Race and the Experiences of Mothers with HIV/AIDS

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July 2007
**SPECIFIC AIMS**

Motherhood represents a key identity for most women in society, but how do women with HIV/AIDS experience motherhood? Most American mothers struggle with fatigue and self-doubt while pursuing the cultural standard of the good mother, even under the most ideal circumstances. How do women with HIV/AIDS fulfill socially constructed expectations of motherhood while coping with HIV? The experience of race also exerts a strong impact on the experience of raising children. What, if anything, differentiates the experiences of non-Hispanic African American HIV positive mothers from their non-Hispanic White counterparts?

Women comprise the fastest growing HIV-infected population in the United States (Centers for Disease Control and Prevention 2007; Faithfull 1997; Hackl et al. 1997). The prime childbearing and childrearing ages for women are the ages when the vast majority of women are diagnosed with HIV/AIDS (Centers for Disease Control and Prevention 2007; Nelms 2005). In fact, as of 2000, 91% of women infected with HIV were between the ages of 13 and 49 (McCreary et al. 2003). Thus, the overwhelming majority of HIV positive women in the United States either have children or will become mothers after becoming HIV positive. In the United States, 70,000 children are born to HIV positive mothers each year (CDC 2007). Also, it is virtually impossible to determine the number of children whose mothers have become infected with HIV following their births (Lather and Smithies 1997). HIV positive mothers often provide the sole care for their children, some of whom are also HIV-infected (Marcenko and Samost 1999; Tompkins et al. 1999). Moreover, HIV positive mothers report that family members expect them to remain in the role of primary child and family caregiver in spite of their HIV infection (Hackl et al. 1997).

Researchers acknowledge that, until quite recently, most AIDS research has neglected to consider women outside of their role as caregivers to men with HIV/AIDS or as carriers of infection to men and infants (Barnes, Taylor-Brown, and Wiener 1997; Ciambrone 2001; Faithfull 1997; Hogan 2001; Sandelowski and Barroso 2003a and 2003b). This situation reflects
a broader social trend of concern for women’s health only in terms of their sexual and reproductive functions—in other words, only when women’s illness affects the health of others. Furthermore, research on women with HIV/AIDS has traditionally followed a pathology model (Wyche 1998), rather than incorporating the lived experiences of women into the focus of the research. This pathology model approaches the experiences of HIV positive women from the perspective of researchers as experts and assumes that there is something inherently inferior, wrong, or lacking about HIV positive women’s behavior and perspectives, indicated by the presence of HIV infection. In addition, little research to date has examined the impact of race and AIDS stigma on the lives of HIV positive mothers. My research project aims to address these gaps by using qualitative interview methods to approach the experiences of HIV positive mothers from their own perspectives, focusing on the impact of race, AIDS stigma, and maternal ideologies on the everyday experiences of mothers living with HIV/AIDS.

This research project’s main objective is to use qualitative interviews to understand the experiences of native non-Hispanic Black and non-Hispanic white mothers (hereafter referred to as Black and White women or mothers)¹ living with HIV/AIDS from the perspectives of the women themselves and to understand the meanings they make of their experiences. The primary research question is: How do the cultural ideologies surrounding motherhood and race affect the experiences of mothers with HIV/AIDS? To address this question, this thesis project has three specific aims:

1. to describe how Black and White HIV positive women with dependent children experience motherhood,

2. to understand how HIV positive mothers perceive cultural expectations and ideologies surrounding motherhood, and

¹ Research usually refers to African American and White native non-Hispanic women. However, some studies include African immigrants and non-Hispanic Caribbean immigrants. The present study will include only White and Black women born in the United States of non-Hispanic heritage. I use the term White to refer to non-Hispanic native-born White women. I will use the terms African American and Black interchangeably to refer to non-Hispanic native-born Black women.
3. to explore how social messages surrounding HIV and motherhood affect HIV positive mothers’ everyday lived experiences as mothers.

**BACKGROUND AND SIGNIFICANCE**

A review of the social science literature on HIV positive women and motherhood identifies certain main themes. Stigma clearly plays a central role in the lives of HIV positive mothers, both in terms of the experience of social stigma and the use of stigma reduction strategies. Issues related to the disclosure of one’s HIV serostatus to others represent another key concern for mothers with HIV/AIDS. The interplay between motherhood, illness, and identity, as well as the experience of time, are other strong themes. Despite the amount of research now available on women and HIV/AIDS, several omissions remain. Relatively little research has examined how race and AIDS stigma affects the lives of HIV positive mothers and potential differences by race in the maternal ideologies that shape HIV positive mothers’ lives. These themes and gaps in the literature are further discussed below.

