinic focused on providing integrated treatment for advanced HIV/AIDS and provides services for over 5000 eligible men, women, adolescents, and children. Patients can receive primary care and specialty care services at this clinic as well as social support services. To qualify for treatment at the Ponce clinic, an adult must have a previous AIDS diagnosis and/or a nadir CD4 count below 200.[42] The Ponce Clinic is part of Grady Health System, the fifth largest public hospital in the United States,[43] and, as such, the patients served at this safety-net facility are especially the medically underserved.[44] Women who did not speak English were excluded from the study because of potential inability to understand and participate in the qualitative interviews.

Study recruitment began in June 2012 at the Family Clinic located in the Ponce Clinic. The recruitment process involved screening patient charts upon their checking in for their clinic appointment that day. Eligible participants were recruited in the waiting area or referred by their provider from Monday to Friday. Inclusion criteria were: women with a

positive HIV status, at least 18 years of age but no more than 55 years of age, and sexually active within the last six months. If a woman they met the age and gender criteria, then a member of the research team would call the patient back to a treatment room where the details of the study were explained and the final inclusion criterion assessed. All patients who qualified and agreed to participate in the study were given a copy of the consent form and had the consent explained by a research team member. After patients were consented, they were assigned a participant ID and scheduled for either an IDI and/or FGD.

Interview guides for both the IDIs and FGDs were created by the research team to garner information about the women's knowledge, attitudes, and practices of reproductive health. Questions were created to evaluate three domains: fertility intentions, family planning, and sexual health behaviors. Questions were based on key themes identified from the literature and from the author's clinical and research experience. This analysis will focus mainly on the area of fertility intentions, which includes addressing perception of ideal family size, including social, familial and partner pressures regarding fertility, the influence of HIV and ART on these intentions, concordance among couples on fertility intention, how relationship status influences fertility intentions, and reproductive health issues which may influence fertility intentions. An open-ended technique was used, which allowed the interviewer to focus participants' responses into areas previously not anticipated or areas deemed significant by the participants. The IDIs were designed to be conducted in less than one hour, and FGDs were designed to be between one and two hours in length. All interviews were tape-recorded and professionally transcribed in order to facilitate a detailed narrative analysis.

FGDs were conducted first. Once information saturation, i.e. the information obtained during the focus groups became repetitive and no new information was being gathered, was reached during the focus groups, one-on-one IDIs were conducted to gather

more in-depth data and for triangulation of already gathered data. Attempts were made to ensure that focus groups contained individuals of varying ages and varying lengths of time since diagnosis. Each FGD had three to six participants and, one to three members of the research team present. The focus groups took place at the Ponce Clinic, lasted from one to two hours, and were conducted until information saturation was reached. At the start of each focus group, after verbal consent was obtained, patients were asked to choose a color. The color they chose became their "name" for the duration of the group, in order to maintain patient confidentiality during the recording. Because several women chose the same color, the women were given pseudonyms for analysis and data presentation. A total of four focus group discussions (FGDs), in which 18 women participated, were conducted for this study. After four FGDs, the research team decided saturation was achieved and the interviews were changed to one-on-one in-depth interviews (IDIs) to triangulate findings from the FGDs and to delve deeper into topics with participants. Nine women completed IDIs.

The IDIs were also conducted at the Ponce Clinic and were conducted until saturation was reached. For each IDI, the participant also chose a color to replace their name, filled out the same demographic intake sheet, and was verbally consented before beginning the interview. A total of nine IDIs of approximately one hour in length were conducted. All IDI and FGD participants received a $20 gift card to compensate them for their participation after completion of their respective interviews.

The FGD data were rich, with the women discussing their stories openly. The women responded to both the moderator and each other during discussions. A single interviewer conducted all the IDIs and the conversations, overall, appeared to be less free-flowing in the IDIs, with the participants giving shorter answers and elaborating less than

participants in the FGDs. The data gathered during FGDs was corroborated and enhanced by the IDIs since similar themes arose in both interview types.

This thesis focuses on the analysis of a subsection of the data related to pregnancy, children, and motherhood. This focus was chosen because of the knowledge gap in existing literature, strength of data quality, and the general alignment with stated intent of the thesis. A multi-step approach was used to analyze fertility desires and choices. First, all quotes relating to the code *pregnancy, children, motherhood* (from now on called the pregnancy code) were analyzed. Then the pregnancy code was analyzed again by looking at where it overlapped with other codes thought to be important on the initial analysis. These codes included contraception, anxiety, stigma, passage of time, health/wellbeing, HAART, and social support/family influence. Analysis was done separately for FGDs and IDIs and then the results from the two were compared for similarities and differences. Finally, other codes (mainly contraception & condom use) were looked at in order to expand upon issues mentioned in the pregnancy coded sections that needed further exploration with the goal of best presenting all issues associated with fertility desires.

Data were analyzed using MAXqda version 10 (Verbi GMBH, Berlin). The transcripts of all the interviews were uploaded and a systematic reading of each interview was done. An initial list of codes was developed and then tested on two FGDs and two IDIs. Based on the applicability and usefulness of codes, and after discussion with several members of the research team about the codes, the list of codes was revised. A final set of codes developed, with explanations for criteria for coding. All transcripts were systematically coded using the final list of codes.

The Institutional Review Boards (IRB) of both Emory University and Grady Memorial Hospital reviewed all study materials and protocols. Written informed consent was obtained at recruitment and verbal informed consent was again obtained from all patients

prior to beginning the IDI or FGD.

