Exploring the Lived-Experience of Antiretroviral Treatment among Pregnant Women

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THESIS

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I would like to dedicate this thesis to all of the nurses and educators that have impacted my journey as a nurse researcher, especially my Chair Susan Vonderheid. Also to Pamela Andresen who guided me as a young nursing student and has mentored me to become the nurse I am today. Finally, I would like to acknowledge my husband, Edwin C. Bagley, for his love and support, without which, my work would not be complete and to my son, Edwin Jackson Bagley, may you find your passion and make your world a better place.

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LIST OF ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Therapy
CDC	Centers for Disease Control
HIV	Human Immunodeficiency Virus
US	United States

SUMMARY

A literature review examining adherence to antiretroviral therapy (ART) among pregnant women living with Human Immunodeficiency Virus (HIV) was conducted to understand the current state of the literature. The implications of low adherence are substantial and costly to the health care system, family and those infected with HIV. Gaps in the literature existed in describing why some pregnant women are adherent and others have low adherence. A qualitative study that used interpretive phenomenology to better understand the experience of taking ART during pregnancy was conducted to fill these gaps. In-depth interviews with ten women living with HIV in the second or third trimester uncovered the unique collective experience of taking ART during pregnancy. The overarching theme discovered was a balancing act of taking ART. The four interrelated subthemes that emerged from the data were struggles, motivators, reminders, and support. These themes will inform the care provided to pregnant women living with HIV and provide pilot data in developing interventions target at increasing adherence to ART during pregnancy.

I. INTRODUCTION

The purpose of this study was to better understand adherence to antiretroviral therapy (ART) during pregnancy among women living with Human Immunodeficiency Virus (HIV). A literature review was conducted to collect and review the current literature related to adherence during pregnancy in the United States (US). Significant gaps that were identified during this review: a lack of a consistent measurement of adherence during pregnancy and the factors associated with adherence during pregnancy. Driven by the gaps identified in the literature review, a qualitative study was conducted to better understand the lived experience of pregnant women living with (HIV) taking ART. The qualitative study used phenomenology as the methodology to better understand the experience of taking ART during pregnancy. Ten women in their second or third trimester of pregnancy were enrolled into the study. Each woman had a one-time 60-minute in-depth interview and basic demographics were collected. Data analysis included a thematic analysis, and a identification of paradigm cases and exemplars. The overarching theme that was uncovered was a balancing act of taking antiretroviral therapy and the four interrelated subthemes were struggles, motivators, reminders, and support.

This dissertation includes the findings of two research studies, presented here at two manuscripts. The first manuscript includes findings from the literature review that provided the evidence that further research was needed to better understand pregnant women's adherence during pregnancy. The second manuscript includes findings from the qualitative study that explore the lived experience of taking antiretroviral therapy during pregnancy. In the appendices, I have included approval letters for this research from the Institutional Review Boards at the University of Illinois at Chicago and Northwestern University, and my vita.

II. ANTIRETROVIRAL THERAPY DURING PREGNANCY

Background

Globally 35.3 million people are living with Human Immunodeficiency Virus (HIV) (World Health Organization, 2013). In the US approximately, 1.1 million people are currently living with HIV (Centers for Disease Control, CDC, 2012). About 280,000 women are living with HIV in the US and 80% are in their childbearing years (CDC, 2011). Twenty percent of all new HIV diagnosis were among women in 2010 (CDC, 2012). There are substantial racial and ethnic disparities: 1 in 32 black women and 1 in 106 Hispanic women will be diagnosed with HIV infection in their lifetime, compared to 1 in 526 for white women (CDC, 2012). Heterosexual contact is the mode of transmission for most women in the United States (US) (CDC, 2011). HIV infection rates are skyrocketing among heterosexual women, especially black women compared to other groups (CDC, 2012). In a recent study, 31.5% of HIV-infected women (mean age 20.6) with sexually acquired HIV desired pregnancy within the next 6 months (Finger, Clum, Trent, Ellen, & Adolescent Medicine Trials Network for HIV/AIDS Interventions, 2012). In 2009, approximately 8,600 women living with HIV delivered in the US (CDC 2014). Perinatal transmission occurs to about 200 infants annually (CDC, 2014).

To prevent perinatal transmission and to improve the health of pregnant women, ART is prescribed during pregnancy (Connor et al., 1994; Perinatal HIV Guidelines Working Group, 2014). Women who are diagnosed with HIV during pregnancy or were not previously taking ART are started on ART immediately, with a goal of initiating ART by 12 weeks gestation (Perinatal HIV Guidelines Working Group, 2014). Initiating ART early in pregnancy can decrease the risk of maternal transmission (Aziz & Smith, 2012). Pregnancy itself is a critical life transition filled with dramatic psychosocial and physiological changes (Anderson, 2012). For women living with HIV pregnancy presents additional unique challenges including those related to the complexity of ART that require carefully tracking of multiple medications and dose times. Because of expected physiological changes during pregnancy and changes in medication

metabolism, required dose changes in ART during pregnancy further complicate an already challenging pregnancy experience. However, the benefits of ART to decrease perinatal transmission and the overall health of the women is critically important (Perinatal HIV Guidelines Working Group, 2014).

Perinatal transmission can be reduced from 40% to less than 1% of women in part by providing ART to women during pregnancy, labor and delivery (CDC, 2011). Prevention of perinatal HIV transmission saves an estimated $660,930 per infant or a total of $132,186,000 nationwide annually (McCabe, Goldie, & Fisman, 2010). Along with the financial impact of preventing perinatal transmission, the infants avoid a lifetime of chronic poor health that requires treatment, as well as adverse psychosocial issues. Children perinatally infected have an increased risk for multiple health problems including mental health problems, cardiovascular disease, cognitive disorders, asthma, skin disorders, and adherence problems with ART for their own treatment. (Malee et al., 2011; Mellins et al., 2011; Patel et al., 2013; Rice et al., 2012; Siberry et al., 2012).

The primary goal of ART is viral suppression, and 100% adherence leads to maternal virological suppression (Bardequez et al., 2008, CDC, 2011; Cohn, Umbleja, Mrus, Bardequez, Andersen, & Chesney, 2008; Demas et al., 2005). When suppression is achieved, viral resistance to ART, AIDS, and an increased risk of perinatal transmission occurs (CDC, 2012; Nachega, Marconi, van Zyl, Gardner, Presier, Hong, et al., 2001). Development of resistance to the recommended ART during pregnancy results in many treatment challenges (Bardequez et al., 2008). Alternative therapies often require additional medications and more frequent dosing, and carry a greater risk of side effects for the mother (Bardequez et al., 2008).

Interventions aimed at increasing adherence have not been developed for pregnant women. Interventions aimed at non pregnant patients to increase adherence consisted of specific strategies to assist patients with ART adherence (Chaiyachatia, Ogbuojib, Priceb, Sutharc, Negussiec & Barnighausen, 2014; Rueda, Park-Wyllie, Bayoumi, Tynan, Antoniou, Rourke, & Glazier, 2009; Simoni, Amico, Smith, &

Nelson, 2010). A review of the literature described Interventions such as "readiness to initiate" therapy (Simoni et al., 2010) that focuses on allowing patients time to learn about HIV, cope with their diagnosis, and accept the need for therapy. This intervention is not feasible with pregnant women because initiating ART immediately is critical to reduce perinatal transmission. Another intervention that has been effective in the non pregnant population is use of a multi disciplinary team approach to increase adherence (Simoni et al., 2010). While this approach is already in place in many clinics serving pregnant women, adherence rates remain low (Bardequez et al., 2008). Reviews examining pregnancy and ART adherence include older studies evaluating monotherapy that focused on whether medications were taken at the scheduled dose times, and the relationship between adherence and infant outcomes (Demas et al., 2005; Vitalis, 2013). There is a paucity of information about taking combination ART during pregnancy and how providers can help women improve their adherence to currently recommended regimens.

