UNDERSTANDING CHILDBEARING DECISION MAKING WITHIN THE CONTEXT OF SEXUAL AND REPRODUCTIVE HEALTH CARE NEEDS OF WOMEN LIVING WITH HIV/AIDS IN SOUTHWEST NIGERIA

A Dissertation in
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by
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Abstract

In sub-Saharan Africa, women continue to be disproportionately affected by HIV/AIDS. In 2009, of the 22.4 million persons living with HIV and AIDS (PLWHA), 13.4 million were women (UNAIDS, 2009). Women in sub-Saharan Africa between the ages of 15 and 24 years constitute 76% of those at risk for contracting HIV, and the risk of infection for this age group is three times that of the general population (UNAIDS, 2008). As the epidemic enters its third decade, the reproductive choices available to women living with HIV/AIDS (WLHA) are constantly evolving. This is in part due to the availability of antiretroviral drugs (ARVs) and prevention of mother-to-child transmission (PMTCT) services which have contributed significantly to sustaining the reproductive intentions of many WLHA.

The purpose of this study is to examine the sexual and reproductive healthcare (SRH) needs of WLHA in a clinical setting in southwestern Nigeria, and the factors that influence their childbearing (CB) decisions. In this dissertation, I answer three primary questions: (a) How do the perceptions of WLHA SRH needs influence and/or affect their CB decisions? (b) How are the CB decisions of WLHA influenced by their partners’ desires for children? and (c) How does a supportive healthcare system influence the CB decisions of WLHA? In the first three chapters, I describe HIV infection in Lagos and in Nigeria, distinguish between fertility desires and intentions, and describe motivations for childbearing, the theoretical frameworks employed, and the methods used to conduct the study.

Paper 1 (Chapter 4) is based on the first phase of data collection and is grounded in the PEN-3 cultural model. I describe the factors responsible for the CB decisions of WLHA in Lagos, Nigeria by identifying: (a) WLHA perceptions that may promote or hinder healthy
behaviors when factored into CB decisions; (b) enablers, such as healthcare support services, that may influence healthy behaviors and practices; and (c) nurturers, such as partners and family members who may support or discourage childbearing among WLHA.

Paper 2 (Chapter 5) is based on the second phase of data collection and is grounded in the PEN-3 cultural model and the Ottawa Decision Support Framework (ODSF). In this paper, I examine WLHA perceptions of male partner support in the CB decision-making process after disclosure, pre-partum, and post-partum. In particular, I determine whether male partners were supportive, and how this support was shown to their female partners living with HIV. The results reveal that all of the male partners were supportive except one, and the level of support provided remained consistent.

In Paper 3 (Chapter 6), I describe how WLHA interactions with the healthcare system shape their CB decisions. Specifically, I address how WLHA perceive the support and recommendations of healthcare workers (HCWs) related to their CB decisions pre- and post-partum, and what contextual factors within the healthcare system promote or hinder WLHA acceptance of healthcare recommendations. The results reveal that the role of faith was more significant to WLHA pre-partum, while the role of HCWs and access to available healthcare services were important for favorable CB outcomes post-partum.

All three studies provide evidence that CB decision-making is a process that may change over time based on different factors. If the UNAIDS/ WHO goal of eliminating new pediatric HIV infections by 2015 is to be achieved, closer attention must be paid to multiple contextual factors such as cultural expectations and spirituality that may influence CB decisions of WLHA. Furthermore, HIV and other SRH service personnel in resource-limited settings should consider
WLHA perceptions of their partners and the healthcare system when designing interventions in order to help them make informed reproductive decisions.
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Chapter 1. Introduction

Statement of the Problem

HIV/AIDS is a global health problem as well as a social, political, development, and economic problem (UNGASS, 2010) that affects not only individual wellbeing but every aspect of family, political, and economic systems. UNAIDS estimated that in 2008, of the 33.4 million adults living with HIV/AIDS worldwide, about 15.7 million were women; in sub-Saharan Africa, 13.4 million out of the 22.4 million people living with HIV and AIDS were women (UNAIDS, 2009). Most (76%) were young women between the ages of 15 and 24 years, and this age group was three times more at risk of contracting HIV than young men (UNAIDS, 2008). According to the 2010 USAID report, Nigeria is estimated to have 2.98 million people living with HIV and AIDS. In Africa, Nigeria and South Africa are the two countries with the largest number of people living with HIV/AIDS. In 2008, the Federal Ministry of Health’s Antenatal Care Sentinel Survey estimated the national rate of HIV infection in Nigeria to be 4.6% (FMOH, 2010), while the UNAIDS global report in 2010 reported the rate to be 3.6% (UNAIDS, 2010). Comparing the two reports between 2008 and 2010, there has been a 1% drop in HIV prevalence rates among adult women aged 15 to 49 years, which indicates either an actual reduction in HIV infection among women or a large number of unreported and undiagnosed cases. It should be noted that HIV prevalence among pregnant women aged 15 to 49 years who visit antenatal clinics (ANC) is widely used as a proxy to estimate HIV prevalence in the general population (FMOH, 2010).

Healthcare System in Nigeria

The healthcare system in Nigeria is a decentralized, comprehensive system managed by the three tiers of government (federal, state and local government), and private/ non-governmental health care providers (Gupta, Gauri & Khemani, 2003; FMOH, 2004; Tulchinsky
& Varavikova, 2009). In a decentralized healthcare system, authority for managing healthcare is transferred from higher to lower levels of government to try to improve the efficiency of service delivery (Saltman et al., 2007, Tulchinsky & Varavikova, 2009). According to the 2004 Revised National Health Policy (p. 7):

The goal of the National Health Policy shall be to establish a comprehensive health care system, based on primary health care that is promotive, protective, preventive, restorative and rehabilitative to every citizen of the country, within the available resources, so that individuals and communities are assured of productivity, social well being and enjoyment of living.

The 2004 Revised National Health Policy (p. 10), describes three levels of care in Nigeria’s comprehensive health care system:

1. Primary: This level of care includes general health services such as preventive and curative measures and is the responsibility of local governments with support from State Ministries of Health. Private practitioners and traditional healers provide health care at this level.

2. Secondary: This level of care includes specialized services such as physiotherapy, laboratory testing, blood bank services, obstetrics and gynecology for patients referred from primary healthcare practitioners and is the responsibility of state governments.

3. Tertiary: This level of care includes highly specialized services provided by practitioners at teaching hospitals (academic medical institutions) and other specialist hospitals. Advanced medical technology is available at this level. Institutions at the
tertiary level serve as resource centers for the other levels of care. This level of care is largely the responsibility of the federal government.

The Nigerian healthcare system is valued for its comprehensiveness, multi-sectoral inputs, community involvement, and collaboration with non-governmental providers of healthcare (FMOH, 2004; Tulchinsky & Varavikova, 2009).

**Response to the HIV/AIDS crisis.** In 2004, the Nigerian Federal Ministry of Health revised its national policy, which was first formulated in 1988, in response to the HIV/AIDS crisis. The overall goal of the HIV/AIDS policy is to curtail the spread of HIV by providing equitable care and support for persons living with HIV/AIDS (PLWHA) and to focus on prevention so that HIV is no longer a concern for all Nigerians (FMOH, 2004). In addition, the national policy established appropriate institutions at all levels of government (local, state and federal) that are responsible for resource mobilization, monitoring, and evaluation, and for fostering international partnerships to enhance the effectiveness of HIV/AIDS program management (FMOH, 2004). By fostering collaborations among institutions such as the National Agency for the Control of AIDS (NACA), the State Agency for the Control of AIDS (SACA), and the Local Government Action Committee on AIDS (LACA), the Nigerian government has been working to reduce the spread of the disease (NACA, 2001; FHI, 2009). NACA is the main coordinating organization at the federal level that has directed the establishment of SACAs and LACAs to coordinate HIV programs at the state and local levels, respectively (HERFON, 2006).

**Overview of HIV/AIDS in Lagos**

According to the 2008 Federal Ministry of Health’s ANC Sentinel Survey, even though the national prevalence rate is 4.6%, the HIV prevalence rate in Lagos is 5.1% among adult women aged 15 to 49 years, the highest in southwestern Nigeria. In particular, women in urban
areas of Lagos aged 15 to 24 years were most affected by HIV and AIDS with a prevalence rate of 6.1% (FMOH, 2008). Some of the factors reported to be responsible for the spread of HIV in the state include: ignorance about HIV and the modes of transmission and prevention, inadequate STD prevention/diagnosis/treatment, stigma of PLWHA, inadequate care and support of PLWHA, and poverty, especially among the lower class (LSACA, 2006). In an effort to curtail the spread of HIV, the Lagos State AIDS Control Agency (LSACA) was established in 2001 with a mission to “coordinate HIV/AIDS control activities in Lagos State, reduce its incidence, advocate policy formulation and mitigate its impact on both the infected and affected through community participation” (LSACA, 2011).

Given the disproportionate prevalence of HIV among women in Nigeria—about 1.2 million men and 1.73 million women (UNFPA, 2012)—there’s a need to explore the complex cultural norms and social expectations an HIV/AIDS diagnosis has on WLHA fertility and childbearing decisions. These expectations are usually revealed in the ways in which the desire for children competes with a partner’s desire, healthcare support, and anxiety over exposure to HIV.

**Background**

Globally, international agencies such as the World Health Organization (WHO) and several United Nations agencies have issued calls to integrate sexual and reproductive health (SRH) and HIV services to achieve the Millennium Development Goals related to improving maternal health, reducing child mortality and preventing HIV/AIDS (UNAIDS, 2010; UNFPA, 2009; WHO, 2006; WHO/UNFPA, 2006; WHO/UNFPA/UNAIDS/IPPF/UCSF, 2009). Locally, and in response to these calls, in 2010 the Lagos state government created a strategic objective of achieving gender-responsive SRH-HIV service integration by 2015, with at least 80% of adults
accessing these services (LSACA, 2010). A limited number of scholarly studies in Nigeria have offered findings that address the SRH needs of WLHA, including the importance of service integration to achieve optimum health benefits for women.

Two reasons are given for this integration, in addition to the economic implications of cost-effectiveness, such as a reduction in government spending on separate HIV prevention and treatment services. The first is to provide people living with HIV and AIDS with access to all types of services in an efficient and non-stigmatizing manner. Second, integration benefits women more because, compared to men, they are the most affected by HIV due to sexual and reproductive health problems, risk of transmission of HIV to their children and partners, and the risk of unintended pregnancy that may lead to extra spending on treating complications associated with unsafe abortions (Iwuagwu, 2009; UNAIDS, 2010; WHO, 2006). In addition, it is important to acknowledge certain cultural and social norms that place demands on WLHA.

Notwithstanding, integration is bound to increase pressure on providers in the current healthcare system since they are already overworked and stressed due to limited time for patients each day, poor working conditions, and relatively meager remuneration.

Nigeria’s current policies and practices regarding family planning and SRH are based on the 2004 National Policy on Population for Sustainable Development. At the core of this policy is respect for the sexual and reproductive rights of all Nigerians by addressing and meeting their SRH needs, which impacts the population growth rate and the economic development of Nigeria. Furthermore, the policy calls for a reduction in the total fertility rate (TFR) of 0.6 children every 5 years and at least a 2 percent increase per year in the number of married women ages 15 to 49 who use modern contraceptive methods (NPC, 2004). Lastly, the policy suggests improvement in
services by linking SRH with family planning in order to expand and strengthen fertility options available to women (NPC, 2004).

This research has several implications. The findings can potentially: (a) improve our understanding of the SRH needs and fertility desires/intentions of WLHA; (b) help us understand the factors affecting CB decisions of WLHA; and (c) inform policy in Lagos aimed at providing cost-effective integration of SRH-HIV services for WLHA.

Need for the Study

In the summer of 2010, I visited the HIV clinic at the Lagos State University Teaching Hospital in Nigeria where I observed interactions between healthcare workers (nurses and physicians) and HIV patients at the clinic. One particular observation stands out. An HIV-positive woman who visited the clinic was provided with male condoms by nurses and instructed to always engage in protected sex. This was the only information provided to her about safer sex: Always use condoms (i.e., male condoms). On closer observation, I came to realize that all women who visited the clinic received the same condom use directive and were given male condoms. No instructions were given on how to improve or protect their sexual health, nor did healthcare providers assess the women’s sexual health needs and/or reproductive desires.

Initially, I assumed such basic counseling and advice must be provided by physicians, since I did not observe the nurses counsel women on their SRH needs. To confirm this assumption, I asked to sit in on a patient consultation with a physician. During this observation, I realized that physicians also were not addressing issues pertaining to the SRH needs of WLHA. In fact, unless women asked questions related to their probability of having children, no attempt was made by doctors to address this need. In one such instance, a WLHA asked about her chances of getting pregnant since she had no children of her own and was feeling better due to
the antiretroviral therapy drugs (ARVs); the doctor referred her to the gynecologist in another section of the hospital. Given the protocol observed at the hospital, with women arriving as early as 6 a.m. to ensure time with the doctor that same day, it is highly likely that the referred woman did not return to see the gynecologist, and even more probable that the gynecologist would not have responded to the woman’s questions about her reproductive desires.

In clinical encounters like those described above, WLHA are unlikely to obtain answers to their questions, which may lead to unintended pregnancies that may increase the likelihood of passing the HIV virus to their children and uninfected partners. Given the importance of motherhood in Nigeria, the lack of educational interventions for WLHA (particularly those in their prime reproductive years) represents a missed opportunity to prevent the spread of HIV and improve support for these women. Instructing WLHA to not get pregnant by giving them condoms is unrealistic, especially if they believe their health is improving from ARV use (Oladapo et al., 2009; Ujiji et al., 2010). These women continue to contend with a cultural expectation of having children despite their HIV-positive status; a trained public health educator could provide required information and basic SRH education to women at the clinic.

Advances in ARVs ensure that many WLHA are now living longer. The implication is that many WLHA wish to be married and have children (Barnes, 2009; Nduna et al., 2009; Smith et al., 2007). Since marriage and children are cultural expectations, and ARVs are improving and prolonging the lives of WHLA, it is important to obtain a better understanding of these women’s SRH needs so that healthcare workers may better support them.
Purpose of the Study

The purpose of this study is to examine the SRH needs of WLHA who attended a clinic in Lagos, Nigeria and the impact of the healthcare system and their partners’ desires on their childbearing decisions.

Gaps in Existing Knowledge

Previous research findings in the literature demonstrate that women’s childbearing motivations are predictors of fertility outcomes (i.e., fertility desires and intentions), and depend on several factors ranging from personal desires to the influences of partners/significant others and healthcare providers (Cooper et al., 2007; Cooper et al., 2009; Gogna et al., 2010; Nduna et al., 2009; Oladapo et al., 2005; Ujiji et al., 2010). While most of these studies have focused on pregnancy decision making, contraceptive use and the economic and caregiving demands that WLHA experience, only a few studies conducted in Nigeria have explored the complex socio-cultural expectations HIV/AIDS has on their childbearing decisions (Cooper et al., 2007; Nduna et al., 2009; Rutenberg et al., 2000; Smith et al., 2007; Wusu et al., 2003).

Thus, there is a need to understand the SRH needs of WLHA, and the influence of partners/significant others and the healthcare system on childbearing decisions. In this dissertation, I examine the relationship between fertility desires/intentions and childbearing motivators/deterrents within the cultural context of Lagos, Nigeria.

Research Questions

My dissertation research is designed to address gaps in the existing literature by examining the SRH needs of WLHA. The results will improve the ability of WLHA in Lagos to make informed reproductive decisions and live a sexually fulfilling life. The research questions addressed in this dissertation are:
1. How do the perceptions of WLHA regarding their SRH needs influence and/or affect their childbearing decisions?

2. How are the childbearing decisions of WLHA influenced by their partners’ desires for children?

3. How does a supportive healthcare system influence the childbearing decisions of WLHA?

**Research question 1.** Findings offered in the literature demonstrate that women’s motivations for having children depend on several different factors ranging from personal desires to influences from partners/significant others and healthcare providers (Cooper et al., 2007; Cooper et al., 2009; Gogna et al., 2010; Nduna et al., 2009; Oladapo et al., 2005; Ujiji et al., 2010). These factors determine how women feel about carrying a pregnancy to term and whether they will access healthcare services such as ARVs and PMTCT (Gruskin et al., 2008). With regard to personal desires, many African women have been socialized into believing that as wives and mothers, they must fulfill certain roles and expectations (Cooper et al., 2009; Smith & Mbakwem, 2007, 2010). Since motherhood has been shown to affirm a woman’s agency in African societies (Airhihenbuwa, 2007; Amadiume, 1987; Nzegwu, 2006; Oyewumi, 2003), many WLHA want to have children to prove that they are “normal” regardless of their HIV status (Cooper et al., 2007; Cooper et al., 2009; Oladapo et al., 2005; Ujiji et al., 2010). In addition, as shown in previous studies, having children gives some women hope, a reason to live, and the ability to leave a lasting legacy after death (Cooper et al., 2007; Gogna et al., 2010; Iwuagwu, 2009; Oladapo et al., 2005). Recent studies have further suggested that SRH-HIV services must address and support the childbearing needs of WLHA (Gogna et al., 2010; Nduna et al., 2009; Ujiji et al., 2010; Smith & Mbakwem, 2010). Otherwise, WLHA will be discouraged
from seeking advice that will inform their childbearing decisions. While research has suggested the importance of addressing the SRH needs of WLHA, only a few studies in Nigeria, and none in Lagos, have used interviews with WLHA (Oladapo et al., 2005; Iwuagwu, 2009; Smith & Mbakwem, 2007, 2010) to determine their exact SRH needs, whether they are being met, and how they influence fertility desires and intentions. I examine these cultural norms and expectations in my dissertation.