Table 2

Characteristics of Participants

Interview	Name[1]	Age	# of children	Diagnosed in pregnancy	# of Children since diagnosis[2]	Pregnancy Desire at time of interview
FGD 1	Anna	41	3	No	0	No
	Camille	52	1	No	0	No
	Carol	44	2	No	2	Yes
	Eve	20	1	Yes	1	Maybe
	Erica	35	4 (3 alive)	Yes	3	No
	Sarah	50	1	No	0	No
FGD 2	Diana	35	2	Yes	2	No
	Janet	52	2	Unknown	1	No
	Jenna	52	2	No	0	No
	Patty	49	5	Unknown		No
	Leann	48	1	No	0	No
	Miranda	57	3	Yes	1, and 1 abortion	No
FGD 3	Jasmine	34	4	Yes	4	No
	Lisa	40	4	No	0	Yes
	Jane	49	4	No	0	Yes
FGD 4	Taylor	23	1	Unknown	1	Eventually, not now
	Nicki	26	0	N/A	0	Yes
	Tina	46	3	No	0	No
IDI 1	Sandy	43	3 (2 alive)	Yes	1	No (did until AIDS)
IDI 2	Gladys	52	7	No	0	No
IDI 3	Amy	49	1	No	1	No
IDI 4	Darlene	45	1	Yes	1	Yes
IDI 5	Mary	48	2	No	1	Yes
IDI 6	Eleanor	45	1	No	0	No
IDI 7	Lydia	31	1	No	1	No
IDI 8	Lauren	24	2	Yes	2	Yes
IDI 9	Brenda	37	2	No	0	Yes

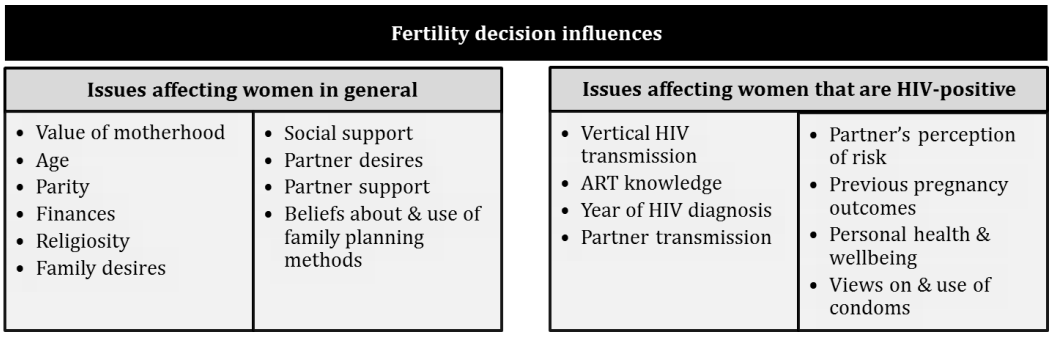
[1] These are pseudonyms given to the participants and not their real names
[2] If diagnosed in pregnancy, includes that child

RESULTS

RESULTS SYNOPSIS

Our results indicate that fertility intentions are complex and multifaceted regardless of HIV status. Women in this study had the influences on fertility intentions that women without HIV have but also an additional set of concerns that complicated their decision-making. The importance of motherhood was echoed in every interview, but, as with women in general, many factors played into whether women then desired pregnancy or chose to become pregnant. Factors that influenced fertility desires and decisions in this cohort of women that are not specific to the HIV-positive population included age, parity, money, partner's fertility desires, family pressure, and views on contraceptive use. HIV-positive women faced an extra set of issues influencing their decisions, including, vertical HIV transmission, transmission of HIV to their partner, pressure to use condoms, partner's and own feelings about unprotected sex, and health status. Furthermore, as the landscape of HIV has changed in the last two decades, these influences have not been stagnant and depending on when a woman was diagnosed, how much was known about HIV and ART early in her disease course, and her access to and knowledge about services also factored into the fertility desires equation.

Figure 1
Fertility Decision Influences



GENERAL FACTORS INFLUENCING FERTILITY INTENTIONS

Value of motherhood & desire for pregnancy

The value of motherhood was clear in every FGD & IDI, with women making statements such as "I think children are the life" (Anna, FGD 1), "That's a real important part of some people's life is to have kids" (Sandy, IDI 1), "Start[ing] my own family, my own generation, that's my biggest issue right now" (Nicki, FGD4) and "It's just that I love kids and I would do anything possible, if I could get pregnant" (Darlene, IDI 5). Almost no variability existed in the data, and all women affirmed that childbearing and motherhood were of great significance, both to themselves and to other women.

Although the value of motherhood was evident, this did not necessarily translate in this group to a desire for pregnancy. Unlike the unanimous views on the value of motherhood, not all women interviewed desired pregnancy at the time of their interviews (eight desired pregnancy, one was unsure, and one desired a child eventually but not at the time of the interview). Largely women who did not want to become pregnant had already achieved their fertility desires. Since their HIV diagnosis, 14 of 27 women interviewed had given birth, and nine women desired pregnancy at the time of the interview. Fertility desires and choices result from the interplay of the often-competing forces of desire for motherhood and HIV-status, along with many other factors, as noted by one interviewee:

> How does a woman decide [whether or not to become pregnant]? For me, my deciding issues would be are we financially stable? Are we both healthy enough to take care of a child? Whether HIV positive or not? I just want our home life to be, you know, stable. Those are the things … the issues I have during that time, well, being pregnant. […] Am I actually ready? Am I emotionally ready for a child? –Sandy (IDI1)

Age

The data revealed that desires often changed as women aged, although older age did not necessarily preclude women from desiring pregnancy. The majority of women over 35 years no longer desired pregnancy, and gave age as one reason influencing their pregnancy desires: "I decided I was getting too old for children" (Sandy, IDI 1). Two women over age 40 still desired pregnancy, so there was no age where one could say a desire for pregnancy no longer exists. However, even for these women, age was still a consideration. Lisa commented that she has to try to conceive "before I get too old. I can't be running around with no 10-year-old child and I'm almost 60."

