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# Sexual and Reproductive Decisions and Experiences of Women Living With HIV/AIDS in Abuja, Nigeria

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# SEXUAL AND REPRODUCTIVE DECISIONS AND EXPERIENCES OF WOMEN LIVING WITH HIV/AIDS IN ABUJA, NIGERIA

By

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A Dissertation
Submitted in Partial Fulfillment of the requirements for the
Doctor of Philosophy Degree

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DISSERTATION APPROVAL

# SEXUAL AND REPRODUCTIVE DECISIONS AND EXPERIENCES OF WOMEN LIVING WITH HIV/AIDS IN ABUJA, NIGERIA

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A Dissertation Submitted in Partial
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June 9, 2009

# ABSTRACT

## AN ABSTRACT OF THE DISSERTATION OF

STELLA C. IWUAGWU, for the Doctor of Philosophy degree in HEALTH EDUCATION, presented on June 9, 2009 at Southern Illinois University Carbondale.

TITLE: Sexual and Reproductive Decisions and Experiences of Women Living With HIV/AIDS in Abuja, Nigeria

MAJOR PROFESSOR: Dr. Kathleen Welshimer

Over 60% of those living with HIV/AIDS are women. The majority of them are in their sexual and reproductive years (UNAIDS, 2006). With antiretroviral (ARV) drugs, most of them are living longer and healthier lives to engage in sexual and reproductive activities (WHO, 2006). This study explored the sexual and reproductive decisions and experiences of women living with HIV/AIDS (WLWHA) in Abuja, Nigeria. Only those who became pregnant and had a child after being diagnosed with HIV participated in the study.

The study employed interview based qualitative research. The design of the interview guide was informed by the PEN-3 Model (Airhihenbuwa, 1995). A combination of purposive and snowball sampling techniques was used to select 17 WLWHA aged between 26 and 41. Most of them had limited education. Only the three of them with post secondary education had professional jobs. The rest were either housewives or petty traders.

Most of the women had reduced sexual desire, but felt compelled to acquiesce to their husband’s sexual demands due to cultural and religious senses of duty or fears that their husbands would have sex outside marriage and/or beat them. While a few used condoms, most either did not use condoms or used them inconsistently. Condoms were used mainly to prevent re-infection with another strain of HIV or to prevent infecting a negative partner. Reasons given for not using condoms included a reduction in sexual pleasure and the belief that condom use “is not for wives.” Some also believed that being on ARV precludes the need to use condoms. Often, condom negotiation led to violence. Most of the women still wanted more children and did not use contraceptives. Among the few who used contraceptives, the methods of choice were condoms, hormone injections, intrauterine device (IUD) and tubal ligation.

The women chose to have babies to secure their marriages, fulfill maternal instincts, and to “leave something behind”. Their decisions were informed by the belief that ARV would keep them alive and that Prevention of Mother to Child Transmission (PMCTC) programs would prevent the infection of their babies. To conceive, they had unprotected sex during ovulation. Two serodiscordant couples used syringes to inseminate. Most of them had experienced obstetric challenges including infertility, miscarriages, preterm births and infant deaths. Most of the women bottle-fed to prevent infecting their babies. However, they were under tremendous pressure to breastfeed due to the cultural value attached to breastfeeding.

Women living with HIV/AIDS in Abuja, Nigeria had unmet sexual and reproductive health needs. Their sexual and reproductive decisions were influenced by their individual circumstances, including their levels of education, poverty, cultural and family influences, partners’ HIV status, stigma and discrimination surrounding HIV/AIDS and access to PMTCT and ARV programs. To meet the sexual and reproductive health needs of WLWHA, program planners and policy makers should take these factors into consideration and ensure that programs are comprehensive and integrated.

# DEDICATION

To my parents, **Janet and Livinus Nwanguma**, who never stopped believing in me.

To my Children, **Crystalbel and Richard Iwuagwu**, the reason I never gave up.

To my Siblings- my **FLESH AND BLOOD** (F&B), this is our joint achievement.

# ACKNOWLEDGEMENT

To my dissertation committee, Dr. Kathleen J. Welshimer, Dr. Joyce V. Fetro, Dr. David A. Birch, Dr. Kathryn B. Ward, Dr. Collins O. Airhihenbuwa, thank you for mentoring, teaching, editing and guiding me through this process. Each of you brought unique perspectives that enriched my work and my life. Dr. Welshimer (Chair), your patient guidance, flexibility and ability to pull the best out of me is remarkable. Dr. Fetro, my respect for your high standards kept me on my toes to submit nothing but my best work to you. Dr. Birch, beyond your excellent academic contributions, you are my bridge builder. Dr. Kathryn Ward, even while I was bed bound and have no memory of the interviews I conducted, you took my hands and showed me how to take tiny steps each day. Dr. Arihihenbuwa, your special understanding of cultures in Nigeria was invaluable in the research design and analysis. Dr. Colyar, although your name is not in the final list of committee members, I thank you for giving me a strong qualitative research base and for your contributions up to the presentation of my prospectus.

Thanks to the director of graduate studies, Dr. Mark Kittleson. In today's technology driven world, I am grateful knowing that I can still turn to you for expert guidance. Joyce Ambler and Christine Cisco, thank you for being great sisters. You consistently went beyond the call of duty to assist me with things I could not do for myself.

To Assistant Dean of the graduate school, Patricia Mcneil, thank you for being a great mentor and for finding me worthy to receive the prestigious Dr. Walker Presidential Fellowship three years in a row. You are a great cheerleader.

While collecting data for this research in Nigeria, I was in a vehicle accident that left me a paraplegic and in chronic pain. That I am alive to finish this dissertation is due to the Grace of God and the kindness of many people. In Nigeria, while I laid in bed watching in despair as I lost feelings from my toes to my chest, mentors were working frantically to air evacuate me to Ghana where my surgery was done. Dr. Adhiambo Odaga, Ms. Katherine Perry, Dr. Mike Egbo, Natalia Kanem, Mrs. Amina Ibrahim, Dr. Goodluck Jonathan, Dr. Otive Ibuzor, Dr. ChiChi Aniagolu-Okoye, Mr. Bright Ekweremadu, Mr. Clement Nwankwo and many others I do not remember or know about, thank you. May God send you angels at your points of need. Thank you Dr. Jerome Boatey and the surgical, nursing and rehabilitation team of Korlebu Teaching Hospital, Korlebu, Ghana, for carrying out the spinal surgery that my country could not do for me. Mrs. Juliana Cudjoe, you are an exceptional Social Worker. Thank you for taking a leap of faith to nurture Hope with me. Mrs. Yvonne Abbam, thank you for commandeering your family to care for me. Deborah Lakai, thank you for the gift of your sister and a great friendship.

Thank you to my dear friends Diane Speir, Rachel Yassky, Kathleen Welshimer and Rosaline Liwo. While I laid in my recovery bed in Ghana, you handled the logistics of bringing me back to the US and checking me into one America’s best spinal rehabilitation institutes in St Louis. Since then, thanks to the dedicated care of my doctors, V. Oksana, N. Juknis, D. Mclain, R. Perkins; and my physical therapists, Stacy Kinsler, Robin Cutting and Kim Booker, I am now able to walk with a walker. I was blessed with dynamic, cheerful, and creative therapists. Skip Cuttings, thank you for being the creative engineer and the extra pair of hands that made home therapy effective.

The constant and sometimes miraculous generosity of the Carbondale community, friends and strangers far and near, always still brings tears of gratitude and wonder to my eyes. I was amazed to learn that even grade school children made and sold arts to raise money for me. You gave me more than money; you gave me strength to rise against constant pain and depression. The only way I could thank you was to finish this dissertation, get a job and continue the circle of giving. This is for you too.

I must thank the many friends and mentors who since my arrival in the US have given me their time, prayers, money, love, encouragement and whatever was necessary to ensure my success. To list these friends and how they touched my life would take a book. However, I must mention a few including John Holmes, Sandi, Khaleela, Faith, Tina, Ashaki, Noel, Melissa, Paul, Chendrika, Kim, Fredanna, Pepper, and Janice.

To People Living with HIV/AIDS, especially the women who participated in this study, thank you for trusting me with you stories, your pains and your triumphs. Your pains mirrored my pain and gave me courage to fight for justice, for you and eventually for myself. For many years, I encouraged you to hold tight to hope. I did not know how soon I would have to take my own advice. Because you survived under difficult circumstances, I cherished even more my privileged access to healthcare in America.

I owe a debt of gratitude to the board, management and staff of Center for the Right to Health (CRH) for keeping the center strong in my absence. I am particularly grateful to Mr. Bede Eziefule CRH Project for successfully wearing two hats (mine and his) these many years. I am grateful to Abimbola Onigbanjo-Williams and Onyinye Ogu for completing the interviews after my accident. Thank you my F&B for surrounding me with strength and prayer. Together and with the Grace of God we are invincible, our destinies will be fulfilled. Thank you for taking care of all the family issues that I could not focus on during this process. My dear children, you are indeed miracles from God and comfort to my soul. You have shown extreme maturity and patience during this process. I am glad this is over. Behold, “Dr. Mommy.”

Most importantly, I thank God almighty who snatched me from the jaws of death and destruction, and reassured me that “it is well.” My plea, dear Lord, is that your purpose for my life be fulfilled. I ask myself often “Now what?” I am available. It is in your hands now, Lord, use me.

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# CHAPTER 1

HIV/AIDS is a global health and social challenge that impacts on and is impacted by the sexual and reproductive experiences of women, whether they are HIV positive or not. This study explored the sexual and reproductive decisions and experiences of women living with HIV/AIDS in Abuja, Nigeria. This chapter presents an overview of the study starting with a personal reflection that sets the background to the problem. It includes a true story that embodies some of issues that first piqued my interest in the study. It presents the global, regional and local epidemiology of HIV/AIDS and its impact on sexual and reproductive lives of women, especially those living with HIV/AIDS. This chapter also presents the research questions, purpose, need and significance of the study, as well as an overview of the research design, limitations, delimitations, assumptions and definitions of terms.

## Background to the Problem

### *Personal Reflection*

I have worked with people living with HIV/AIDS since 1995 when I cared for them as a nurse. In the hospital, I witnessed colleagues who refused to care for HIV infected patients. They were afraid to serve them food, oral medication or change their intravenous fluids. Many of my colleagues talked about HIV infected persons with disdain and had no hesitation sharing patients’ personal information with hospital staff who had no business knowing, an obvious breach of confidentiality. I have seen women with HIV/AIDS denied care because the health worker was concerned about getting infected despite the availability of materials for universal precaution that are supposed to protect both the health workers and the patients.

These patterns of discriminatory and unprofessional behavior motivated me to establish a not-for-profit organization called *Center for the Right to Health (CRH).* The mission of CRH is to advocate for the full realization of the right to health in Nigeria and to promote respect for ethics and human rights in health care policies and practices, especially for vulnerable groups such as people living with HIV/AIDS, women, youths, and children. One of the first projects carried out by CRH was the documentation of the abuse of human rights experienced by people living with HIV/AIDS (CRH, 2001). Findings revealed extensive abuse of the rights of people living with HIV/AIDS, including their sexual and reproductive rights. Women living with HIV/AIDS were often denied medical care, including gynecological and obstetric care. Their HIV status was often revealed to relatives and employers, resulting in abandonment and loss of jobs and livelihood. These findings were confirmed further by a large scale USAID funded study conducted in 2004 by CRH in partnership with Physicians for Human Rights and the Policy Project for the Nigerian Federal Ministry of Health (FMOH) in 2006.

During my one decade of activism, I facilitated the establishment of several support groups of people living with HIV/AIDS. These people have now been empowered to be powerful advocates of their own rights. Unfortunately, many of them continue to suffer under the impact of the HIV/AIDS epidemic. Issues about their sexuality often are glossed over or filled with myths and misconceptions among people living with HIV/AIDS themselves, health workers and the general public. Some tend to think that a diagnosis of HIV/AIDS means the end of their sexuality and their lives. This perception is far from reality. In the course of my interactions with people living with HIV/AIDS, I have had the honor to share their pain, fear, frustration and confusion as they struggle with their lives, their sexuality and their reproductive health. Among the many factors that motivated my interest in this topic is the true story narrated below.

### *A True Story*

Julie, face wrinkled in confusion, asked in a soft timid voice, “Ms. Stella is it okay for a woman with HIV not to have sex?” I said it is okay if it is a voluntary decision with which she is comfortable. Sensing that there was more on her mind, I asked, “Would you want to chat some more about this?” She said yes and continued, “Some of the women in the support group said that it is important for people with HIV/AIDS to have sex regularly in order to shed the virus. If not the virus will accumulate inside and kill the person.” Julie, a 37 year old widow living with HIV, is a member of a support group of people living with HIV/AIDS that I facilitated in Nigeria.

Obviously, Julie is not the only one interested in the sexuality of people with HIV/AIDS. Sex and reproduction among those living with HIV/AIDS is filled with silence, myths and challenges that impact negatively on the control of the pandemic as well as the quality of life for infected and affected individuals. This is especially true for women. My perceptions are that some PLWHA are not having sex due to fear and censure. Some could be having unsafe sexual practices for recreation, procreation and economic purposes. From my knowledge and experience with cultures in Nigeria, I believe that cultural forces, such as the pressure to prove their fertility, the requirement to satisfy a husband or partner's sexual needs or economic survival, influence the sexual and reproductive decisions and experiences of women living with HIV/AIDS. In addition, policy issues, such as access to affordable treatment, education and programs to reduce mother to child transmission of HIV/AIDS, also would influence their decision.

## *HIV/AIDS and Women*

According to estimates from the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the World Health Organization (WHO) AIDS epidemic update (2005), 38 million adults and 2.3 million children were living with HIV at the end of 2005. Sub-Saharan Africa, comprising just over 10% of the world's population, is home to over 60% of all people living with HIV. This percentage translates to about 25.8 million people living with HIV/AIDS in Sub-Saharan Africa. Nigeria, Africa's most populous nation at about 140 million people, had an average national prevalence of 4.4% in 2005, reflecting a marginal decrease from the 2003 rate of 5% (Federal Ministry of Health, 2005). In real terms, 2.84 million Nigerians are living with HIV/AIDS, representing the third highest HIV global burden after South Africa and India (UNAIDS, 2006).

Studies and anecdotal evidence have demonstrated the feminization of HIV/AIDS. Women are disproportionately affected by the HIV/AIDS epidemic. Women account for nearly half of the 39.4 million adults living with HIV worldwide. In the worst-affected region – sub-Saharan Africa – almost 57% of adults living with HIV are women (UNAIDS, 2005). In sub-Saharan Africa, three-quarters of all 15- to 24-year-olds living with HIV are female. The prevalence of HIV infection among young women in sub- Saharan Africa is three times that of young men. Furthermore, young people, especially young women, are becoming sexually active each day with little or no access to HIV prevention services (UNAIDS, 2004).

In 2003, an estimated 2.5 million of the 200 million women worldwide who became pregnant were infected with HIV (CIDA, 2004). In many countries of southern Africa, one in five pregnant women is infected with HIV. In Nigeria, tests of women randomly selected from prenatal clinics revealed that 5 in 100 women were HIV positive (Federal Ministry of Health, 2003).

### *Sexual Decisions*

Throughout life, sex, pleasure, intimacy and reproduction are central aspects of being human (Heise, 1995). Sexuality is experienced in thoughts, fantasies, desires, beliefs, attitudes, values, behaviors, practices, roles and relationships. Sexual decisions are influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, historical, religious and spiritual factors (WHO, 2005).

The challenges associated with women’s sexuality have raised the interest and ire of feminists. This is mainly because society’s interest in women’s sexuality has focused on behaviors that have implications for demographics and diseases rather than on women’s pleasure, rights, equality and quality of life (Vance, 1984; Teifer as cited in Benzemer et al, 1992). The idea of attaching rights to human sexuality became prominent during the 1990s, particularly after the International Conference on Human Rights in Vienna in 1993. This conference affirmed that violence against women nullifies and impairs their enjoyment of fundamental rights. The concept of sexual rights was further elaborated at both the International Conference on Population and Development (ICPD,

1994) and the Fourth World Conference on Women (4WCW, 1995). The Beijing Platform of Action of the Fourth World Conference on Women explained that “the human rights of women include their right to take control over and decide freely and responsibly on matters related to their sexuality, including sexual and reproductive health, free of coercion, discrimination and violence” (A/CONF.177/20, 1995, p.4).

For many women today, especially in Africa, the promises of the ICPD and the Beijing Platform remain a mirage. Women’s sexual decisions and experiences are associated with and often increase their vulnerability to HIV/AIDS. Most women infected and affected by HIV/AIDS in Africa are at the prime of their sexual and reproductive lives, and must continue to make sexual decisions as they live with HIV/AIDS (WHO, 2005).

Sexual and reproductive decision making is a highly complex and sensitive issue for most women and may be even more daunting for women living with HIV/AIDS. Women living with HIV/AIDS often have to deal with concerns of finding a sexual partner, disclosing their HIV status, risking stigma, rejection and sometimes violence (Doyal & Anderson, 2005). If they find a sexual partner, WLWHA must decide whether to have or not have sex. If they choose to abstain from sex within a relationship, this decision should be mutual. Otherwise they could face the possibility of abandonment or violence from unsatisfied partners (Gray et al, 1998; Ryder et al., 1991). If they chose to have sex, they would have to decide whether to engage in safe or unsafe sex. If they decide to have safe sex, condom use remains their best option. But they would have to have access condoms and know how to use them (Jewkes, Levin, Loveday, & Penn-

Kekana, 2003; Iwuagwu, 2000; Iwuagwu, Olaseha, & Ajuwon, 2000; Preston-Whyte, 1995; Wallman & Bantebye-Kyomuhendo, 1996).

Access to condoms is increasingly challenging because political, religious and cultural gatekeepers often discourage condom use. International funds for HIV/AIDS related responses are dwindling. Some funding comes with conditions that prohibit money from being used for condom purchase and distribution.

### *Reproductive Decisions*

In Nigeria as in most African countries and cultures, a woman’s worth and sense of fulfillment are often tied to her fertility and ability to bear children (Okonofua, 1999; Barnett et al, 1999; Koster-Oyekan, 1999; Orubuloye et al, 1992). Not being able to bear a child could be a traumatic burden for an African woman. HIV/AIDS has been documented to reduce the fertility of those living with the virus (Gray, Wawer, & Serwadda, 1998; Ross, Morgan and Lubega, 1999; Ntozi, 2002; Hunter, Isingo & Boerma, 2003). Men are also under cultural and personal pressure to prove their manhood by fathering children. They, in turn, pressure their HIV positive partners to help them achieve their procreation goal. Women living with HIV/AIDSare further weighed down by concerns about their own mortality and the associated fear of leaving orphaned children. They also are consumed with the fear of infecting their babies during pregnancy, birth and/or breastfeeding (Ciambrone, 2003; Doyal & Anderson, 2005; Green & Sobo, 2000).

The risk of infecting an HIV negative partner (serodiscordant) in the process of procreation adds additional obstacles to the quest of WLWHA to have children. Even when both partners were HIV positive, re-infection with other sub-types and strains of the virus is possible. Pregnancy causes reduction in the immune system and lowered CD4 count putting WLWHA at greater risk of infection during pregnancy.

Mothers living with HIV/AIDS are advised not to breastfeed their babies to prevent infecting their babies. However, in a society where breastfeeding is the cultural norm, not breastfeeding could raise suspicion and expose the woman to stigma and discrimination. Furthermore, with the high level of prejudice and stigma among health workers and the poor continuing education among health care professionals in the country, women living with HIV/AIDS have difficulty finding obstetricians and midwives who can provide the specialized care they need. Although Nigeria has been implementing prevention of mother to child transmission (PMTCT) programs, many of them are located in specialized urban centers. Most WLWHA who are not fortunate enough to be in PMTCT programs are too poor to afford specialized obstetric services and milk alternatives (Ciambrone, 2003; Tapper & Fransen, 2000).

Sexually active WLWHA who do not want to become pregnant have to make decisions about contraception. These decisions present challenges like finding a knowledgeable health worker who is willing to provide such services to a woman with HIV/AIDS. With limited access to family planning services and the difficulty associated with condom use, it is likely that a woman with HIV could end up with unintended pregnancy. They would either give birth to the child or have an abortion. In Nigeria, abortion is illegal unless it will save the life of a woman. Even if the woman’s life is at risk, many health care providers discriminate against people living with HIV/AIDS and would refuse to provide abortion services. The only option available to women, including those with HIV, is clandestine abortion which usually is unsafe with grave consequences (DeBruyn, 2002).

## Need for the Study

Advances in antiretroviral therapy have increased the length and quality of lives of People Living With HIV/AIDS (PLWHA). This creates more opportunities for sexual and reproductive activities, with implications for the spread of HIV and the wellbeing of PLWHA. The rise in the number of women with HIV/AIDS who are of reproductive age creates a compelling need to explore their sexual and reproductive decisions and experiences. The issues and challenges explored above reveal that making sexual and reproductive decisions is daunting and life threatening for many WLWHA in Africa. Nigeria bears about 10% of the global HIV/AIDS burden. Despite these glaring needs, research specific to the sexual and reproductive lives of WLWHA in Nigeria is lacking. Most research on the sexuality of PLWHA has been conducted in the western hemisphere. The western studies focused predominantly on the sexuality of men who have sex with men and drug users who are HIV positive. Some publications have explored sexual practices and issues around disclosure of HIV status to partners (Bedimo et al, 1998; Van Benthem et al, 2000; Sunderland, 1990). Only a few studies have dealt with heterosexual women living with HIV/AIDS. Most of these focused on women in developed countries (Sunderland, 1990; Bedimo et al, 1998; Weisser et al, 1998; Richter et al, 2002). These studies mainly explore contraceptive choices. Some are focus specifically on pregnancy decisions and access to safe abortion (Sunderland, 1990; Weisser et al, 1998; Richter et al, 2002).

## Purpose of the Study

The purpose of this study was to explore the sexual and reproductive decisions and experiences of women in Abuja, Nigeria, who became pregnant and had a child after knowing their positive HIV status.

## Research Questions

Specific research questions of this study were:

1. What are the sexual and reproductive decisions and experiences of women living with HIV/AIDS in Nigeria?
2. What factors influence their sexual and reproductive decisions and experiences?

## Significance of the Study

One goal of health education is to empower people to make decisions conducive to health. Among the key responsibilities of a health educator is the ability to “assess individual and community needs for health education” (National Commission for Health Education Credentialing, 2006, p. 18). Health educators must develop a clear understanding of the populations they serve so they can better address their specific health needs and concerns. Part of this learning process involves acknowledging issues unique to a given population including how and why they make certain decisions.

Women living with HIV/AIDS are a special population whose sexual and reproductive decisions and actions have the potential to impact the health of the whole community. Understanding of the sexual and reproductive decisions that these women are making and how they are experiencing their decisions will equip health educators to plan and implement culturally sensitive programs. Additionally, documenting these unique experiences will add to the body of knowledge from which health educators can draw to build theories about sexuality issues in the face of HIV/AIDS. Findings of this study also will be useful to others outside the field of health education, such as family planning specialists, obstetricians and gynecologists and others in the health professions whose expertise and skills are important not just to women with HIV/AIDS, but to the community at large.

## Research Design

Qualitative research methods were used to explore the sexual and reproductive decisions of women living with HIV/AIDS. One hallmark of qualitative research is the deep involvement in issues of gender, culture and marginalized groups (Lincoln & Guba, 1985; Bodgan & Biklen, 2003). Women living with HIV/AIDS are marginalized both for their gender and their disease condition. They are affected by the cultural norms in a multiethnic, paternalistic Nigerian society. Their sexual and reproductive experiences would vary depending on their context. Qualitative research has allowed me to use procedures, such as open ended, in-depth interviews. For many, participating in the research was possibly their first time of reflecting, verbalizing and sharing these experiences. Only the prolonged relationship of trust and flexible interaction between the researcher and the participant in a naturalistic approach can allow such depth of emotional sharing and meaning making (Kvale, 1996; Creswell, 1998). Because of the cultural context of the research, the PEN- 3 Model (Airhihenbuwa, 1995) was used to design the interview guide used in the in-depth interviews with the participants.

## Sample Selection

A combination of purposive and snowball sampling was used to select the study participants. After securing human subjects approval, I contacted some of my former clients and told them about my research and the type of participants for whom I was looking. I asked them to refer WLHA in their social network to participate in the study. I also recruited participants by making announcements at their support group meeting requesting that WLWHA who met the study criteria contact me by my phone if they would like to participate. Those who participated in the interview also were asked to refer other WLWHA.

The study criteria include WLWHA who could speak English or Pidgin English and who became pregnant and had a child after knowing that they were HIV positive. This insured that the women chosen for the study have lived with HIV/AIDS long enough to have confronted the issues related to this study.

## Data Collection

Data were collected using in-depth interviews. An interview guide was developed based on constructs of the PEN-3 Model (Airhihenbuwa, 1995) and other information derived from literature review. The questions were open-ended and semi-structured. The goals of these interviews were to get participants to talk about their experiences of living with HIV/AIDS and to share how they have dealt with sexual and reproductive issues. A pilot in-depth interview was conducted with two participants at the office of CRH in Abuja to ensure that the interview guide and process would be appropriate. Because no changes were made after the pilot, these participants were added as part of the data thereafter. 15 more in-depth interviews were conducted making a total of 17. The interviews took an average of 76 minutes.

## Data Analysis

The interviews were transcribed verbatim and saved in a Word document. Each transcript was reorganized and color coded by major headings such as demographics, sexual activity, pregnancy and contraceptives, infant feeding and child care among others. Each transcript was then uploaded into NVIVO qualitative data management software. NVIVO made it easier to organize and retrieve the data. Each transcript was printed, manually coded, and transferred to NVIVO. The first sets of emerging categories were initially coded as free nodes in NVIVO. Related categories coded as free nodes were grouped and coded as Tree nodes, or themes. Collections of related tree nodes were organized to form patterns. NVIVO made it easy to record or reorganized as new ideas or insight emerged.

## Assumptions

The following assumptions were made at the beginning of the study:

- Participants would be willing to participate in the in-depth interview sessions and discuss their sexual and reproductive decision and experiences.

- Participants would be honest about the information they shared about their experiences.
- Participants would be capable of expressing their own understanding of the factors influencing their sexual and reproductive decision and experiences in English or Pidgin.
- The researchers would be objective in questioning and representation.
- The interview questions would be adequate to elicit responses to answer the research questions.

## Delimitations

The study was delimited to:

- Women who became pregnant and had a child after knowing they were HIV positive.
- Participants who resided or worked in Abuja and its outskirts.
- Participants who can speak English or Pidgin English.

## Limitations

The following were limitations to the study:

- Being in an accident and having to be flown back to the USA after doing only six interviews, I had to delegate the rest of the interviews (11) to CRH staff who though trained, would have different interviewing skills from me.
- Interviewing only women who could express themselves in English or Pidgin English means information from women who could only speak their native

language may have been lost. Since these women are the least educated and least financially empowered, they may have suffered more hardship or had other unique experiences that are not reported in this study.

- The best interviewer could have varying rapport with each interviewee due to the interviewee's personality and the sensitive and personal nature of the issues discussed. This could have affected the depth of self revelation of the interviewees and the quality of the data.
- My personal involvement and experiences with some of the issues may have influenced my questioning, interpretation and analysis of data.
- Limiting participants to only women who have had a child since being diagnosed enabled me to focus the research. But it turned out that all the participants were married because pregnancy outside marriage is discouraged in Nigeria. This also meant that I lost the perspective of single women who probably had different experiences.

## Definition of Terms

***Contraception***: literally, the prevention of a conception**.** The term is used for methods or policies aimed at the avoidance of unintended pregnancies (FHI, 2005).

***Disclosure*****:** disclosing one's HIV status to others especially a sex partner (WHO, 2006).

***HIV/AIDS*****:** this term includes the diagnosis of HIV infection (not AIDS), a diagnosis of HIV infection and a later diagnosis of AIDS or concurrent diagnoses of HIV infection and AIDS (CDC, 2005).

***HIV Sero-status*:** the absence or presence of antibodies for HIV antigen. Positive means exposure to HIV. Negative means no detectable exposure to HIV (CDC, 2005).

***Infertility*:** the inability to conceive or carry a pregnancy to term after one full year of normal, regular heterosexual intercourse without the use of contraception (Parker & Gagnon, 1995).

***People Living With HIV/AIDS (PLWHA):*** people who are diagnosed with HIV, AIDS or both. This term was used to bring positive language and hope at a time when a diagnosis of HIV/AIDS was presumed to be a death sentence (UNDP, 2005).

***Reproductive Decisions:*** decisions pertaining to procreation. This includes deciding to be pregnant or not, to use contraceptive or not to have an abortion (Parker & Gagnon, 1995).

***Sexuality:*** giving and receiving sexual pleasure, as well as enabling reproduction. Sexuality is a total sensory experience, involving the whole mind and body--not just the genitals. Sexuality is shaped by a person's values, attitudes, behaviors, physical appearance, beliefs, emotions, personality, likes and dislikes and spiritual selves, as well as all the ways in which one has been socialized (WHO, 2006).

***Sexual decisions:*** decisions to have or not have sex, type of sex, with whom and when to have sex and whether sex will be safe or not (Parker & Gagnon, 1995).

***Sexual health*:** a state of physical, emotional, mental and social well-being in relation to sexuality. It is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled (WHO, 2006).

***Sexual rights:*** Human rights that are already recognized in national laws, international human rights documents and other consensus statements. They include the right of all persons, free of coercion, discrimination and violence, to:

- the highest attainable standard of sexual health, including access to sexual and reproductive health care services;
- seek, receive and impart information related to sexuality;
- sexuality education;
- respect for bodily integrity;
- choose their partners;
- decide to be sexually active or not;
- consensual sexual relations;
- consensual marriage;
- decide whether or not, and when, to have children; and
- pursue a satisfying, safe and pleasurable sexual life.

The responsible exercise of human rights requires that all persons respect the rights of others (WHO, 2006).

***Stigma:*** attribute that is deeply discrediting and that reduces the bearer from a whole and unusual person to a tainted, discounted one (Goffman, 1963). Stigmas commonly result from a transformation of the body, blemish of the individual character or membership in a despised group. Goffman emphasizes the relationship between an attribute and a stereotype. Building upon this definition, Link and Phelan (undated) defined stigma as, “that which exists when a person is identified by a label that sets the person apart and links the person to undesirable stereotypes that result in unfair treatment and discrimination” (pg.5).