**Research question 2.** Childbearing is deemed a necessary part of marriage in traditional African society (Cooper et al., 2007). Studies show that WLHA lose their desire for sex and are concerned about their failing health or pregnancy’s effects on their health. Despite these issues, however, some WLHA decide to have children to satisfy their partners (Cooper et al., 2009; Iwuagwu, 2009; Nduna et al., 2009). Married WLHA face even more pressure to bear children from their husbands, extended family, and in-laws (Cooper et al., 2007). For example, as shown in findings from the South African HIV stigma study, some WLHA who insisted on dual protection (using condoms to prevent pregnancy and HIV transmission) were abandoned by their husbands who married other women (Sofolahan et al., 2012). Fears of eviction from their matrimonial homes, marital infidelity, and domestic violence are several reasons that many African women, and particularly WLHA in the South African HIV stigma study, decide to have children. Despite the risk of transmitting HIV to their partners and fetuses and without disclosing their status, many WLHA give in to the pressure to have children (Iwuagwu, 2009; Nduna et al., 2009; Smith & Mbakwem, 2007, 2010). Oladapo and colleagues (2005) found that WLHA whose partners desired children also had positive childbearing aspirations.

**Research question 3.** The healthcare system is comprised of healthcare workers and healthcare services such as access to contraceptives, PMTCT, and ARVs. WLHA perceptions of
healthcare workers’ attitudes determine whether they will discuss their childbearing plans with them or even access available treatment services. According to findings from previous studies, WLHA believe that they lack support from healthcare workers (HCWs) and are unsure of how HCWs will react to their childbearing intentions (Cooper et al., 2007; Gogna, et al., 2009; Nduna et al., 2009).

Gogna and colleagues (2009) discovered in a national survey conducted in Argentina that very few WLHA who desired children had discussed their childbearing plans with HCWs. These women reported that childbearing discussions were held only with HCWs perceived to be sympathetic and sensitive to their needs (Cooper et al., 2007; Gogna et al., 2009, Iwuagwu, 2009). Similarly, Cooper et al. (2009) found in a large cross-sectional survey conducted in Cape Town that not only were WLHA failing to discuss their childbearing plans with HCWs, but 11% of WLHA who were not taking ARVs had unintentional pregnancies after their HIV diagnoses, clearly demonstrating their desires and intentions to bear children. Given a healthcare system that neither acknowledges their intentions nor seeks to address their needs, many WLHA are discouraged from seeking treatment options and advice from medical practitioners (Cooper et al., 2007; Harries et al., (2007); Iwuagwu, 2009).

Recommendations commonly made by HCWs to WLHA either include using condoms or waiting for their CD4 counts to be high enough to indicate good health for bearing children (Harries et al., 2007; Nduna et al., 2009; Ujiji et al., 2010). However, for WLHA who desire to have children, condom use is at odds with their childbearing intentions. Many oppose the idea of waiting for their CD4 counts to rise before commencing childbearing, especially when they are experiencing good health due to ARVs. WLHA feel that childbearing is an empowering domain that is under their control; HCW requests to wait for higher CD4 counts are perceived as
restrictive (Ujiji et al., 2010). For these reasons, WLHA stop seeking counseling and treatment advice from HCWs and instead try to conceive children.

In this dissertation, I address how WLHA perceive the support and recommendations of HCWs related to their CB decisions, whether they believe that HCWs are sufficiently addressing their SRH needs, and the contextual factors within the healthcare system that promote or hinder WLHA acceptance of healthcare recommendations.

Assumptions

In this study, it was assumed that the participants were willing and able to honestly discuss their experiences of living with HIV, the care they received and the SRH factors influencing their childbearing decisions. It was also assumed that the participants were willing and comfortable in sharing their childbearing motivations, desires and intentions. Lastly, it was assumed that the interview questions would evoke responses that would be useful in answering the research questions. These assumptions are justified because the women recruited to participate in this study were receiving hospital-based HIV care or were involved in a support group at the hospital. In addition, the semi-structured interview guide was developed by Cooper et al. (2007, 2009) for a similar study conducted in South Africa, and was culturally adapted to fit the context in Lagos, Nigeria. As such, the interview guide was relevant and assumed to evoke responses that would answer the research questions.

Summary

Echoing the words of the former United Nations Secretary-General, Kofi Annan, HIV/AIDS in Africa continues to have the face of a woman. This statement further reflects that young women between the ages of 15 and 24 years continue to be disproportionally affected by HIV/AIDS, especially in sub-Saharan Africa. Nigeria, the most populous African country, ranks
among the African countries with the highest number of PLWHA, estimated to be 2.98 million. This disproportionate prevalence of HIV among women in sub-Saharan Africa (SSA), and advances in ARVs have created a need to examine the SRH needs of WLHA and factors affecting their childbearing decisions. Based on a conceptual framework, an understanding of the different factors that link the relationship between childbearing motivations to fertility outcomes can help identify the information (counseling) and basic education WLHA need to prevent the transmission of HIV to their children and partners, and to better support their sexual and reproductive decisions.
Chapter 2. Literature Review

Childbearing Motivations versus Fertility Desires and Intentions among WLHA

Reproductive desires and intentions, fertility desires and intentions, reproductive expectations, childbearing motivations and parental desires are used synonymously in the literature to refer to the desires of women, and expectations from the collective (family, community members, healthcare workers, socio-cultural environment) to have children now or in the future (Chen et al., 2001; Cooper et al., 2007; Kanniappan et al., 2008; Miller, 1994; Oladapo et al., 2005; Paiva et al., 2007). Previous research findings have documented that women’s intentions, availability of ARVs and the expectations (from the collective) about having children in the future were predictors of future fertility (Chen et al., 2001; Cooper et al., 2007; Paiva et al., 2007).

For the purpose of this study, I distinguish between childbearing motivations, fertility desires, and intentions among WLHA. Using Miller’s definition, motivations are defined as the disposition to act positively or negatively in childbearing, desires are the wishing or longing for children, and intentions represent plans to act on the desire (Miller, 1994). Due to the synonymous use of these terms in the literature, it is important to make these distinctions in the beginning to allow for consistency and clarity.

Child Bearing Motivation: Factors Influencing WLHA Fertility Desires and Intentions

Culturally, having children is deemed as a necessary part of a “successful” marriage in traditional African society. Married women consistently report facing more pressure to bear children due to expectations from their husbands and extended family (Cooper et al., 2007; Iwuagwu, 2009). The motivation to bear children stems from the fact that motherhood is central to an African woman’s identity (Amadiume, 1987; Nnaemeka, 1997; Nzegwu, 2006; Oyewumi,
Furthermore, having children affirms an African woman’s agency, such that a vast majority of adult women, regardless of HIV positive status, still desire to have children. An understanding of WLHA childbearing motivations within the socio-cultural context of Nigeria is therefore important to meeting SRH needs and providing the support needed to help them make positive and informed decisions concerning their fertility.

The decisions of WLHA to bear children are largely dependent on a number of different factors, most importantly, their partners, extended family, and healthcare workers. In addition, the ability to make such decisions depends on the information available to these women, the location of power, and how independent or autonomous they are within their families, society, and the overall healthcare system. Airhihenbuwa (2007) made a distinction between autonomy and independence to frame the different agencies of a woman’s decision-making ability in different cultural settings. According to him, autonomy does not mean being independent in and of itself, but “as long as one’s role and contribution in society are duly recognized and valued economically, culturally, and socially” (Airhihenbuwa, 2007). WLHA in many African countries, do not have the independence or autonomy to go against the socio-cultural expectation of having children, even though they are usually afraid of infecting their children and concerned about the negative impact pregnancy would have on their health (Cooper et al., 2007; Cooper et al., 2009; Harries et al., 2007; Nduna et al., 2009).

**Theoretical Framework**

A number of different theories have been proposed for studying fertility desires and intentions. Some of these theories have been conceptualized based on the psychological value of having children (Arnold & Fawcett, 1975; Bulatao, 1981; Hoffman & Hoffman, 1973). None of the nine psychological benefits identified by Hoffman related to having children acknowledge
the socio-cultural role of the family and community as determinants of an individual’s fertility decisions (Hoffman et al., 1978). In spite of these limitations, among popular value-expectancy models, Fishbein and Ajzen’s Theory of Reasoned Action/Theory of Planned Behavior (TRA/TPB) is still the most commonly used to explain fertility behavior (DelaCruz, 2010; Finocchiaro-Kessler, 2009; Miller, 1994). TPB is based on the assumption that individuals do not have full control over their behavior, and the determinant of a behavior is the intention to act on that behavior (Glanz, Rimer, & Lewis, 2002; Martin, Zolnierek, & DiMatteo, 2010). TPB has three components that consider the roles/expectations of significant others in predicting human behavior: attitude, subjective norms, and perceived behavioral control (Martin, Zolnierek, & DiMatteo, 2010).

However, such theoretical frameworks do not account for the collectivistic nature of many African societies. In these societies, childbearing does not constitute an individual affair, but a culmination of social factors that transcend the individual (Airhihenbuwa & Obregon, 2000). Therefore, the theoretical framework that guided the overall study, data collection, and analysis is the PEN-3 cultural model. The PEN-3 cultural model allowed me to ask questions relevant to the domains of the model, and was flexible enough to allow me to explore other emergent issues such as the role of spirituality.

**PEN-3 model.** The PEN-3 cultural model was developed by Dr. Collins Airhihenbuwa of Penn State University to aid in understanding the role of culture in addressing Africans’ health behaviors and decisions (Airhihenbuwa, 1995; Airhihenbuwa, 2007; Airhihenbuwa & Webster, 2004). PEN-3 has three domains, and each domain has three dimensions. The three interconnected domains are Cultural Empowerment, Relationships and Expectations, and Cultural Identity. In the first domain, Cultural Empowerment, PEN stands for the *Positive* values
that promote the health decisions or behaviors of the person; *Existential* values, those unique attributes specific to the culture that pose no threat to the health of the person; and *Negative* values, those health decisions or behaviors rooted in cultural practices that may cause harm to the individual. The second domain of Relationships and Expectations includes *Perceptions* held by people (WLHA) that may promote or hinder health behaviors and decisions; *Enablers* that may encourage or discourage healthy behaviors and practices (e.g., the healthcare system); and the *Nurturers* that are supportive in reinforcing or discouraging the behavior (influence of partners/significant others). The third domain of Cultural Identity, which is usually the point of entry for the intervention, examines how one’s identity plays a critical role in influencing decisions from the context of the *Person*, the *Extended Family* and the *Neighborhood*.

The Relationships and Expectations domain was of particular interest in this study and was used to qualitatively explore the roles of partners and healthcare practitioners, WLHAs’ perceptions of their SRH needs, and the subsequent impact on fertility desires and intentions.
Figure 1. The PEN-3 cultural model.

**Ottawa Decision-Support Framework (ODSF).** In Paper 2 (Chapter 5), I used the Ottawa Decision-Support Framework (ODSF) as the theoretical framework. ODSF was developed by O’Connor and colleagues (2006) at the Ottawa Health Decision Center to help practitioners and patients make informed healthcare decisions. ODSF is designed to guide individuals in making high-quality, informed decisions that are consistent with their personal values (Doull et al., 2006). According to ODSF, decision-making is influenced by several factors, such that the decisions made may be modified through the support available to make such decisions (Allen & Berry, 2011). These decision-determining factors include: (a) perceptions about the decision, (b) perceptions of significant others, and (c) personal and
external resources available to make the decision. In the second paper, I focus on WLHA perceptions of the role of male partners in childbearing decision-making. Perceptions of significant others such as male partners may include factors such as pressure to make a certain decision, support for decisions made, the role of partners in decision making, or perceptions of what partners think (Allen & Berry, 2011; Doull et al., 2006).

Summary

In this chapter, I began by distinguishing among terms commonly used in the literature to refer to fertility desires and intentions, such that an operational definition of how the terms will be used in this study was outlined. Because the reasons behind the desires of women living with HIV/AIDS to bear children are quite complex and diverse, I explored some of the factors influencing their childbearing decisions. I examined some of the theories commonly applied in understanding fertility behaviors and noted their limitations. The PEN-3 cultural model, the theoretical framework guiding the overall study, addresses the limitations of these theories. I discussed how this research fits in with existing theories commonly used to understand fertility behaviors.
Chapter 3. Methodology

Study Location

Nigeria. Nigeria is a country situated in West Africa and it is bordered by the Republic of Benin on the west, Niger on the north, the Gulf of Guinea on the south, and Chad and Cameroon on the east. The total area is 923,748 square kilometers, making it the 32nd largest country in the world (CIA World Fact book, 2011; Motherland Nigeria, 2011). Nigeria is comprised of 36 states and a federal capital territory, and is divided into six geo-political zones: South-East, South-West, South-South, North-East, North-West, and North-Central.

Figure 2. Map of Nigeria.
Nigeria is the most populous country in Africa with an estimated 158 million people as of 2010. This number is expected to increase to 326 million by the year 2050 (PRB, 2010). The total fertility rate (TFR) of 5.7 children born per woman is one of the highest in the world making Nigeria a country with a high population growth rate (NPC, 2008; PRB, 2010).

Although English is the official language, Nigeria has three main ethnic groups/languages; Yoruba, Hausa, and Igbo. There are over 500 languages and more than 250 ethnic groups (CIA World Fact book, 2011). In addition, Nigerian Pidgin English is a popular lingua franca spoken in almost all parts of Nigeria. Christianity is the predominant religion in the South among Igbos, Islam is predominant in the North among the Hausa/Fulani, and Yorubas practice either Islam or Christianity. Many others practice traditional African religions to varying degrees (NDHS, 2008).

**Lagos.** Lagos is located in the southwestern coastland of Nigeria. It is bounded by Ogun state in the North and East, the Republic of Benin in the West and the Gulf of Guinea in the South (LSACA, 2006). Until 1991, Lagos was the capital of Nigeria, and it remains the commercial capital.

The population of Lagos state is estimated at 9 million people, and the total fertility rate of 5.4% makes it the second most populous state in Nigeria (NPC, 2006; NBS, 2006). Lagos is considered to be “a melting pot of cultures” with a blend of people from different ethnic/cultural groups (LSACA, 2006). However, the main ethnic group is Yoruba with sub-ethnic groups of Awori, Ogu, and Ijebu (LSACA, 2006). English is the official language, Yoruba is the main language spoken, and Pidgin English is used mostly for commercial purposes.

**Study site.** This study was conducted at a government teaching hospital in southwestern Nigeria. Participants were recruited from the hematology and pediatric departments at the Lagos
State University Teaching Hospital (LASUTH). Lagos State University Teaching Hospital (formerly Ikeja General Hospital) was commissioned in 1995 for treatment of HIV patients for residents of Ikeja and its environs. In 1999, it was transformed into a teaching hospital and it is now a 484-bed specialist hospital. It has a staff of 134 consultants (including 8 professors), 239 junior and senior resident doctors, 459 management staff, 176 technical staff, 22 physiotherapists, 691 registered nurse/midwives, 26 dentists, 112 administrative staff and 384 support staff (catering, cleaning, domestic, engineering, laundry, transport and security), that collectively serve over 51,000 patients every month (LASUTH, 2010). The hospital includes a general outpatient unit, a critical care unit, and a family medicine unit, and provides community health, accident and emergency services (LASUTH, 2010). This hospital is considered to be one of the best teaching hospitals in Lagos; it is known for producing quality research and training a large number of health care professionals to cater to the needs of Lagos state inhabitants.

LASUTH was chosen as the study site since HIV care was being provided at a highly subsidized rate by the Lagos state government. Such subsidies enable WLHA from diverse backgrounds to access care, thereby providing a form of purposive sampling called maximal variation sampling. WLHA with diverse views on the topic of SRH needs and their fertility desires/intentions were recruited to participate in the study. According to Cresswell and Clark (2011), this sampling strategy is rigorous in reflecting the different views of the participants and providing a complex view of the phenomenon studied.

**Study Design**

A semi-structured interview guide adapted from Cooper and colleagues at the University of Cape Town was used during the pilot phase of this study to explore childbearing desires and sexual and reproductive healthcare (SRH) needs, and their influence on the childbearing
decisions of WLHA. During the follow-up phase, I used a semi-structured interview guide to explore WLHAs’ childbearing experiences, future childbearing desires, husbands’/partners’ feelings about previous pregnancies, and role of partners after disclosure of HIV status and during pregnancy. The Chief Nursing Officer (CNO) at the hematology clinic was very supportive of the research and served as the gatekeeper who facilitated my entry into the clinic.

**Phase 1 (Pilot).** The study was conducted in the hematology section of the outpatient clinic at LASUTH. Three days of the week were reserved as clinic days for attending to HIV cases. The clinic opened its doors at 8 a.m., but some women arrived at the gate of the clinic as early as 5 or 6 a.m. to wait in line. After the gates were opened, the women were ushered in to wait under a shed outside the hospital building. While there, the nurses took their vital signs such as weight and blood pressure. Some activities took place under the shed before the nurses began their duties, including lectures from nutritionists and dentists about healthy eating and oral hygiene, and pastors praying for PLWHA. Once the nurses finished taking the vital signs, they organized the patients’ folders in order of arrival time for distribution among the physicians on duty. The patients were ushered into the waiting area inside the clinic by the nurses and waited patiently until their names were called either by the nurse or by an orderly to be seen by the physician. Usually, five or six physicians were available to consult with patients. Once patients had seen a physician, they proceeded to the counseling section where a counselor verified medication adherence. Afterwards, they were sent to the records department to schedule their next appointments. Finally, they took a number and waited for their turn at the pharmacy to receive a 3-month supply of ARVs. The pharmacy is usually where patients waited the longest. Usually, three or four pharmacists were on duty. The pharmacists counted pills and recorded all information by hand.
Recruitment. The first project phase was conducted between July and August 2011. Purposive sampling was used to recruit WLHA from the HIV clinic at the Lagos State University Teaching Hospital (LASUTH). The inclusion criteria were: women 18 years of age or older, clinical diagnosis of HIV, receipt of hospital-based care or involvement in a support group at the hospital, and willingness to discuss experiences related to living with HIV and care received. Initially, participants were recruited through referrals from the resident physicians. About a week into the study, however, I realized that physicians often forgot to refer potential participants to the study because the clinic was so busy. In addition, when referrals were made, potential participants were not interested in extending their time spent at the hospital by participating in interviews, as they simply wanted to complete the tasks that brought them to the hospital. So, we devised an alternate approach and recruited potential participants while they were waiting to collect a 3-month supply of ARV drugs at the pharmacy. This approach worked better, because WLHA were more relaxed during the final stage of their visits.