The purpose of this review is to describe how ART adherence during pregnancy is measured and the factors associated with adherence to ART during pregnancy, and to identify the gaps that exist in the current literature. Findings may be used to develop innovative interventions specific for pregnant women living with HIV.

Methods

This study used a scoping literature review method as described by Arskey and O'Malley (2005). A narrative review of the literature is conducted and includes the following steps: (1) identifying the research questions, (2) identifying relevant studies, (3), study selection, (4) charting the data, and (5) collating, summarizing, and reporting the results (Arskey & O'Malley, 2005). The purpose of a scoping study is to provide an in-depth and wide ranging review of current literature, specifically for this study reviewing literature to describe what is known of pregnant women living with HIV and adherence to ART.

Electronic databases searched included CINAHL, PubMed, PsychINFO. Databases were searched using the following keywords: “HIV”, “pregnancy”, “antiretroviral therapy” and “adherence”. To obtain a broad search keywords were used individually and in different combinations. Studies published up through May 2014 were included. Studies were sought that met the following inclusion criteria: sample included pregnant women living with HIV, examined combination therapy, described ART adherence, described women’s health outcomes, published in English, and full-text available. Exclusion criteria included studies that examined monotherapy or single dose therapy and included non-US populations. While articles published in the last 5 years were sought, few articles fit the inclusion criteria; and therefore, the time horizon was extended to 2000 when combination therapy and adherence rates was first described in the literature. Titles and abstracts were reviewed to prescreen study inclusion and exclusion criteria. Full text articles were then screened for inclusion into the study. An ancestry search was also conducted using the references from relevant studies (Cooper, 2010). To chart the data, key study components were abstracted from each article. Results chart the data by key study components (Arskey & O’Malley, 2005). Six studies met inclusion criteria.

Results

Six studies were found that met inclusion criteria. One study was a global metaanalysis of adherence rates that including US studies (Nachega et al., 2012), two studies were retrospective chart reviews (Kapetanovic et al., 2009; Loius et al., 2005) and three studies were prospective observational studies (Bardequez et al., 2008; Cohn et al 2008; Mellins et al, 2008). The two retrospective studies were chart reviews describing specific clinics’ experiences (one urban Michigan clinic and two urban California clinics). Two out of three multisite prospective studies that included women across the US examined the natural course of HIV with a focus on maternal and infant biomedical outcomes and included women across the US. The third prospective study described metabolic syndrome in pregnant women. Studies did not use a conceptual framework to guide the research.

Measurement of ART Adherence During Pregnancy

Reported measures of adherence varied by study design. The tool used to measure adherence in all three of the prospective research studies was the widely accepted self-report Adult AIDS Clinical Trials Network (AACTG) questionnaire. This questionnaire measures number of missed doses, general health symptoms, and frequency of feeling happy (Bardequez et al., 2008; Cohn et al., 2008; Mellins et al., 2008). Development of the AACTG questionnaire included asking 75 HIV patients who were predominantly white males from the United States to evaluate the length of the questionnaire and to provide general feedback to assess feasibility for future studies (Chesney et al., 2000). Content validity was not reported. Researchers using retrospective reviews of medical charts used HIV RNA results as a proxy for adherence and documented patient self-report of missed doses (Kapetanovic et al 2009; Loius et al., 2005). These measures of adherence are routinely collected. Clinical providers ask their patient if they have missed any of their HIV medications and rely on HIV RNA results to determine adherence and make changes in ART regimens. In the metanalysis, Nachega (2012) identified numerous measures of adherence: number of pharmacy refills, pill counts, hemoglobin levels, maternal and cord blood PK levels, and self-report using ACCTG. In summary, there is no universal definition of adherence, researchers and clinicians use different measures, and data collection methods vary.

Variations in measures of adherence might contribute to a range of adherence rates across studies. Although guidelines recommend 100% adherence or all of the doses are taken, the actual percentage required to minimize perinatal transmission is not known. This has lead to researchers defining optimal adherence differently across studies. In a recent metanalysis, Nachega, et al. (2012) found that optimal adherence rates were defined as 80%-100% across studies and calculated a pooled adherence rate of 73.5% for pregnant women globally. This means that greater than one out four women did not achieve optimal adherence. Studies specific to women in the US also found a range of adherence rates as well as timing of the measurement during pregnancy. For example, Mellins et al. (2008) found that only 61% of

women self-reported 100% adherence during third trimester. Bardequez et al. (2008) found 75% of pregnant women self-reported 100% adherence at the reporting nearest to delivery, Cohen et al. (2008) found similar adherence rates of 74% measured between 20 to 34 gestational weeks, and Kapetanovic, et al. (2009) report that 82% adherence with an unknown timing of this assessment. Overall, the reported adherence rates included in this review are substantially lower than the recommended 100% adherence rate (Perinatal HIV Guidelines Working Group, 2014).

Factors Associated with Adherence to ART during Pregnancy

Researchers used quantitative methods to examine factors associated with ART adherence and low adherence during pregnancy. Examination of factors was a secondary aim of all studies and focused on clinical characteristics (e.g., whether had AIDS or perinatal depression diagnoses, health symptoms) and substance use with the exception of measuring the frequency women felt happy (Bardequez, et al., 2008). The majority of these factors are collected during routine clinical care and the use of the AACTG self-report adherence questionnaire is used in research studies. Adherence was measured from different perspectives, some researchers reported factors that were associated with perfect adherence (100% adherence) and others reported the factors associated with missed doses. Factors associated with low adherence were advanced HIV disease status, higher HIV RNA, more health-related symptoms, prepregnancy illicit drug use, and alcohol, tobacco and cocaine use during pregnancy and missed prenatal vitamins (Cohen et al., 2008; Mellins, et al., 2008). Having a perinatal depression diagnosis was also linked with suboptimal adherence (Kapetanovic et al., 2009). Factors associated with adherence were initiated ART during pregnancy, did not have an AIDS diagnosis, never used marijuana, and felt happy all or most of the time (Bardequez et al., 2008). Together, findings from these studies can help providers identify who is at greatest risk for not adhering to ART.

Gaps in Knowledge about Measurement of Adherence

There is a lack of a uniform definition of adherence including variation in what is considered "optimum" adherence across studies making it difficult to compare findings across studies. The measurement of adherence to ART during pregnancy relies primarily on proxy measures (e.g., viral load) and the patient's ability to remember their doses, which leads to recall bias. The AACTG self-report questionnaire was developed with a white and male sample, which was the patient population of HIV when the questionnaire was designed in the late 1990's. However, the HIV population today is much more diverse and no studies have examined whether the AACTG or other questionnaire are appropriate for pregnant women (Chesney et al., 2000). While HIV RNA levels provide some insight to providers in determining if viral suppression is being achieved, these levels are a measure of viral replication not adherence. Although linked to adherence, HIV RNA is not a direct measure of adherence. Best practice for the timing and frequency of assessing ART adherence during pregnancy is unknown. ART adherence assessments are currently consistent with prenatal care visit schedules rather than based on evidence. A major gap in the literature is how and when adherence should be measured during pregnancy.

