

“MOTHERHOOD IS OUR COMMON DENOMINATOR”:  
A PHENOMENOLOGICAL ANALYSIS OF THE EXPERIENCES OF  
HIV-POSITIVE MOTHERS

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Submitted to the faculty of the University Graduate School  
in partial fulfillment of the requirements  
for the degree  
Master of Arts  
in the Department of Sociology,  
Indiana University

September 2010

Accepted by the Faculty of Indiana University, in partial fulfillment of the requirements for the degree of Master of Arts.

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Storytelling is an act of witness.  
-- Arthur Frank

What would happen if one woman told the truth about her life?  
The world would split open.  
-- Muriel Rukeyser

For Caleb Leo

## ACKNOWLEDGEMENTS

First of all, to all of the remarkable and amazing women who were willing to open up their lives and their homes to me, for having the courage and generosity to share their stories with me, I extend my deepest thanks and appreciation. I thank you for teaching me so much, with grace, openness, and good humor.

To Carrie Foote, my teacher, mentor, and friend, I express my sincere gratitude. Your support, encouragement, and patience mean more to me than I can possibly articulate. Thank you for everything.

To Robert Aponte and Betsy Fife, thank you for your continuing enthusiasm for my research interests, the insights you have provided, and your continuing feedback and encouragement. I am truly fortunate to have such a supportive, helpful, and enthusiastic thesis committee.

To Peter Seybold, professor, mentor, and friend, thank you for your unwavering kindness and encouragement. I count myself truly fortunate to have had the opportunity to learn so much from you.

I extend my deepest gratitude to the Sociologists' AIDS Network for the generous contribution of research funds through the SAN Scholarly Activity Award, and to the IUPUI Department of Sociology for the provision of a generous thesis grant to support my research.

And finally, to my son, Caleb Leo Callan, thank you for being such a constant joy in my life. I love you fiercely, enormously, and unendingly. I am so proud of the kind young man you have become and I will never forget how lucky I am to be your mom.

## **ABSTRACT**

Erica S. Reichert

**“MOTHERHOOD IS OUR COMMON DENOMINATOR”:  
A PHENOMENOLOGICAL ANALYSIS OF THE EXPERIENCES OF  
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This study explored the experiences of raising children in the context of living with HIV/AIDS. In the fall of 2007, semi-structured qualitative interviews were conducted with 17 HIV-positive mothers (8 African American and 9 white) living in Indiana. Spillover theory was used to describe the interacting effects of the experience of living with HIV/AIDS and the experience of motherhood on one another. Findings indicate that maternal ideologies critically affected how the women experienced both their HIV-positive status and their mothering experiences. Findings also show that the mothers developed strategies to help them reconcile their valued identity as mothers with a stigmatized identity as HIV-positive women. Recommendations are made regarding directions for future research, social policy, and social service provision.

Carrie E. Foote, Ph.D., Chair

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## CHAPTER ONE: INTRODUCTION

Motherhood represents a central defining experience, core identity, or master status for most women in U.S. American society. Most American mothers struggle with role conflicts, competing demands, fatigue, and self-doubt while pursuing the cultural standard of the good mother, even under the most ideal circumstances. However, mothers living with HIV/AIDS face unique challenges in their efforts to fulfill socially constructed expectations of motherhood while coping with HIV. Yet their experiences are still less understood than those of other, more stereotypical groups living with HIV/AIDS.

Women currently constitute one of the fastest growing HIV-infected populations in the United States (CDC 2008; Faithfull 1997; Hackl et al. 1997). Moreover, the vast majority of HIV-positive women are diagnosed during their prime reproductive years (CDC 2008; Nelms 2005). 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 2008). 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-positive (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).

Mothers with HIV face the necessity of incorporating illness into their identity, the possibility of transmitting a serious disease to any additional children they may bear, and the dual challenges of caring for themselves and their children simultaneously. In addition, they must negotiate powerful cultural expectations, such as breastfeeding, protecting children from harm, and prioritizing children's needs above their own (Bell 2004; Glenn 1994; Murphy 2000; Ruddick 2002; Woodward 1997). The challenges of meeting these deeply internalized expectations, while grappling with the demands of illness, can be daunting for mothers living with HIV.

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 wrong, lacking, or inferior about HIV-positive women's behavior and perspectives, indicated by the presence of HIV infection. Scant research has examined the experience of HIV-positive mothers from their own perspective and for their own sake. In addition, little research to date has examined the impact of maternal ideologies and that of race on the lives of HIV-positive

mothers. This research project aimed 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 AIDS stigma and maternal ideologies on the everyday experiences of mothers living with HIV/AIDS.

This research project's main objective was to use qualitative interviews to understand the experiences of mothers 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 was: How do the cultural ideologies surrounding motherhood affect the mothering and illness experiences of HIV-positive mothers? To address this question, this thesis project had three specific aims: (1) to describe how HIV-positive women with dependent children experience motherhood, (2) to understand how HIV-positive mothers perceive cultural expectations and ideologies surrounding motherhood, and (3) to explore how social messages surrounding HIV and motherhood affect HIV-positive mothers' everyday lived experiences as mothers.

### **Literature Review**

A review of the literature on HIV-positive women and motherhood identifies certain main themes. Stigma 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-positive status 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, also present significant themes. Despite the amount of research now available on women and HIV/AIDS, several omissions remain. Little research has examined either how maternal ideologies affect the

lives of HIV-positive mothers or potential differences by race in the maternal ideologies that shape HIV-positive mothers' lives. On the whole, scarce research has examined the experience of mothers with HIV from their own perspectives and for their own sake.

These themes and gaps in the literature are further discussed below.

### *HIV, Motherhood, and Stigma Management*

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, injecting drug users, and commercial 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 1999b).

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, attempts 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, as Herek (1999) notes, concealing one's HIV-positive status contributes to isolation, thereby depriving one of needed social support (see also Faithfull 1997; Nelms 2005). Consequently, Ingram and Hutchinson (2000) find that deliberating on 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; Ciambone 2001; Hogan 2001; Sandelowski and Barroso 2003a, 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 (Ciambone 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). For example, 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 mothers 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, and even "cruel and uncaring" (Ingram and Hutchinson 1999a: 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 1999b: 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 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 being non-white, poor, a former drug user and/or commercial sex worker find in motherhood strategies to resist marginalization and assert a positive social identity (Ingram and Hutchinson 1999a, 1999b, 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 appeared 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 they had died. Likewise, Sandelowski and Barroso (2003a and 2003b) coined the idea of “virtual motherhood” to denote the future-oriented strategies HIV-positive mothers use to compensate for illness-related constraints placed upon their mothering. For example, virtual motherhood includes creating physical mementos for their children, making detailed plans for their children’s futures, leaving long letters for their children to read after the mothers’ 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 within local communities. For example, virtually no research has examined racial differences in mothering experiences in the U.S. Also understudied is the impact of maternal ideologies, by race, on these mothers’ experiences. Some literature suggests that African American women with HIV may experience motherhood differently than white women, but direct comparisons are lacking (Mallory 2008; Wyche 1998). 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 own 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. Overall, scarce research has examined the experience of mothers with HIV from their own perspectives.

Significantly, most of the literature on HIV-positive mothers remains based on data collected in the period prior to the emergence of HAART (highly active antiretroviral therapy). That research does not reflect the contemporary experience of HIV/AIDS as a chronic illness rather than a terminal illness. Themes central to the terminal illness experience of HIV/AIDS for mothers, such as the certainty of leaving children behind after death and the need to prepare children for this inevitable tragic outcome, retain little salience to afflicted mothers in the contemporary scene. Other themes, more in line with the present, such as balancing the care of children with the long-term management of chronic illness, are poorly represented in the current literature and thus remain to be adequately explored.

*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. It focuses on the perspectives of African American and white HIV-positive mothers and the issues that 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 set 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 also aimed to 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 contributes to theories about how marginalized groups actively engage in constructing identities in the face of stigma and other challenges.

## CHAPTER TWO: METHODOLOGY

For this qualitative study, I conducted a series of semi-structured in-depth interviews using a purposive sample of self-identified HIV-positive women with dependent children. A qualitative approach was the most appropriate for the purposes of this research in order to uncover the meanings that HIV-positive 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; Ciambone 2003).

The study was phenomenological in nature (Creswell 1998), as it intended 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 required 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 this study, in-depth interviews of a targeted sample of participants promised to generate rich data which can provide the foundation for further study.

I used a critical feminist theoretical paradigm to guide the research process (Esterberg 2002; Reinharz 1992). 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 1989: 75).

### **Researcher Role**

This study involved 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 research 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). Central to feminist research, reflexivity helps 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 concepts 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 a natural choice 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 ideologies and social inequalities. Furthermore, the more reading and research on women and HIV/AIDS I have done, the more deeply I have recognized what a passion I have for this topic of research.

In conducting the research, I adopted an outsider researcher role (Naples 2004) because of my lack of shared HIV-positive status with my study participants. However, I did simultaneously focus on shared attributes and experiences, primarily motherhood. Moreover, I found that many respondents' experiences deeply resonated with my own.

My own personal experiences and social location served as potential sources of bias, in both the negative and positive implications of the term (Hammersley and Gomm 1997). This means that although I could act as an empathetic interviewer, I lacked the perspective that comes with being part of the community under study. However, I rarely encountered challenges in establishing rapport and building trust with interview participants. In addition, perceptions of my bias against the traditional U.S. health care system and my sympathetic feelings toward women with HIV may have distorted the type of responses participants gave. Other factors, such as my race, perceived age, and role as a college graduate student may also have impacted the quality of data I was able to obtain, either positively or negatively. However, I also had the advantage of distance, which may have helped me to better understand how the social context impacts the phenomena under study.

I engaged in a process of self-reflection in order to address my biases. I kept a research journal in which to document my thoughts, feelings, and observations during the



research and writing process. I also used peer review and regular critique from my faculty advisor to help with validity and compensation for potential biases.

### **Sample and Recruitment**

My research sample consisted of 17 self-identified HIV-positive women living in Indiana. In order to avoid focusing on the additional complications of teenage motherhood and due to ethical concerns which prohibited me from interviewing minors, participants had to be 21 years of age or older. I also stipulated that participants had to have one or more dependent children aged 18 or younger living with them in the home at least half of the time. True to the literature supporting the centrality of the phenomenon of othermothering in the lives of many African American women, I allowed for a broader definition of motherhood for recruitment purposes. I considered potential participants eligible for the study if they were the primary caregiver of at least one child living in their home.

Due to ethical concerns about the increased vulnerability of newly-diagnosed HIV-positive research participants, participants had to have been diagnosed with HIV at least two years prior to the interview date in order to meet the eligibility requirements for participation. As the research focused on racial differences as the main point of comparison, I selected my sample by race-ethnicity so that half of the sample consisted of native non-Hispanic white women and the other half consisted of native non-Hispanic Black women (referred to hereafter as white and African American women). Eligibility requirements excluded members of particularly sensitive populations, including women with cognitive impairments, women who were incarcerated at the time of the study, and women who were 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 focused 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 were excluded.

HIV-positive women represent a hidden population and consequently require the use of purposive and participant-driven (snowball) sampling measures in order to obtain a sufficient research sample. Recruitment involved 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 also used 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.

### **Research Instruments**

Between August and November of 2007, I conducted 17 private in-depth semi-structured interviews with mostly open-ended questions. The interviews lasted one to two-and-a-half hours in length. I recorded the interviews with participants' consent and took handwritten fieldnotes following each interview. I also kept a research journal in order to capture my experiences and insights gained during the research process. Semi-structured interviews served as the best method for uncovering the meaning that HIV-positive mothers make of their experiences because they allowed participants to voice their own perspectives and assert what is important to them from their own standpoints.

At the beginning of each interview, I acquainted the participant with the purpose of my research. Then, I went 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 gave her a \$25 gift card for her time. Next, I asked the participant a series of demographic questions, followed by a series of open-ended questions with prompts and follow-up questions. Finally, I asked her a series of closing questions, thanked her for her participation, and when appropriate gave her flyers to give to any potential participants she might know. If appropriate, I also shared with her the contact information of AIDS service organizations that she could contact for counseling and other assistance.

### **Data Analysis**

I analyzed the data generated by the interviews using grounded theory techniques (Charmaz 2004, 2006; Glaser and Strauss 1967). The open-ended questions generated a set of rich data full of thick description, providing a strong foundation for intensive qualitative analysis. While I initially planned to use a qualitative computer application for the analysis, I ultimately chose a combination of index cards and tables created in a word processing program.

Within one week of conducting each interview, I transcribed the interview recording. I used line-by-line coding to locate emergent themes in the transcripts. I also used information gained from early interviews to guide later interviews, letting emergent themes guide my questions. Next, I used focused coding to gather repeating themes into categories.

For the next phase of focused coding, I used focused coding to gather repeating themes into categories. I created themes cards by organizing repeating instances of themes from the interviews together into a set of index cards. From there, I created a themes chart. I used Charmaz's (2006) series of memo-writing techniques to delve deeper into categories and to draw connections between categories. Finally, I used these memos to generate a complete analysis of the data.

### **Research Challenges and Study Limitations**

Although this research aims to generate useful findings concerning HIV-positive mothers' experiences, its limitations should be kept in mind. In particular, the sample is not representative of all mothers with HIV/AIDS. The sample was recruited from social networks, AIDS service organizations, and medical clinics in Indiana. These recruitment techniques excluded many potential participants, including institutionalized women, women who were very ill, and non-English speakers, to name only a few. Furthermore, given the tremendous stigma associated with HIV/AIDS, the risks study participants undertook 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 have proven 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.

### **Participants**

The research sample consisted of seventeen participants. Table One below summarizes each of the women's age, race/ethnicity, number of children, relationship status, and number of years living with HIV. Eight participants identified as African

**Table 1: Research Participants**

<i>Pseudonym</i>	<i>Age</i>	<i>Race-Ethnicity</i>	<i>Number of Children</i>	<i>Marital/ Partnership Status</i>	<i>Years HIV-Positive</i>
Andrea	mid-20s	white	2	partnership	5
Anita	late-30s	African American	1	single	3
Diana	late-50s	African American	4	widowed	17
Georgette	mid-40s	African American	2	single	14
Gloria	early-40s	African American	1	widowed	12
Janet	early-40s	white	3	divorced	4
Jillian	late-30s	white	1	divorced	19
Joy	early-30s	white	2	married	16
Laurel	late-30s	white	2	single	12
Leah	late-30s	white	2	married	6
Linda	late-30s	white	1	married	9
Naomi	late-20s	African American	2	single	9
Nina	mid-20s	white	3	partnership	5
Olivia	early-30s	African American	2	single	8
Rachel	early-30s	white	2	partnership	11
Ruth	mid-50s	African American	3	divorced	12
Tabitha	mid-30s	African American	3	separated	12

American and nine identified as white. Participants' ages ranged from 24 to 58 years of age, with a median age of 37. Participants had between one and four children.

Children's ages ranged from less than a year old to 42 years of age, although all of the participants had at least one child aged 18 or younger living in their custody, per the study's sample requirements. Only two of the respondents had an HIV-positive child.

One participant had a developmentally disabled child. Four participants had lost their partners to AIDS. An additional six participants had HIV-positive partners or ex-partners. Seven participants had male partners in the home, and the remaining ten were single, divorced, or widowed with no male partner in the home.

The participants had been living with HIV for between four and 19 years. Five of the 17 participants had received an AIDS diagnosis. Because of my sample parameters, each study participant had tested positive for HIV at least two years prior to our

interview. In reality, most had lived with HIV for at least five years. The average length of time between testing positive and participating in the interview was ten years. Moreover, a number of the women had experienced acute illness related to being HIV-positive, including PCP (pneumocystis carinii pneumonia), MRSA, MAC (mycobacterium avium complex), and Legionnaire's Disease. Many study participants also reported managing other health problems in addition to HIV/AIDS; these included Hepatitis C, diabetes, asthma, thyroid conditions, arthritis, bacterial infections, and neurological conditions. Four participants reported having been clinically diagnosed with mental health conditions; one was being treated for bipolar disorder and posttraumatic stress disorder, another for depression and PTSD, and two others for depression. Seven participants reported a history of substance abuse.

Participants' highest level of education ranged from an elementary school education to completion of a post-graduate degree. Two had less than a high school education, eight had only a high school education, six had completed some college or an Associate's degree, and one had a professional degree. Six of the participants were employed at the time of their interview. All but three of the participants were receiving some form of public assistance.

### **Findings Overview**

This study of mothers living with HIV/AIDS examined two primary and interrelated aspects of participants' experiences. The first, the impact of HIV/AIDS on motherhood, explored how living with HIV influenced, if at all, how these women experienced and performed their role as mothers. The second, the impact of motherhood on the experience of living with HIV/AIDS, involved the corresponding influence that

occupying the role of mother exerted on the ways that these women experienced and coped with HIV/AIDS. Next, I explored whether such experiences differed between African American and white mothers and whether maternal ideologies affected their experiences in positive or negative ways. Surprisingly, racial differences did not emerge and therefore are not addressed in the findings. However, maternal ideologies, as expected, critically affected how the women experienced both their HIV status and their mothering experiences.

The findings are divided into two chapters. In chapter 3, I address how participants' experiences of motherhood have been influenced by living with HIV/AIDS (which I describe as *HIV/AIDS to motherhood spillover*). In chapter 4, I address how their experiences living with HIV/AIDS have been influenced by their motherhood status (which I describe as *motherhood to HIV/AIDS spillover*). Importantly, the term *spillover* is borrowed from the literature on work/family, which has examined how family life and work spill over into each other (Bowen 1988; Lambert 1990). The spillover perspective posits that the "structure, values and experiences in the work arena can either facilitate or undermine a person's ability to discharge responsibilities at home and vice versa" (Bowen 1988: 185). Although not a perfect transference to illness/motherhood experiences, I use this model as a framework for this study because it is a good fit to examine how the experiences of living with HIV/AIDS affect the ability of the women to perform their mothering roles as well as the ability of mothers to manage their illness.