Parity

The number of children a woman already had, and ideally wanted, also influenced desire for pregnancy. Seventeen women had children before being diagnosed with HIV, of whom only five had children after diagnosis as well. Among women with no children at diagnosis, all but one had a child after diagnosis, and the one without a child desired one at the time of participation in the study. Among the women interviewed, the number of desired children that varied, and there was no number of children after which the desire for pregnancy ended. For a few participants, having one child fulfilled the woman's desire for

motherhood and she did not want any more children. For some, having one child was not enough and they sought further pregnancies.

> I had made up in my mind that two kids were enough for me and I was fortunate to have those. -Carol (FGD 1)

> I was like, well, no, you know I'm HIV positive. I have my son. I don't want to have any more kids. -Erica (FGD 1)

> I think I was going through just something; I was missing the fact that I only had one child. […] we were planning our future and this [having a baby] is what we had planned on doing. -Mary (IDI 5

Finances

Few women mentioned that financial stability influences their pregnancy decisions. Of the four who did discuss the role of finances, one mentioned specifically that money did not affect her decision. Another said the exact opposite, that money was the number one contributor to her fertility decisions. Finally, two noted that finances were a consideration but not the most important.

Religiosity

Religion and God was frequently discussed in both the FGDs and IDIs. Women often "Thank God" for not having transmitted HIV or becoming pregnant, and some mention that religion influenced contraceptive use. It is unclear if God is mentioned merely as a cultural expression. However, there are more active mentions of prayer and references to God, suggesting that religion is an important influence in some participants' lives. In particular, there are mentions of prayer regarding mother-to-child, partner transmission, and fertility.

> I told him, 'Well, you know, we have a child, there's a risk the child can be HIV

> positive. It's a risk that the child will be running back and forth to the hospital a lot and stuff like that.' He told me not to think about that. We just pray and stuff, you know. –Lisa (FGD3)

> At one point, [I] was saying, 'Well, God isn't going to give me no baby because He knows what I'm living with.' –Darlene (IDI 4)

> I don't think there should be birth control. I believe people should have how many kids they want to have. That God want to let them have. –Jasmine (FGD 3)

Family and social influences

In this study, extended family appeared to have little influence on women's decisions to become pregnant. In all of the transcripts, only five short quotes mention the influence of families on fertility decisions. In fact, only one woman mentioned having family or friends' support as a positive influence on her pregnancy desires. In contrast, another woman mentions specifically that her family played no role in her fertility decisions, but explains that this is not the case for all women.

> So, that's one thing, after your medicine and stuff, is cost and who going to help you raise them […] They [family members] said they was going to help me and... mmm-mmm. They was there for a while and they came because I wanted to have an abortion. –Brenda (IDI 9)

> [My family] didn't but I have friends that are being pressure now, even in their forties, to have more children. –Eleanor (IDI 6)

Partner influences

Partners' fertility desires factored into the women's decision-making about childbearing in multiple ways. For three women, it was important to be able to give their partner something they wanted; several women mention their partners' desires when

discussing their own or suggested that childbearing was an important aspect of being in a relationship. For other women, their childbearing decisions were discussed irrespective of relationship status or a partner's desire for children.

> Well when you love somebody, that's like… you want to have, I don't know, a part of the other person. -Amy (IDI 3)

> We were trying to build a future together but he wasn't at the point where he wanted to have a child. He went into his, whatever, his depression, I guess. […] So we ended up having an abortion. –Mary (IDI 5)

> Well I... actually I know like three people that done that, they not even together, but they wanted to have a baby together. […] they both raise the baby together, but they weren't in a relationship though, but they want to have a child with each other. -Brenda (IDI 9)

> In my situation I would because I'd go ahead, because, me and my child's father, he wanted to have one and I did too but then he tried to end his life. So what's the difference in not having one [a baby.] –Taylor (FGD 4)

Participants appeared to believe that women have decision-making capacity about pregnancy. Four of nine women in the IDIs believed that women make pregnancy-related decisions alone, three thought that both people in a relationship make the decision together, and only two believed the man makes the decision. However, it should be noted that not all pregnancy decisions are the result of pre-pregnancy planning, they may also reflect decisions to keep a baby once conception has occurred: "If I'm pregnant, hey, I'm having a baby" (IDI 6).

Some women mention their partners' support during their interviews, but there is also a sense that pregnancy and childbearing tie a man and woman together in a unique way. Women were not directly asked about their current relationship status. For the majority of women, however, it is possible to get a sense for the types of relationships they

had been in. Based on careful review of the transcripts, only seven women had ever been legally married; at the time of the interview, four were married, and one was married but in the process of divorce.

The majority of women appeared to be with a husband or a stable partner at the time of conception. Women clearly valued these long-term relationships and the support they added to their lives. It appeared that many women had also had children with multiple partners; of the 17 women with more than one child, seven women had children by more than one partner. For the remaining ten participants, it is not possible to deduce this information from the transcripts.

> Women have all kinds of reasons for having kids by men. They try to trap them. They love them. For many reasons. For security, good father… they can be good men. –Gladys (IDI 2)

> Well, I think half of the time is unplanned and the other half I think they be wanting to do it because they think the man going to stay, and I keep telling people that's not going to work, that's not going to work. –Brenda (IDI 9)

> It was kind of hard knowing that you're positive and you are pregnant but I had a husband who was understanding who's been there for me. –Eve (FGD 1)

> I'm not saying that I would never expect or want to be married, but just having that connection that I feel like a lot of married people don't have anyway. I know that he's going to be there regardless, and it's not just a stop by, drop by type of thing. –Lauren (IDI 8)

Family planning method knowledge and use

Contraceptives such as intrauterine devices (IUDs), female sterilization, and oral contraceptive pills (OCPs), and condoms were often mentioned interchangeably by participants, however we will discuss condoms separately below because of their unique

role in the prevention of HIV transmission. It is a somewhat artificial distinction, however, as participants often discussed condoms in response to a generic question about family planning methods.