Participants. Sixty-three WLHA were recruited, but only sixty were interviewed. Three participants refused to participate in the study, either because they did not want to be recorded or time constraints. Participants were interviewed individually in a private room at the clinic. All interviews were audio recorded and conducted in one of the three main languages spoken in Lagos (English, Pidgin English, or Yoruba). Verbal informed consent was obtained from participants prior to recording. Each interview lasted between 45 and 60 minutes. The participants were given 1000 Naira ($7) as an incentive to cover their transportation costs. Ethical approval was obtained from the Institutional Review Boards of Penn State University and LASUTH.
Phase 2 (Follow-up). The second part of the study was conducted between July and August 2012 in the pediatric and hematology sections of LASUTH. The pediatric clinic was visited twice a week, because infants of WLHA were primarily seen on those days. In order to protect the privacy of patients, a special code on their folders indicated HIV exposure or infection. The caregivers who brought the children to the clinic were mostly women—mothers, grandmothers or aunts. As in the hematology clinic, most of the staff members were women. Upon arrival at the clinic, the women and children waited under a shed outside the building. The nurses then ushered the women and their children in batches of 10 to 15 inside the clinic, where they sat in order of arrival until they were called into the physician’s office. While in the waiting area inside, the nurses checked the weights of the babies and recorded the information in their folders. Out of the five rooms in the clinic, only two were used for consultations. One or two medical students in training usually assisted the physicians. During consultations, the physicians compared each baby’s current weight to his or her previous weight at the last visit, checked the results of each baby’s HIV test, confirmed ARV use, and asked each caregiver if she had any questions or concerns. Due to a lack of space at the clinic, once the women were done with the physicians, I would interview them in the resident physician’s private lounge area or I would take them to a private room in the hematology clinic.

Recruitment. A total of 15 WLHA were recruited from the pediatric clinic and the hematology clinic, including six of the women who were previously interviewed during the pilot phase of the study. Out of the 11 pregnant participants in 2011 who had approved further contact for follow-up interviews in 2012 after the births of their children, only six were able to be interviewed. Of the five participants lost to follow-up, two had miscarriages, two were no longer willing to participate, and one had changed her number. Prior to the beginning of the study, the
11 pregnant women who were previously interviewed were contacted via telephone three
different times over the course of the year. The first call was to ask how the pregnancy was
progressing and to find out if they had given birth. The second call was to check up on them and
the babies. The third and final call was to remind them about the study and to reconfirm
participation in the follow-up as they had agreed the previous year. In addition to the six who had
agreed to follow-up interviews, nine new women who had babies during the year were recruited
to participate in this phase of the study.

Participants. The inclusion criteria were that participants had to be between the ages of
18 and 43 years, and have a child less than 1 year old. Participants were interviewed individually
in a private room at the clinic. All interviews were audio recorded and conducted in either
English or Pidgin English. Verbal informed consent was obtained from participants prior to
recording. Each interview lasted between 30 and 45 minutes. The participants were given 1,000
Naira ($7) as an incentive to cover their transportation costs. Ethical approval was obtained from
the Institutional Review Boards of Penn State University and LASUTH.

Qualitative Data Analysis

All interview transcripts from the pilot phase were read thoroughly to become immersed
in the data, and then loaded into NVivo 9 to aid in organization and data management. Using
constant comparison consistent with Glaser and Strauss’ (1967) approach to open coding, free
nodes were generated. Based on similarities, these free nodes were organized into related
categories or themes guided by the PEN-3 model to generate tree nodes (axial codes). Finally,
emerging themes were organized into categories within the Relationships and Expectations
domain of PEN-3. To ensure data reliability and validity, member checking was used, whereby
another researcher reviewed the codes.
All interview transcripts from the follow-up phase were read and coded independently by the researchers to ensure intercoder reliability. A reflective memo and log of ideas that emerged during the coding process also facilitated the process. Morse and Field’s (1995) approach to content analysis was used to organize responses from the in-depth interviews into categories; data were sorted into each category until saturation was reached. Using the PEN-3 model as a guide, the categories were grouped into themes based on similarities.

**Summary**

In this chapter, I presented the theoretical framework guiding the study, and described the study setting and location as well as the methods used for data collection and analysis. The PEN-3 model emphasizes the need to focus on cultural factors that influence childbearing decision-making among WLHA. By conducting the study in two qualitative phases, this study offers a unique opportunity to better understand the different views of WLHA before and after their childbearing experiences. The qualitative research design provided an in-depth understanding of the SRH needs and childbearing decision-making process of WLHA by enabling their voices to be heard.
Chapter 4. Paper 1

Childbearing Decision Making: A Qualitative Study of Women Living with HIV/AIDS (WLHA) in Southwest Nigeria

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Human Participant Protection: The study protocol was approved by the Institutional Review Boards of Penn State University and the Lagos State University Teaching Hospital. Informed consent was obtained from all participants.

About the Authors: Yewande Sofolahan and Collins Airhihenbuwa are with the Department of Biobehavioral Health, Penn State University, University Park, PA.

Conflict of Interest: No conflict of interest has been declared by the author.


* Since this is a 3-paper dissertation, paper 1 appears in its published format, and the reference style required by the AIDS Research and Treatment journal was preserved even though the entire dissertation used APA style.
Abstract

Using the PEN-3 model, the purpose of this qualitative study was to understand the factors responsible for the childbearing decisions of women living with HIV/AIDS (WLHA) in Lagos, Nigeria. Sixty WLHA who sought care at a teaching hospital in Lagos were recruited to participate in in-depth interviews. The average age of the participants was 30 years, and 48 participants were receiving antiretroviral therapy. Healthcare and spiritual practices, healthcare provider-patient communication about childbearing, and husband/partner support emerged as factors that contribute to the childbearing decisions of WLHA. The findings reveal the importance of discussing sexual reproductive health and childbearing issues with WLHA in the healthcare context prior to pregnancy.
Introduction

Childbearing (CB) is a source of concern for women living with HIV/AIDS (WLHA), because of the risk of HIV transmission to children and sexual partners [1-4]. WLHA must consider many factors when making childbearing decisions, including support from partners and healthcare providers [1, 3, 5].

As the HIV/AIDS epidemic enters its third decade, the reproductive choices available to WLHA are evolving. The initial recommendations of the CDC in 1985 and the American College of Obstetrics and Gynecology in 1987 discouraged WLHA from getting pregnant [6]. In 1994, the American Society for Reproductive Medicine encouraged physicians to discuss other options such as assisted reproductive technology [6]. Unfortunately, some of the recommended assisted reproductive technologies are not widely accessible to WLHA in resource-constrained settings [4]. However, given that many women believe that a woman’s identity is affirmed by her motherhood status [5, 7, 8, 9], many WLHA in these settings make plans to have children with partners whose HIV statuses are sometimes unknown. By doing so, WLHA are at an increased risk for infection with other STIs or re-infection with a different strain of HIV by engaging in unprotected sexual practices to become pregnant [1, 4].

Women in sub-Saharan Africa between the ages of 15 and 24 years constitute 76% of those at risk for contracting HIV, and the risk of infection for this group is three times that of the general population [10]. Because HIV affects mostly women in their reproductive years, decisions about childbearing among WLHA continue to be a subject of debate in resource-constrained settings. Despite advances in antiretroviral (ARV) therapy and prevention of mother-to-child transmission services, many WLHA in these settings wrestle with the decision to have
children [1, 3]. Moreover, since it is perceived that many healthcare workers are unsupportive of WLHA childbearing plans, WLHA often are discouraged from having children [3].

In this paper, we examine the ways in which childbearing decisions of WLHA are influenced, especially by partners, families and healthcare workers [1, 2, 4, 11, 12]. Moreover, the power to make such decisions depends on the information available to these women and how independent or autonomous they are within their families and society at large [7]. Many WLHA in this study population in Nigeria do not have the independence or autonomy to make decisions on childbearing outside their socio-cultural norms [7, 13].

Our aim was to examine the childbearing decision making process of WLHA by utilizing the culture-centered PEN-3 model. We assess the values and beliefs that underlie WHLA perceptions; reveal enablers, such as available healthcare support and resources; and identify nurturers, such as the influence of partners involved in their decision-making.

**Theoretical Framework**

The PEN-3 cultural model is used to examine the role of culture in addressing beliefs and behaviors that contribute to health decisions [7, 14]. The PEN-3 model emphasizes the need to focus on the cultural factors that influence decision-making [7]. In other words, the emphasis is not on the individual, but on multiple factors that collectively shape health decisions.

PEN-3 has three domains, and each domain has three dimensions (see Figure 1). The three interconnected domains are cultural empowerment (CE), relationships and expectations (RE), and cultural identity (CI). CE considers the positive, existential and negative cultural values that are factored into health behaviors and decisions. RE considers factors such as perceptions, enablers and nurturers that influence health behaviors and decisions. CI reveals the appropriate level of focus for health interventions – the person, the extended family, or the
neighborhood – by addressing how one’s identity plays a critical role in influencing health decisions [7, 14].

RE is the domain of interest in this study, which explores the perceptions, enablers and nurturers that facilitate or hinder childbearing decisions of WLHA. Perceptions include the values and beliefs that may promote or hinder healthy behaviors when factored into childbearing decisions of WLHA. Enablers are the institutional (healthcare) support services that may influence healthy behaviors and practices among WLHA that may affect childbearing decisions. Nurturers are partners and family members who may support or discourage childbearing among WLHA.

Figure 3. The PEN-3 model.
Methods

**Study site.** The study was conducted in July and August 2011 at the hematology clinic of the Lagos State University Teaching Hospital (LASUTH), located in Southwest Nigeria. With a population of about 9 million, a total fertility rate of 5.4%, and a mix of Nigerians from different ethnic groups, Lagos is one of the most populous states in Nigeria [15-17]. The study site was ideal because it provides HIV care and treatment free of charge, which enables WLHA from diverse backgrounds to access care. The clinic also provides free counseling and testing services, as well as HIV support groups.

**Study design.** Using a qualitative research design methodology, in-depth interviews were conducted over a 2-month period with 60 WLHA who attended the hematology clinic. A semi-structured interview guide adapted from Cooper et al. [1] was used to explore childbearing desires and sexual and reproductive healthcare (SRH) needs, and their influence on the childbearing decisions of WLHA. The first author interviewed participants individually in a private room at the clinic. All interviews were audio recorded and conducted in one of the three main languages spoken in Lagos (English, Pidgin English, or Yoruba). Verbal informed consent was obtained from participants prior to recording. Each interview lasted between 45 and 60 minutes. The participants were given 1000 Naira ($7) as an incentive to cover their transportation costs. Ethical approval was obtained from the Institutional Review Boards of Penn State University and LASUTH.

**Recruitment.** Purposive sampling was used to recruit WLHA between the ages of 18 and 43 years who were receiving care at the hospital. The first author obtained permission from the department head at the clinic after explaining the purpose of the study and eligibility criteria to the resident physicians. Initially, participants were recruited through referrals from the resident
physicians. About a week into the study, however, we realized that physicians often forgot to refer potential participants to the study because the clinic was so busy. In addition, when referrals were made, potential participants were not interested in extending their time spent at the hospital by participating in interviews, as they simply wanted to complete the tasks that brought them to the hospital. So, we devised an alternate approach and recruited potential participants while they were waiting to collect a 3-month supply of ARV drugs at the pharmacy. This approach worked better, because WLHA were more relaxed during the final stage of their visits. Out of the 63 participants recruited, three refused to participate in the study, either because they did not want to be recorded or due to time constraints.

Data analysis. The first author conducted a preliminary analysis of the transcripts from the first five interviews to determine the aspects of the interview guide that needed to be revised or removed for clarity. All interview transcripts were thoroughly read by the first author to become immersed in the data, and then loaded into NVivo 9 to aid in organization and data management. Using constant comparison consistent with Glaser and Strauss’ [18] approach to open coding, we generated free nodes. Based on similarities, we then organized these free nodes into related categories or themes guided by the PEN-3 model to generate tree nodes (axial codes). Finally, we organized emerging themes into categories within the Relationships and Expectations domain of PEN-3.

Results

Demographics. Participant demographic information is summarized in Table 1.
Table 1. Characteristics of the Study Population (Phase 1)

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<tr>
<th>Characteristic</th>
<th>Number</th>
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<tbody>
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<td>Interquartile range</td>
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<td>26-30</td>
<td>8</td>
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<td>Delta Ibo</td>
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Using the PEN-3 model, the results from our in-depth interviews revealed three themes and two sub-themes:

1. The role of faith in perceptions about childbearing decisions;
2. Patient-healthcare provider communication as an enabler in child bearing decisions; and
3. Partner support as a nurturing influence on childbearing decision making, including
   a. Support informed by knowledge and awareness of HIV; and
   b. Support informed by denial of infected partner’s HIV status.

**Perceptions in childbearing decision making: Role of faith.** Even though many of the participants held strong spiritual beliefs, almost all of them recognized the importance of utilizing available healthcare services instead of relying solely on spiritual practices such as faith healing. Nevertheless, some of the women felt they had to consider other spiritual alternatives in order to become mothers, since they believed that medical care alone would not result in successful childbearing. While some women believed in a combination of healthcare and spiritual (prayer) practices, others believed in just one or the other.

One of the most revealing findings that emerged was the perception that HIV is a spiritual problem caused by “evil or wicked forces” that curse a woman, thereby preventing her from becoming a mother. Most of the women who held these beliefs had lost multiple children or had experienced difficulty getting pregnant, even after adhering to the HIV treatment regimens recommended by their physicians. One participant said:

I believe that somebody that has HIV does not die quickly, that’s why I wanted to know why I lose baby after 25 days, because I used my drugs faithfully when I was pregnant and followed what the doctors told me to do. Next time, I will go to the church since this
thing may be a spiritual problem and spiritual problems need spiritual solution. (28-year-old)

Most women still utilized the services of the clinic during pregnancy, especially for delivery. Many also continued faith healing practices, which they believed would help their children to be born HIV-negative. Most acknowledged that faith healing would not cure them of HIV, but they did believe that such practices would cure them of the underlying cause of childlessness: the “evil forces.”

Some women thought that adhering to ARVs would prevent all medical problems associated with pregnancy. One participant said:

I was very angry; you know that after all my effort taking the drugs and following all the doctor’s advice, I still lost another baby. So, in 2008 when I got pregnant again, I decided to just go to the church for prayers and my ANC [antenatal care]. I [went to the hospital] and told the doctor to go through CS [cesarean section], I didn’t breastfeed and I was not taking any drugs and my baby is negative. During this pregnancy, I was not going to a hospital. I was just going to the church for prayer because I believe that God will help me break the evil [curse] so I can keep a pregnancy. (34-year-old)

When asked if she would do anything different if she were to get pregnant again, she responded:

If I want to get pregnant, I will be careful. I will follow what they tell me to do here [hospital] and I will also go to church for prayer. Let nurses help me on [what to] do [so] that the baby would not contract HIV again. That is the only thing that I need from them.

**Enabling factors in childbearing decision making: Patient-provider communication.**

Our interviews revealed that most women wanted healthcare workers to initiate discussions
about sexual reproductive health (SRH) and CB. When healthcare workers simply ask if WLHA have any complaints or problems, it does not encourage open discussion about SRH and CB issues. One 27-year-old participant noted, “some people may not have the heart to talk about it... For some people if you don’t ask they will not say anything. You ask, ‘Is everything okay?’ They say, ‘Okay,’ even if it is not.”

Very few WLHA who desire and intend to have children have initiated these conversations with their healthcare providers due to the perceived stigma associated with childbearing among WLHA [22]. WHLA are more likely to initiate these discussions with healthcare workers whom they perceive as supportive of their childbearing goals [1, 23]. WLHA are more likely to open up when healthcare workers ask them specific questions about their childbearing desires and intentions [24]. For many participants, healthcare workers who initiated such discussions enabled them “to open up freely.” One 33-year-old participant remarked, “It is good if they start asking about it [CB] so that many of us can open up and they can advise us.” Another participant added that it is beneficial when healthcare workers initiate these discussions, because:

It will help them [healthcare workers] touch every other part of your life that has to do with this thing [HIV] that most people are shy or don’t have the confidence to discuss. If they notice that you are asking them the questions and you are interested… they will open up about their childbearing plans... and use it (the information) to help themselves and things will get better. (25-year-old)

When physicians initiate SRH/CB discussions, WLHA “have the free mind to start telling them about the other [related] things,” which results in better provider-patient dialogue and, potentially, better healthcare experiences.
When healthcare workers did not ask questions related to SRH, some women perceived that such topics were off limits and not to be discussed. One participant noted:

Well, if perchance during consultation a doctor asks leading questions, then it can prompt you to open up, but where they don’t even broach such subjects at all, then there is no way you can open up, because it’s like we’re here for A and you’re talking about B. It’s a different thing where a doctor says that even though I know that we’re here for A, you can talk about B. Feel free to talk about B, C and D. (34-year-old)

On the other hand, some women saw initiating such conversations as being beyond the scope of healthcare services. Others were unsure of the type of SRH/CB conversations they could have with their healthcare providers or the right time to broach certain topics, particularly given their sensitive and intimate nature. One 25-year-old participant with persistent itching and discharge in her genitals said, “I was thinking in my mind whether I can ask him or show him something like this. Can I tell the doctor something like this?” This sentiment also was expressed by a 28-year-old participant who had recently experienced a miscarriage. When asked if she told her physician about the miscarriage, she explained that she did not, because “if they don’t ask you, you will not say.” When healthcare workers do not ask questions related to SRH/CB needs, it is a missed opportunity and a great disservice to WLHA.

For those WLHA who summon the courage to ask questions about SRH and CB, the advice they usually get from healthcare workers is, “When you are ready, tell us and we will let you know what to do.” In this setting, being ready refers to fulfilling marital and reproductive goals, referred to as life projects of marriage and reproduction [8]. For WLHA, being armed with SRH and CB information prior to getting pregnant is essential, since some pregnancies are
unplanned. One 27-year-old said, “They can also be telling those of us that are not married so that we will know what to do and how to go about it when that time comes.”