### **CHAPTER THREE: THE IMPACT OF HIV/AIDS ON THE EXPERIENCE OF MOTHERHOOD**

Managing HIV required a good deal of the mothers' time, attention, and energy, often undermining their ability to care for their children and protect their children from harm. One nearly universal observation from the mothers was that as mothers living with HIV/AIDS "some days are good and some days are not." Having HIV often entailed dealing with medication side effects, episodic illness, and fatigue that could make it difficult to take care of children. Life with HIV also brought with it a tremendous amount of uncertainty about if and when the mothers would become ill or die, resulting in the perpetual uncertainty of "not knowing if I'm going to be here for [my children]." In addition, having HIV often meant experiencing grief over being unable to fulfill their expectations of motherhood, such as having a natural delivery and breastfeeding. Finally, being an HIV-positive mother often increased the mothers' anxieties about their children being harmed because of their mother's HIV status.

Yet despite the mostly negative spillover effects of living with HIV/AIDS on their mothering experiences, the major lesson derived from the analysis is that for the most part the mothers described rewarding motherhood experiences. The main reason for this discovery may stem from several coping strategies that the mothers used to reduce the negative effects that HIV could have on their mothering roles, such as relying on family members for help or managing the timing of breaks and medication.

Importantly, having HIV/AIDS may also enhance the women's mothering experiences. For example, living with HIV/AIDS provided many of the mothers with a heightened awareness of the risks involved in unprotected sex and drug use that led them



to play a very active role in educating their children about sex and drugs. The findings suggest that this awareness and activity around sex and drug education likely had positive results. Additionally, the heightened awareness of the ephemerality of life brought on by their experience with HIV often motivated the mothers to take advantage of the time available with their children by cultivating nurturing relationships and creating lasting memories. These findings are discussed in more detail below.

### **HIV/AIDS to Motherhood Spillover**

Several themes regarding the way the women's HIV/AIDS status negatively spilled over into their roles as mothers emerged from the analysis. These include: (1) how having HIV/AIDS made it difficult to meet the demands of motherhood, (2) how the uncertainties of living with HIV/AIDS made them worry about who would care for their children and about missing out on seeing their children grow up in the event that the mothers became ill, (3) how having HIV/AIDS often led the women to experience a loss of control over reproductive choices and childbirth and breastfeeding options, and (4) how having HIV/AIDS could lead to the stigmatization of their children. Only one positive spillover effect was salient: (5) protecting their children from harm.

#### ***Seizing Good Days and Surviving Bad Days:***

##### ***Experiencing Difficulty Meeting the Demands of Motherhood***

The first way that HIV/AIDS could negatively affect mothering was in making it difficult to meet the demands of motherhood. A substantial part of being an HIV-positive mother involves the day-to-day struggles of managing illness while meeting parenting responsibilities. For many mothers living with chronic illness while balancing the needs of children and other obligations, life becomes a series of “good days and bad days”

(Charmaz 1997: 1). On good days, illness subsides into the background of daily life to the extent that mothers can focus on other things, especially their children. For example, Georgette reported of the good days spent with her young daughter,

We do a lot of watching television together. We spend time together, me and her. And that makes me feel good. Um-hmm. Yep. Bake cookies and bake cakes. Yeah, I let her get up on top of the—she wanna get on the counter and stir. You know, stuff like that. We get up in the middle of the night. Any time we want, we just get up in the middle of the night or whenever we feel like it. She says, “Momma, I wanna make some cookies.” Well we get up in the middle of the night and we make cookies. Stuff like that, you know?

Georgette identified a number of simple mother-daughter activities as opportunities to take advantage of good days with HIV. Moreover, she seemed to give herself and her young daughter license to seize the good days by indulging in spur-of-the-moment amusements, like baking in the middle of the night. Her *carpe diem* attitude is reflected in the fact that she and her daughter did not observe regular bedtimes, instead seizing opportunities for fun and togetherness whenever the spirit moved them. In sum, good days are best characterized by the absence of illness.

In contrast, bad days involve “immersion in illness” (Charmaz 1997: 9). On these days, illness dictates the terms of almost every detail of everyday life. Bad days make it difficult for mothers to meet the demands of motherhood because having HIV could sometimes leave them with little time and energy for their children. Study participants often characterized bad days in terms of being too tired or too sick to perform daily tasks or enjoy everyday life. Participants reported, “I have days where I just can’t get out of bed” (Leah), “every once in a while you just get tired” (Jillian), and “there’s been times I’ve been pretty sick” (Laurel). While trying to describe her overwhelming experience of recurring bad days, Janet asked, “What way is up? Like a lot of times it feels like you’re

just under the surface of the water and no matter what, that's where you're gonna stay. And that's really hard." Similarly, Georgette described her own experience with bad days: "Try taking seven or eight, well fourteen pills a day. That's at least. Try taking those every day. Try being sick. You know, not feeling good, not wanting to get up but you got to get up. You know, try that." Being sick and tired despite also being responsible for the care of children left these women having to figure out how to manage the demands of their illness along with the responsibilities of parenting.

Accommodating bad days also meant that some of the women had to sacrifice a great deal as mothers in order to manage from day to day. In particular, they had to give up time with their children. For example, Linda allowed her son to play video games alone for hours in their basement game room so that she and her husband, who also had HIV, could rest after taxing workdays. She and her husband also granted their son much more autonomy than his elementary-school-aged peers, including having his own cell phone and bank account and scheduling his own activities. For many participants juggling multiple demanding roles, weekends became devoted less to spending time with children, and more to recuperating from excessive work hours and other demanding obligations that were exacerbated on bad days.

For working mothers, bad days presented special complications as these women struggled to function during the workday and were completely sapped of energy by the evening, unable to meet the demands of the notorious "second shift" (Hochschild 1989: 4). For non-working mothers, recurrent bad days often precluded entering the work force. For example, Janet suggested,

If I wasn't HIV-positive, I wouldn't be so... I wouldn't feel so sorry for myself. You know, right or wrong, you feel that way. And I would already

be working a full-time job and the problems that I have, I probably wouldn't have as bad as I do because I'd rather be in bed sleeping than working a full-time job.

Some of the other mothers were forced to quit jobs when the demands of taking care of children and working through frequent bad days became physically and emotionally overwhelming.

Many mothers also reported having to wait until they felt physically well before they could plan for an activity with their children, like taking them out to dinner, taking them to the zoo, attending their extracurricular events and school activities, or setting up a variety of other family activities that most mothers take for granted. Consequently, planning activities with their children was a constant challenge for many of the women in the study because of frequent bad days. Furthermore, these mothers struggled with the guilt associated with feeling that they were constantly putting their children on hold. For the mothers who also struggled to find the financial means to provide the extras for their children, this struggle and its attendant guilt were particularly acute.

Financial barriers made it especially difficult to manage good days and bad days. Thus, one of the greatest frustrations a number of women reported involved the fact that good days and financial flexibility did not often coincide. Consequently, when mothers felt physically able to perform a long-postponed activity with their children, they often lacked the financial resources to do so. For example, as Naomi explained, financial barriers often prevented her from being able to plan fun outings for her nine-year-old daughter and frustrated her greatly:

Because I do suffer from a lot of side effects from the medicines itself too, and on a normal day—'cause I see moms out here all the time, you know, taking their kids to the park and stuff like that, being able to do more things with 'em. That affects me a lot because my days are really limited.

‘Cause one day I might be feeling okay, but may not have the expenses to do what I could be doing today. Then it’s like when I do have a little enough money to do stuff, then I’m feeling sick so it’s kind of give and take. But every now and then I’ll get a day in where I’m okay and I got the expenses to do something, basically, ‘cause a lot of things cost, like Chuck E. Cheese and stuff like that. But that’s basically just dealing with the side effects from the medicine. Plus the other side effects from other medicines that I take.

Likewise, Andrea complained that the only activity for her preschool-aged son involved remaining confined to their small apartment playing a violent age-inappropriate video game because of the difficulty of coordinating good days with discretionary funds. She explained,

I really never had the money to even just take ‘em to Chuck E. Cheese. The only time we can do usually stuff like that is tax return time. That’s the only time. [...] I hate it, ‘cause I always promise my son, “Well, we’re gonna go do this and we’re gonna go do that.” And we never have the money to.

Even simple everyday activities, like planning a social gathering for their children with their friends or taking their children to a place like Chuck E. Cheese, the zoo, a museum, or the park became complicated undertakings because of frequent bad days.

In conclusion, balancing good days and bad days with the constant demands of raising children could become a perpetual tug of war for the mothers in the study. As Leah observed of her daily life as a mother living with HIV, “Some days are good and some days are not.” Linda, who had been living with HIV/AIDS for almost a decade, described the evolving experience of adapting to good days and bad days:

I feel that when you are positive, you’re on this roller coaster. You know, you have your good days. You have your bad days. You deal with things this way, you know? But, especially when you’re first diagnosed. You’re going really up and down all the time. But it does kind of just become little bumps, you know? You’re just, a little curve here, and you gotta go over here, to work it out and sometimes it’s scary and stuff.

As she suggested, the unpredictable cycles of good days and bad days could resemble riding a roller coaster. Moreover, her account suggests that in order to reduce these periodic disruptions, one can draw on experience to develop coping strategies to work out the problems that arise. In other words, managing good days and bad days becomes easier over time as one develops strategies and tactics for coping with chronic disruption. Similarly, Ruth, with twelve years of experience living with HIV, described her efforts to cope with intermittent good days and bad days:

I guess, you know, some days I'm way up here on the mountaintop. Some days I'm way down here in the valley. I'm having those rough days and I'm crying and I'm, you know, depressed and... Because I do. I still get those, I still have those days. Even anybody that's not sick has those days. But when I do, I always turn to God and I pray, call my pastor, you know, or his wife, you know, who is aware of my status. We talk it through, you know, and they encourage me. You know, "Ruth, it's gonna be okay. You just hold on." That's basically... or go in and hug my daughter, you know, go in Becca's room and hug her and, "What's wrong, Mommy?" she'll say. And I'm like, "Oh, I just need a hug," you know? And sometimes hugs are just something, you just need 'em sometimes. So I'll get a hug from her and turn on my gospel music. Music soothes me or I'll read or... You know, those are things that I turn to. Yeah. And they work.

Like Linda, Ruth appeared to accept the inevitability of bad days occurring along with good days, and she learned to recognize helpful strategies to make bad days more bearable and manageable. As Ruth and Linda's experiences suggest, bad days become easier as one identifies effective coping strategies, but they never completely go away.

### ***"Anything Can Happen":***

#### ***Experiencing Fear and Uncertainty***

The second way that living with HIV/AIDS negatively influenced the experience of motherhood involved the experience that becoming HIV-positive introduces an uncomfortable degree of uncertainty and fear into the mothers' lives. While all HIV-

positive women may experience uncertainty because HIV is an uncertain illness, HIV-positive mothers face the additional fear of not being able to take care of their children, leaving their children orphans and missing out on their children's lives should they become ill or die. Ruth observed, "I just think it's a lot of fear when you're a mother and you're HIV-positive and you have children." These fears center on becoming seriously ill unexpectedly, and dying, thus leaving children without a mother. For example, Joy identified the most difficult thing for her about raising children as an HIV-positive mother: "The fear of the unknown. Not knowing... if I'm gonna be here to see them graduate from high school, to help them when they have children of their own..." Similarly, Tabitha shared her greatest concern about being a mother with HIV: "It's just being around for my girls, that's all that bothers me." Georgette likewise described her fear for the future: "I know eventually there's gonna come a time where I am gonna get sick and you know and... And I don't know what's gonna happen to [my daughter]." Likewise, Janet named her greatest worry as an HIV-positive mother: "Not knowing if I could get sick and something'd happen." Naomi alluded to her greatest fear: "I don't know what the future's gonna hold." In particular, she worried, "You might just fall just sick all of a sudden and they got nothing can help you." Anita worried, "To know that I do have HIV, that's the hardest thing, because I know in due time that it's gonna overpower me. I think in the long run that it is gonna overpower me."

Diana alluded to how the value she placed on her life had changed because of the uncertainty of her future as a mother living with HIV: "Maybe God'll be merciful, and let me get in a train wreck, like I'm always talking about. I could get hit by a car the way these people drive. Anything can happen. I want [my children] to be taken care of."

Similarly, Ruth explained, “I always prayed that I could live long enough to raise [my youngest daughter] [...] when I found out in ’95. [...] She was still young, and I said, ‘Lord, just give me, grant me a favor and let me raise my baby.’” In a similar vein, Diana related: “I just don’t know what’ll happen. Where it’s probably inevitable, but I’m hoping that the Lord’s gonna be merciful, and let me get these kids up. That’s all I’m thinking about. Getting my kids up.” Confronting profound uncertainty required these mothers to pare their lives’ expectations down to the most critical priorities and focus on their children’s futures.

Fears and perpetual uncertainty surfaced in nearly every interview as one of the toughest struggles with which these mothers had to contend. Such uncertainty was a direct result of their HIV-positive status. Their interviews resounded with comments about worrying about the future, fearing the unknown, being fearful for their children, facing uncertainty, confronting an uncertain future, anticipating limited time and a foreshortened lifespan, perceiving continued health as uncertain or as in jeopardy, and remaining constantly aware that anything can happen and that nothing is for certain.

***“It’s Just Out of My Hands”:***

***Losing Control Over Reproductive Choices***

Mothers with HIV face the challenge of incorporating illness into their identity. Sometimes this process involves incorporating HIV into their identities before incorporating their role as mothers, while for others the mother identity precedes the HIV-positive identity. Regardless of the order of identity adoption, a major aspect of this process centers on the possibility of transmitting a serious disease to their children. As such, a third way that HIV/AIDS could adversely affect mothering experiences involves



reproductive experiences. Some of the mothers in this study saw their control over whether to have children, how to give birth, and how to care for their infants drastically reduced because of their HIV status. For example, when Jillian was first diagnosed in the late 1980s, she initially thought that becoming a mother was no longer an option for her. Years later, she shifted her perception of her options and decided to have a child with her husband, but then experienced infertility and sought help from a fertility clinic. She explained how she was horrified upon learning that clinic staff would not care for her because of her HIV status and how she felt as if her passage to motherhood was suddenly no longer under her control but solely under that of the medical establishment:

They were uncomfortable treating me. They did not want to provide care to me 'cause I was HIV-positive. [...] And I just felt like, it's beyond my control. It's just out of my hands. My ability and desire you know to have a child which is dependent on these medical treatments is just, I could see it slipping away from me. Just kind of going away.

All of the mothers who tested positive during or before pregnancy followed the standard medical HIV pregnancy and delivery care that was available at the time of their children's births. For some of the mothers, this meant experiencing profound grief over not being able to actualize their deeply held expectations like making the passage to motherhood, experiencing a natural delivery, breastfeeding, having more than one child, and/or managing their fertility largely outside of the overarching involvement of the medical establishment. In terms of achieving normative motherhood, the issue of breastfeeding became a salient issue for a number of participants. For example, Linda confronted criticism because she could not breastfeed her son. Acquaintances' questions implied that she was not properly considering the health of her infant son, when in fact

not breastfeeding was a choice she made in the interest of her child's health. Linda explained,

Anybody that would say anything, you know, "Well you're not a good mother if you don't breastfeed." And, you know, "You gotta do it and it's for the health of your child." You know, I was like, "Oh for the health...!" [*She imitates crying.*] "Is he gonna have all fingers?" And you know, because they really don't know back then as much as they know now.

Beyond perceiving breastfeeding as a normal expression of motherhood, being unable to breastfeed her son in the face of expectations that she do so in order to be a good mother became a painful issue for Linda even before her son was born. Similarly, Jillian identified concerns about being unable to breastfeed as a potential problem had she not eventually chosen to adopt her son.

One mother who learned of her HIV-positive status after giving birth and whose child subsequently also tested HIV-positive experienced profound guilt over her son's status. In her attempts to fulfill her own and society's expectations of intensive natural mothering, Gloria pursued a natural vaginal delivery and extended breastfeeding. Ironically, she identified these efforts as exposing her now-HIV-positive son to the virus even though she did not know that she had HIV at the time. Gloria explains,

I let my son know that, if I had known that I was HIV-positive when I was pregnant with him, I would not have delivered vaginally. I would not have breastfed. Because then it wouldn't have been transmitted to him. You know? But, because I didn't know those things, it happened. You know?

Having lost her husband to AIDS, while having also lost numerous other close family members during the same period, Gloria felt that she needed to account for her choices to her son, and possibly to herself as well.

***“My Children Will Be Teased”:***

***Stigmatizing Children***

Most of the mothers were acutely aware of AIDS stigma and the resulting courtesy stigma (Goffman 1963) that could be transferred to children because of their mothers' HIV status. Thus many of the mothers' greatest fears for their children involved being stigmatized in their communities as the children of HIV-positive mothers, being taken away by a non-custodial parent or extended family members because of their HIV status, or becoming the victim of violence because of AIDS stigma. This was the final way that living with HIV/AIDS could negatively impact the experience of motherhood. For example, Leah agonized about her children's susceptibility to courtesy stigma in their backward rural community: "Living in a small town, everyone knows [my status] and I have that fear that my children will be teased." In fact, Leah's fears for her children being stigmatized went so far that she had attempted suicide, in part to protect them: "I was thinking my children would be better off if I wasn't here because they wouldn't be teased." In particular, she lamented of her teenage son's regular confrontations with tormenting peers, "He's just a little skinny guy. You know? And I hate that he has to go through that. That's the hard part. Not being able to protect your children." In the context of their insular rural community, Leah had been unable to shield her teen son from the pervasive AIDS stigma that dogged her and her family. The best she could do was to try to teach her son to withstand it. Overall, living with HIV/AIDS created an additional challenge for these mothers as it increased their anxiety and worry about the potential for their children to be mistreated because of HIV.