There was a moderate level of knowledge when it came to family planning. All women knew about condoms; the other methods most often noted were Depo-Provera and tubal ligation. The data suggests that higher knowledge of Depo-Provera and female sterilization may be related to provider bias; one participant notes that her HIV-care provider recommended tubal ligation and Depo-Provera only in a comment about not all methods being available at the Ponce Clinic.

> Jasmine: She [my provider] keeps telling me to go to Grady and get my tubes tied because I had forgot if my tubes could have been tied. She was saying you need to get your tubes tied. She said that after my second child, my third child and my fourth child.
>
> Moderator: Your doctor was encouraging you to get your tubes tied? Did she talk to you about anything else? Any other kind of birth control?
>
> Jasmine: Depo. –Jasmine (FGD 3)

> I think my doctor was saying they were going to have to send me to somebody else to get the Mirena. –Unidentified participant (FGD 4)

All methods, including less known methods such as the sponge and diaphragm, as well as modern methods like contraceptive implants, patches and rings, were mentioned at some point during the study. About half of the women used oral contraceptive pills (OCPs) at some point in the past, but most were no longer using them. Much less was known about IUDs, including Mirena and the copper IUD, which were mentioned in three of four FGDs and in seven of nine IDIs. One woman had never heard of an IUD, and another said that it was not a commonly discussed method in the community, "I heard a little bit about it—not much talk about it" (Sandy, IDI 1). In contrast, one participant noted that she knew several

women using the Mirena. At times, it appeared that participants did not have a thorough understanding of specific methods.

> Women have all kinds of reasons for having kids by men. They try to trap them. They love them. For many reasons. For security, good father… they can be good men. –Gladys (IDI 2)

> Since the Mirena is out, I'm going to say I done met over 10 women who have the Mirena. I used to think that it might have been painful, but they say you don't even feel it or nothing. If I was to have go through, I would have went through the Mirena instead of the other things because so many people have complication from Depo and the pills –Lydia (IDI 7)

> And the…what that thing is? The IUD or something? -Brenda (IDI 9)

> I could do the Mirena. That's something that they…I don't know if the NuvaRing is the same as that but they insert that in your cervix too. You go maybe about four years without having a cycle. –Unidentified participant (FGD 4)

Contraceptive implants were more rarely discussed, with very few mentions other than one woman who had previously used a Norplant and another who was currently using an implant. Female sterilization was better known; five of the 18 women in the FGDs discussed having a tubal ligation; risk aversion and being HIV-positive were prominent factors in several women's decisions.

> I found out [my HIV status] when I was pregnant with my son. Immediately I talked to my doctor about getting my tubes tied. […] I was like, 'Well, no, you know I'm HIV positive. I have my son. I don't want to have any more kids.' – Erica (FGD 1)

Two of the five women expressed regret, however, and noted they would have opted differently had the HIV treatment options for safe conception and pregnancy been available, or if they had had more knowledge about transmission-prevention services. The women who chose sterilization had all had children; their choice to have a tubal ligation was made

at different times in their HIV disease course. However, it is clear that all women who had the procedure after HIV diagnosis (four of five), the decision was almost wholly influenced by her desire to avoid perinatal HIV transmission.

> I too after my last child got my tubes tied because I felt like I was fortunate to have those two without any complications and without any problems, but I knew that I didn't want to have a child that was HIV positive. […] Now there are some times that I wish that I hadn't had my tubes tied because I do want another child, but I'm very grateful that I went on and did what I needed to do. –Carol (FGD 1)

Family planning method education

In the interviews, the majority of women noted that they had had little discussion with HIV-care providers about contraceptive options. Women said that they were asked about sexual activity at some point, rarely by an advanced care provider however, and in response were given condom. Service providers did not address fertility desires or advanced contraceptive needs and concerns.

> They kept telling me, 'But do you need condoms?' I'm like, 'Ahh I ain't even doing nothing… no, I got three, four bags you gave me before.' –Brenda (IDI 9)

> Other than the first initial meeting, there really is not a lot of talk with your provider about your essential habits and practices and wants and needs. They always ask when they take your vitals, "Are you sexually active?" That's where they ask. That's just somebody that's just taking your temperature and blood pressure. Other than that, other than the very first time I ever came here, my provider asked me whether I'm sexually active then. At that time, I wasn't; I was at a nursing home and I said, 'No, I'm not.' Even when I got out of the nursing home and then I had a roommate/boyfriend and did become sexually active, that subject did not come up very much at all. –Janet (FGD 2)

> They basically just ask you that just to give you condoms. If you don't address the issue and bring it to them, then you don't … it's not even an issue. –Unidentified Participant (FGD 2)

FACTORS INFLUENCING FERTILITY INTENTIONS SPECIFIC TO HIV-POSITIVE WOMEN

Vertical HIV transmission & antiretroviral therapy (ART)

For all women interviewed, except one for whom finances were of primary concern, HIV and the risk of transmitting the virus during pregnancy or childbirth was the biggest concern when considering fertility decisions. Women in both FGDs and IDIs expressed opinions both for and against HIV-positive women becoming pregnant. Participants who were diagnosed after completing childbearing were more likely to have negative views about pregnancy among HIV-positive women, although these views were in the minority. Also, most women appeared to understand that pregnancy and motherhood are important, and that women would want to have children regardless of HIV status.