**Mothering Against Stigma**

Stigma represents a common experience for mothers with HIV/AIDS. Goffman (1963) defines stigma as “an attribute that is deeply discrediting” (3). Stigmatized individuals possess a trait that marks them as different from and inferior to others. Thus, stigma reduces the individual in the minds of others “from a whole and usual person to a tainted, discounted one” (Goffman 1963: 3). However, Heijnders and van der Meij (2006) point out that stigma represents a social construct rather than an attribute of individuals. Stigma refers to society’s discrimination, rejection, marginalization, condemnation, and punishment of those possessing a stigmatized attribute and their close associates.

Cogan and Herek (1998) define AIDS stigma as “a pattern of prejudice, discounting, discrediting, and discrimination directed at people perceived to have HIV/AIDS, their significant others and close associates, and their social groups and communities” (416). They describe AIDS stigma as the product of fears of contagion and preexisting prejudice against the deviant
social groups most closely associated with the epidemic, namely gay men, intravenous drug users, and sex workers (see also Herek 1999). Carr and Gramling (2004) argue that “the stigma of HIV/AIDS is linked to everyone who is diagnosed regardless of their age, innocence, morality, gender, or race” (31). According to Parker and Aggleton (2003), however, stigma is employed to cement power relations and legitimate social inequalities, such as those based on race, gender, class, or sexual orientation. Similarly, Nyblade (2006) notes that AIDS stigma often compounds other pre-existing stigmas, such as those toward gay men and lesbians, single mothers, and the poor. According to Link and Phelan (2001), “stigma exists when elements of labeling, stereotyping, separation, status loss, and discrimination occur together in a power situation that allows them” (377). Accordingly, HIV positive women face a “double burden of discrimination” based on the intersection of AIDS stigma and gender inequality (Center for Reproductive Rights 2005: 11).

Berger (2004) devised the concept of intersectional stigma to address the experiences of HIV positive women for whom AIDS stigma intersects with other devalued or disempowered social statuses, particularly those statuses concerning race, class, gender, sexual orientation, substance abuse history, and criminal history. Race, class, and gender oppression thus may combine with AIDS stigma to further disadvantage those who occupy devalued statuses such as Black men and women, homosexuals, and the poor. However, the impact of these intersectional stigmas on women’s social roles, particularly as mothers, needs more attention.

AIDS stigma places tight constraints on HIV positive women’s realistic options, restricting access to health care, information, and social support systems (Carr and Gramling 2004; Center for Reproductive Rights 2005; Heijnders and van der Meij 2006; Herek 1999). Carr and Gramling (2004) found that fear of AIDS stigma served as a barrier to women’s efforts to maintain or enhance their health following their diagnosis with HIV/AIDS. Fear of AIDS stigma also exerts a significant influence on decisions concerning disclosing one’s HIV status to others (Carr and Gramling 2004; Duffy 2005; Herek 1999). For HIV positive mothers, the fear of
AIDS stigma constrains their ability to disclose their status to their children, their ability to take care of themselves, and their ability to obtain medical treatment. Many HIV positive mothers report fearing that disclosing their HIV status could result in immediate custody loss of their children (Hackl et al. 1997). Consequently, their need to restrict information causes many HIV positive mothers to feel that they are leading double lives (Ingram and Hutchinson 1997).

Their association with someone with HIV may cause family members and caregivers of people with HIV/AIDS to experience courtesy stigma (Duffy 2005; Herek 1999), a stigma acquired as a result of being related to a person with a stigma. This suggests potential stigmatization of children of HIV positive mothers, regardless of their own HIV serostatus. Ingram and Hutchinson (2000) found that fear of introducing stigma into their children’s lives constrained HIV positive mothers’ health care choices.

HIV positive mothers use a number of techniques to manage stigma. For example, attempting to educate others about HIV and to advocate for others who share the stigma of HIV serve as potential stigma reduction strategies (Heijnders and van der Meij 2006). Limiting the number of people who are aware of one’s HIV status represents another stigma management technique. However, Carr and Gramling (2004) describe disclosure as a “double-edged sword” (p. 37). As Herek (1999) notes, concealing one’s HIV positive status contributes to isolation, thereby depriving one of badly needed social support (see also Faithfull 1997 and Nelms 2005). Consequently, Ingram and Hutchinson (2000) find that the decision to disclose their HIV status to their children represents a particularly problematic conflict for HIV positive mothers. Disclosure can help to empower children against the stigma associated with their mother’s HIV status by giving them the tools to challenge social prejudice. On the other hand, social pressures may also encourage mothers to protect their children from upsetting information and suggest that knowledge of their mother’s HIV positive status will devastate children. Faithfull (1997) discovered that fear of AIDS stigma and the resulting secrecy led to increased familial conflict and disruption for HIV positive mothers, causing their children to act out and exhibit
other discipline problems. However, despite the wealth of literature concerning the impact of AIDS stigma on women and their children, research specifically addressing the impact of intersecting stigmas associated with race and HIV on the experiences of mothers living with HIV/AIDS is still needed.