Gaps in Knowledge about Factors Associated with Adherence

The factors associated with adherence identified in this review arise primarily from clinical characteristics that can assist providers in identifying women at risk for low adherence. Little is known about the psychosocial aspects of women's lives affecting ART adherence. The gap also includes the broader context of the women's daily lives, social support and other facilitators and barriers to adherence. How being pregnant affects adherence is also not described in the literature. Lastly, the available literature is not grounded in a conceptual framework to guide the research.

Implications for Practice and Research

Measurement tools developed and tested with pregnant women is needed to accurately measure adherence during pregnancy for clinical providers and researchers. Consistent adherence

definitions and tools to measure adherence are needed to identify women that have low adherence so that appropriate interventions can be implemented.

Without a comprehensive understanding of adherence during pregnancy, it is not possible to develop evidence-based interventions targeting low adherence. While providers might be able to identify women at risk of low adherence, next steps are uncertain as interventions have not been developed to support pregnant women through adherence to ART. Professional guidelines recommend that providers offer adherence counseling to women when they initiate ART and throughout pregnancy. Yet, recommendations do not include specific topics nor counseling methods. The lack of recommend counseling methods, likely leads to wide variation in counseling and subsequently, its effectiveness. The behavioral factors associated with adherence need to be identified to develop interventions to support adherence. How disclosure of HIV affects adherence needs to be examined. Women who disclose their HIV status may obtain more support in taking ART, leading to greater adherence. Factors such as support, access to ART, and timing of HIV diagnosis are potential factors that need to be examined to understand their role in adherence during pregnancy.

Conclusion

Adherence is critical in ensuring positive health outcomes for pregnant women and their infants. Development of a uniform definition that directly measures ART adherence in realtime is needed to better understand adherence and consistently identify women having low adherence. Facilitators and barriers to combination ART must also be identified to develop interventions tailored for pregnant women. Research examining women's lives is needed to take into account the uniqueness of having to take ART during pregnancy and to shed light on the complexity of adherence for pregnant women.

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III. EXPLORING THE LIVED-EXPERIENCE OF ANTIRETROVIRAL TREATMENT

Background

Approximately, 1.1 million people are currently living with Human Immunodeficiency Virus (HIV) in the United States (US), of whom more than 280,000 are women and 80% are in their childbearing years (CDC, 2011; CDC, 2012). Annually, about 8,600 women living with HIV deliver infants in the US (CDC, 2014). Because HIV rates are rising fastest among women of childbearing age and half of all pregnancies are unintended in the US the number of HIV-infected women who deliver is expected to rise (CDC, 2011; CDC, 2012; Finger & Henshaw, 2006). Antiretroviral therapy (ART) is effective in preventing perinatal transmission (Connor et al., 1994; Perinatal HIV Guidelines Working Group, 2014). Adherence rates to ART during pregnancy are between 61-75% (Nachega et al., 2012; Mellins et al., 2008). Non-adherence has been associated with adverse health symptoms, depression or overwhelmed feelings, non-adherence to prenatal vitamins, illicit drug use, and alcohol and cigarette use (Anderson, 2012; Bardequez et al., 2008; Nachega et al., 2012; Mellins et al., 2008; Stevens & Hildebrandt, 2009; Wilson, Ickovics, Fernandez, Koenig, Walter, 2001). The clinical problem is that adherence rates among pregnant women are too low and that clinicians could benefit from finding out about what motivates women so we can design better interventions their experience of ATR adherence. Perinatal transmission of HIV can be significantly decreased from 40% without ART to less than 1% with ART provided to women during pregnancy, labor and delivery (including elective C-sections) and to their exposed infants (CDC, 2011; CDC, 2012). Despite the US public health goal of a 0% perinatal transmission rate, maternal transmission occurs to about 200 infants annually (CDC, 2011; CDC, 2014). Although this population is relatively small, the effects of a preventable transmission to an infant is costly to the infant, family and health care system; preventing a single perinatal transmission of HIV saves an estimated $660,930 (McCabe et al., 2010).

Women's adherence to ART during pregnancy is critical to maximizing the health of women and decreasing transmission to the infant (CDC, 2011; CDC, 2012; Bardequez et al., 2008; Nachega et al., 2001; McCabe et al., 2010; Mellins et al., 2008). Non adherence is associated with virologic failure, viral resistance to ART, disease progression (Acquired Immunodeficiency Syndrome), higher transmission rates to sexual partners and an increased risk of perinatal transmission occurs (Bardequez et al., 2008, CDC, 2011; Cohn, Umbleja, Mrus, Bardequez, Andersen, Chesney, 2008; Demas et al., 2005). Development of resistance to the recommended ART during pregnancy results in many treatment challenges (Bardequez et al., 2008). Alternative therapies often require additional drugs and more frequent dosing, and carry a greater risk of side effects for the mother (Bardequez et al., 2008).

Non-adherence among pregnant women has been associated with adverse health symptoms, depression or overwhelmed feelings, non-adherence to prenatal vitamins, illicit drug use, and alcohol and cigarette use (Anderson, 2012; Bardequez, et al., 2008; Nachega, et al., 2012; Mellins et al., 2008; Stevens & Hildebrandt, 2009; Wilson, Ickovics, Fernandez, Koenig, Walter, 2001). To our knowledge, there is no evidence that describes the contextual factors affecting HIV-infected pregnant women and their experience with ART in the US. The earlier viral suppression is obtained during pregnancy, the more likely transmission does not occur to the infant, and initiating ART in first trimester should be considered (Bardequez et al., 2008) Newly diagnosed pregnant women only have a couple weeks to process a life altering HIV diagnosis and initiate ART (Bardequez et al., 2008) Interventions targeted to increase adherence have been employed, which include utilizing peer support groups, employing modified directly observed therapy, treating depression, incorporating multidisciplinary teams such as pharmacy into standard care and one-on-one approaches that focus upon daily scheduling of dosing (Simoni, Pearson, Pantalone, Marks, & Crepaz, 2006). These interventions have been implemented with pregnant women and adherence rates are still 75% at best (Bardequez et al., 2008) In order to develop further interventions targeted to increase adherence during pregnancy, women's experience during this

time must be better understood to tailor interventions specifically for use in pregnancy. We aim to fill this gap by exploring the lived experience of pregnant women taking ART during second and third trimester.

Methods:

We used hermeneutic phenomenology employing a method developed by Benner (1994). In addition, we drew from feminist approaches to uncover hidden common meanings and experiences of a particular shared lived experience, phenomena (Benner, 1994; van Mannen, 1990). The interpretive phenomenology process requires that the researcher: 1) investigates the experience as it is lived it rather than how the experience is conceptualized; 2) becomes aware of presuppositions and assumptions during the research process and considers how these affect each stage of the study; 3) remains open to the phenomenon; 4) conducts in-depth interviews with those experiencing the phenomenon is one approach to investigating the lived experience; and 5) discovers essential themes and reflects on how the phenomenon is characterized by the participants (Benner, 1994). The interpretive phenomenology process allows the researcher to identify themes and leads to understanding commonalities and differences among participants considering the corporality, spatiality, temporality, and relationally of the lived experience (Benner, 1994; Benner & Wrubel, 1989). During interviews, participants were treated with continued respect because we acknowledge that each woman is the expert on her own experience. This emphasis on understanding the participants' individual experiences reflects the feminist approach. Keeping detailed memos on thoughts and patterns that are observed in the data ensures dependability. (Benner & Wrubel, 1989).