### *Protecting Children From Harm*

One of the potentially positive effects that living with HIV could have on the mothers' experiences is that it made mothers acutely aware of the need to protect children from a number of specific potential threats and helped motivate their efforts to protect their children. Although protecting one's children from harm is by no means unique to mothers with HIV, some of the specific types of harm that could arise in the context of HIV may be more apparent to HIV-positive mothers and their children. Their experiences of living with HIV/AIDS may confer a heightened awareness of some of the risks and dangers facing young adults. In addition, how these mothers went about protecting their children from harm may also differ from uninfected mothers. As a result, it is possible that this heightened awareness and the ways of protecting their children from harm could lead to reduction in the harm that could result from unprotected sex or drug use.

All of the mothers in this study expressed concern about protecting their children from harm, particularly with respect to the risks associated with engaging in unsafe sexual activity, drug use, and other risky behaviors. These mothers feared for their children based on their own experiences, and they used these same experiences to protect their children. The HIV-positive mothers involved in the study drew their authority from their own lived experiences. In particular, many were able to draw upon their own personal experiences that led them to become HIV-infected to convey a sense of authority in regard to harm that could happen to their children and they became more willing to open themselves up to frank discussions with their children based on their own unique experiences. While many parents may wish to enjoy an unblemished image in

their children's eyes, most HIV-positive mothers cannot entertain that luxury. Overall, these HIV-positive mothers made efforts to be more open, honest, and communicative with their children in efforts to protect them.

Below I detail the various strategies the mothers in the study employed to protect their children from harm. These strategies include: (1) educating children about sex, (2) educating children about drug use, and (3) creating a safe space for children to talk to their mothers about anything.

### ***1. Educating Children about Sex***

Nearly all of the HIV-positive mothers in this study expressed concern about the potential for their children to engage in unsafe sex. For many HIV-positive mothers, talking to their children about safer sex and other forms of risk prevention represents a particularly important part of protecting children. For many parents, whether HIV infected or affected, discussing sex with children is understandably a painful challenge. Opening a dialog with children about sex means opening oneself up to questions one may not be prepared to answer. However, many of the mothers made an active effort to educate their children about the risks involved in sexual activity. For these women, sex education occurred first and foremost in the home. For the most part, the mothers engaged in sex education that promoted the use of condoms and placed responsibility for choosing safe sex behaviors on their children rather than their children's partners. Moreover, the majority of these mothers focused on condom use for STD prevention rather than for contraception.

A number of participants discussed talking about sex and other risks with their children. For example, when asked about how being a mother affects how she thinks about HIV, Janet responded,

I have an eighteen-year-old boy. I get bags of condoms from [a local AIDS service organization] and I just pull his comforter back on his bed and dump ‘em upside down and pull the comforter back up. I mean, he knows. I’ve preached and preached and preached that it’s not just about somebody getting pregnant. Now it’s about dying. And, you know, you don’t know who that girl’s been with, and that person was with and that person was with and that person was with. You know? And it’s not worth it. You know, I know you’re gonna do it, but you’re gonna make sure that you’re protected. Yeah, I’m a fanatic about that. My son’s got condoms growing out his ears. I mean he has since he was fourteen.

When asked whether she had discussed sex with her daughters, she was more restrained because they were several years younger than her son. Moreover, she had not yet disclosed to her youngest daughter that she was HIV-positive. Consequently, Janet replied,

Not as extensively, obviously, as I have [my son]. ‘Cause I don’t feel like, [my older daughter]’s only thirteen. But I have told them, again, it’s not all about preventing getting pregnant. There’s diseases out there. You know, because obviously I have to bring my youngest in on it too, and I’m not gonna tell her. But I tell her that there’s things out there that you can die from now, you know? And she’s heard some at school, you know?

For some of the mothers, the sex educator role extended to safe sex talks with other family members. For example, Leah described her role as safer-sex educator in her small community of friends and relatives.

I have, like my sister’s children and my best friend’s children, which they’re not children anymore. They’re all teenagers. You know, they have all come and talked to me and asked me questions and I’m honest with them. And I keep condoms, and I tell them all where the condoms are. Their parents know that I’ve talked to ‘em and that they know they can get condoms from me. You know? So, all I can do is be honest with them and show ‘em where the condoms are. And I push the issue, you know. “Make sure you use a condom. Make sure you use a condom.”

Again, here is an example of a mother emphasizing the importance of condom use during sex. Because of her HIV-positive status, Leah felt comfortable asserting her own experience in order to serve as a sex educator. Moreover, members of Leah's extended family were all well aware of her intervention in their own children's lives and appeared to approve of her providing condoms to their children.

Likewise, Joy reflected on the positive value of her experience with HIV in terms of raising her awareness about the need to educate her children to protect themselves.

She explained,

As for my children, I think that [my experience with HIV]'s been a good thing, to a certain extent. Because HIV and AIDS is so rampant, and to let them know that Mommy's not perfect and that things can happen. And that, not to not trust everybody, but don't trust anybody with your life. And things can happen. They can happen.

Like Janet and Leah, Joy drew authority from her personal experiences as an HIV-positive woman to warn her children about making unsafe choices related to sexual activity. Furthermore, Joy drew on religious authority to help solidify her message. She explained,

I mean, I don't scare the heebie-jeebies out of 'em, you know? But I educate them. And now that my son is getting older, I told him that I would kill him [*laughs*] if he was to become infected through unprotected sex. Because God protected him—Now I don't know why God wouldn't protect somebody else's child, okay?—But I just know in my own situation. You know, I told him, I said, "God has protected you, and do *NOT* go and mess that up." So I think that it has been very very very very helpful to my children.

While Janet and Leah's efforts seemed to empower their children to better negotiate safer sex choices such as condom use, other mothers' attempts to educate their children may have disempowered their children or prohibited them from making safer sex

choices. For example, Tabitha recalled using her HIV-positive status to intervene in her teenage daughter's sexual risk-taking. She reported confronting her:

For a minute there she was out there [engaging in sexual activity]... I don't know if she was having protected sex or unprotected sex, but I sat down and talked to her and was like, "You don't want what Mommy has." And she was like, "No," and she was like, "I use protection."

She later elaborated, "I don't give my daughter condoms 'cause I don't approve of her having sex. But she is on Depo [Provera], and like I told her, if she is to have sex, it's up to the boy to provide the condoms. And if they don't have one, do not have sex with 'em."

In Tabitha's case, although she presented herself as taking efforts to protect her sexually active daughter from harm, traditional gender norms may have prevented her from empowering her daughter to negotiate safe sex. Based on some of her other comments which related extra-marital sexual activity to a moral or religious concept of sin, her personal values and gender-based norms may have placed her own daughters in a no-win situation in terms of being able to protect themselves in sexual relationships.

For some mothers, the need to make sure that their children were using safe-sex methods compelled them to violate their children's privacy. For example, Ruth described intervening in her teenage daughter's sex life by searching her room, among other things.

She explained:

When I find condoms, I'm cool. But if I don't find no condoms I'm not cool. You know? Yeah, [being HIV-positive] makes you become more aware of what they're doing with their life and not to hope they make the same mistakes you made.

Ruth's statement clearly demonstrates how being HIV-positive can create an acute awareness of the risks to children from sexual activity. Moreover, while discovering



condoms in a teenaged child's bedroom may upset many parents, living with HIV impels mothers like Ruth to focus on safe sex and risk prevention.

An important way to understand how different mothers conceived of radically different approaches as efforts to protect children involves the choice to use threats and scare tactics. In this regard, women used very different strategies to protect their children. Some mothers focused on maintaining a reassuring atmosphere in which to provide matter-of-fact information and dispel fear. Other women conceived of a more radical approach, using scare tactics, issuing threats, concealing information, and forbidding the use of condoms or contraceptives as a way to keep children out of harm's way. Diana explained,

I use a lot of scare tactics in my kids' life, though. I do. I scare them about strangers, about infections they can get, that you can catch something and you will never ever move again. I scare them. They know about AIDS from school. But I depict a person, you'll weigh ninety pounds, you'll look like a skeleton, and then you'll die, and all from sex. So, that's the way I do mine.

Others chose to arm their children with information and resources, trusting that they would make the best decisions. For example, Joy consciously avoided using scare tactics with her children. As she explained, "I don't scare the heebie-jeebies out of 'em, you know? But I educate them."

## ***2. Educating Children about Drug Use***

These mothers' efforts at educating their children about risk prevention extended beyond safer-sex talks. Many of the mothers also discussed risk prevention in terms of talking to their children about the potential risks involved in drug use. These mothers understood HIV transmission risk via drug use in complex ways. In particular, they recognized that drug use could expose one to a number of sexual as well as intravenous

transmission risk factors, as it had for some of the mothers themselves. For example, Diana, a 20-year intravenous drug user in recovery, mentioned the need to educate her children about the dangers of drug use.

Of course when they get to be teenagers, I will tell them about drugs, that I used drugs. 'Cause they need to know that so that I can show them another one of those things, when I'm telling you, "Don't do it," and this is why, because Mommy knows.

Similarly, Georgette, a recovering crack cocaine addict, described her efforts to educate her young daughter about the perils of drug use and protect her from repeating her own mistakes. She reflected,

I want her to know about all this. I take her to all my meetings and stuff like that. So, I even take her to drug meetings. I go to my NA meetings and stuff like that, I take her. I take her and I want her to be involved. You know, I want her to be aware.

As with sex education, mothers use their personal experience with drugs as a basis of authority to protect children from risk in the context of drug use.

### ***3. Creating a Safe Space for Children to Talk to Their Mothers about Anything***

A number of participants identified the importance of creating a safe space for their children to talk to them about anything as contributing to their ability to protect their children. Leah remarked, "I tell my children that I'm so far from perfect, but I love 'em, and I always tell 'em. And they know they can come to me with anything." Establishing an atmosphere in which children "know they can come to [their mother] with anything" contributes to protecting children from potential harm by maintaining communication between children and their mothers while eliminating fear, shame, and secrecy.

Children's ages often determined the types of discussions mothers felt comfortable introducing. Women whose children were still very young sometimes

anticipated discussing HIV, sex, and drugs with them at an appropriate time in the future.

For example, Jillian reflected:

I've thought about that. Like when do you have the conversations... You wonder. Maybe it is good to just kind of be open in very simplistic terms about, you know, sex and things like that sort of thing there. So... we'll see. I'm not sure. I figure it'll happen kind of when it happens, and he'll start asking questions and then I'll just answer. You know, I've tried to instill in him one thing that's very very important to me and I guess 'cause I felt like I couldn't do this when I was growing up is I've really tried to tell him, "You can come to us, [my partner] and I about anything." It doesn't matter what it is. "It doesn't matter what it is, but you can talk to us," 'cause I know he's not gonna be able to talk to his father. ... Part of it too around HIV and AIDS is not being afraid to ask questions about how do you get or sex or "I heard this" or "I heard that" and that kind of thing. It's kind of all linked... I just want him to know that he can come to us. He can. And that we're always going to be a safe place for him to come talk to.

As Jillian's response indicates, many of the mothers recognized that encouraging children to ask questions played an important role in HIV prevention. Overall, HIV-positive mothers like Joy, Leah, Jillian, and Ruth strived to foster an atmosphere of openness with their children. This required them to overcome feelings related to their own experiences with stigma as well as any discomfort or reticence toward broaching sexual issues.

On the whole, HIV-positive mothers draw authority and wisdom from their own personal life experiences in order to protect children from harm. In talking about sexual risks, potential drug use, and other problematic issues, HIV-positive mothers may need to violate certain conventional social norms related to proper mothering in order to keep their children safe. In particular, most study participants sacrificed their place in the cultural good mother mythology in order to provide condoms to their teenage children, even when they belonged to churches or other communities whose proposed values asserted abstinence as the only viable option for teenagers. Providing their children with

condoms may be interpreted as condoning or even facilitating early sexual activity. However, most of the mothers accepted their teenaged children as maturing toward adulthood and interpreted their own roles as helping them to make this journey safely.

### **Strategies to Manage Negative HIV/AIDS to Motherhood Spillover**

The mothers in this study articulated a variety of strategies that they used to manage negative HIV/AIDS to motherhood spillover. These included: (1) carving out time for rest and illness, (2) seizing everyday moments, (3) managing courtesy AIDS stigma, (4) sharing parenting and household responsibilities, and (5) creating and sustaining supportive communities. These strategies are explained below.

#### ***Carving Out Time for Rest and Illness***

The mothers developed a number of different strategies to help them get through bad days with their children and homes intact. One of these involved making sure that they had time to rest so they would have the energy to take care of their children and homes. Similarly, some of the mothers carefully tried to manage symptoms and medication side effects in ways that would reduce the chance that such experiences would make it harder to take care of their children. For example, Joy set a timer so that she could have short rest periods while her children played. Linda took short naps as soon as she came home from work. Janet reported, “I always make it a point somehow to sleep at some point during the day.”

Some mothers also tried to manage symptoms and cope with medication side effects by carefully timing and planning events in the day. For example, some women planned their physical breakdowns and medication doses around their children’s daily schedules. Thus, many mothers of school-age children tried to schedule a nap during the

day while children were at school or time medication doses in order for periods of acute side effects to occur at night after children were in bed. Joy and Janet both mentioned planning their naps around the times when her children were in school. Throughout our interview, Linda repeatedly emphasized her faithful adherence to a strict routine in order for her and her HIV-positive husband to manage an unpredictable cycle of good days and bad days along with overwhelming work schedules and family responsibilities.

***“Do It Now!”:***

***Seizing Everyday Moments***

Because they lived with daily fear and uncertainty about the future, many participants learned to appreciate the importance of taking advantage of everyday opportunities to live their lives with their children to the fullest. Many expressed living with a unique sense of urgency or haste in everything they did as a strategy to manage the negative effects of uncertainty that came with an HIV/AIDS diagnosis. They resolved to take advantage of the present moments and not to take life for granted because the future is so uncertain. Their interviews resonated with messages of having to do everything now, trying to give everything their all right now, living in and for the present, placing a priority on the here and now, doing a lot of activities with children now, trying to spend lots of time together with their children, refusing to miss important moments and special rites of passage, and making up for lost time.

Joy remarked of her haste to have children after she tested HIV-positive in her teens, “I was in such a rush to have a family and to have children because I was so afraid of being HIV. You know? And, ‘Oh my God, I’m gonna die. I gotta do it *now*.’ You

know, ‘Do it *now!*’” This sense of urgency to “do it now” because of an uncertain future resonated throughout many of the interviews. For example, Georgette explained,

I put everything into today ‘cause, you know, I never know when I’m—you know, I try to give it all I got now, because, like I said, I don’t know when it’s gonna come a time when I’m not gonna be able to do it or I’m gonna wanna do it and then I’m not gonna be able to. You know, I’m not gonna feel like doing it. I’m not gonna be able to do it. So now, whatever we wanna do, we just do it.

Similarly, Naomi reflected, “I think [HIV] plays a strong role in my life because it’s almost like I want to do all the right things because I know the timing is valuable and I want my daughter to do the right thing. So that’s why, now it’s like I take—even from when she was little though, I tried to instill the good values and important things so that she can carry on with her as she becomes an adult.” Ruth described her efforts to make up for lost time and seize available moments with her youngest daughter, now quickly approaching adulthood:

What I do is I try to spend as much time as I can with her. Because like I said, I was in addiction a little part of her life and before my [oldest] daughter took her up here to keep her until I got myself straight. She—we missed a lot of... We missed probably eight to eleven. Three years. Three years between eight years old and eleven. We missed those years and those were really good developmental years that I missed. So I know I couldn’t make ‘em up to her, but what we do is we play games now. You know, she likes to play Monopoly and all kind of stuff like that. So we bought games. So we play games, stuff I missed. We read together. We read the Bible together. We go places. We go shop together. I go to the doctor with her. She goes to the doctor with me sometimes. Just different things that we normally, I wouldn’t do. But we try to spend as much time as we can together.

In Ruth’s case, not only does she feel that she must take advantage of available moments in the present against an uncertain future, but she is also catching up for lost time and making up for the past, for years lost to drug addiction, homelessness, and separation from her children. The corresponding urgency and singular focus with which Leah

approaches her life with her family may similarly result from the years she lost to drug addiction, incarceration, and separation from her children. As she explained, “I don’t take life for granted. [...] I don’t wanna play anymore. I wanna be a good wife and a good mother. And my family’s the most important thing to me.”

Other experiences contributed to making some participants acutely time conscious. For example, Gloria reflected on how experiencing the premature deaths of a number of close family members, including her husband’s harrowing death of AIDS, had given her a unique awareness of the value of time. Consequently, she regarded the moments she had in the present as especially precious and not to be taken for granted. She concluded, “I really appreciate God giving me this time that He’s given me.”

Participants also related appreciating the importance of seizing every opportunity to communicate to their children how much they loved them. Joy explained, “Our ritual, you know—whether we’re on the phone or when their daddy picks ‘em up or I drop them off to their daddy, whatever. We tell one another, ‘I love you whole bunches. I praise God for you.’ That’s our thing.” Similarly, Janet noted, “I always make sure I tell my kids fifty times a day, you know, that I love them and when they’re away from me I miss ‘em. They might drive me nuts but when I get away from ‘em I miss ‘em. But *never*, I can’t imagine them going a day without me saying... I kiss ‘em and I hug ‘em and I love ‘em, you know? That’s the most important.”

At the same time, a heightened awareness of limited time and foreshortened mortality make seizing available moments all the more imperative. Slowing down, focusing on one’s children, spending quality time together, and making memories become important whenever good days allow. For example, Laurel explained, “I do a lot

of things with [my children] in the summertime. A lot. We go to a lot of baseball games. We go to a lot of concerts. We go shopping. We went to the Football Hall of Fame. Things that I would never have probably done any other time. I'm trying to do things with them that I would probably never do otherwise. Things that they can look back and say, 'Hey, we did *this*.'" Creating memories for her children to look back on has become an important focus for Laurel's good days, as for many other study participants.

The constant knowledge of living with HIV/AIDS encourages these mothers to seize everyday opportunities to make lasting memories with their children, and as a result they are able to reduce the negative effect that HIV/AIDS may have on their mothering roles. Their unique awareness of the uncertainty of the future imbues their lives with a special sense of urgency. Along with the fear and uncertainty they face, these mothers learn to adopt a *carpe diem* attitude toward their lives, in particular to their relationships with their children, intent on doing today what they may not be able to do tomorrow. In effect, they end up being able to have rewarding mothering experiences despite the difficulties of HIV/AIDS.