**Motherhood as Social Construction**

The social context in which it occurs profoundly shapes one’s experience of motherhood. Motherhood occurs in specific historical situations framed by interlocking structures of race, class, and gender (Collins 1994: 45). Thus, as Glenn (1994) stresses, mothering is not only gendered, but also racialized. American cultural constructions of motherhood are built on a solid foundation of race, class, and gender ideologies. Specifically, the social construction of motherhood in the U.S. has been shaped by white, middle class, heterosexual norms which leave little room for the broad historical, cultural, class, and ethnic diversities in mothering. Consequently, Patricia Hill Collins (1994, 2000) challenges the basic cultural definition of a mother. She argues that through cultural practices like “othermothering,” which she defines as acting as an informal surrogate parent for children in the community, most women including non-mothers participate in the activities and relationships of nurturing and care traditionally defined as mothering.

The study of mothers living with HIV/AIDS provides an excellent means to examine the social construction of motherhood in U.S. culture and how such constructions may vary by race. Until recently, HIV research only focused on women in their role as caregivers or as vectors of infection to men and infants (Barnes, Taylor-Brown, and Wiener 1997; Ciambrone 2001; Hogan 2001; Sandelowski and Barroso 2003a and 2003b). The overwhelming focus on vertical transmission in the literature on women and HIV/AIDS reflects the cultural devaluation of women and their health except as it affects their sexual and reproductive roles. As Hogan (2001) points out, within HIV/AIDS discourse, the cultural ideology of motherhood reduces
women to their sexual and reproductive capacities and disorders without considering their own health needs.

Expectations of self-reliance and self-sacrifice are central to cultural ideals of proper motherhood. Mothers who are ill are often still expected to care for others while also taking responsibility for their own health (Ciambrone 2001). Shouldering primary or sole responsibility for child care and household labor, most mothers have little time left for self-care activities and face barriers to seeking medical treatment. Like many women, HIV positive mothers internalize a “duty of care” which leaves little room for their own health needs (Wilson 2007: 617). Wyche (1998) uncovers an ethic of self-sacrifice running through her interviews with HIV positive African American mothers, as they assert their choice to “let me suffer so [my kids] won’t have to” (184). Likewise, Wilson (2007) finds that the strong moral discourses surrounding motherhood restrict the ways in which mothers with HIV/AIDS can legitimately speak about their status or assert their own needs and identities. However, the role of maternal discourse and the ethic of self-sacrifice in the experiences of mothers living with HIV/AIDS have not yet been compared across race.

Motherhood, Illness, and Identity

Researchers have linked having children with a number of positive consequences in the lives of women with HIV/AIDS. For example, children decrease their mother’s sense of isolation and taking care of children enhances the mother’s sense of competence and self-esteem (Tompkins et al. 1999). Also, many HIV positive women report that they rely on their children for social support (Bunting 2001; Williams et al. 1997). However, having children may introduce additional complications and stressors into the lives of women coping with HIV/AIDS. For example, Tompkins (1999) found that HIV positive mothers had a greater incidence of clinical depression compared to HIV positive women without children.

Ingram and Hutchinson (2000) note that motherhood represents a valued role for women in the United States, providing an important sense of identity, self-worth, and belonging.
However, reproductive and motherhood issues unique to women with HIV/AIDS lead many HIV positive women to face a “double bind” in their maternal role, in terms of the fact that social messages encourage women to fulfill the expectation to have children yet condemn reproduction among HIV positive women as deviant, even “cruel and uncaring” (Ingram and Hutchinson 1999: 118). Of HIV positive mothers’ unique conundrum, they find, “As women, they were socialized to have children by the society and culture in which they lived,” yet unlike HIV-negative women, “they feared being discredited as mothers by that same society” (Ingram and Hutchinson 1999: 101).

Identities may be simultaneously threatened and reinforced by illness (Wilson 2007). As HIV/AIDS undermines other sources of identity, the importance of a key identity such as motherhood status is amplified (Wilson 2007). Thus, Wilson (2007) found that HIV positive mothers place great emphasis on establishing and maintaining identities as good mothers and they tend to regard HIV infection as “a moral and existential threat to their identities as mothers” (611). Furthermore, women who occupy devalued social locations such as those defined by non-white race, poverty, former drug use, and commercial sex work find in motherhood strategies to resist marginalization and assert a positive social identity (Ingram and Hutchinson 1999, 2000). Moreover, Wilson (2007) discovered that HIV positive mothers’ role as mothers of dependent children seems to supply a moral justification for their continued existence, while the threat of no longer being needed as a mother appears to provoke fears of no longer serving any useful purpose.