Setting and Sample

Ten participants were recruited from a large urban Midwestern academic medical center outpatient clinic providing integrated HIV and obstetric care to HIV-infected pregnant women. The clinic serves as a referral center for the metropolitan area and provides multidisciplinary care.

The sample was representative of the clinic and included those born in the US and non US born. Cross-sectional convenience sampling technique was utilized to recruit women who were currently pregnant and prescribed ART. Redundancy was achieved after 10 participants were interviewed. Phenomenology studies using this technique obtained redundancy and clarity of the lived experience with samples of 7-11 participants (O'Mahony, 2000; Forsberg, Nilsson, Krantz & Olausson, 2004; Ross, Sawatphanit, Draucker & Suwansujarid, 2007; Schenk & Kelley, 2010; Taylor, 2000). The inclusion criteria were: 1) women at least 18 years of age, 2) viable pregnancy greater than 13 weeks, 3) ability to give informed consent 4) currently receiving Infectious disease and obstetrics care, 5) English speaking, and 6) prescribed ART for HIV infection. The exclusion criteria were based on providers' recommendations: 1) pregnant women not planning on being a primary care taker of infant once born, 2) history or current symptoms of serious psychiatric symptoms, and 3) diagnosis of genetic or acquired birth defects of fetus.

Data Collection and Procedure

IRB approval was obtained by the parent and recruitment site, and all women provided written informed consent. Data were collected during a one-time interview with each woman. The interviews were conducted in a private confidential office at the recruitment clinic. There were two components of the interview: a brief structured questionnaire to obtain demographics and semi-structured, open-ended questions to obtain the participant's description of the lived experience. The interview guide was developed after careful reflection of the Principal Investigator's (PI) assumptions, including extensive clinical experience with this population, consultation with experts in the field of phenomenology, obstetrics and HIV, and current literature on pregnancy and HIV. Interview length ranged from 25 to 47 minutes.

The PI conducted all interviews and was not a current health care provider in the clinic thus, promoting an equal balance of power between the PI and participants. The interview guide was

developed to facilitate ample opportunities for participants to candidly express their lived experience of ART during pregnancy. An example of a facilitating question was “Is there anything else you would like to tell me about your medications or pregnancy?” During the interview the PI projected a non-judgmental attitude in verbal and non-verbal communication. Open listening to the participant’s responses and then checking for understanding during the interview assisted with data collection and analysis (Benner, 1994). Brief notes were taken during the interview to prompt additional probes to return to during the interview for clarification. Clarity and redundancy of the lived experience occurred after 10 participants.

Following the interview, the PI, recorded detailed field notes describing immediate post interview thoughts and capture non-verbal communication. Additional observations were added to the field notes to provide insight into the participant’s world. The PI transcribed the first two interviews and a professional transcriptionist transcribed the remaining interviews as they were conducted. The PI remained close to the data by listening to each interview to ascertain transcription accuracy and by editing as needed . Throughout data collection the PI repeatedly listened to each interview several times to remain close to the data (Benner & Wrubel, 1989). Memos were maintained to describe the PI’s thoughts, feelings, and assumptions during the research process and how methodological decisions were made. Dedoose 4.5 (2013),a web-based qualitative software platform, was used to manage and organize the data.

Analysis

Interpretive phenomenology uses the hermeneutic circle, which is the process in which the researcher goes back and forth between the participant’s narrative of the lived experience (transcriptions of interviews) and her own assumptions and the interpretation of the lived experience (pre-understanding, field notes and memos) (Benner, 1994).There are 3 interrelated processes to data analysis: identification of paradigm cases, thematic analysis, and analysis of the exemplars (Benner,

1994) Paradigm cases are the frequently appearing patterns of meanings that contain the rich descriptive information needed to understand that actions are a consequence of the participant's situational context (Benner, 1994). Thematic analysis interprets the commonalities and differences between participants by considering situation, embodiment, temporality, concerns and common meanings. The themes identified are the general categories that comprise the foundation of the study's results (Benner, 1994). There were 24 initial codes that were developed from the data that lead to one overarching theme, balancing act of ART and four subthemes: struggles, motivator, reminders and support. Identification of exemplars is the extraction of all similar episodes of a particular situation and the participant's concerns, actions and practices (Benner, 1994). Analysis of the examplars included examination of their meaning within each theme. Exemplars for the overarching theme and four subthemes were identified in each woman's narrative.

Rigor

Rigor was enhanced through credibility, dependability confirmability, and transferability (Lincoln & Guba, 1985). Credibility was supported by having regular team debriefings to discuss patterns and themes during analysis and sharing these with clinical providers specializing in ART with pregnant women (Benner, 1994; Lincoln & Guba, 1985). Dependability was fostered by having two research team members review the transcripts and have agreement of themes, and also maintaining an audit trail of study procedures (Lincoln & Guba, 1985). Confirmability was enhanced by the PI critically on her own assumptions during the research process and staying close to the data through reflexive journaling. Rewriting during the analysis phase was also conducted (Benner, 1994; Lincoln & Guba, 1985). Transferability was strengthened using thorough description of sample, setting and thick descriptions (e.g., quotes) of the lived experience as depicted by the women (Lincoln & Guba, 1985).

Results

Ten pregnant ethnic minority women participated in this study (Table 1) that examined the lived experience of taking ART. The women obtained integrated HIV and obstetric care at a large Midwestern academic medical center. Six out of ten women had at least one other pregnancy since being diagnosed. Two women were diagnosed with HIV during the current pregnancy and two additional women were pregnant for the first time since being diagnosed with HIV. Gravidity ranged from one to six (mean 3.6) and parity ranged from zero to 5 children (mean 2.5). We found an overarching theme, a major pattern of meaning, across all the interviews, the balancing act of taking ART. Four interrelated subthemes were struggles, support, motivators, and reminders. Themes are presented with quotes that use fictitious names to protect confidentiality.

Balancing Act of Taking ART

The overarching theme reflected in the interviews was a balancing act of taking ART - balancing the good and the bad aspects of this experience as a pregnant woman living with HIV. All ten women discussed how intensely they disliked having to take ART, but acknowledged the importance of taking ART in the context of pregnancy. They connected the act of taking ART with their own health and the health of their unborn child, specifically not being HIV-infected. The act of taking ART, Mary stated,

> It was hard at first. I'm not going to lie, it was hard because it was like I really have to do this now and it's like, it's not easy because it's like you just know that it's nasty, but you know it's good for you. It's like, I have to do this because if I don't then I'm not going to be healthy and my baby's not going to be healthy and I want to live long because I want my babies to grow and I want to see them grow and I don't – because I know that if I don't take the medicine I'm going to be sick and I just don't want to be sick to the point where I have to make a will [out], as young as I am."

Women described not wanting to take the pills because they were large and difficult to swallow. Mary described the actual pills as “nasty” and she linked the ART to causing negative side effects. Women spoke about physical side effects such as nausea and vomiting above and beyond those expected during pregnancy.