### *Summary*

HIV/AIDS continues to rage unabated especially in Sub-Saharan Africa. Nigeria, Africa’s most populous nations, has about 2.7 million people living with HIV/AIDS and has declared HIV/AIDS a national disaster. Women are disproportionately infected and affected (UNAIDS, 2006). One of the areas impacted by HIV/AIDS is the sexual and reproductive health of women living with HIV/AIDS (WLWHA). To deepen our understanding of the challenges experienced by WLWHA, a qualitative interview based study was used to give voice to women living with HIV/AIDS and enable them describe their decisions and experiences.

The next chapter presents a review of literature on the socio-demographic characteristic of Nigeria, the sexual and reproductive practices within the Nigerian socio-cultural context and its implication to the HIV/AIDS trend. It also presents the review of literature about women’s vulnerability to HIV/AIDS, access to treatment and sexual and reproductive options for women living with HIV/AIDS. It also discussed the PEN-3 model which informed the design of the interview guide.

# CHAPTER 2

# LITERATURE REVIEW

## About Nigeria

### *Demographics*

Nigeria is situated on the coast of West Africa. She is bounded on the West by the Republic of Benin, Niger Republic on the North, Republic of Chad and Cameroon on the East and Gulf of Guinea on the South. Nigeria as a state came into being following independence from Britain in 1960 (see figure 1). Nigeria is divided into 36 states which are further split into 774 local government areas and a federal capital territory- Abuja. Abuja is the seat of the government of Federal Republic of Nigeria. For ease of administration, the country is divided into six geopolitical zones namely: North-East, North-West, North-Central, South-West, South-South, and South-East.

Nigeria is the most populous country in Africa with a population of about 140 Million (NPC 2006). About 48.3% of the population lives in the urban area while 51.7% are in the rural area. Nigeria is a predominantly young population with nearly half (42.3%) of the population under age 15 (http://esa.un.org/unpp, 2004).

[1]*Figure 1. Political Map of Nigeria*

The population growth rate is 2.7%. The fertility rate is 5.5 children/woman. The birth rate is 126 births /1,000 and the death rate is 17.18 deaths/1,000 populations (UNFPA, 2006). About 28% of women have given birth by age 18 (PRB Youth Data Sheet, 2006). The infant mortality rate is 100 deaths/1,000 live births and the life expectancy rate at birth is 44 years for the total population (UNICEF, 2007). The

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[1] From “Political Map of Nigeria” from US Central Intelligence Retrieved June 5, 2006, from http://www.lib.utexas.edu/maps/africa/nigeria_pol93.jpg. "Courtesy of the University of Texas Libraries, The University of Texas at Austin."

maternal mortality rate is 800/100,000 live births (UNFPA, 2006). Less than half of the populations have access to potable water. Of those over 15 years, 68% can read and write (male: 75.7% female: 60.6%) and about 60% of the population lives below the poverty line (United States Library of Congress, 2006).

### *Governance and Economics*

Nigeria is a federal republic modeled after the United States with executive power resting on the president. It models the United Kingdom in the composition and management of her upper and lower legislative houses. Nigeria is blessed with several natural resources chief among them petroleum. She is the world's 8th largest exporter of petroleum and has a GDP per head is $692. Nigeria has a turbulent history of about 16 years of military dictatorship that was characterized by corruption and graft that squandered the nation's resources, dragged her into debt and instituted the International Monetary Fund's Structural Adjustment Program (SAP) wherein most of the country's revenue was used to service debt to the detriment of social services and economic development. This has contributed to the entrenchment of poverty in the country where 70.8% survive on less that US$1 per day (UNDP, 2006). As at 2005 the gross national income was US$560/capita while the gross domestic product was US$98,951 million. There is however a potential for improvement with the 1.15 billion US dollars that was freed up when 60% of Nigerian's international debt was forgiven (World Bank, 2006).

### *Health*

The national health expenditure from private and public sources is about US$51/ capita. There are 28 physicians per 100,000 people, and only 35% of births are attended by skilled health staff (UNDP, 2006). Diseases like malaria and tuberculosis remain endemic and are complicated by HIV/AIDS which afflicts an estimated 2.8 million people (UNDP, 2006). About 29% of children aged 0-5 years are malnourished (UNICEF, 2007). On average, only about 49% of the population has access to essential medicines (UNDP, 2004).

### *Ethnicity, Language and Religion*

Nigeria is a multiplicity of cultures, customs and languages with over 250 distinct ethnic groups and 510 languages. The following are the most populous and politically influential ethnic groups: Hausa and Fulani 29%, Yoruba 21%, Igbo (Ibo) 18%, Ijaw 10%, Kanuri 4%, Ibibio 3.5%, Tiv 2.5% (CIA World Fact Sheet-undated). The major languages spoken in Nigeria include Hausa, Kanuri, Ibo, Yoruba, Efik, Fulfulde, Idoma and Adamawa. The official language of Nigeria is English, chosen because many parts of Nigeria spoke English due to the colonial occupation by the British. English is widely used for education, business and official transactions. Most rural areas speak in their native language. However, Nigerian Pidgin English often referred to as ‘pidgin or ‘broken’, is a popular *lingua franca.*

The Nigerian population has a variety of religious practices that vary by ethnic and regional affiliations. Fifty percent of the population is Muslim, 40% are Christian and 10% practice indigenous religions. The Igbos are predominantly Christian. The Hausa-

Fulani are largely Moslems, while the Yorubas are a mixture of Christians and Moslems (National Population Commission, 2003). Ethnicity and religion color every aspect of the country's profile including politics, economy and the laws. For example, there are four distinct legal systems in Nigeria: the 'English Law' derived from Colonization by Britain; 'Common Law' derived from post-colonial independence; 'Sharia Law' derived and used in the predominantly Muslim, northern regions of the Hausa-Fulanis and; the 'Common Law' derived from indigenous traditional norms and practices.

## Abuja

Abuja, the location of this study is the Federal Capital Territory of Nigeria. It is in the center of Nigeria and is the seat to national government. It has a land mass of about 8000sq km and a population of about 5 million people. There are four main districts: Central, Garki, Wuse and Maitama, with several satellite towns. Residents of neighboring states such as Nassarawa, Kogi, Niger and Kogi often travel to Abuja for work, trade and services. The Federal Capital Territory is a melting pot of people from different ethnic groups and socio-economic classes who are either native of the place or migrated there for employment, education, trade and other quests for livelihood. There are several long distance bus and truck parks (FCT, 2006). Migration is also one of the reasons for the high HIV prevalence in Abuja (8.4%). It is the location for many international and national events and has been referred to as the fastest growing city in Africa. It is a haven for commercial sex work as men who are away from their families to seek work in the city find sexual comfort in the thriving sex work industry.

## Culture and Sexuality in Nigeria

### *Female Virginity Emphasized*

There are as many cultures as there are ethnic and religious affiliations in Nigeria. Nigerian culture is a combination of cultures from the about 250 ethnic groups combined with their various religious affiliations and the effect of western cultures acquired through colonization, the ubiquitous presence of the global media and ease of travel. Irrespective of the culture or religion, sexuality is consigned to the realm of marriage and loaded with silence and secrecy outside of marriage. All ethnic groups in Nigeria believe strongly in sexual purity for women. In times past, the virginity of the female at her marriage called for a family celebration with appropriate gifts and visits from the in-laws. Girls who are virgins at marriage are praised and showered with gifts while girls who are found not to be virgins are publicly disgraced. Some cultures such as the Edos, require the wife to confess to any premarital relationship at the husband's ancestral shrine. In traditional Etsako, and Igbo land, older women and daughters of the village respectively, strip the young wife naked and checked the condition of the hymen to make sure it was intact (Ikpe, 2004). Virginity is not expected of the male.

Since the introduction of western values and education in Nigeria, there has been an increased tendency to delay marriage and an increased incidence of premarital sexual relationships. In some tribal cultures, especially among the Bini, Yoruba, and Ibos, it is more common today to demand pregnancy as a proof of fertility rather than virginity as a prerequisite for marriage. This is mainly because complications from untreated sexually transmitted diseases results in infertility which is unaccepted in many families because reproduction is seen as the primary reason for marriage (Esiet, 2001). At the same time, the rising incidence of HIV and other STIs has also led to an increased call for premarital sexual abstinence for both sexes.

### *Early Marriage and Varied Marital Arrangements*

Thirty-four percent of 15- to 19-year-old females are married and 27 percent of adolescent married women are in a polygynous union, with rural and northern women more likely to be in such a union. Early marriage, whether consensual or forced, is an accepted means of containing adolescent sexuality especially in the Northern part of Nigeria (Esiet, 2004). In the past, many girls experienced menarche in their husband's home. Many parents especially in the northern Muslim part of the country, still maintain the practice of marrying their daughters off by age 12, mostly to older men (Yusuf, 2001). In this kind of relationship the wife is not only economically dependent on the husband. She must defer to him as an elder thus creating a big power differential to the wife's disadvantage. Sometime the man is so old he is unable to meet the girl's sexual needs, but recruits his older sons to help out. At times the girl seeks her own partners and is punished severely for adultery when discovered.

Nigeria is a patriarchal society where women defer to the men. The men are believed to have more sexual needs than the women and the women have been socialized to accept this. Most Nigerian cultures allow and even encourage a man to contract polygamous marriages. Although extramarital sex is publicly condemned, a man who engages in extramarital sex is privately hailed for his behavior. The same culture deals severely with married women caught in adultery. The situation is worst in the northern part of the country where the conservative Muslim Sharia legal system operates. A woman may be sentenced to death by stoning for adultery as in the two celebrated cases of Shaffiyatu and Amina Lawal. Shaffiyatu was charged before an Upper Area Court for committing adultery with one Yakubu Abubakar, which resulted in the pregnancy and delivery of a child. Yakubu was discharged because the prosecution witnesses did not prove the offence of adultery against Yakubu. Safiyyatu was found guilty and sentenced to death by stoning. However, her sentence was quashed at the court of Appeal following large local and international outcry.

In Amina Lawal's case, she and Yahaya were suspected to have committed adultery resulting in the delivery of a baby girl. Amina confessed to committing the offence with Yahaya, but he denied it and was discharged. Again Amina was found guilty of adultery and sentenced to death by stoning. It also took the intervention of several international human rights advocacy groups for the Sharia Court of appeal in Kastina State to quash the death sentence.

In other parts of the country, adultery is controlled by beliefs that the gods will strike an offender to death if she does not confess and participate in a cleansing rite carried out by cultural gatekeepers. No consequence befalls an adulterous male. However, there are some culturally approved forms of adultery. For example, in Ibibioland, a diviner could appoint a consort for a childless woman until she gets pregnant. In some parts of Igboland and among the Biroms, a man with multiple wives can permit a young man who has declared interest in one of his wives to have a sexual relationship with her in exchange for gifts and a pledge to work for him. Among the Tiv, it is the highest level of hospitality for a husband to allow an important guest have sex with his wife. Among families in Ilorin, brothers sleep with each other's wives. These practices are forms of sex with multiple sexual partners and have implications for HIV and other STI transmission and will require rethinking and renegotiation (Ikpe, 2004).

It not clear if the women involved in these practices are comfortable with their lots. However, many of these practices are discriminatory against women and do not affirm the dignity of women. It is also contributory to the rising prevalence of HIV/AIDS among women. Both articles One of the Convention on Elimination of All Forms of Discrimination Against Women (CEDAW) and Two of the Protocol to the African Charter on the Rights of Women (Women Protocol) forbid all forms of discriminatory practices against women.

## HIV/AIDS and Women

The HIV pandemic is perhaps the greatest health challenge of our time. Despite promising developments to address the AIDS epidemic, including increased access to effective treatment and prevention programs, the 2006 AIDS Epidemic Update (UNAIDS & WHO,2006) reports that the number of people living with HIV has risen in every region in the world. More women than ever before are now living with HIV. The 17.7 million women living with HIV in 2006 represent an increase of over one million compared with 2004. Almost 60% of all people living with HIV in sub-Saharan Africa in 2006 were women. For every ten adult men living with HIV, about 14 adult women are infected with the virus.

At the end of 2006, Nigeria has an estimated national HIV sero-prevalence rate of 3.9 % among adults aged 15-49. This estimate translates to about 2.9 million PLWHA

(UNAIDS, 2006). In an addition, there are an estimated 240,000 children aged 0-14 living with HIV/AIDS at the end of 2005. The risk of HIV transmission among women remains a challenge. Fifty five percent, or an estimated 1,600,000 of the 2.9 million people living with HIV/AIDS, are women (Federal Ministry of Health, 2005). In Sub-Saharan Africa, three-quarters of all 15- to 24-year-olds living with HIV are female. The prevalence of HIV infection among young women in this region is three times that of young men (UNAIDS, 2006).

UNAIDS (2006) estimates that about 2.5 million of the 200 million women worldwide who become pregnant each year are infected with HIV. In a random sampling of pregnant women attending prenatal clinics in selected sites across Nigeria, 5 in every 100 tested were found positive in 2003 (FMOH, 2003). Women’s vulnerability to HIV has a direct impact on their children and families. Globally, there are an estimated 1,800,000 under 17 children who have lost their parents, mother, father or both to AIDS. 930, 000 of these children are in Nigeria (UNAIDS, 2006). Many of these children, especially the females withdraw, from school to care for their siblings or sick parents and are often exposed to HIV risk, resulting to the vicious cycle known as the feminization of HIV/AIDS. Many factors are responsible for women’s increasing vulnerability to HIV/AIDS globally and in Nigeria. A brief discourse of the HIV trend in Nigeria will increase appreciation of how cultural and socio-economic factors have contributed to a burgeoning epidemic that threatens the lives of all, especially females.

## Women's Special Vulnerability to HIV/AIDS and other STIs

In Nigeria as in most Sub-Saharan African countries, more females than males are infected with HIV/AIDS. Several factors contribute to women's special vulnerability to HIV and other STIs. Biologically, women are more susceptible to HIV and other STIs than males. Women's exposure to HIV virus is greater than men's because women as receptive partners in both vaginal and anal intercourse have more surface area exposed to the virus in the seminal fluid which stays within her for longer period increasing the opportunity for infection. Also there are more viruses in the seminal fluid than there are in vaginal fluid. Another complicating factor is the cultural preference for "dry sex" among some partners, which makes the vagina more susceptible to lacerations (UNAIDS, 2004). In 'dry sex', the natural lubrication that prepares women for sex and protects the vaginal wall from harm is not welcomed. Rather women insert herbs in their vaginas to shrink the walls and reduce lubrication.

Sexually transmitted infections (STIs) in women are usually asymptomatic in females, not in males. Therefore women are more likely to have untreated STIs than males. This increases women's susceptibility to HIV infection.

Traditional gender roles often promote sexual practices that put women more at risk of HIV/AIDS even within stable relationship. Men are more likely to engage in sex with multiple and sometimes non-marital partners. Due to the patriarchal nature of the Nigerian culture, wives cannot influence their husband's behaviors and have limited ability to negotiate sex.  Economic dependence on men, denial of inheritance rights and reduced access to information are among the factors that limit women's ability to negotiate safe sex (UNAIDS et al, 2004) and protect themselves. For example, a survey of knowledge of HIV/AIDS and understanding of risk showed that more men had knowledge of HIV/AIDS and ways of preventing it than women. The study also showed that women have a lower perceived risk of acquiring HIV than men (NACA, 2005).

## HIV/AIDS Trends in Nigeria

Nigeria reported her first case of AIDS in a 13 year old girl in 1986. Since then, the HIV prevalence increased from 1.8% in 1991 to 5.8% in 2001. An intensive multi-sectorial response to combat the epidemic resulted to a downward trend of 5% in 2003, 4.4% in 2005 (FMOH, 2006) and 3.9% in 2006 (UNAIDS, 2006). This downward national trend does not present the whole picture. There are explosive localized epidemics in different parts of the country. For example, the sero-prevalence rate in Cross River state is 12%, followed by Benue state at 9.3%. The prevalence rate in the Federal Capital Territory is 8.4%. Overall, 13 of Nigeria's 36 states had prevalence rates over 5% (National Action Committee on AIDS (NACA), 2005).

Prevalence rate is influenced by both number of new cases and deaths among existing cases. It is not clear whether the reduction in prevalence rate is due to reduction of incidence (new cases) or increasing death rate among the infected. An estimated 310,000 deaths due to HIV/AIDS have been recorded. Death rates are unclear because of under-reporting as many deaths are not certified in any medical institution and among those certified, cause of death may be listed as any of the opportunistic infections like pneumonia instead of HIV/AIDS due to HIV related stigma (NACA, 2005).

About 80% of HIV infections in Nigeria are transmitted by heterosexual sex (NACA, 2005). Several factors have contributed to the rapid spread of HIV/AIDS in

Nigeria. These include sexual networking practices such as polygamy, a high rate of untreated STIs, low condom use, poverty, low literacy, poor health status, low status of women, stigma and denial of HIV/AIDS (UNAIDS, 2005). Of the other 20% of HIV infections, blood transfusions account for 10% of all HIV infection while the remaining 10% of HIV infections are acquired through other routes such as mother-to-child transmission, homosexual sex and intravenous drug use. There are an estimated two million AIDS orphans in Nigeria. There has also been an alarming increase in the number of HIV positive children, 90% of who contract the virus through mother to child transmission (UNAIDS, 2004).

## Access to Anti Retro-Viral (ARV) Drugs

The introduction of antiretroviral (ARV) drugs as part of HIV clinical care for people living with HIV has changed the perception of HIV infection from a death sentence into a chronic manageable illness in many parts of the world (WHO, 2002). Provision for affordable, accessible and good quality treatment and care for people living with HIV is essential for tackling the epidemic and improving lives. Although ARVs are not a cure for HIV/AIDS, they can inhibit replication of the virus which effectively slows disease progression and improves a patient’s quality of life (Family Health International, 2005). They have the capability to prolong lives and revitalize the infected person to lead a normal life for a considerable period of years.

Until 2005, only 5% of the six million people who required ARV treatment in resource-limited countries could access it (UNAIDS, 2005). In Nigeria, a 2004 assessment of HIV/AIDS care in Nigeria by USAID observed that current capacity fell far short of the number of patients requiring treatment. Public facilities providing ARVs experienced severe budgetary constraints limiting their ability to provide HIV services. Patients bore 35% of the financial burden of the ARV and only few Nigerians can afford this cost. As such, only 5% of the estimated 800,000 people in urgent need of ARV in Nigeria are receiving the medication. This number is expected to increase with the 2005 presidential directive to treat 250,000 individuals by the end of 2006 (Idoko, 2006). Of the number of women in need of ARV to prevent mother to child transmission, only about 1 % are receiving it (Adewole & Adeyi, 2006). Antiretroviral drugs are mainly provided by a few special government owned centers, private institutions such as oil companies and nongovernmental organizations. All of these providers are located in the urban areas (Idoko, 2006).

Access to treatment constitutes part of the recognized human right to health. Article 12 of CEDAW (1979) provides that women should be guaranteed the same access to health care services as their male counterparts. It specifically provides attention for pregnant women. The Committee monitoring the implementation of the CEDAW has observed that state parties to the Convention are under obligations to ensure that women enjoy comprehensive health care services taking into cognizance women’s specific needs. Similarly, the Committee monitoring the implementation of the Covenant on Economic, Social and Cultural Rights (ESCR) (1966) in its Comment 14 has observed that health goods and services should be made accessible and affordable to the marginalized and vulnerable groups including women in the society. Article 14 of the Women’s Protocol of the African Charter on Human and People’s Right (1981) in a more dynamic and radical manner provides that the right to health of women, including sexual and reproductive health, should be respected and promoted. In addition it states that:

> states should respect and promote their right to: control their fertility; decide whether to have children; the number of children and the spacing of the children; choose any method of contraception; self-protection and to be protected against sexually transmitted infections; be informed on one’s health status and on the health status of one’s partner, particularly if he is infected with sexually transmitted infections, including HIV/AIDS, in accordance with internationally recognized standards and best practices; have family planning education (Art. 14)

## Sexual Practices

Data from several parts of Nigeria point to increasing sexual activity especially among adolescents of both sexes with progressive decreasing age at initiation and poor contraceptive use (Orji, Esimai, and April, 2005). Generally by age 20, more than three quarters of women have had sex and by age 25, almost all women (nine in ten) have had sex (National Population Commission, 2005). The median age at first sexual intercourse is lower among the older women than the younger women. For older women age 45-49, the median age at first intercourse is 15.5 years. For younger women (age 20-24), the median age at first intercourse is 17.6 years. Early marriage for older women may be responsible for the earlier sexual initiation compared to younger women who tend to stay longer in school and marry later. The recent emphasis on abstinence for the prevention of HIV/AIDS and other sexually transmitted infection may have encouraged delay in sexual initiation.

In addition, rural women have their first intercourse at younger ages than their urban counterparts. Among the regions, age at first sex is lowest in the North East and North West (15 years or less) and highest in the South East and South West (Approximately 19 years). Women with low education start sexual activity as early as 15 years of age while women with secondary or higher education have their first sexual intercourse after age 18 (National Population Commission, 2003). This pattern in sexual initiation also mirrors age at first delivery which will be discussed under reproductive experiences.

## Sexual Practices of People Living with HIV/AIDS

An HIV positive woman is faced with many decisions which include sexual and reproductive decisions. She must decide whether to have sex or not. If she chooses to have sex, she must be concerned about the prevention of sexually transmitted diseases. If her partner is not infected with HIV, she may have to deal with protecting the partner. Even where both partners are HIV positive, there is also the risk of re-infection with other viral subtypes and strains and increasing their viral load. These concerns may affect whether women chose to be sexually active or not as well as the frequency of sexual activities. De Vincenzi et al, (1997) in a study among HIV positive women found that the proportion of women who were not sexually active rose four times from five percent before diagnosis to 20 per cent after diagnosis. Frequency of sexual intercourse among women infected with HIV/AIDS is reduced. A study in Rakai by Gray et al (1998) finds lower coital frequencies among HIV positive women in Zaire. As long as women engaged in sexual activities, the risk of partner infection and woman's re-infection with other sexually transmitted infections were possible. The probability of pregnancy is also very high in such unprotected sexual intercourse. Some women erroneously believe that they cannot get pregnant because of HIV infection (Family Health International, 2005).

Sexual and reproductive choices of HIV positive women are often influenced by their sources of information. This is determined by demographic factors such as level of education and social network. A study by Otokpa and Lawoyin (2004), among women attending prenatal clinic in Abuja revealed that educated mothers were more likely to have used condoms than uneducated mothers. Peers and referent others often influence the behavior of an individual including sexual and contraceptive behaviors (Moronkola, Ojediran, & Amosu, 2006). Myths also play a role in their decision making (Family Health International, 2005). For example women living with HIV in the support group that I facilitated believe that the virus needs to be shed regularly through intercourse to reduce the viral load. From a contraceptive perspective, 31.5% of women attending family planning clinic in Ibadan, Nigeria believe that having sex once with a man will not result in pregnancy (Moronkola , Ojediran, & Amosu, 2006). Pressure of gender-based norms that relegate women as objects of men’s sexual pleasure and vessels for bringing forth children, as well as their economic dependence on their male partners may influence an HIV positive woman’s sexual and reproductive choices. Many women find it difficult to disclose their HIV status to their partnersor initiate condom use for fear they will be labeled unworthy, beaten and abandoned. In Northern Nigeria, a tailor stabbed his female partner to death with a scissors when she revealed that she was HIV positive (Vanguard Newspaper, 2001). Reluctance to notify their partners of their HIV status affects their ability to have safe sex. In a study of 238 women infected with HIV in Kinshasa, Zaire, more than 97% of the women were unwilling to inform their sexual partners of their HIV status because of fear of divorce, physical harm or public scorn (Ryder RW et al., 1991).

Very few documented studies are available on sexual decisions of women living with HIV/AIDS in Africa, and Nigeria in particular. But whether or not women know (or suspect) they are infected with HIV or fear becoming infected through unprotected sexual intercourse with their partners, a proof of their fertility maybe more important to them than the fear of infection. Pregnancy to them can affirm the woman's health, or at least her capacity to bear a healthy child. Women use pregnancy to demonstrate the absence of HIV infection and the presence of continuing good health. They frequently cite fear of abandonment as the underlying motivation for demonstrating good health—and avoiding any suspicion of HIV infection (Family Health International, 2005).

## Reproductive Health Indicators

### *Fertility*

Sub-Saharan Africa has led other regions in levels of fertility. At an estimated average level of about 6 children per woman, the region has the highest levels in the world (UNAIDS, 2006). The total fertility rate (TFR) in Nigeria is 5.5 children per woman (National Population Commission (NPC, 2003). Nigerian women experience their prime reproductive years during their twenties and early thirties.

On the average, rural women will have one more child than urban women (6.1 and 4.5, respectively). The rural age specific fertility rates (ASFRs) rise sharply from age 15-19 years to age 20-24, peak at age 25-29 and then decline. On the other hand, the urban ASFRs assume a more gradual pattern, an indication both of delayed marriage and some deliberate attempt to postpone or terminate births (contraception) by urban women (National Population Commission, 2003, Abanihe, 1996).

In Nigeria and in most African countries, fertility is strongly correlated with education and wealth attainment. The higher a woman's educational attainment and the more economically advantaged her household, the lower her fertility (National Population Commission, 2003). In most African countries and cultures, a woman's worth and sense of fulfillment are often tied to her fertility and ability to bear children. Not being able to bear a child can be a traumatic burden for an African woman.

### *Age at the Onset of Child Bearing*

Early child bearing is more of a rural phenomenon with 30% of rural women age 15-19 having begun child bearing compared to 17% of urban women in the same age group. The median age at first birth in Nigeria is 20.3 years for women age 25-29; whereas for women age 35 years and above, it is less than 19 years (National Population Commission, 2003).

Early pregnancy in adolescent girls puts them at great health risk. This may include loss of life and risk of obstetric fistulae. A fistula is a maternal disability arising from obstructed labor that has been reported particularly in parts of Africa and Asia (WHO, 1991). In addition to obstetric risk, the immature vaginal and cervical tissues are more permeable by HIV.

## Infant and Maternal Mortality

The infant mortality estimates from the 2003 National Demographic and Health Survey (NDHS) is 100 per 1000 live births (National Population Commission, 2003). A child’s weight is an important indicator of his or her survival chances. Children reported to be small at birth have a substantially higher mortality rates. Children whose mothers did not receive antenatal or delivery care also have higher mortality rates. Mortality risks are greater for children who are born to mothers who are too young or too old, children born after a short birth interval or mothers who have had many children. Women with HIV/AIDS are often nutritionally compromised due to inadequate intake. They are therefore prone to have low birth weight babies and more in need of obstetric care. Women are primary care takers of children, empowering them with information and resources to make decisions and act effectively in their own. Their child’s interest enhances the health and survival of their infants (National Population Commission, 2003).

## Contraceptive Use

The 2003 National Demographic and Human Survey (NDHS) found that 79 percent of all Nigerian women age 15-49 know at least one method of family planning. Knowledge of any modern method is higher among sexually active unmarried women (91 percent) than currently married women (76 percent) and unmarried women who never had sex (66 percent). The most widely known modern contraceptive methods among all women are the pill (60 percent), the male condom (59 percent), injectables (57 percent) and female sterilization (37 percent). The diaphragm and foam/jelly are the least widely known (each reported by 9 percent of women), along with implants (10 percent) and male sterilization (11 percent), (National Population Commission, 2003).

Contraceptive use varies with region, level of education, number of living children and the economic status of the household. A total of 13 % of currently married women are using a method of family planning, including 8% who are using a modern method. Urban women are twice as likely as rural women to use a method of contraception (20% versus 9%), (National Population Commission, 2003). Periodic abstinence and withdrawal are the most used traditional methods across all age groups of married women and men. This is of particular concern because periodic abstinence and withdrawal do not prevent transmission of sexually transmitted infections (National Population Commission, 2003). There is a direct negative relationship between the number of living children and the use of contraceptive method. There is also a positive relationship between social economic class and contraceptive use. Thirty percent of married women in economically advantaged households are more likely to use a method of contraception compared to 7% of those in the economically disadvantaged households. A woman’s desire and ability to control her fertility and her choice of contraceptive method are affected by her empowerment status and self image (National Population Commission, 2003). Moronkola, Ojediran, & Amosu (2006) in a study in Ibadan Nigeria found that among the women attending the family clinic sampled, 74.9% revealed that their husband’s approval is major determinant of contraceptive use.

## Contraceptive Options for Women Living With HIV/AIDS

A review by Family Health International (2005) estimates that more than 150 million married women of reproductive age worldwide have an unmet need for contraception to postpone or avoid pregnancy. In the majority of countries in sub-Saharan Africa, more than 20 percent of married women of reproductive age have an unmet need for contraception.

Unmet needs for contraception create a particular hardship for WLWHA who may wish to avoid pregnancy, but do not have access to contraceptives or family planning services. Contraceptive options for WLWHA are similar to those of non-infected women. Women with HIV have many contraceptive methods from which to choose. These include barrier methods, hormonal methods, intrauterine devices, female and male sterilization and the lactational amenorrhea method also known as LAM (FHI, 2005). When used correctly every time a couple has intercourse, the male condom has a pregnancy rate as low as 2 percent, and the female condom has a rate of 5 percent. In common use, their pregnancy rates are much higher – around 15 percent for the male condom and 21 percent for female condom (Hatcher, Trussell, Stewart, et al, 2004).

Condoms are the only method proven to reduce the risk of all STIs, including HIV (FHI, 2005). Evidence of condom effectiveness in reducing HIV transmission has come from studies of serodiscordant couples in which one person is infected with HIV and the other person is not. One study demonstrated that with consistent condom use, the HIV infection rate among the uninfected partners was less than one percent per year. However, in situations where one partner is definitely infected, inconsistent condom use was shown to be as risky as not using condoms at all. The study found that 13.3% of inconsistent users became infected compared to 14.4% of non-users (Deschamps, Pape, Hafner, et al. 1996).

Hormonal methods are also appropriate for women with HIV, and most offer excellent pregnancy protection. All hormonal methods are easy to use, especially injectables and implants which require very little action on the part of the client. However, hormonal contraceptive use by WLWHA could theoretically increase release of more HIV through vaginal secretions. This would increase the risk of HIV transmission to an uninfected partner. However, the data are inconclusive about such a relationship (FHI, 2005).