### ***Managing Courtesy AIDS Stigmatization of Their Children***

A third strategy to manage the negative impact of HIV on their experiences as mothers was to incorporate various stigma management strategies to protect their children from the negative effects that could result from courtesy stigma. Although the mothers could not completely protect their children from experiencing courtesy stigma, many mothers were able to inoculate their children through frank discussions about HIV and about stigma and discrimination. The mothers also attempted to build up children's healthy self-image as armor against potential ill treatment. For example, Joy talked to her



son and daughter on a regular basis about AIDS stigma and intervened when adults in her children's lives treated them poorly because of her status. Similarly, Naomi took regular opportunities to have frank heart-to-heart discussions with her HIV-positive daughter about overcoming stigma, establishing friendships with accepting peers, and asserting a confident self-image.

Participants' sometimes radically different approaches to stigma management were all conceived of as efforts to protect their children from harm. For example, whether or not they told their children that they were HIV-positive, most mothers regarded the issue of disclosure as a matter of protecting children. In this regard, Diana remained intensely protective of her children and fiercely resistant to any threat that they discover her status. Other mothers used disclosure of their HIV-positive status as a teachable moment for their children. For example, Joy regularly used her experiences with HIV/AIDS to guide her children in making responsible life choices. Moreover, Joy directly linked disclosure to her ability to protect her children: "I *knew* that I wanted the kids to just grow up knowing [my status], because I did not want them to become infected."

Joy also inoculated her children from shame or embarrassment by taking preemptive action to educate them about the realities of HIV and the images others might associate with HIV/AIDS. Joy regarded disclosure and teaching her children about HIV and AIDS as the best way to protect them. She explained, "By them knowing, growing up knowing that I was HIV, I felt like that that helped to keep them safe at the same time."

Diana, on the other hand, assiduously concealed her status from her children and guarded against giving any sign that would connect her with illness and stigma. Perhaps the most acutely image conscious with concern to her children of all of the study participants, she took enormous pains in the interest of stigma management. Diana was acutely aware of her presentation of self to others and how others judged her, especially people involved in her children's lives. She emphasized the importance to her of presenting a flawless image at her children's school and criticized other mothers who neglected their appearance when representing their kids. To illustrate her point, she criticized the mother of a rising R&B star for appearing on television without dentures, thereby embarrassing her daughter and tainting the singer's emerging career. She also criticized another study participant for neglecting her appearance and disclosing her HIV-positive status to her family and community, thereby giving her children cause for embarrassment and worry.

In contrast, Diana portrayed herself as taking every precaution to protect her children from courtesy stigma. She described her visits to her children's schools and events involving her children: "I'm gonna be on point when I come. I'm gonna be sharp. I'm gonna look presentable. I'm gonna depict a good image. All that is about the kids, 'cause it's their turn. And so I want to leave them with a good memory." For Diana, presenting a flawless image was a way of mitigating or combating stigma and protecting her children.

***“I Just Don’t Think I Could’ve Done It Alone”:***

***Sharing Parenting and Household Responsibilities with Loved Ones***

Because the mothers were living with a serious chronic illness while meeting the demands of taking care of children, in many cases while also working, many found the need to split parenting with partners, ex-partners, other adult family members, and occasionally their children in order to make their workloads more manageable. This fourth strategy is discussed below and divided between support and assistance from partners and ex-partners, and that received from mothers, sisters, and children.

***1. Receiving Support and Assistance from Partners and Ex-Partners***

For some, these co-parenting strategies with partners and ex-partners worked remarkably well. For example, as Joy described her children’s father, “He is very involved with the kids. There’s good communication—*great* communication—between the two of us. [...] So he is *such* a good daddy. Such a good good daddy.” Likewise, Jillian described the indispensable help her partner provided:

Where [my partner] really, really is just amazing is with [my son]. I mean, he really is. I mean, considering, it’s not easy for somebody to come in and love somebody else’s child. But he’s done an amazing job at it. I mean, just amazing. And [my son] loves him to death, you know? [...] He’ll help me out, you know, he’ll take [my son] to the Children’s Museum if I want to go into work and things like that. He helps me at home, you know, with the little things. You know, reading to him at night, you know, that kind of thing. If he sees I’m getting frustrated with [my son], he’ll try to take over. He helps with the discipline and all that kind of thing. So I mean just he’s been amazing with that, just helping me there. ‘Cause I just don’t think I could’ve done it alone.

Similarly, Leah related how her husband helps her: “I have days where I just can’t get out of bed. And my husband takes care of everything. He takes care of the house. He takes care of [my son’s] homework and his bath, and me. You know, he’s the stepfather but he

spends more time with him than [my son]’s own father.” Laurel described her oldest daughter’s father as very involved with both of her daughters. Although the two were no longer together as a couple, Laurel’s ex-boyfriend remained available to help with both of Laurel’s daughters, taking them on trips, and otherwise sharing responsibility for the children.

For women whose husbands or partners were also HIV-positive, supporting each other with child care and parenting responsibilities became especially important. Linda remarked of her husband, “We’ve always had each other to lean on.” Rachel and Nina both reported that their respective partners were always available to take over child care duties, although both women assumed the role of primary caregiver.

For the women in dual-earner couples, organizing a routine of shared parenting became especially important in terms of helping these mothers continue to work. Consequently, the struggles and strategies for couples involved in juggling work and child care stood out as a prominent theme for a few of the participants. For example, Linda described in detail the elaborate strategies that she and her husband had employed over the years so that each partner could consistently maintain one or two jobs while keeping child care costs to a minimum. At first, this meant that her husband would bring their infant son to work with him on slow days. Eventually, Linda and her husband staggered their work schedules so that one parent would be home with their son before and after school. Similarly, Andrea and her boyfriend worked opposite schedules so that one of them would be able to stay home with their young children while the other was at work.

## ***2. Receiving Support and Assistance from Mothers, Sisters, and Children***

The other most common relatives to provide support were mothers, sisters, and children. For example, Laurel relied on her mother, sister, and eldest daughter to prepare meals and run errands when she felt too sick or exhausted to do so. Similarly, during the times when Laurel had to be hospitalized for AIDS-related health complications, she turned to her mother, sister, and oldest daughter to take care of basic responsibilities at home, such as taking her children to school, doing grocery shopping, preparing meals, and paying bills.

Another strategy for surviving bad days involved relying on their children to become more independent and accept more responsibility for daily routines and household tasks. For example, Rachel relied on her ten-year-old daughter to help during bad days by taking care of her baby when Rachel felt too sick to do so. She explained,

I have migraines. At times they get really bad to where it affects my vision. And I have to lay down and just take a nap to get rid of it. I take my Imitrex and I lay down. And [my daughter] is great. If I'm sick and I don't feel good, she takes that baby and she'll feed it lunch. She'll change her diaper. She'll give her a bath. Yeah, she's great in that aspect. She usually keeps my dishes done. They're a little bit behind this weekend because she was at a friend's house. But she does the dishes. She loads the pops in the 'frigerator. She keeps her room clean. She makes our bed.

In effect, an adolescent took on caregiving responsibilities for her younger sibling along with the adult responsibilities of managing household chores on days when her mother was ill. In fact, many participants relied on their older children to help with household chores and to take care of younger siblings. Children also had to become more self-sufficient and responsible for their own care. For example, Jillian reported relying on her four-year-old son to take more responsibility for himself when she was experiencing a bad day. She recounted,

But I do tell him sometimes, like I get tired or sometimes, you know, I don't feel well and things like that. Now that may not be related to AIDS. But part of it too is I think how I tell him is in the context that I have a chronic illness. I don't say that but I just say, "You know, every once in a while, Mommy doesn't feel well," or "I need to lie down," or "I really need your help." You know, like getting his pajamas on at night, I really—he knows how to do it but he's still, "You help me, you help me." But sometimes I feel bad because I don't want him to feel like, oh he has to help his mom. He has to do this, this heroic effort in a way. But I do sometimes tell him, and say, sometimes I just really don't feel well and it really helps me if you help me with this. You know, it's hard for me to do that and that kind of thing. Just little things, simple things like help get dressed or brush your teeth yourself, instead of my jumping in and trying to help him. 'Cause little things like that can get tiring. Like for any mother. Not just someone with HIV.

While these situations gave children opportunities to develop self-confidence, independence, and maturity, they also created conflicting feelings of pride and guilt for their mothers. Thus many mothers noted that their children were exceptionally mature and responsible for their age or lamented that their children had to grow up unusually fast. For example, Gloria noted that growing up with an HIV-positive mother required of her son that he accept more responsibility for himself than other children his age. Similarly, Leah observed, "I think that with everything that my oldest boy has went through, he's had to mature. He's had to grow up fast. He's had to learn to be responsible." Similarly, Janet expressed pride in her teenaged son for becoming exceptionally responsible and assuming an adult role as the man of the house.

In Tabitha's case, being forced to give her oldest daughter more responsibility in times of illness caused problems for Tabitha in terms of eroding her parental authority when she was well. Her repeated extensive hospitalizations for AIDS-related health complications caused her to put her oldest in charge. Once she returned home, however, her daughter refused to abdicate her newfound adult role and the freedom that went with

it. As Tabitha explained, “My now-fifteen-year-old had to take the responsibility of being mother role to my eleven-year-old. And it kind of got out of hand last summer because she thought she was grown.”

Consequently, concentrating on helping children grow up and become independent became a central focus for many of the study participants. For example, Laurel focused all of her thoughts and energies on “getting them through to be an adult.” The mothers also concentrated on their eldest children reaching a level of independence and stability at which they could become responsible for younger siblings in the event that, through severe illness or death, their parents were no longer able to care for them. Thus, Laurel focused on: “My youngest daughter graduating from high school and [my oldest daughter] graduating from college and getting a halfway decent job, and taking care of herself. And then if something happens to me, hopefully she would take care of my other daughter.” Others concentrated on children reaching driving age, graduating from high school, entering college, joining the military, or some other social milestone or personal marker indicating self-sufficiency and independence. For many mothers, this preoccupation served as almost a kind of daily mantra, guiding their efforts and focusing their energies.

Although most of the participants were able to negotiate workable arrangements with at least one family member, for others, they found their partners, children’s fathers, and other family members disappointingly unforthcoming with help. Although Naomi’s ex-husband shared parenting responsibilities with her when they were living together, once their relationship dissolved due to his physical abuse, his assistance likewise vanished. Tabitha related the breakdown of responsibility in her family, “[My husband]

left everything on me rather than taking a parental role.” Janet reported that her HIV-positive ex-husband had nothing to do with their three children and refused to pay child support for them beyond “twenty dollars here and twenty dollars there,” which he used as leverage in order to make Janet spend time with him and take care of him. Janet observed, “As hard as it is to be a single mom, it’s twenty times harder to be a single mom with [HIV].” Olivia received no help and little contact from her own family and reported of her sons’ fathers, “I haven’t been in contact with neither of their fathers from day one.” Considering that Olivia was chronically mired in intersecting crises, including numerous evictions and housing instability, losing her one form of reliable transportation, and chronic job insecurity, her estrangement from her family and her children’s fathers significantly contributed to her problems by shutting her off from virtually all emotional support and practical resources.

***“I Really Got to Know People”:***

***Creating and Sustaining Supportive Communities***

The final strategy the mothers used to manage negative spillover on mothering experiences that could result from living with HIV/AIDS was to engage in active efforts to create and sustain supportive communities. Their narratives of turning to community demonstrate how networks based on mutual support and care help HIV-positive mothers cope with the emotional struggles and day-to-day challenges of living with HIV while raising children. Because all of the study participants faced different structural constraints as mothers living with HIV, their ties to a supportive community became vital lifelines for them. For example, Joy and Diana as busy stay-at-home mothers with heavy family responsibilities that often tied them to the home, Jillian and Linda as busy mothers



with demanding professional careers, and Leah and Laurel as severely ill mothers living in rural communities that harbored pronounced AIDS stigma, all created their own community networks to help them cope with the demands of their life circumstances.

Participants reported a number of different ways that they helped to build and maintain supportive communities. These included getting involved with HIV/AIDS advocacy groups, participating in HIV-themed Internet chat rooms and listservs, attending support group meetings, and being active in church groups and faith-based communities. In particular, a number of participants talked about getting involved in their local AIDS service organizations. For example, Rachel described at length the many ways she had volunteered her skills at her local ASO. She described the motivation behind her activities: “I feel like I’m giving back to a center that’s given me so much.” Gloria also reported taking leadership roles in her local ASO and an international AIDS advocacy organization.

A number of participants also reported attending workshops and retreats for HIV-positive women and their families. Andrea remarked, “Every workshop that comes along, I go to it.” Linda shared, “Probably the most uplifting, honest thing that I do that helps me is going to [HIV-positive] women’s events. Just being around other women.” She described the important role HIV-positive community events fulfill in her life:

It really cleanses—at least for me—my mind. You know? I just, I come home and I’m just so pumped up. I’m ready to conquer the world. And I love seeing the people that I haven’t seen for a year, or sometimes, or somebody I haven’t seen for a couple years because they didn’t make it to the last time that I made it to. [...] But I do try and go, and I wish they had more of them. But that’s a very good outlet for me.

Laurel similarly described HIV-positive women’s retreats and other HIV-positive community events as an important part of her life. A number of other participants

reported attending weekly support groups for people with HIV/AIDS at local ASOs and other community organizations in order to maintain supportive ties to the larger AIDS community. However, being a part of the HIV-positive community extended beyond attending face-to-face events. For example, with her responsibilities as an active stay-at-home mother of two children, Joy relied on the community she found in HIV-themed Internet support groups when she was too busy to attend face-to-face community meetings and events.

For many participants, communities of faith also served as fundamental resources for support. For example, Naomi described the importance of her inclusive church community for helping her cope with life as an HIV-positive single mother. She explained,

My ministry at church, that too, 'cause I went there. And I do go to a predominately white church, 'cause it's where there's a lot of white people. But the thing about it, I went there on a humble. I just knew it was like the closest church around that I could worship at, to where I could at least feel like I'm closer to God. And once I got there, I didn't plan on staying there, but it was like the people in the church were so friendly to me and they didn't, you know they wasn't judgmental about nothing. You come, you don't have to dress up every Sunday or whatever. You come as you are. They wasn't judgmental or nothing, and I felt so comfortable there that I joined it after a while, you know. And I said, well that just told me right there that they're not judgmental or nothing and they don't make no issue about my race or none of that. I'm just like another person there to worship and do what they're doing and to serve the Lord, and that in itself, that helped me. That helped me get over a lot of my issues being able to be closer to God. And it has. It has. They was pretty cool.

Similarly, Gloria described the central role her church played in her life: “That keeps me going. Church functions, cooking at church, and being a member of the choir at church, and my son recently was baptized. And so that was—that keeps me going.” Ruth also reported turning to her church for help and support.

Ruth regarded her plan to create a faith-based community of HIV-positive recovering addicts as a mission from God. She explained, “This is something that I want in my life, to be clean and sober, and to be close to God, and to reach out and help others that are struggling with the same problem I had.” Moreover, by reaching out to others and creating community, Ruth had taken steps to transform the impact of HIV on her life. She described the benefits of establishing community ties in her life: “I really got to know people. Meet people. That’s been a positive thing for me.”

A number of participants also became involved in groups not necessarily overtly related to HIV, but which overlapped with HIV in their lives. These supportive communities included 12-step groups like Narcotics Anonymous and other groups focused on recovery from drug and alcohol addiction. Others turned to groups for survivors of domestic abuse and family violence.

Some women created their own informal support networks with friends. Georgette formed a close supportive alliance with a long-time friend based on their shared struggles with street life, homelessness, the criminal justice system, drug addiction, and HIV. She explained,

I have a friend, but she live in Detroit, Michigan, but I still stay in contact with her. She’s still fighting her drug addiction. Yeah, she’s still fighting hers, but I still—and she have HIV, and I have to be on her constantly telling her to make sure she’s taking her medicine, make sure she go to her doctor’s appointment. ‘Cause she, like I said, she’s out there still doing drugs and she don’t even care. And I care about her and she care about me. And so, if I don’t stay strong for her, she’s—I don’t know. So I have to take care of her too, even though it’s long distance. Yeah. So, but she’s supportive though. Um-hmm. Yeah. It’s more like I’m supporting her. But yeah, she keeps me—and she said, “Georgette, I don’t see how you can do it,” she said, “I can’t stay clean,” she said, “but you can stay clean.” I said, “Because people like you motivate me.” She said, “How am I motivating you, and I’m the one that’s doing all this here?” I said, “‘Cause I have to

keep on you. If I don't stay clean, who gonna straighten you out?" So, I call her about two or three times a week, we talk.

Similarly, Gloria created mutually supportive relationships with other HIV-positive women in her community. She explained,

A young lady that's at my church, we support each other. And, actually, there's another girl that I actually went to high school with that I had seen at a HIV/AIDS conference, and we just looked at each other and hugged each other, and every time we see each other we always give each other a big hug and let 'em know that we love ya and hang in there.

Educating and advocating are essential tasks for creating and sustaining community, itself a vital coping strategy for living with HIV/AIDS. The importance of community and intimate support networks is most clearly seen when contrasting isolated women and families with those who were securely tied into one or more support networks, whether HIV-centered or not. Leah, profoundly isolated in her small rural town by pervasive AIDS stigma and often debilitating mental health problems while disconnected from anyone else living with HIV/AIDS, reported of her experiences living with HIV: "It's very lonely. It's a very lonely virus." Ruth, on the other hand, whose family was tied tightly into a network of overlapping support networks, reported, "My support group is very broad." For almost all of the study participants, becoming part of a community served as a strategy for defeating stigma and feeling accepted and supported, as well as accepting others and providing support.