> For other people there might be other factors but if you're HIV positive I think that's one of the main factors. […] the main factor is will they pass it to their child—that was the main factor for me. –Mary (IDI 5)

> Personally, I don't think anybody should even attempt to bring a child in to this world with the possibilities of giving them HIV […if someone knowingly transmitted HIV]. I would have them put to death. –Jenna (FGD 2)

> I would have thought about it. If I had wanted to get pregnant, I don't think I would have made that decision not to because by me being HIV and dealing with it, I wouldn't want to have a child that had to deal with the same problem that I had. If it was me, no, I wouldn't have had children. - Camille (FGD 1)

> Every woman's dream, I think, is to have a child one day. A lot of kids that you see now young, they've got it [HIV] from their parents and they grew up with it. Then,

> some catch it from unprotected sex. [...] AIDS is AIDS no matter how you got it. With kids, young people, they want to have kids; they want to have them with their mates. Miranda (FGD 2)

Since ART therapy plays a pivotal role in transmission risk, knowledge of therapies available to prevent mother-to-child transmission are central to fertility desires and beliefs in the data. All women knew that ART could reduce transmission; however the level of knowledge varied. A couple of women knew specifically that the combination of viral load and T-cell count, not just ART, affects HIV transmission to the baby and partner. Other participants mentioned that medication regimens often need changing during pregnancy but were unclear of the exact effects on transmission. Finally, some comments indicated confusion about the statistics the women had heard.

> It's the viral load really and not really … and the T-cells. […] The medication is what helps the viral load and the T-cell count so yes, it's the medication if you're on the right regimen. –Gladys (IDI 2)

> Brenda: I kind of think some of them [HAART medications] you can't take while you pregnant and so I don't know if [they] increase the chances or anything, but I know some women have to change they therapy so the baby won't get it.
>
> Moderator: Okay. So, the medicines make it less likely for the baby to get it?
>
> Brenda: Less likely. That's why they have to change them.
>
> Moderator: Okay. When they get pregnant?
>
> Brenda: When they get pregnant you have to change the medicine you on.
>
> Moderator: Okay. Now, does it affect the ability to give HIV to your partner; the anti-retroviral therapy?
>
> Brenda: That I don't know. -Brenda (IDI 9)

> It was like a 25% chance if you take the medicine and then have a C-section, and take the medicines it was more like 100%. -Jasmine (FGD 3)

Knowledge about ART and its effects on mother-to-child transmission influenced how women interpreted risk and what levels of risk they found acceptable. For some, ART reduced transmission enough for them to consider pregnancy: "I'd stand a good chance [at having a baby without HIV]," or "Yeah, it makes me feel better about it" (Lisa, FGD3) or "Well it makes me feel comfortable" (Nicki, FGD4). Even knowing that the risk of transmission is not zero with ART, women seemed to feel it was an acceptable risk. Nevertheless, women differed in where they drew the line for permissible risk. Some felt that no level of transmission risk as worthwhile (e.g. Jenna FGD2), whereas Darlene (IDI 4) said that a 5% transmission risk was acceptable, while Nicki (FGD 4) stated 5% was too high.

> The medication influences a lot because I know that if take it like I should … like I said, I might become undetectable, the chances are not zero, but lessened. If I was to be pregnant with a child, you know, my child won't get HIV. –Sandy (IDI 1)

The data showed that the risk of vertical transmission influenced participants' pregnancy desires and decisions. For almost all women who desired pregnancy but opted to not have more children, vertical transmission risk was a main factor driving the decision. Of note, women who were diagnosed in the earlier years of the HIV epidemic more often said that they chose to not have children after their diagnosis of HIV.

> I decided to have only one because I don't want to get a sick baby. If God give me one healthy, I'm going stay that way. –Amy (IDI 3)

> Well, a while back … when you think about all the health issues that the child might have to go through. Had I known that I was HIV positive before I had my daughter, I probably would have opted not to get pregnant. Things have changed a lot, you

> know. If I was still able to get pregnant now, I would love to have another child. Now I'm 43 years old and, you know, the body's not equipped for all that right now, so I wouldn't do it, you know. -Sandy (IDI 1)

A few women also mentioned the possible effects of ART on the baby as considerations in fertility decision-making. Brenda (IDI 9), for instance, was concered about side effects: "Yeah, because you don't know the side effects…the medicine will have on the baby and all that." Two other women wondered about specific effects that ART medication may have had on their children.

> I think the medicine or the viruses are sort of in their system, so they can be sick or not. With colds. One child, she used to get diarrhea a lot. She always say, 'What medicine are you taking when you [get it]?' My sisters and brothers, they don't never get diarrhea like I do. I guess it was the medicine that they was on. I don't know. –Jasmine (FGD 3)

> She had allergies, skin problems. She like to diet in February from this thing that they said they couldn't control; they don't know where it came from. Then, what else, she has a lot of weight on. I wonder if because of me having all of these different reactions from the medicine and stuff […] It always stays with me—I wonder if it's that medicine. –Darlene (IDI 4)

Personal experience with HIV & Pregnancy

Several women noted that the outcome of a previous pregnancy influenced the desire to have more children. Previous experience made women more comfortable with knowing about services and methods to prevent mother-to-child transmission. If a previous child was negative, this made the possibility of having another HIV-negative child more real. Similarly, if a previous pregnancy resulted in an HIV-positive child, the desire for pregnancy was sometimes quelled. Women who transmitted HIV to their child expressed strong feelings of guilt. These feelings did not always remove the desire for more children. In one

case, a woman said that her fear of transmitting HIV to another child led her to terminate a subsequent pregnancy.

> When my child was born, my son, when he was born, they immediately started doing tests and they gave him medication. At about 18 months, they told me that his system would kick in. There was still that underlying fear that he would become positive, but he wasn't. In light of at first going through what I went through with him, I was shocked to find out seven years later when I had my second child I was more prepared for what was going to happen. I was more confident that it would be okay because of what I had already been through. -Carol (FGD 1)

> Well, I'm still fertile, but I have not been sexually active and I haven't thought about having no more kids. […] I don't want to go through that again because I had to take medications to prevent him from having the virus and that is something that I should have done with my first son. I just, I don't know. When a man come to me and he want a baby, I'm running. -Diana (FGD 2)

> I felt guilty when I had my son and he had AIDS because I didn't feel like he deserves that. -Miranda (FGD 2)

Personal health status

About one third of the women discussed the importance of their own health in the context of childbearing and motherhood. Five women indicated that their health status directly affected their decision to become pregnant. It was evident that although an HIV-positive woman may desire pregnancy, if she believed her health was compromised, she opted to not become pregnant. The reverse was also true; women who considered their health to be good proceeded with childbearing. Finally, two participants mentioned that health changes over time influenced their motherhood desires and pregnancy choices.