There is evidence that HIV/AIDS has increased the use of contraception. Glynn et al (2000) found that WLWHA who have had a child used contraceptives more than HIV negative women. The proportion of WLWHA using modern contraceptives were 34.5% compared to 17.5% among HIV negative women in Yaoundé, Cameroon and 20.3% compared to 14.8% respectively in Ndola, Zambia in 1998. Also Ryder et al. (1991) compared 238 WLWHA and 315 HIV negative women in Kinshasa, Democratic Republic of Congo. They found the percentage of WLWHA who were using modern contraceptives was significantly more (26.4%) than with the uninfected women (16.3%). The proportion using a modern method increased with the progression to AIDS stage (42%).

## Impact of HIV/AIDS on Fertility

One of the impacts of HIV/AIDS on individual women and populations in severely affected areas of sub-Saharan Africa has been change in fertility levels through proxy determinants such as marriage, contraception, pregnancy, abortion, breastfeeding and postpartum abstinence (Ntozi, 2002). Fertility can decline or increase due to HIV/AIDS, depending on the mechanism. With marriage, which exposes women to sexual relations, individual women are likely to respond to HIV/AIDS epidemic by delaying their first sexual intercourse. Those who are already sexually active reduce premarital sexual relations due to fear of infection. There is also a possibility of girls postponing their marriage or deciding not to marry at all. Those women that are married may decide to separate with unfaithful spouses to avoid infection. Due to increased death of partners, more women become widows, thus reducing their reproductive lifetimes. Widows and divorced women find it more difficult than before to remarry for lack of suitors who fear possible HIV infection. All these behavioral actions reduce the exposure of women to pregnancy and hence depress fertility (Ntozi, 2002). Studies in Cote D'Ivoire and Uganda have indicated that HIV infected women have fewer pregnancies than HIV negative women. Regardless of other factors such as demographic and social variables, the pregnancy rate was consistently lower in HIV infected than in HIV uninfected women (Gray et al., 1998).

De Vincenzi et al (1997) studied French women living with HIV/AIDS, comparing their experiences before and after being diagnosed with HIV. They found that that the incidence of pregnancy decreased significantly from 20.4 per 100 person years before HIV diagnosis to less than half, 7.9 per 100 person years after HIV diagnosis. The study also showed that 29% of the women interrupted a pregnancy before they were diagnosed with HIV while 63% did after learning of their HIV status. The percentage of spontaneous abortions and ectopic pregnancies increased significantly from 8.3% to 25.4% of those conceived before and after HIV diagnosis respectively.

HIV infected women concerned with the likelihood of infecting their babies and not wanting to leave children orphans use contraceptives to prevent pregnancy, leading to lower fertility. Women with HIV, seeking to reduce the progression of the disease, may abstain from sex or use condoms in order to prevent re-infection with HIV and other STDs. HIV negative women increase condom use to prevent HIV infection and other STDs. This also depresses fertility.

HIV/AIDS can work through a natural fecundity mechanism to affect fertility. First, fetal deaths through spontaneous abortion and still births due to HIV infection reduce the live births which are used in the calculation of fertility. Second, because of frequent sickness due to HIV/AIDS, women are less able to engage in sexual intercourse and hence less exposed to getting pregnant. A study in Uganda revealed a progressive reduction of fertility from the time of HIV infection to the development of AIDS. This could correspond to progressive failing health. Thus, women with HIV in Africa who have symptoms have greater reduced fertility than those who were not exhibiting any symptoms (Ross, Morgan and Lubega, 1999). An HIV infected woman may also voluntarily terminate a pregnancy for fear of disease progression and wanting to save the baby from vertical infection or dying and leaving the child orphan.

HIV could lead to increase fertility through the following mechanism. In light of high HIV/AIDS related infant mortality, both HIV infected and uninfected persons may desire more children to ensure that the preferred minimum number survives and to replace the dead children or even other beloved dead relatives. Secondly, to increase protection against HIV/AIDS, women using efficient contraceptives would switch to using condoms, which may be less efficient in preventing pregnancies and result in higher fertility (Ntozi, 2002). Breast-feeding and post abstinence are two proximate determinants that can increase fertility. Consistent breastfeeding is a natural method of contraception. However, to avoid mother-to-child transmission of HIV, women may decide to reduce or not breastfeed. This increases the chance of pregnancy occurring, especially if no contraception is used. Furthermore, in some communities, practicing long post-partum abstinence is a form of family planning. However, women may reduce the duration of abstinence to discourage regular partners from engaging in extra-marital relationships that may infect the family with HIV. Also, with the death of an infant due to HIV/AIDS, women would automatically stop breastfeeding and postpartum abstinence, thereby increasing the chance of another pregnancy and hence higher fertility.

Long spousal separation increases the possibility of extra marital relationship, which in turn increases the risk of HIV transmission. Therefore, couples promote mutual fidelity by avoiding long spousal separations, which promote frequent sexual intercourse. In the absence of effective contraceptive use, this would create more opportunity for pregnancies, leading to higher fertility (Ntozi, 2002).

## Impact of Pregnancy on HIV/AIDS

The natural history of HIV infection in women is not affected by pregnancy (O’ Sullivan, et al, 1995, Alliegro et al, 1997, Weisser et al, 1998, French & Brocklehurst, 1998, Saada, et al. 2000). CD4 count is used to assess the strength of the immune system and is an indicator of the HIV progression. In a population-based study of fertility in HIV positive women in Africa, both HIV positive and negative women experience decline in CD4+ count cells in pregnancy. When comparing changes in CD4 count/percentage, no difference existed between HIV pregnant and non pregnant women, suggesting that pregnancy does not accelerate a decline in CD4+ cells (O' Sullivan, et al, 1995). Weisser et al (1998) had similar findings in large Swiss study.

Meta-analysis of seven prospective cohort studies found no overall significant differences in death, HIV progression, progression to an AIDS defining illnesses or CD4+ decreases to below 200/mm3 between pregnant and non-pregnant women (French & Brocklehurst, 1998). In another study of 331 HIV positive women for a median period of 5.5 years, 69% of the women conceived during this time. No difference in progression was found between those who were and those were not pregnant during follow up (Alliegro et al, 1997).

Ryder et al, (1991) in a study in Zaire, found that pregnancy has little or no effect overall on HIV progression in asymptomatic women or women with early infection, although it may accelerate HIV infection in women with advanced disease. Pregnancy complications that have been observed more frequently among HIV positive pregnant women than among HIV negative women include genital and urinary tract infections, more frequent and severe blood loss, anemia, bacterial pneumonia, intrauterine growth retardation, preterm labor and premature rupture of membranes, premature delivery and low birth weights (McIntyre & James, 1999).

However, pregnancy often carries serious consequences for the infants of HIV positive mothers. Without treatment, about one third of HIV infected mothers pass the virus to their newborns during pregnancy, delivery and breastfeeding. Some evidence suggests that pregnancy in women with HIV increases the risk of stillbirth and infants with low birth weight (French & Brocklehurst, 1998). De Vincenzi et al (1997) studied a cohort of French women living with HIV/AIDS and compared their experiences before and after being diagnosed with HIV. They reported that the percentage of spontaneous abortions and ectopic pregnancies increased significantly from 8.3% to 25.4 % of those conceived before and after HIV diagnosis respectively.

## Prevention of Mother to Child Transmission of HIV (PMTCT)

Across the globe, approximately 2.2 million children are currently living with HIV. Ninety percent (90%) of them became infected through mother to child transmission (MTCT) during pregnancy, delivery and breast-feeding. This is also known as vertical transmission (UNAIDS 2004). The highest rate is found in Africa with a large population of women of reproductive age, high birth rates, a tradition of prolonged breastfeeding and a lack of effective interventions aimed at preventing mother to child transmission (Adewole et al, 2006). Mother to child transmission of HIV represents a tragic dimension of the burden of HIV/AIDS particularly in resource constrained settings, where fragile and poorly funded health care systems hamper care and prevention efforts. At least one third of HIV infected children in developing countries die within their first year of life (Dabis et al, 2000). A three-fold strategy has been proffered to prevent babies from acquiring HIV from their infected mothers (UNAIDS/WHO, June 2005). It includes:

- Preventing HIV infection among prospective parents
- Avoiding unwanted pregnancies among HIV positive women,
- Preventing the transmission of HIV from HIV positive mothers to their infants during pregnancy, labor, delivery and breastfeeding.

Prevention of mother to child transmission is achieved by the use of antiretroviral drugs, modification of obstetric practices and safer feeding practices in HIV infection (Chama et al, 2004). In the absence of treatment, an infant’s risk of acquiring HIV from a mother living with HIV/AIDS ranges from 15% to 30% among women who do not breast-feed their infants. The risk of transmission increases when a woman has a higher viral load, or if an infant is directly exposed to the mother’s infected body fluids during birth. If an infant born to an HIV positive mother does not contract the virus during pregnancy or childbirth, studies estimate that the child has a 5–20% chance of acquiring the virus from the mother’s milk if he or she is breastfed (UNAIDS, 2004). The most effective PMTCT treatments involve a combination of drugs with pregnant women having advanced HIV disease receiving combined therapy for their own health, as well as to prevent MTCT. But a number of studies have shown that the protective benefit of drugs is diminished when babies continue to be exposed to HIV through breastfeeding (UNAIDS/WHO, 2005). Mothers are advised not to breastfeed whenever the use of breast milk substitutes (formula) is acceptable, feasible, affordable, sustainable and safe. However if they live in a country where safe water is not available, then the risk of life-threatening conditions from formula feeding may be higher than the risk from breastfeeding (WHO, 2005).

For HIV positive women who choose to breastfeed, exclusive breastfeeding is recommended for the first months of an infant's life because a baby fed on infant formula does not receive the special vitamins, nutrients and protective agents found in breast milk. Further, the cost of infant formula often puts it beyond the reach of poor families in resource poor countries, even if the product is widely available (UNAIDS/WHO, 2005).

Many women also lack access to the knowledge, potable water and fuel needed to prepare replacement feeds safely, or simply have no time to prepare them. If used incorrectly - mixed with unsafe water, for example, or over-diluted - a breast milk substitute can cause infections, malnutrition and even death. Furthermore, if a mother chooses not to breastfeed in settings where breastfeeding is the norm as in Nigeria, then this may draw attention to her HIV status and invite discrimination, violence or abandonment by her family and community. Another factor worth noting is the contraceptive effect of breastfeeding, (lactation amenorrhea) which can help to lengthen the interval between pregnancies (Coutsoudis et al, 2001).

In the face of political insecurity HIV was not a priority. Hence, Nigeria did not implement PMTCT until July 2002 when sero-prevalence had hit 5.8% (Federal ministry of Health, 2005). By that time there were an estimated 849,000 AIDS orphans and 755,000 established pediatric AIDS cases in the country (Chama et al, 2004). Although conceived as a pilot project in six tertiary health institutions, eleven such institutions now offer PMTCT services. In all more than 22,973 women have benefited from the program (Adewole et al, 2006). Despite these recorded achievements Adewole notes that PMTCT program in Nigeria suffers from some setbacks. These setbacks include the over concentration of PMTCT centers in urban areas and in tertiary health institutions. This poses the danger of excluding the majority of pregnant women infected with HIV/AIDS living in the rural areas. Another challenge is affordability. Affordability refers to not only the expense of ARVs, but also the cost associated with safe alternatives to breastfeeding, facility upgrading and personnel. Another problem of the Nigerian PMTCT program is the fact that attention is merely focused on the unborn child while the woman herself gets little attention. Women's rights advocates have criticized this approach as merely reducing a woman to being used as an avenue for providing treatment for the unborn child.

Several studies revealed that women living with HIV/AIDS are consumed with fear of infecting their baby during pregnancy, at birth or during breastfeeding (Green & Sobo, 2000; Ciambrone, 2003; Doyal & Anderson, 2005). Many however, have opted to have babies despite their fears (Nyblade & Field, 2000; Ciambrone, 2003). This is more so in Africa where a woman's worth is tied around her ability to raise offspring (Isiugo, 1996).

## The Orphan Challenge

By 2003, 15 million children under 18 had been orphaned by HIV/AIDS worldwide. About 12 million of these live in sub-Saharan Africa, and it is expected that this number will rise to more than 18 million by 2010 (UNAIDS/WHO, 2004). Eight out of every ten children who have lost their parents to HIV/AIDS live in sub-Saharan Africa. Tragically, the number of orphans in sub-Saharan Africa will continue to rise in the years ahead due to the high proportion of sub-Saharan African adults already living with HIV/AIDS and the continuing difficulties in expanding access to life-prolonging antiretroviral treatment (UNAIDS, UNICEF, USAID 2004).

In African countries that have already had long, severe epidemics, AIDS is generating orphans so quickly that family structures can no longer cope. Throughout sub-Saharan Africa, there have been traditional systems in place to take care of children who lose their parents for various reasons. But the HIV pandemic is slowly phasing out this traditional practice by overloading its caring capacity and deepening poverty level due to loss of labor and the high cost of medical treatment and funerals (UNICEF, 2003).

The vast majority of orphans in sub-Saharan Africa continue to be taken in by the extended family. Here, the extended family has historically formed an intricate and resilient system of social security that usually responds quickly to the death of a mother or father. For example, it is traditional in many southern African communities for the deceased father’s nearest male relative, such as a brother or a nephew, to inherit the deceased man’s wife and children. Similarly, if a mother dies, the husband would then marry a close female relative of the deceased, who would then be obliged to regard any of his children as her own (McDaniel and Zulu, 1996). With HIV/AIDS this traditional support system is under severe pressure. In many instances has already been overwhelmed, increasingly impoverished and rendered unable to provide adequate care for children.

The distress and social isolation experienced by children who have lost one or both parents to HIV/AIDS, both before and after the death of their parent(s), is strongly exacerbated by the shame, fear and rejection that often surrounds people affected by HIV/AIDS. Because of this stigma and often-irrational fear surrounding AIDS, children may be denied access to schooling and health care. And once a parent dies, children may also be denied their inheritance and property. Often children who have lost their parents to AIDS are assumed to be infected with HIV themselves. This further stigmatizes them and reduces their opportunities including the opportunity to be taken in and cared for by a relative.

Although research has shown that many HIV positive women are concerned about the fear of leaving orphans (Nyblade & Field, 2000; Engender Health and UNFPA, 2006), little research is available on how much this concern influences their decisions to have children or not .

## The Theoretical Framework

### *The PEN-3 Model*

Naturalistic studies do not often start, nor are they driven by, a specific theoretical framework. For this study, however, the semi-structured interview guide will be informed by constructs from the PEN-3 model. That it is semi-structured requires that there is room for the real voices of the women to emerge. Therefore it will not be rigidly limited to the constructs of the model alone.

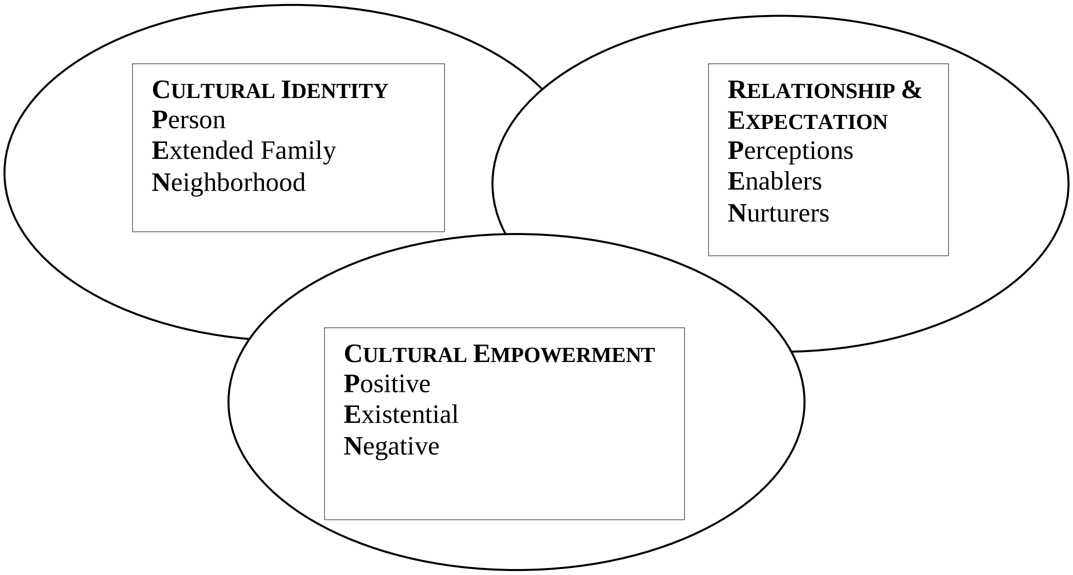
Several theories, such as the Health Belief Model, Theory of Reasoned Action and Social Learning Theory, can be used to explain health decision and experiences. However, many of these theories do not capture the cultural context within which most health decisions are made and reinforced. Understanding cultural belief systems and the meaning people make of them as they make health decisions is critical to successful planning and implementation. Airhihenbuwa (1995), recognizing the centrality of cultural sensitivity to health communication and health promotion, developed the PEN-3 model used in health promotion and disease prevention (Erwin & Spatz, 1996; Green & Kreuter, 1999; Kline, 1999; Paskett et al., 1999, Airhihenbuwa, Webster et al, 2003; Walker, 2006, Kannan, Webster, et al, 2006 ).

The PEN-3 Model consists of the following three interrelated domains: ***Cultural Identity, Relationship & Expectation and Cultural Empowerment.*** Within each domain are 3 categories that correspond to the acronym PEN (Figure 2).

***E - Extended Family –*** Seeks to understand the role or influence of the extended family in the health beliefs and actions of the individual and the community. Understanding this will enable health educators to know when to design programs to target the family or an individual within the context of their environment and the influence of the extended family on health decisions and actions.

***N – Neighborhood –*** Recognizes the critical role a community's members and its leaders play in the health beliefs ad actions of its member. Because community leaders are gatekeepers of cultural beliefs and practices, it is important to identify what kind of influence they exert and involve them in the design of culturally appropriate health programs.

***Relationship & Expectation*** explores factors that influence individual, family and community health actions. It is similar to constructs of Health Belief Model (Rosenstock, 1974), Theory of Reasoned Action (Fishbein & Ajzen, 1975) and the PRECEDE-PROCED framework (Green & Kreuter, 1991). It explores how **P**erceptions, **E**nablers and **N**urturers influence and predict health behaviors. However, PEN- 3 expands these same constructs to include an exploration of how cultures define the roles of persons and their expectation in family and community relationships such that personal actions are examined as functions of broader socio-cultural context (Airhihenbuwa, 1995; Airhihenbuwa & Webster, 2004).



[2]*Figure 2. The PEN-3 MODEL*

***P – Perceptions***- refer to knowledge, attitudes, values and beliefs within a cultural context that may facilitate or hinder personal, family or community motivation to change. For example, in Nigeria, women believe that having several children in quick succession is a way to assert their importance and earn prestige in their family and community. This motivates their desire to have many children quickly. Therefore, appropriate health education interventions should begin with an understanding of the motivations driving a person's perceived needs and desires, which sometimes will conflict with the expert defined needs.

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[2] From "*Health and culture: Beyond the western paradigm,*" by C. O. Airhihenbuwa, 1995, C A: Sage Publication, p. 56. Copyright1995 by C. O. Airhihenbuwa. Reprinted with permission of the author.

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***E – Enablers-*** are the cultural, societal, systematic or structural influences that may enhance or create barriers to health action. They may include availability of resources, accessibility, referrals, government officials, skills and types of services. For example, in some places in Nigeria, although ARVs are free, some women are not allowed to go out alone in public for cultural or religious reasons. They must find a trusted one to take them to the clinic, that is if, they can afford transportation or the regular laboratory tests that are associated with treatment.

***N – Nurturers-*** refer to the degree to which health beliefs, attitudes and actions are influenced and mediated or nurtured, by extended family, kin, friends, peers and the community. Nurturers could also include extended family, peers, employers, health personnel, religious leaders or government officials. For example, breastfeeding is seen as a completion of the motherhood process. As such mothers are under pressure from their significant others to breastfeed the newborns. This could make prevention of HIV transmission through breast milk difficult.

***Cultural Empowerment*** explores how culture drives individual, family and community behavior and is an affirmation of the range of possibilities within culture. As denoted by the acronym, cultural beliefs and actions could be *Positive, Existential or Negative***.** Airhihenbuwa (1995; Airhihenbuwa & Webster, 2004) notes that each of these three dimensions can relate to perceptions, enablers and nurtures within historical and cultural context.

***P – Positive-*** these are behaviors that are based on health beliefs and actions that are known to contribute to improved health status and must be encouraged. These positive health practices are essential to the empowerment of people, families, neighborhoods and communities.

***E – Existential-*** refers to cultural beliefs and practices that have no harmful health consequences and, therefore, need not be changed.

***N – Negative-*** these health beliefs and actions that may lead individuals, families, or communities to follow health practices that are harmful to their health. It is therefore important for health educators to strive to examine and understand these negative behaviors within their cultural, historical and political contexts before attempting to change them.

The PEN-3 model has been used in research and interventions in Africa and among immigrant and minority groups in the USA. In 1990, the PEN-3 model was put in action in Nigeria during a training of 20 health workers 10 African countries. The participants were assigned to four intervention groups: oral dehydration therapy, expanded program on immunization, nutrition and high-risk births. Based on their filed experiences, they were asked to develop a list of reported positive, existential and negative health beliefs that reflect the perceptions, enablers and nurtures of members of the communities for a particular intervention. The following list emerged in relation to high risk births:

- Positive: sexual abstinence during pregnancy reduces the incidence of pelvic inflammatory disease
- Existential: Post partum sexual abstinence prevents semen from mixing with breast milk.

- Negative: A pregnant woman who eats eggs, meat or chicken will have babies too big to deliver normally.

Based on some of these findings the health workers had a workshop to discuss these health beliefs especially those rooted in tradition and culture (Airhihenbuwa, 1995).

Erwin, et al, (2005), used PEN-3 to guide analysis of a focus group discussion among Latinos from Arkansas and New York in order to create a culturally competent breast and cervical cancer education program. Beech & Scarinci used the PEN-3 model to explore smoking attitudes and practices among low-income African Americans. The results indicate that specific contextual and familial factors can contribute to smoking initiation, maintenance and cessation among this group. James (2004) used PEN- model to explore how culture and community impact on the nutrition attitudes, food choices and dietary intake in African Americans in north central Florida, as well as to identify segments of the community that should be targeted for education programs, desirable components of nutrition education programs. Again, Hendrick et al (2001) also used the PEN-3 model to guide focus group discussions that explored how second generation Moroccan immigrants balance traditional attitudes and safe sex. Walker (2000) used it in an intervention research related to cardiovascular risks reduction in South Africa. Webster (2003) used the PEN-3 model to guide an evaluation of cultural interpretations and meanings of the use of the female condoms to reduce HIV transmission.

For the purpose of this study, the PEN- 3 model will guide the design of the interview guide to ensure that questions are asked that cover the various aspects raised. However the researcher will be open explore other issues that the participants may raise that are not within the PEN-3 model thereby guaranteeing the open-mindedness that is among the hallmark of qualitative research.

## Qualitative Research

Quantitative and qualitative research designs are two main methods of inquiry that are often contrasted. Both quantitative and qualitative research use similar elements which include a clear purpose, problem statement or question, a defined research population, data collection using specific methods and instruments and analysis of data and outcomes. They both rely explicitly or implicitly on theory and are concerned with rigor. The difference however lies in how researchers put these elements together and the goal they want to achieve (Glesne, 2006). Sometimes both methods are used complementarily in the same study to achieve a more holistic understanding of a phenomenon.

Quantitative research aims at making generalizations about some social phenomena, creating predictions concerning those phenomena and providing causal explanations for them. It usually starts with a theory about the phenomena being studied. Guided by the theory the researcher poses hypotheses and tests them using methods that are designed to be objective. Data are reduced to numbers which are subjected to statistical analysis. Generalizations are made from the study group to other persons in other places (Glesne, 2006).

Qualitative research on the other hand typically takes place in the natural environment rather than in a controlled environment and is emergent rather than fixed (Rossman &

Rallis, 2003). It aims at understanding some social phenomena from the perspectives of those involved, contextualizing issues in their particular socio-cultural-political milieu and sometimes transforming or changing social conditions. Qualitative research has two unique features. The researcher is the instrument and the purpose is to learn about some facet of the social world (Rossman & Rallis, 2003).

Qualitative researchers seek to interpret how various participants in a social setting construct the world around them. The researcher must make interpretations based on the multiple perspectives of the participants. This often requires in-depth, long-term interactions with participants in the field. Qualitative researchers usually begin their study with an exploratory, open mindset and often generate hypotheses at the end of the study. Rarely do they begin with a theory (Glesne, 2006). Rather than controlling for variables as quantitative research does, qualitative studies are open-ended and thus “lead the researcher into unforeseen areas of discovery within the lives of the people she is investigating” (Holliday, 2002, p.5). Qualitative researchers often look for patterns, but do not attempt to reduce the multiple interpretations to a norm (Glesne, 2006). Qualitative research has the ability to provide rich, thick descriptions. “A thick description creates…truth-like statements that produce for readers the feeling that they have experienced, or could experience, the events being described” (Denzin, 1989, p. 84).

## Interviews

James (1985) states “to understand other person’s constructions of reality – we would do well to ask them” (p.46). Rogers and Bouey (1996) note that interview is the most utilized data collection method in qualitative research studies. Interview, according to Kvale (1996) is a powerful process of knowledge creation through conversation between the researcher (interviewer) and the participant (interviewee). Through this conversation we get to know other people, learn about their experiences, feelings, hopes and the world they live in.

Qualitative interviews can be structured, unstructured or semi-structured. In structured interviews, also called standardized interviews; the researcher asks different interviewees the same set of questions in the same order and using the same words. Structured interviews are convenient for comparing different interviewees' answers to the same questions, as well as when a team of researchers is involved in conducting the interview. Unstructured interviews are also referred to as informal conversational interviews. As the name implies, there is no predetermined set of questions. Instead the researchers and interviewees talk freely (Burgess, 1991b). Unstructured interviews are often used in combination with participant observation. This can be tricky as the researcher has to generate and develop questions according to what the interviewees say. Semi-structured interviews, also called guided interviews, are somewhere between structured and unstructured interviews. The researchers prepare interview guides which consist of a set of questions. The interview guides allows the researcher to generate questions to develop interesting areas of inquiry during the interviews. Semi-structured interviews are more widely used in qualitative research (Flick, 1998). Sometimes, all three types of interview can be used in combination (Patton, 1990).

## Summary

This chapter presented the geo-political and socio-demographic character of the Federal Republic of Nigeria as well as the cultural practices in relation to sexuality and reproduction which have implications for the lives of women living with HIV/AIDS and the HIV/AIDS control program. It presented the epidemiology of HIV/AIDS and the fact that women are increasingly being infected with HIV/AIDS as well as the management of the HIV/AIDS stressing the limited access to anti-retroviral (ARV) drugs. It also discussed the inter-related impacts of HIV on fertility and pregnancy and the fact that pregnancy do not seem to affect the natural history of HIV/AIDS. The prevention of mother to child transmission (PMTCT) program is a top priority now. Unfortunately it is still limited to women in the urban areas and is particularly threatened by cultural beliefs and practices. At the same time, many children are orphaned by HIV/AIDS which beyond its heart wrenching challenge, could also be a reflection that current prevention of mother to child programs focuses on urban children and do not put the needs and wellbeing of children and their mothers as equally important. This situation has drawn the ire of many activists.

# CHAPTER 3

# METHOD

This study explored the sexual and reproductive decisions and experiences of Women Living with HIV/AIDS (WLWHA) in Abuja, Nigeria. This chapter presents the research design, the population and sample, data collection method and data analysis, as well as steps to ensure trustworthiness.

## Research Design

Qualitative research was used to explore the sexual and reproductive decisions and experiences of women living with HIV/AIDS in Abuja, Nigeria. Qualitative research seeks an in-depth understanding of human behavior and the reasons behind the behavior. It enables us to examine the why and how of sexual and reproductive decision making, not just the what, where, and when. Creswell (1998) defined qualitative research as:

> *"a process of understanding based on distinct methodological traditions of inquiry that explores a social or human problem. The researcher builds a complex, holistic picture, analyzes words, reports detailed views of informants, and conducts the study in the natural settings" (pg. 15).*

Qualitative research represents human beings as whole persons, living in dynamic, complex social arrangements (Rogers, 2000; Peshkin, 1993). With its multiple cultures and religions, Nigeria is indeed a complex society. Understanding the sexual and reproductive decisions and experiences of WLWHA in this society required the use of a qualitative research design that would produce a holistic and contextual understanding of the women's' decisions and experiences from their own perspectives.

## Research Method

In-depth interviews were used to collect data. Interview, according to Kvale (1996), is a powerful process of knowledge creation through conversation between the interviewer and the interviewee. Through this conversation, interviewers get to know other people, learn about their culture, experiences, feelings, hopes and the multiple contexts of their lives. The PEN-3 model emphasizes this co-creation of knowledge. Because PEN-3 model has culture at its center, it was used to design an open-ended in-depth interview guide (see Appendix E) used to collect data.

## The Interview Guide

An open-ended interview guide was developed based on, but not limited to, the constructs of the PEN-3 Model. This model, discussed in detail in chapter two, consists of the following three dimensions of health beliefs and behavior that are interrelated and interdependent: ***Cultural Identity, Relationships & Expectations, and Cultural Empowerment.*** Within each dimension are three categories that correspond to the acronym PEN. The first dimension, ***Cultural Identity,*** reflects the commitment of health education to the ***Person***, the ***Extended Family***, and the **Neighborhood**, hence the importance of understanding these categories before designing health education interventions. The second dimension, ***Relationships & Expectations,*** expands constructs 1, depicts PEN-3 model domains, with explanation of the constructs.