### **Analysis: The Impact of HIV on Motherhood**

Living with HIV/AIDS forced these mothers to adopt a number of interlocking strategies that they might not have been as motivated to pursue had they not been raising children while living with a serious chronic illness. The ways in which they structured and organized their families' daily lives had everything to do with HIV/AIDS. The

interviews uncovered that negotiating the ups and downs of good days and bad days, confronting fear and uncertainty, seizing everyday moments with their children, creating communities of mutual support, and sharing parenting responsibilities with partners, children's fathers, and other family members became essential coping strategies for the women who were living with HIV while raising children.

In some ways, an HIV-positive diagnosis could enhance the mothering role. For example, living with the uncertainty of an HIV-positive diagnosis compelled these mothers to focus all of their energies on their children in the present and to make sure their children were prepared for the future. Their experiences living with HIV/AIDS also motivated many mothers to take aggressive measures to protect their children from harm. However, in other ways, HIV interfered with their ability to be the best mother they could be. For example, frequent periods of illness limited many mothers' opportunities to spend quality time with their children.

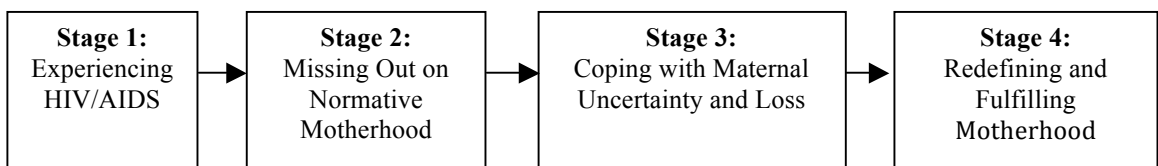
Fundamentally, living with HIV/AIDS required of these mothers that they adopt a certain orientation to their roles as mothers, family members, and members of their communities that had profound implications for their children, their families, and their communities. For example, many of the participants mentioned engaging in a process that can be described as global mothering. Through this process women come to interpret their status as mothers as a mandate to make the world a better place not only for their children, but for all children, based on whatever expertise they possess (cf. Ruddick 2002). For example, Rachel framed her efforts to educate local middle and high school students about the dangers of contracting HIV and other STDs in the light of her role as a mother living with HIV. In this regard, she extended her sense of responsibility

as a mother beyond her own children to encompass her children's peers and their whole generation.

Because of their experiences with HIV, these mothers felt the urge to protect not only their own children but others' children as well. In this way, they perceived a broader role for themselves as mothers. As a result, socially conscious and active mothers built common communities with others based on their HIV-positive status. Specifically, by sharing information and creating supportive communities, these women transformed their roles as mothers and their self-perceived mandate into a wider role in the community.

Furthermore, there appears to be a social process occurring here in which the major problem that the mothers experience in HIV-to-motherhood spillover is the problem of loss of maternal identity when one becomes HIV-positive. This process involves the loss of being able to live up to normative expectations and experiences of motherhood. The mothers attempted to cope with the problem through a four-stage process (see Figure 1).

**Figure 1: HIV/Motherhood Identity Integration Process**



Through this process, women face the challenge of reconciling their identities as mothers with the fact that they are HIV-positive. Initially, on receiving an HIV-positive diagnosis, the women experience HIV/AIDS as a disruption to their lives and identities. They tend to regard HIV/AIDS as an impenetrable barrier to a normal life trajectory, in

particular as prohibiting the experience of normative motherhood. They seek to reconcile their evolving HIV-positive identities with the desire or reality of motherhood in their lives. Finally, they are able to redefine their own interwoven experiences of HIV and motherhood as redemptive second chances or as congruent with their former identities.

## **CHAPTER FOUR: THE IMPACT OF MOTHERHOOD ON LIVING WITH HIV**

The previous chapter addressed the impact of HIV on motherhood. The following section explores the corresponding dimension of HIV-positive mothers' experiences, the impact of motherhood on the experience of living with HIV/AIDS. Just as living with HIV/AIDS exerts a profound impact on women's experiences as mothers, the experience of being a mother exerts a parallel impact on the experience of living with HIV/AIDS. These influences are both positive and negative, in that motherhood can enhance life with HIV/AIDS while also complicating it. By motivating women to take better care of their health, to take an active role in health care and reproductive care decisions, and to resist allowing HIV/AIDS to dominate their lives and identities, being responsible for children can enhance HIV-positive women's lives. However, other aspects of motherhood place negative pressure on HIV-positive women. In particular, the imperative to put others first could undermine these mothers' efforts to place a priority on their health care regimens. The following sections explore the double-sided nature of motherhood for women living with HIV.

### **Motherhood to HIV/AIDS Spillover**

Several themes regarding the ways the women's motherhood status positively spilled over into their experiences of managing HIV/AIDS emerged from the interviews. These included: (1) being a mother motivated women to take care of themselves, (2) women drew on their maternal authority to trust the self to make reproductive and medical decisions, (3) being a mother helped them to put HIV in perspective, and (4) being mothers drove women to advocate and educate others about HIV. Two final themes emerged that were directly linked to the women's maternal ideologies, one that



exerted positive spillover effects and a second that exerted negative effects. First, (5) being a mother helped the women to diminish their stigmatized illness identity, but at the same time (6) being a mother and living up to the maternal ideal of putting one's children first could lead women to not take care of themselves. These themes are illustrated below.

***“I Need to Be Around”:***

***Drawing Motivation from Children***

The ways being a mother and living with a serious chronic illness intersect in the lives of HIV-positive mothers are particularly apparent in how being responsible for children served as a central motivating force for study participants to take care of their health. For most of the HIV-positive mothers in the study, having children served as a primary motivation to place a premium on their health and to take an active role in their health care. For example, Laurel explained, “If I didn’t have [my daughters], I probably would not have worked so hard to get where I’m at. If I didn’t have kids, I wouldn’t’ve worked so hard to stay well. You know, ‘cause there’s other people to worry about.” Similarly, Nina explained, “Now since I have kids and this issue [HIV] on top of everything else, it’s more like, you know, it drives me to do what I need to do, instead of sitting around and doing nothing.” Naomi reflected on the role of motherhood as a source of motivation in her life: “It gives you a drive to want to do more while you can. It definitely does that. It gives you more motivation. I guess more responsibility. ‘Cause you know you got to get you right before you can do anything to help your kids. If you’re sick, who’s gonna help ‘em? It does give you more motivation.” Likewise, Joy described her children as the main reason for her to try to stay healthy. She explained,

I think that I will live longer because of them. I really believe that. Really really really. Even if I died tomorrow, I will have lived longer than what I probably should have, because of my children. Because they give me the will to keep going. Because the thought of my children standing at my casket *really* sucks ass. I don't want that. I do not want that. And there's people, like my husband now, he would be fine without me. Would he be hurt and would he be upset? Yes. But he would be fine. My children? That would just really really throw 'em for a loop, and I don't want that. I don't want that. I do not want that. Because there's been *many* times that I've thought, "Screw it. I don't even want to be here. I give up. I'm just gonna lay here and die." Wrong! I can't do that. I can't, I can't do that. I have to keep going because of my children. They need me. I am their momma and I don't want some other broad to be their momma. I'm their momma! [*She laughs.*] And I'll whoop somebody's ass if they try to be their momma. You know? But, yeah... So that keeps me going.

The sense of being needed by her children and her aversion to being replaced in her role as their mother serve as intense motivators for Joy to fight to remain healthy. Ruth, a much older African American woman with a much more complicated life trajectory, similarly explained,

[My children] are a motivation. My daughter's been a motivation.... She's been a motivation for me to just do right. Do the next right thing. And keep on doing the right thing so that I can live and see her and see my grandchildren from her, you know, my baby girl.... It motivates you to... Because you just want to... There are so many things in their life that you want to see come to fruition.

For Ruth, doing the right thing included taking a proactive approach to HIV, undergoing a prolonged course of treatment for Hepatitis C, treating her diabetes, and committing to an intensive and lengthy recovery program for drug addiction.

A number of participants reported taking medications for their children. Nina identified the motivation her children provided her to continue taking her HIV medications despite uncomfortable side effects: "I'm not taking my medicines for me, I'm taking it for them." Linda and her husband had created a code word based on their child's name to motivate each other to take their HIV medications despite busy schedules

and harsh medication side effects. She explained, “We call it ‘4B.’ Our medicine? That’s kind of our little help. You know, ‘Hey! 4B!’ You know, for taking it. And it’s ‘*for Bobby.*’ That’s what we consider ‘4’ is that we take it so that we’re healthy for him.” By creating a shared code, Linda and her husband were reaffirming daily the importance of taking care of their health for the sake of their son.

Joy expressed the imperative for taking care of one’s own health that motherhood entails. She explained, “You can’t be careless. Gotta take better care of yourself. ‘Cause it’s not all about you anymore. It is so, so not all about you.” Similarly, Rachel elaborated, “I think [being a mother] changes how you deal with [HIV]. You know? In the aspect that you do more to keep yourself healthy, so that you can take care of them and be the best mom that you can.” Georgette described how assuming sole responsibility of her daughter introduced motivation into her life to actively seek wellness. She explained,

Well, I always take my medicine. Before she came along, I always took my medicine and you know I did what I had to do. But I wasn’t—I just did it, you know. It wasn’t—I didn’t have no motivation or nothing like that. But when she came into my life, then, you know, I started getting, you know, like I said, I was taking my medicine. I never skipped. But I started thinking about it, being serious about it. I said, you know, I don’t wanna get sick. I wanna get better, because she needs me. And they put her in my care so they must think that I’m capable, you know, of taking care of her. And so, it’s different but it gets me motivated, you know, and makes me say I wanna get better and, no, I don’t wanna get sick. And she’ll be right there, “Momma, did you take your medicine? You gotta take your medicine, Momma.” You know, she makes sure I take my medicine. “I don’t want you to get sick, Momma.” So she’s there for me and she makes me motivated to want to get my life together and not get sick. ‘Cause if I get sick, who’s gonna take care of her? She needs me.

Being totally needed by a dependent child forced Georgette to value her health and longevity. Moreover, beyond serving as a motivating symbol in her life, her daughter

actively motivated her to take care of her health by verbally reminding and encouraging her to take her medications. Likewise, Laurel's daughter and Naomi's daughter both also actively reminded their mothers to take their meds as well. Later in our interview, Georgette reflected,

Right now, she's my main source [of motivation]. She's the reason why I feel like I want to fight this thing and I wanna live, and you know be there for her and teach her, you know, that—about you know the stuff that's going on, to make her aware. Maybe she could help other people.

Similarly, Jillian explained how her son became her primary motivation to undergo treatment for Hepatitis C:

I kind of felt like, you can't be selfish anymore. You gotta take care of yourself, because you've brought this little boy in the world now, into your lives, and you have a responsibility to take care of him. You have a responsibility to be there for him. And so one of the main motivations for doing that was because of him. I finally made the decision—it was like, "Okay." This is what got me to say, "Okay, I'll do it." It was the final, like here's—that swayed it into the positive of doing the treatment.

Later, Jillian returned to the point about her son serving as motivation for her to make efforts to improve her health, in this case by undergoing treatment for Hepatitis C:

Just thinking of the Hep C treatment, and [having my son] gave me another—well, I need to be around. You know? I can't be selfish and say I'm not gonna do a treatment 'cause I don't want to experience those side effects. I don't care if I die younger. I can't, you know, quantity-quality of life type thing. I can't really be selfish like that, in a way. I've got to think about this little being who's totally dependent on me and a couple of other adults in his life, and he's gonna grow a bond with me and he's not gonna want to lose his mom.

Jillian's testimony is important in part because it highlights the ideal of "not be[ing] selfish anymore" as it fits into the cultural image of the good mother. Ironically, by deciding to act unselfishly and put their children first, these HIV-positive mothers are placing a priority on caring for their own health. However, this may push mothers to

accept a sick role or patient role and comply with an authoritarian medical system that uses women's roles and responsibilities to guilt them into unquestioning compliance. For example, some mothers may feel pressured into taking medications about which they have concerns or undergoing invasive treatments.

On the other hand, many women may feel profound guilt for failing to sufficiently adhere to a health care agenda despite their children's dependence on them. Ways that mothers deviated from treatment plans could be a source of guilt or shame. Failure to completely adhere to a complicated or demanding treatment regimen may trigger worries about being selfish. For example, Jillian expressed guilt over drinking alcohol because of the potential for alcohol use to jeopardize her health. Likewise, Leah's multiple suicide attempts, drug use, and subsequent incarceration caused her profound guilt in terms of the risks to her health and the years she felt she had stolen from her children. Looking back, she lamented, "I was really selfish then. I didn't consider my children." Later in the interview, she returned to this theme by confiding, "What's hard for me knowing that I was a terrible mother for about three years because I was selfish. [...] That weighs on me. That makes me feel like a terrible mother."

Some of the mothers pointed out that, beyond merely motivating them to take better care of their health in the face of a serious chronic illness, having children kept them from contemplating suicide in the face of potentially devastating news. Thus, the presence of children can encourage women to continue to find value in living when testing HIV-positive disrupts their identities and devastates their sense of a coherent life trajectory. For example, recounting the day she received her HIV-positive test results, Nina explained,

When you first find out, they sit there and they're like, "You're okay with it? You're not gonna hurt yourself or anybody else?" And you're like—I look at the lady like, "No. Do you see my kids? I got things to go home and do, not worry about hurting myself or others." So, I can see why people who didn't have kids can't handle it and get stressed and why some people might, you know, take their own lives and go a drastic step like that. Because you do have days like that. But when you have like kids and a family to fall back on, it makes it a little bit more you can tolerate it a little bit better. You can get your mind off of that issue. And now you have to do this with that child right now or, you know.

Later, she elaborated, "Basically if you don't want to live for yourself, you can live for [your children], is like bottom line. You know?" Tabitha reflected,

I believe if I would'a had [HIV] and I didn't have no kids, I would've probably killed myself. I probably would'a. Because it was actually hard finding out when I had my girls, but I was like I had to live life for them, for as long as I could possibly live. But I think if I didn't have 'em I probably would've committed suicide.

Rachel, who discovered she was HIV-positive while pregnant with her first child, explained,

If it hadn't been for the fact that I was carrying a child and bringing a child into this world, I think I probably would have been in such a depression state that—and you know your mental aspect of all of it and how positive you stay plays a major role in how the virus can take over. So yeah I think that played a major part. It made me stronger. And I did probably a lot more to take care of me and [my partner] so that we can be around for [our children].

Clearly, assuming a positive social role as a mother injects new value into one's life in the face of chronic illness and identity disruption.

When chronic mental health issues, poverty, family violence, and addiction compounded the effects of chronic illness, having children continued to serve as a motivation for the women with the most disadvantaged and complicated lives. For example, Andrea confided, "That's what's making me want to live, because of my kids."

Leah observed, "I have difficult days where it's hard to get up, but... You know, that's

what keeps me going. I know I have to be there for them.” Later, she explained more specifically,

[My son]’ll come in sometimes, and I’ve been, you know, depressed, and I’ve been in bed for a couple days, and he’ll come in and sit with me and say, “Mom, will you fix me something to eat?” And he does things like that, because he knows that’ll get me up. That’ll get me up. To be able to get up and fix him something to eat or take him somewhere or whatever will help me. So, I mean, he helps me. He helps me when I need it.

Despite the effects of chronic illness and chronic mental health concerns, Leah was able to rally her limited physical and emotional resources because her son needed her. Thus, being needed by her children provided a motivating focus for her.

Being a mother and being responsible for the welfare of children served as a strong impetus to stay healthy for most of the mothers in the study. Becoming a mother highlights the importance of one’s survival in ways that few if any other life experiences can. However, motherhood and the experience of HIV intersect in important, but not exclusive ways. Having children cannot be the only way for HIV-positive women to treasure their health and themselves. This study focused specifically on the experiences of mothers living with HIV. However, HIV-positive women could as easily find immense value in work as community activists, mentors, educators, or a number of other roles in society.

### ***“I Went with My Gut Feeling”:***

#### ***Practicing Self-Advocacy in Reproductive and Medical Decisions***

For many participants, being HIV-positive required that they learn to trust themselves and develop confidence in their ability to make wise decisions for themselves and their families. Beyond gathering information, they had to develop confidence in their ability to make decisions in the context of constantly imperfect and incomplete

information. Given the great extent to which their parenting confronted medical authority, they were faced with the challenge of learning to advocate for themselves and their families. As such, being a mother helped the women become better advocates for their health care.

In terms of medical decisions, participants had to make decisions and assert choices in four key areas: reproductive or fertility care, pregnancy and delivery, health care for children, and medication and treatment choices for themselves. Reproductive health choices included the choice to conceive, the choice to use fertility treatments, use of contraceptives and condoms with partners, and more permanent contraceptive choices like undergoing a tubal ligation. Decisions around pregnancy and delivery included the choice to take AIDS medications like AZT during pregnancy and delivery and whether to undergo a C-section or vaginal delivery. Medication and treatment choices for themselves included whether to begin taking HIV medications, whether to continue taking a medication despite harsh side effects, whether to treat co-morbid conditions like Hepatitis C, and the choice to remain in the hospital during a period of acute illness.

Study participants also described the need to learn to follow their gut feelings. For example, Nina emphasized the importance of following one's own gut feelings. She explained, "You just kind of have to go with your gut feeling on things, is what I end up doing." Like Nina, Joy described how her two pregnancies challenged her to assert her ability to make wise choices for herself and her family in encounters with sometimes hostile doctors and nursing staff. About her choice to have children despite being HIV-positive, Joy concluded, "I'm very very thrilled that I did not listen to the doctors. And that I went with my gut feeling."



Joy reported that health care providers challenged her at every stage of reproductive decision-making. Her ongoing conflicts with medical authorities over her choice to have children demanded that she develop faith in herself. She reflected, “I’m telling ‘em, ‘Piss off,’ because I know with every part of my being, my baby’s gonna be fine.” Joy continued, “I *knew* with every part of my *being*, every part of my being—I mean I don’t know how to, how else to describe it—that my children were going to be fine. You know? I just *knew*.” Moreover, Joy used the authority conveyed by motherhood as the basis for sticking by her choices and standing up for her right to make health care decisions. She explained, “I’m very adamant when it comes to doctors and how I’m treated and... when it comes to my children, you know, you don’t... You know, you can do everything you want to to me, but don’t screw with my children.” The fact that she was responsible for the welfare of children as well as for herself helped Joy justify her right to be assertive.