> I decided to have the baby because I was very healthy. I take care of myself a lot. Eating well. My life is kind of quiet, nice. And that was kind of a decision between my doctor and me and my husband to have that baby –Amy (IDI3)

> Well, I wanted more kids, but then I had my boys and by me having HIV that aggravated it more […], and I was like, 'No that's going to be too much.' -Brenda (IDI 9)

> I would think about—pregnancy is hard on a woman's body. […] I'm healthy now am I going to stay healthy later? –Eleanor (IDI 6)

Unplanned Pregnancy

Most women believed that HIV positive women should consider their HIV-status when considering pregnancy and stated that planning pregnancies was important.

> Of course, it should be something that you are thinking about because if you are HIV positive you should be using condoms. It [pregnancy] should definitely be something that you plan. –Unidentified Participant, FGD 4)

> Until you're physically able and mentally ready in the HIV community that I think that a person should plan on giving birth. –Sandy (IDI 1)

A number of women experienced unplanned pregnancies, yet clearly stated the importance of having planned pregnancies when HIV-positive. A few women who had unplanned pregnancies offered explanations:

> [Pregnancy] was just something that happened with me. My children's daddy, we, after I found out I was positive, we were using condoms. Like I said, he was giving me other sexually transmitted diseases and he was the type where the position was doggie style, and he would take the condom off. –Erica (FGD 1)

> [Pregnancy] kind of happened because for a long time I didn't think I could get pregnant because I had been, as I said, trying it. I had been having unprotected sex

> with all kinds of people, and I was getting STDs left and right. Finally, I got into a stable relationship and we were having unprotected sex, and I came up pregnant. I didn't think I could have children because I had been trying. -Carol (FGD1)

Several other women in the study shared the belief that she was unable to get pregnant because of a history of unprotected sex that did not result in pregnancy. There were also comments in the data that suggested that pregnancies were neither planned nor unplanned.

> Well, I think half of the time [pregnancy] is unplanned and the other half I think they be wanting to do it because they think the man is going to stay. –Brenda (IDI 9)

> If you get pregnant, you get pregnant, and then you just have to deal with it. –Gladys (FGD 2)

Termination of Pregnancy

Several participants in this study discussed considering abortion due to transmission risk. A total of three women in FGDs and four in IDIs strongly considered abortions when pregnant after being diagnosed with HIV. Only two, however, reported terminating a pregnancy after diagnosis. For a few women, the pregnancy was too far along when it was diagnosed, precluding an abortion. Two others considered terminating the pregnancy but were convinced otherwise by a partner or family members. Finally, some women said that they were against abortion, yet they still considered terminating a pregnancy because of their disease state.

> I was scared. I didn't know nothing about a woman being HIV positive and being pregnant. I didn't know. I just didn't want my child to be infected you know what I'm saying. […] Like I said if I wouldn't have been too far along I think she probably would have been gone, but hey by the grace of God, you know what I'm saying, she's safe. -Lydia (IDI 7)

> I actually have had an abortion before so it passed through my mind, but like I said, the friendship we had, the relationship we have, I cried, but the first thing I did was I called him. I told him, and I told him I'm scared, 'What do you want me to do?' We know that we want to be together, we know that we already have a child, and he's like, 'It's not even a question.' So that was it. -Nicki (IDI 8)

> I was afraid of having a child who was positive and going through the same thing that I'm going through, that's the only reason. But me, I don't believe in abortion so that was like a real hard decision. I got pregnant with them [first two children] positive, and one is 13 and the other is 12. But unfortunately when I got pregnant with my son I had already fell into AIDS. So it was a hard fight with that, but I thought about it through the whole pregnancy. –Erica (FGD 1)

Partner transmission & condom use

Among the women in this study, partner transmission was also an important factor in women's decisions about pregnancy. Women were asked in the IDIs what concerned them more: having an unplanned pregnancy or transmitting HIV to their partner. Eight of nine women stated transmission was worse. The majority of women also were concerned enough about transmitting HIV that they insisted on condom use, even against their partner's wishes.

> I just would not want it on my conscience that you like that person and you let yourself get talked into not using a condom or something one time. If you were responsible for making someone else positive, that's something that you have to live with for the rest of your life. –Unidentified participant (FGD 2)

> Every time he puts pressure on me to not use a condom, by the way, we have sex, it's like, 'No, no that's not for me.' […] Either you use a condom or we're not doing it. I'm sorry, that's it. There is plenty condoms in the drawer. He tries and he pushes, 'One time is not going to matter.' 'Yes, one time matters for me because I have HIV, okay? It only takes one time.' –Janet (FGD 2)

> Well back when I found out, there wasn't as much treatment as there is now, so my big concern was would I pass it to my unborn child. You know and during the process of getting pregnant was I going to give it to the man. –Eleanor (IDI 6)

Partner transmission seemed to differ from vertical transmission in one key way—partners were able to make a decision about assuming the risk of their own accord. Women appeared willing to have unprotected sex and risk transmitting HIV to their partner if their partner accepted the risk and one or both desired pregnancy. This was evident for women in both serodiscordant and seroconcordant relationships.