For most participants, the sex of the physician was not a major issue in determining the content of their discussions. However, the physician’s approach and interactions with them seemed to matter more in influencing the doctor-patient relationship. A 25-year-old participant said:

There are some doctors that you meet and the way they welcome you will give you more assurance to open up to him or her. When a person is approaching you like that, you will feel free to open up and your mind will be relaxed. It does not matter to me if it is a male or female doctor.

In addition, a physician who “shows real interest” and does not see a WLHA “as an object or a figure” will encourage open discussion. Some women noted that supportive and encouraging healthcare workers can make them feel at ease and “alive” when discussing SRH/CB issues.

Before I open my mouth to tell the doctor that I want to get pregnant, I just read his face. Within that 2 or 3 minutes I read his face to know [that] he is not harsh, and that is what gave me the zeal to ask him questions. When I said I had questions, he said, ‘Oh go on my ears are welcome.’ When I now told him, he said, ‘What are you waiting for [that you have not had another baby]? If na me be your husband, I for dem give you double belle [If I were to be your husband, I would have impregnated you with twins by now].’ He was just saying it jokingly and that made me feel comfortable to go ahead and get pregnant. There are some doctors I cannot talk to like that, because of how harsh they are. (32-year-old)
Nurturing influences in childbearing decision making: Role of partners. Contrary to the negative message in the literature focusing on the non-supportive role of partners of WLHA, most participants reported that their husbands and partners were supportive. Although the definition and degree of partner support varied, some forms of support were informed by knowledge and awareness of HIV, while others were informed by denial of their partner’s HIV status. Support could take on different forms, from the partner “being there” to “encourage,” “advise,” “fight HIV together,” “share each other’s burden,” and “console,” to more tangible support, such as going along to the hospital or providing transportation money.

Most of the women who had disclosed their status to their partners reported that their partners were supportive and saw them as “normal,” and “not as someone who is positive.” This form of support can have potentially negative consequences for their partners. One 28-year-old participant said:

When I told my husband, he told me to remove my mind from it and I should not think about it [HIV]. He is like second god to me. He advises me a lot. Right from the first day, I don’t think about it at all and forget there is something like this in me because of his support. I live my life normal, even sleep with my husband normal [unprotected].

Most women reported being indebted to their partners for the kind of support they received. As such, they were willing to do anything to reward their partners, even engage in unprotected sex. One participant adhered to her medications for this very reason:

I will allow him to have his fun [sex] with me, and that is why I don’t miss my drugs. I know I am not protecting myself only; I am also protecting people around me. If that is what he wants, I will allow him because of the kind of support he has given me (30-year-old).
This sense of indebtedness is driven by the fact that HIV “has broken many homes;” in fact, “there are some women that are having problems at home because of their status.”

Childbearing was central to the support provided by husbands to their wives. Many husbands stated that the reason they stood by their wives was because they wanted to have children. As a way of thanking husbands for their support, WLHA were willing to do whatever it took to have children. One participant expressed fear of losing her marriage, and discussed how she actively showed appreciation to her husband for his support:

This [children] is what my husband wants and this is what I will give him, because he has been patient and supportive from day one... You don’t know their mind at all. All these men can be funny with your status again. And he is negative. Anything can happen to your marriage. (32-year-old)

Negative past experiences influenced some women to “secure the relationship” by waiting until they got married and became pregnant before disclosing their status.

I only told my boyfriend who is now my husband, about my status when I got pregnant, because I had several relationships before him and after I told them, it did not work out. So I had to wait before telling my husband until after I got pregnant. (28-year-old)

Nurturing and support based on knowledge and awareness of HIV. After learning from counselors and support groups at the clinic about HIV and ways to avoid transmission, most women reported that they went back home to educate their partners. After educating their partners, participants often received their full support.

I told him he doesn’t have any problem because I have been using my drugs, and there is a way to have children. They lectured us then I used that lecture to teach him. After that, I brought him to the clinic… for counseling. They talked to him, even the lady counselor
was positive, too. She said she got married and had kids after, so he supported me. He did the test and he was negative. Since then my husband supports me fully. We did not tell his family because we don’t want family problems. (28-year-old)

Another participant explained that after disclosure, her partner expressed his support by wanting to learn more about HIV/AIDS in order to continue with the relationship:

The only thing he asked me was that, ‘What do I do? What am I supposed to do as I am the opposite person? Do I run a test? Do I take drugs? Do I do this or that?’ I just told him, ‘Be yourself.’ He even comes to the hospital with me because he wants to know more about HIV. (25-year-old)

Another way in which partners showed their support was by covering for their wives in the presence of his family (her in-laws), specifically about infant feeding practices and mode of delivery. When in-laws started to become suspicious, husbands would step in to dispel any rumors.

I did not breastfeed my baby at all, and my husband’s family had a problem with that. They [in-laws] would call my husband and ask him why I am not breastfeeding. My husband had to lie that because of the CS [cesarean section] I did I can’t breastfeed because the child will reject the breast milk, so we have to give her SMA [formula]. (28-year-old)

WLHA also reported that they were able to extend the support received from their partners to encourage other WLHA who were in similar situations. A 29-year-old participant described an encounter with a devastated WLHA who had just learned of her HIV positive status:
Because of my own experience, I went to her and asked why she was crying. She said she’s HIV positive. I said, “Is that why you are crying? If you see me on the road, will you know that I am HIV positive?” The woman said, “No. So, you are positive?” I said, “Yes.” I told her, “You are not falling sick, you can do things on your own; your health is okay, so why are you crying?” I asked if her husband knew about her status and she said, “Yes.” I told her, “If your husband is not giving you problem, and he is negative, then why are you giving yourself problem?”

A 41-year-old participant also described how she felt when she had just discovered her status and how she is using that experience to help others: “When I discovered, it really weighed me down. I just felt that all was lost. I felt negative about life. But with the help of my husband who supported me, now I can encourage other younger ladies around.”

**Nurturing and support based on denial of infected partner’s HIV status.** Some husbands and partners refused to accept the fact that their partners were infected with HIV. This type of support has potentially negative consequences, since such partners tend to neglect necessary protective measures to prevent disease transmission.

He is negative and I am positive, but he still doesn’t protect himself from me. Any other man that knows his wife is positive and he is negative will use every opportunity to protect himself at all times, but he doesn’t do that. (25-year-old)

Some women reported that their partners provided support to them, but refused to accept their HIV-positive status, especially those partners who were HIV-negative. For example, a 28-year-old participant noted, “When I first knew [of my status], if my husband wants to make love with me I will give him the condom. He will say, ‘No.’ He will tell me, ‘You don’t have anything like that.’” This form of support could be problematic, because it prevents WLHA from
taking necessary precautionary and preventive measures until it is almost too late, as in the case of a 41-year-old participant:

He was even the one that confused me. He gave me the impression that I didn’t have it, because he was negative. He said I should forget about it and rule it out of my mind and that was why I did not start treatment until when I had the crisis.

**Discussion and Conclusion**

**HIV seroconversion in infants and pregnant women.** Infants of HIV-positive mothers are at increased risk for HIV infection, and when infants are infected, the disease progresses rapidly [19, 20]. Due to the latency period associated with HIV seroconversion, a child is declared free from pediatric HIV at 1 year of age after repeat testing or 6 weeks after breastfeeding has ended [20]. In addition, maternal seroconversion of HIV status can occur during early pregnancy (< 14 weeks), late pregnancy or even postpartum; that is why repeat testing in late pregnancy (32-34 weeks) and postpartum is often recommended for pregnant women [21]. The World Health Organization (WHO) recommends testing of HIV-exposed infants between 4 and 6 weeks of age, and repeat testing at 9 months and 18 months, as well as 6 weeks after cessation of breastfeeding [19, 21].

Our findings expand on previous work highlighting the dynamic and complex nature of childbearing decisions, which are deeply rooted in personal beliefs and support from significant others [3, 4, 25]. Our findings describe the childbearing decision making process for WLHA within a context of competing priorities among the women, their partners, and healthcare workers. A majority of participants desired to have children despite their HIV status. This was due, in part, to *securing the relationship*. Moreover, their partners wanted them to have children as soon as there were physical improvements in their health, whereas healthcare workers
recommend waiting for a high CD4 count and a low viral load before commencing childbearing [1, 3, 4].

Participants believed that combining healthcare services with faith healing practices was the best way to achieve favorable childbearing outcomes. Women sought alternate practices when they believed that medicine could not ward off “spiritual forces” or that healthcare practices had failed them. Our results on the role of faith in childbearing complement findings from Adogame [26], although his study did not focus on childbearing, but on how African Pentecostals deal with HIV/AIDS. Our results also confirm previous findings on the role of spirituality in future childbearing [27, 28, 29].

Supportive healthcare workers encouraged WLHA to discuss their childbearing plans with them when they were ready to have children [30]. However, not all women in our study discussed their childbearing plans with healthcare workers [1, 4]. Consistent with findings from previous studies, some WLHA resented the information they received from healthcare workers about planning pregnancy and timing unprotected sex [1, 3, 31]. Given that some WLHA viewed pregnancy as “something that just happens,” not discussing SRH/CB issues in the healthcare setting is a cause for concern due to possible implications for access to preventive and treatment services.

Our findings indicate that most partners were supportive of WLHA, and that this support was expressed in many different ways. Partner support encouraged future childbearing and empowered participants to provide emotional support to other WLHA who were discouraged. This finding is contrary to prior findings that WLHA experience negative consequences such as domestic violence, abandonment, and infidelity after disclosing their status to their partners [1, 2].
Consistent with other findings, many participants expressed confusion about serodiscordance, leading them to engage in risky sexual behaviors with their partners or fail to access needed treatment [4]. As found by Smith et al. [32], participants expressed unprotected sex as a marker of partner support and trust. In addition, partners showed their support by becoming “co-conspirators” and covering for their wives in the presence of family and friends [32].

This study has some limitations that should be considered. Participants were not randomly selected, and as such, the findings are biased towards WLHA who access healthcare in clinical settings. Therefore, the results should not be generalized, since they are not fully representative of all WLHA.

Despite these limitations, the results of this study have implications for healthcare providers. Healthcare workers should provide necessary SRH/CB information to all WLHA, whether they are planning to get pregnant or not, so that they can be prepared to make the right decisions. This is important, because not all pregnant WLHA will come to the clinic for antenatal care; some will seek alternative forms of care. If SRH/CB issues are not discussed prior to pregnancy, WLHA may engage in practices that may be harmful to both themselves and their children.
Acknowledgments

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Chapter 5. Paper 2


Abstract

The purpose of this study was to understand the importance of male partner support in the childbearing (CB) decision-making process of women living with HIV/AIDS (WLHA) by exploring perceptions of WLHA after disclosure, during pregnancy, and after childbirth. Specifically, we assessed whether male partners were supportive, and how this support was shown to their female partners. We conducted in-depth interviews with 15 WLHA who were receiving clinical HIV care at a teaching hospital in Lagos. The results revealed that all male partners were supportive, except in the case of the only unmarried mother. The level of support provided remained consistent both after disclosure and after childbirth. Furthermore, male partners provided emotional support and reassurance to WLHA by relating to them as they normally would, as well as spiritual support and other tangible forms of support. These findings have implications for HIV treatment and care programs geared towards improving the health of men, women and children. Policies must be made to include men in discussions on sexual and reproductive health, and maternal and child health.
Introduction

Much of the research on the sexual and reproductive desires/intentions of people living with HIV has focused on women and largely excluded their male partners. A review of the literature shows that the role and support of male partners is a key factor considered by women living with HIV/AIDS (WLHA) when making childbearing (CB) decisions (Beyeza-Kashesya et al., 2010; MacCarthy et al., 2012; Ujiji et al., 2010). In addition, several studies have confirmed that the overall health and wellbeing of women and children improves when male partners are involved in CB decision-making, voluntary counseling and testing services (Conkling et al., 2010; Farquhar et al., 2004; MacCarthy et al., 2012; Ramirez-Ferrero et al., 2012). Many WLHA in Nigeria do not make CB decisions independently due to socio-cultural and gender norms. Even when WLHA wish to stop having children, such decisions could be challenged by partners who desire additional children (Crankshaw et al., 2012). In a study conducted in South Africa among HIV positive men and women in discordant relationships, Crankshaw and colleagues (2011) reported that when WLHA stated that a pregnancy was unplanned and unintended, there was usually strong male partner desire for the pregnancy, which eventually led to the women acceding to their partners’ desires.

According to the WHO, 50% of PLWHA are in serodiscordant relationships (i.e., they have HIV-negative partners). Many of these PLWHA are neither aware of their partners’ statuses, nor have they disclosed their status to their partners (WHO, 2012). Most HIV infections in sub-Saharan Africa occur in committed, heterosexual relationships where infected partners may not have disclosed their status (Ramirez-Ferrero, 2012). Several studies have reported that men resisted seeking HIV testing and counseling, even after discovering their partner’s status because they usually assumed that their own HIV status was the same as their HIV positive
partners or would eventually become the same, which contributed to them engaging in risky behaviors (Crankshaw et al., 2012; MacCarthy et al., 2012; Ramirez-Ferrero, 2012; Rujumba et al., 2012). Thus, it is important to consider the role of male partners in the CB decision-making processes of WLHA regardless of whether they are involved in serodiscordant (+/-) or seroconcordant (+/+) relationships.

Many women believe that a woman’s identity is affirmed by her motherhood status (Airhihenbuwa, 2007; Nduna et al., 2009; Smith et al., 2007). Accordingly, WLHA in Nigeria and many African countries make plans to have children with partners whose HIV statuses are sometimes unknown (Sofolahan et al., 2012). Chen et al. (2001) reported that knowledge of a partner’s HIV status influenced CB desires and expectations of WLHA. Women in discordant relationships who wish to have children face the possibility of transmitting HIV to their uninfected partners in the process of fulfilling their CB desires, while those in concordant relationships risk re-infection with a different strain of HIV or with other STDs when trying to conceive (Cooper et al., 2007; Matthews et al., 2011).

In this paper, we expand on the current literature by exploring WLHA perceptions of male partner support in the childbearing decision-making process after disclosure, during pregnancy, and after childbirth. In particular, we explore whether male partners were supportive, and how this support was shown to their female partners living with HIV. Since male partner support is critical to a family’s health and wellbeing, we argue that HIV programs designed for women and children, such as PMTCT, should involve men.

**Theoretical Framework**

Two models were used in this research. The PEN-3 cultural model was used as the overall organizational framework for the study and the Ottawa Decision-Support Framework
(ODSF) was used as the theoretical framework. ODSF is designed to guide individuals in making quality informed decisions that are consistent with their personal values (Doull et al., 2006). According to ODSF, decision-making is influenced by several factors, such that the decisions made may be modified based on the support available to make such decisions (Allen & Berry, 2011). These decision-determining factors include (a) perceptions about the decision, (b) perceptions of significant others, and (c) personal and external resources available when making the decision. In this paper, we focus on WLHA perceptions of the role of male partners in childbearing decision-making. Perceptions of significant others such as male partners may include factors such as pressure to make a certain decision, support for decisions made, the role of partners in decision making, or perceptions about what partners think (Allen & Berry, 2011; Doull et al., 2006).

**Method**

**Study site.** The study was conducted between July and August 2012 at the Lagos State University Teaching Hospital (LASUTH), located in southwestern Nigeria. With a population of about 9 million, a total fertility rate of 5.4%, and a mix of Nigerians from different ethnic groups, Lagos is the second most populous state in Nigeria (NBS, 2006; NPC, 2006). The study took place in the pediatric and hematology sections of the clinic.

**Study design.** Using a qualitative research design methodology, in-depth interviews were conducted over a 2-month period with 15 WLHA. A semi-structured interview guide was used to explore their childbearing experiences, future childbearing, husband/partner feelings about previous pregnancies, and the role of partners after disclosure of HIV status and during pregnancy. The first author interviewed participants individually in a private room at the clinic. All interviews were audio recorded and conducted in either English or Pidgin English. Verbal
informed consent was obtained from participants prior to recording. Each interview lasted between 30 and 45 minutes. The participants were given 1000 Naira ($7) as an incentive to cover transportation costs. Ethical approval was obtained from the Institutional Review Boards of Penn State University and LASUTH.

**Recruitment.** Six women from our previous interviews in 2011 who had given us approval to contact them were recruited via telephone. In addition to these six, purposive sampling was used to recruit an additional nine participants who attended the hematology clinic or sought care for their children at the pediatric clinic. The eligibility criteria were that participants had to be between the ages of 18 and 43 years, and have a child less than 1 year old.

**Data analysis.** All interview transcripts were thoroughly read by the first author to become immersed in the data, and then analyzed using Morse and Field’s (1995) approach to content analysis. Responses from the in-depth interviews were organized into categories, and data were sorted into each category until saturation was reached. Using the PEN-3 model and ODSF as guides, the categories were grouped into themes based on similarities between categories. The transcripts were also read by the second author to ensure intercoder reliability in the key themes generated by the first author.

**Results**

Participant demographic information is summarized in Table 2.
Table 2. Characteristics of the Study Population (Phase 2)

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Based on the participants’ responses, the level of male partner support was consistent both after disclosure of HIV positive status and after childbirth. Words used by participants to describe how their partner supported them included “being there,” “back up,” “stand behind,” and “encourage with his words.” The themes presented below are based on all of the 14 married WLHA who had delivered a baby in the past year, and who reported being supported by their male partners. All of these married WLHA reported that their partners were supportive of their childbearing goals. The only instance where a partner was reported as being unsupportive was in the case of the only woman in the group who was an unmarried mother. Three major themes emerged from the in-depth interviews and the qualitative analysis: (a) emotional support and reassurance, (b) partnership and faith, and (c) tangible support.