Linda described her efforts to assert wise choices during her pregnancy and delivery with her son. “I had him vaginally. And, at that time, you know, they were like, ‘No, you have to’—they wanted me to have a C-section, just because of that short area where he could pick it up. But I was like, ‘You know, I’m doing everything I’m supposed to.’ So we decided for me to have as normal of a pregnancy as possible that we were going to do it this way.” She elaborated about the process:

I made up my mind that it’s my life, and what I choose to do with it, or take the information from everybody, or any resources that I can to help me make educated decisions, then that’s at that point, that’s when I was like, okay. And then that’s when the doctor wanted to put me on the medicine. That’s when I did the Internet and the books and talking. And then I was just like—you know, it’s the first time ever that I’ve ever kind of felt that I resisted authority, or you know, someone of a professional manner like that, saying well—‘cause he was very adamant. ‘No, Linda.

You have to do this.’ I was like, ‘No, I don’t. You show me the studies or results or whatever and then... But until then, no.’ I was like, ‘You don’t—There’s nothing out there that can tell me that’—Now, the one that I *was* taking, there was information so I knew that that one was fine. But the others, I’m like, ‘No. I’m not gonna take the Sustiva until you tell me, or until the baby is fully developed. I’ll give you that.’ And he was like, ‘Well, you really need to start it.’ You know, I was like, ‘This is what I’m gonna do,’ you know, kinda? And it was very shocking to me, again looking back, that I would take up for myself that way or not take that authority, or doctor’s opinion, or his—that I was saying no to him.

For Linda, refusing to take Sustiva or other HIV medications that might harm her child meant asserting her ability to make wise health care choices. Similarly, when providers dismissed her chronic symptoms of fatigue as post-partum depression rather than as side effects of the AIDS medicines she was taking, Nina was able to assert her own knowledge in order to get proper treatment: “I’m like, ‘No. I know my body. Thank you, though.’”

A number of participants suggested that they found faith and confidence in themselves by assuming a highly validated social role as mothers. For example, in contrast to all the stigmatized and devalued social statuses of Georgette’s past, being put in charge of her adopted daughter injected a new feeling of competence and authority into her life. She explained, “They put her in my care so they must think that I’m capable, you know, of taking care of her.”

Many participants were able to draw a sense of authority and confidence in the rightness of their decisions from the role of being a mother. Assuming the role of a parent could confer a certain basis for authority, and being responsible for the care of children often puts one in the position of having to be assertive and stand up for the health and wellbeing of one’s children.

However, for women whose adult lives were fraught with opportunities to lose faith in themselves or second-guess their life choices, asserting their own knowledge and ability to make decisions became especially challenging. Other participants continued to struggle with the challenge of trusting themselves, feeling confident of their choices, and asserting themselves with medical authorities. Others resigned themselves to a passive relationship with health care providers. Tabitha explained, “I never ask [for my counts]. [...] ‘Cause when they tell me I’m undetectable, it makes me seem to want to stop taking my meds, so I just don’t ask. I just let it go. And they never tell me, so I just never ask.” Similarly, Andrea found that her efforts to obtain HIV/AIDS medications from her health care providers were repeatedly rebuffed. Only by becoming pregnant was she able to obtain the treatment she sought. She explained, “Actually that’s the main reason why I got pregnant the second time. They would not let me on medicine for nothing. [...] So a couple months later, I found out I was pregnant with her. And actually, I actually was happy because I got to get on medicine.” For Andrea, becoming pregnant with her second child served as an effective health care manipulation strategy when confronted with an uncooperative and insensitive health care system.

***“Worry About It When It’s Time to Worry”:***

***Putting HIV/AIDS in Perspective***

A third way that being a mother positively affected how the women experienced HIV/AIDS was by giving them an additional reason to put their HIV-positive status in perspective within the broader scope of their lives and thereby minimize the extent to which HIV/AIDS consumed their identities. They identified the impact of stress and the need to ameliorate it by putting HIV/AIDS in perspective. Particularly as mothers, with

competing demands on them, they had specific reasons and ways to redirect their attention and worries. Below I first describe the attitude of putting HIV/AIDS in perspective that many of the women shared. In describing this perspective, the women clearly articulated that several factors contributed to this attitude, such as being a long-term survivor of HIV, poverty, domestic violence, substance abuse, and other chronic illness. In addition, these women also specifically described how being a mother especially helped them to maintain a “worry about it when its time to worry” attitude.

A number of participants consciously resisted adopting a catastrophic perspective of life with HIV. For example, Joy suggested, “You may have been dealt a bad deck of cards but, you know, you can still play euchre. It’ll be all right.” Similarly, Diana suggested that with HIV, as with all things in life, one can only “throw the chips up and they fall where they may.” Laurel found that her efforts to put HIV in perspective and to limit her focus on the impact of HIV in her life served as an important coping technique in terms of reducing the emotional stress in her day-to-day life. She explained,

I just, I try not to think about it every day, being HIV-positive. I know I take my medicine everyday, but that’s not something—I don’t dwell on being HIV-positive. So it kind of helps it when you don’t dwell on, well, you know, I’m sick and... I try to be silly. I have my grown-up moments, but most of the time I’m a child [*laughs*]. So that helps. I mean, I try not to stress myself out too much, ‘cause that doesn’t help at all. So, you know, I just try to take life one day at a time. And try to, if something stressful comes up, try to deal with it then. I try not to let it go too far. So, you know, I just take it one day at a time, and as it comes at me, I try to deal with it.

Likewise Joy related, “We joke and we kid about it. You know, about me being HIV. Because I would much rather kid about it than cry about it. You know? Yeah, I have my pity parties. Absolutely I do. But laughter is the best medicine.”

For others, the simple passage of time helped to diminish the stress of living with HIV. For example, Jillian reported, “It’s hard in a way because I’ve lived with HIV for so long that a lot of times it’s like it’s not even there. Like I don’t even have it, you know?” As a 20-year survivor of HIV, time and experience diminished the amount of time she spent thinking about HIV if not the stress it exerted on her life.

By putting HIV in the context of her age, other chronic health conditions, former risk-taking behaviors, and length of time living with HIV, Diana was also able to detract from worries about her status. She explained,

If I feel a somber moment, which maybe I don’t have good sense, but I just don’t. Because I’m a optimistic person. If they might not have a cure, I’m getting older anyway. I probably would’a died anyway. I was on drugs twenty years. I didn’t die, I didn’t overdose—I overdosed twice and didn’t die. So the Lord’s blessed me. I got HIV in ’90. This is almost twenty years later.

Some women reduced the stress of HIV by comparing it to other chronic illnesses. Ruth reflected on being HIV-positive, “So what? People get sick. People have cancer. People have diabetes. People have all kind of diseases.” Elaborating on why her HIV-positive status held little salience for her as a mother, Olivia explained, “I look at it like I have diabetes or something like that, because if you look at it in a different way, it becomes a weight bearing.” Olivia continued, “For me, [HIV]’s a learning experience, and if I treat it the same way my mother treats her diabetes than I’m okay, ‘cause she’s had diabetes probably—I’m 31—for 31 years.” Similarly, Tabitha related,

I don’t think about it. I don’t—I really actually don’t think about it. ‘Cause I get up... My grandmother was a diabetic and she got up and take her medicine, I get up and take my medicine. And I have to take my medicine twice a day, so I just take it right when I get up in the morning and right before I go to bed at night and I just look at like being a diabetic.

Like Olivia, by relating HIV to a chronic illness with which she was familiar through a family member's experience, Tabitha was able to transform her relationship with HIV into that of living with a manageable chronic condition. Of her experiences living with HIV, Leah reported, "It's hard... But it could always be worse. I tell myself that all the time. No matter how bad it may seem, it could be worse. I could be dying of cancer." Diana observed, "All of the things that have happened to me in my life being my age, I have come to see that [HIV] is not the worst hand dealt." In the context of managing high blood pressure, a thyroid condition, rheumatoid arthritis, a painful knee replacement, respiratory problems, and the lasting effects of chronic heroin addiction while simultaneously playing an active role as the cornerstone of her family, HIV diminished in significance for her.

Nearly all of the women mentioned how being a mother was also critical for helping them to avoid being consumed by their HIV status. For many, the day-to-day experience of raising children helped them to keep HIV from becoming monolithic. Georgette described how the experience of raising her adopted daughter had shifted her focus away from HIV. She explained of the impact of taking care of her daughter,

That made me put my condition in the back of my head, you know. That's not even important now. She's important. Yeah. My condition is second. Um-hmm. I get up and I take care of my baby. Yeah. Yeah. Like I said, she's not into—she's something else now. Yeah, but it's worthwhile. I don't sit around and think about AIDS all the time. You know, I got a baby to think about.

Similarly, Diana related of her busy family life distracting her from worrying about HIV,

See with all that stuff going on, it's not no room for no HIV. With all that mess going on, it's not room. I got grandkids and all kind of stuff. It just doesn't come up. See I'm too busy with other stuff to have to revel in my misery. 'Cause I don't even have any.

Adopting a perspective that “it could be worse” while concentrating on the positive aspects of their lives seemed to help some women not focus exclusively on HIV and become overwhelmed. For example, Joy acknowledged, “I *definitely* always remind myself that I need to be very very thankful. That I need to get over whatever is pissing me off. ‘Joy, get over it.’ You know? Because I have two children that are negative, beautiful, *healthy* children.” Later, she reflected, “You have all this other shit that you have to worry about with your children. And so that kinda helps whip me back into shape and go, ‘Hello? Get over it. Get over it, get over it. Be happy and move on.’” Linda recounted of the period when she and her husband were newly diagnosed and still uncertain of their newborn son’s HIV status,

When we would go to [the hospital] to have the tests done, and seeing all the other children there that you could tell weren’t healthy, you know, then it was like, okay, well maybe if this is, or does happen, we gotta think it could be worse. You know what I mean? With other things that a child could have, that you know this is just something he’ll just take medications like we are for the rest of—you know, kind of thing? So that was kind of a two-sided coin there too, you know.

From a mental health perspective, all of these reflective techniques contributed to reducing the stress of living with a stigmatizing chronic illness. Moreover, these stress-reduction efforts may well have far-reaching positive health effects, as a number of participants convincingly argued.

### ***Seizing the “Opportunity to Witness”:***

#### ***Sharing Information***

A fourth way that being mothers positively affected how the women experienced being HIV-positive was that it motivated the women to advocate and educate others about HIV/AIDS. As HIV-positive women, study participants sought out and passed on

information related to HIV/AIDS in order to make their own lives easier and to share their knowledge with others. In particular, and of direct relevance to their role as mothers, they tended to interpret motherhood as a special responsibility to pass on knowledge. Although being a mother naturally places women in a teaching and information-sharing role, for many HIV-positive mothers, living with HIV makes sharing HIV-related information all the more imperative.

Particularly in their drive to share information, study participants regarded motherhood as a mandate to make the world a better place. Many participants suggested that they took from their role as mothers a kind of imperative to share information with others in efforts to improve society and the day-to-day lives of others, touching on the more global aspect of mothering (Ruddick 2002). In this way, they perceived their role as mothers to extend to a more global or holistic basis of authority and responsibility.

Furthermore, their status as mothers further enhanced their perceived authority and they were able to use this maternal authority to draw attention to the HIV/AIDS-related information that they sought to pass on. They found that others were more willing to listen to their messages because they were mothers. Beyond the fact that they could assert an expert status based on their experience of living with HIV, people trusted them because they were mothers. Thus, many of the study participants found opportunities to speak at local schools, church groups, and community events and to share information through the local press.

Thus, one way that HIV-positive mothers try to make meaning out of their experiences with HIV is by gathering and sharing information related to HIV/AIDS. By sharing information, HIV-positive mothers are able to transform their experiences with



HIV/AIDS into hard-won wisdom others can use. Thus these women transform personal struggles into public information. In this way, they are able to empower themselves while helping others to benefit from their knowledge and experience.

These HIV-positive mothers often find themselves in a social role wherein they can share information with others, as well as advocate for their own rights and needs and those of other women who share their status. Sharing information and educating others can include sharing medical information, resource referrals, and personal experiences with health care providers, social service providers, family members, friends, coworkers, and other HIV-positive women. They are able to help others both by contributing to HIV and STD prevention efforts and by offering their own experiences and real-life wisdom to others living with HIV.

A number of participants articulated that they found meaning in living with HIV and created a positive dimension to HIV by pursuing ways that they could reach out to help others and share information about HIV and AIDS. For example, Linda related of her search for meaning after she was diagnosed as HIV-positive, “I just figured that... God, this is the way it’s supposed to be and somehow I’m gonna be able to do better with it or help someone with [HIV].” Linda moved beyond surviving to thriving with HIV by becoming a self-made expert, and she was able to help others with HIV by sharing information and support. Linda emphasized throughout our interview the centrality of gaining and exchanging information in her efforts to adjust to and cope with her life with HIV. In one instance, she explained of her approach as a newly-diagnosed HIV-positive mother:

I was like, “Okay. Gotta have a plan.” You gotta figure out if this happens, that you’ve got two roads to go down, which one to go, which one’s

better, that kind of thing. So I've read a lot. The networking. Again, like I said, I get a lot out of those. Just even people that are pregnant now, it's so different than when I was. And I share my experiences with them about things that I went through, the feelings I felt, you know, and stuff like that. And know that knowledge is the best thing about this. It can't hurt you. It can only help you. So that's all that I try to do. Maybe a little obsessive sometimes, as my husband would say. [*She laughs.*] But I do.

Linda continued in her information-seeking and information-sharing efforts throughout the intervening years. She reported attending many HIV/AIDS-related panels, workshops, training sessions, and consumer advisory board meetings in order to gain and exchange information, thereby making herself a more empowered consumer and advocate. She passed that sense of empowerment forward when she used her knowledge to help inform other women living with HIV. She noted of the importance of various meetings for sharing information and strategies,

That's [HIV-positive women's events] a very good outlet for me, in helping me through the blue stages. Because you do pick up a lot things, because now we are starting to get older. And some of the people that are like, say that they've had this or that happen, it's like, "Oh, yeah, that happened to me. This is what you need to do," or "This is what worked for me." Instead of you dwelling on, "Okay, is this it?" or, you know what I mean? "Am I only gonna get worse now?" So that's helped.

Exchanging information and problem-solving with other HIV-positive women helped Linda to avoid focusing on her fears and uncertainty about the future.

Like Linda, Ruth also emphasized throughout our interview the importance of gaining and sharing information in her efforts to cope with HIV/AIDS. Ruth explained of her passionate drive to find and share information about HIV: "I don't want to know it for me. I want to know it so I can share it." Rooted in her missionary Christian outlook, Ruth regarded herself as a conduit for HIV/AIDS-related information to reach a broader audience. She reflected on her passionate pursuit of information:

I want to know it so I can share it. [...] Everything you take in, if you don't give it out, then what good is it to take it in? You know, why? Like a closed hand, if you don't open it up you can't receive anything. So if you keep it closed, you just got a closed fist. So you have to open up and share. And that's basically what I feel is important. Not just keep it, not hoard it for yourself, but to share it. That's why you have to be a witness. That's why you have to stand up and speak.

For Ruth, teaching others about HIV and AIDS was clearly an obligatory imperative.

Similarly, Ruth advised other HIV-positive women, "Make sure if you can find it in yourself to witness, to be a witness to somebody, and share your knowledge about the disease, that would be great."

Immediately following their diagnosis as HIV-positive, most participants seem to have ardently set about gathering all the information available related to HIV and AIDS.

Describing the cumulative effect of her research efforts, Nina said, "I think I am a walking encyclopedia." Following testing HIV-positive, Leah reported:

For a long time I got pamphlets and anything I could to read about [HIV]. You know, I learned as much as I could about it. I mean, I'm sure there's more I could learn about it, you know, 'cause there's changes all the time. But I just tell the people—even strangers. When I was in jail there was girls talking about me and I said, "Hey. I'm HIV-positive. If y'all have any questions, ask me. I'm a human being. And I'll be honest. I have nothing to fear. You know, just ask me." You know? And that's what I tell my family. "If you have any questions about me, what's going on, [inaudible], how I am, any questions. Just ask." And for the most part, they do.

In spite of her isolated and stigmatized social status within the women's prison and in her own small rural Midwestern town, Leah was able to assert an expert identity as a woman living with HIV/AIDS, reaching out to help others while creating her own positive self-image. Jillian explained of her continuing efforts to remain up-to-date with HIV/AIDS-related information and advances in the literature:

I read everything. I, you know, was up to date and I could understand the journal articles you know, that the doctors read and all that. So I'd read the professional literature. I'd read the popular literature. And I would see, follow all the latest developments and see all that, so I could see the knowledge and how it changed around HIV care over the years.

Throughout our interview, Ruth repeatedly described her life as dedicated to educating and advocating. She explained,

It [being HIV-positive] gives me opportunity to witness, to stand up and be a witness, you know, to help educate. The things that I probably never would be. You know, like trying to start this faith-based agency. I never would probably have done any of those things if I had not been HIV-positive myself. I do, I used to do peer counseling at Metropolitan Hospital, at the [infectious disease clinic] over there and work with Joan Baker. And I used to get matched up with the ladies that are just new finding out they're HIV-positive. Well, I was a support person for them and they would match me with the lady and I'd just talk to 'em and try to just give 'em hope and, you know, support in any area, show 'em where they needed to go, what they needed to do.

Ruth successfully transformed her experiences with HIV/AIDS and her thirst for knowledge into a formidable role as a self-made community health educator and HIV peer counselor. In fact, Ruth took our interview as an opportunity to tell me about my HIV testing options and made sure I left her house with flyers listing testing sites. Later, Ruth explained,

This [HIV education] is a passion for me, so I talk about it. I could talk about it for days and days and days and won't get tired. It's just something that I think I'm supposed to do. I do. I tell people all the time, "If you don't want me to talk, don't ask me no questions."