Table 1

*PEN-3 Model Constructs as Used in the Design of the Interview Guide*

| Cultural Identity | Relationships and Expectations | Cultural Empowerment |
|---|---|---|
| Person | Perception | Positive |
| Roles of participant in her family and community<br>*(Q1. Tell me about yourself.*<br>*( Q 2. What roles if any do you play in your immediate, extended family and community and how have living with HIV/AIDS affected these roles if any?* | Knowledge, attitudes, values and beliefs within a cultural context that may facilitate or hinder health behavior.<br>*(Q5. Tell me about your beliefs about HIV and sex?*<br>*Q6. Can you share with me how you have dealt with sexual issues since living with HIV/AIDS? Probe for--safe sex practices.*<br>*Q6. What are your thoughts about HIV and having children? Probe- for contraceptive use and abortions Q7. What has been your personal experience with pregnancy and childbirth since been diagnosed? If she have had a child, probe for experience with prevention of mother to child transmission including labor and breastfeeding* | Behaviors that are based on health beliefs and actions that are known to be beneficial and must be encouraged<br>*Q10. Please share with me beliefs and practices people in your culture share with regards to sex, contraception, childbearing and breast feeding*<br>*Q11. Which of these cultural beliefs and practices do you hold dear and practice too?* |
| Extended Family | Enablers | Existential/Exotic |
| Role of the extended family in | Cultural, societal, systemic or structural | Cultural beliefs, practices |

| | | |
|---|---|---|
| the participant’s life and that of her family.<br>*(Q3. What kind of influence does your family play in your life?* | influences or forces that may enhance or be a barrier to health behavior<br>*Q8. What factors do you think influenced your decisions about sex and having children?* | or behaviors that are indigenous to a group and have no harmful health consequences<br>*Q10 an 11* |
| Neighborhood | Nurturers | Negative |
| The nature of participant’s neighborhood or community and which community leaders or stakeholder play a role her life and that of her family.<br>(*Q4. Apart from your family, who in your community or neighborhood plays a role in your life?* | The degree to which health beliefs, attitudes, and actions are influenced and mediated or nurtured by extended family, friends, peers and community<br>*(Q9. Please can you share with me how if any your family, friend, or community/religious leaders influence your decisions about sex and having children?* | Cultural beliefs and actions that are known to be harmful to health<br>*Q10 and 11* |

The interview guide (see Appendix E) reflects constructs of the PEN-3 model to enable to participants to share information about themselves, their extended families and neighborhoods, as well as their perceptions of belief systems that affect their reproductive and sexual decisions and experiences. The interview guide was not meant to be rigidly followed. The interviewer was open and followed up on leads from the participant as the interview evolved. The interview guide was developed with input from the doctoral committee members. One of my doctoral committee members is the author of the PEN-3 model, while another is an expert in qualitative methodology. A pilot study showed that the interview guide was appropriate for data collection and required no major revision.

## Study Population

Nigeria, populated by about 140 million people, is Africa’s most populous country (NPC) (2006). There are thirty (36) states and one Federal Capital Territory (FCT), Abuja. The study was carried out in Abuja, the Federal Capital Territory which is analogous to the District of Columbia in the USA. Abuja has a population of about five million people. It is a melting pot of people from different ethnic groups and socio-economic classes. It has an HIV prevalence rate of 8.4% (FMOH, 2006).

The study target population was women living with HIV/AIDS who became pregnant and had a child after their diagnosis. These women were more likely to have lived with HIV long enough to have confronted the sexual and reproductive issues that the research explored.

## Sampling and Data Collection

A combination of purposive and snowball sampling was used to select the study participants. In purposive sampling, the researcher applies his or her own discretion based on prior knowledge and experience to select the respondents who best meet the purpose of the study (Neutens & Rubison, 2002). Snowball sampling is a technique for developing a research sample where existing study subjects recruit future subjects from among their acquaintances. This sampling technique often is used in hidden populations which are difficult for researchers to access (Salganik &Heckathorn, 2004). Women living with HIV/AIDS are a hidden population due to the stigma associated with their condition.

In the course of my ten years of working with PLWHA in Nigeria, I had interacted with many women living with HIV/AIDS and some of the experiences they shared with me motivated this study. On securing the approval of the Southern Illinois University Carbondale's Human Subjects Committee, I contacted some of my former clients and told them about the research and the kind of participants I was looking for. I asked them to refer WLWHA in their social network to participate in the study. I also recruited participants by making an announcement at their support group meeting requesting WLWHA who met the study criteria to contact me through my phone if they would like to participate in the study. Those who participated in the interview were also asked to refer other WLWHA.

When prospective participants contacted me through the phone, I asked if they had been pregnant and had a child since being diagnosed with HIV/AIDS. To those that said yes, I explained the purpose of the research and scheduled the date, time and venue of the interview. All the interviews took place at the office of Center for the Right to Health in Abuja. They were told that a meal would be served and their transportation would be reimbursed. They were also told that child care was provided for those who came with their children.

### *Pilot Study*

A pilot study is rehearsal of the main research project (Sarvela & McDermont, 1993). A pilot study helps the researcher by producing information that may not have been considered in the initial planning of the interview guides and research process. To simulate the research project, the first two participants who contacted me were used as the pilot to determine if the interview guide was effective in getting the participants to share their stories and to answer the research questions. It was also an opportunity to see if the time budgeted for the interviews was adequate. The pilot revealed that both the guide and the time allocated for the interviews were appropriate. No major revision was needed. For this reason, the two pilot interviews were included in the study.

## Interviews

When participants arrived for the interview, they were told that their participation was voluntary and they were free to withdraw at any time without any negative consequences. They were told that the interviews would be audio taped and kept confidential. Their names and identifying information would not be used in the report; however, their verbatim quotes would sometimes be used in the report. They were told that tapes and transcripts will be secured in a locked cabinet in the researcher's house and destroyed at the end of the research. They were encouraged to ask questions. Ensuring that they understood all of these conditions, they were asked to sign an informed consent.

Before each interview, the researcher and participant shared a meal.  Sharing a meal is an icebreaking and bonding process in Nigeria and helped participants to relax and get more comfortable. One quality of a good interview is to be able to make the interviewee comfortable and generate trust. Because of my history of advocating for the human rights of people living with HIV/AIDS and my campaign to break the silence around sexuality issues, many people living with HIV/AIDS tended to trust me and speak openly with me. I believe this reputation increased my credibility and enhanced the interview process. Each interview was in a quiet room to ensure privacy. One of CRH staff served as note-taker during the interview. At the end of the first phase of the interview, the interviewee was offered refreshments. During the break, the note taker and I reviewed our notes and generated a summary of the key issues raised in the interview. During the second phase, I read the summary to the participant giving her an opportunity to confirm, negate or expand the content.

Unfortunately, I had conducted only six of the scheduled interviews when I broke my back in a motor accident and was airlifted out of Nigeria for surgery and rehabilitation. Two CRH staff with master's degrees in public health (MPH) who were trained and experienced in conducting qualitative research helped to complete the remaining eleven interviews. My note- taker, who had been sensitized to my interview style, was the interviewer while the other staff took notes of verbal and non verbal communication.

A total of 17 interviews were conducted. The notes were sent to me at the end of each interview. I reviewed each set of notes and kept tabs on the emerging issues. We stopped interviewing when we reached saturation because no new issues were emerging. They shipped the tapes to me for transcription and analysis.

## Data Analysis

I listened to each tape and made notes. I transcribed each tape verbatim into a Word document and stored them in a password protected folder on my computer. A master copy was be printed and filed away in a locked cabinet along with the tapes. I printed the transcripts and color coded the broad headings in each transcript. For example, I used a different color for sexual issues, another for pregnancy and yet another for breastfeeding issues etc. As I read through each transcript, I jotted down questions, comments, observations and queries in the margins next to the corresponding data. After working through the entire transcript in this manner, I went back over my marginal notes and comments and grouped notes and comments that seem to go together with the corresponding quotation(s). I kept a running list of these groupings attached to the transcript and on a separate paper as a memo to myself. I created a phrase that summarizes groups of constructs as codes and wrote the codes next to the appropriate bits of data in the transcripts. For example condoms, were coded into things like "use condom," "do not use condom," "use it to prevent pregnancy," use it to prevent disease" etc. I used NVIVO qualitative analysis software to further my data analysis.

NVIVO made it easier to organize and retrieve qualitative data. Instead of having to make several paper copies of the transcripts and cut up segments and try to organize and link these cuts, I did it electronically with NVIVO. First, I entered demographic characteristics of the participants (cases) into NVIVO. Then, I uploaded the cleaned transcript of each participant (cases) into NVIVO and linked it her demographic data. I also uploaded the notes I made about each interview into NVIVO, which also stores data under the corresponding case. Thereafter I started the electronic coding process which involves transferring the codes I had already done on paper margin into NVIVO. During this phase, all initial codes were stored as free nodes, such as "condom use," "non use," "use for pregnancy prevention," "use for disease prevention" etc. Each phrase is linked to the paragraph of associated quotes and to the case. Similar groups of free nodes were pulled together as tree nodes, or sub-themes. For example, "use for pregnancy prevention," "use for disease prevention" etc, was pulled into a tree node labeled "reason for condom use". Everything that had to do with condom use was pulled together into another tree node, a theme that I called "condom chatter." If a code did not fit, I recoded as appropriate. A click on a node showed me what each participant said, making it easy to reference. The final report was written based on themes and authenticated with direct quotations linked to pseudonyms of the participants.

## Trustworthiness

Recalling that the researcher is the instrument of data collection and analysis, the truthfulness and accuracy of interview data is based on the interpretation of the researcher. The researcher takes various steps and actions to ensure that she collects accurate data and makes the right representation and interpretation despite her personal beliefs and values. Trustworthiness is the term used to establish the confidence in the truth and accuracy of the findings (Krefting, 1999). Trustworthiness is analogous to validity and reliability as used in qualitative research. It ensures that the study has been conducted with academic rigor, is representative of what is being studied and is worthy of being read by other scholars (Lincoln & Guba, 19895; Marshall & Rossman, 1989; Morse & Field, 1995; Schwandt, 1997). These authors use the following terms when describing ways of establishing trustworthiness: credibility or truth value; transferability or applicability; dependability or consistency, confirmability or neutrality.

### *Credibility or Truth Value*

Credibility establishes the truth and believability of the research findings. Schwandt (1997) described credibility as the steps the researcher takes to ensure that there is a fit between the participant's views and the meanings they make of their lives and the researcher's reconstruction and representation of the same. Morse and Field (1995) call credibility "truth value." It depends on participants' affirmation that the researcher's report is a true reflection of what the participant has shared.

*Member check* is one way of establishing credibility. This process involves sharing transcripts or draft outlines of the analysis of each participant's interview with that participant. The goal is for the participants to confirm that their viewpoints were faithfully represented, that there were no gross errors of facts and the account made sense to them (Giacomini, et al., 2000a). Member checking was used to establish credibility in this study. To achieve credibility, the interviewee was offered refreshments at the end of the first phase of the interview. During the break, the note-taker and I reviewed our notes and generated a summary of key issues raised in the interview. During the second phase, we told the interviewee that I would read a summary of each segment of our interview and so she could tell me if that represents what we discussed or if she would like to add to it. Many participants used the opportunity to expatiate on earlier points and correct misrepresentations.

*Peer review* was another method that was used to increase credibility of the study. Peer review involved the review of the data and research process by someone or a group of people external to the study who were trained in qualitative research. "A peer reviewer provides support, plays the devil's advocate, challenges the researcher's assumption, and asks hard questions about methods and interpretation" (Creswell & Miller 2000, p.130). Two colleagues who had been trained in qualitative research served as my peer reviewers. After the initial coding, I sent four sets of interview transcripts to the peer reviewers to code. The goal was to see whether we would all come up with similar categories. While we had common categories, there were some categories I had that they did not have and some they had that I did not have. I integrated all categories and arrived at a comprehensive list of categories after discussion with the peer reviewers. An outline of the themes and sub-themes was presented to two members of my committee. My discussions with them enabled me to reorganize the themes and sub-themes to make them more coherent and meaningful.

### *Dependability or Consistency*

Dependability also referred to as consistency, is a way to ensure that the researcher reports what actually happened and that the results would be similar if another researcher were to replicate the study using the same or similar participants (Morse & Fields, 1995). To establish dependability, Schwandt (1997) suggested that the researcher follow a logical process that is traceable and documented. This documentation then can be audited by a third party. Audit is the process whereby a third party systematically reviews the documented steps (audit trail) maintained by the researcher to confirm that the conclusion reached is logical when judged against the process taken. To establish dependability or consistency of this study, I kept a paper trail of the steps I took in the field. I also reviewed the paper trail of the two researchers who carried out the remaining interviews. I kept logs of my thoughts, feelings and reactions after reviewing each interview transcript and during coding to enable me to check the evolution of my interpretation and concluding. The NVIVO software is also great at recoding the coding trail, including free nodes, tree nodes, memos and linkages.

### *Transferability or Applicability*

Transferability or applicability refers to the extent we can extrapolate the findings from a particular situation or population to another (Maxwell, 1992, p. 309). In quantitative research, the use of random and large samples makes generalization possible. This option is not usually possible with qualitative research, where the sample size is usually small and purposively selected. To generalize the results of this study to all women living with HIV/AIDS in Nigeria is not appropriate and is not the goal of this study. Rather, inferences about the findings are limited to women living with HIV/AIDS who have similar circumstances to those studied. The researcher has the responsibility to describe the circumstances of the participants in the study so that readers can decide for themselves the degree of similarity between the study participants and those to whom they might want to make inferences (Schwandt, 1997). To this end, I have described the study population and how they were selected in great detail. I also transcribed all interviews verbatim and used direct quotations of the participants to support and substantiate my results section. This depth of details is referred to as “thick and rich description” (Bodgan and Biklen, 2003).

### *Neutrality or Confirmability*

Neutrality is a way to ensure that the data and interpretation are based on reality, not the imagination or biases of the researcher (Schwandt, 1997; Krefting, 1999). Researcher reflexivity is a way to improve neutrality in qualitative research. Reflexivity involves the researcher’s self disclosure of her entering assumptions, beliefs, and biases which she is required to set aside throughout the study. This process also is known as bracketing (Creswell & Miller, 2000). Disclosing previous assumptions, beliefs and biases early in the research process allows readers to understand the researcher's position and thus make their own judgment of the researcher's findings and interpretations (Creswell & Miller, 2000). In my personal reflection in chapter one of this study, I disclosed my experiences, beliefs and biases in relation to the topic. I believe that this narrative would acquaint readers with my experiences and enable them to judge my potential biases. A log of my personal reflections and experiences throughout the study enabled me to me isolate (bracket) my biases and provided useful insight during analysis and discussion (Giacommini et al. 2000a).

## Summary

In this chapter, I explained that qualitative research design and interview methods were used to collect data about the sexual and reproductive decisions and experiences of women living with HIV/AIDS in Abuja Nigeria. Snowballing and purposive sampling techniques was used to select participants who were interviewed using an interview guide inspired by the PEN-3 model. Interviews were transcribed verbatim and analyzed by organizing constructs into categories and themes using NVIVO qualitative analysis software. Trustworthiness was established using a combination of researcher reflexivity, member check, peer reviews, audit trail review and journaling.

# CHAPTER 4

## FINDINGS

This study explored the sexual and reproductive decisions and experiences of women living with HIV/AIDS (WLWHA) in Abuja, Nigeria. It specifically targeted women who became pregnant and had a child after knowing they were HIV positive. The study also explored how culture and other factors influenced these women's decisions and experiences. This chapter presents the key findings of the research, including the demographic characteristics of the participants, their HIV and obstetric history, family relationships, disclosure of their HIV status, sexual decisions and experiences, reproductive decisions and experiences, and child care decisions and experiences.

### Demographic Characteristics of the Participants

Table 2 presents the demographic characteristics of the 17 women living with HIV/AID (WLWHA) who were interviewed in this study. They were between 26 and 41 years old. All of them were married except one widow who was in a relationship with an HIV positive widower.  Most of the participants were Christians. Only seven (41%) completed secondary (high) school. About half (47%) of them were housewives. The women hailed from 11 states and the federal capital territory (FCT). Five of them hailed from Benue state, which has the highest HIV prevalence in Nigeria (FMOH, 2006)

Table 2

*Demographic Characteristics Participants*

| Name | Age | Marital Status | State | Religion | Education | Occupation |
|---|---|---|---|---|---|---|
| Agnes | 35 | Widow | Benue | Christian | Primary | Hair stylist |
| Asabe | 26 | Married | Abuja | Christian | Primary | Tailor |
| Christy | 29 | Married | Kaduna | Christian | Secondary | Trader |
| Eli | 41 | Married | Kogi | Christian | Primary | Housewife |
| Esther | 33 | Married | Benue | Christian | Primary | Housewife |
| Glad | 33 | Married | Benue | Christian | Primary | Housewife |
| Grace | 39 | Married | Kogi | Christian | Primary | Food Vendor |
| Jemila | 30 | Married | Kastina | Muslim | Primary | Caterer |
| Kate | 32 | Married | Rivers | Christian | Tertiary | Banker |
| Lizzy | 40 | Married | Imo | Christian | Secondary | Housewife |
| Margret | 30 | Married | Benue | Christian | Primary | Trader |
| Martha | 32 | Married | Ondo | Christian | Secondary | Housewife |
| Nneka | 27 | Married | Enugu | Christian | Secondary | Trader |
| Ogechi | 33 | Married | Imo | Christian | Secondary | Housewife |
| Sami | 37 | Married | Kaduna | Muslim | Tertiary | Counselor |
| Uduak | 28 | Married | Akwa Ibom | Christian | Primary | Housewife |
| Vero | 31 | Married | Kogi | Christian | Primary | Housewife |

Table 3

*HIV and Obstetric History Participants*

| Name | Yrs HIV + | Partner status | Diagnosed in pregnancy | # kids | # pre HIV | # post HIV | # HIV+ | # Dead | # Miscarried |
|---|---|---|---|---|---|---|---|---|---|
| Agnes | 18 | + | Yes | 5 | 4 | 1 | 0 | 0 | 0 |
| Asabe | 2 | - | Yes | 2 | 1 | 1 | U | 0 | 0 |
| Christy | 4 | + | Yes | 2 | 1 | 1 | 0 | 0 | 0 |
| Eli | 6 | + | Yes | 2 | 0 | 2 | 0 | 0 | 0 |
| Esther | 5 | + | No | 4 | 3 | 1 | 0 | 0 | 0 |
| Glad | 6 | - | No | 2 | 1 | 1 | 2 | 1 | 1 |
| Grace | 18 | + | Yes | 3 | 2 | 2 | 2 | 1 | 0 |
| Janet | 6 | + | Yes | 2 | 1 | 1 | 1 | 0 | 0 |
| Jemila | 2 | + | Yes | 5 | 4 | 1 | 0 | 0 | 4 |
| Kate | 7 | - | Yes | 2 | 0 | 2 | 0 | 0 | 0 |
| Lizzy | 5 | Unknown | Yes | 3 | 2 | 1 | 0 | 0 | 1 |
| Margret | 9 | + | Yes | 3 | 0 | 4 | 1 | 1 | 0 |
| Martha | 6 | + | Yes | 2 | 1 | 2 | 0 | 1 | 3 |
| Nneka | 6 | - | Yes | 3 | 0 | 3 | 1 | 0 | 0 |
| Ogechi | 4 | + | No | 7 | 5 | 2 | 1 | 0 | 0 |
| Sami | 9 | + | No | 8 | 6 | 2 | 1 | 7 | 0 |
| Uduak | 8 | + | No | 6 | 4 | 2 | 1 | 0 | 0 |
| Vero | 7 | + | Yes | 3 | 0 | 3 | 1 | 2 | 0 |

## HIV and Obstetric History of the Participants

Table 3 revealed that the women had been living with HIV for periods ranging from two to eighteen years. Four women had HIV negative husbands (this is called serodiscordant). Another's husband's HIV status was unknown because he refused to be tested. Meanwhile, he and his wife assumed he was HIV negative. The rest were HIV positive. Twelve (70.2%) of the women found they were HIV positive during prenatal care (which is referred to as antenatal in Nigerian parlance). Women had between one to four children after knowing that they were HIV positive. Seven of their children were HIV positive, 13 children died. Four of women experienced a total of nine miscarriages.

## Family Relationship

Most of the women reported that their families were their pillars of support. In discussing their "families" and also "sharing with families", participants did not limit it to the nuclear family. They expanded it to include their extended family, such as sisters, brothers, parents and in-laws.

### *Extended Family as Family*

*"I have five children. We are about thirteen in my family. My mum was the first wife and gave birth to four" (Agnes).*

*"My parents have 10 children, I am the first born. My husband's parents are dead. He has a younger brother" (Eli).*

*"My parents are dead, my father has 12 wives. In my mother side we are 3, 2 of them die remaining only me. On my husband side, they are nine, he is number 4. His father is dead, but his mother is alive" (Grace).*

## Disclosure and Reasons for Disclosure or Non-Disclosure

Only three participants were openly HIV positive. A majority of them revealed their status selectively to those they felt could handle it and show support. This group was represented by the *selective* disclosure category. For a few women, their HIV status was a secret shared only with their husbands. This group was represented as the *non-disclosure* group.

### *Non disclosure*

*"Apart from my husband, nobody knows that I am HIV positive" (Nneka).*

*"Only I and my husband know our HIV status. No other person knows that I am HIV positive" (Jemila).*

*It is only me and my husband that knows about my HIV problem. We did not tell anybody" (Margret).*

### *Open disclosure*

*"I and my husband are openly HIV positive" (Martha).*

*"Everybody in my family and community know that I am HIV positive, I have even being on TV and go from place to place to talk about HIV prevention" (Sami)*

### *Selective disclosure*

*"My parents don't know about my status, but my sister, my brother and my first son (he is 20 years old) knows. My other children do not know because they are still small" (Agnes).*

*"All my siblings are aware of my HIV status and they have been very supportive but my parents are not aware… No one knows from my husband's side" (Kate).*

> *All my family knows but the man's (Husband) people did not know what was going on, even up till today they did not know what was going on. They only know that he was sick once, they don't know what was happening and the man warn me not to tell his people, but he explain everything to my people, he did not hide anything from my people (Vero).*

### *Reason for non-disclosure*

Fear of stigma is the main reason for non-disclosure. Margret said, "*We don't want people to be running away from us and telling other people about our problem." Jemila said, "Me and my husband we no tell anybody because we don't like stigma and discrimination"* A few of them wanted to protect aging parents with hypertension. Kate reported "my *parents are not aware, they are both old and hypertensive, we do not want to worry them to their grave."* This was also echoed by Christy " my *grandmother is still alive...I want to tell her, but she has hypertension, if I tell her now she is too old and could die."*

*Reason for disclosure*

One woman reported that she disclosed her HIV status to her son to educate him about HIV, she said *"I decided to talk to him because he is a young man now, he might do risky behavior… so I decided to open up to him" (Agnes).* Most of the women disclosed their HIV status to relative they perceived would be supportive. For example, Asabe discussing disclosure to her sister said, " *I told her that I am HIV positive and that I am pregnant…She directed me to where they give ARV drugs and where to go for antenatal (Asabe).* Eli said, *"I told my parents…I don't think I can hide it from them, so that I wouldn't die in silence*." Glad said, *"When I confirm that I am positive they (family) assist me, they encourage me, they show me love the way they suppose to. In short they are the ones that help me stay alive."* Kate said:

> *All my siblings have been very supportive… My younger sister has been teaching me how to relax. She is so sophisticated; you think she is the senior. Hmm hmm (she giggles), each time my husband is coming home from a trip, my sister will buy me a new negligee, perfume and candles and we will rehearse how I can relax and enjoy sex with my husband.*

## SEXUAL DECISION AND EXPERIENCES

Initially, the women were reluctant to talk about their sexuality. They looked surprised, alarmed. Some were demure and looked down in embarrassment, but opened up after they were reassured about confidentiality and non judgment. A few of them for the onset were vocal and eager to talk, with body language and facial expressions that seemed to say at last, here is someone with whom I can share troubling issues. For several of women, it was like a catharsis. Our discussions seemed more like a counseling session than an interview. They wanted help with marital conflicts around sexual and reproductive issues. These women were referred to counselors at CRH for counseling.

Three major categories emerged under sexual decisions and experiences: sexual desires and activity, wives cannot say no to sex, and condom chatter: reasons for use or non use of condoms.  With regards to sexual desire and activity, there were two major themes representing women who reported that their being HIV positive did not affect their sexual desires and activities. Another group revealed that being HIV positive took away or reduced their sexual desires and activities. Another theme, wives cannot say no to husbands' sexual desires, described the reason why women acquiesced to their husbands' sexual demands (although they had little or no sexual desires). Their reasons included cultural/religious expectations, fear of infidelity/divorce or polygamy, and violence.

## Sexual Desires and Activity

A few women reported that being HIV positive did not limit their sexual desires or activities. They were able to initiate sex and respond to their husbands' sexual desires. They asserted that sex was natural and that being HIV positive did not preclude sexual desires and activity. However, more women reported limited sexual desires and reduced frequency of intercourse since being HIV positive.

### *Unaffected Sexual Desires and Activities*

> *That I am HIV positive does not mean I do not have sex urge. I have sex urge like every normal human being should, and when it comes, I call my husband to the room express the passion and he will respond (Eli).*

> *Sex is good; no woman can stay without sex, because you feel it, even without man, even though only you, you feel it. If my husband feels it, he will asks me and I give him. I feel it, and I am inside room, I know how to start it, I will start like play…I will touch him, from there, he too will feel am (it)… he will continue do it (sex) (Asabe).*

*"As a human being, you have to do it (sex)…if I say I don't have sex, am just lying to you, because I have a friend who is positive too" (Agnes).*

### *Reduced Sexual Desires and Activities*

*"We dey manage ourselves, we no do like before again, We go stay one month, three week we never sex ourselves we dey pray to God, that's what we are doing now" (Grace).*

*"It has not been easy, since knowing my status my sexual drive took a nose drive and stayed there" (Kate)*

*"I don't feel anything, since this HIV thing, but if my husband wants it and he touches me, then we do it" (Ogechi)*

*"I normally make sex with my husband freely but since I discover this in fact I'm not feeling or doing  sex  as before" (Uduak)*

> *Before I get HIV, me and my husband we meet (have sex), my husband can need me every day, sometimes two times a day no problem. Now we could stay up to 5 days and not meet, if he touches me I think about HIV (Jemila).*

> *I usually had good sex with my husband until I became sick and went to the hospital and they tested me for HIV… Now left to me, I will not even have sex; I do not have any feeling. He is the one that usually wants it and I say yes (Esther).*

### *Reasons for Reduced Sexual Desires*

Reasons for their reduced interest in sex included preoccupation with the infection, weakness and low self image. Women whose husbands were HIV negative report that fear of infecting their husbands suppressed their desires.

#### *Weakness and thoughts of HIV.*

*"My oga want to meet every night every night but me I don't like to meet. I am always tired" (Christy)* (Oga means master, referring to her husband).

*“Me ma, as far I am concerned, I don’t even want the sex unless to make baby. Whenever he touches me, fear will go seize my body, I no want make he get the disease” (Glad-serodiscordant)*

*Now if my husband touches me, I remember the problem, because my mind is not with my husband, if he touches me I think about HIV” (Jemila).*

*“I don’t even feel like having sex, I have no feeling, when he approaches me I will tell him I have headache, I am tired, any excuse. Sometimes when I tire to fight I will just let him do it like that. But I am afraid he may bring another infection to me” (Sami).*

### *Fear of infecting HIV negative husband.*

*“Me ma, as far I am concerned, I don’t even want the sex unless to make baby. Whenever he touches me, fear will go seize my body, I fear he will catch the disease” (Glad-serodiscordant).*

> *When my husband returns, I will have constant headache from thinking. I will stay busy in the kitchen until he goes to sleep, then I will sneak into bed and stay as far away from him as possible. Each time he reaches out for me in bed, I will freeze; I will tell him I am tired. I will give all kinds of excuse. The truth is that I am afraid. I am afraid of infecting him I am positive and he is negative. He reassures me that if he uses condom he will not get infected, but I am still scared...I just love him too much. I don’t want to infect him. If he ever gets HIV I*

> *will kill myself. He has taken the test several times, so far it is negative (Kate – serodiscordant)*

> *One day my husband came home, I was wearing one of those flimsy night gown, he held me and I froze again, he made me get up and led me to the mirror, he said open your eyes what do you see, he started describing how beautiful and desirable he finds me, but… all I see is a 'tainted woman', the woman who could kill him with a deadly virus (weeping) (Kate- serodiscordant).*

### Wives Cannot Say no to Husbands' Sexual Demands

The women reported that even thought they had no interest in sex, they acquiesced to their husbands' sexual demands because their religions and cultures expected them to do so. Other reasons for their acquiescence were the negative consequences of refusing husbands' sexual advances. These ranged from violence and discord, to fears that their husbands would have sex with someone else and bring home sexually transmitted diseases, divorce them or marry a second wife.

### *Religion and Culture Supports Sexual Submission of Women*

*"As a Christian we have been taught that, if husband have feelings towards you, you shouldn't reject it, so even if I don't have the feelings at that moment, there is a way he will play with me that will make me to accept it" (Esther)*

*In my culture they believe that when you are married, even if your husband wants to have sex with to you, that you don't have any right to say no (Nneka)*

*"As a wife, I cannot deny him, you know men, I he may go out and bring another thing (disease) in which will make matters worse" (Ogechi)*

*I am a woman I cannot say no when he wants it (sex) because if I say no he can probably go outside again, and his people will support him and that will bring another problem. I cannot refuse" (Vero)*

### *Consequences of Refusing Husband's Sexual Advances*

*Violence*

*"He always wants to meet; he does not want to hear that I am tired or not feeling like sexing. We will fight sometimes when I say no" (Lizzy).*

*"Anytime he no use condom, me ma, I no agree, and we go start to fight. That is the problem we are having now" (Grace).*

*"If ask  him to use condom, but he refuse, and if I did not allow him, he will be accusing me saying, maybe I am going outside, we will start quarreling and fighting something like that, there is nothing I can do" (Lizzy).*

*"As a wife, I cannot deny him, you know men, he may go out and bring another thing which will make matters worse" (Ogechi).*

> *Even for good 10 months we were in the same room but we don't sleep together, so that now brought problem between us. The man started beating me in the night. Anytime he say he want me, I say no, it will bring fight, so, I now talked sense to myself, I say ok, now you are not a small kid again, if the man say he wants you, it is better I release myself to him, than to be beating and wounding me. So I let him have me when he wants (Vero).*

> *Since he will not buy the drug, I was not ready to have sex and end up with another pregnancy so I refuse to have sex with him. He will fight with me, every night we are fighting still I refused. He said will report me to my people that I have refused to have sex with him, I told him that if he tells them, then I will tell them that I refused to sleep with him because he infected me with HIV. My husband is the first and only man I have ever slept with. So he left me alone. After some weeks, he stopped giving me money for the house, so me I stopped cooking. We started fighting again. I still refused to have sex with him (Sami).*

*Threats of Infidelity, Divorce or another Wife*

*"As a wife I cannot withhold myself from my oga (husband). He will go outside come bring another disease" (Christy).*

*"When you say no or when you are not giving your husband sex anytime, he may start looking outside…That's the reason why they are saying that any time your husband need it, you have to give him so that he will not be going outside" (Nneka).*

*"If your husband wants you, you give him yourself. A man fit send him wife back to her people (divorce) if you no give am sex. He can also go outside or marry another wife" (Asabe).*

## Condom Chatter: Reasons for Use or Non Use of Condoms

Condom Chatter represents the multiple voices associated with condom negotiation and use. This category includes both those who use or do not use condoms, and their reasons; and those who like or do not like condoms and their reasons.