Transcending Time

For many women with HIV/AIDS, the experience of having children offers the opportunity to alter their experience of time in the face of potentially uncertain futures and foreshortened lives. Of the multiple studies they reviewed, Sandelowski and Barroso (2003a) report, “The HIV-positive women… found in motherhood not only a reason to live but also a way to live forever” (166). Barnes (1997) describes the phenomenon of “eternal mothering” in which HIV
positive mothers redefine their roles as mothers in order to transcend the limitations illness places upon them. For example, the HIV positive mothers in her study used video cameras to record themselves giving advice and telling family stories in order that they could continue to offer guidance and support to their children even after the mothers had died. Likewise, Sandelowski and Barroso (2003a and 2003b) create the concept of “virtual motherhood” in order to account for the strategies HIV positive mothers use to compensate for illness-related constraints placed upon their mothering. For example, virtual motherhood includes creating material mementos for their children, making detailed plans for their children’s futures, leaving long letters for their children to read after the mother’s deaths, appointing caregivers for their children, and negotiating with God on behalf of their children’s wellbeing.

Research Gaps and Limitations

Despite prevalent research on women and HIV/AIDS, certain gaps remain. The relationship between HIV-positive women’s social location and their mothering experiences has received very little attention. When this type of research has been conducted, it has mostly compared the experiences of HIV positive women in developing nations with those of women in the world’s industrialized nations. Relatively little research has examined such differences in local communities. For example, virtually no research has examined racial differences in mothering experiences in the U.S. This represents a serious gap. Overall, the impact of intersectional stigmas pertaining to race and HIV positive status on motherhood remains to be explored.

Research on the mother-child relationship in the context of HIV/AIDS has also neglected to examine the extent to which the experience of motherhood affects the stress of coping with HIV. Little research has focused on how HIV positive mothers regard their and their children’s futures and how they make decisions related to their children. Furthermore, few studies focus on HIV positive mothers’ subjective accounts of their lived experiences.
This study is timely and significant for several reasons. This study elaborates on current understandings of motherhood among women living with HIV/AIDS with dependent children by focusing on the perspectives of Black and White HIV positive mothers and the issues they identify as central to their experiences. Using the rich responses generated by in-depth interviews, this study aims to determine how women actively construct their identities as mothers in a broader social context which may place tight constraints on women’s childrearing roles. The research sets out to empower women to reflect on their experiences and determine their needs and goals in the context of their own families by encouraging them to adopt the role of expert and recognize the unique importance of their own experiences and perspectives. It will also give health care providers and care coordinators information about the needs and experiences of motherhood from the perspective of HIV positive women themselves. The study of the experiences of motherhood for HIV positive women also promises to address issues of identity and the social construction of motherhood. More generally, this study promises to contribute to theories about how marginalized groups actively engage in constructing identities in the face of stigma and other challenges.

**Methodology**

For this qualitative study, I will conduct a series of semi-structured in-depth interviews using a purposive sample of self-identified HIV positive women with dependent children. A qualitative approach is most appropriate for the purposes of this research in order to uncover the meanings that HIV-infected mothers of dependent children construct from the perspective of the mothers themselves. Researchers studying the experiences of people with HIV/AIDS and other chronic illnesses have successfully employed this approach to uncover the meanings and identities that people actively construct from the context of their lives (Berger 2004; Charmaz 1997; Ciambrone 2003).

The proposed study is phenomenological in nature (Creswell 1998), as it intends to focus on the lived experiences of women who share the same phenomenon of raising children.
while coping with HIV/AIDS. Therefore the objectives of the study require the use of qualitative interviewing in order to generate an in-depth, holistic understanding of complex personal experiences from the perspective of the research participants themselves. Due to the exploratory nature of the proposed study, in-depth interviews of a targeted sample of participants promise to generate rich data which will provide the foundation for further study.

I will use a critical feminist theoretical paradigm to guide the research process (Esterberg 2002). This theoretical perspective identifies the role of subjectivity in all research activity, seeks to understand the subjective experiences of members of disempowered social groups, recognizes that social research represents a social and moral activity, and regards the empowerment and emancipation of oppressed groups as a central goal of any meaningful research (Esterberg 2002; Rubin and Rubin 2005). Well suited for qualitative research using in-depth interviews, feminist research “insists on the value of subjectivity and personal experience” (Black qtd. in Reinharz 1992: 3).

**Researcher Role**

This study involves certain reflexivity concerns. Reflexivity refers to the researcher’s scrutiny of her research plan, experiences, decisions, and interpretations in ways that bring the researcher into the process and allow the reader to assess how and to what extent the researcher’s interests, positions, and assumptions influenced the research (Charmaz 2006: 188). Reflexivity serves as the means for me to find an ethical way of “telling stories that are not mine” (Lather 1995: 53).

The idea for the study developed out of a combination of personal experiences and intellectual interests. On a personal level, my experiences as a member of a stigmatized social group prompted my interest in the experiences of other members of stigmatized social groups. In addition, my experiences as a mother motivated me to examine the social construction of motherhood in Western societies. The relationship between my stigmatized status and my role as a mother prompted me to try to understand the experiences of other women for whom the
experience of stigma and other difficult circumstances pose challenges to their mothering. Additionally, my intellectual interests have driven me to pursue research that explores the concept of stigma, the relationship between social roles and individual agency, gender, and social inequalities in health and illness. Therefore, a study of mothers’ experiences of HIV/AIDS was easy for me to pursue as it allowed me to combine my personal and intellectual interests.