Taking ART while pregnant was also constant reminder that the women are living with HIV, a life-threatening illness. Women who already had children indicated that they were committed to taking ART to be present for their children. They balanced the gravity of ART during pregnancy and the consequences if they do not take their ART. Nina described starting ART by saying, “I had to get used to it. It was a mind game and trying to do it for my kids. In order to see my kids grow up, I've got to continue to take it to stay healthy.” Women who took ART prior to the current pregnancy identified that taking ART during pregnancy was different and more difficult than when not pregnant. Sarah talked about wanting to be “normal” and how even when she was taking her medication without problems, she wished she did not have to take them. She described this by stating “No worries of that thought crossing across your head – Oh, if you don’t take them, it's going to get worse, you're going to die. Those thoughts…worry about my viral load and baby”.

Struggles

The women described physical and emotional struggles associated with the living experience of taking ART. Physical symptoms such as nausea and vomiting were described by Diana,

> First it (taking ART) was hard because I've never taken, like, three pills for one day or 2 pills, so it was really hard to take, just to swallow and keeping – and like after I would take them like a couple – always after I'll feel nauseous and I just want to throw up. So it was kind of hard, but now I'm fine.

The act of swallowing pills was also described as a struggle, and some women were prescribed liquid formulations of the ART rather than pill forms since pills were difficult to swallow. An emotional struggle

associated with the physical struggles was the actual act of swallowing the medications. This act forced women to think about living with HIV and brought their HIV diagnosis to the front of their consciousness. Coming to terms with a new diagnosis or an existing diagnosis was also part of the struggle of taking ART during pregnancy. Linda described her feelings about her pregnancy and having to take ART:

> I was excited and (clapped hands), and I wanted to tell the baby's father about being pregnant. It all went well and I'm still excited about it and my first child. As far as the diagnosis (strong emphasis on diagnosis), it overwhelmed me at first.

Maria described taking ART as "horrible" and was very aware of the emotional toll of her experience: "I just feel ashamed coming here (the clinic) seeing all these people. It's just – I don't know. I'm – how do I explain it? I just feel ashamed, I let myself down. Why should I get something like this?"

The women reported trying to not miss any doses of ART, but that it was an ongoing struggle to take every dose on time. Women felt badly about missing doses and acknowledged that they were dealing with competing responsibilities. Sarah felt "disappointed" in herself when she missed a dose or was late; her goal was to take her ART at the same time every day. She further explained,

> It's hard because since I'm so busy I have to make sure I don't miss none because I don't want to worry about my viral load's going to go up or down … taking my son to school, making sure he's properly dressed, fed, making sure [my other son] is fed, then I wake up my brother to tell him I'm heading out to work. Then got to wait till my son gets out of school. By the time I get home it's already 4:30. Come home, cook, feed [my son], feed my older one, feed the father, then get the clothes ready for the next day.

Motivators

Women identified multiple motivators that kept them committed to taking their ART as part of the lived experience. Their own health was a key motivator because they recognized the importance of

the medication to keep their “viral load down and T-cells high”, so that they could be alive for their children. Laura described,

> I can't let it go into the AIDS factor and then I get sick and then I die, so I've got to take my medicines to keep it where it's at, knowing it'll probably go there, but not right now. We not on that. Got to keep it where it's at, keep my levels down, keep the up levels where they supposed to be, keep the down ones where they supposed to be. So, take my medicine.

The unborn baby was also strong motivator to take ART. All the women identified the importance of taking ART for the health of their unborn child. When Nina was asked why she takes her ART, she reflected,

> I think – because before I was pregnant I really didn’t have to take any medicine because my immune system was still good, but now that I'm pregnant I think I have to get back into the use of taking medication, because I wasn’t taking it before. So now it's like I have to take it so I can have a healthy baby.

Another woman simply stated, “Got to be healthy for the babies”.

Women were also motivated to take ART because the baby was “innocent” and did not deserve to have HIV; the women knew that they were responsible for reducing the risk of perinatal transmission. This motivation is illustrated by Maria,

> I will do anything to be okay, so I know I have to take this drug and I don’t want anything to be wrong with this baby because she is innocent, she doesn’t know anything. I got this HIV on my own, so I don’t want anything – I don’t want it to affect anybody. Let me not even say – anybody. I take responsibility for everything that happens to me, so I will do anything not to affect any other person. I just pray it doesn’t affect the baby. That's what I've been thinking of. That's why I'm taking my meds. I will do anything just not to pass it to the baby.

Laura who had been pregnant before and taken ART during her prior pregnancy, was motivated to take her ART since her son did not have perinatal HIV, “As long as I'm taking my medication, she should be fine. [My son] was – well, my son was fine. So I know she'll be fine as long as I keep on my medication and do it at the time I'm supposed to”.

Reminders

Reminders played an important role in the experience of taking ART. Some women relied solely on themselves and some women were reminded by others. Some reminders were simple and practical. Having a specific schedule or setting an alarm helped to remind women when to take their ART. Being purposeful about taking ART the same time everyday and being prompted by routine activities of daily life were also reminders. Gina had multiple reminders of her dose times, “Yeah, I'm on a schedule and then besides that if I'm not at home and I know it's time for me to take my medicine I got reminders on my phone, so I know.” When asked if there is anything that helps to remember her medications Sarah responded, “Before my bed – before I go to sleep. That's when my soap opera starts”. Some women intentionally relied on themselves to take ART, while others felt they had no one else to rely on for reminders. Linda described using an alarm on her phone and that no else helped to reminder her because it was her “business”.

Fathers of the babies also provided reminders to women to take their ART. Gina described the father of her baby as checking in with her about her ART,

> Besides me, my boyfriend would be the next person because he's there. We stay together, so it's like he'll ask like, "Oh, have you – remember you've got to take your medicine today. Have you took your medicine today?" I'll be like, "Yeah, I took it."

Similarly, Nina talked about how her boyfriend woke her up to ensure she took her nighttime dose.

Support

As part of the lived experience, women reported many sources of support that assisted them with taking ART during pregnancy. Sources of support were health care providers, mother of the women, other family members, friends/peers and the father of the baby. As Diana described her experience, support was identified as significant and she shared,

> At first it was a little bit hard, but I'm learning to deal with it. I have not started group but I'm about to start a group where I talk to other ladies with HIV and pregnant, so I think that's going to help me out a big deal and like I said, my aunt is giving me a lot of support emotionally. So she has helped me out, but at first it was very hard and for me to come to this, to Hospital, it has helped me a lot because they have really – they have not just been doctors to me, they have been just like friends – I feel like friends actually because they just give me that support where you can call us any time and sometimes I call I'm like I'm so up and down.

Health care providers served as support for the women as well, many described them as more the doctors, nurses or case manager. Health care providers did not just prescribe the ART, but they also supported the women in taking it.

The mothers of the women played a key role in supporting their daughters. Linda, who was diagnosed during pregnancy, described the support she receives from her own mother when she told her the news of being pregnant,

> … and then it was my mom, she, she couldn't believe it, she found out about both (HIV diagnosis and pregnancy). She was excited about it (the pregnancy), buying gifts and things. As far as HIV diagnosis, it took a while to really tell my mom. I really wanted to keep it to myself until I was ready. Give her the news. Eventually, she was going to find out because at the time I had her picking up my meds and things like that. So I just decided, hey, she is going to find out, mom, I was like, I have HIV. And even since then she has been a great support.

Although Linda's mother was concerned about the HIV diagnosis when first learning about the pregnancy, the mother was reassured after discussing HIV and pregnancy with the physicians and other health care professionals at the clinic.

Eight out of the 10 women described their relationship with the father of the baby as supportive in regards to their HIV and also taking ART. The other two women reported not being able to freely discuss HIV with the father of their babies (who were also living with HIV) and did not receive support when taking ART. Most of the individuals who were supportive knew of the women's HIV status; however, some women had not disclosed their HIV status with those who were identified as supportive.