### *Condom Use and Reasons for Use*

All the participants who used condoms reported that they had been advised to use condoms to prevent re-infection with drug resistant strains or other types of HIV and to prevent infection with other STIs. They also mentioned that condom use would increase their length and quality of their life. Those with HIV negative partners said they used condoms to prevent infecting their partners. However, a few reported they or their husbands did not like condoms but used them anyway in order to stay alive and raise their children.

### *Prevent Re-infection and Prolong Life*

*"I have a friend who is positive too, whenever we want to have fun, we use condom" (Agnes).*

*"We abide by the advice given to us; by using condom…It is a way to help ourselves to live longer" (Esther).*

*"I don't enjoy using condom but it prolongs my life we decide that way. That is the only way we can prolong our live and look after our children" (Esther).*

> *In the hospital the nurse said HIV is type by type, if my husband has another type and I have another type then we will be re-infecting each other, so we use condom..We enter Umar Support Group and they give him advice that we should be using condom. As long as he use condom if he want it, I say yes (Jemila).*

> *The man has to use condom because of infection…maybe you have been taking your drug properly, you know this virus they will hide in the marrow where even though you do the test they will not see it again, but the wicked ones can still come out and when you have sex like that you may penetrate into you and begin to form again and you have infection and that one will be another case. They would have to place you on second line ARVs, so it is better you use condom (Vero).*

### *To Protect Negative Partner*

*"I am positive and he is negative. He reassures me that if he uses condom he will not get infected…He has taken the test several times, so far it is negative." (Kate)*

*"Normally we use condom so my husband will not get the infection" (Nneka).*

## Non-use of Condoms and Reasons for Non-use

Some women wanted their husbands to use condoms, but they refused. The husbands reportedly had varying reasons, most notably, loss of sexual satisfaction and belief that condoms were meant only for prostitutes and not for wives. Some of the women also echoed the belief that condoms are not for wives. Another believed that condoms would be retained in her womb and cause death. A few of the participants reported that being on ARV precluded the need for condom use; being on ARV for a long time would increase CD4 counts and reduce one's viral load, thereby making unprotected sex safe. Although this is not a good clinical advice, they reported that their doctors either suggested it or were in support of it.

### *Condoms Interfere with Pleasure*

> *They gave us condoms at the support group meetings. If I give him, he refuses to use them. He keeps them under bed, he says, if he use condoms he does not feel it, it does not satisfy him very well. I beg him, and he will say, If he is going to get HIV he go don get am (Asabe is serodiscordant).*

*"He does not like it, he would say 'you know I don't like this condom, it make me feel somehow' I told him you know they told us in the clinic to use condom" (Margret).*

### *Condoms Not for Wives*

*I beg him to use condom, but he will not. He said how can he use condom on his own wife?"(Glad, HIV discordant).*

*"He say no, for their own place (his community) they forbid the use of condom for their wife, he say make we put everything for prayer nothing will happen. That is what we are doing now" (Grace).*

> *It has been difficult. I am positive, I don't want to infect him, that it is better we use condom, but he refuses, he said he cannot use condom with somebody that he married, that the person is not a harlot, so I use to explain to him so that he can understand, but he could not, so that's the challenges. I went to a Counselor and narrated all these to her, the matron told me that I should not deny him, he is my husband that if I do, it is a sin rather I should put it into prayer, take it to God (Lizzy).*

> *I don't like the condom; it's as if I am harlot (prostitute)…the time I small, my mother say there is one woman that die, the woman used condom and the condom enter the womb of the woman and the woman stomach started swelling, from there the woman died, em that's why I dey fear condom…"I don't like*

> *condom…(laughing), in my mind, my spirit I don't like it, am still fearing it (Ogechi).*

### *ARV precludes condom use*

*"My husband say since we have started drug, nothing will happen again, that we born one child inside the sickness that we will take it as how God want it, so he refuse to use condom again" ( Grace).*

*"But there is one doctor in that National Hospital, the doctor said that he cannot contact HIV again since am on drugs now for over 2 years, because when am not on drugs, he didn't contact it when I had my first child that is positive" (Nneka-serodicordant).*

*"We don't use condom all the time, em because em my husband has already started ARV drugs and me I have also started" (Ogechi).*

*"My husband doesn't like condom, the doctor said since we do take our drugs and my husband CD4 count is high we can do it like that (have sex without condom)" (Martha).*

## Contraceptive Decisions and Experiences

The women reported that their culture did not like contraceptives. Rather, women were encouraged to have as many children as possible. They acknowledged that poverty made it difficult to raise many children and that contraceptives helped women have fewer children. From the women's accounts, another reason to delay pregnancy was to raise

CD4 levels and improve obstetric outcomes. From the women's experience, low CD4 count often led to miscarriages, premature births or ill health during pregnancy.

### *Culture Discourage Contraception*

*"For our culture, they take family planning like abomination" (Grace).*

*"They like plenty children in my place. They believe that having plenty children is good so that in future those children will take care of them (Esther).*

*"Some Hausa Fulani like plenty children. If you enter house you see ten, twelve, thirteen, fourteen, fifteen children" (Jemila).*

*"Because my husband is the only child, some people will tell me to have 8 or 12 children" (Nneka).*

*"I will not tell anybody that I have tied my womb…I will not say anything about it, even to my mother in-law, I will not say anything" (Ogechi).*

### *Need for Contraception*

#### *Poverty*

*"It is not as if am old and cannot have child, I don't have enough money, I need funds. I don't think he will need a child, because of the challenges we face. What will we eat? I don't think we will cope" (Agnes).*

> *You don't just wake up and get pregnant, because it's not easy. Even if you want to have a child, you will plan for the child and not give birth to a baby that will start suffering … So I told him(husband) that even if we want to have children, let's have 3 or 4 in order to be capable of training them (Nneka).*

*"To continuously born born (too many births) is not good, because there is no money to send them to school. It is good if you born three or four so that you can take care of them" (Agnes).*

*"I don't like bearing too much children because of the hardship in the country. Bearing too much children you won't be able to take care of them is not good. When you don't take proper care of them because of the hardship, they turn against you" (Esther).*

*" Too many children can have bad effect on the woman because it's not easy giving birth all the time…Now that I have gotten 4 children at least I want to maintain it, so I now adopted family planning" (Esther)*

*To Raise the CD4 Count and Improve Obstetric Outcome*

> *If I get pregnant, the pregnancy will come out (miscarriage), if it reaches three months, four month, period will come out and I will be bleeding too much. I go*

> *hospital and doctor say… because of the HIV; he thinks my C4 count is low. He said I have to delay pregnancy so they can bring my CD4 up (Jemila).*

> *I was sick and was going to the hospital all the time during pregnancy, the baby died…After that again I had miscarriage and I lost a lot of blood… So the hospital people ask me to hold on from getting pregnant for a while. We have decided to rest small now (not get pregnant) (Glad).*

*"The doctor did some test and said my CD4 count is very low, that I should not get pregnant until I use the ARV and bring my C4 count up" (Sami).*

*"I am waiting to get stronger. Then Doctor said my CD4 is too low, say make I take the ARV to bring it up before I get pregnant" (Margret).*

*"Then they said he (son) was HIV positive. So I started thinking…they (doctors) said my CD4 count was too low…they told me I have to stay(not get pregnant) till my CD4 count get to 500, but that pregnancy came, when my CD4 count was 300… The doctor now told me that I should still wait, until my CD4 count come back up to 600 that I should forget about the pregnancy" (Vero).*

### *Contraceptive Choices*

Most of the participants were still planning to have more babies, so they were not considering contraceptives. A few of them planned to use or were using contraceptives.

The types of contraceptives they used or planned to use include condoms, hormone injections, intrauterine device (IUD), sterilization, monitoring ovulation and abstinence during ovulation. Although none of the participants used any of the traditional methods, they reported that these were options in their culture.

*Modern Contraceptives*

*"I use condoms to prevent pregnancy" (Nneka).*

*"I am using the injections. I forgot the name" (Esther).*

*"I go to family planning session they put IUD inside me, they said it will last five years. My husband said we do not need another baby now and I agree" (Jemila).*

*"I am pregnant now, me and my husband has agreed that if I deliver this one, I will tie my womb, so that I will not be pregnant again" (Ogechi).*

*"I monitor my cycle. If I know that I am not on my ovulation period I can meet my husband normal, but if I am on my ovulation period we use condoms that's how I normally do it" (Vero).*

> *We were using condoms before and I kept getting pregnant, because I do not trust my husband with condom, he has tricked me 2 times, so I went to family planning*

> *and they put IUD in my womb. They said it will prevent pregnancy for up to 5-10 years. I did not tell my husband" (Sami).*

*Traditional Contraceptives (these were not used by the women)*

*Herbs.*

*"You know there are some people whereby when they have 2 or 3 children, they don't have too much money to go to hospital, so they go on root and herbs that will help them to prevent pregnancy" (Uduak).*

*"Hausa Fulani believed in drinking Hausa medicine (herbs)" (Jemila).*

*Jigida (Waist) Beads.*

*"In some parts of Kaduna, their girls wear bead for waist, so that even if they have sex with a man, they will not get pregnant. Some girls wear it as fashion also" (Christy).*

> *The woman will wear jigida (beads on the waist). They also put stone ring around the waist. Some can put it for decoration, it is two types… fashion jigida and medicine jigida for my baby… But now that education have entered the community small, small (gradually) people go to hospital for family planning (Jemila).*

> *Juju.*
>
> *For our culture, they take family planning like abomination, but they have traditional ways of doing it. If you want to do it, you go to one Juju (deity) for our place, if you and your husband agree, two of you will go to village. Then you will tell the old man who is taking care of the Juju this is our plan, if the man agree, you will go and serve the Juju so that if you start the family planning the Juju will not bother you. But if you did not do like that, you or your husband will die or if I go and do it by myself, the thing will affect me (Grace).*

## Pregnancy Related Decisions and Experiences

### *Reasons WLWHA Choose to have Babies*

All the participants had been pregnant and had a child after knowing they were HIV positive. I asked why they had a child after knowing they were HIV positive, considering the risk of transmitting HIV to their children or the potential of dying and leaving orphans. The women revealed that in their culture a woman's value and security in marriage depended on having children, especially male ones.  They were pressured by their in-laws and husbands to have children. They also revealed that they were sometimes beaten or threatened with another wife if they did not bear children on time.

The women also said they had children for their own personal fulfillment and to leave something behind. They were also encouraged by the availability of prevention of mother to child transmission programs (PMCTC) and seeing HIV positive women who had HIV negative babies or having had an HIV negative child themselves. In addition, they were confident in their belief that they would live long enough to raise their children, considering the availability of medication (ARV), care and support. They mentioned repeatedly that God would protect them from death, noting that women who did not have HIV also died and left orphans.

### *Children Ensure Security in Marriage and Self Fulfillment*

#### *Pressure from in-laws.*

> *What is a woman when she has no child? Even though I had five that died, they still treat me like a barren woman. That is why I kept trying, our culture like children. They want you to born plenty children. If you do not have children they will say it is the fault of the woman. Sometimes they will force their son to drive you out. The mother will be crying, don't you want me to see my grandchildren. Some will say you married your fellow man and put in the house, they say she is a cock, cocks don't lay egg. They pour all kinds of insults on you. My mother in-law and my husband's family, they said I was a witch eating all my children. They were even planning to bring another woman for my husband to marry… When you have no child at all, the things your in-laws will say and do to you, it will be better to die than not have a child (Ogechi).*

> *How can a woman not have children? In my place if you don't have children, your husband will marry another wife to born children for him. After some time the new wife and the husband people will gang up and drive you away…. I have*

*fear of infecting the babies. This two girls that I have, if they cough, I will fear maybe I have infected them, if they stool too much I will run to the hospital I will ask the doctor to test. I am afraid, but how can I face my family and in-laws if I don't have children, what will I tell them? (Martha).*

*I have the fear, but we still want to born because when you marry and you have one issue your husband people will be saying, you are barren, you can't have children. Even now that I have two kids my last issue is five (years), they are disturbing me asking why I don't want to have another baby (Glad).*

*In my place they like many children. They expect a woman once she marries to produce many children. A woman without a child has no respect…For example, has it been that I didn't get pregnant immediately I got married, they would have said ooh, maybe she have done abortion and finished all her babies before she came (Sami)*

*But immediately I got married, I got pregnant too, and that was what made my family people to welcome me initially, even when I was not a Muslim. This is because they want to see their son's child…Before I knew of this problem I suffered. I had five children, they all died before they reach one year old from one problem or the other. Every year I am pregnant yet my hands are empty of a child. I was in deep sorrow. My husband was very miserable. His family was pushing him to marry another wife. They accused me of being a witch that ate her*

> *children… they decided that he should go and married another woman, so that the wife will give him a hundred children…So child bearing is very important (Sami).*

> *Pressure and Violence from Husband*
>
> *e e dey for (it is in ) my husband hand. He said nothing pass God, so anything God want e go do, if God say we should born, we continue to born, we born even in this sickness. I ask him 'what if something happens to me or you, what of the children? He says nothing can happen.  I pray I don't want to born (give birth to) another one again, but as he don't want to hear it, it will bring problem always, we fight always (Grace).*

> *It is because of my husband. He is not happy, he isn't happy, he wants more children, he fights with me, what can I do? He will say he has told me that nothing is wrong with me, that it is this ARV drug that I'm taking is the reason I'm not getting pregnant, he wanted me to get more children (Lizzy).*

*"I did not want anymore baby after the HIV. I was afraid, very afraid (of infecting baby), but my husband trouble me, he will fight with me, I was so afraid that if I take it, I will get miscarriage four times" (Jemila).*

*"It was my husband, he said those 4 (children) are not enough, at least if can give birth to five children, he will forget about giving birth to another child. That is how I agreed with him" (Uduak)*

*"He just begged me to give him one more after that no more" (Ogechi).*

*Pressure to Produce a Male Child*

> *I wanted to give him a son. A son is important to carry on his name. My mother had nine children because she is looking for a son; his mother had 6 children because she is looking for a son, what I will tell them is my reason for not giving him a son? They value pregnancy. Sometimes the in-laws will prefer that the bride to be become pregnant with their son's baby before the real wedding. Having children especially male children is a main way to secure your place in your husband's house (Kate).*
>
> *My husband is very understanding, he is a good man, he stood by me, but his family has been harassing him to take another wife that will give him a son. He needs a son to carry his family name. They said my family is cursed, that I am like my mother, she had six girls. Left for me, I am satisfied with the two girls, but I want to make my husband happy. Now he is spending all his money on his family. If I give him a son, he will plan better for his children (Martha).*

*“My last son that I have, after I tested positive, both of us know that we are positive and I really need that child, I need to have a son, so I got pregnant, the boy is negative” (Agnes).*

*“ the only thing they have interest on is a male child, they have to train to the extent their level is up to, in my own culture this thing , they don’t care for female child like that” (Agnes).*

### *Self Fulfillment and to Leave Something Behind*

> *It is natural for a woman to have babies. A woman feels good when she has babies. HIV does not stop me from being a woman. I don’t give dam to what people say, I don’t care what they say, I know I can do better, better than those who HIV negative are. I take care of myself and my children (Agnes).*
>
> *It is bad to say women with HIV/AIDS should not have children, they can have children. They should be able to do what other women without AIDS can do, why should they be denied children, women who do not have AIDS also infect their children with other diseases or the child could die even without any disease (Vero).*
>
> *Initially my husband did not want any more children; he did not want anything that will affect my health negatively. I begged him to please let us try one more time. You see, it is not easy to know that you could die anytime; I wanted to leave*

> *my husband with children that will keep him company if I am not anymore. Thank God he is negative; he will stay and take care of them. At least I would have left something in this world (Kate).*

*"But I was also happy to have a baby; the baby will stay with my husband, if something happens to me" (Asabe).*

*"HIV is a disease that can kill a mother and infect the child, but not having a child at all can kill a woman with thinking. Before when people test positive they believe they are not going to have babies and they are going to die soon, some of them commit suicide"(Eli).*

*Expecting to Live Long and Have HIV Negative Children*

> *Availability of PMTCT services to protect baby.*
>
> *You can protect your child not to have HIV. When you are pregnant you go to PMTCT, there are drugs they will give you and your baby. They will encourage you, if you don't want your baby to have this HIV virus you follow their advice. There are three stages, stage one they will encourage you, to do CS or if you want to deliver normally, it is better you go to the hospital where they know your problem, where they know your status, when you go to that hospital, they know your status, they will deliver you very well so that no cut or blood will not touch the baby (Martha)*

> *I was afraid, the first one became infected because I breastfed him, but with the other two I did everything the counselor told me. I did not breastfeed them and they are negative….When I was pregnant with these my two children that are negative, I have them through CS. Normally in National Hospital, they made everything free for us (Nneka).*

> *Then when I finally take in, during the labor, they gave me one drug, I swallowed it before I born the baby, they say that the medicine will separate me and the baby and prevent the baby from getting HIV. Since when I born the baby boy I went to test many several times nothing, he doesn't have HIV (Grace).*

*"God forbid, it is not like you want o infect your child on purpose. The counselor will educate you on what to do to prevent the infecting your baby" (Ogechi).*

*Having or seeing other WLWHA with HIV negative children.*

*"When I born (delivered) the first one…was HIV negative…When she reach two years, they test her again she was negative. My oga (husband) say make we me born another one" (Christy).*

*"I have concern, it is not easy taking care of a child with HIV, and we are in the hospital all the time. It is the one that I gave birth to when I did not know my status that has HIV. I see many women in our support group, their children are negative" (Uduak).*

*"I see plenty women for our support group there children no get HIV" (Asabe).*

*Expecting long life with the help of drugs and good care.*

*"With drug, even though you are not on drug, if you take care of yourself you will live fine. There are some women that I know that are living with HIV/AIDS for more than 12 years now, they are still living and nothing happen to them" (Vero).*

*"If we take care of ourselves, eat good food, take our medicine, do the things doctor say do, our children will be negative and we will live long and train them" (Uduak).*

> *I believe in myself is that HIV will not depart me from my children, it will not even depart me from my husband. But whatever they tell me to do, I will make sure I do it, in terms of my drugs because they say if you start jumping (missing) your drugs you may start having drug resistant. So anything that will stop me from taking my drugs…I will not do it…I have seen some people on drugs live for 17years and half now… I didn't even have in mind that HIV/AIDS will kill me tomorrow and I will leave my children (Nneka).*

> *HIV is not a dead sentence…When you go to hospital, they have ways to take care of person, and there are drugs now. So if you are HIV positive you can go to hospital they test you and put you on drugs, if you take your drug all the time, so nothing go happen to you. Some people if they go to the hospital, they give them*

> *blood. Take my husband now if you see him, if they tell you say he is positive you won't believe it, because he is very healthy (Christy).*

*"I will look after myself and take my drugs, by the Grace of God I will be alive to look after them. Since I no die with my first five children that died, God will not let me die before these ones" (weeping) (Ogechi).*

*Belief in God to Keep Them Alive*

*"It is only God that decides when one will die, not HIV or man, after all, even people that have no HIV they die in labor, die in accidents, and leave their children. I pray all the time and put my whole family for God hand" (Uduak).*

*"By God's grace we will be alive to raise our children" (Eli).*

*"As for death, I am not praying for that anymore. I have survived. God will keep me alive to raise my children" (Jemila).*

*"We are born again children of God, so we believe that our case is before God and there is nothing God cannot do and with that God took our own problem, so we don't take our own problem upon our shoulder because God took it upon himself" (Esther).*

*"People without AIDS die too and leave babies, dead in God's hands" (Agnes).*

*"But those that don't have HIV they do die too, they do leave their babies, it is not only those women that has HIV/AIDS, so I do not agree to that. The God that took care of their children will take care of mine too" (Martha).*

*"God who gave me the pregnancy, only he will know how to do it, if it is God's will my child will not get HIV, that was my prayer, I pray all the time I carry the pregnant and true, true, God answered me. The baby is HIV negative, so I thank God" (Grace).*

*As for dying, death is in God's hand. I have believe that with God all things are possible, that one day, one day there will be cure for HIV" (Martha).*

## Pregnancy, Infertility, Miscarriages, and Premature Births

Over a third of the women found out they were HIV positive during pregnancy. Subsequent pregnancies presented some challenges. To get pregnant, most of the women monitored their ovulation and had sex without condoms during their ovulation to increase the odds of pregnancy and reduce the risk of re-infection. To reduce the risk of infecting their husbands, serodiscordant women said their husbands ejaculated into condoms, collected the semen with syringes and injected the semen high into their vagina (artificial insemination). However, most of the women said they had difficulty getting pregnant (infertility), which was often associated with low CD4 counts. Repeated miscarriages, preterm delivery and infant death were common painful experiences for most of the women. Their anguish was a reason for a cry break during almost all the interviews.

### *Pregnancy a Vital Opportunity for HIV Diagnosis*

*“I found out my HIV status when I was pregnant with my third child” (Agnes).*

*“I know my HIV/AIDS positive status when I was pregnant. I go hospital during pregnancy in 2004; they forced me to do test” (Christy).*

*“When I went to antenatal, I did the HIV test, and they said I was positive” (Eli).*

*“It was during my first pregnancy that I confirm HIV positive” (Glad).*

*“It was while I was pregnant that I found out about this sickness” (Grace).*

*“I was 4 months pregnant with my first child when I registered for antenatal care. HIV is part of the required test. During my next visit, the doctor told me I was HIV positive” (Kate).*

### *Monitoring Ovulation for Pregnancy*

*“If you want to have children, you will gap yourself and know your circle, know when you have your ovulation, your husband can go to you straight,(have sex without condoms) that is how I did it” (Vero).*

*“When we want to get child, we go meet doctor, he will do test to know when the egg is ready, when it can be able to make baby” (Margret).*

*"The way we used to have pregnancy is like this; check my ovulation period. When I am ovulating, we normally have sex without using condoms" (Ogechi)*

*"To get pregnant, I usually monitor my ovulation, around that time, when we meet, we no use condoms, that is how the counselor advice us" (Jemila).*

*Serodiscordant couples inseminate with syringes*

> *My brother's fiancé is a midwife; she gave us a special kind of condom that has no spermicide. During my ovulation, my husband will release the sperm in the condom, he will immediately use syringe to withdraw the sperm and inject it deep inside my vagina. We tried it several times. Finally last year I took in (Kate).*

> *But to have baby, the method we are using is this, during my ovulation period we normally use the syringe that they gave us at National Hospital. There is one big syringe that they gave us, so that when I notice that am starting ovulation, so after making love with condom, my husband will use the syringe to remove the sperm from the condom and insert the sperm inside me. The counselor at the hospital said we will do it before five minutes, immediately we come out, we remove the condom and use the one big syringe like that we use it to collect the whole sperm and he will insert it on me. At times we do it the first and second day of my ovulation. So that syringe is what we have been using when am in ovulation, instead of to infecting him (Nneka).*

## Obstetric Challenges

### *Infertility*

*"This second baby, it took a long time for me to get pregnant again, we tried for over 4 years" (Kate).*

*"It was difficult getting pregnant, after that one died in the year 2002; I got pregnant again in 2004" (Martha).*

*"Then Doctor said my CD4 is too low, he say make I take the ARV to bring it up before I get pregnant. But it is over five years now no pregnancy" (Margret).*

*"I found out when I carry the third child, that one died, then I try to get another belle but it was hard. For almost four years I was trying, trying, no luck. It was on the fourth year that God answered me and I carry the fourth belle (pregnancy)" (Grace).*

*"I stay long time before I became pregnant, five years, it was terrible time. I was always crying. There was no peace" (Jemila).*

### *Miscarriage*

*"I was 5 months pregnant, then I got miscarriage, but we didn't know that we have problem, me and my husband, we thought it is ordinary. I became pregnant again and in*

*the 3rd month, I have miscarriage too, then the 3rd time, that one was 4months I have miscarriage too, that one I nearly die because when the baby things came out, I was bleeding seriously, is only God that saved my life because we don't know it was this problem even my husband we don't know" (Martha).*

*"Again I have miscarriage then I lose a lot of blood and they still give me blood. So the hospital people ask me to hold on for a while" (Glad).*

> *If I have pregnant, the pregnant will come out (miscarriage), if it reaches three months, four month, period will come out and I will be bleeding too much. I will get miscarriage four times I go hospital and doctor say she want to check me, so doctor say it is because of the HIV, he thinks my CD4 count is low (Jemila).*

### *Prematurity Birth and Infant Death*

> *I went to labor and deliver the baby, the baby is seven months baby girl…I delivered in the morning you won't believe it is seven months baby, very big and she was looking at us, me and my husband were playing with her, so towards evening around six o'clock the baby was doing somehow, I now call my husband to come and look this baby oo, he checked the baby, we now called the doctor, before the doctor came, the baby died (Martha).*

> *I started having waist pain when the pregnancy was six month, and in the seventh month and two weeks, the waist pain became too much, they now rushed me to the*

> *hospital, they say that there's not enough water in my body and that they should give me drip. They gave me drip, but I delivered the baby premature and the baby died again (Vero).*

> *I deliver my first born 2004, so the baby was healthy until one year and five months, he started being sick. I went to the hospital they gave us some drugs, part of which I now give the boy. Then the boy's body was too hot. I thought that it was malaria I took him to the hospital by 7 o'clock in the evening by then there is no test, the lab was close then, so the doctor himself thought that it was malaria, he now gave him some injections, before we know it, his eye went up and down, the neck started turning to the back, before the doctor now discover that it was convulsion he died. Then they said he was HIV positive (Vero).*

> *I am happy because before, all that my children that die, five children, I didn't know then that I have HIV ….When I am pregnant I was sick all the time. If you see my babies they were very sick, in short, my babies were not good, and you will not even want to carry them. You known they were sick all the time. I will spend money, my mother ah! My mother will bring me money, but all the money we spend for the hospital, in the end they will die (Ogechi).*

*"Before I knew of this problem I suffered. I had five children, they all died before they reach one year old from one problem or the other. Every year I am pregnant yet my*

*hands are empty of a child. I was in deep sorrow. My husband was very miserable" (Sami).*

*"Later the baby died they started accusing me that I killed his baby sha, I said I cannot kill my baby I don't know is only God that know why this sickness come like that" (Glad).*

*"I born my first son he die in the HIV sickness…The third child, that one died too" (Grace).*

*"The baby was sick all the time, she started purging, purging and died, he was HIV positive" (Margret).*

## Health in Pregnancy Delivery Choices and Quality of Health Care

While few of the women reported being strong and healthy during pregnancy, the vast majority of them said they suffered poor health. Those with low CD4 count suffered disproportionately more illnesses while pregnant than those with high CD4 count.

Caesarean section (CS) has been an important strategy to prevent HIV transmission from mother to child. Most of the women reported that they were counseled about it and opted for CS for the safety of their babies. However, they also reported being afraid of CS, but were motivated by the possibility of having an HIV negative child and hearing about other women who had CS and had negative children. All but one of the women who had CS reported having negative children.

With regards to quality of healthcare, the women were in three groups: those who had good care (treated in caring and loving ways), those who had bad care (reporting being stigmatized, ignored, made jest of) and those who sought no care at all. One said she was scheduled to deliver by Caesarean section, but because the nurses did not call her obstetrician on time, she ended up delivering per vagina and the baby died of AIDS. Women who did not seek care at all opted for home care and delivery care because they were afraid of the HIV/AIDS stigma.

A couple of the participants used 'then' and 'now' to describe their health care experiences. According to them, 'then' was in the 1990's when most health care workers were not trained about HIV/AIDS, were afraid of being infected and treated WLWHA poorly. 'Now' represents more recent (2000s) when more health care workers have been trained and reflect their training through more compassionate care.