In the fall of 2006, I conducted a small exploratory interview study of HIV positive women’s experiences of pregnancy and childbirth. The research experience and the findings that emerged prompted me to want to explore HIV positive women’s motherhood experiences from the standpoints of maternal and racial ideologies and social inequalities. Furthermore, the more reading and research on women and HIV/AIDS I do, the more deeply I recognize what a passion I have for this topic of research.

In conducting the research, I will adopt an outsider researcher role because of my lack of shared HIV positive status with my study participants. However, I can simultaneously focus on shared attributes and experiences, primarily motherhood. My own personal experiences and social location serve as potential sources of bias, in both the negative and positive implications of the term (Hammersley and Gomm 1997). This means that although I can be an empathic interviewer, I lack the perspective that comes with being a part of the community under study. I may encounter challenges in establishing rapport and building trust with interview participants. In addition, perceptions of my bias against the traditional health care system and my sympathetic feelings toward women with HIV may distort the type of responses participants give. Other factors, such as my race, perceived age, physical appearance, and role as a college graduate student may also impact the quality of data I am able to obtain, either positively or negatively. However, I also have the advantage of distance which may help me to better understand how the social context impacts the phenomena under study.

I will engage in a process of self-reflection in order to address my biases. I will keep a research journal in which to document my thoughts, feelings, and observations. I will also use
peer review and regular critique from my faculty advisor to help with validity and compensation for potential biases.

Sample and Recruitment

My targeted research sample will consist of 16 self-identified HIV positive women in Indiana. In order to avoid focusing on the additional complications of teenage motherhood and due to ethical concerns which prohibit me from interviewing minors, participants must be 21 years of age or older. Participants must have one or more dependent children aged 18 or younger living with them in the home at least half of the time. Due to ethical concerns about the increased vulnerability of newly-diagnosed HIV positive research participants, participants must have been diagnosed with HIV at least two years prior the interview date in order to meet the eligibility requirements for participation. As the research focuses on racial differences as the main point of comparison, participants will be selected by race-ethnicity so that half of the sample will consist of native non-Hispanic White women and the other half will consist of native non-Hispanic Black women (referred to as White and Black women). Eligibility requirements exclude members of particularly sensitive populations, including women with cognitive impairments, minors, women who are currently incarcerated, and women who are participating in an inpatient treatment program for alcohol or drug abuse. It is not uncommon for women with HIV/AIDS to lose custody of their children or to make alternative living arrangements for them. Since this study will focus solely on women whose children reside with them in the home, the unique struggles and challenges of this specific group of mothers with HIV/AIDS experiencing separation from their children will be excluded.

HIV positive women represent a hidden population and consequently require the use of purposive and participant-driven sampling measures in order to obtain a sufficient research sample. Recruitment will involve advertising the study through AIDS service organizations, social service agencies, Ob/Gyn clinics, public health clinics, infectious disease clinics, and support groups throughout Indiana. I will also post announcements on HIV/AIDS-related e-mail
listservs catering to Midwest residents. I will also use a chain referral method of recruitment (Watters and Biernacki 1989) by asking study participants to give flyers to other HIV positive women who might be eligible to participate in the study. Once potential participants contact me by telephone or e-mail through the information listed on study advertisements, I will conduct a pre-screening interview to determine their eligibility for participation. Upon determining participants’ eligibility, I will schedule interviews with eligible participants.

**Research Instruments**

I will conduct private in-depth semi-structured interviews with mostly open-ended questions. The interviews will run one to two hours in length. I will tape record the interviews with participants’ consent and take handwritten fieldnotes following each interview. I will also keep a research journal in order to capture my experiences and insights gained during the research process. Semi-structured interviews will serve as the best method for uncovering the meaning that HIV positive mothers make of their experiences because they allow participants to voice their own perspectives and assert what is important to them from their own standpoints.

At the beginning of the interview, I will acquaint the participant with the purpose of my research. Then, I will go through the informed consent process with her, informing her of her rights as a study participant, potential risks involved in the study, and contact information for concerns and questions. Then I will give her a $25 gift card for her time. Next, I will ask the participant a series of demographic questions, followed by a series of open-ended questions with prompts and follow-up questions. Finally, I will ask her a series of closing questions, thank her for her participation, and give her flyers to give to any potential participants she might know. If appropriate, I will share with her the contact information of AIDS service organizations that the participant can contact for counseling and other assistance. I will also take time to follow up with any participant who appears upset after the interview.
Data Analysis

I will analyze the data generated by the interviews using grounded theory techniques (Charmaz 2004, 2006; Glaser and Strauss 1967). Within one week of conducting each interview, I will transcribe the interview recording. I will use line-by-line coding to locate emergent themes in the transcripts. I will use information gained from early interviews to guide later interviews, letting emergent themes guide my questions. Next, I will use focused coding to gather repeating themes into categories. I will use Charmaz’s series of memo-writing techniques to delve deeper into categories and to draw connections between categories. Finally, I will use these memos to generate a complete analysis of the data. I will also use peer reviews and external critiques at all stages of the research process with my thesis advisor to improve the validity of my findings.