Discussion

This study is unique in that it directly uncovers the pregnant women's experience from their own perspective (their thoughts, feelings and actions) to better understand taking ART during pregnancy. Previous studies have described what is linked to non-adherence: adverse health symptoms, depression or overwhelmed feelings, non-adherence to prenatal vitamins, illicit drug use, and alcohol and cigarette use (Anderson, 2012; Bardequez, et al., 2008; Nachega, et al., 2012; Mellins, et al., 2008; Stevens & Hildebrandt, 2009; Wilson, Ickovics, Fernandez, Koenig, Walter, 2001). In contrast, our study provides rich details and insight into the experience of what it is like to be pregnant living with HIV and taking ART. The results highlight how taking ART affects multiple aspects of their daily life and the balancing act that these women experience when taking ART. Women juggled to deal with the negative physical and emotional consequences of ART and the positive health outcomes that ART promised. The negative aspects of ART were immediate (e.g., side effects and feeling their own mortality) and resulted in the women often felt overwhelming. The positive outcomes were far less tangible and in the future, such as having a baby free of HIV and being healthy themselves to be an active part of their children's lives. Participants derived meaning out of their ART experiences by having hope for their own and their baby's future and health, which is similar to previous findings when women were diagnosed with HIV

during pregnancy (Kelly, Alderdice, Lohan, & Spence, 2012). Women felt a constant battle between negative and positive aspects of taking ART during pregnancy, some days women focused on the negative whereas other days the positive outcomes were the focus. Taking ART was not easy for the women, and even those who denied missing dose of ART reported a struggle when taking ART. Similar results in non pregnant women found missing doses to be part of the experience and that even taking a dose late was better than missing it completely; life is complicated and women found taking medications difficult (Stevens & Hildebrant, 2009).

Women identified multiple motivators to help them take ART. The two strongest motivators were maintaining their own health to be present as their children grew up and minimizing the risk of perinatal transmission to their babies. A new finding was the substantial amount of reminders that the fathers of the babies provided to some of the women to assist them with remembering to take ART. Previous research had not identified the father of the babies as providing any reminders for pregnant women to take their ART.

Consistent with previous research that found many young women do not disclose, this study also found that some key support persons during the pregnancy were not aware of the women's HIV status (Carter et al., 2013). The lack of disclosure of HIV status to family and friends that are providing social support for the pregnancy resulted in a disconnect between the amount of support these critical individuals provided related to ART and the amount of support the women actually needed. Disclosure to the women's mothers has been shown in other studies to be linked with increase adherence to ART (Demas et al., 2005).

There were numerous struggles associated with taking ART during pregnancy. Consistent with other studies (Mellins et al., 2008), women experienced negative side effects of ART that made it difficult to adhere to their schedule. In addition to physical struggles, women also encountered emotional struggles unique to women living with HIV. Even women who had been living

with HIV for years and had other children since being diagnosed continued to battle with coming to terms with the diagnosis itself and with the life-altering need to manage a chronic and potentially life threatening disease.

Women who seem to be managing being pregnant and taking ART also described facing a multitude of barriers. On the surface one woman appeared to have a secure and communicative relationship with her husband and adequate financial resources which would contribute to her success at taking ART. She and her husband had been trying to become pregnant for four years. But as the interview progressed she expressed a more complete picture of her ART experience and revealed significant struggles taking her ART. She and her husband have not disclosed their HIV diagnoses to anyone and do not speak about the diagnoses with one another. Therefore there was an absence of social support in her life regarding living with HIV. During the interview, as the woman shared that this was the first time she spoke about her diagnosis, the researcher felt a great sense of sadness fill the room. This extreme case of having no social support around HIV and ART lead to a sense of social isolation that was palpable during the interview. This woman was alone in her struggles with ART and HIV without support.

Continual support from nurses and other providers is vital both when women are showing signs of struggling with taking ART and when they are not showing overt signs of struggling. Our findings suggest that women can easily begin to struggle after being able to take ART consistently. During the prenatal period, allowing enough time for and initiating the conversation about the different aspects of their lives that may help or hinder their ability to take their ART is critical in understanding their experience. Frequent and ongoing discussions about who the women can ask for can help and what type of help they might need to support ART adherence is needed rather than focusing solely on pill counts and viral load. Nurses can help to identify potential support persons and how to approach the topic of ART and what type of information might be needed. For some women, this information might

include a discussion about how to disclose HIV as well as strategies to adhere to ART. Encouraging women to foster supportive relationships during pregnancy and also after the birth when many new mothers need extra support. We know that adherence drops dramatically postpartum and our findings suggest that the balancing act after delivery is more difficult (Bardequez et al., 2008; Mellins et al., 2008). All of the support received while pregnant to minimize transmission to the baby no longer exists postpartum. Nurses and other providers need to collaborate with their patients to identify facilitators and barriers of ART so that individualized ART plans are developed prenatally that can promote adherence.

A limitation of this study is that the sample was recruited from an academic clinic with intensive resources that are not typically found in smaller clinics. The recruitment site has a multi-disciplinary team approach to delivering care, which may be unique in comparison to other clinics providing care to pregnant women and affect the lived experience. The goal of this study is not to generalize the results, but to understand the lived experience that these women described. Women who agreed to participate may have viewed the PI as a healthcare provider and may have limited their responses about missing doses of ART, however the women all seemed to openly discuss their experience with ART.

Conclusion

ART is critical in decreasing perinatal HIV transmission and pregnant women have reported balancing act that taking ART requires. Nurses can provide the support that is needed when taking ART during pregnancy. Further research is needed to develop specific interventions to support women during their pregnancy while taking ART.

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Table I

Sample Characteristics

Characteristic	Total sample (N = 10)
Maternal Age (mean, range)	28, 21-41
US born	7
Ethnicity	
Black/African American/African Non Hispanic	8
Hispanic	2
Partner	
Boyfriend or spouse	8
Father of baby not a current partner	2
Current weeks pregnant at time of interview (mean, range)	25.1, 19-37
Highest level of education	
Some high school/ high school graduate	4
Some college/college graduate	4
Graduate degree	2
HIV diagnosis during this pregnancy	2
Prior Pregnancy with HIV diagnosis	6

APPENDICES

APPENDIX A

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AT CHICAGO

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Approval Notice

Initial Review – Expedited Review

May 9, 2013

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Phone: (773) 370-0990

RE: Protocol # 2013-0440

"Exploring the Lived-Experience of Antiretroviral Treatment among HIV-Infected Pregnant Women"

Dear Dr. Shore:

Members of Institutional Review Board (IRB) #3 reviewed and approved your research protocol under expedited review procedures [45 CFR 46.110(b)(1)] on May 7, 2013. You may now begin your research.

Please note the following information about your approved research protocol:

Protocol Approval Period: May 7, 2013 - May 7, 2014

Approved Subject Enrollment #: 0 Total; 20 at Northwestern University

Additional Determinations for Research Involving Minors: These determinations have not been made for this study since it has not been approved for enrollment of minors.

Performance Sites: UIC, Northwestern Memorial Hospital

Sponsor: Sigma Theta Tau Honor Society Alpha Lambda Chapter (UIC)

Research Protocol(s):

a) Exploring the Lived-Experience of Antiretroviral Treatment among HIV-Infected Pregnant Women, Version 1, Date: March 14, 2013

Informed Consent(s):

a) Consent will be obtained at the Northwestern University/Northwestern Memorial Hospital. Data analysis will occur at UIC and only de-identified data will be shared with UIC.