### *Healthy and Strong in Pregnancy*

*"During pregnancy, I was not weak, I was very strong during the pregnancy and during delivery, God took control I delivered safely and the baby is alive and negative" (Esther).*

*"When I was pregnant, I was taking local medicine, I was strong, my baby was strong until I delivered" (Margret).*

*"But the second one when my CD4 count went to 500, I was not sick at all, not even headache. Since I started my ARV for good 3years, I have never had any headache, up till now" (Vero).*

*"Because my CD4 was high, I was not sick throughout the pregnancy" (Sami).*

### *Sick in Pregnancy*

> *Though the first one was tug of war, at first, the CD4 count was 300, which I don't advise any women of with a CD4 of 300 to have pregnancy, I was sick from the day one, I know I was pregnant, sick, vomiting, I can't eat, so sad. I was collecting injections; even I had two injection abscesses (Vero).*
>
> *After about 4 months, I started vomiting and being sick. I went to see the doctor, initially we thought it was drug reaction to the ARV, when I did not get better, the doctor did pregnancy test and found out I was 3 months pregnant. I did not even notice that I missed my period. My CD4 count was still very low, I was mad. I went home and confronted my husband that I was pregnant and he was happy. I said, how can you be happy, how come I am pregnant; you used the condoms, how come? He was laughing; I suspect he had put a hole in the condom (Sami).*
>
> *I started the pregnancy very easy and simple, but towards the time that I want to deliver, I experience different kind of sickness, tiredness, at times blood will be coming out of my nose and always I look tired. Even before then, I was having bleeding at least for good 2 weeks and I went for the test they told me I'm infected. I was treated, they gave me some drugs and I take the drugs, and it*

> *stops. I was still having pains, until they admitted me in hospital for good one month (Uduak).*

*"But in this belle (pregnancy) I always had fever, fever, fever. I come do the test and they say I am positive…during that time I was very sick" (Christy).*

*"Hun-un it was too hard. The pregnancy was too hard. I felt bad about myself, I was not at peace, I was vomiting, I could not eat or drink well, I could not hear anything" (Jemila).*

*"When I get pregnant, if I do any little work, I will start to bleed, If I do hard work I will bleed, but is not too much, small. Then after sometime it will stop. Then I started having waist pain, back pain, pain on my side" (Asabe).*

*"During the pregnancy, I was very sick, I almost died" (Ogechi).*

### *Baby Delivered Through Caesarean Section (CS)*

*"During that time I was very sick, I born the baby with CS" (Christy).*

*"I buy my normal CS things and they did CS on me" (Eli).*

*"We decided to do CS this time, we did not allow the pregnancy to reach 9month, at exactly 81/2months, and we did CS" (Kate).*

*When I get pregnant with these my two children that are negative, I have them through CS. Before the ninth month they admitted me and operated on me. (CS)" (Nneka).*

*"And the second one I do it through C.S he is negative and this third one now, the third one am pregnant with, I decide to do C.S again so that, he or she will be negative" (Ogechi).*

*"I born them with CS. The ones that die I born them normal. If CS will save my children I will do it" (Ogechi).*

*"So I thought it is better for me do the CS than for the baby to have the sickness, to avoid the infection to the baby I will do the surgery" (Uduak).*

*Fear of CS*
*"When my time reach, I went to another clinic where they do not know that I have HIV because that time we don't like CS" (Glad).*

*"So how I wish I have another one but I don't think I will have again because the CS now is too tight, me ma am scared of another CS" (Nneka).*

*"I was afraid when they told me to go for surgery (CS), instead of going for normal delivery. I was so sick thinking, crying every blessed day, my husband sympathized with me, giving me examples, even some doctors came to tell me they have passed through CS time without numbered, some say even more than 2 times, my neighbors there also say the same thing, that is when I say ok however, be the case, if God has stayed with me, I would rather go and come back successful, so when the day reach the doctor told me that I should prepare to be there for the operation and I went there, I was operated and I came back safely" (Uduak).*

### *Good Care*

*"They (health workers) take good care of me when I born my first baby" (Christy).*

*"I buy my normal CS things and they did CS on me, because of my problem, they (health workers) receive me very fine and they took care of me" (Eli).*

*"In the hospital they use to pet us like babies so that we wouldn't be thinking…They (health workers) will be telling us what to do, how to do, don't do that, so they don't use to be harsh to us. Immediately they see you are positive, they start taking care of us, they don't shout on us" (Martha).*

*"I had very good experience. When they were operating (CS) me, they (health workers) bring out my baby, they gave him ARV drugs and they gave me the ones I will give him for 6weeks" (Nneka).*

*But now it is better, they (health workers) don't do it (stigmatize) again, when I delivered the second one they even embrace you, hold you, because they have got the awareness, they know they cannot be infected, so now, even though you are pregnant you go there (hospital) you will be happy, they will help you, baby you, everything is fine now (Vero).*

### *Bad Care*

*The challenges I faced 'then' were great, once they (health workers) see your file and they know you are HIV positive, people in the hospital will wear double gloves, they will tie their mouth and everything, what you will be seeing is their eyes, because they don't want to relate with you, because you are HIV positive. They thought that when they touch you, they are going to be affected, they hardly can talk to you like this (gesturing to our face to face talk), they will stand afar and be talking to you, even if they want to give your injection, they will wear many gloves before and then coming to labor, oh, it is another thing, you are on your own. We face a lot of pain living with HIV in those early days. For the doctor, nurse, what have you and especially ward attendants, some of them will just see you and they will shake their head and some of them would say eh! This one would soon die (Agnes).*

*You know that time they are not taking care of people like now, because now if you are HIV positive, the government will take care of you both in your delivery* *and everything but as of them, we are buying drugs very costly from this Abalaka, from general hospital, in fact that time to be sincere I went through hell. That time the nurses will not want to approach you, if to say you are the one that caused your HIV, may be due to your useless behavior. I will cry and cry the nurses no come; it is only God that saved me. But things have changed now. They take care of women with HIV now (Lizzy).*

*By then it was not easy, when they know that a women is HIV/AIDS case, the way the nurses will speak to me oh!, it was not good at all, at time they see you, they talk to you anyhow, they will tell you am I the one that give you HIV/AIDS. When the labor is too much you call them (nurses), they will not even speak to you; some will even look at you and dump you like that (Vero).*

*The doctor told me not to worry, to eat good food and take my ARV, that when the time reaches, she will use CS and bring out the baby to reduce the risk of transmission. I started labor late on Friday; I went to the hospital, all the nurses and doctors they were running from me. I was begging them to call my doctor; she is the only one that agrees to take care of people with AIDS. They did not call her on time; by she came on Saturday afternoon I have delivered the baby. They started the baby on ARV syrup. The doctor said I should not breastfeed her, so I gave her only Nan. The baby died after 8 months, she was HIV positive (Sami).*

*"The nurses that knew my problem, when I was in the labor room they are afraid to come near me when I call them… I said you are running from me because of something, she said 'madam don't you know that you are positive?" (Glad).*

*"Most times if we go to hospital, the doctors don't treat us well, they discriminate against us, and they don't attend to us well. Even when we are sick they will say wait till appointment day, anything can happen when we are waiting. So we want Government to help in that area" (Jemila).*

> *You know when you are in the hospital, there is power issue, especially doctors in the hospital they will first mess you up, but for me I don't take it as anything, if you feel like because I have HIV you are making jest of me , you go on and do your own test, know what is in your body first, so I battled with them, I took all those things I have encountered in the hospital to God. (Eli).*

### *No Care: Home Delivery and Risky Care Due to Fear of Stigma*

> *"I was too afraid to go for antenatal. I did not want to deal with the health workers. I was afraid they will stigmatize me. My brother (A Pharmacist) started giving me ARV and he confided in his girlfriend who was a midwife, she was the one that took care of me. We decided to do a home delivery, when I started labor she gave me Nivaripine, once the baby came out she placed her on ARV too. Thank God nothing went wrong (Kate).*

> *We decided to do CS this time (second pregnancy). Even then, I had to go to another state to do it, because I did not want to deal with any doctor that I could possibly run into here in Abuja. I always believe that they will tell their wives or a common friend that knows me... I work in a bank, if they find out that I am HIV positive, I will lose my job. We have retainer-ship with many hospitals, I could have had free delivery, but I hate to go to the hospital because I am afraid the doctor will find out about my HIV and write it in my file and inform my office. If they find out they will terminate my job (Kate).*

*"I deliver my babies in our house because I was afraid of going to the hospital" (Margret).*

## Infant Feeding and Care Decisions and Experiences

Infant feeding practices have played an important role in child survival. The women reported that their culture values breastfeeding. Every woman is expected to breastfeed her child. A popular saying was "every animal feeds its own". There were some beliefs that if a child is fed cow milk, he/she will act like an animal. For this reason, in their cultures, families used measures such as herbs to stimulate the flow of breast milk or a wet nurse when the child's mother died.  Yet all the women were aware of the risk of infection through breastfeeding and made choices which varied from giving formula, breastfeeding or a combination of both. They also had to balance the cultural expectations and pressures to breastfeed against their need to prevent infecting their babies, as such they had unique responses to explain why they were not breastfeeding.

### *Cultural Beliefs about Breast Feeding*

#### *Every Mother is Expected to Breastfeed*

*"My people believe that if you have baby, you must breastfeed your baby that it is what makes you a mother. They don't believe in giving cow milk, they say the child will behave like cow" (Lizzy).*

*"They value breastfeeding too much; they will tell you every animal feeds its young" (Kate).*

*"They said that a child you didn't breastfeed will behave like animal, because when you are giving them the milk that you are giving them. The formula is collected from animal breast" (Nneka).*

*"My culture value breastfeeding, every mother is expected to breastfeed her child. It is very important. If you do not breastfeed your baby they will be asking you too many questions" (Martha).*

*"My people say if you give pikin (child) breast, he will grow very well, be intelligent and he no go sick. My mama told me that a baby can get sickness from his mother if he sucks the breast. I remembered that and used it to cover up not breastfeeding my baby" (Asabe).*

*"They value breast feeding very well in my place, if you decides not to breastfeed, they will keep on talking against you, that you are giving birth, you don't like to breastfeed, that's what they will be saying"(Esther).*

> *Well they must ask why, why that is this person is not breast feeding the baby because they know that it is useful to breastfeed their child. Like in my village now if you give birth, they expect you to breastfeeding the child which is normal anywhere and without that, it will look suspicious, that may be there's something behind that, there's something (Lizzy).*

*Herbs to Stimulate Breast Milk*

*"You go just see the breast like person never born, just hard no water, if they start to give that leave medicine the breast water will start coming out so the woman can feed the baby"(Martha).*

*"They will say if the child refuse take breast you can force it, or they will boil herb and give the child and he will begin to suck the breast" (Grace).*

*"They will find every means possible to make the breast milk come out. They will use hot water, herbs and message to bring it out" (Kate).*

*"Normally there are some people when they put to bed, their breast will have no water to give to baby, in the olden days they cook all these leaves to bring breast milk out because*

*there is no baby food to give them but now thank God for man and all these kind of baby food is available to give them" (Eli).*

*Wet Nurse*

*"But if some times, in some cases if a woman give birth to a child and the woman happen to die, the woman's mother would be asked to take money to the grave and buy the breast milk from the dead, after that the grandmother's breast will start bringing milk"(Asabe)*

*"Well where they do it, is may be like me now I'm married, I born a new baby and die may be my mother take my baby and be breastfeeding the baby but since there is HIV now, except my mother go for test and tested negative before she can breastfeed my baby"(Eli).*

*"Sometime, if the baby mama die, take now if I die and have little baby, my Oga sister (sister-in-law) can breastfeed my child" (Grace).*

*"Even when a mother dies, they will get another woman relative who is nursing to breastfeed the child. This is mainly in the village, but in the cities, people easily give formula" (Kate).*

> *If the mother die, if there is another woman may be the husband's brother wife, sister or relation that gave birth around the same time, that woman will*

> *breastfeed the baby. There is one that happens recently, the woman delivered and died, though her husband sister married elsewhere but delivered same period, she is the one breastfeeding the baby so it is just as if the woman delivered twins. If there is no any woman in that relation that delivers of that same period, the child will be taken to motherless baby home (Lizzy).*

### *Thoughts on Cultural Beliefs about Breastfeeding*

*Wet Nurse Presents Risk of HIV*

*"Like the breastfeeding one, when a woman give a birth and the mother dead, yes for that child to be alive because may be the parent of that people they don't have enough money to feed that child with milk (formula)"(Agnes).*

*"If the person has disease like HIV, she could infect the child, unless they test the person" (Martha).*

*Pressure to Breastfeed Could Lead to Infecting Baby*

*"Breast feeding is good, but sometimes women are so worried about what people will say that they risk breastfeeding their babies and they end up having HIV"(Sami).*

> *They said that a child you didn't breastfeed will behave like animal, because when you are giving them the milk that you are giving them. The formula is*

> *collected from animal breast, whatever. But I doubt it , I really doubt it because, I will give example with my second child that I didn't breastfeed, he didn't even see my breast talk of tasting it. He is smarter more than the one I breastfeed a year and six months. The saying that if you breastfeed your child they will behave like human being and if give your child cow milk they will behave like animal, it is a lie. I don't believe it (Nneka).*

## *Feeding Choices*

Most of the women bottle-fed their babies with infant formula (NAN) given for free at the PMCTC centers where most of them had their babies. A few of the women breastfed exclusively, while some breastfed for a couple of months and then switched to bottle feeding. They weaned their babies with pap (fermented corn) and mashed potatoes. The women who chose to bottle feed their babies had challenges including but not limited to: pressure (stigma) from family and friends for not breastfeeding, painful breasts from engorgement, juggling and cleaning feeding utensils, cost of formula, conflict with baby friendly programs that promote exclusive breastfeeding.

### *Breastfeeding*

*"Breastfeeding is very good and for somebody who is positive as I did my own, I breastfeed my baby for 6 month" (Agnes).*

*"That time, they said I should do exclusive feeding. I gave my baby only breast, for six months" (Lizzy).*

*“The one that lived for a little, I breast fed him for three months (Vero).*

### *Bottle-feeding*

*The nurse ask me which decision that I am going to take, are my going to give the baby breast or NAN (infant formula), my husband told us he will only try his best to buy NAN, so I will not give my baby breast since that time. I no give the first one breast and this one again I no give them breast” (Christy).*

*“After giving birth to the baby we shouldn’t breast feed the baby, the baby was fed artificial milk, baby food” (Esther).*

*“So immediately I born they carried the child away from my place, they give her, her own bed, I don’t breastfeed her. So when I go home I did not breastfeed her. I gave her formula” (Grace).*

### *Combination Feeding*

*“ I gave her breast milk for three months and then stopped and started to give her milk (infant formula)” (Asabe).*

*“The doctor gave me advice after delivery through CS; he said no breast milk for baby. I gave my baby NAN (infant formula) for one year and two months” (Jemila).*

*"I gave both of them infant formula. I was asked not to breast feed" (Kate).*

*"I went to the antenatal clinic and my doctor counsel me. He said first and foremost, I will not breastfeed the baby…So I gave the baby formula" (Uduak).*

*Weaning*

*"After six months I started giving light food, sometimes, I boil potatoes and make it very soft and the water" (Agnes).*

*"I gave my baby only breast, for six months, after that I started giving him pap" (Lizzy).*

*"I used infant formula…When they reach six to seven months I started Akamu (pap). When they reach a year, they start eating by themselves" (Ogechi).*

*"After three months…I started giving him pap and NAN (infant formula)" (Vero).*

## *Challenges of Infant Feeding*

### *Expensive Baby Formula*

*"They gave us some formula in the hospital, but it was not enough, and my husband had to look for money to buy more" (Uduak).*

*"The problem is the baby food from the hospital is not enough. They used to give four tins each month from day one to four months, then they change it to three each month for six months, when it reaches nine months they stopped. This is because people are many" (Eli).*

*"I want you people to help us with formula because it is too costly" (Ogechi).*

*Carrying and Caring for Feeding Utensils*

*"You have to be very careful when you are feeding the baby everything has to be very neat so that the baby would not have cough" (Agnes).*

*"I buy some feeding bottles, at list five, six, find one bullet (sterilizing tablet) and put all of them inside bucket and pour hot water, with salt. The first one I used feeding bottle, but this last one, I use cup and spoon" (Ogechi).*

*"They gave me a bucket and always gave us water guard (sterilizing tablet), when I put my water, I put the water guard for 30 min, before we start drinking it, the bucket have tap and when you just open the tap it will just fill it for you, I have no problem with water" (Vero).*

> *The only way they can contact infection is if I am not keeping the feeder very clean, they can start purging. So what I normally do is that I will boil the feeder. I will normally boil it two times in a day and I soak everything in one bucket, so*

> *even if I feed them, even if I give them only water I will still soak it in warm water that I normally put a little salt because of germs, it is work but I do it to protect them (Nneka).*

> *I gave my baby NAN (infant formula) for one year and two months, I don't sleep well, I carry flask, carry NAN, carry big bag because of my baby food. Any minutes or second I would think the baby is hungry. I would worry that she is not getting enough food. I will complain that she is small. In the night after three minutes my baby will wake up and I will go and wash cup, wash spoon to feed her, because hospital say don't give feeding bottle, give her for inside cup, you can boil hot water put for inside bucket and put Milton to sterilize it. Sometime my husband helps me with feeding my baby (Jemila)*

### *Conflict with Baby Friendly (Exclusive Breastfeeding) Policy*

*"When we go to baby friendly workshop they lecture us give baby only breast milk for six months. But the baby may look healthy, but later the baby will fall sick because it sucked the HIV out of me. I don't encourage myself breast feeding baby" (Glad).*

> *So when I was feeding the baby, one nurse came and was trying to throw away the bottle, I told her not to throw away the feeding bottle because she don't know my problem I know my problem so let them leave me alone. They said it is baby friendly hospital that I have to leave the clinic if I must give bottle. So I left (Glad).*

### *Painful Engorged Breast/ Early Weaning from Breast*

*"Initially my breast was swollen and painful, and I had to tie my breast, but after about two weeks it relived me" (Sami)*

*"When I stop to give her breast, she will cry and cry, I will pity her and start crying too" (Asabe).*

### *The Pain of Deadly Milk - Breast that Cannot Feed*

Apart from the physical pain of engorged breasts and the stress of dealing with pressures to breastfeed, the women shared the emotional pain of knowing that their breasts had led to the death of their infant or had the potential to infect and caused the death of their infant. In a culture where breastfeeding was seen as an integral part of the reproductive process, their decision not to breastfeed was painful and made them feel inadequate.

### *Breast Milk Led to HIV Infection*

*"I gave my babies breast milk, but I think it is the breast milk that made the last one to die…He get the HIV, it pains me a lot" (Margret).*

*"I am not feeling fine, I am not happy for not breastfeeding them, but I did it for the sake of their life" (Nneka).*

> *My first one, I breastfed him for 1yr and 6months and expose him to the virus, he is now HIV positive, he also has TB. He is taking the drug…he is not feeling well. Wherever I am going, am going with him, nobody will take care of him more than me, because am wearing the same shoe with him. We normally take our drug seven in the morning and seven in the evening. So if I want to go out now, and I know I will stay more than seven, I will carry him and we must go with our drugs so that immediately it is seven o clock, I will give him and I will take myself. But if all my other children are positive that means is not an easy work. That is the reason why I did not breastfeed the other two (Nneka).*

*Breast that cannot Feed*

*"I feel pity for the baby. I have breast she cannot suck" (Asabe).*

*"I feel bad that I can't give my baby breast, but it is the baby's life that is more important" (Eli).*

*"It feels bad for a woman not to breastfeed my child, God gives you breast to feed your child, then he allows the same breast to kill them" (Nneka).*

> *It was not easy not to breastfed your child, you have this feeling of not fulfilling your role as a mother. After all, the breast is there to make milk that will feed your baby, yet you cannot feed her. Your breast milk could end up killing your*

> *baby. But when you have lost seven children to HIV, you will do whatever they ask you to do to save your child (Sami).*

*Baby will not Recognize me*

*"I am always afraid that they will not recognize me as their mother since they did not feed on my breast milk" (Kate).*

### *Stigma/Pressure to Breastfeed and Responses to these Pressures*

A direct consequence of the cultural beliefs discussed above is that the women were pressured to breastfeed and harassed if they were not breastfeeding. They had to deal with their mothers and mother-in laws, their friends and neighbors and sometimes the community at large. The women were not without their own devices. They crafted creative ways to respond to these queries and pressures with truths, half truths and outright lies to save their babies and not reveal their HIV status. Only a few of them who were living publicly with HIV were able to tell the truth. The most common line is that it was the doctor's orders to drugs, followed by claiming that the baby refused breast milk. Another common excuse was that the drug they were taking was in the breast milk.

*Pressures to Breast Feed*

> *My mother-in-law, she said, 'My wife why are you not feeding bon-boy again?' I said, 'Mommy I don't want him to bite my nipple. I don't want my breast to go down I want it to be there for my husband.' We joke like that and she said nothing. She went to the son and asked the son saying 'Why your wife is treating*

> *this one like this. Your wife was not like this before', the son say 'that is how she want it and it is what she wants that she would do, the baby is ok what is your problem' and she close her month… My mama will ask me every time why I do not give the baby breast (Agnes)*

> *They disturb me a lot. Always asking why I no give my baby breast I go say nothing. When I go village, my mother in-law and the village people they ask why you no give your baby breast, I tell them, doctor say I should not give my breast, my breast is not good, they say make I come to my village come wash my breast with medicine, this, that (laughs). I say no. After sometime, my Oga (husband) gave me money to go back to Abuja because of this stupid question. Since I born (delivered) this one I never carry am go village. I go wait until when she grow and start to the waka (walk), before I go. Because if I go now they go ask me why again, because my village they always say why is it that I am giving breast (Christy).*

> *When I went home it was hell because some women will purposely come and even pinch the baby for the baby to cry so they will see whether you will breast feed the baby. If you don't they will be asking you say madam come carry your baby and breastfeed. When you tell them that you cannot, they want to find out why (Glad).*

*" My neighbors, they will come say why can't you give the child breast…I travel home my husband mother ask me why the baby is not taking breast" (Grace).*

*"Many of them will always ask why you are not giving the baby breast. But me, am the one that is carrying the cross, I know where it pinches me. So my neighbors they are asking me why are you not breastfeeding the baby, this this that, I will give them my own reason" (Nneka).*

*"My friends kept asking me why I didn't breastfeed my baby" (Eli).*

*"They quarreled with me and asking me why I am not breastfeeding? I say my breast is not good, they say why? And all kinds of question I got" (Ogechi).*

*"Yes, I didn't breastfeed him sha because there's a nurse that is assisting that time. That time the stigma was too much so they want to know why I didn't breast feed my baby" (Glad).*

### *Responses to Pressure to Breastfeed*

#### *Not to Infect Baby with HIV*

*"I told them this is my problem. I told them why I don't want to breastfeed my baby is because I don't want my baby to be infected" (Eli).*

*"It is not like I don't like breastfeeding, I like it, it is because I am HIV positive, so that it will not affect my baby" (Ogechi).*

*"When you try to feed that baby for more than six months and if the baby happens to bite your breast you know that baby automatically will be infected" (Agnes).*

*Doctor's Orders not to Breastfeed*

*"I tell them, doctor say I should not give my breast, my breast is not good" (Christy).*

*"When they asked me why I still give baby formula, I told them it is what my doctor told me to do" (Uduak).*

*"Doctor advised me not to give breast milk to the baby" (Kate).*

*"I would tell that I was told not to breastfeed in the hospital, because my breast has problem" (Margret).*

> *I told her (mother-in-law) the doctor say I should not breast feed her (baby) so she does not become sick. And to stop her from getting sick they give me this medicine (HIV prophylactic drug) to give her every day. I told her if this one no get better, that I will be asked to feed NAN to all my children in the future. She don leave me alone since then (Asabe).*

> *So my neighbors, they will ask me, I will tell them I have hepatitis B, the doctor now told me not to breastfeed, that it is not good for me to breastfeed the baby while I have hepatitis B or I give all sorts of reasons. Is not what I tell this person that l tell the other one. Because am ready from the first month to the ninth month, I have made up my mind that I will not breastfeed. So I was cramming what I will be telling them (Nneka).*

### *Baby Refuse Breast Milk*

> *When I went to the village, my in-laws ask 'why I no breastfeed', I told them the baby refuse the breast after one and half month. Even when I went to my own place that is how they continue asking me, my senior sister even ask me I say the baby refuse to take breast that is how they leave me alone (Glad).*

> *I say no, from the beginning my child they will not take breast, the first one did not take breast, the second one the same thing and this one now is not taking breast too. So my children I no give them breast, only God take care of them…"I say maybe it is from your family, because my husband no gree take the mama breast. I say him children are copying him. So na the way we take handle the breast issue (Grace)*

*"I tell them the baby does not like the breast milk" (Sami).*

*"I say the baby doesn't want breast, he want to take NAN" (Vero).*

*Drug in Breast Milk*

*"I tell her the drugs I was taking entered the breast milk" (Kate).*

*"I told her I had hepatitis that is why I was taking the drug" (Kate).*

*"I tell her that I the boil I had in my breast in my first baby affected the breast this time" (Asabe).*

> *I said to her, the drugs they give me, where they cut me, the doctor said it will spoil the milk. So if I breastfeed the baby now, it is like I will choose if I want to kill the baby or I want the baby to be alive. So you know she is an old woman, she will just believe me that way, because she know quiet alright, that I born through CS. She asked why? I said the baby did not lie well, so when they now give me the injection to help the baby come out, the injection now spoil the breast milk (Nneka).*

*Other Disease in Breast*

> *I said I started going hospital and them do test for my breast and they said my breast is not good that it why my five babies died. But here and there they continuously asking me, that first one and this second one, this time I still tell them that my breast has spoiled…Since then nobody disturbed me (Ogechi).*

> *I tell my neighbors I have hepatitis B, the doctor now told me not to breastfeed, that it is not good for me to breastfeed the baby while I have hepatitis B. I give all sorts of reasons. Is not what I tell this person that l tell the other one. Because am ready from the first month to the ninth month, I have made up my mind that I will not breastfeed. I was cramming what I will be telling them (Nneka).*

*Fed Baby in Secret*

*"I felt very bad, I insist on feeding them myself in the privacy of my room. I will hold them close to my breast as I feed them, I will cry, and recite the rosary as I feed them for God to keep them free from HIV" (Kate).*

*"Sometimes when I am tired of answering query I will make sure I feed the baby in the house before we go out, when the baby cry in public I will give him water"(Sami).*

*"It got to a stage where even if I want to give infant feeding I will give it secretly, if the baby cry and they say give him breast, I will just collect the baby go inside room and use infant formula, just for them not to know, but when my mother know about my status she try as much as possible to cover me…when the baby is crying they say come give breast, my mother will quickly come and carry my baby" (Sami).*

*" I am staying in the barrack, and sometimes I refuse to come outside to feed the baby because the stigma is too much there, so I still confuse them sha, the baby is alive I thank God"(Glad).*

## Plans for Care of Orphaned Children

Part of child care includes planning for their future in the event you are not there. Most of the women had no plans for the future care of their children. While poverty was cited as a reason for not having any plans, most of women believed they would live long enough to raise their children. They believe God would help them live long and take care of their children. Among the few that had plans or intended to make plans, their main plan was educating their children, followed by opening bank account and bequeathing house or farmland. Only two of the women mentioned their relatives as a fall back support. One woman actually believed that her husband's relatives would exploit the children in the event of the parent's death.

### *No Plans, We will Live Long or God Will Take Care of Them*

*"God no go let anything happen. We no get plan for them, but God will take care of them" (Asabe).*

*"I will not die until they grow, God will not agree" (Jemila).*

*We will take care of ourselves and live long. We have no plans yet, not at all" (Sami).*

*"By God's grace we will be alive to raise our children" (Eli).*

*"Me I don't take HIV to be anything again, I don't take it as sickness that will kill me. People that do not have HIV die too and leave their children. The God that took care of their children will take care of mine too" (Lizzy).*

*"We don't have any plan for them now because they are in school. The first one will finish secondary school, the Second one is in SS one now, the third one I can say the third one na small boy is in nursery school" (Grace).*

### *Poverty*

*"I don't have enough money. I need funds. What will we eat? I don't think we will cope….the ones I had before, their father died, their school, sometimes you might get to the house and there is nothing in the house that children could eat" (Agnes).*

*"I delivered in the morning we stayed there since that morning waiting for one of my husband's brother to come and bring us money, even kobo to buy food we did not have… a nurse gave us ₦50 which I used to buy sachet Bornvita"(Martha).*

*"That is the problem; we are barely managing to eat. We have not finished taking care of this one and he wants more children" (Sami).*

*"Had it been I've something doing; I will be planning for them" (Lizzy).*

### *Education*

*"My plan is to train them in school as far as possible. To the extent that if anything happens to me or my husband, since they are educated, they can take care of themselves" (Eli).*

*"My husband is sending them to school, he like education, they will be fine" (Jemila).*

*"My plan is to give them quality education, because when they are learned they will be able to help themselves, but for now I have nothing on ground yet, but I believe that maybe before I leave from the surface of this earth I will be able to make provision for them" (Agnes).*

*"We put them in school so that if we leave, they will take care of everything" (Margret).*

### *Build House Bequeath Farm Land, Open Bank Account*

*"My plan, my husband and I have discussed about setting up something, because no one knows tomorrow, we don't know when death will come, it's our prayer to live longer because no one pray to die, so we have decided to build a house for them, open an account for them and all that" (Martha).*

*"Well we are still planning what we will do for them, me and my husband we are still planning. We plan that they will take over their fathers' farm land in the village" (Margret).*

*"I wouldn't mind opening account for them with their name if I've resources where income is coming in case of anything in future happens" (Lizzy).*

### *Supportive Relative*

*"Well maybe, not even maybe if am not there, my sisters are there for them, my brothers are there for them. Whenever their family people call, they first ask for my children, how are they doing, they call from time to time to know how am doing with my children" (Agnes).*

*"I know my sister and my brother will help them" (Asabe).*

### *Exploitative Relatives*

*"The only thing they (relatives) want is where the money your father kept? They don't care. God forbid if anything happen, they fit drive us out the house him papa build" (Christy).*

In chapter five, I will summarize and synthesize the main result of the study and link them to literature, discuss the implication to policy and practice and make recommendations towards meeting the sexual and reproductive health of women living with HIV/AIDS

# CHAPTER 5

# SUMMARY CONCLUSION DISCUSSION AND RECOMMENDATION

## Summary

Women are disproportionately affected by HIV/AIDS. Over 60% of the 33 million people living with HIV/AIDS are women. The majority of them are in their sexual and reproductive years (UNAIDS, 2006). With increasing access to antiretroviral (ARV) drugs, most of them are living longer and healthier lives and are able to engage in sexual and reproductive activities (WHO, 2006). Sexual and reproductive activities come with inherent risks like STIs and unintended pregnancies. The biologic, cultural and structural challenges that make women more vulnerable than men to HIV in the first place, do not go away after women become infected. Being HIV positive often intensifies these challenges and impacts the sexual and reproductive decisions WLWHA make and how they experience them.

This study explored the sexual and reproductive decisions and experiences of WLWHA in Abuja, Nigeria. Only those who became pregnant and had a child after being diagnosed with HIV participated in the study. The study employed an interview based qualitative design. The PEN -3 Model (Airhihenbuwa, 1995) informed the design of the interview guide. A combination of purposive and snowball sampling techniques was used to select 17 WLWHA. A pilot study, comprised of in-depth interviews with two WLWHA, was conducted at the office of Center for the Right to Health (CRH), to assess the appropriateness of the interview guide and process. Because no changes were made, their interviews were used as part of the data. Thereafter 15 more women were interviewed. The transcripts were prepared and analysis was done using NVIVO qualitative analysis software.

Result revealed that the participants were women between ages 26 and 41 years old, almost all married, from different parts of Nigeria. Only seven of them graduated from high school and most were of them were either housewives or in petty trades. They had lived with HIV between two and eighteen years. Four of the women had husbands who were HIV negative. The women have large families that included their extended one. While a few were living openly with HIV, most shared their HIV status selectively with family members who would be supportive. Fear of stigma and discrimination was the main reason for non disclosure.

Most of the women reported that being HIV positive reduced their sexual desire and activities. Physical weakness, worrying about HIV and fear of infecting a negative partner were the main reasons for reduced desires. Despite their lack of interest in sex, they said they had to meet their husbands' demand for sex out of religious and cultural sense of duty, as well as out of fear that their husbands would have sex with someone else, marry another wife and/or beat them. The women also experienced violence when negotiating condom use and whether or not to conceive. The participants used condoms mainly to prevent re-infection with other types or strains of HIV or to prevent infecting a negative partner. Most did not use condoms due to perceived pleasure reduction, belief that condoms are not for wives, ARV use precluded condom use and fear that condoms would be retained in the womb.