> The males knew that I was HIV positive and the males still chose to have unprotected sex. –Carol (FGD 1)

> We did a study, it was like a six month study [to investigate partner transmission of HIV in partners desiring pregnancy]. You had to have one positive partner and one negative partner and we did it for like six months. After going through that study and talking to my doctor for about six months, he convinced me that there were ways that it could be done and my counts were really good at that point, if that is what I really wanted to. –Mary (IDI5)

When asked if it would be worse to transmit HIV to a partner or to have their own health worsen, eight of nine women interviewed feared more for their own health. In particular, women cited a fear of becoming re-infected with HIV, of sexually transmitted infection (STD or STI) acquisition, or worsening health.

> Not knowing what strain of HIV he has and not knowing which one I have. They probably are two different ones. I don't want his. Mine is enough to deal with, so if ...either you use a condom or we're not doing it. –Janet (FGD 2)

> I prefer to use a condom too because I don't want no more than what I already got because really I don't want what I got plus I have hepatitis C. –Camille (FGD 1)

Women also mentioned other factors that contributed to condom use, and thus ultimately affected their fertility. These factors included knowledge ART can decrease rates of partner transmission, relationship status, their own dislike of condoms, fear of physical harm if they transmit HIV to a partner, and lack of disclosure of their HIV-status to their partner.

A few women mentioned female condoms during their interviews, and typically expressed positive opinions. They also endorsed increased education about this method; one woman noted she had heard of the method but did not know how to use it. A couple of women stated that the use other forms of family planning led to decreased condom use. However, when discussing themselves, many women denied that this applied to them.

> A lot of men don't want to wear condoms, but I haven't heard any complaints about the female condoms. […] [more female condom promotion is needed] because a lot of people have never heard of the female condom. –Eleanor (IDI 6)

> I don't want to wish this [HIV] on anybody and I have to protect myself so that I don't get any sicker, so I use condoms, dental dams, female condoms. If he don't want to use a condom, they have female condoms […] He can go bare but I need a female condom. –Carol (FGD 1)

> Moderator: It makes them more likely to use the condom or less likely to use them [if using another family planning method]?

> Brenda: Less likely. […] Because they always be, 'Well, I'm on birth control.' So, they don't worry about nothing else. –Brenda (IDI 9)

> Yes [it decreases condom use], cause most of them are only concerned about getting pregnant, they are not concerned about other things. –Eleanor (IDI 6)

Finally, although not analyzed in-depth for this paper, it was clear from the transcripts that many misconceptions and misinformation existed about various family planning methods. These misconceptions appeared to be barrier to contraceptive use.

CHAPTER 4: CONCLUSION AND RECOMMENDATIONS

DISCUSSION

Motherhood previously has been shown to be a foundational aspiration for many women, "a necessity, an absolutely essential part of a young woman's life, the chief source of identity and meaning."[45] This study confirmed that this aspiration is also prevalent amongst HIV-positive women. The study also revealed a variety of pregnancy decision-making experiences that illustrate the general complexities of fertility intentions, especially among HIV-positive women. Despite the complexity of the decision-making, more than half the women chose to become pregnant or continue a pregnancy after HIV diagnosis. This is different from other studies in which women have not chosen to become pregnant after HIV diagnosis.[6] This is likely an indication of the changing attitudes and knowledge about the impact of HIV on pregnancy choices. Changes to medications, life expectancy, and quality of life, appear to have made a significant impact on the desires of women with HIV to bear children.

The goal of this study was to understand and explore the factors that HIV-positive women consider when deciding on pregnancy, how they have changed over time, and if the factors are different than those experienced by women without HIV. The study looked at African American women of low socio-economic status in the US South, who represent a key demographic for HIV studies. The AIDS epidemic has taken a foothold within this group, with blacks accounting for 44% of both new HIV infections and those living with HIV.[46] In addition, the US South exhibits the highest rates of HIV diagnoses and number of people living with HIV in the nation.[46] Understanding the fertility desires of HIV-positive women in this group presents a significant opportunity to proactively mitigate both vertical and partner HIV transmission through better education and increased counseling.

It was clear that every participant in the study deemed motherhood a key element to leading an enriched and fulfilled life. This supports recent data on the importance of motherhood in HIV-positive populations, and its influence on childbearing desires.[47] Literature on the value of motherhood among American women reveals that motherhood plays a role in women's identities and drives reproductive behavior.[47-49] HIV-positive women in this study considered a similar array of issues when thinking about pregnancy; however their decisions were also strongly shaped by factors related to being HIV-positive, such as ART, vertical HIV transmission, partner transmission, knowledge about transmission prevention strategies, and personal health status and prognosis.

It is important to understand the drivers of fertility to optimize counseling and treatment recommendations. This study revealed that there is a lack of communication with HIV-positive women about their fertility desires and family planning. Women in the study received counseling at diagnosis or when starting care, but noted a lack of follow-up discussions with their health care providers about condoms use, family planning methods, and fertility desires. Many women stated that follow-up counseling would have been valuable.

This study reveals how women's desires and perceptions change over time and with different experiences; thus a one-time discussion is insufficient to address patient needs. In addition, these data suggest that the depth of these discussions is rarely sufficient to adequately understand the complexities of HIV-positive women's fertility desires. This and other studies have shown women rarely discuss fertility desires and intentions with providers, and that when those discussions do occur, they are more likely to be initiated by the patient than the provider.[30] [29] There are several potential reasons for this gap in care. Providers may be uncomfortable with counseling about safe conception and pregnancy, may lack training in this area, or may feel uncomfortable about recommending services that

are not available to low-income women[29, 50] Finally, providers may also project their own stigmas towards people living with HIV.[14, 51] Further research is needed to better understand barriers to counseling, in particular for low-income women, and to create strategies to best address these issues. Of note, several women in the study mentioned going to HIV-education groups, which emphasizes the importance of health promotion groups as adjuncts to clinical care in addressing fertility desires, pre-conception planning and risk-reduction.[32]

Concern for vertical HIV transmission was the main concern when making fertility decisions. This supports earlier findings that HIV-positive women's pregnancy-related attitudes and decisions are mainly associated with assessments of transmission potential.[14] However, the level of risk of transmitting HIV during pregnancy that women were willing to accept varied, and women who had not achieved their fertility desires before becoming HIV-positive were more likely to accept the risk of having an HIV-positive baby. This study included women who were diagnosed early in the HIV epidemic as well as those who were diagnosed more recently, complicating our ability to sort out perceptions of risk from knowledge about HIV and ART. Today, in the era of ART, providers must remember that many women are likely to desire fertility. Providers should discuss pre-conception planning and risk-reduction with patients, and work to improve knowledge of ART and its effects on vertical transmission.