HIPAA Authorization(s):

a) Authorization will be obtained at the Northwestern University/Northwestern Memorial Hospital. Data analysis will occur at UIC and only de-identified data will be shared with UIC.

Your research meets the criteria for expedited review as defined in 45 CFR 46.110(b)(1) under the following specific categories: 6, 7

(6) Collection of data from voice, video, digital, or image recordings made for research purposes.,

(7) Research on individual or group characteristics or behavior (including but not limited to research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Please note the Review History of this submission:

Receipt Date	Submission Type	Review Process	Review Date	Review Action
04/25/2013	Initial Review	Expedited	05/07/2013	Approved

Please remember to:

→ **Use only the IRB-approved and stamped consent document(s) enclosed with this letter when enrolling new subjects.**

→ Use your **research protocol number** (2013-0440) on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with all requirements on the enclosure,

"**UIC Investigator Responsibilities, Protection of Human Research Subjects**"
(http://tigger.uic.edu/depts/ovcr/research/protocolreview/irb/policies/0924.pdf)

Please note that the UIC IRB has the right to ask further questions, seek additional information, or monitor the conduct of your research and the consent process.

Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact the OPRS office at (312) 996-1711 or me at (312) 355-1404. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Sheilah R. Graham, BS

IRB Coordinator, IRB # 3

Office for the Protection of Research Subjects

Enclosure(s): None

cc: Susan Vonderheid, Faculty Sponsor, Women, Child, & Family Health Science, M/C 802
Barbara McFarlin, Women, Child, & Family Health Science, M/C 802
OVCR Administration, M/C 672

UNIVERSITY OF ILLINOIS
AT CHICAGO

Office for the Protection of Research Subjects (OPRS)
Office of the Vice Chancellor for Research (MC 672)
203 Administrative Office Building
1737 West Polk Street
Chicago, Illinois 60612-7227

April 1, 2014

Jessica Shore

Women, Child, & Family Health Science

Women, Children, and Family Sciences

845 S Damen, M/C 802

Chicago, IL

Phone: (773) 370-0990

RE: Protocol # 2013-0440

"Exploring the Lived-Experience of Antiretroviral Treatment among HIV-Infected Pregnant Women"

Dear Ms. Shore:

Your Continuing Review was reviewed and approved by the Expedited review process on March 25, 2014. You may now continue your research.

Please note the following information about your approved research protocol:

Protocol Approval Period: March 25, 2014 - March 25, 2015

Approved Subject Enrollment #: 0

Additional Determinations for Research Involving Minors: These determinations have not been made for this study since it has not been approved for enrollment of minors.

Performance Sites: UIC, Northwestern Memorial Hospital

Sponsor: Sigma Theta Tau

Research Protocol:

b) Exploring the Lived-Experience of Antiretroviral Treatment among HIV-Infected Pregnant Women, Version 1, Date: March 14, 2013

Informed Consent:

b) Consent will be obtained at the Northwestern University/Northwestern Memorial Hospital. Data analysis will occur at UIC and only de-identified data will be shared with UIC.

HIPAA Authorization:

b) Authorization will be obtained at the Northwestern University/Northwestern Memorial Hospital. Data analysis will occur at UIC and only de-identified data will be shared with UIC.

Your research meets the criteria for expedited review as defined in 45 CFR 46.110(b)(1) under the following specific categories:

(6) Collection of data from voice, video, digital, or image recordings made for research purposes., (7) Research on individual or group characteristics or behavior (including but not limited to research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Please note the Review History of this submission:

Receipt Date	Submission Type	Review Process	Review Date	Review Action
03/20/2014	Continuing Review	Expedited	03/25/2014	Approved

Please remember to:

→ Use your **research protocol number** (2013-0440) on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with all requirements on the enclosure,

"UIC Investigator Responsibilities, Protection of Human Research Subjects"
(http://tigger.uic.edu/depts/ovcr/research/protocolreview/irb/policies/0924.pdf)

Please note that the UIC IRB has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact OPRS at (312) 996-1711 or me at (312) 355-1609. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Rahab Mwangi, MPH

IRB Coordinator, IRB # 3

Office for the Protection of Research Subjects

cc: Barbara McFarlin, Women, Child, & Family Health Science, M/C 802
Susan Vonderheid, Faculty Sponsor, M/C 802
OVCR Administration, M/C 672

Appendix B

Institutional Review Board Office
Northwestern University
Biomedical IRB
750 North Lake Shore Drive
Suite 700
Chicago, Illinois 60611
312-503-9338

Social and Behavioral Sciences IRB
600 Foster Street
Chambers Hall, Second Floor
Evanston, Illinois 60208
847-467-1723

NORTHWESTERN UNIVERSITY

4/4/2013

Mrs. Jessica Shore
Northwestern Memorial Hospital (NMH)

jshore@nmh.org

IRB Project Number: STU00076508
Project Title: Exploring the Lived-Experience of Antiretroviral Treatment among HIV-Infected Pregnant Women
Project Sites:

Northwestern University (NU)
Northwestern Memorial Hospital (NMH)

Submission Considered: New Submission **Submission Number:** STU00076508
Study Review Type: Expedited
Review Date: 4/4/2013

Status: APPROVED **Approval Period:** (4/4/2013 - 4/3/2014)

Dear Mrs. Shore,

The IRB considered and approved your submission referenced above through 4/3/2014. As Principal Investigator (P.I.), you have ultimate responsibility for the conduct of this study, the ethical performance of the project, and the protection of the rights and welfare of human subjects. You are required to comply with all NU policies and procedures, as well as with all

applicable Federal, State and local laws regarding the protection of human subjects in research including, but not limited to the following:

- Not changing the approved protocol or consent form without prior IRB approval (except in an emergency, if necessary, to safeguard the well-being of human subjects).
- Obtaining proper informed consent from human subjects or their legally responsible representative, using only the currently approved, stamped consent form.
- Promptly reporting unanticipated problems involving risks to subjects or others, or promptly reportable non-compliance in accordance with IRB guidelines.
- Submit a continuing review application 45 days prior to the expiration of IRB approval. If IRB re-approval is not obtained by the end of the approval period indicated above, all research related activities must stop and no new subjects may be enrolled.

IRB approval includes the following:

Written Consent Form/Consent Form and Authorization for Research:

Name
consent-form-no-hipaa HIVPregnancy[1] edits 03_21_13.doc

Protocol Document:

Name
protocol 3_14_13.doc

Survey/Questionnaires:

Name
DemographicsIRB.docx

Interview Scripts:

Name
Interview GuideIRB.docx

Institutional Review Board Office
Northwestern University
Biomedical IRB
750 North Lake Shore Drive
Suite 700
Chicago, Illinois 60611
312-503-9338

Social and Behavioral Sciences IRB
600 Foster Street
Chambers Hall, Second Floor
Evanston, Illinois 60208
847-467-1723

2/28/2014

Mrs. Jessica Shore
Northwestern Memorial Hospital (NMH)
jshore@nmh.org

IRB Project Number: CR1_STU00076508
Project Title: Exploring the Lived-Experience of Antiretroviral Treatment among HIV-Infected Pregnant Women
Project Sites:

Northwestern University (NU)
Northwestern Memorial Hospital (NMH)

Submission Considered: Continuing Review **Submission Number:** CR1_STU00076508

Submission Review Type: Expedited
Review Date: 2/27/2014

Status: APPROVED **Approval Period:** (2/27/2014 - 2/26/2015)

Dear Mrs. Shore,

The IRB considered and approved your submission referenced above through 2/26/2015. As Principal Investigator (P.I.), you have ultimate responsibility for the conduct of this study, the ethical performance of the project, and the protection of the rights and welfare of human subjects. You are required to comply with all NU policies and procedures, as well as with all applicable Federal, State and local laws regarding the protection of human subjects in research including, but not limited to the following:

- Not changing the approved protocol or consent form without prior IRB approval (except in an emergency, if necessary, to safeguard the well-being of human subjects).
- Obtaining proper informed consent from human subjects or their legally responsible representative, using only the currently approved, stamped consent form.