**Emotional support and reassurance: “He doesn’t push me away because I have HIV.”** Participants referred to the emotional support male partners provided WLHA by relating to them in a non-stigmatizing manner. This provided many WLHA with some reassurance that their male partners were not going to abandon them because they were HIV positive. Some of the women reported that their partners showed support by continuing to see them as normal, not believing they were infected with HIV, and relating to them just as they had before disclosure. One woman explained:

He supported me because I told him everything. Even up till now, he doesn’t believe that I even have HIV, because before I did not take drugs, but due to the baby I started taking the drugs. Maybe now that I am taking drugs, he will believe somehow. He doesn’t push me away that because I have HIV… the only problem now is [convincing] him to come and know his status.
Another participant noted how the fact that her husband did not believe that she was infected with HIV served as a barrier against her taking necessary protective and preventive measures:

My husband does not even believe that I have this disease. He still sees me as normal. He doesn’t believe in anything HIV so even when I force him he refused to use condoms. Even when I told him, he told me to remove my mind from it and I should not think about it [HIV]. Right from the first day, I don’t think about it at all and forget there is something like this in me because of his support.

Some of the phrases used to describe partner support included: “He assures me that he will stay with me and that he is not going anywhere;” “It is as if I don’t have it [HIV]. He doesn’t push me away because I have HIV;” “He doesn’t look at me like I have this condition and he has to stay away;” and “He gives me the power to stand knowing that nothing will happen to me;” among many others.

Participant narratives revealed the positive effects of partner support. One participant described:

He advises me, calms me down and makes me happy. Anytime I look at my back I see him there standing by me. I met someone here that was telling me her husband does not know about her status and she said that if he knows, “I am going back home to my father’s house straight.” I told her that my husband knows and I am still at home.

Learning of one’s HIV positive status can be devastating, especially if there is no support system. Partner support helps buffer some of the stress associated with being infected with HIV: He has been very, very supportive in all aspects as if I don’t have it. He helps me a lot and he takes care of me... I almost killed myself when I found out [HIV positive]. If not
for him and my doctor friend I am sure I would be gone now [dead]. The only thing [that is different] is that I come to the clinic and I take drugs. Even with that he doesn’t love me less. He loves me more.

One of the participants revealed how she secretly went for family planning shortly after the birth of her first child without her husband’s awareness. After expressing concerns about her health to her husband, she was surprised by his response about limiting the number of future children he wanted:

I did family planning after Kemi without telling my husband. If not, I would have taken in sooner than that. I told him I wanted Kemi to grow and for my tissues to heal very well, because of the CS [cesarean section] before taking in again. My husband has even said he would like to have 4 or 5 children, but because of this thing [HIV] he would reason with me. [What is important is] that it is about my life first and the life of the children. After we have one more to make three [he agreed] that it is okay so I will go for family planning.

Partnership and faith: “My husband joined me in prayers and faith.” Participants referred to the spiritual support male partners provided WLHA when they shared similar values of their faith. Most of the women interviewed stated that their husbands felt very happy about their most recent pregnancy, especially when it was planned and expected. However, couples who were pregnant with their first children were afraid of infecting their unborn children with HIV. To conquer this fear of pediatric HIV, many women relied on prayer while accessing prevention of mother-to-child transmission (PMTCT) services at the hospital:

I won’t do anything different the next time I get pregnant, because my first child is okay. So I will still follow the same thing—come to the hospital and follow what they tell me to
do. My husband was very happy, because the time I was pregnant, two of us used to pray for our baby to be negative and God answered us.

Husbands supported their wives in their faith through the naming of their children. The meaning of their children’s names also reflected the circumstances surrounding their birth. One participant explained:

When I was pregnant, my husband and I held hands and did a prayer of agreement with faith for 10 minutes that we want this baby to be a boy since God has blessed us with a girl. We believed, even before we did scan that the baby I am carrying is a boy. That is why we chose the name Kamsiyochukwu that means Samuel from the Bible. I asked from the Lord and He gave him to me.

Further supporting this point, another participant stated:

With my prayer and Christianity it helped me a lot and everything with my pregnancy went normally. That’s why we named her Amarachukwu. It means the miracle of God, the grace of God. Before we were able to get pregnant, it was by God’s grace; that I was able to carry this pregnancy, God made it to be so. Delivery was even the same thing. It was by God’s grace that I did everything and so that was why we gave my baby Amarachukwu… My husband joined me in prayers. I had to have faith. My life is in God’s hand.

Tangible support: “Somebody doing 5% before, now he does 10% more.” Tangible support refers to the physical support provided by male partners. For WLHA, this tangible support may take the form of assistance with household chores, financial assistance, medication reminders, and being accompanied to their doctor’s appointments. Pregnancy or the birth of a child was stated by the participants as a strong reason for husbands to be supportive of their
wives. One participant described this support as, “somebody doing 5% before, now he does 10% more for me not to think.” In addition, many women expressed that their partners were very supportive by helping with household chores such as cooking, cleaning, fetching water; providing transportation money for hospital appointments; reminding them to take their medications at certain times; using condoms even when they prefer sex “flesh to flesh,” and purchasing vitamins, fruits and vegetables. These women further expressed the importance of having this tangible form of partner support especially when pregnant, because “there are some jobs [household chores] a pregnant woman cannot do.”

Delivery and infant feeding emerged as other times when husbands fully supported their wives. Whether it had to do with delivery location or mode of delivery, breastfeeding or formula feeding, all women stated that their husbands were supportive of whatever decisions they made. One participant explained about her mode of delivery:

My husband was having faith that I will be able to deliver normally, but he had given me part payment for the cesarean section of #50,000, just in case, which I had deposited at Ifako. During antenatal care... they just saw that I had given birth before with CS, so they advised that once I have been cut, I should forget about delivery pack [for normal delivery]. It’s my husband that was even cleaning and dressing the stitches for me.

When deciding where to deliver her baby, one participant explained:

I told my husband that I want to deliver at the redemption camp and he agreed. Even if I was living far from the camp, I will still prefer to deliver at camp, because I waited for 6 years before I conceived and there are some spiritual challenges I passed through so I believe it is only through prayer I was able to deliver safely.
Another participant stated how her husband supported her on making the best decision for their family on infant feeding:

When I told him that I wanted to breastfeed since they said it is [a] 50/50 [chance of infection] he said no, that he doesn’t want anything bad to happen so he is going to provide the formula and that I should not worry. Sometimes if I feel bad about it [not breastfeeding] he will say that I should not worry. Even when the family was pressurizing me that I should breastfeed, he was angry with them and they were quarreling. With my first child, the battle was too much about breastfeeding and my husband really backed me up.

The only instance where a partner was described as being unsupportive was in the case of a single mother:

He did not support me at all when I was pregnant. I would call his phone and it would be switched off or even when it is not, he will not pick his calls… After I gave birth to the baby in February, he called to ask how the baby and I were doing. He came that weekend to see the baby. Since then, I have not set my eyes on him. The day she saw him she was so happy and that was the very first time I saw my baby laugh. Last week I tried to call him to tell him that the baby is sick and running temperature. I called his number throughout that day he didn’t pick up. After that I turned off my phone. I cannot kill myself. I will just keep on managing to take care of this child.

**Discussion and Conclusion**

The aim of this study was to illustrate the ways in which the different forms of male partner support influenced the CB decisions of WLHA who attended an outpatient clinic in Lagos, Nigeria. Our findings expand on previous work by highlighting the complex nature of
childbearing decisions, which are deeply rooted in personal beliefs and support from significant others, especially male partners (Kanniappan et al., 2008; Matthews et al., 2011; Ujiji et al., 2010;). This is important, because childbearing is deemed a necessary part of a successful marriage in traditional African society, and also because the success of HIV prevention and treatment programs geared towards women and children depends on the support they receive from male partners and significant others (Beyeza-Kashesya et al., 2009; MacCarthy et al., 2012; Ramirez-Ferrero et al., 2012). Historically, most sexual and reproductive health programs have been linked to women’s health, and have largely excluded men (Ramirez-Ferrero, 2012). This has proved to be detrimental to the sexual health of both men and women, especially when it comes to efforts aimed at HIV prevention and treatment. Our findings suggest that the CB decisions of WLHA were not always influenced by their partners’ desires for children; the desire to balance the gender distribution among their children was a greater determining factor in WLHA CB decisions. For example for some participants who already had a female child, the desire to have a male child or vice versa usually served as the driving force behind their CB decisions.

Decision making is a process that may change over time based on several factors (Beyeza-Kashesya et al., 2009). One factor that played a role in the participants’ CB decision making was their prior CB experiences. Although WLHA and their male partners may decide to have a certain number of children, that number may change based on their CB experiences. Women who reported experiencing stressful pregnancies or difficult deliveries wanted to wait longer before having more children or they no longer wanted to have more children, regardless of what their male partners wanted. This finding is similar to findings from other studies reporting that WLHA feared getting pregnant and worsening their health (Chen et al., 2001;
Cooper et al., 2007; Nduna et al., 2009). None of the participants interviewed expressed fear of being abandoned by their partners, or experiencing intimate partner violence based on disclosure of HIV positive status or CB decisions. This is contrary to findings reported in previous literature (Iwuagwu, 2009; Nduna et al., 2009; Smith & Mbakwem, 2007, 2010).

Extended family members such as in-laws are also involved in the CB decision-making process. This can create an additional source of stress on WLHA, especially when their male partners are not supportive of their CB decisions. Some of the participants reported that their husbands’ support influenced the relationship with extended family, especially in-laws, to create an environment conducive to certain practices such as formula feeding, alternative delivery options such as cesarean section, contraceptive use, HIV treatment (e.g., PMTCT, ARV use), and keeping clinic appointments (Ramirez-Ferrero et al., 2012). Smith and Mbakwem (2007, 2010) noted that male partners and husbands supported their wives so much that they become co-conspirators in hiding their wives’ HIV status from family members.

This study has some limitations that may affect its generalizability to the population of all WLHA in Lagos, Nigeria. WLHA were interviewed on their perceptions of male partner support in CB decision-making, and since we did not have data from their partners to back this up, their responses may not truly reflect their male partners’ views. Social desirability bias may have played a role in how participants portrayed their partner’s support to the researchers. Future research should include partners and spouses of the women. The findings from this study are biased towards WLHA who access healthcare in clinical settings. Given that this hospital is considered one of the best in Lagos state when it comes to care of PLWHA, it may not be representative of other outpatient clinics providing PMTCT, HIV treatment and care services.
Despite the limitations, this study has several strengths. LASUTH is highly subsidized, and provides high quality of care PLWHA, and enables WLHA from diverse backgrounds to access care. This allowed for the recruitment of WLHA with diverse views on the topic to be interviewed. Second, the follow up postpartum allowed us to compare whether or not there were changes in the CB motivations of these women during pregnancy and after childbirth. It also enhanced credibility since participants revealed more to the researchers over time as trust was established.

Notwithstanding the limitations, the results of this study have implications for HIV treatment and care programs geared toward improving the health of men, women and children. If the UNAIDS vision of getting to zero (i.e., zero new infections, zero AIDS-related deaths and zero discrimination) is to become a reality by 2015, we cannot exclude men from the conversation. Policies must be created that include men in sexual and reproductive health and maternal and child health discussions.
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Chapter 6. Paper 3

Perceptions of Women Living with HIV/AIDS of Healthcare Support in Childbearing Decision Making

Abstract

Evidence from previous studies suggests that for women living with HIV/AIDS (WLHA), healthcare experiences drive their use of sexual and reproductive health (SRH) services, which influences their childbearing (CB) decisions. The aim of this study was to understand WLHA interactions with members of the health care system and subsequent effects on CB decisions. Specifically, we address how WLHA perceive the support and recommendations of healthcare workers (HCWs) on their CB decisions pre- and post-partum, and identify contextual factors within the healthcare system that promote or hinder WLHA acceptance of health care recommendations. We conducted in-depth interviews with 15 WLHA who were receiving clinical HIV care at a teaching hospital in Lagos. Six of these participants were interviewed pre- and post-partum. The results reveal that the role of faith is very significant pre-partum, while the opinions of HCWs and access to available healthcare services influence CB decisions post-partum. Participants found it difficult to accept recommendations on mode of delivery and infant feeding practices, due to conflicts with their personal preferences and values. These findings provide evidence for contextual factors within the healthcare system, cultural expectations of the birthing process, and personal preferences influence whether WLHA discuss their CB plans with HCWs and/or incorporate HCW recommendations into their actual CB decisions.
Introduction

Despite efforts being made towards preventing mother-to-child transmission of HIV worldwide, new pediatric HIV infection remains a problem in low- and middle-income countries (UNAIDS, 2010), where it is estimated that more than 90% of new pediatric HIV infections occur (Mazzeo et al., 2012). Women of reproductive age in sub-Saharan Africa (SSA) account for the majority of those at risk for contracting HIV (Sofolahan et al., 2012; UNAIDS, 2008). In 2009, an estimated 13.4 million out of the 22.4 million people living with HIV and AIDS (PLWHA) in SSA were women (UNAIDS, 2009). In order to achieve the UNAIDS/WHO goal of eliminating new pediatric HIV infections by 2015, healthcare providers must address the childbearing intentions of women living with HIV/AIDS (WLHA) (UNAIDS, 2009; WHO, 2010).

With advances in antiretroviral drugs (ARVs), and prevention of mother-to-child transmission (PMTCT) services, many PLWHA have expressed a desire to have children (Chen et al., 2001; Cooper et al., 2007; Cooper et al., 2009; Finocchiaro-Kessler et al., 2012). However, this expressed desire is often fraught with conflicting emotions as to whether they are making the right decision for their (unborn) children. The support of healthcare providers is one of many factors PLWHA (especially WLHA) tend to consider when deciding whether to have children, (Mazzeo et al., 2012; Sofolahan et al., 2012). A supportive healthcare system allows WLHA to communicate their childbearing intentions and access the care and treatment services that protect their health and that of their children, which in turn leads to a decrease in new cases of pediatric HIV infections.

The World Health Organization (WHO) 2010 guidelines recommend providing ARVs for pregnant WLHA with a CD4 cell count $\leq 350$ cells/mm$^3$ to both treat the mother and protect the
unborn child. For women with a CD4 cell count $\geq 350$ cells/mm$^3$, it is recommended that they start ARVs early in pregnancy from about 14 weeks, and continue through delivery and until one week after breastfeeding has stopped (WHO, 2010). However, in 2012, the WHO guidelines were revised to recommend that all exposed infants born to WLHA on ARVs, regardless of their CD4 count or the mode of infant feeding, should use nevirapine or AZT for 4-6 weeks (WHO, 2012). WHO also recommends testing of HIV-exposed infants between 4 and 6 weeks of age, and repeat testing at 9 months and 18 months, as well as 6 weeks after cessation of breastfeeding (Levin et al., 2012; WHO, 2012). There has been evidence linking early initiation of ARVs during pregnancy to effective prevention of mother-to-child transmission (WHO, 2010).

Therefore, it is important for healthcare workers (HCWs) to provide the necessary sexual and reproductive healthcare (SRH) information needed by these women to adequately prepare them for successful childbearing (CB) experiences. In order for this counseling to occur, there must be a dialogue between WLHA and HCWs about CB desires and intentions. HCWs can only provide adequate guidance on having a successful pregnancy if they are aware of the CB plans of WLHA (Finocchario-Kessler et al., 2010).

While some studies have reported the benefits of HCWs communicating with WLHA on their CB plans, few studies have explored how WLHA perceive the advice and support given to them by HCWs and whether they factor it into their actual CB decisions (Cooper et al., 2007; Finocchario-Kessler et al., 2010; Finocchario-Kessler et al., 2012; Ujiji et al., 2010). In this paper, we address: (a) how WLHA perceive HCW support and recommendations related to their CB decisions pre- and post-partum; and (b) what contextual factors within the healthcare system promote or hinder WLHA acceptance of healthcare recommendations.
Theoretical Framework

PEN-3 has three domains, and each domain has three dimensions (see Figure 1). The three interconnected domains are cultural empowerment (CE), relationships and expectations (RE), and cultural identity (CI). CE considers the positive, existential and negative cultural values that are factored into health behaviors and decisions. RE considers factors such as perceptions, enablers and nurturers that influence health behaviors and decisions. CI reveals the appropriate level of focus for health interventions – the person, the extended family, or the neighborhood – by addressing how one’s identity plays a critical role in influencing health decisions (Airhihenbuwa et al., 2004; Airhihenbuwa, 2007).

RE is the domain of interest in this study, which explores the perceptions, enablers and nurturers within the healthcare system that are factored into the CB decisions of WLHA. Perceptions include the values and beliefs that may promote or hinder healthy behaviors when factored into CB decisions of WLHA. Enablers are the institutional (healthcare) support services that may influence CB decisions of WLHA. Nurturers are the healthcare providers who may support or discourage CB among WLHA.

Methods

Study site. The study was conducted in July and August 2012 at the Lagos State University Teaching Hospital (LASUTH), located in southwestern Nigeria. With a population of about 9 million, a total fertility rate of 5.4%, and a mix of Nigerians from different ethnic groups, Lagos is one of the most populous states in Nigeria (NBS, 2006; NPC, 2006). The study took place in the pediatric and hematology sections of the clinic.

Study design. Using a qualitative research design methodology, in-depth interviews were conducted over a 2-month period with 15 WLHA who attended the hematology clinic or
sought care for their children at the pediatric clinic. A semi-structured interview guide was designed to explore the role of healthcare workers during the CB experiences of WLHA. Participants were interviewed individually in a private room at the clinic. All interviews were audio recorded and conducted in either English or Pidgin English. Verbal informed consent was obtained from participants prior to recording. Each interview lasted between 30 and 45 minutes. The participants were given 1,000 Naira ($7) as an incentive to cover their transportation costs. Ethical approval was obtained from the Institutional Review Boards of Penn State University and LASUTH.