The existence of misinformation in this population is of particular concern because in order to see the greatest reduction in vertical HIV transmission with ART, women must have undetectable viral loads.[52] Another ART-related issue that has not been thoroughly enough explored is some women's fear that their children would be born with negative outcomes due to ART. A few women in this study attributed disease states, such as increased infections and rashes, to ART. This has the potential to be a growing concern in

the HIV-positive community as more and more babies are born to mothers on ART and warrants exploration. Several women in this study experienced unplanned pregnancies; prior studies have shown that women with intended conceptions are more likely to recognize early signs of pregnancy and receive early prenatal care, which would be particularly beneficial in this high-risk population.[53]

In discussing fertility desires and intentions with patients, providers should consider a woman's personal experience with pregnancy and HIV. For women (who were diagnosed with HIV while pregnant) in this study who were pregnant when diagnosed as HIV-positive, the outcomes of these pregnancies affected their future fertility decisions. Good pregnancy outcomes with no vertical transmission appeared to increase a woman's desire for another child and vice versa. Women who transmitted HIV to their child appeared to still be struggling with feelings of guilt, and healthcare providers should also be prepared to address these issues.

For women in this study, partners exerted an inconsistent level of influence on women's decisions about fertility. Some women noted that partners played a role in deciding whether to consider pregnancy or keep a pregnancy. Women were not always married to the partners whose children they were having, and their overall relationship history might suggest that break ups and re-partnering were common. It may be that marriage and relationship support were less important than motherhood among the women in this study, as has been seen in other low-income women.[45] The context of multiple partnerships may confound our understanding of partner influences in this population. It is also possible that having an additional child means something different to women who are beginning a new partnership as compared to those who remain with the same partner and father of their prior children. All of these issues emphasize that providers should not refrain from counseling older women or women who already have children.

Another important way that partners influenced women's fertility decisions was in their willingness to have unprotected sex. The data from this study highlight the need for a greater understanding of male and female condom use, as well as the interplay between barrier methods and other family planning methods in this population. More research is also needed to understand male partners' understanding of and willingness to accept the risk of acquiring HIV. Finally, providers should increase promotion of female condoms since most discussion about lack of condom use indicates that it is men who often do not want to use condoms studies show that female condoms are often not being promoted by healthcare providers, yet their acceptability and satisfaction among women is high.[54, 55]

Religion also influenced fertility desires and outcomes. Given that all participants in our study were African American and that African Americans are considered the most religiously committed racial or ethnic group in the US, religion may play a greater role in this than in other studies.[56] Religion influenced women's use of birth control, making some women less likely to use contraception because of the belief that God should determine how many children a woman should have. Women were also more likely to proceed with childbearing since prayer added an additional perceived protection from vertical transmission of HIV. Finally, although the influence of religion was not explored directly in discussions about abortion, it likely played a role in women choosing not to terminate pregnancies. African Americans report higher levels of conservative ideology and are more likely to oppose abortion than other Americans.[56] Nevertheless, several women in our study considered terminating pregnancies because of HIV status. It is important for providers to consider religious influences on fertility decision-making and family planning use when counseling women. More research is needed to understand how to incorporate religion and religious groups into pre-conception planning, HIV-transmission prevention, and family planning interventions among HIV-positive women.

Greater focus should be given to planning pregnancy in the HIV-positive population. It is important that pregnancy planning be promoted in this population since pregnancies are higher risk because of HIV-status, and studies have shown that women with intended conceptions are more likely to recognize early signs of pregnancy and receive early prenatal care.[53] Further research is needed to understand the factors influencing the disconnect seen between women saying pregnancy planning is important yet having unplanned pregnancies. Furthermore, research is needed to understand the discrepancy between women saying they do not desire conception, yet not using family planning methods to actively prevent pregnancy. Insufficient knowledge of family planning methods and lack of education by providers likely contribute to the rates of unplanned pregnancy and leave room for improvement in educating HIV-positive women about these methods and the role of dual protection.

LIMITATIONS

Of note, the women in this study represented a unique subset of the HIV-positive population due to several key characteristics. First, they were integrated into the HIV health care system at a clinic that provides comprehensive health services for people with HIV. Second, they likely had more severe disease than the general population, since they have had a CD4 count less than 200 or an AIDS defining illness. Third, the women were all African-American and living in the Southern US. Finally, the women are likely to be of lower income and socioeconomic status.[3] The unique characteristics of the women in this study may limit how applicable the findings of this study are to other HIV-positive women. Qualitative research methodology also limits the ability to generalize findings as well as the

[3] Based on income requirements for Ponce Clinic eligibility, since it is part of a safety network of hospitals in the Atlanta area

ability to quantify findings. Finally, because of the breadth of topics addressed in the IDIs and FGDs, not all topics achieved saturation.

CONCLUSIONS

The desire for motherhood remains a defining force in many women's lives, including women that are HIV-positive. This study confirmed that fertility desires indeed remain strong, and are influenced by a variety of factors that evolve throughout the women's lives. In addition, the study highlights the lack of depth and frequency in current treatment options. As such, health care providers should re-evaluate their approach to addressing fertility desires, pre-conception counseling, safe practices, and family planning for women with HIV. If properly addressed, these changes could produce a sizable impact on the reduction of HIV transmission.

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