Although their culture did not support contraception, 40% of the women used contraception. Poverty, delaying pregnancy in order to raise the CD4 count and ensure positive obstetric outcome were some of their reasons for using contraception. Condoms, IUD, hormone injections, sterilization and periodic abstinence were the methods of choice for the few women that were using or plan to use contraception. The rest still wanted more children. The women reported that they chose to have children despite the risk of infecting them or dying and leaving them orphans. They gave these reasons. In their cultures, a woman's value and security in marriage depended on having children; they wanted to leave something behind; PMCTC services improved the odds of having HIV negative babies; ARV and good care would keep them alive; God would keep them alive.

To conceive, they had sex without condoms during their ovulation. Serodiscordant couples used syringes to inseminate. Most of them experienced miscarriages, premature births and infant death. Low CD4 count was associated with the increased odds of negative obstetric outcomes. Most of them delivered through Caesarean section, in order to have negative babies. The participants used "then" and "now" to describe to their experience. "Then" was in 1990s, when most health care workers abused, dehumanized, abandoned or refuse to care for WLWHA. 'Now' refer to recent years, when more health care workers were trained in safe and humane care of WLWHA. A few of them reported they continue to be stigmatized. Fear of stigma motivated two of the women to opt for home delivery and care and or to go to clinics where their status was not known.

Infant feeding choices were also influenced by cultural beliefs that highly valued breastfeeding. Although most of the women bottle fed, they reported being pressured by family and friends to breastfeed. The women gave reasons such as doctor's orders, baby refused milk or my breast milk was bad to avoid having to disclose their HIV status. Some of the women reported that not breastfeeding their babies, made them feel incomplete and fearful that their babies would not recognize them. Only few of the participants had back up plans for their children in case they are left orphans. Their plans included education, bank accounts and property. Only two of the participants mentioned their relatives would take care of their children if they were to die.

## Conclusion

The study revealed that:

1. Lack of formal education, entrenched poverty and gender inequities undermined the ability of these WLWHA to make reproductive decisions that could reduce their vulnerability of HIV/AIDS and STIs.
2. When married WLWHA disclose their status, they tend to be selective, disclosing to people they believe would be supportive, such as siblings.
3. Lack of agency and control over their bodies is reflected in their inability to refuse unwanted sex.
4. Depression, insecurity, fear of infection and violence limit these women's ability to enjoy their sexual rights.

5. Condoms were not used or were used inconsistently due to cultural belief that condoms are not for wives and that being on ARV precludes the need to use condoms.
6. Cultural pressure, women's natural desire to procreate, improved health due to ARV and access to PMCTC program inspire women living with HIV/AIDS to assert their right to procreate. However, lack of contraception, infertility, multiple miscarriages, preterm births and infant deaths were common and have the potential to worsen the high rate of maternal and infant mortality in Nigeria.
7. Infant formulas, though given freely in most PMTCT , are experienced to be culturally unacceptable. Therefore mothers with HIV had to find acceptable explanations to justify bottled feeding. Fear of stigma prevents them from sharing that they were bottle feeding to prevent infecting their infants with HIV.
8. Religious and cultural beliefs are key factors in sexual and reproductive decisions of married WLWHA

## Discussion and Recommendation

### *Demographics Characteristics of the Participants*

The 17 participants interviewed came from 10 of the 36 states of Nigeria, including the federal capital territory. This diversity of state of origin was expected considering that people from different parts of Nigeria live in Abuja. Five (30%) participants were from Benue state, which has the highest HIV prevalence in Nigeria (FMOH, 2006). This number could also be as a result of snowball sampling technique which increased the likelihood that participants would recommend someone from their state or ethnic group. Abuja has a variety of resources for PLWHA including, ARV centers, PMCTC programs, support groups and several not for profit and religious groups that provided care and support services. These kinds of support were not available in all states and barely exist in rural areas. It is, therefore, very important to replicate this study in resource poor states and rural in areas of the country.

Only 40% of the women completed secondary (high) school. Females in developing countries typically receive less education than do males (Ozaal 1997), which increases gender inequity. Lack of education reduces women’s occupational options and income earning capacity. Without education, women lack skills they need to access information, enter the labor force and rise above poverty. This perpetuates women’s vulnerability to HIV infection (WHO, 2006, UNAIDS, 2006). Only two of the participants had post secondary education or had professional jobs, the rest were either involved in petty trades/vocations. Most were unemployed housewives depending on their husbands for economic support. This dependence made it difficult for women to negotiate safe sex or leave in the face of violence or infidelity that threatened their health and lives (UNAIDS, 2004).

The women in the study were between ages 26 to 41, an age group that is typically sexually active and having children. According to UNAIDS (2007), 80% of the people living with HIV are within this age group. Women living with HIV/AIDS within this age group had sexual and reproductive health needs and concerns similar to most people of their age group in the general population. But they also had special needs and concerns by virtue of being infected with HIV/AIDS.  The need to understand their unique sexual and reproductive challenges and ways of meeting them cannot be overemphasized.

## Family Relations Disclosure and Serodiscordance

All women reported having large families. In their description of their families, they included their extended family fluidly as part of the family unit. This finding affirms literature assertions that Nigerians have large families (NPC, 2003) and that extended family is included as part of the family unit and plays important roles (Airhihenbuwa, 1995). Throughout the study, family, especially the extended ones, played a role in many facets of the women's sexual and reproductive decisions experiences. Often, people within the family to which a WLWHA discloses her HIV status and from which she gets support, seek advice from when conflict arises in their marriage. That the in-laws could push a woman out of her marriage if she did not bear a child added to the pressure women felt to procreate or not use contraceptives. The women had to justify their infant feeding decisions to their families. Families were a resource for money, emotional support and information among others. It is therefore very important for program planners to understand and take into consideration the importance of family including the extended ones in the health related beliefs and decisions of WLWHA. This inter-relationship and influences which are grounded in the culture of the people is the heart of PEN-3 model (Airhihenbuwa, 1995).

Women had been diagnosed with HIV for a period between 2-18 years is evidence that access to ARV and care and support services had led to increased length and quality of life of most PLWHA (WHO, 2006). All participants reported that they had disclosed their HIV positive status to their husbands/partner. Only three had told everyone about their HIV status. About half shared their HIV status selectively with someone in their immediate and extended family. The rest had not told anyone other than their husbands because they were afraid of rejection, stigma and discrimination. Stigma and discrimination militated against HIV /AIDS prevention and care. It prevented the infected from taking advantage of the wonderful emotional, physical, and financial support that families can provide at this crucial time. If their families knew about their HIV positive status, they probably would be more understanding of the women's need to delay pregnancy or to bottle-feed. Even when a WLWHA can cope without the support of her family, the effort and subterfuge involved in keeping their HIV status from their family was emotionally and physical stressful and debilitating. Women living with HIV/AIDS would benefit from sharing their HIV status with their family. Other WLWHA who had family support after sharing their HIV positive status could be invaluable resource for women struggling to disclose. They also would benefit from skills building activities, such as coaching and disclosure role plays.

It is, however, important to know that disclosure could portend danger including death to the person living with HIV. The care provider must therefore listen to the client's circumstances, appreciate their fears and work with them to come up with client centered disclosure plan over time (WHO 2006, Shapiro & Ray, 2007). On the community level, education is needed to help families learn to live safely with their HIV positive loved ones. Families of people living with HIV/AIDS (especially husbands who are HIV negative) could be invaluable resource when they share how they transitioned from being disclosed to, to being a support for their loved ones living with HIV/AIDS.

Four women reported that their husbands were HIV negative. Another said her husband had refused to test. He and his wife assumed him to be HIV negative. When one partner is HIV positive and the other is negative, they are said to be serodiscordant. When both are positive they are known as seroconcordant (Shapiro and Ray, 2007). Serodiscordance is a common occurrence. A study by de Walque (2007) in five African countries revealed that about two-thirds of infected couples are serodiscordant. In 30-40% of them, the woman is the HIV positive partner. However, their self reported incidence of sex outside of marriage was disproportional. While 26% of the men admitted having extramarital affair, only 1-4% of the women did. The common belief is that it is unfaithful men who bring infection into the marriage. However, women also engage in extra-marital sex for pleasure and in exchange for money, advancement at work or other favors. Often, women were raped and or coerced into sex. (Koster, 2003), but were unwilling to admit it.

It is also possible that women may have been infected in non-sexual ways, including unintentional infection in hospitals. For example, Ganczak and Barss (2008) reported that 5.4% of all global transmission of HIV/AIDS is from contaminated injections alone and nosocomial HIV infection happens more in poor countries. More women than men visit hospitals and experience medical procedures, such blood transfusions, injections and invasive pelvic procedures. Women are, therefore, more likely than men to be infected with HIV in the hospitals. Irrespective of the source of infection, sero-discordance presents unique challenges to the sexual and reproductive lives of WLWHA that would be discussed in a later section.

### *Sexual Desires and Activities*

Of the 17 women interviewed, only three reported that being HIV positive did not affect their sexual desires and ability to give and receive sexual pleasures from their husbands. These women affirmed the fact that some WLWHA have sexual feelings and like other women, have a right to express them. However, with rights comes responsibility to self and others, including but not limited to practicing safe sex to prevent getting infected with other HIV types or strains and other STIs or infecting others. Healthcare providers could help WLWHA achieve healthy sexuality through counseling and education. Yet, in my interactions with other health workers and via anecdotes, many health workers do not think that PLWHA should have sex. This negative attitude discourages WLWHA from voicing their sexual concerns and getting the education and support they need to achieve pleasurable and safe sexuality (Paiva, Latorre, Gravato, et al 2002).

The majority of the participants reported that being HIV positive reduced their sexual desires and willingness to engage in sex. This finding is consistent with those from other studies (Devincenzi et al, 1992; Gray et al, 1998; ICW, 2006). Preoccupation with thoughts of HIV is likely to depress WLWHA. It is understandable that anxiety, fear of infecting a partner, fear of re-infection, guilt, anger, shame and stigma would contribute to their depression. Depression robbed WLWHA of their desire for sex and their vitality. A few of the women reported that weakness was one of the reasons they had no sexual desire and were unable to respond to their husbands advances. If not diagnosed early, HIV/AIDS weakens the immune system and increases the body’s vulnerability to other diseases which also saps it of vital energy, leaving little or none for sex. Some women living with HIV/AIDS may also have low self esteem. For example, one woman referred to herself as a "tainted woman." Women who perceived themselves as tainted were not likely to be excited about sex. Yet, these women have husbands with sexual needs, which when not met, could bring marital discords including infidelity and violence. This tension underscored the need for programs that would help WLWHA deal with mental health problems that prevent them from achieving optimal sexual and reproductive health. Yet, most HIV/AIDS programs in Nigeria had focused mainly on HIV prevention, antiretroviral drugs and treatment of opportunistic infections and rarely on their mental health and sexuality.

It was not surprising that most of the women in the study had no interest in sex. They associated sex with HIV. They said "when my husband touches me, I think of HIV/AIDS." It would take major mental health adjustment for most people to get comfortable with an act that had caused them harm. This adjustment is possible with counseling and support to help these women feel good about themselves again. Strategies to achieve positive mental health include mental health therapy, group discussions in a safe place like in support groups and learning from other WHLWHA who have successfully transitioned from the depressive phase to fully exercising pleasurable and safe sexuality. Health care providers and counselors would play a major role in this transition, but they would need continuing education on the sexual and reproductive and health of PLWHA, the challenges they face and strategies to meet their specific needs.. However, the culture of silence around sexuality would require that health workers get comfortable with their own sexuality, adjust their attitudes towards the sexuality of those living with HIV/AIDS and learn to discuss their own sexuality with ease and positivity.

## Wives Cannot Refuse Sex: Violence a Consequence for Refusing

Although participants had little or no strength or sexual desire for sex, they felt compelled to acquiesce to their husband’s sexual demands out of cultural, religious, and personal sense of duty. They were afraid that their husbands would engage in extra-marital sex, (with the added risk of re-infection and infection with other STIs) marry another wife and/or send them away. The quote below from one of the participants succinctly captured the women’s plight.

*I am a woman, I cannot say no when he want it because if I say no he can probably go outside again, which will bring another problem. I cannot refuse” (Vero, 31)*

Violence is a common experience for women living with HIV/AIDS. It is used to coerce the women into sex. Over one quarter of the women said they had been beaten by their husbands for refusing sex. Many more feared they would be beaten if they refused sex. So to avoid being beaten, they acquiesced to sex. Women in the study also experienced violence for insisting on condom use and or for not procreating on time. Women Living With HIV/AIDS are more likely to experience violence than women who are HIV negative mainly because they are blamed for bringing HIV into the family (Maman, 2002, van der Straten 1998, Dunkle, 2004).

The foundation of sexual rights is that all women should have agency over their bodies, and they should be able to, without violence or coercion, decide when and with whom to have sex (WHO, 2002). Unfortunately, this right has yet to be realized for most women, especially those living with HIV/AIDS in Nigeria where patriarchal culture gives husbands rights over their wives' bodies Women have been historically beaten and raped by their husbands and other men with little or no administrative or legal recourse for redress. To reduce this trend and help women have agency over their body and sexual health will require multiple strategies that target women, men, cultural gate keepers, judicial and law enforcement agencies.

However, health educators and other healthcare providers should be alert and observe for signs that a woman has experienced violence and help her through counseling and referral. Health professionals could offer couples counseling and education that promotes communication to address the underlying problems and help them achieve fulfilling safe sexual health. For example, in the absence of sexual desire, a woman will require patient and affectionate stimulation from her husband to arouse her desire. Lubricants can also help ease dryness and pain. Dry sex causes abrasion making it easier for HIV re-infection or infection with other STIs. The risk of infection with other STIs can be assumed since some women expressed concern that their husbands would have extra marital sex. In view of this fact and that most women are asymptomatic to most STIs, care providers should routinely screen WLWHA for STIs and treat those who are infected (WHO, 2006; Shapiro and Ray, 2007).

## Condom Chatter: Negotiating and Using Condoms

Being HIV positive increases the need to use condoms even when both partners are HIV positive because of the risk of re-infection with other strains or types of HIV or infection with other STIs. When used correctly and consistently, the male latex condom is 80-95% effective in preventing HIV/AIDS and most STIs. Yet, myths, misconception, poor access and misuse limit their benefits (WHO, 2004; Weller and Davis, 2004; Steiner and Cates, 2006).

I called the theme in this section “condom chatter” because the same issues that limit condom use among HIV negative people in the general population were the case among women living with HIV/AID in this study. A few participants said they used condoms, but some condom users used them inconsistently. Their reasons for using condoms included: to prevent re-infection with a different strain or type of HIV, other STIs, and to prevent pregnancy. Serodiscordant women used condoms to prevent infecting their HIV negative husbands. These were all important and valid reasons for using condoms and consistent with other studies (Steiner and Cates, 2006; Weller and Davis, 2004; Buchacz, van der Straten, Saul et al, 2001)

Among those who did not use condoms or used them inconsistently, their reasons for not using condoms included reduced pleasure. Deschamps, Pape and Hafner et al (1999) found that inconsistent condom use is as bad as non condom use. Sexual pleasure with condom use can be improved by teaching couples how to put a drop of water based lubricant into the tip of the condom to increase pleasurable feeling for males and on the outer part of the condom for ease of penetration and pleasure for females.

Myths and misconception about condoms hindered their use among the participants. One of the participants expressed fear that condoms could be retained in the womb and cause death. Condom slippage is often a result of misuse. This misconception again can be addressed by teaching couples to remove the condoms immediately after ejaculation when the penis is still erect. These misconceptions underscored the need to demonstrate correct use of condoms to increase users' skills and confidence.

Women also reported that they have difficulty convincing their husbands to use condoms. One said she was beaten for insisting on condom use. This finding is consistent with studies that have shown that violence against women is a common consequence of requesting condoms (Garcia-Moreno and Watt s, 2000; Iwuagwu, Olaseha and Ajuwon 2001). Not requesting or using condoms, increased women's vulnerability to HIV/AIDS, and other STIs. Negotiating condom use within marriage presents unique challenges because married couples are supposed to trust their partners' fidelity.  Sometimes, condom negotiations within marriage have fatal consequences. For example, in Benue State Nigeria, a HIV positive man insisted on having sex without condoms with his HIV negative wife. Instead of honoring his wife's plea to use condom, he beat her down with a cudgel and raped her without condoms. As they continued to fight, the wife hit him on the head with the cudgel and he died. She was charged with murder (Akpodovhon, 2009).

The women also reported that when they asked their husbands to use condoms, they were told condoms are not for wives, but for prostitutes. Some women also said that using condoms made them feel like prostitutes. This perception stemmed from early prevention efforts that singled out sex workers as HIV high risk group and encouraged patrons to use condoms, so that men use condoms mainly when they have sex with prostitutes. One would think that they were HIV positive should have helped them realize that HIV affects non-prostitutes. It is obvious that more work is needed to de-stigmatize condoms, and market their use as responsible and pleasurable.

The other common misconception associated with condom use was that being on ARV or having increased CD4 count precludes the need to use condoms. Some women stated that their doctors encouraged them (even discordant couples) not to use condoms since they were on ARV. This kind of misinformation is very dangerous and needs to be addressed with great urgency. It is important to educate doctors and other care providers to educate PLWHA that antiretroviral drugs do not cure HIV. Even though CD4 count is high and viral load is low, it is still possible to infect negative partners or re-infect each other with other subtypes or strains. This education is especially important as drug resistant HIV strains emerge. The emergence of drug resistant HIV strains underscores the need encourage correct and consistent condom use among both HIV discordant and concordant couples (Smith, Richman & Little 2005; Cheonis, 2007; Overbaugh, 2006).

Although a recent study by Quin, Wawer, Sewankabo, et al (2008) revealed that PLWHA who were on ARV and had achieved a certain level of undetectable viral load (>1500 copies per milliliter) did not infect their HIV negative partner even though they did not use condoms. There is need for more studies in this area. Even if this finding was to become an established trend, it would be of limited use for people in resource poor countries like Nigeria with limited access to viral load testing equipment. Also, viral load is not static. It could increase as a result of stress and other diseases, which will in return increase the risk of HIV transmission to a negative partner.

The difficulty women have negotiating and using the male condom has been the basis for research and advocacy for other female controlled technologies like the female condom and microbicides. Female condoms have been in existence for many years, but its access and use has been limited by cost. Even the female condom requires negotiation, underscoring the need to empower women with condom negotiation skills. There are also calls to use other methods which, though not as effective as condoms, have been shown to reduce the risk of infection of STIs and HIV. For example, the use of lubricants reduces abrasion, which in turn, reduces the ease of transmission of HIV and other STIs (Philipott, Knerr and Boydell, 2006).

## Reproductive Decisions and Experiences

### *Contraception*

Study participants reported that their culture did not encourage contraception. Rather it rewards women who have many children and punishes those who do not produce enough children. Most of the women said they wanted more children and did not use or plan to use any form of contraception. Contraceptive use among married women in Nigeria is about 13% (NPC2003), but some studies suggest that WLWHA use more contraceptives than uninfected women (McIntyre & James 1999). Poverty and lack of resources to raise many children motivates women to limit the size of their families. This reason is valid for contraception for all women and more so for WLWHA who incur additional expense associated with being HIV positive.  Most women who breastfeed do not ovulate nor menstruate (lactational amenorrhea). This natural contraception is not available to WLWHA who bottle feed their children. This is another reason to promote contraception among WLWHA.

Obtaining a positive obstetric outcome is a compelling need to promote contraception among WLWHA. When the CD4 count is low, women are least likely to conceive, more likely to be in poor health during pregnancy, have miscarriages, have preterm births or infant deaths (Cohan, 2003, McIntyre and James 1999). For this reasons, WLWHA were often asked by their doctors to delay pregnancy until the CD4 count was elevated. Yet, only one woman reported being specifically told to use condoms for contraception. In view of this pattern, it was therefore not surprising that some women became pregnant before their CD4 count was high enough to sustain successful pregnancy. Hence, there were multiple cases of miscarriage, preterm delivery, and infant death.

From these reports, one can infer that there were unmet needs for contraception. Integrating HIV treatment and care program with family planning program would ensure that the contraceptive needs of WLWHA are met. It is understandable that doctors may not have the time or the expertise to meet both the HIV care need and family planning needs of a woman living with HIV/AIDS, but they can refer to other professionals in order to meet their patients' contraceptive needs. Family planning care providers also would need training to ensure they meet the unique family planning needs of women living with HIV/AIDS without stigmatizing or discriminating against them.

Less than a fourth of the women used or planned to use contraception. Their methods of choice included condoms, intrauterine device, injectable hormones, tubal ligation, withdrawal and periodic abstinence during ovulation. These choices confirmed that WLWHA could use just about any of the contraceptives used by other women.

### *Why WLWHA Chose to Have Babies*

When asked why they chose to have babies after knowing their HIV/AIDS status despite the risk of transmitting HIV to their babies or dying and leaving them orphans, most said that children are central to a woman's value and security in marriage.  All the women said that not having a child was not an acceptable option. In-laws and husbands exerted great pressure that made these women chose to have children no matter the risks. Culturally, not having a child could be grounds for divorce or polygamy. A couple of the women reported that they were beaten for not procreating. These pressures could place additional strain on the health of the women, especially since being HIV positive increases the risk of infertility.  Before negative judgment is passed on these women who decided to have children, it is important to understand their decisions within the social cultural context in which they live. Therefore, policy makers, program designers and implementers should consider not just the individual, but take into account the family and community in which the individual exist and do everything possible to help WLWHA achieve their sexual and reproductive aspirations.

Unfortunately, many health care workers have negative attitude towards WLWHA who decide to have children. Health workers with negative attitude are least likely to give WLWHA the information and support they need to procreate successfully. Also, WLWHA were unlikely to discuss their procreation intention with a health worker they suspect had negative attitude toward them. For example, a study in Brazil and Zimbabwe revealed that women living with HIV/AIDS did not share their desire to have children with their health care provider out of fear that they would be or were sometimes actually reprimanded by health care workers (Paiva, Latorre, Gravato et al, 2002, Santos, Ventura,-Fillipe, and Paiva, 1998; Feldman, Manchester and Maposhere, 2002). The negative attitude some health workers have toward the right of WLWHA to procreate have often led them to recommend or coerce women to undergo sterilization (International coalition of women living with HIV/AIDS (ICW), 2009; Santos, Ventura,-Fillipe, Paiva, 1998).

Apart from external pressures from husbands and in laws, the women affirmed that they have a human right to procreate like other women who were not infected with HIV. Thankfully, with more education and empowerment, many PLWHA have found their voices and are asserting their rights to procreate. Apart from the need to assert their rights, the participants reported that they wanted to leave something behind. This finding is consistent with other studies (Cooper, Bracken, Myer et al, 2005, Chen, Philips, Kanouse et al, 2001).

However, despite their desire to procreate, the women were aware of the possibility of infecting their babies and this possibility bothered them. Their concern were somewhat ameliorated by their knowledge that if they follow the steps they were taught in the prevention of mother to child transmission (PMTCT) programs, they have 98% chance of having HIV negative babies. Their confidence in the program was heightened when they saw other HIV positive women who had negative children. Almost all the women took advantage of the PMTCT programs. From anecdotes and from my personal interactions, health workers and people who believe that WLWHA should not have babies did not know that with PMTCT program the risk of transmitting HIV from mother to child reduces to about 2%. If more people were aware of this fact, perhaps they would be more supportive of the women's decision to procreate.

However, despite the benefit of PMTCT programs, most pregnant WLWHA did not have access to this program. In Nigeria, PMTCT programs are concentrated mainly in urban areas where they provide services to WLWHA at no cost. There has been international advocacy to expand PMTCT program to cover all pregnant WLWHA. This expansion would require substantial human and material resources. There are concerns that these services cannot be sustained in the absence of donor support. Also, there are concerns about equitable distribution of health resources. If so many resources are dedicated to HIV/AIDS, would there be enough for other equally important health challenges, such as malaria, tuberculosis and childhood disease to mention but a few?

Another factor that influenced the women's decision to procreate was their confidence that they would live long enough to raise their children. This confidence was based on the availability of ARV and other care and support services, as well as their strong spiritual belief that God will keep them alive. Their confidence was further bolstered by seeing other PLWHA who have lived with HIV for over 20 years. Being HIV positive used to be a death sentence, but with the availability of ARV and good care, HIV has become a chronic disease. Therefore, both health workers and the public would need a paradigm shift in the way they see HIV/AIDS.  Pharmacological research needs to keep pace with the changing nature of HIV and continue to produce effective ARV and vaccines.

Irrespective of religion, spirituality play important role in the decision making process of people including those living with HIV/AIDS in Nigeria. The women believe that God determines who dies or lives. They noted that HIV negative women also die and leave their children orphans. They believe that the God who took care of those children will take of theirs. Spirituality is so important that UNAIDS recommends that it should be factored into HIV/AIDS program planning and implementation (UNAIDS and Penn State, 1999).

### *Obstetric Challenges*

Having established how important it was for women to have children, it was sad that most women had obstetric challenges ranging from infertility, miscarriage, preterm births and infant deaths. One woman had seven infant deaths. Another had four miscarriages. These ware common among WLWHA (Gray et al, 1998; Deveincenzi, 1997; Ross Morgan and Lubega, 1999; WHO, 2006) and underscore the need for integrating and scaling up reproductive health services for WLWHA to enhance their reproductive outcomes, which would in turn, reduce maternal and infant mortality in Nigeria (UNFPA, 2006, NPC, 2003).

Even becoming pregnant presented a risk of infection, especially among serodiscordant couples. To become pregnant while reducing the risks of re-infection, concordant women monitored their ovulation and had unprotected sex around their ovulation period. Serodiscordant couples also monitored their ovulation, but had sex with spermicide free condoms around their ovulation period. They withdrew the semen with a special syringe and injected the semen into the woman’s vagina. These were in accordance to the recommended strategies to help women achieve conception while minimizing the risk of infecting themselves or their partners (WHO, 2006). More health workers need to be aware of these strategies and share them with PLWHA to help them achieve procreation safely.

## Pregnancy and Delivery Experiences

About two thirds (70.2%) of the women found out their HIV positive status when they were tested as part of routine prenatal care. Testing pregnant women for HIV was an important opportunity to identify those who were HIV positive so they can be enrolled into ARV treatment and PMTCT programs. However, the challenge is to ensure that the prenatal HIV test sand all HIV tests for that matter were ethical. In Nigeria, when pregnant women report to prenatal clinics, HIV testing is among the routine and mandatory test that pregnant women were required to do.

In the 1990s and early 2000s, the stigma and fear associated with HIV was such that the women were not even told they were being tested for HIV. Instead of writing HIV test on the laboratory form, health workers would write codes, such as "*XYZ,*" "*sero-test.*" Only health workers know the meaning of these codes. This writing in code was a ruse to prevent the few literate women from knowing what kind of test they were being asked to do. There was little or no pretest counseling, an obvious violation of the women's privacy. When women test positive, sometimes they were not told their result. Rather they were asked to bring their husbands who were told the result - a breach of confidentiality often with severe consequences. Some women were subjected to domestic violence and/or abandoned. Some of the women in the current study said they had similar experiences.

Thankfully, with increased training, there have been some positive changes in practice especially in urban centers implementing PMTCT programs. Pregnant women are routinely tested after receiving pretest counseling. Those who test positive are enrolled into the ARV and the PMTCT programs. The same cannot be said to obtain in semi-urban and rural communities where PMTCT programs were non-existent. Even in urban centers, some women reported that they still had negative experiences underscoring the need for ongoing training of health workers and steep sanctions against those who stigmatize or violate the rights of WLWHA.

Another reason to intensify uptake of voluntary counseling and testing in the general population is the fact that most participants did not know when they were infected. Some of them said that, according to their doctors, they have had the virus for a long time. The longer HIV is untreated in the body, the more it would deplete the CD4 cells. Low CD4 count results in poor obstetric outcomes (McIntyre & James 1999; Brocklehurst & French, 1998; Abrams, Milner, Kwiek et al, 2004).

The participants used “then” and “now” to describe to their experience with health care providers during pregnancy and delivery, ‘Then’ was in the 1990s and early 2000s when most of the health care workers were untrained and are afraid of being infected. They treated WLWHA very poorly. ‘Now’ represents more recent times when more health care workers were trained and reflects their training through more compassionate care. While most of the women said they had good experiences, a few still had negative experiences, stating that they were ignored during labor, their obstetrician was not called on time, they were stigmatized and made jest of. Studies in Nigeria and other places have shown that the stigma and discrimination PLWHA experience within the health care system were pervasive and destructive (Obi, Waboso, Ozumba, 2005; Gruskin, Ferguson and O”Malley 2007; CRH, 2001; FMOH, 2005). Some women reported that fear of being stigmatized prevented them from seeking obstetric care. Some chose to deliver their baby at home or go to centers where their HIV positive status was not known. Under these circumstances, WLWHA were more likely to have negative obstetric outcomes. Also, there was the additional risk of infecting others in home settings who may not have knowledge, skills or materials for universal precautions.

### *Delivery Choices*

All the women who used prenatal services were counseled that delivering their babies through Caesarean Section (CS) reduces the risk of mother to child transmission (WHO, 2006). Most of them opted for CS. All the women who delivered through CS had HIV negative children. However, the women struggled with fears and concerns about the safety of CS, as well as with cultural beliefs that make women feel like failures if they did not have vaginal deliveries. The women's knowledge of the benefits of CS and desire to protect their babies helped them overcome their fears and concerns. Also, knowing other women with HIV/AIDS in their social network who have had CS with positive results also encouraged the women chose CS. Health care providers and counselors could use this information or bring WLWHA who have had successful CS with a negative baby to help convince a pregnant WLWHA to choose CS.

Most of the women did not pay out of pocket for their CS because it was funded by Nigerian Government and PEPFAR PMTCT program. Caesarian section is an expensive procedure that most women ordinarily cannot afford. This cost brings concern about the affordability and access to other WLWHA in areas not served by PMTCT programs. There are also concerns about the long term sustainability of these programs in the face of other competing health budget needs. Also, Caesarian sections have inherent risks of their own (Cohan, 2003; Read and Newell, 2005; Burdge, Money, Forbes et al, 2003). The need for Caesarian section can be reduced if women find out their HIV/AIDS status earlier and are placed on ARV to reduce their viral load such that they would not need CS during delivery (Ministry of health Brazil, 2004).