**Recruitment.** A total of 15 WLHA were recruited from the pediatric clinic and the hematology clinic. All WLHA had given birth to a child within the last 12 months. This sample included 6 of the women that were previously interviewed while pregnant during the pilot phase of the study. These six women were among the 11 pregnant participants in 2011 who had given us approval to contact them for follow-up interviews in 2012 after the births of their children. Of the five participants lost to follow-up, two had miscarriages, two were no longer willing to participate, and one had changed her phone number and could not be reached. Prior to the beginning of the study, the 11 pregnant women who were previously interviewed were contacted at three different times over the course of the year via telephone. The purpose of the first call was to ask how their pregnancies were progressing and to find out if they had given birth. The purpose of the second call was to check up on them and the baby. During the third and final call, I reminded them about the study and obtained consent to participate in the follow-up as they had agreed in the previous year. In addition to the six who agreed to a follow-up interview, nine other WLHA who had delivered babies during the previous 12 months were recruited through
purposive sampling to participate in the study. The inclusion criteria were that participants had to be between the ages of 18 and 43 years and have a child who was less than 1 year old.

**Data analysis.** All interview transcripts were thoroughly read by the first author to become immersed in the data, and then analyzed using Morse and Field’s (1995) approach to content analysis. Responses from the in-depth interviews were organized into categories, and data were sorted into each category until saturation was reached. To ensure intercoder reliability, the second author also read the transcripts and arrived at the same key themes that were identified by the first author. Using the PEN-3 model as a guide, the categories were grouped into themes based on similarities.

**Results**

The results from our in-depth interviews revealed three main themes:

1. Role of faith prior to successful CB versus the role of healthcare workers after successful CB;
2. Acceptability, affordability and accessibility of healthcare services; and
3. Expectations of the CB experience.

**Perceptions: Role of faith versus role of health care workers.** All six participants who had been interviewed previously while they were pregnant focused on their faith as playing a more prominent role, because “doctors do not know it all.” However, after the births of their children, five of those six participants and six out of the nine newly interviewed women acknowledged the role of healthcare workers and access to available healthcare services as key determinants of a favorable childbearing outcome. Of note, the women who focused more on their faith in pregnancy were those who had never had a child, had only one child, or had
experienced miscarriage or infant death. One participant who had previously experienced miscarriages and infant death explained:

I believe somebody that has HIV does not die easily. That’s why I wanted to know why I lose baby after 25 days, because I used my drugs faithfully when I was pregnant and followed what the doctors told me to do. Next time I will go to the church since this thing may be spiritual problem and spiritual problems need spiritual solution. Doctor said if we let them know when we are ready to have children, they will program the time and give us a go ahead. I never believe in that. I tell people that are the doctors God that provide children? I don’t base my faith on doctors. I don’t follow people’s mouth. I believe in God and I leave everything for God. (#9, 28-year-old, 0 children)

This same participant was interviewed a year later at follow up after successfully giving birth to her HIV-negative baby. When asked if she would do anything differently in terms of future childbearing, she stated:

No, I am not going to do anything different since nothing happened to this child I have. I will follow the same procedure—be prayerful, eat well and follow doctor’s rules. I cannot do anything different, except I don’t love my child.

Similarly, another woman expressed how her Christian faith helped her maintain a positive attitude while pregnant:

I believe that anything God knows about, nothing bad can happen as far as you hope on God. If you believe in God and you know God will really do this thing for you he will surely do it. With my prayer and Christianity it helped me a lot during my pregnancy and everything went normally. (#15, 38-year-old, 1 child)
After giving birth successfully a year later, this same participant acknowledged the role her doctors played:

The doctors told me… I can still have children, but I should start right away on the drugs.

They told me that I should take the drugs for some time before trying to conceive, so I took the drugs for a year until they told me it was okay to try to start conceiving.

While some participants were quick to acknowledge that their “pregnancy was through the help of doctors,” a majority of the nine new participants acknowledged that it was a combination of their faith and healthcare services that led to favorable childbearing outcomes.

The exception was the case of the only participant whose child was HIV positive. She stated that after she delivered her twins, HCWs told her that if she had chosen to deliver by cesarean section (CS), the other twin would not have been infected with HIV and would not have died. She blamed the HCWs for not informing her that there was a chance one of her twins may contact HIV during a vaginal delivery. However, she also noted that even if they had given her that information, it still would have been difficult for her to choose to deliver by CS. It is worth noting that faith was particularly salient in the few cases where participants reported that they were still waiting for their children’s HIV test results. They believed that as long as they had faith and followed the recommendations outlined by their healthcare providers, they were guaranteed a successful outcome. One participant said:

It is the belief I have in God that gave me the courage that my baby will be perfectly fine if I just do what they [HCWs] tell me to do and so I just believed. I didn’t give up and… when I gave birth my baby was fine. (#4, 28-year-old)

Another participant with a very high CD4 count noted how helpful the doctors were:
These two children that are alive don’t have it [HIV]. The doctors here are really trying. My prayers and faith in God have also helped me a lot and I have seen miracles. When I became pregnant I insisted that they should place me on drugs… I pray all the time that the Egyptians [HIV] I see I will see them no more, and I still take my drugs. When I get pregnant again I would still come to LASUTH for antenatal care. (#10, 31-year-old)

Finally, another participant described how everything worked out for her:

I am not regretting anything, because I stick to the advice the doctor gave me and I noticed that it worked for me. It is just God that did everything. I also went to Mountain of Fire for the prayer meeting for pregnant women throughout my pregnancy, and we cast and bind anything that will be an obstacle on that day of your delivery. (#14, 34-year-old)

**Enablers: Acceptability, affordability and accessibility of healthcare services.**

**Acceptability.** Almost all participants (12 out of 15) stated that the recommendations provided by HCWs, especially on mode of delivery, were often at odds with their personal preferences and values. This often made it difficult for participants to discuss their CB plans with HCWs, and to fully accept the advice given to them. One participant who gave birth to twins (one of whom later died) wished she had been counseled on the chances that her baby could be infected if she had a vaginal delivery:

If they [HCWs] had told me that there was a chance the baby may contact HIV during normal delivery, maybe I would have gone for CS… It would still be hard for me to decide on CS, because… from the background of my mother’s side we don’t use operation to deliver children *no be me go be the first* [I will not be the first]. (#9, 34-year-old)
Another participant explained how most doctors advise HIV-positive patients to deliver through CS without taking into consideration each person’s situation. Most women felt guilty for not having their unborn child’s best interest at heart.

I believe that not every woman has to born through CS. They [HCWs] will tell everyone, that is [a] PMTCT [patient] that you have to born through CS and that if you don’t born through CS, so, so, so thing will happen to your baby. I said lai lai! [never!] I will not do operation to deliver and my baby will be normal. They are just using this CS thing to sing every time to us and it is not good. Like if you don’t agree to it you are a bad mother and you don’t want what is best for your child. (#15, 38-year-old)

Cost associated with mode of delivery (affordability and accessibility). Regardless of acceptability of HCW recommendations and accessibility of services when needed, affordability was a major determining factor in whether pregnant WLHA had their babies via CS or vaginal delivery, and in a private or public hospital (general/teaching hospital). The costs associated with the services usually determined what mode of delivery participants chose. One participant berated physicians for “putting fear in people’s minds” by recommending CS to most WLHA. According to her, “When they [physicians] talk like that fear will catch some people if they don’t have money for CS.” Even after finally accepting the possibility of delivering their babies via CS, because “at times when problem comes… you need it to save lives,” many participants noted that the cost associated with this mode of delivery was often not affordable. For example, one participant who had been counseled by her physicians to deliver through CS explained why she decided not to for financial reasons:

I had stopped working so I didn’t have money for CS. That was what made me decide not to do CS. I told the doctor to forget it since I don’t have the capital and I don’t want to
put my hand in something I cannot handle... I said let me try my own luck and I delivered normal and had the same luck… These 2 children that are alive don’t have it [HIV]. (#10, 31-year-old)

Several women were worried about the cost of repeat CSs if they wanted to add children to their families in future.

I want to have more children, but it is money because I know that any child I have now will have to be through CS. Since I have had the first and second by CS, no doctor will allow me to push by myself. If there is a solution for it, I would like to push. (#11, 32-year-old)

At LASUTH, a public teaching hospital, “CS cost 36,500 Naira [$232]. Buying the drips [IV fluids], drugs and everything else will put the total at about 60,000-70,000 Naira [$382-$446]. I had to pay additional 10,000 Naira [$64] for my discharge and for some other things.” Although, this participant was able to afford the cost of a CS, she would her future CB experiences to be different.

Because of the fear and pressure on me about MTCT I just had to go for CS, but I don’t want to use CS again. I didn’t feel it when they brought out this baby. I want to have normal delivery because my husband does not have much, even this CS I had it was my parents… that rescued me and paid for it. My husband is working, but that CS of 50,000 Naira [$318], he doesn’t have the power. (#14, 34-year-old)

Unavailability of services at the hospital due to strikes were also a common theme related to accessing care at the government hospitals. “I remember when I was in labor and I came to the hospital they could not attend to me.” Another participant said, “because of the strike I have not seen the result for the HIV test I did for the baby over 4 months ago.” Many of the physicians
working at the government teaching hospitals are also affiliated with other private hospitals. When employees of government teaching hospitals go on strike (which is very common), some physicians offer to see patients in their private clinics at a higher cost. One participant described one such encounter when she experienced early labor during a strike:

The doctors were on strike when labor started early for me. When I got there [hospital] they said they cannot attend to me except I go to my doctor’s private hospital and I should hold about 180,000–200,000 Naira [$1144–$1271]. This was after I had already deposited the 50,000 Naira [$318] before the strike. (#14, 34-year-old)

Participants who could not afford the cost of a CS explained how some programs run by U.S.-based non-governmental organizations (NGOs) provided free services. One woman said, “I delivered by CS in LUTH [Lagos University Teaching Hospital]. They were doing a program for positive mothers where everything was free. I think it was the U.S. government or an NGO, but now they have stopped it.”

Despite the strikes common at government teaching hospitals, many participants still preferred using their services. “I will advise any positive pregnant woman to go to a teaching hospital… because they will give you the best treatment.” Many participants agreed that government teaching hospitals have better resources and more experienced healthcare professionals available. One participant who developed complications during her delivery said:

After giving birth, the placenta refused to come out. Before the baby came out he was weak, so they picked the baby up instantly and gave him oxygen. I thank God, because if not for that big general hospital and the experienced doctors, something would have spoiled. Assuming I delivered in the private hospital, with what happened to me we might be telling a different story. I thank God I delivered in general hospital. (#12, 29-year-old)
Nurturers: Expectations of the childbearing experience.

Infant feeding. Out of the 15 women interviewed, only five said that they were told they could breastfeed. Due to the uncertainty associated with breastfeeding while HIV-positive, however, not all five women who were given consent actually breastfed their babies. When asked what they would like to do differently with future children, almost all the women interviewed who had not breastfed previously stated that they would like to breastfeed as long as it does not cause harm to their children. Participants expressed the degree to which breastfeeding is expected by their families, communities and the healthcare workers. One participant said, “no woman will give birth and will not like to breastfeed her child.” For some participants, they felt very strongly that it was better not to have any child at all than to have a child one is not able to breastfeed. One participant who waited for six years before giving birth said:

I was waiting on God [for a child] so I now said, “God if you know that I am not going to breastfeed my baby, don’t give me a child. Let me just stay like that.” I cannot give birth to a child that I cannot breastfeed. After I have been waiting for 1, 2, 3, 4, 5 years, I will not breastfeed now that the baby has come, I did not want that. (#8, 34-year-old)

Although most participants stated that they would like to breastfeed their children, they were often unsure as to whether it would harm their babies. Since breastfeeding is a practice expected by the women, their families and communities, this can create some tension. They wanted HCWs to provide better information on infant feeding practices while living with HIV. One participant stated:

I only gave breast for 2 months because my mind was not clear whether I was causing harm to my baby so I stopped it. If they [HCWs] can give us more information on breastfeeding … Breastfeeding is causing many problems in the home … When you give
birth some people will come to know whether you are giving breast or not. My mother-in-law came and my mother came and when they asked I told them that because of the stress I faced during CS I don’t have the strength to breastfeed again. (#11, 32-year-old)

This kind of tension between doing what these women consider to be the right thing sometimes competes with what is expected of them as mothers. It becomes even more difficult for these women if the counseling they receive is not precise about breastfeeding. Many women stated that the information provided by HCWs was sometimes vague:

I wish we were clear on the breastfeeding aspect so that we as positive mothers know what to do. They [HCWs] should enlighten people more on breastfeeding, because most women want to breastfeed their children. I am already used to people asking why I don’t breastfeed. If I should get pregnant again, I would like to breastfeed. (#3, 33-year-old)

Regret and guilt was often associated with not breastfeeding:

I did not breastfeed any of my children. I wish I could have breastfed them. It makes me feel like a bad mother somehow. At times like this, even with this baby now when I look at him I feel bad, but there is nothing I can do. (#4, 28-year-old)

When asked what kind of information HCWs provided to them on infant feeding and the influence that it had on their decision, it was evident that the lack of counseling on breastfeeding remain a problem for these women.

They said I can breastfeed, but I should not mix with milk formula. They told me to breastfeed for 3 months and I decided to extend it till 6 months, because… my CD4 count was still okay... Since they said it is a 50-50 chance, I just decided to breastfeed. When someone says 50-50 that means they are not sure. Assuming they said 80-20 or 90%
chance then I would just stick to their advice and not breastfeed, which means they are sure. I have met people that breastfed and their baby didn’t have it. (#10, 31-year-old)

Another participant explained the information she was given:

They said if you gave birth through CS you are free to breastfeed and they are 80-100% sure that the baby will not have it [HIV]. If you have normal delivery and breastfeed they are not sure about that. I didn’t want to take any risk so I decided to just give formula. (#12, 29-year-old)

In this case this mother opted for a choice she felt guaranteed that the child would be protected. Yet, in other instances mothers are reprimanded for not breastfeeding. The degree to which breastfeeding is expected by most HCWs is highlighted in the case of one participant who was reprimanded for not breastfeeding by a HCW who was unaware of the mother’s HIV status.

When the nurses at the immunization health center see you with feeding bottles, they will shout at you, seize the bottle from you and throw it away saying you should be giving the baby breast since breastfeeding is the best. They have done this to me twice. I have to be telling them the history of why I am not breastfeeding. Sometimes, it is difficult for me to share the reason with everyone. One day, I had to call the nurse that threw my bottle away to tell her that I am [a] PMTCT [patient]. She asked me, “What’s the meaning of that?” I was surprised she didn’t know the meaning, and she calls herself a qualified nurse and a government health worker. I told her that I am HIV-positive mother. She said, “Eh ya [Pity].” She felt really bad and told me that she cannot go and pick the feeding bottle [from the garbage] and give it back to me. She offered to give me money to buy another one. I told her that I don’t need the money, and that I just wanted her to know the reason why I am not breastfeeding. It is not because I don’t wish to. She really
felt bad. She started condemning herself on the way she acted towards me and she begged me. (#14, 34-year-old)

This case above is a good example of the competing priorities of child survival programs and HIV prevention programs such as PMTCT. Child survival programs prioritize breastfeeding while PMTCT does not. Some of the key components of child survival programs include breastfeeding and immunization (UNICEF, 2003). From the example above it is evident that what is needed is education for both HCWs and patients.

**Discussion and Conclusion**

In this study, I examined how Nigerian WLHA perceived the support and recommendations of HCWs related to CB decision-making. Based on the expectations and perceptions of WLHA I assessed whether the services provided by HCWs align with the CB needs of WLHA. This is one of just a few studies to specifically address contextual factors within the healthcare system that promote or hinder WLHA acceptance of healthcare recommendations (Cooper et al., 2007; Harries et al., 2007).

As pediatric HIV infection still remains a challenge in resource-constrained settings, it is important to note that the acceptability and use of healthcare services such as PMTCT will be influenced by the interactions of WLHA with the healthcare system (MacCarthy et al., 2012). Furthermore, it is important to note that just because HCWs provide information on safe CB based on international health organization guidelines, it does not mean that WLHA will accept and follow those recommendations. This is the case particularly when recommendations do not offer a 100% guarantee of success to mothers. Most mothers with HIV want what is best for their children, which in this context means HIV-negative status. However, making CB decisions as an HIV-positive mother is a complex process that is often heavily influenced by a combination of
HCW recommendations, cultural expectations of the birthing process, and what it means to be a mother. For many mothers the CB experience is not just about birthing a child, but doing so in a culturally acceptable way, often “the way nature intended.” Culturally, vaginal delivery and breastfeeding are central to motherhood. Hence, conflicts arise over decisions about breast versus bottle feeding, and CS versus vaginal delivery.

Our findings indicate that the nine new participants felt that a combination of their faith and healthcare services led to favorable childbearing outcomes. However, uncertainty about their children’s HIV statuses post-partum tended to be a factor in reliance on faith just as uncertainty about pregnancy outcomes pre-partum tended to be a factor in reliance on faith for the six women interviewed during pregnancy. Overall, findings for the nine new participants were consistent with those of the six participants interviewed both pre- and post-partum, suggesting that all 15 participants shared similar values. From this, we can infer that since similar views were expressed by all participants; if these nine participants had also been interviewed pre-partum there is a high likelihood that they would have responded similarly to the original participants.

The findings of this study reveal that HCW recommendations on mode of delivery and infant feeding practices are not always consistent with the personal preferences of WLHA, which creates tension. Such tension makes it difficult for WLHA to discuss their CB plans with HCWs, to fully accept the recommendations given to them, and to incorporate them into their actual CB decisions. For HCWs, the lack of consensus over the role of breastfeeding in HIV transmission is an important issue that must be resolved. HCWs must incorporate the most recent international guidelines into their recommendations.
This study has some limitations that may affect its generalizability to the population of all WLHA in Lagos state. Since LASUTH is considered one of the best in Lagos state when it comes to care of PLWHA, this clinic may not be representative of other government teaching hospitals in Nigeria providing PMTCT, HIV treatment and care services. Since some participants were interviewed immediately after interactions with physicians, nurses and other HCWs, it is possible that their answers were affected by the nature of their interactions. To minimize this effect, not all participants were interviewed on the day when they sought care or interacted with HCWs.