Similarly, Rachel described her very active role in the local HIV-positive community:

Usually I'm more of a support network for [other HIV-positive women]. Because a lot of them were tested later. So I'm kind of the veteran. Usually they have a lot of questions. A lot of questions, and I usually know a lot of the answers, because I've been there.

Like Linda and Ruth, Rachel used her years of experience with HIV to help people who were more recently diagnosed with HIV. Her role as an HIV veteran gave Rachel a position of authority in which this HIV-positive stay-at-home mom could reach out to the community in a variety of fundamental ways. She listed some of her many activities in the service of education and advocacy:

I do videos. I did a video to Congress for the Gilead Center. I go to schools and talk. I've also been in like where they have a new client come in to the Gilead Center that has children, that has a lot of questions, they'll call me and say, "Do you mind to come in and talk to her?" And I've done that before. [...] I did a video for them. I'm in their pamphlet. My picture and my story is in their pamphlet. My picture's hanging on their wall. So, I've done a lot in that aspect.

Linda, Rachel, and Ruth all extended their information sharing efforts to actively seek out opportunities to counsel the newly-diagnosed—Rachel through a local ASO, and Ruth and Linda through infectious disease clinic settings. In this way, they found opportunities to integrate their ability to share their extensive HIV-related information with their profound natural empathy.

For many women, information-sharing efforts extended to sharing information with friends about safer sex and warning them about the dangers of unprotected sex.

Gloria described how she used her experience with HIV to intervene in a friend's safer-sex choices:

One of my girlfriends that I just got in contact with, she's out dating, and she's having unprotected sex. And I told her, I said, you know, I said, "We need to talk." I hadn't seen her for a while. It was like, "You really need to be safe." And I said, "I'm HIV-positive." She goes, "No you're not." I'm like, "Yes I am. And you're out there having sex with just not even thinking about it." She goes, "Well now that you told me..."

Similarly, Nina described sharing information about HIV sexual transmission risks and safer sex practices with her friends: "When they have scares, and a few of them have had

scares, they are quick to run to me and ask me a hundred million questions like I'm a physician.”

In these ways, because of their expert status with friends, family members, and other people living with HIV/AIDS, HIV-positive mothers can become de facto community health educators. Based on their unique and extensive knowledge and experience, they can gain a special position of trust or authority from others in their communities. The fact that HIV-positive mothers can fill this important peer educator role has enormous community health policy implications.

A number of participants also reported sharing information in an advocacy role. In this sense, outspoken women sought out opportunities to speak out and advocate for HIV-positive women as a group. The audiences of these efforts included church congregations, health care providers, and schoolchildren. By giving a voice to people living with HIV, sharing information thus extended to advocating for women with HIV/AIDS and dispelling AIDS stigma.

Many of the women I interviewed reported speaking regularly at local schools and churches about their experiences with HIV. Both Rachel and Tabitha reported speaking repeatedly to assemblies at local schools. Gloria, Naomi, Ruth, and Joy had spoken to church congregations. Ruth also spoke at a number of local African American community events. Some of the study participants also reported serving on consumer advisory boards and other community information-sharing bodies in order to serve as a voice for women living with HIV/AIDS.

A few participants even extended their information-sharing efforts to health care providers. For example, Jillian reported her efforts to help educate fertility clinic staff

and infectious disease specialists, and dispel their fear of HIV-positive women having babies: “I had to go really out of my way to kind of prove to people that [trying to have a child as an HIV-positive woman] is an okay thing to do. Even when I went to doctors, I’d come in with my whole literature. ‘This is okay for me to do because I’m HIV-positive. I can do this. Here’s the literature to support it.’” In particular, Jillian described her efforts to share information while seeking treatment at a fertility clinic.

I went in with all my ammunition, which is a whole stack of articles on all these articles saying basically, I don’t know if I gave these to you, but they’re articles saying um how it’s time to treat people who are HIV-positive with fertility care. We need to support them. It’d be unethical not to treat them. Um, all those kinds of articles there. Just so they know that, basically, if you deny me treatment, there’s a problem here.

By deploying her arsenal of information, Jillian sought to share information that would help her to receive the care and respect that she deserved from infertility specialists and staff. Moreover, by sharing this information with providers, Jillian also helped to open the door for other HIV-positive women seeking fertility treatment.

Beyond their own efforts to share information with others, some of the mothers had raised children who became educators and advocates in their own right. For example, Ruth’s daughter helped her peers to get tested for HIV and spoke along with Ruth at HIV-themed community events. Ruth elaborated:

She brings people from her school to be tested. So she was a runner because she had the car and she was taking people back and forth. So she’s really an advocate also. She spoke with me that day at the convention center. She was up there with me. A mother infected and a child affected. So she spoke too.

Others planned on such an advocacy role for their children in the future. For example, Georgette explained that she took her young daughter with her to support group meetings and taught her about HIV and drug addiction in the hopes that she would be able to help

others as she grows older. In this way, these mothers were able to extend their information-sharing mission into the next generation.

***“I’m a Good Mom”:***

***Confronting the Double-Edged Nature of Maternal Ideologies***

As mothers living with a stigmatizing chronic illness, study participants regularly grappled with (often problematic) social standards and cultural images of motherhood in the contemporary U.S. This study attempted, in part, to explore how HIV-positive women with children interpret gendered social messages about motherhood. Questions asked to assess feelings about motherhood and perceptions of cultural injunctions included: *What are the minimum responsibilities of a mother? Do you think that these responsibilities of motherhood change when the mother is living with HIV/AIDS? Do you think that they should? What are the qualities of a really good mother? Many women report feeling strongly encouraged by society and by people in their lives to become mothers. However, many HIV-positive women report feeling strongly discouraged from becoming mothers by society and by people in their lives because they are HIV-positive. Have you experienced either of these types of pressures and how so?*

Two final themes emerged in response to these questions. These themes seemed directly linked to the women’s culturally-derived preconceptions of what it means to be a good mother. One theme asserted positive spillover effects and the other exerted negative spillover effects. First, (1) being a mother was the most important identity for these women and it helped them to diminish their stigmatized illness identity. However, at the same time, (2) being a mother and living up to the maternal ideal of putting one’s



children first could lead the women to neglect to take care of themselves. These themes are illustrated below.

### ***1. Asserting a Maternal Identity and De-stigmatizing an Illness Identity***

When asked about their experiences as mothers living with HIV/AIDS, participants repeatedly underscored their relationship to the normative experience of motherhood in the U.S. For example, many participants asserted that as HIV-positive mothers, they were all “just like any other mom.” For example, Georgette observed, “We’re just like any other person. We’re just like any other women, you know? Just like any other mom. You know, we’re just living with HIV, and that’s it. That’s it.” Nina stated, “We’re basically just like any other mom. We just... We’re basically like any other mom. Just have a little more on our plate, health-wise. And sometimes maybe not.” Similarly, Olivia explained, “I really don’t look at it as being a mom being HIV-positive. I’m a mom first. So that’s just it.” These women were in effect normalizing their HIV-positive status by virtue of sharing in the identity of being mothers.

Most of the women I interviewed reported that being a mother was the most important identity that they had attained, and the most important role that they had wanted to attain. Several of the women I interviewed also held jobs and pursued careers, and most of them occupied other social roles, but being a mother remained the most salient, compelling, and centering role for them. A number of participants shared that, in terms of their identity, being a mother eclipsed being HIV-positive.

Being a mother meant achieving a consummately important social role and identity, often in the face of stigmatizing statuses. In the case of women whose street life careers had seemed to foreclose the chance of a socially normative identity, becoming a

mother and shifting gears into domestic life created the opportunity to establish a self-affirming and socially-sanctioned identity. In the cases of women for whom an HIV-positive diagnosis served to derail an otherwise normative gendered life trajectory of love, marriage, and family, becoming a mother helped to reassert their identities as “good girls” and “real women.” Raising healthy children and managing solid families gave these women a chance to reflect back to society that HIV had not changed them.

Being a mother is a part of life to which many women look forward. Most women idealize motherhood as the path to adulthood, the marker of arriving at womanhood, the cultural standard of being female. For women living with the mark of a stigmatizing chronic illness, the assumption becomes that all paths toward a normative adult life are cut off. However, becoming a mother and raising a family can become a redemptive path for an HIV-positive woman’s identity, a way to present a normative and validating identity to society in the face of profound stigma.

When asked about their experiences, most participants emphasized the centrality of motherhood in their lives and identities. For example, Joy described her life as, “All about my babies.” Laurel emphasized that for her, “Being a mom comes first.” Despite a 20-year history of chronic drug use, drug sales, and other illicit activities, Diana asserted that following her HIV-positive diagnosis, she left her street life to assume her role as a full-time mother: “I stay where I am, for my children’s sake.”

For Jillian, struggles with infertility made her desire for children clear to her. She recalled, “I really wanted to be a mom.” Once she adopted her son, she realized, “I never thought I really wanted to be a mom that bad but I did.” Discussing the lasting importance of motherhood to her, Joy reflected:

I've *always* always always always wanted to be a mother, and I'll be damned if I was gonna let the guy who infected me stop me from being a mother. Wasn't gonna happen. Wasn't gonna happen.

Despite becoming HIV-positive in her teens when her boyfriend concealed from her that he had AIDS, Joy actively resisted allowing him to alter her identity and her life trajectory. Despite becoming HIV-positive and losing her partner to AIDS, Joy married and gave birth to two HIV-negative children. Ultimately, Joy asserted: "I love being a momma." She elaborated, "And then having the kids just really made a big difference for me. Made a huge—gave a whole new light—whole, whole new light on life. I got to be a momma. I got to be a momma."

Many participants articulated a belief that motherhood was the most important role for women to attain, and that every woman should become a mother. Gloria suggested, "I really feel that it's a good thing to be a mother." For example, Linda observed, "Everyone's supposed to have children." Janet asserted, "I believe every woman should never go through life without having at least one [child]. Because there's nothing... If you don't experience that, you haven't experienced what life's all about." Again, she concluded, "No woman should go through life without [having children]."

## ***2. Negotiating Negative Maternal Ideology and Role Expectation Spillover***

HIV-positive mothers are faced with balancing their own, their partners', their families', and society's expectations of mothers with the severe constraints of being a mother who is living with HIV. A number of participants articulated the norm or expectation that all (good) mothers be perpetually self-sacrificing, always putting children and others first. Conforming to or grappling with this type of ideology could become particularly problematic for mothers living with HIV. For example, Linda

reported, “Being a busy mom and working and taking care of—and the way mothers do is they take care of everybody else. There were some times that we, you know, I was missing dosages and stuff like that.” Observing another problem, Linda related about HIV-positive mothers, “We’re so busy with the home, the family, the job, you know, everything, that we don’t really take care of our own mental [health].” Similarly, Jillian observed, “Except, having a child now, I’m just trying to think—and again this is hard to say whether it’s work or being a mom or the combination of the added responsibility—I don’t take care of myself as well.” Reflecting on her willingness to sacrifice pride and comfort in order to provide for her children in spite of chronic illness, Rachel reflected, “It’s harder for men I think than it is for women. We do what we gotta do to take care of our kids.” Similarly, Janet explained of her willingness to take on a six-day-a-week job despite her poor health, “No matter what, them kids are here, you know? And I have to suck it up and take care of them, no matter what.” Of all the participants in the study, Diana represented herself as possibly the most self-sacrificing mother, to the point of approaching martyrdom. She characterized her life as “For my kids. Everything is for [my] kids.” Describing the nearly frenetic pace of life this nearly sixty-year-old woman living with multiple chronic illnesses maintained in order to care for a full household, Diana related,

You know, I’m almost sixty years old. I’m trying to live a life of a thirty-something-year-old woman. I had to go trick-or-treat the other night. My legs don’t feel like doing that. My arms don’t feel like doing that. I have to get my body up to doing all that. Cooking for eight people. I mean that’s really taxing. Then I try to rest through the day. Then something happens, I gotta go to school, or something’ll happen with something, something, something, something. I get to bed around eleven, twelve at night and I’m up every morning at five. *Every day of life*. Sunday. Saturday, Sunday, I’m moving all day long. I mean I’m moving, moving, moving. And all my

friends say, “Diana, you’re gonna have a heart attack.” All that. It’s just so much quickness in my life.

Many participants compared themselves to the cultural image of the ideal mother. For example, Ruth concluded, “I’m a good mom. I just want the best for my kids.” Leah, on the other hand, expressed profound guilt for the fact that drug addiction and incarceration had kept her from achieving the maternal ideal. Of her years addicted to crystal methamphetamine and in jail, she concluded: “I was really selfish then. I didn’t consider my children.” She agonized, “What’s hard for me knowing that I was a terrible mother for about three years because I was selfish. And the abortion, that was selfish. That weighs on me. That makes me feel like a terrible mother.”

For all women, the process of becoming a mother involves negotiating socio-cultural ideologies of proper motherhood and the difficulties of actualizing them. However, in the actual lived experiences of most mothers, the process is even more complicated. This condition is particularly acute for mothers living with HIV/AIDS. The socio-cultural image of the good mother assumes the absence of obstacles—not being tired, not being ill, having a partner, being one of a parenting dyad, enjoying middle class economic standing, living in a safe neighborhood, having access to sufficient childcare, and so on. However, most participants faced additional challenges in their efforts to perform ideal mothering. Most commonly, participants lived with the symptoms of chronic illness. Additionally, many participants reported facing additional challenges including living in dangerous neighborhoods, being single mothers, caring for elderly parents, raising other family members’ children, recovering from addictions, juggling busy schedules, receiving public assistance, surviving family violence, and subsisting on poverty-level incomes.

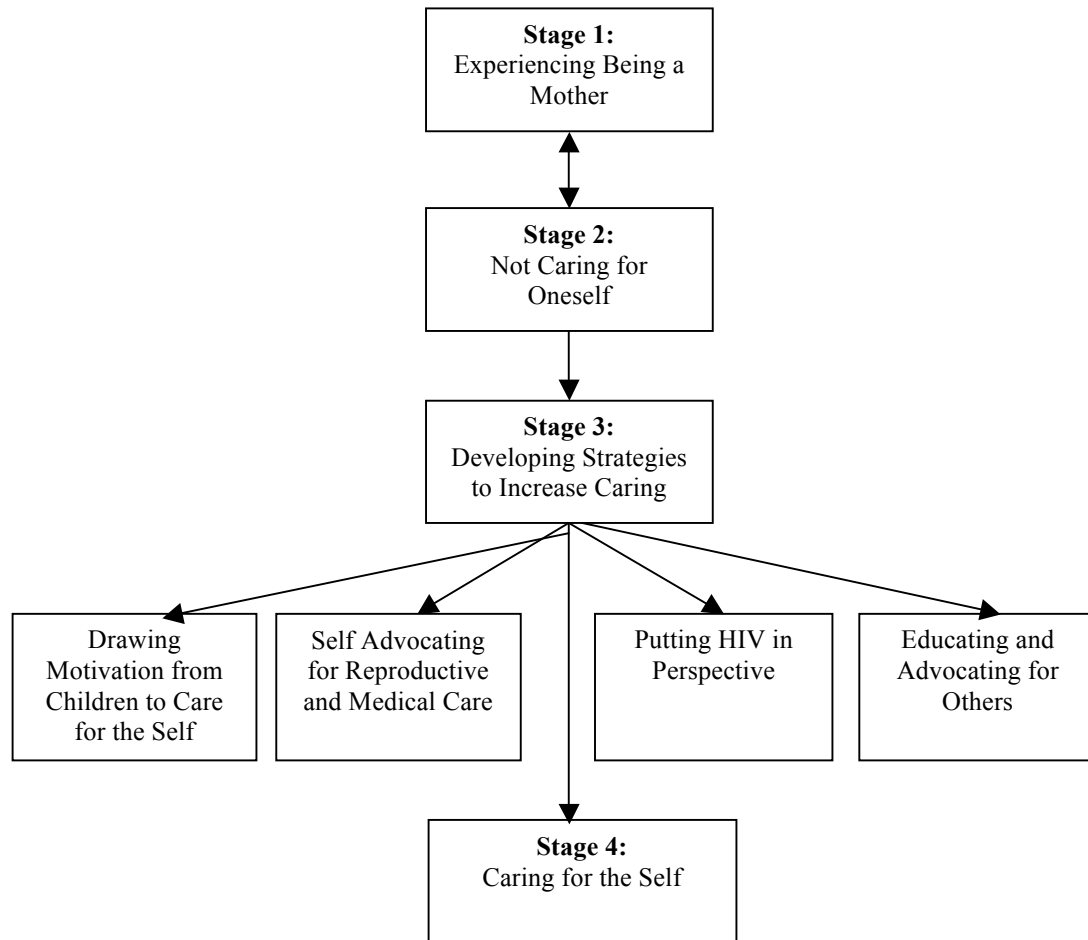
### **Analysis: The Impact of Motherhood on HIV/AIDS**

The experience of being a mother exerts a considerable impact on the lives of women with HIV/AIDS. Just as living with HIV/AIDS exerted a profound and lasting impact on mothers, living as a mother exerted a correspondingly profound and lasting impact for women living with HIV and AIDS. Being a mother meant that these HIV-positive women were able to assert a positive, self-affirming identity in the face of profound stigma. For the women from the most disadvantaged backgrounds, this meant that they were able to assert a counter-identity and thus resurrect themselves in their communities.

Living as a mother with HIV/AIDS was a transformative process for several study participants. In particular, study participants developed the skills and confidence to assert their choices with health care providers and others in positions to exercise authority over them and their families; and their children and their roles as mothers provided motivation to take care of their health and to keep going despite obstacles. Moreover, throughout their experiences, these mothers continued to grapple with their diagnosis of HIV and their relationship with dominant social ideologies of motherhood.