Potential Risks and Limitations

This study involves certain risks to participants. The most likely risk to participants would concern the risk involved in disclosure of one’s HIV positive serostatus. Considering that one’s HIV status is private and sensitive, with the potential to lead to discrimination and stigmatization, any breach of confidentiality of responses could cause harm to participants. Additionally, participants might experience emotional or psychological discomfort in responding to questions of a personal nature regarding their experiences with HIV/AIDS and parenting. Every effort will be made to monitor these risks and the study will receive IRB approval.

Although this research aims to generate useful findings concerning HIV positive mothers’ experiences, its limitations should be kept in mind. In particular, the proposed sample will not prove representative of all mothers with HIV/AIDS. The sample will be recruited from social networks, AIDS service organizations, and medical clinics in the U.S. Midwest. These recruitment techniques will exclude many potential participants, including institutionalized women, women who are very ill, and non-English speakers, to name only a few. Furthermore, given the tremendous stigma associated with HIV/AIDS, the risks study participants will
undertake to participate in the study suggest advantages over HIV positive women for whom the risk of potential disclosure and the resources required to participate would prove prohibitive. Thus, the sample may be biased toward mothers who are more open about their HIV status and who have the resources such as child care and transportation that make it easier for them to participate in research.

**CONCLUSION**

A review of the research literature suggests that motherhood is a key social role for many HIV positive women. Having children has a definite impact on the lives of women with HIV/AIDS. However, current research is limited in helping us understand how the interplay of AIDS stigma and marginalized racial status impacts HIV positive women’s experiences as mothers. Furthermore, how HIV positive women construct meanings and identities out of their experiences as mothers in a social context with constrained definitions of motherhood has been insufficiently examined. The proposed research study intends to help close these gaps.

**TIMELINE FOR COMPLETION OF THESIS**

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<thead>
<tr>
<th>DATE</th>
<th>TASK DESCRIPTION</th>
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<tbody>
<tr>
<td>July 5, 2007</td>
<td>Submission to the IRB for Approval</td>
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<tr>
<td>July 19, 2007</td>
<td>Thesis Proposal Meeting</td>
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<tr>
<td>August-December, 2007</td>
<td>Data Collection and Analysis</td>
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<td>January 1, 2008</td>
<td>Plan to Complete Data Collection and Analysis</td>
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<td>January-March, 2008</td>
<td>Write Thesis</td>
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<td>April, 2008</td>
<td>Thesis Defense</td>
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REFERENCES


Wilson, Sarah. 2007. “‘When You Have Children, You’re Obliged to Live’: Motherhood, Chronic Illness and Biographical Disruption.” *Sociology of Health and Illness* 29: 610-626.

HIV+ Mothers Needed!!!

I am looking for African American and White HIV-positive women of non-Hispanic heritage to participate in a 1-2 hour taped interview concerning the unique experiences of HIV+ mothers.

Confidentiality is my first priority.

I am a student in Sociology at IUPUI conducting graduate research on motherhood and related experiences of women with HIV/AIDS.

I want to hear your story!

Who can participate?

Non-Hispanic African American and Non-Hispanic White women 21 and older who are HIV positive, tested positive at least 2 years ago, have at least one child 18 or younger at home, and who can participate in a 1 to 2 hour audio-recorded private interview

Every participant will receive a $25 gift card for participating in the study.

Private interview location is secured or I can come to you.

For more information or to become a participant, please call Erica at (317) ###-#### or e-mail ereicher@iupui.edu

Deadline to enroll is November 1, 2007.

Make your voice heard!

Research conducted through Indiana University-Purdue University Indianapolis IUPUI/Clarian IRB Approval #
APPENDIX B: SAMPLE RECRUITMENT E-MAIL

I am a graduate student researcher with the IUPUI Department of Sociology in Indianapolis and I am conducting an interview study of HIV-positive women with dependent children.

If you fit the criteria of being a non-Hispanic African American or non-Hispanic White woman 21 years old or older, having tested HIV-positive at least 2 years ago, and have at least one child 18 or younger living at home, I want to hear your story. Participation in the study consists of participating in a private one-on-one taped interview lasting between one and two hours. You will be compensated with a $25 gift card for your participation. All responses will be kept completely confidential.

Please call me at (317) ###-#### for more information or to become a participant. Thank you so much. I am eager for your input!