Despite the limitations, this study has several strengths worth mentioning. Due to the fact that LASUTH is highly subsidized, WLHA from diverse backgrounds are able to access high quality care. The large number of patients at the hospital allowed for the recruitment of WLHA with diverse views on the topic. Secondly, the follow up post-partum allowed us to compare whether or not the CB motivations of these women changed during pregnancy and after childbirth. It also enhanced credibility since participants revealed more to the researchers over time as trust was established.

Notwithstanding the limitations, the results of this study have implications for HIV treatment and care programs geared towards improving the health of women and children. One such implication is the improvement of provider-patient relationships in HIV clinical care settings. If the UNAIDS/ WHO goal of eliminating new pediatric HIV infections by 2015 is to be achieved, there is a need to pay closer attention to multiple contextual factors such as cultural expectations and spirituality that influence communication between WLHA and HCWs about CB plans and acceptance of healthcare recommendations. To this end, reproductive and family planning services in resource-constrained settings can benefit from understanding how WLHA
perceive HCW recommendations either as barriers or facilitators of their CB plans and activities. Future studies that seek to bridge the gap between HCWs and WLHA are needed since there seems to be a disconnect between the needs and desires articulated by WLHA and the assumptions made by HCWs. It would be beneficial in future to include HCWs in the interviews to assess their views on the SRH of WLHA.

**Recommendations**

1. Healthcare workers should receive regular training on the most recent updates in infant feeding and mode of delivery practices for WLHA.
2. Healthcare workers, particularly those working in other areas such as child survival programs, should be re-educated on the goals of PMTCT.
3. As a part of counseling, healthcare workers should discuss the financial implications of delivery by CS.
4. Healthcare workers should expect patients to rely on faith when faced with uncertainty, but that should not discourage HCWs from providing counseling and education.
References


Chapter 7. Conclusion

In this chapter, I present a summary of the overall study, reflections on the research process, implications of the findings for policy and practice, and future directions.

Summary of Findings

In Chapter 4, the focus of the preliminary study was to understand the factors influencing the childbearing decisions of WLHA who attended the hematology clinic at LASUTH in Lagos, Nigeria. This study found that the role of faith was significant in the childbearing decision-making process. While some WLHA believed in combining their faith with available healthcare services, others believed in just one or the other. Another theme that emerged was communication between healthcare providers and patients about childbearing, with WLHA wanting HCWs to initiate discussions on SRH and CB. Finally, most participants reported that their husbands/partners were supportive. This support stemmed from both the knowledge and awareness of HIV or denial of their partner’s HIV status. These findings suggest the importance of discussing sexual reproductive health and childbearing issues with WLHA in the healthcare context prior to pregnancy. From the findings, we conclude that WLHA are not deterred from having positive fertility desires and intentions regardless of whether or not their SRH needs are being met.

In the second phase of the study (Chapter 5), I examined the relationship between male partner support and WLHA childbearing decision-making after disclosure, during pregnancy, and after childbirth. The results revealed that all male partners were supportive, except in the case of the only unmarried mother. In addition, the level of male partner support reported was consistent, and it did not matter whether the support provided was after disclosure of HIV-positive status or after childbirth. Furthermore, male partners provided emotional support and
reassurance to WLHA by relating to them as they normally would, as well as spiritual and other tangible forms of support. These findings suggest that the relationship between the support provided by male partners and the CB decisions of WLHA may be different from what has been reported in previous literature, since none of our participants expressed the fear of being abandoned by their partners, or experiencing intimate partner violence. From the findings, I conclude that desire among WLHA to have children was not always influenced by partners’ desires for children. Instead, the desire to balance the gender distribution among their children, and their previous CB experiences were greater determining factors.

The two theoretical models used in this dissertation framed the approach used in the research. PEN-3 model, which was used as the overall guiding theoretical model, was developed to understand the role of culture in addressing health behaviors and decisions of Africans and people of African descents. It takes into account the collectivistic nature of many African societies, such as the role of partners and extended family in the CB decision-making process. Specifically, the Relationships and Expectations domain of this model was used to explore the role of partners and the healthcare system, WLHAs’ perceptions of their SRH needs, and the impact on fertility desire and intentions. The model was used to frame research questions such that we were able to elicit responses that allowed us to document the support and encouragement that WLHA received from their partners rather than focusing only on partners not being supportive as typically reported in the literature. The ODSF was the second model used and it was used only in chapter 5 (Paper 2). This framework emphasizes that decision-making is influenced by several factors such as: (1) perceptions about the decision; (2) perception of significant others; and (3) personal and external resources to make the decision. In fact, this model complements PEN-3 as an overarching framework. In using ODSF, we focus on WLHA
perceptions of the role of male partners in childbearing decision-making. Perception of significant others such as male partners may include factors such as pressure to make a certain decision, support for decisions made, role of partners in decision making or perceptions about what partners think (Doull et al., 2006; Allen & Berry, 2011).

In the second phase of the study (Chapter 6), we examined how WLHA perceive the advice and support of HCWs, and whether or not those are factored into their CB decisions. In this chapter we focused on the pre- and post-partum experiences of WLHA. The results revealed that the role of faith was very significant pre-partum. However, most participants acknowledged the role of healthcare workers post-partum, and access to available healthcare services as determinants of favorable childbearing outcomes. Also, participants found it difficult to accept recommendations on mode of delivery, because they were often at odds with their personal preferences and values. Another barrier to the acceptance of HCW recommendations on mode of delivery was the accessibility and affordability of services. Not being able to access services at the public hospitals due to strikes was also a common theme. Furthermore, many women reported being uncertain about infant feeding practices. Most of the participants stated that they would like to breastfeed as long as they could be sure that it would not harm their children. They wanted HCWs to better inform them about infant feeding practices while living with HIV, since the information provided was usually vague.

These findings provide evidence that contextual factors within the healthcare system, cultural expectations of the birthing process, and personal preferences influence WLHA discussions about CB plans with HCWs, and the incorporation of HCW recommendations into actual CB decisions. From the findings, we conclude that the desires of WLHA to have children were not always influenced by the support they received from the healthcare system. The desire
to balance the gender distribution among their children and their previous CB experiences were greater determining factors.

The two theoretical frameworks used in this dissertation add to the richness of the study. The PEN-3 model, which was used as the overall guiding theory, was developed to understand the role of culture in the health behaviors and decisions of Africans. It takes into account the collectivistic nature of many African societies, such as the role of partners and extended family in the CB decision-making process. Specifically, the Relationships and Expectations domain of this model was used to explore the role of partners and the healthcare system, WLHAs’ perceptions of their SRH needs, and the impact on fertility desire and intentions.

The ODSF was only used in Chapter 5 (Paper 2). This framework emphasizes that decision-making is influenced by several factors such as: (a) perceptions about the decision; (b) perceptions of significant others; and (c) personal and external resources available to make the decision. In using this framework, we focus on WLHA perceptions of the role of male partners in childbearing decision-making. Perceptions of significant others such as male partners may include factors such as pressure to make a certain decision, support for decisions made, role of partners in decision making or perceptions about what partners think (Allen & Berry, 2011; Doull et al., 2006).

**Reflections on the Research Process**

*You can’t really understand another person’s experience until you have walked a mile in their shoes.*

- Author Unknown

As I reflect on the past 3 years of working on this research project, I feel like I have grown not just as a researcher, but also as an individual, and most importantly, as a woman. I
have learned much more from each of the 75 participants I interviewed than I ever thought possible. I feel more connected to each one of these women now more than I ever imagined would be the case when I first started this research journey. I am now confident in saying that I feel their pain, and I can understand and better appreciate their plight as women. This section explores my data collection experience, and some of the ethical challenges of working in this setting that I faced while trying to navigate the system, and at the same time adhere to the research protocol approved by Penn State Institutional Review Board (IRB). I will illustrate these challenges using one case example taken from my field notes.

**Powerful emotions.** “I have no right to be angry.” I kept repeating those words to myself with the hopes that it would soon take root in my psyche. However, my emotional state, or at least my mental state, did not seem to be in agreement with the words coming out of my mouth. Even though I felt disrespected when her husband spoke to me rudely yesterday and hung up the phone on me, I still insist that I have no right to be angry. I question myself again, “Is my anger really justified?”

It first started out as anger. How dare she? I have called her several times within the past year, and she initially agreed to participate in a follow-up interview. After all, she was the one who gave me her number. What has changed between then and now? Mary has a bachelor’s degree, she is young and full of life, and I felt we connected the first time I interviewed her. She had just discovered her status about 5 months earlier after her wedding, and she was also pregnant with her first child. I felt connected and drawn to her story, like the many others. I felt she understood that what I was doing would be beneficial to her and others like her in making their voices heard. I felt that unlike some others who did not have her educational background she would be more receptive and open knowing that I was, after all, a researcher.
I wondered, “When and where did things go wrong?”

I felt angry because I felt disrespected.

I felt angry because I felt we connected.

I felt angry because I assumed that she was educated.

I felt angry because I thought I was being manipulated.

I felt angry because that is one follow-up participant gone down the drain.

After the anger dissipated came my sense of reasoning and questioning.

*Anger?* I have no right to that, because I have not walked in her shoes and cannot truly know the emotional turmoil (maybe even worse than *my* anger) going on inside her. After all, it is her life’s story.

*Disrespect?* I have no right to that either, when I have never been disrespected and treated like an animal for seeking medical care for a stigmatized disease.

*Connection?* No matter how many interviews I conduct with *people like her* or knowledge I have, I will still be like a stranger in a foreign land trying to understand their experience.

*Education?* Education has nothing to do with her not participating, because cultural expectation usually transcends levels of education. Education goes out the window when one is confronted with a situation that seems beyond one’s control.

*Manipulation?* I am wearing the “researcher” hat (a fact that I should never forget), and as such I will always be regarded with suspicion as to my true intentions. I never stopped to think for a moment about her perception of me. Perhaps she thought that I was trying to exploit and manipulate her for information.
This incident allowed me to pause and reflect on some things, which left me with a lot of questions. How do these women view me? What is my motive for conducting this study (in Nigeria)? Was it to get as many participants as possible that would give me good data? Was it just to finish a dissertation and get a degree? Was it just to have my work published in some fancy journal? Why was I interested in this population? Who is this research really for?

**Confidentiality and Ethical Issues**

I was extremely mindful of the fact that I never wanted my research participants to feel exploited or coerced into being a part of the study. I know most people, especially those who are part of a vulnerable group, have a negative view about research. I made it clear to them from the outset that they were free to stop me at any time if they no longer wanted to participate in the interview. I also made it clear that if they had any questions about the study they could contact me at any time. I faced several ethical dilemmas, which I describe below.

One of the challenges I faced was trying to get all of the 11 pregnant women I had previously interviewed in 2011 to participate in follow-up interviews in 2012. Even though I had made every effort to keep in touch through telephone calls at three different times over the course of the year, I still lost five participants whom I could not interview. Of the six participants I was able to interview, I was able to get three to participate fairly easily. As for the remaining three, many of my phone messages were not returned, and when they did answer my calls, they sounded very hostile. As a last resort, one of my gatekeepers at the hospital suggested that she would call to tell them that researchers at the hospital needed to speak with them about the care and treatment they were receiving. When this gatekeeper called she asked them to come and see her at their next clinical appointment. Since this gatekeeper was very well known and trusted by the group, this gave participants a sense of confidence and trust in the research study.
Liamputtong (2008) stated that, “potential research participants want to identify a common person whom they themselves and the researcher know as a way for them to check the researcher’s credibility and trustworthiness.” During the support group meetings, this gatekeeper introduced me to the group, and gave them some details about my study. This general introduction to the group was later helpful in my recruitment of potential participants, as some of them commented that I was the “doctor from America” when I approached them days later. In addition, I found out that being in the clinic on the days when WLHA came in for their appointments, and interacting with the healthcare workers made it easier for potential participants to agree to participate in my study when I eventually contacted them.

The second challenge I faced was that some of the pregnant women who had given me permission to contact them for follow-up interviews had given me either fake names or fake phone numbers; in other cases, I had their real names, but they had changed their phone numbers. In trying to locate these women, my gatekeeper directed me to another department within the clinic to verify their contact information. One of the people I was directed to offered to help by checking the information database, and matching it with the demographic information I had to locate these women. Even though I was initially thrilled by the idea, I knew that it would be a breach of confidentiality.

Lessons Learned

_Ti a ba de oju s’ile a ma ri imu._ [Whenever the eye carefully looks downwards it would clearly see the nose.]

- Yoruba proverb

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One of the greatest lessons I have learned from this study is being able to take a step in these women’s shoes. The opportunity to share in their lived reality for a moment has been a humbling experience. I have learned to search deep within myself to extract empathy for others that I never knew existed. I have listened to women cry as they told me about their painful experiences of miscarriages, stillbirths, pediatric HIV infections, and infant deaths from HIV. I have learned to be grateful for the little things in life. I have learned to be optimistic in whatever circumstances I find myself. I have learned how to relate with people better. I have learned to never make the assumption that being educated gives you leverage over people who are uneducated. This is a reminder that one can learn a lot from those who do not have formal schooling. They also tend to be the ones who are more receptive towards you and more trusting. Perhaps, those with more formal schooling and higher education are more suspicious because they are aware that researchers can wreak havoc. I have learned to be patient, flexible, and to be an active listener. I thought I was going in to extract information from these participants to help them live a better quality of life. Little did I know that if my eye looked down carefully, it would enable me see my nose, such that they were going to reciprocate by teaching me valuable life lessons that would enhance the quality of my life and the value I place on relationships.

Finally, I realize that each story is uniquely different, and needs to be told. Most importantly, I feel indebted to my sisters, these brave women. I feel the need to be their advocate, to be their voice. It is my responsibility to capture their collective struggles and give voice to their views through their stories. They entrusted me with these stories to tell, hoping that doing so would bring about change make life better for them. I feel a sense of obligation to represent their perspectives in the literature. In doing this, I realize that I must be mindful of the fact that this data is someone’s life story—her life story. Therefore, she has every right to deny me access
to this cherished piece of information. For her, it is her life story; for me, it is data. From this perspective, what right do I have to get angry?

**Implications for Practice**

**Provide pre-conception counseling for WLHA and their partners.** Most of the women in our study stated that they would like for HCW to provide them with SRH and CB information prior to getting pregnant since some pregnancies are unplanned (Chapter 4). That way they are better prepared on what steps to take when they eventually get pregnant. HCWs can provide support to WLHA and their partners through pre-conception couples counseling on how to achieve their CB intentions without jeopardizing their health, or that of their partners or their unborn children. This opens up the lines of communication between HCWs and WLHA on their SRH and CB plans, and it improves the quality of care being provided.

**Continuing education and training of HCWs.** Our study (Chapter 6) revealed that WLHA wanted HCWs to provide them with clear instructions on infant feeding practices (breastfeeding), and mode of delivery. Since some HCWs are unaware of the latest guidelines, they end up providing vague information to WLHA, leaving them unsure of what to do. Information on the SRH and CB processes of WLHA is constantly evolving. Thus HCWs must receive ongoing training in order to pass on the latest information and provide the most accurate recommendations to their patients.

**Integration of SRH services and HIV care.** HCWs working in different sections of the hospital, such as those working in pediatrics, HIV, and maternity clinics, function separately, and are sometimes unaware of what is being recommended to support WLHA on successful childbearing outcomes. For example, HCWs in areas such as child survival programs may be promoting breastfeeding of all infants while HCWs in PMTCT programs may be discouraging
breastfeeding. In addition, family planning programs may be promoting condom use without taking into consideration the barriers faced by WLHA in safely negotiating condom use. Integrating these services will provide better support for the SRH needs and CB intentions of WLHA.

**Role of faith when discussing CB plans.** Given the stigma that is sometimes associated with CB intentions of WLHA, they may disapprove of the recommendations provided by HCWs. Therefore, HCWs cannot assume that WLHA will adhere to the recommendations they provide. In addition, the reliance of patients on faith when dealing with uncertain CB outcomes is to be expected, but that should not discourage HCWs from providing the necessary counseling and education.

**Recommendations for Future Studies**

**Inclusion of men and couples.** Since we did not include the male partners of WLHA in our study, we are only able to rely on WLHA perceptions of partner support in their CB decision-making. These responses may not truly reflect their male partners’ views. In addition, it would be beneficial to include serodiscordant and seroconcordant couples on the strategies they employ to prevent HIV infection or re-infection while achieving their CB goals.

**Inclusion of healthcare workers.** Since we did not interview HCWs in our study, we are only able to rely on WLHA perceptions of healthcare support in their CB decision-making. Results from our study (Chapter 6) revealed that there seems to be a disconnect between the SRH needs stated by WLHA and what HCWs think they need. There should be a dialogue between both parties in order for HCWs to effectively meet the SRH needs of WLHA, which will hopefully lead to successful CB. Researchers who conduct future studies should interview HCWs about the SRH and CB needs of WLHA.
Role of spirituality. Results from our study (Chapter 6) revealed that the role of faith was very prominent pre-partum. However, most participants acknowledged the role of healthcare workers post-partum and access to available healthcare services as a determinant of favorable childbearing outcomes. Therefore, future studies should further explore the complex ways spirituality is expressed in the CB decision-making process of WLHA pre-partum compared with post-partum.
References


Appendix A. Study Recruitment

**Title of Project:** Sexual and Reproductive Healthcare (SRH) needs: Impact on Reproductive Decisions of Women Living with HIV/AIDS (WLHA) in Lagos, Nigeria

**Introduction:** Hello, my name is Yewande Sofolahan and I am conducting a study on the Sexual and Reproductive Healthcare (SRH) needs of Women Living with HIV/AIDS (WLHA) in Lagos Nigeria. This study is conducted for research purposes and the results from this study will be used for a doctoral dissertation by a student from Penn State University in the United States.

**Eligibility:** There are several criteria to be included in this study:
Are you between the ages of 18-35 years old? Have you been clinically diagnosed with HIV? Are you currently receiving HIV care in the hospital or are you involved in a support group? Are you willing to discuss experiences living with HIV and the type of care being received?