- Promptly reporting unanticipated problems involving risks to subjects or others, or promptly reportable non-compliance in accordance with IRB guidelines.
- Submit a continuing review application 45 days prior to the expiration of IRB approval. If IRB re-approval is not obtained by the end of the approval period indicated above, all research related activities must stop and no new subjects may be enrolled.

IRB approval includes the following:

Protocol:

Name
protocol 3_14_13.doc

For more information regarding IRB Office submissions and guidelines, please consult. Institution has an approved Federalwide Assurance with the Department of Health and Human Services: FWA00001549.

VITA

NAME Jessica Elizabeth Shore

EDUCATION

2014 University of Illinois at Chicago, Doctor of Philosophy in Nursing Science (expected)
2002 Loyola University Chicago, Bachelor of Science in Nursing, cum laude

LICENSURE AND CERTIFICATIONS

2002 - present State of Illinois Registered Nurse: 041-331033
2007 - present Certified Medical Surgical Nurse

PROFESSIONAL EXPERIENCE

2013- present Manager, Office of Research
Northwestern Memorial Hospital, Chicago, IL

2011 - 2013 Research Compliance Coordinator
Northwestern Memorial Hospital, Chicago, IL

2004 - 2011 Nurse Specialist, HIV and Transplant Infectious Diseases Research Nurse
Northwestern University Feinberg School of Medicine
Department of Medicine, Division of Infectious Diseases – Chicago, IL

2006 - 2010 Float Pool Staff Nurse
Northwestern Memorial Hospital, Chicago, IL

2003 - 2004 Clinical Research Associate Nurse, HIV Research Nurse
Rush University Medical Center Rush College of Medicine
Department of Medicine, Section of Infectious Diseases – Chicago, IL

2002 - 2003 MICU Staff Nurse
Northwestern Memorial Hospital, Chicago, IL

2002 - 2003 Clinical Lab Instructor,
Niehoff School of Nursing Loyola University Chicago

A**WARDS, HONORS, AND DISTINCTIONS**

2013 2nd Place Poster "Perceptions of Alcohol Substance use in Malawi Male Adolescents" Palmer Symposium, Chicago, IL
2010 Young Alumna Award Niehoff School of Nursing 75th Anniversary, Loyola University Chicago
2009 Sigma Theta Tau Nursing Honor Society Induction, University of Illinois Chicago
2002 Robert Wood Scholarship, Niehoff School of Nursing, Loyola University Chicago
2001 Niehoff School of Nursing Service Award, Loyola University Chicago

RESEARCH FUNDING

2013 Seth Rosen Research Award, College of Nursing ($500)
2013 Sigma Theta Tau, Alpha Lambda Chapter Dissertation Award ($1,000)

PUBLICATIONS

Asmuth D., Murphy R., Rosenkranz S., Lertora J., Kottilil S., Cramer Y., Chan E., Schooley R., Rinaldo C., Thielman N., Li X., Wahl S., Shore J., Janik J., Lempicki R., Simpson Y., Pollard R. AIDS Clinical Trials Group A5192 Team. (2010). Safety, tolerability, and mechanisms of antiretroviral activity of pegylated interferon Alfa-2a in HIV-1 monoinfected participants: a phase II clinical trial. *Journal of Infectious Diseases 201* (11), 1686-1696. (peer reviewed)

Gerschenson, M., Kim, C., Berzins, B., Taiwo, B., Libutti, D., Choi, J., Chen, D., Weinstein, J., Shore, J., da Silva, B., Belsey, E., McComsey, G., Murphy, R. (2009). Mitochondrial function, morphology and metabolic parameters improve after switching from stavudine to a tenofovir-containing regimen. *Journal of Antimicrobial Chemotherapy(63)* 1244-50. (peer reviewed)

PROFESSIONAL AND SCIENTIFIC SERVICE

2010 - present Illinois Department of Public Health Advisory Committee for HIV Prevention of Fetal and Infant HIV Transmission, Chicago, IL
2009 - 2011 Consultant, Social & Scientific Systems Inc. NIH task order "Anti-Viral and Immune Plasma Infrastructure Development".
2009 Visiting Scholar, HIV and Pregnancy: Siriraj Hospital, Bangkok, Thailand

2004 - 2010 Field Representative, A5192: A Phase II, safety, tolerability, and mechanisms of antiretroviral activity of pegylated interferon Alfa-2a in HIV-1 monoinfected participants, Adult AIDS Clinical Trials Group, National Institutes for Allergy and Infectious Diseases

PRESENTATIONS

Shore, J. (2012, May 18). *Informed consent document: friend or foe?* 3rd Annual Clinical Research Mini Symposium, Chicago, IL.

Jere, D., Shore, J.,Ricca, P., Norr, K. (2012, April 14). *Perceptions of alcohol, substance use, and risky sexual behavior in Malawian youth.* MNRS Annual Research Conference, Dearborn, MI.

Shore, J. (2011, July 14 and 21). *Adherence to HAART and Nursing Interventions.* PEPFAR Tanzania Nursing Conference, Dar es Salaam, Tanzania.

Shore, J. (2011, July 13 and 20). *PMTCT and Breastfeeding Guidelines: TZ Country Update.* PEPFAR Tanzania Nursing Conference, Dar es Salaam, Tanzania.

Kelly, B., Shore, J., Fabiyi, C., Wodda, A. (2011, May 20). *From the Concrete Confines: Genesis of Performance Ethnography Across Disciplines.* Seventh International Congress of Qualitative Inquiry, University of Illinois at Urbana-Champaign, IL.

Shore, J. (2009, September 26 and October 24). *"Top 10 Greatest Hits" Tips for Study Coordinators for Executing 303 Protocol.* BioCryst International Investigator's Meeting, Chicago, IL.

Shore, J. & Williams, L.(2007, April17 and September 19). *HIV Update 2007: The new face of HIV.* Lunch and Learn series. Northwestern Memorial Hospital, Chicago, IL.

COMMITTEE SERVICE

2011 - present Nursing Research and Evidence Based Practice Committee, Northwestern Memorial Hospital
2011 - present Clinical Specimen Release Committee, Northwestern Memorial Hospital
2011 - present Institutional Review Board, Northwestern University
2006 - 2008 President, Niehoff School of Nursing Alumni Board, Chicago, IL
2005 - 2007 Quality Improvement Committee, HIV Center, Northwestern Memorial Hospital
2003 - 2010 Niehoff School of Nursing Alumni Board, Chicago, IL

PROFESSIONAL SOCIETY MEMBERSHIPS

Midwest Nursing Research Society
Sigma Theta Tau International
Academy of Medical Surgical Nurses
Association of Nurses in AIDS Care