Sincerely,
Erica Reichert
APPENDIX C: INTERVIEW GUIDE

INTERVIEW GUIDE
Race and the Experiences of Mothers with HIV/AIDS

PRE-SCREENING INTERVIEW protocol

The interview process will begin when a potential participant contacts me about the study by telephone. After making a brief introduction, I will conduct a telephone screening interview to establish that the potential interviewee meets the study’s eligibility requirements. If she is eligible, I will schedule the interview.

1. Introduction
How did you learn about the study? Okay, you received a flyer. Well, as indicated in the flyer, I am looking for HIV-positive mothers. If you fit this description, I would like to talk to you about your experiences as a mother with HIV/AIDS. I am a Sociology graduate student at IUPUI and I am interested in the experiences of HIV-positive women with children. You will be compensated with a $25 gift card for your time and everything you share with me will be kept confidential.

2. Prescreening Questions
First, I need to ask you a series of questions to determine whether you are eligible to participate in this study. Do you have any questions for me before we proceed? All right.

<table>
<thead>
<tr>
<th>Screening Interview Questions</th>
<th>Participant must answer the following for eligibility</th>
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<tbody>
<tr>
<td>1. Are you male or female?</td>
<td>Female</td>
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<tr>
<td>2. How old are you?</td>
<td>21 years old or older</td>
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<tr>
<td>3. How would you describe your race and ethnic background?</td>
<td>White or African American/Black (Probe for non-Hispanic)</td>
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<td>4. What year did you test HIV-positive?</td>
<td>At least two years ago</td>
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<td>5. How many children do you have?</td>
<td>One or more</td>
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<td>6. What are their ages?</td>
<td>At least one 18 years old or younger</td>
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<td>7. Where do they live?</td>
<td>With participant at least half-time</td>
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3. Schedule Interview
Wonderful! You are eligible for the study. Can we schedule an interview? When would be a good time for you? I can reserve a room here on campus at IUPUI or I can come to your home, which ever would be more convenient for you. Or, if you have another place in mind, it is possible that we could do the interview there. Also, if it is all right with you, I will give you a reminder call or send you a reminder e-mail the day before the interview.
DRAFT INTERVIEW PROTOCOL

4. Introduction
I want to thank you for taking the time to talk to me today. I really appreciate your willingness to help me out with this interview. Have you ever been interviewed before? Well, the main reason why I would like to interview you is to learn about your experiences as a mother with HIV/AIDS. Findings from this study will be used to help health care providers, care coordinators, and others better understand the unique experiences of HIV-positive women with children.

5. Interviewer/Interviewee Role
I want for you to feel that this is your interview. I am here to listen to what you have to say. I am very interested in hearing about your experiences and feelings, so please feel free to share anything that comes to mind. Basically my job is to listen to you so that I can better understand these experiences.

6. Explain Taping Procedures
Is it okay that I record our conversation so that I do not have to take notes and so that I can get your complete answer?

7. Assure Interviewee of Confidentiality
Please feel free to speak openly with me. Your privacy is very important to me and anything you say during this interview will be kept confidential. I will not include your name or any other identifiable information in my report. Also, if I ask you any questions that you do not want to answer, you can just say "pass" and we will skip those questions.

8. Time Frame of Interview
The interview will last about an hour to two hours. If you need a break at any time, just let me know.

9. Obtain Informed Consent
Before we begin, I would like to go over the study’s informed consent form, which describes the nature of the study, your role in the study, the measures taken to maintain your confidentiality, and the voluntary nature of the study. You will need to sign the form to indicate that you agree to participate and I will give you a copy for you to keep.

10. Provide Compensation
Thank you again for taking the time out to come and talk to me about your experiences. Here is the gift card I mentioned as a way of saying thank you for taking the time to participate.

11. Questions?
I have covered everything I needed to tell you. Do you have any questions about the interview? Okay, I am going to start recording now. Let’s begin with some background questions so that I can get to know a little bit more about you before we talk about your experiences. I already asked you some of these questions when I spoke to you on the phone about your eligibility, but I need to ask them again to make sure that I record your answers for the study. I will use the answers to these questions for an overall description of who participated in the study.

12. Background Questions:
(Remind participant that she does not have to answer any question that she does not want to answer and that some questions may overlap.)

   a. How old are you?

   b. How would you describe your race and ethnic background? (Probe for Hispanic, biracial, etc.)
Race and the Experiences of Mothers with HIV/AIDS

c. How would you describe your sexual orientation?

d. What is the highest level of school you have completed? (Probe for how long ago completed.)

e. Are you currently employed?

f. What kind of work do/did you do?

g. Do you receive any type of financial assistance, like SSI, food stamps, Section 8, Medicaid, or Hoosier Healthwise?

h. What is your marital or partnership status? (Probe for married, separated, living with someone, in a long-term partnership, divorced, never married, or single.)

i. How many children do you have? (Probe for ages and residence.)

j. Were any of your children born after you tested HIV-positive? If so, was the pregnancy planned?

k. What is your child(ren)’s HIV status?

l. What year did you test HIV-positive?

m. How do you think you became infected with HIV?

n. To your knowledge, have you ever been diagnosed with AIDS?

o. Have you ever had an opportunistic infection?

p. Are you currently taking any HIV medications (like AZT, Nevirapine, Sustiva, or Kaletra)?

q. What is the lowest that your CD4 count has ever gone?

r. What is your current CD4 count and viral load count?

s. Do your children know your HIV-positive status?