**Procedures (What participants will be asked to do):**

If participant meets eligibility criteria stated above, the study will be explained to them as follows:

You will be asked to answer questions on contraceptive use, having children, while living with HIV/AIDS, role of your partner, type of care and support from health care system and your SRH needs. Interviews lasting about 1 hour will be audio-recorded and conducted in pidgin English or Yoruba with you while you are waiting to see the doctor. You will not lose your place in line, should you decide to participate in our study.
If participant is interested, the following steps will be explained to them: “Since you meet our initial eligibility criteria, the next step is to go over the informed consent form with you, ask questions and let me know if you are interested in participating in this study.

Right to Ask Questions: If you have any questions about your rights as participants in this research study, or if you do not like what is being done, you can either contact the researcher, Ms. Yewande Sofolahan, at yas108@psu.edu.
Appendix B. Phase 1 Interview Guide

THE RECORDING OF THE IN-DEPTH INTERVIEW THAT FOLLOWS THIS MUST BE LABELED WITH THIS STUDY IDENTIFICATION NO. ______ ______ ______ ______

Demographic Information

| 1. Ethnic group | 1 = Yoruba  
|                 | 2 = Hausa     
|                 | 3 = Ibo       
|                 | 4 = Other     
| [SPECIFY]:      |
| 2. Sex          | 1 = Male      
|                 | 2 = Female    |
| 3. Age          | ______ (in years) |
| 4. Education – highest grade passed: | 1 = Employed  
|                 | 2 = Unemployed |
|                 | 3 = Working for self |
|                 | 4 = Seeking work |
| 5. Employment status: | 1 = Yes; 0 = No |
| 6. Do you currently have someone who you consider to be your main sexual partner? |
| 7. IF YES: How many do you currently have? |
| 8. IF YES: How would you describe your main partnership? | 1 = Husband  
|                 | 2 = Living together stable partnership |
|                 | 3 = Boyfriend -live in |
|                 | 4 = Boyfriend – stable but not live in |
|                 | 5 = Casual relationship |
|                 | Other ________ |
| 9. IF YES: How long have you been in this main relationship? | ______ _____ (weeks)  
<p>|                 | ______ _____ (months) |
|                 | ______ _____ (years) |
| 10. How long have you known about your HIV | ______ _____ (weeks) |</p>
<table>
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<tr>
<th>Question</th>
<th>Response Options</th>
</tr>
</thead>
</table>
| 11. What is your main partner’s HIV status?                            | 1 = Positive  
2 = Negative  
3 = Unknown |
| 12. How would you rate your current state of health?                   | 1 = Poor  
2 = Fair  
3 = Good  
4 = Excellent |
| 13. Have you had any illnesses that a doctor or nurse told you was related to HIV that you have been treated for? | 1 = Yes 0 = No |
| 14. IF YES: What has/have this/these been?                             |                                   |
| 15a. Are you currently on antiretroviral treatment/ARV’s?               | 1 = Yes 0 = No                    |
| b. Do you feel sick or are you getting better? Why?                    |                                   |
| 16. Are you currently using any other medications or herbs?            | 1 = Yes 0 = No                    |
| 17. IF YES: Can you say what it is for?                                |                                   |
| 18. Have you ever heard of a CD4 count?                                | 1 = Yes 0 = No                    |
| 19. IF YES: Can you explain to me what you understand by it             |                                   |
| 20. Have you had a CD4 count done yet?                                 | 1 = Yes 0 = No                    |
| 21. IF YES: What is it?  
DESCRIBE BELOW                         | 1 = Still to return for results  
0 = Unsure |
| 22. How many times have you ever been pregnant? This includes miscarriages and terminated pregnancies, or pregnancies where the baby died after birth. | -99 = Refused |
| 23. How many living children of your own do you have?                  | Number of boys  
Number of girls  
None |
| 24. Are you currently using condoms/contraception?                     | 1 = Yes 0 = No                    |
25. Do you use condoms/contraception?  
1 = With all partners  
2 = Only with some partners  
If only with some, with what partner/partners?  

26. IF YES: what method/s are you using or have previously used?  

<table>
<thead>
<tr>
<th>Method</th>
<th>No</th>
<th>Yes</th>
<th>DK</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Oral contraceptive pills</td>
<td>0</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>b. Male condom</td>
<td>0</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>c. Female Condom</td>
<td>0</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>d. Intra-uterine device (IUD)</td>
<td>0</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>e. Withdrawal (man pulls out)</td>
<td>0</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>f. Non-penetrative</td>
<td>0</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>j. Emergency contraception</td>
<td>0</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>j. Anything else, such as abstinence, anal sex, rhythm, other medicine [SPECIFY]:_____________</td>
<td>0</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>-99 = Refused All</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

27. Where do you go for your contraceptive method?  

Questions on Contraception and Sex  

1. For some HIV+ people, an HIV diagnosis changes their thoughts, attitudes, and behaviors about sex, while for other HIV+ people, an HIV diagnosis has no effect at all. Do you think having HIV has affected or not affected your sex life?  

*IF YES:* Why and in what ways?  
- Desire to have sex  
- Having sex while HIV-infected  
- Frequency of having sex  
- Pleasure in the sexual act (enjoy it more or less)  
- Need to have safer sex., e.g., abstinence, limit partners, use condoms  

*IF NO:* Why not?  

*ASK ALL:* How important or unimportant is it for you to have sex at this time in your life? Why/why not?  

2. What do your HCW think about HIV+ persons having sex?  
- What have we you heard or experienced?  
- Has this had any effect on what you think, feel, or do?  

3. If you really want to have sex with someone and still keep yourself safe from new infections, what do you do?
**PROBE** for male and female condom use, monogamy, does not have sex

4. What are your thoughts about refusing unsafe sex?
   - What happens when you want safer sex and your partner does not want to?
   - What happens when your partner wants safer sex and you don’t?

5. Since you learned you are HIV+, do you tell or not tell your sexual partners that you want to have safer sex?

*IF YES:* Why? How?

*IF NO:* Why not?

   - Does it depend on the kind of partner you are with? What kind of partners do you tell? How?

   - Think of a situation when you told a sexual partner you wanted to have safer sex. Why did you do this?
     - What did you say or do?
     - What did you partner say or do?
     - When in the course of being together, did this happen?
     - What happened?

   - Now think of a situation when you did not tell a sexual partner you wanted to have safer sex. Why didn’t you in this situation?

**Questions on Having Children**

1. How important is it to you to have/not have (more) children?
   - What are some of the reasons that you feel this way?

2. What effect, if any, does HIV have on your desire to have/not have (more) children?
   - What are some of the reasons that you feel this way?

   **PROBE** for participant’s feelings prior to being diagnosed HIV+ compared with what feelings are now

   *IF FEELINGS CHANGED, PROBE* for how is this affected by:
   - How you currently feel physically and emotionally?
   - Your partner’s HIV status: What if negative? What if also positive? What if your partner(s)’ status is unknown?
   - How would you feel if you were negative and your partner was HIV-positive?
   - The chances of your infant becoming infected with HIV?
   - The level of support available to you?
• Would it make any difference if:
  • [You/your partner] already [have/has] children or not?
  • [You/your partner] already has had a child who is infected with HIV or who has died of AIDS?
  • [You/your partner] [have/has] experienced the death of someone [else] in family from AIDS?

3. How important is it to your partner to have/not have (more) children?
   • What are some of the reasons that you feel this way?
   • [Has this had/would this have] any effect on what you think, feel, or do?

4. What effect, if any, does HIV have on your partner’s desire to have/not have (more) children?
   • What are some of the reasons that you think your partner feels this way?

5. Would your feelings or what you [do/intend to do] be affected by [you/your] partner being on antiretroviral treatment?
   • Check if they are aware of and know what ARV treatment is.
   • Would you want to have a child in your current state of health? Why?

6. Many women discover that they are HIV+ when they become pregnant. What do you think they should do?
   • Under what particular circumstances, if any, do you think HIV+ women who are pregnant should discontinue their pregnancy?
   • Under what particular circumstances, if any, do you think HIV+ women should continue with their pregnancy?

Questions on SRH-HIV Service Integration and SRH Needs

1. As an HIV+ woman/man, what do you feel are your most important sexual and reproductive health needs?
   • In what ways, if any, are your needs different from uninfected women and men who use reproductive health services?
   • What are these needs in relation to your fertility desire/ intention

2. How do these needs affect your desire/ intention for children?

3. How common is it that a doctor or nurse will discuss sexual and reproductive health issues with you?
   • Is this being done routinely or not?
   • If discussed: What issues have [you/they] discussed? PROBE for reproductive intentions; contraceptive needs; dual protection/method use; EC; TOP; sterilization; cervical cancer screening
   • Do you feel that issues of sexual and reproductive health are being adequately
discussed?
• What factors may make these discussions difficult?
• What factors could help facilitate these discussions?

4. Does how supportive a doctor/nurse is in addressing your SRH needs influence your fertility desire/intention?
• If YES, how so?
• If NO, why?

5. What are the major challenges you face in obtaining sexual and reproductive health services at the clinic?
• If services are not fully integrated, what challenges do you face:
  • In HIV care?
  • In S&RH care?

6. In what ways could the health care you currently receive services be changed to better meet your needs?
• What improvements or additions would you recommend to improve services for sexual and reproductive health?

  PROBE for types of services, regularity in providing services, tailoring information to the needs of HIV+ women and men, accessibility of services, more S&RH-friendly policies

7. How would you feel about getting reproductive and sexual health services as part of your HIV care?
• Why/why not?
• What do you see as the best ways to integrate reproductive/sexual health and HIV care services?
• What would you see as some of the benefits of receiving reproductive and sexual health services as part of your HIV care?
• What would be some of the drawbacks of receiving reproductive and sexual health services as part of your HIV care?
• What about integrating HIV into reproductive and sexual health services?
  • What would you see as some of the benefits?
  • What would be some of the drawbacks?
• Do you prefer receiving HIV care as part of your reproductive and sexual health services, or receiving reproductive and sexual health services as part of your HIV care? Why?
Appendix C. Phase 2 Interview Guide


IRB Approval #: 33929

THE RECORDING OF THE IN-DEPTH INTERVIEW THAT FOLLOWS THIS MUST BE LABELED WITH THIS STUDY IDENTIFICATION NO.

Demographic Information

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Ethnic group</td>
<td>1 = Yoruba &lt;br&gt; 2 = Hausa &lt;br&gt; 3 = Ibo &lt;br&gt; 4 = Other &lt;br&gt; [SPECIFY]:</td>
</tr>
<tr>
<td>2. Sex</td>
<td>1 = Male &lt;br&gt; 2 = Female</td>
</tr>
<tr>
<td>3. Age</td>
<td>_ _ _ _ _ (in years)</td>
</tr>
<tr>
<td>4. Education – highest grade passed</td>
<td>_ _ _ _ _</td>
</tr>
<tr>
<td>5. Employment status</td>
<td>1 = Employed &lt;br&gt; 2 = Unemployed &lt;br&gt; 3 = Working for self &lt;br&gt; 4 = Seeking work</td>
</tr>
<tr>
<td>6. Do you currently have someone who you consider to be your main sexual partner?</td>
<td>1 = Yes; 0 = No</td>
</tr>
<tr>
<td>7. IF YES: How many do you currently have?</td>
<td></td>
</tr>
<tr>
<td>8. IF YES: How would you describe your main partnership?</td>
<td>1 = Husband &lt;br&gt; 2 = Living together stable partnership &lt;br&gt; 3 = Boyfriend -live in &lt;br&gt; 4 = Boyfriend – stable but not live in &lt;br&gt; 5 = Casual relationship &lt;br&gt; 6 = Other _ _ _ _ _</td>
</tr>
<tr>
<td>9. IF YES: How long have you been in this main relationship?</td>
<td>_ _ _ _ _ (weeks) &lt;br&gt; _ _ _ _ _ (months) &lt;br&gt; _ _ _ _ _ (years)</td>
</tr>
<tr>
<td>10. How long have you known about your HIV status?</td>
<td>_ _ _ _ _ (weeks) &lt;br&gt; _ _ _ _ _ (months)</td>
</tr>
<tr>
<td>Question</td>
<td>Options</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------</td>
<td>---------------</td>
</tr>
<tr>
<td>11. What is your main partner’s HIV status?</td>
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</tr>
<tr>
<td></td>
<td>2 = Negative</td>
</tr>
<tr>
<td></td>
<td>3 = Unknown</td>
</tr>
<tr>
<td>12. How would you rate your current state of health?</td>
<td>1 = Poor</td>
</tr>
<tr>
<td></td>
<td>2 = Fair</td>
</tr>
<tr>
<td></td>
<td>3 = Good</td>
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<td>13. Have you had any illnesses that a doctor or nurse told you was related</td>
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</tr>
<tr>
<td>to HIV that you have been treated for?</td>
<td>0 = No</td>
</tr>
<tr>
<td>14. IF YES: What has/have this/these been?</td>
<td></td>
</tr>
<tr>
<td>15a. Are you currently on antiretroviral treatment/ARVs?</td>
<td>1 = Yes</td>
</tr>
<tr>
<td>b. Do you feel sick or are you getting better? Why?</td>
<td>0 = No</td>
</tr>
</tbody>
</table>
The Childbearing Experiences of Women Living with HIV and AIDS

1. Tell me about your delivery and childbearing experience.

   PROBE: Was this experience different from your initial thoughts and ideas of what the experience would be like?

   a. When did you deliver your child?
   b. How and where did you deliver?
   c. Did you breastfeed or use formula?
   d. What is your child’s HIV status?

2. What was the advice you found most useful given by healthcare workers that helped prepare you for this experience?

   PROBE: If none, where did you get information you found useful from?

   a. What type of information were you given?

3. Now that you have had your baby what types of question or things would you wish you knew before going through this experience?

   PROBE: If none, what have you learned through this experience?

4. Based on your experience what are the top 3 topics you would like for healthcare workers to provide more information on in the future?

5. Do you still want to have more children?

   PROBE: Would you do anything different to help with future childbearing?

   a. How did your husband/ partner feel about your last pregnancy?
   b. Does he still want more children?

6. What religion do you practice?

   a. What role do your spiritual beliefs play:
      • in your experience as a woman living with HIV/AIDS?
      • in your childbearing experience?

7. Has your partner (husband) been supportive since he knew about your status?

   PROBE: In what way has he been supportive? In what way has he been unsupportive?
Appendix D. LASUTH Approval

LAGOS STATE UNIVERSITY TEACHING HOSPITAL, IKEJA

HEALTH RESEARCH AND ETHICS COMMITTEE

REG. NO. NHREC 04/04/2011

PROJECT TITLE: SEXUAL AND REPRODUCTIVE HEALTHCARE (SRH) NEEDS IMPACT ON REPRODUCTIVE DECISIONS OF WOMEN LIVING WITH HIV/AIDS (WLHAs) IN LAGOS NIGERIA

REP. NO.: LREC/10/09/162
PRIN. INVESTIGATOR: YEWANDE ADEKEMI SOFOYAN
ADDRESS: DEPARTMENT OF BIODEVIATIONAL HEALTH, COLLEGE OF HEALTH AND HUMAN DEVELOPMENT, THE PENNSYLVANIA UNIVERSITY, USA.
DATE OF RECEIPT OF VALID APPLICATION: 03/05/2011
DATE OF APPROVAL: 14/06/2011

This is to inform that the research described here in the submitted protocol, the consent forms, advertisements and other participant information materials have been reviewed and given full approval by the Health Research & Ethics Committee.

This approval dates from 14/06/2011 to 13/06/2013. If there is any delay in starting the research, please inform the HREC so that the dates of approval can be adjusted accordingly.

Note that no participant accrual or activity related to this research may be conducted outside of these dates. All informed consent forms used in this study must carry the HREC assigned number and duration of HREC approval study. In multiphase research, endeavor to submit your annual report to the HREC early in order to obtain renewal of your approval and avoid disruption of your research.

The National code for Health Research Ethics requires you to comply with all institutional guidelines, rules and regulations and with the tenets of the code including ensuring that all adverse events are reported promptly to the HREC. No changes are permitted in the research without prior approval by the right HREC except in circumstances outlined in the code. The HREC reserves the right to conduct compliance visits to your research site without previous notification.

PHD (O. GUNDIPE)
Chairman, HREC-LASUTH

OLABODE O. EGINDABO
DEPUTY DIRECTOR OF CLINICAL SERVICES AND TRAINING

DR. FEM OLUGBIE
DEPUTY DIRECTOR OF CLINICAL SERVICES AND TRAINING

127
VITA

YEWANDE A. SOFOLAHAN

EDUCATION
2013  Ph.D. Biobehavioral Health, The Pennsylvania State University, University Park, PA
2011  M.S. Biobehavioral Health, The Pennsylvania State University, University Park, PA
2007  B.S. Biology (Pre-med), East Stroudsburg University, East Stroudsburg, PA

PROFESSIONAL EXPERIENCE
2008-2013  Graduate Research and Teaching Assistant, Department of Biobehavioral Health, The Pennsylvania State University, University Park, PA
2007-2008  Clinical Research Assistant, Office of Policy & Planning, University of Maryland School of Medicine

TEACHING EXPERIENCE
Instructor
Introduction to Health & Human Sexuality (BBH 146) (Summer 2011, Summer 2012)
Teaching Assistant
Introduction to Biobehavioral Health (BBH 101), Research and Applications in Biobehavioral Health (BBH 411W & 310W), Behavior, Health and Disease (BBH 119), Strategies for Addressing the Obesity/Diabetes Epidemic (BBH 130), Introduction to Health & Human Sexuality (BBH 146), Values and Ethics in Biobehavioral Health Research and Practice (BBH 301) and Human Sexuality as a Health Concern (BBH 446)
Guest Lecturer
African Health & Development (BBH 402), Introduction to Global Health (BBH 305)

SELECTED PUBLICATIONS


GRANTS AND FUNDING
2012-2013  Hintz Graduate Education Enhancement Fellowship
2010-2011  Hintz Graduate Education Enhancement Fellowship
2011-2012  College of Health and Human Development Research Endowment
2010-2011  Pennsylvania State University Africana Research Center Fellowship