## Infant Feeding Decisions and Experiences

Infant feeding choices not only impact the nourishment and development of infants of WLWHA. They also influence the infants' risk of acquiring HIV from the mother. It is recommended that women living with HIV/AIDS not breastfeed at all. They should use breast milk alternative (infant formula) when it is acceptable, feasible, affordable, sustainable and safe. Otherwise, they should breastfeed exclusively during the first months of life and stop as soon as feasible (WHO/ UNICEF/ UNAIDS/ UNFPA, 2003).

Most of the women in the study fed their babies infant formula, but they encountered challenges around acceptability as well as affordability. Their cultures attached premium on breastfeeding, so much that they would use herbs to stimulate lactation or use a wet nurse in the event of a mothers' death. Some women, valuing their cultural heritage or as result of pressures to breastfeed from significant others such as mothers, mother –in-laws, or due to lack of knowledge, breastfed their infants either exclusively or in combination with infant formula. For some women, not breastfeeding their babies made them feel incomplete. According to them, breastfeeding completes the reproductive cycle. One expressed fear that her baby may not bond with her or recognize her. As a mother who had breastfed exclusively, I had experienced the deep emotional bonding and satisfaction a mother feels as she breastfeeds her child. Therefore, I could empathize with the women's emotions as they struggled to put into words the sense of loss they felt at not being able to breastfeed their children. Health care professionals need to understand the emotional and cultural challenges associated with breastfeeding and give WLWHA the compassionate support they need to deal with these concerns and help them feel empowered to make safe feeding decisions for their infants. Mental health counseling also could help the women deal with their sense of loss.

Those who bottle fed had to overcome many obstacles to keep their babies safe. Their challenges included handling feeding utensils and the inability to afford formulas because the free ones from the clinic were not enough for their babies. The most difficult challenge however, was dealing with relatives and friends who queried them endlessly on why they were not breastfeeding. Their responses to these queries included saying that it was the doctor's orders, that the babies refused their breast milk or that they were taking drugs that affected their breast milk. Sometimes, they fed their babies in secret. Only a couple of women who were living openly with HIV told the real reason they were not breastfeeding - not to infect their babies with HIV. HIV related stigma deterred WLWHA from making the best feeding decisions for their infants and sometimes increasing the babies' risk of being infected with HIV/AIDS.

These were common challenges that motivated the WHO/ UNICEF/ UNAIDS/ UNFPA, (2003) guidelines to take the context of the women into consideration when making infant feeding recommendations. Woman living with HIV/AIDS would benefit from knowing how other WLWHA dealt with infant feeding challenges.

## Plans for the Care of Orphaned Children

The possibility of dying and leaving their children orphan was one of the reasons people express reservation about PLWHA having babies. Most women believed that with ARV, good personal care and the grace of God, they would live long to raise their children. Very few had contingency plans in the event they died and left their children orphans. They mentioned education and opening an bank account in the children’s name, among others. Most of them said that it was hard to plan for tomorrow when due to poverty you are not even sure of food for today.

Poverty is endemic in Nigeria. HIV/AIDS related expenses reduce the amount of money left for other family needs. Programs that encourage skills training and income generation for WLWHA will enable the women take care of their families and invest in their children’s future. Education will indeed help the children of WLWHA and anyone for that matter climb out of poverty. So, women should be encouraged and supported to keep their children in school.

It was surprising that only one of the women said that if she died, her extended family would take care of their children. In Nigeria, extended families usually stepped in care for children of dead relatives. But, due to poverty and HIV related stigma, many extended families were not providing this vital support. Another woman said that the extended family would actually take from the children any asset the parents left behind. Because of some of these concerns, women living with HIV/AIDS would benefit from programs that help them plan their estates and the care of their children to ensure their children would be cared for in the event of their death.

## More Recommendations

I had made several recommendations as part of the discussion to address the many challenges associated with the sexual and reproductive lives of WLWHA. This section provides additional recommendation, while summarizing earlier ones under the categories of research, professional preparation and continuing education of health care providers, policy and programs that ensures cutting edge comprehensive integrated programs to meet the sexual and reproductive needs of WLWHA.

### *Research*

HIV/AIDS is an epidemic that impacts every aspect of the lives of those infected. Its impact of the sexual and reproductive lives of those infected and affected demand expanded and ongoing studies.

#### *Sexual and Reproductive Experiences and Challenges of Other Groups Living with HIV/AIDS*

People living with HIV/AIDS are not a homogenous group. Their sexual and reproductive needs differ depending on their gender, marital status, sexual orientation, and their social, economic and cultural context. While this study focused on married women living with HIV/AIDS, their sexuality is tied to and affected by the perspective and experiences of their husbands. Research that explores the sexual and reproductive experiences and challenges of men living with HIV/AIDS would help to provide a more complete insight of their interrelationship and shape better programs. Other populations that are likely to have unique sexual and reproductive experiences include: unmarried PLWHA, young PLWHA, and PLWHA in same sex relationship.

### *Focus of Rural Areas*

The current study was carried out in Abuja which is very rich with a variety of resources for PLWHA ,including ARV centers, PMCTC programs, support groups and several non-profit and religious groups providing care and support services. This kind of support is not evenly available in other states and barely exists in rural areas. It is therefore very important to replicate this study in resource poor states and rural in areas.

### *Knowledge Attitude and Practice of Health Workers with Regards to the Sexual and Reproductive Health of PLWHA*

One of the conclusions of this study is that health care providers play significant role in ensuring that PLWHA achieve optimal sexual and reproductive health. A study of their knowledge, attitudes and practices with regards to the sexual and reproductive health of people living with HIV/AIDS will help us to understand where the gaps are and strategies to fill them.

### *Carryout Extensive Population Based Quantitative Surveys*

Qualitative studies provide in-depth understanding of the sexual and reproductive challenges of WLWHA. But one of the limitations is that only a small number of people participate in most studies. It is important to carry out extensive quantitative research to help assess the extent and magnitude of the problems associated with the sexual and reproductive health of PLWHA. Quantitative research will help us generalize the findings and monitor the trends. For example, we would know the actual percentage of WLWHA who are using contraceptives or who experience violence in relation to their sexuality.

## *Professional Preparation and Continuing Education of Health Care Providers*

### *Integrated Team Work*

Health care providers are central to ensuring that the sexual and reproductive rights and health needs of PLWHA are met in a positive, respectful, non-discriminatory way. A variety of health care specialists work in an integrated way to meet the sexual and reproductive health needs of PLWHA. They would include medical doctors with several specializations, nurses, health educators, family planning specialist, social workers, counselors, laboratory scientist and pharmacist among others. These health care providers working with PLWHA must make concerted efforts to work as a team and collaborate with each other. This culture must be emphasized right from their primary training programs and through continuing education.

### *Continuing Education*

HIV/AIDS related information changes very fast and requires concerted training and ongoing retraining to keep up with current information. Health care institutions and educational institutions that train health care providers must be mindful of the rapid change in HIV related information in their training and provide opportunities for ongoing learning.

### *Breaking the Culture of Silence about Sexuality among Health Workers*

The culture of silence associated with sexuality make it difficult for health care workers to discuss sexuality issues with their clients in a positive and confident manner. This discomfort can be addressed with role plays and other activities at the primary training institutions or as part of continuing education programs. Health care providers could develop deeper understanding and empathy for PLWHA if they role play being the ones living with HIV/AIDS. They would learn how challenging it could be to walk in the shoes of PLWHA. Inviting PLWHA to share their stories during training sessions of health workers is a helpful strategy.

## *Programs and Policies*

### *Right-based Programs*

Program and policies to meet the sexual and reproductive needs of WLWHA must be based on the foundation that the sexual and reproductive rights of PLWHA are human rights. Women Living with HIV/AIDS, like all human beings, have a right to safe, pleasurable sex and a right to found a family. They have a right to make decisions about their sexual and reproductive lives without coercion, stigma or discrimination.

### *Education and Economic Empowerment of Women and Girls*

Most of the women did not complete high school and are housewives depending on their husbands for sustenance. Educated women are more likely to have access to sexual and reproductive information, and have more control over their bodies. Programs to educate young girls and improve the economic advancement of women would benefit women living with HIV/AIDS, their families and communities. Such programs would also help mitigate the impact of the epidemic.

### *Preventing and Redressing Domestic Violence*

That most of the women lacked agency and control over their bodies was reflected in their inability to refuse unwanted sex and experience of violence for refusing sex, negotiating condoms or not procreating on time. This is a direct violation of the premise of their sexual and reproductive rights. Preventing and redressing domestic violence would require interventions at family, community, policy and judicial level. More men need to be the champions and focus of domestic violence prevention program. Community gatekeepers including women need to be aware of the health and economic impact of domestic violence on women and children. Programs are needed to help men deal with the root cause of the anger and frustration that they take out on women and offer strategies to cope with them.

### *Mental Health Care and Access to Information*

Women living with HIV/AIDS and their partners would continue to need supportive mental health counseling and treatment including group therapy to help them enjoy sex while meeting their partners' sexual and emotional needs. They should have access to comprehensive and correct sexual and reproductive information, education counseling, treatment and support services to enable them make informed decisions and take actions to meet their sexual and reproductive health in ways that protect them and their partners. Programs should engage significant others, policy makers and cultural gatekeepers to ensure that the socio-cultural and economic contexts of PLWHA can enable and nurture their ability to make safe sexual and reproductive decisions and live a healthy fulfilling life.

### *Address Barriers to Condom Use and Advance Women-controlled Protection Methods*

Because condom use continues to be marred by myths and misconceptions, programs should ensure access to condoms as well as education and skills that will enable WLWHA and their partners use condoms confidently. Also, since gender based inequity reduces women's ability and safety in negotiating male condoms, it is imperative that to invest in research and development of women controlled prevention technologies and ensure that they are widely available.

### *Integrated Reproductive Health Services to Improve Obstetric Outcome*

To secure the rights of WLWHA to procreate in the face of their physiologic difficulty with fertility, programs that help women living HIV/AIDS to conceive safely and have positive obstetric outcomes would be invaluable. Those who chose not to procreate or who want to space their pregnancies should have access to integrated family planning services.

### *Safe, Affordable Infant Feeding Options*

Infant feeding is an important part of the reproductive process. Women living with HIV/AIDS will continue to need education, counseling and support to ensure that their infants are fed adequately and safely.

### *Stigma Reduction Programs for Easy Disclosure and Reduction in Pressure to Breastfeed*

Programs to help them safely disclose their status to immediate family will increase the odds that would get the support they need to feed their infants safely instead of pressures to breastfeed. Also community education programs to reduce the HIV related stigma will increase the wellbeing and safety of WLWHA.

## Epilogue

## Personal Reflection on the Research Process and Result

The stories of some of the women in the support groups of PLWHA that I facilitated between 1998 and 2003 inspired me to embark on this research. Sexuality has always been a difficult topic to discuss with most people, including WLWHA. I was very confident that the women would discuss their sex life freely with me, but I have always been an optimist. Because I am very comfortable discussing sexuality, I was hopeful that my comfort level with the subject would help put the interviewees at ease. Initially they were reluctant, bashful, looking down on their laps in obvious discomfort as they hedged around the subject. I would usually say things like “we are all grown women. Forget that I am the director of CRH. Let us talk woman to woman.” Sometimes I would say things like “people who do not have HIV are making decisions and planning programs that affect your lives without hearing your stories. Sharing your experience would ensure that the right programs are implemented." I would tell them that "I am not interested in hearing the politically correct answers. You do not need to tell me what you think is the right response. For example, telling me you use condoms when you do not. That would defeat the purpose of the study. I really want to hear what is happening in your life. I respect what you share with me and would not judge you in anyway." Sometimes, depending on the level of education of the woman, I would revert to Pidgin English to reduce their discomfort as they struggled to speak English. Sometimes I used jokes to make them laugh. With these strategies, the women became more relaxed and shared their sexual and reproductive lives freely with me.

I maintained eye contact and leaned towards them. When appropriate I held their hands, nodded my head or make comments to let them know that what they were saying was important. There were several emotional moments. Sometimes we take a cry break because recounting their experiences was painful. At these times I give them a tissue and rubbed their hands or shoulder. Often I was crying too. Some the painful moments include when they talked about infertility, miscarriage, and infant death. I was infuriated that doctors were not telling the women what to do to prevent pregnancy while they had low CD4 count. Many miscarriages would have been prevented. It was gut wrenching when Sami shared the pain of losing seven children to HIV. With her, I felt her anger toward her husband who would put a hole in the condom and got her pregnant when her CD4 count is still low and would refuse to buy her the ARV to save the child's life.

I felt like shaking Kate out of her self-loathing and inability to forgive herself for being HIV positive while her husband is HIV negative. The love and support of her husband was palpable as she recounted the many ways that he had tried to reassure her. I wished all WLWHA had that kind of support. Kate has lived with HIV for over five years, but had never been counseled because she avoided contact with the health systems where she is likely to received HIV care. This is because she was concerned about being stigmatized and losing her job because one of the health workers would tell her employer. I was surprised that she volunteered to participate in my study. Kate was so distraught that we had to refer her for counseling with the CRH counselor.

I could not help nodding in agreement when the women said they had a right to have sex and question people who think they should not. I also nodded in understanding when the women raised their voice in anger questioning why people thought WLWHA should not have children because they would infect them and or leave them orphans. They mentioned the intense cultural demand on them to procreate, the availability of ARV and PMTCT programs to preserve their lives and that of their children. Being a survivor of domestic violence and abuse, I identified with the pains and frustrations of the women when they recounted being beaten by their husbands for not having sex, for suggesting condom use and/or for not having a child. We were crying when Vero shared her experience of being infected by her husband who refused to disclose his HIV status to her. In her anger she refused to have sex with him, but he would beat and injure her. Her shoulder and face drooped when she said in helpless resignation “ *I now talked sense to myself, I say ok, now you are not a small kid again, if the man say he wants you, it is better I release myself to him, than for him to be beating and wounding me. So I let him have me when he wants (Vero).”* Vero is a frail petite woman. How anyone would hurt her belies understanding.

While doing field work in Nigeria, I had the misfortune of being in a vehicle accident that left me paraplegic. My staff had to complete the interviews for me and sent the tapes to me. After transcribing the tapes, my memory of the actual interviews was vague. Gradually as I recovered, my memory of the women returned and will stay with me for a long time. Their pains inspired me to stay true to their voices even at the risk of having long quotations or being too passionate in my interpretations. I hear the voice of Dr. Julai Colyar my qualitative research teacher saying “Don’t just tell me, show me.” I hope I have succeeded in telling and showing you, the reader, the sexual and reproductive decisions and experiences of WLWHA in Abuja, Nigeria and the factors that influenced their decisions.

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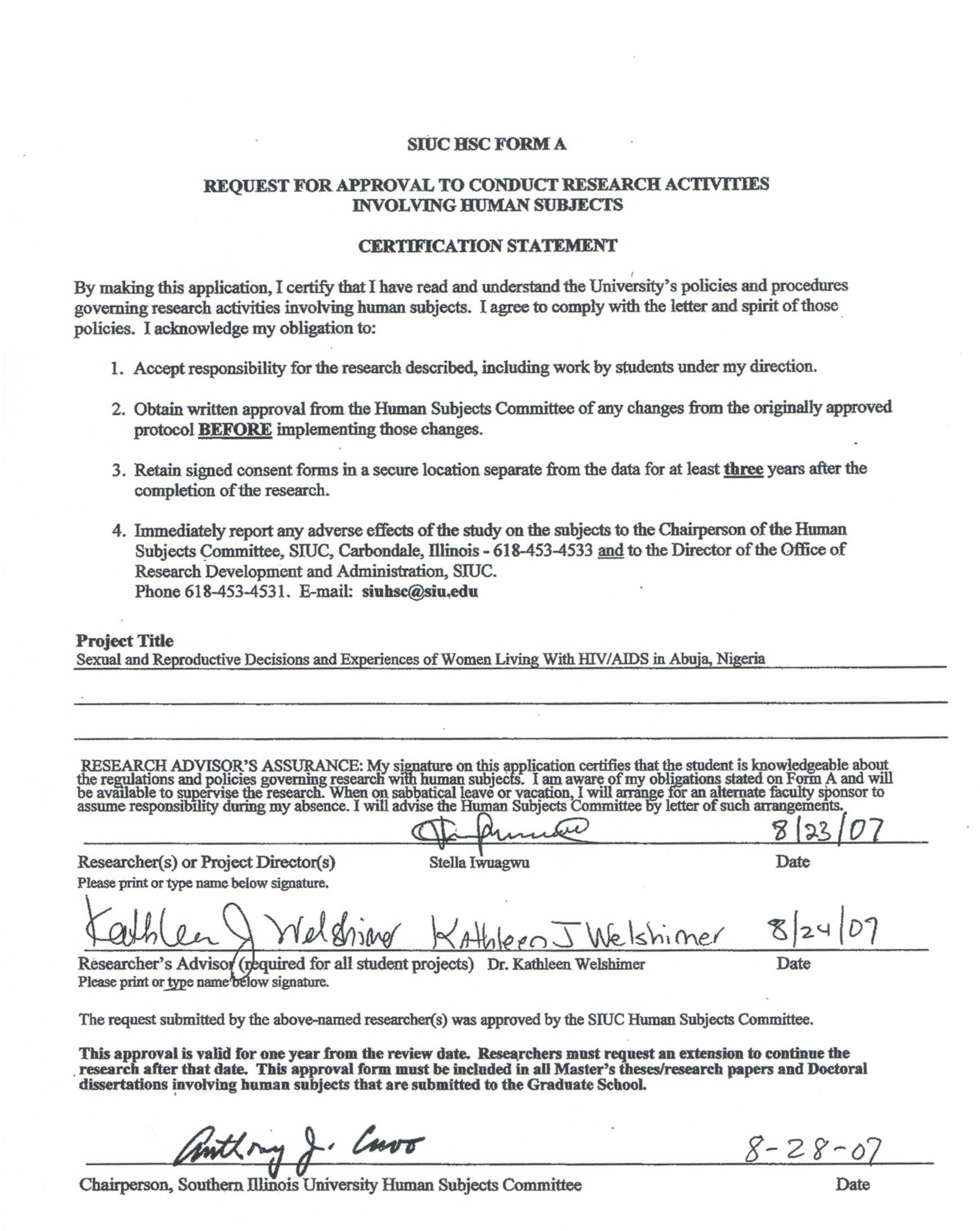
# APPENDICES

# APPENDIX A

# HUMAN SUBJECT APPROVAL



## SIUC HSC FORM A

## REQUEST FOR APPROVAL TO CONDUCT RESEARCH ACTIVITIES INVOLVING HUMAN SUBJECTS

## CERTIFICATION STATEMENT

By making this application, I certify that I have read and understand the University's policies and procedures governing research activities involving human subjects. I agree to comply with the letter and spirit of those policies. I acknowledge my obligation to:

1. Accept responsibility for the research described, including work by students under my direction.
2. Obtain written approval from the Human Subjects Committee of any changes from the originally approved protocol **BEFORE** implementing those changes.
3. Retain signed consent forms in a secure location separate from the data for at least **three** years after the completion of the research.
4. Immediately report any adverse effects of the study on the subjects to the Chairperson of the Human Subjects Committee, SIUC, Carbondale, Illinois - 618-453-4533 and to the Director of the Office of Research Development and Administration, SIUC.
   Phone 618-453-4531. E-mail: **siuhsc@siu.edu**

**Project Title**
Sexual and Reproductive Decisions and Experiences of Women Living With HIV/AIDS in Abuja, Nigeria

RESEARCH ADVISOR'S ASSURANCE: My signature on this application certifies that the student is knowledgeable about the regulations and policies governing research with human subjects. I am aware of my obligations stated on Form A and will be available to supervise the research. When on sabbatical leave or vacation, I will arrange for an alternate faculty sponsor to assume responsibility during my absence. I will advise the Human Subjects Committee by letter of such arrangements.

8/23/07

Researcher(s) or Project Director(s) Stella Iwuagwu Date
Please print or type name below signature.

Kathleen J Welshimer Kathleen J Welshimer 8/24/07

Researcher's Advisor (required for all student projects) Dr. Kathleen Welshimer Date
Please print or type name below signature.

The request submitted by the above-named researcher(s) was approved by the SIUC Human Subjects Committee.

**This approval is valid for one year from the review date. Researchers must request an extension to continue the research after that date. This approval form must be included in all Master's theses/research papers and Doctoral dissertations involving human subjects that are submitted to the Graduate School.**

Anthony J. Cuvo 8-28-07

Chairperson, Southern Illinois University Human Subjects Committee Date

# APPENDIX B

## RECRUITING SCRIPTS AND INFORMED CONSENT

## Recruiting Scripts 1

Dear former client,

My name is Stella Iwuagwu. I am a nurse and doctoral candidate in the Department of Health Education at Southern Illinois University Carbondale. I am currently working on my doctoral dissertation and trying to recruit participants for in-depth interviews. I plan to interview women living with HIV/AIDS who have had a baby since being diagnosed and can converse in English.

As my former client, I cannot use you, but I will be very grateful if you could suggest other women living with HIV/AIDS in your social network that I can contact to participate in my study. I would like them to share with me their experiences since being diagnosed with HIV/AIDS. I am not interested in just those with bad experiences; rather I will like to talk to those with both bad and good experiences.

Reasonable steps will be taken to protect their identity, and the information they share with me. Please write the names, phone number and address of women you would like me to contact on the paper attached. Please can you also contact the women and let them know that you gave me their names and that it is okay for me to contact them.

Questions about this study can be directed to me or to my supervising professor, Dr. Kathleen Welshimer, Department of Health Education, SIUC, Carbondale, IL 62901, 1-618-4532777 or welshime@siu.edu.

Thank you for taking the time to assist me in this research.

Stella Iwuagwu,

Phone number: 08037231221

E-mail: iwuagwus@yahoo.co.uk

This project has been reviewed and approved by the SIUC Human Subjects Committee. Questions concerning your rights as a participant in this research may be addressed to the Committee Chairperson, Office of Research Development and Administration, SIUC, Carbondale, IL 62901-4709. Phone (618) 453-4533. E-mail: siuhsc@siu.edu

# Recruiting Script 2 / Cover letter

Dear Potential participant,

My name is Stella Iwuagwu, I am a nurse and a doctoral candidate in the Department of Health Education at Southern Illinois University Carbondale. I am currently working on my doctoral dissertation and trying to recruit participants for in-depth interviews. I plan to interview women living with HIV/AIDS who have had a child since being diagnosed.

One of my former clients living with HIV/AIDS recommended you. I will like to interview you so you care share with me your experiences since being diagnosed with HIV/AIDS. There will be two interviews of 60-90 minutes each, to be done at a date, time and place of your choice. Your participation is voluntary; no harm will come to you if you choose not to participate or decide to withdraw. The interviews will be audio-taped. We will use a name other than yours during the interviews and transcription. I will take all reasonable steps to protect your identity. The tapes and the transcript will be locked in a cabinet in my house. The tapes will be erased and the transcripts destroyed after the study is published.

I will be grateful if you could agree to participate in my study. Are you willing to participate?

__________ Yes __________ No

If no: Thank you for your time.

If yes: Thank you. I will like to schedule our first interview.

Questions about this study can be directed to me or to my supervising professor, Dr. Kathleen Welshimer, Department of Health Education, SIUC, Carbondale, IL 62901, 1-618-4532777 or welshime@siu.edu.

Thank you for taking the time to assist me in this research.

Stella Iwuagwu,

Phone number: 08037231221

E-mail: iwuagwus@yahoo.co.uk

This project has been reviewed and approved by the SIUC Human Subjects Committee. Questions concerning your rights as a participant in this research may be addressed to the Committee Chairperson, Office of Research Development and Administration, SIUC, Carbondale, IL 62901-4709. Phone (618) 453-4533. E-mail: siuhsc@siu.edu

# Informed Consent Form

I ____________________________, agree to participate in this research project conducted by Stella Iwuagwu, Doctoral Candidate of department of Health Education Southern Illinois University Carbondale.

I understand the purpose of this study is to explore the sexual and reproductive decisions and experiences of women living with HIV/AIDS in Abuja who have had a child since being diagnosed.

I understand my participation is strictly voluntary and may refuse to answer any question without penalty. I am also informed that my participation will last about 10 days.

I understand that my responses to the questions will be audio taped, and that these tapes will be transcribed and kept for 2 years in a locked file cabinet. Afterward, these tapes will be erased and the transcripts destroyed.

I understand questions or concerns about this study are to be directed to Stella Iwuagwu, at 08037231221, iwuagwus@yahoo.co.uk or her advisor Dr. Kathleen Welshimer at 1-618-4532777 or welshime@siu.edu.

I have read the information above and any questions I asked have been answered to my satisfaction. I agree to participate in this activity and know my responses will be tape recorded. I understand a copy of this form will be made available to me for the relevant information and phone numbers.

"I agree _____ I disagree _____to have my responses recorded on audio tape."

"I agree_____ I disagree _____ that Stella Iwuagwu may quote me in her paper"

Participant signature and date

This project has been reviewed and approved by the SIUC Human Subjects Committee. Questions concerning your rights as a participant in this research may be addressed to the Committee Chairperson, Office of Research Development and Administration, SIUC, Carbondale, IL 62901-4709. Phone (618 453 4533. Email:siuhsc@siu.edu).

# APPENDIX C

# PRE-INTERVIEW BACKGROUND AND DEMOGRAPHIC INFORMATION FORM

## Pre-Interview Background and Demographic Information form

Date___________________________

Pseudonym for the interview ________________________________

When were you diagnosed with HIV/AIDS ___________________________

Age____________________Ethnicity ______________________Religion_______________

Level of Education completed________________________________________

Occupation ___________________________________________________________

Nature of current employment _____________________________________

Present marital Status____________________________________________________

How many children have you had before HIV diagnosis?______________________

How many children have you had following diagnosis?____________________

Are you on Antiretroviral (ARV) drugs?

If yes, how long have you being on ARV,

If no, why are you not on ARV?

# APPENDIX D

## INTERVIEW GUIDE

## Interview Guide

Thank you for agreeing to participate in my study

3. Please, tell me about yourself and your family (Probe for extended family relationships/dynamics, and roles and how living with HIV/AIDS have affected these relationships and role if at all).
4. Apart from your family, who in your community, neighborhood or social network play a role in your life and how have they responded to your HIV diagnosis if at all? (probe for religions, and cultural gate keepers and support systems)
5. Some people belief that it is natural to have sexual feelings and desires, and express them in different ways, please share with me your belief about sex and how you have dealt with it before and following your HIV diagnosis.
    a. (Probe for beliefs and experiences e.g abstinence, finding a partner, disclosure to partner, partner's status, sexual negotiation, violence related to sexual negotiation, etc).
    b. (Probe whether condoms and other contraceptives is used, if yes which type, source, challenges if any in getting contraceptives. If contraceptives were not used, why?)
6. Congratulations on having had a baby since being diagnosed with HIV/AIDS, please work me through your experience of pregnancy and childbirth.
    a. (Probe for whether pregnancy was a conscious decision and what factors influenced the decision to get pregnant. Probe for role of husband/partner and extended family, peers, health worker etc in the decision to get pregnant

    b. (Probe for whether there were periods of infertility and how it was resolved.
    c. (Probe for experience with prevention of mother to child transmission including labor and infant feeding options).

7. Please share with me beliefs and practices people in your culture share with regards to sex, contraception, childbearing and breast feeding? Probe -which of these cultural beliefs and practices do you hold dear and practice and which is harmful to health and why)
8. One of the reasons for my study is to ensure that the voices of women living with HIV/AIDS are heard, what other concerns or issues which have not been covered in our discussion you would like to raise? What recommendations if any do you have for resolving some of the challenges you have raised?
9. Thank you for your time. I will go home transcribe, read and do an initial analysis of our conversation. Is it okay to contact you for a second interview if I need more information?

8\. Please, could you recommend other women living with HIV/AIDS who have had a child since being diagnosed to participate in this study?

# APPENDIX E

# MATERIAL USAGE PERMISSION

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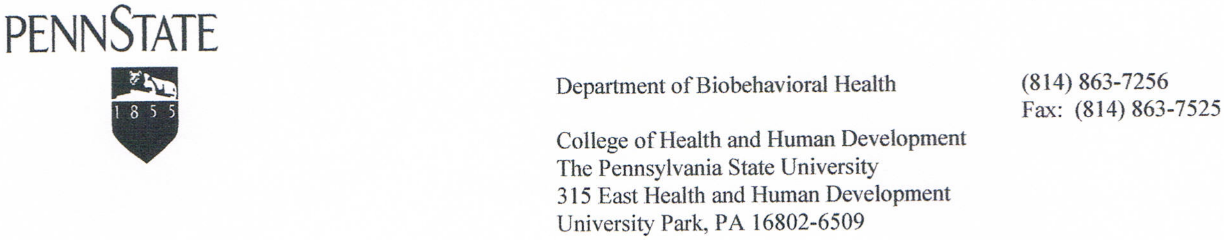

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College of Health and Human Development
The Pennsylvania State University
315 East Health and Human Development
University Park, PA 16802-6509

July 2, 2009

Stella Iwuagwu, PhD
Southern Illinois University
Carbondale, Illinois

Dear Stella,

As requested, this letter is to grant you permission to use the PEN-3 figure in your publication. Please let me know if I can help you in any other way.

Sincerely,

Collins O. Airhihenbuwa, PhD,
Professor and Head

# VITA
Graduate School

Southern Illinois University

Stella Iwuagwu Birth: September 5, 1969

320 S. Birchlane Dr. Carbondale, IL 62901

iwuagwus@yahoo.co.uk

Obafemi Awolowo University, Ile-Ife, Nigeria

Bachelor of Nursing Science, 1992

University of Ibadan, Ibadan, Nigeria

Master of Public Health, 2000

New York University, New York

Master of Science, 2005

Special Honors and Awards:

Ashoka Fellowship for Social Entrepreneur, 2001

African Women Public Service Fellowship, 2002

James Walker Presidential Fellowship, 2006, 2007, 2008

Dissertation Title:

Sexual and Reproductive Decisions and Experiences of Women Living With HIV/AIDS in Abuja, Nigeria

Major Professor: Dr. Kathleen Welshimer

Publications:

Iwuagwu, S.C., Ajuwon, A. J., & Olaseha, I. O. (2000). Sexual behaviour and negotiation of the male condom by female students of the University of Ibadan, Nigeria. *Journal of Obstetrics & Gyneacology. 20 (5), 507-513.*

Iwuagwu, S.C., Durojaiye E., Oyebola, B., Oluduro, O. & Ayankogbe O. (2003). HIV/AIDS and Human Rights in Nigeria: Background Papers for HIV/AIDS Policy Review in Nigeria. Washington DC: Policy Project/ USAID.