13. Main Questions:
Okay, those are all of my background questions. Now we can move on to the interview. My main goals here are to learn about your experiences as a mother with HIV, understand what you see as society’s expectations for mothers, and understand any impact that social messages about HIV and mothers might have on how you experience everyday life as a mother with HIV. Some of the questions I ask you will probably sound very similar to questions I’ve asked you before. I just want to get as full a picture as I can of your experiences in your own words. Also, I know I’m asking you some pretty sensitive questions. I want to learn as much as I can about these important experiences of yours, but I don’t want you to feel any pressure to answer any questions that make you feel uncomfortable. Just let me know if I ask a question that you’d rather not answer and we’ll move on to the next one. Does that sound okay? Do you have any questions before we move on?

Aim One: The following questions will meet aim one, to describe how Black and White HIV-positive women with dependent children experience motherhood.

a. First of all, can you describe your experiences as a mother with HIV?
   Prompt: Can you tell me more about that?
b. What is the hardest part of raising children and having HIV?

c. Who has been the most helpful to you in dealing with HIV while raising children?
   Prompt: Another HIV-positive woman you know? A counselor or care coordinator? Another
   family member? Your partner/the children’s father?
   How has he/she been helpful?

d. Does the children’s father play a supportive role for you with the children?
   How so? What does he do that is helpful? Do you know his HIV status?

e. What helps you most in dealing with HIV while raising children?
   Have any organizations or websites been helpful? How did they help?

f. Have you found any strategies that are particularly helpful to you when you are having a particularly
difficult time with being a mother?
   Writing in a journal?

g. How do you think being a mother affects how you think of HIV?

h. How do you think being HIV-positive affects how think about being a mother?

i. I have found that for many women, having children makes life with HIV a lot more worthwhile to deal
   with, while for many other women, having children creates a number of stressors and difficulties in
   terms of living with HIV, and for most women, it is a combination of the two. How would you say that
   being a mother affects how you experience HIV?

j. Researchers have noticed that particularly with mothers living with HIV, caregiving can be a two-
   way, reciprocal process. Do your children do anything to help you? What in particular do they do to
   be helpful?

Aim Two: The following questions will meet aim two, to understand how HIV-positive mothers perceive
   cultural expectations and ideologies surrounding motherhood.

a. Many women report feeling strongly encouraged by society and by people in their lives to become
   mothers, probably because motherhood is considered such an important role for women in our
   society. However, many HIV-positive women report feeling strongly discouraged from becoming
   mothers by society and by people in their lives because of the stigma attached to HIV and the belief
   that it is somehow wrong for women with HIV to have children. Have you experienced either of
   these types of pressures and how so?

b. What do you see as the minimum responsibilities of motherhood?
   Prompt: What is the least that you are supposed to do for your children?

c. What are some additional qualities of a really good mother?

d. Do you think that these responsibilities change when the mother is living with HIV/AIDS?
   Do you think they should?

e. Do you think that, in general, White women will answer these questions differently than Black
   women?
   How so? or Why not?
Aim Three: The following questions will meet aim three, to explore how social messages surrounding HIV and motherhood affect HIV-positive mothers’ everyday lived experiences as mothers.

   a. Is there anything that you do differently as a mother because of your status?
   Prompt: Conceal medications? Limit use of AIDS-related health services? Limit your children’s social contacts? Limit your own social supports and contacts?
   How does use of these strategies affect you, either for better, worse, or some of both?

   b. How much do you think HIV affects your relationship with your child(ren)?

   c. Have you told your children your HIV positive status?
   How did you decide whether or not to tell them?
   If no, are you planning to tell them in the future?
   Prompt: What exactly did (will) you tell them?

   d. To what extent do you feel comfortable asking others to help you with the children?

   e. What do you think about the future?
   What do you hope for?
   What are your fears?

14. Closing Questions
We are almost finished. Before I ask the final set of closing questions, do you have anything else you would like to share with me about your experiences as a mother with HIV? Okay, now I would like to ask you:
   a. After having had your experiences, what would you tell another mother with HIV?

   b. Do you have any suggestions for what would make your life easier?

   c. Is there anything else you think I should know to better understand the experiences of mothers with HIV?

   d. Is there anything that I should have asked but didn’t?

   e. Is there anything you would like to ask me?

15. Thank you
That’s it for the interview. The information you have shared with me has been very helpful. If you have any additional questions or just want to talk about the interview experience, please feel free to give me a call or send me an e-mail. [Don’t forget to leave flyers.]