In addition, a social process appears to be occurring here in which the major problem that the mothers experienced with regard to motherhood to HIV spillover is the problem of caring for oneself (see Figure 2 below). Being a mother who is also HIV-positive involves the difficult situation of not caring for the self because of the maternal ideology to always put oneself last and one's children first. Because motherhood trumps their HIV-positive identity, this condition is a difficult problem to solve. Interestingly, while motherhood could create this problem, it also seemed to be the source of strategies

**Figure 2: The Process of Addressing the Problem of Caring for Oneself**



that the women could use to manage the negative outcome of not caring for the self. For example, the mothers in this study drew motivation from their children, self advocated for reproductive and medical care, put HIV in perspective of their parenting responsibilities, and educated and advocated for others. Each of these strategies helped the mothers in this study better care for themselves. Motherhood spilled over into the illness identity in ways that had consequences of leading to increased caring and as such may negate the negative outcome of not caring for the self. In other words, being a mother had far more positive influences than negative influences on the women's

experiences with HIV. However, the motherhood to HIV spillover remains a double-edged sword. Interventions might reinforce these ways, as well as explore additional ways to help the mothers care for themselves.



## CHAPTER FIVE: CONCLUSION

The purpose of this study is to describe and understand the lives and experiences of HIV-positive mothers from their unique perspective. Seeking as much as possible to uncover how the women themselves define and interpret the experiences of their lives, I interviewed 17 HIV-positive mothers living in Indiana and asked them specific questions about how they live and understand their lives, both as HIV-positive women and as mothers. This study explored how HIV-positive mothers structure their lives to meet the demands and expectations of raising children while coping with the day-to-day effects of living with a serious chronic illness.

This investigation uncovered a rich description of the mothers' experiences and revealed two salient social processes in such experiences. First, in regard to the experience of HIV/AIDS to motherhood spillover effects, the social process of the loss of maternal identity when one becomes HIV-positive came out of the mothers' experiences. Through this process, women face the challenge of reconciling their identities as mothers with the fact that they are HIV-positive. Initially, on receiving an HIV-positive diagnosis, the women experience HIV/AIDS as a disruption to their lives and identities. They tend to regard HIV/AIDS as an impenetrable barrier to a normal life trajectory, in particular as prohibiting the experience of normative motherhood. They then seek to reconcile their evolving HIV-positive identities with the desire or reality of motherhood in their lives. Finally, in the last stage, they are able to redefine their own interwoven experiences of HIV and motherhood as redemptive second chances or as congruent with their former identities.

Second, in regard to the experience of motherhood to HIV/AIDS spillover effects, the mothers experienced the social process of encountering difficulties caring for oneself. Interestingly, while motherhood could create this problem it also seemed to be the source of strategies that the women could use to manage the negative outcome of not caring for the self. For example, the mothers in this study drew motivation from their children, self advocated for reproductive and medical care, put HIV in perspective of their parenting responsibilities, and educated and advocated for others. Each of these strategies helped the mothers in this study better care for themselves.

This research has implications for mothers living with serious chronic illness. Additionally, this research can apply to the experiences of mothers living with stigma. In this last section of the thesis, I conclude with an overview of some significant findings from this research as well as implications of the study for future research, HIV and health care policy, and HIV-related care and support practices.

***“Being a Mom is Being a Mom”:***

***HIV, Motherhood, and Social Construction of Motherhood***

Although this research project initially focused on race in the context of HIV-positive mothers’ experiences with motherhood and HIV/AIDS, race/ethnicity never materialized as a salient issue for any of the 17 research participants. Researcher bias—the fact that I was white, a graduate student, and ostensibly middle class—may account for the fact that most participants’ responses glossed over the issue of race and ethnicity even when I prodded. Another possibility is that race/ethnicity may not be as critical for this group of mothers compared to mothers not infected with HIV/AIDS.

Although this research project focused on mothers living with HIV/AIDS, the findings generally illuminate a great deal about the experience of motherhood. For example, competing demands and role conflicts can undermine the health of mothers regardless of their HIV status.

There is no one single monolithic experience of motherhood, although the experience of healthy, white, middle class, heterosexual mothers is taken as the definitive experience of motherhood; all others are thus taken as deviant and “other” (Collins 1994; Glenn 1994). Moreover, just as there is no single, monolithic experience of motherhood, this study found that there is also no single monolithic experience of motherhood while living with HIV. As in all else, factors and experiences such as quality of health, sexual orientation, family violence, substance abuse and addiction, poverty, and partner’s and children’s HIV status mediate the experience of motherhood while living with HIV.

Proper childrearing also appears constructed as the individual mother’s responsibility rather than that of the whole or extended family. This may be particularly problematic in reference to HIV-positive mothers facing the additional demands of managing chronic illness. These problems suggest raising children as a community effort may assist these mothers rather than the whole of childcare and childrearing devolving onto the mother.

***“It’s Not a Death Certificate”:***

***Conversion to a Chronic Illness Model***

Participants’ experiences most closely reflect living with a chronic illness. Whereas previous, pre-HAART studies of HIV-positive mothers reflected the mothers’ primary preoccupation with preparing children for the inevitability of their eventual

deaths, the mothers in this study concentrated on living the best long life possible with their children while balancing the demands of long-term chronic illness with the needs of children.

A number of the mothers asserted throughout their interviews that, despite being HIV-positive and/or living with an AIDS diagnosis, they were invested in living long healthy lives. For example, Joy asserted, “[Becoming HIV-positive] doesn’t mean that you have to give up. And I think that that’s something that every woman out there should be told. Not just me sitting and telling you I think that that should be something that everybody should know, that it’s not the end. It’s not a death certificate.”

Similarly, Nina observed,

I still think people are uneducated about [HIV]. They look at it like it’s a death sentence. And I did too when I first found out about it. I didn’t know enough about it. You know, ‘cause you find out about it and you cry and you’re upset ‘cause you think you have like five years to live. That’s not the case. If you comply and do everything you’re supposed to do. It can be a death sentence for some people. But for others, if you do what you’re supposed to do, you know. It’ll be okay.

She related to HIV as a chronic illness demanding that one adhere to a medical regimen rather than as an automatically terminal illness. However, as Nina also notes, many women initially react to a positive HIV test result as if it were a death sentence.

Dispelling the persistent popular perception of HIV as a terminal illness may reduce this initial trauma.

### ***Beyond Patients: Implications for Health Care and Social Service Providers***

Seeing HIV-positive women in their social roles means perceiving HIV-positive mothers holistically—as entire people who are women, parents, workers, and community

members. I will now summarize implications of this research for future research, policy, and practice.

### ***1. Implications for Research***

Much remains to be learned about the lives of mothers living with HIV. For example, this research needs to be replicated with even more diversity among the mothers living with HIV. This research recruited women mostly from metropolitan areas and women who either never had substance abuse problems or who were in recovery. Furthermore, the research only included white and African American women. More research needs to be conducted with mothers in more rural communities, mothers with active addictions or substance abuse problems, and mothers of Hispanic or other racial/ethnic descent to compare and contrast the reciprocal experiences of motherhood and HIV.

In addition, more research needs to be conducted to explore the negative effects that motherhood can have on women's abilities to take care of themselves. Such research is critically needed to develop effective interventions to assist mothers with HIV to care for themselves and adhere to medical regimens.

More research can be done to explore intentions to have children among women with HIV. Several of the women in this study purposely choose to have children and increasingly the literature reports such women intentionally trying to have children. Understanding women's motivations to have children and the different ways they form families will help assist HIV prevention measures, many of which rarely take into account the role that fertility desires may play in condom use.

More research is needed to explore the experience of living with HIV among mothers given the shift that has occurred in the treatment of HIV. This is one of only a handful of qualitative studies that has examined the experience of mothers with HIV in the post HAART era.

This study also raises the question—what about the children’s experiences of having a mother living with a serious and stigmatized illness? Several of the mothers mentioned the difficulties that HIV could have on mothering. In addition to better understanding the experiences of children in such HIV affected families, it will also be important to research issues related to caregiver burnout among HIV-positive mothers.

## ***2. Policy Implications***

Families living with HIV/AIDS face the dual challenge of caring for children and managing the day-to-day demands of chronic illness, not to mention the stigma of living with HIV/AIDS. In the current, post-welfare reform climate, political sentiment generally opposes helping struggling families, even in the presence of stigmatized illness (e.g., drug addiction, mental illness). HIV-positive mothers often require financial assistance. As this research has demonstrated, their struggles with long-term chronic illness often hinder HIV-positive mothers from maintaining the kind of secure living-wage employment on which they can support a family. Although Ryan White funded programs help somewhat with basic necessities, coverage is far from consistent and not all mothers qualify for Ryan White assistance. Mothers living with HIV/AIDS need a safety net.

Several of the mothers mentioned the critical role of significant others as support providers and in some cases as caregivers. Such people ranged from older children to

male partners, husbands or ex-husbands, to mothers. The experience of mothering and living with HIV is experienced by the entire family, yet no programs exist to provide support for these critical others in the mothers lives. Policies might provide benefits to these critical members of the family and should be seen as an investment in improving the health and quality of life outcomes of the mothers and their children in the long run.

### ***3. Implications for Providers***

Findings from this research suggest that care and service providers might reinforce the positive role that motherhood can play in HIV-positive mothers' lives as a way to help them cope with HIV. At the same time, providers should be sensitive to some of the challenges that mothers with HIV face in trying to live up to idealized standards of motherhood, such as neglecting their own health and feeling guilty for contracting their illness. Providers are critical for helping mothers care for themselves. Providers can also play a key role in helping HIV-positive mothers learn strategies and identify resources to help them balance multiple role conflicts.

AIDS service providers are needed to implement structured interventions to help mothers and their families cope, adjust, and plan for the changing, long-term challenges of life with HIV/AIDS. Providers can play a key role by helping with disclosure to children, other family members, and others involved in children's lives. Additionally, providers need to help mothers with other HIV-related communication, for example, planning with other family members in case of a period of acute illness.

AIDS service providers also need to respect mothers' disclosure decisions. As this study and the literature both reflect, HIV-positive mothers regard their choices to disclose or not to disclose their HIV status to their children as a matter of protecting their

children from harm and stigma. In cases in which mothers choose to conceal their status from children and other family members, providers need to problem-solve with the mothers to make certain that concealment does not lead to adverse consequences. Most importantly, their help is needed to prevent mothers' efforts to protect children from stigma from constraining their ability to take care of themselves, obtain medical treatment, and adhere to medication regimens. For those mothers comfortable with disclosure, service providers can help them compile the informational ammunition to educate and advocate in the service of advancing understanding of HIV and dispelling stigma.

Providers need to assess the availability of support for mothers early on in the assessment process, especially support that may be available from families and friends. Current interventions continue to focus on PWAs as individuals. However, this study clearly showed that HIV/AIDS is not an individualistic disease. Supportive family members also experience the illness. Integrating supportive family members in the care of mothers with HIV will benefit the mothers.

### **Conclusion**

This research project asked the question: How do HIV-positive mothers experience their dual roles and identities as mothers and women living with HIV/AIDS? This research project sought to explore the experiences of mothers living with HIV/AIDS from their own perspectives and on their own terms. This study uncovered two social processes that were salient to the experience of mothering while also living with HIV/AIDS—the loss of maternal identity when one becomes HIV-positive and encountering difficulties caring for oneself. The description of these social processes



offers critical information to researchers, policy makers, and providers about mothering while also living with HIV/AIDS. More research is needed to further understand the experiences of mothers with HIV/AIDS, especially as women with HIV/AIDS continue to live longer lives.

## APPENDICES

## APPENDIX A: RECRUITMENT FLYER

# 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) 274-0852 or e-mail [ereicher@iupui.edu](mailto: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 # 0707-588

**IRB APPROVED**

August 02, 2007

## **APPENDIX B: INFORMED CONSENT FORM**

### **IUPUI and CLARIAN INFORMED CONSENT STATEMENT FOR Race and the Experiences of Mothers with HIV/AIDS**

Qualitative Interview Study, Version Date: 8-1-07, IUPUI/Clarian IRB Approval # 0707-58B

You are invited to participate in a research study of motherhood and related experiences of women with HIV/AIDS. You were selected as an interview participant because you identified yourself as an HIV-positive woman who has one or more children in the home. I ask that you read this form and ask any questions you may have before agreeing to take part in the interview.

#### **STUDY PURPOSE**

This study is being conducted by Erica Reichert as part of my graduate program of studies in Sociology at Indiana University Purdue University Indianapolis (IUPUI). The purpose of this study is to become more knowledgeable about the mothering experiences of women with HIV/AIDS. I would like to speak with you in a private one-on-one interview about your experiences of motherhood as an HIV-positive woman.

#### **NUMBER OF PEOPLE TAKING PART IN THE STUDY**

If you agree to participate in this one-on-one interview, you will be one of 24 women who will participate in this research.

#### **PROCEDURES FOR THE STUDY**

Participants will be interviewed in private by me, Erica Reichert, an IUPUI graduate student in Sociology. I would like to talk to you and audio record our conversation about your experiences with motherhood as an HIV-positive woman. The interview will last about an hour to two hours and will take place between July 2007 and December 2007. I will ask you questions concerning your experiences of motherhood as a woman with HIV/AIDS. I will also ask for information regarding your current HIV status and how HIV was acquired. These interviews are confidential and your name will not be revealed to anyone.

#### **RISKS OF TAKING PART IN THE STUDY**

This study involves minimal risks. By taking part in the study, you are revealing your HIV status to me, although your HIV status will be kept confidential (see confidentiality section below). By participating you may also feel some emotional or mental discomfort in discussing personal experiences that may have been difficult for you.

#### **PAYMENT FOR PARTICIPATION IN THE STUDY**

There is no cost for being in this study. As compensation for volunteering to participate in this study, however, you will be given a \$25 gift card during the scheduled interview time at the start of the interview.

#### **BENEFITS OF TAKING PART IN THE STUDY**

You may feel satisfaction by sharing your experiences with someone who is interested in what you have to say. It may feel good to talk about things that are going on in your life. The information you provide may help with future research in this area of study.

#### **ALTERNATIVES TO TAKING PART IN THE STUDY**

You may voluntarily choose to participate in this study without any negative results. You may end the interview at any time or skip any question you do not wish to answer. You will still be given a \$25 gift card even if you do not answer all of the questions.

**PERMISSION FOR CONTACT INFORMATION.**

I will also ask for your permission to have contact information for follow up questions if I have any after the interview. These questions will address experiences that may have been unclear or to verify specific information that you told me. Giving contact information is voluntary and your decision. You may still take part in this study if you do not give contact information. If you would like to give contact information, please complete the contact information box below. Your contact information will be kept private (see confidentiality section below).

**CONFIDENTIALITY**

Keeping your name and information confidential is very important to me. This means that I will take safety measures to protect each participant's name and privacy throughout all aspects of the research study. I, Erica Reichert, and possibly someone hired to transcribe the tapes, will be the only people to hear the audio-recorded interviews. It is highly unlikely that the transcriptionist will be a person known to you. The transcriptionist will be told to remove any specific information, such as your name, that may exist from the interviews during the transcription process. The audio recordings will be erased after the interviews are transcribed. Following transcription, my faculty advisor, Dr. Carrie Foote, might review the transcripts.

Your name will never be used in any reports from this study and specific information may be changed to ensure no one can identify you in reports. All information from this study will be kept in locked offices and secure password protected computers. Your signed consent form and contact information will be kept in a separate locked place from other study reports.

The only organization that may look at and/or copy your research records for quality assurance and data analysis is the IUPUI/Clarian Institutional Review Board. The U.S. Office for Human Research Protections (OHRP) may also review study records.

**VOLUNTARY NATURE OF THE STUDY**

Being in this study is completely voluntary. You can choose to not be in the study, without any penalty. You have the right to withdraw your consent or to discontinue your participation at any time.

**CONTACTS FOR QUESTIONS OR PROBLEMS**

If you have any questions or concerns for me, please feel free to call me at (317) 576-9640 or e-mail me at [ereicher@iupui.edu](mailto:ereicher@iupui.edu). You may also contact my faculty advisor, Dr. Carrie Foote, at (317) 278-8454 or [foote@iupui.edu](mailto:foote@iupui.edu). Also, for questions about your rights as a research participant or to discuss problems, complaints, or concerns about this research study, or to obtain information, or to offer input, please contact the IUPUI/Clarian Research Compliance Administration office at (317) 278-3458 or (800) 696-2949.

**INFORMED CONSENT STATEMENT**

I voluntarily choose to participate in this interview study. I understand that I may end this interview at any time and that I am not required to answer any questions that I do not wish to answer. I agree to be audio recorded as part of the interview study. I, the participant, meet the study's eligibility requirements. I will be given a copy of this informed consent statement to keep for my records.

PRINTED NAME OF PARTICIPANT: \_\_\_\_\_

SIGNATURE OF PARTICIPANT: \_\_\_\_\_

DATE: \_\_\_\_\_

(must be dated by person signing)

SIGNATURE OF PERSON OBTAINING CONSENT: \_\_\_\_\_

DATE: \_\_\_\_\_

(must be dated by person signing)

**CONSENT FOR CONTACT INFORMATION:** By completing the contact information below, I voluntarily consent to give contact information to allow the researchers to contact me for follow-up questions prior to finalizing the research reports.

First Name: _____ Last Name: _____
Address: _____ _____
City: _____ State: _____ Zip Code: _____
Phone: _____ Email: _____
<u>Please check yes or no to the following questions</u>
Yes No
<input type="checkbox"/> <input type="checkbox"/> I agree to answer follow-up questions regarding my interview responses.

I received a \$25 gift card for participation in this study: \_\_\_\_\_

**Signature of Participant**

**Thank you very much for your participation in this project!**

## APPENDIX C: SEMI-STRUCTURED INTERVIEW GUIDE

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

#### PRE-SCREENING INTERVIEW PROTOCOL

The interview process began when a potential participant contacted me about the study by telephone. After making a brief introduction, I conducted a telephone screening interview to establish that the potential interviewee met the study's eligibility requirements. If she was eligible, I scheduled 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 ages 21 or older who have at least one child 18 years of age or younger living with them at least half the time. Because of the way the study is set up, I am specifically looking for non-Hispanic African American and non-Hispanic American white women. If you fit this description, I would like to talk to you about your experiences as a mother with HIV. Your participation would involve meeting with me for a one-on-one private interview where I would ask you about your experiences with living with HIV and raising children. I will be tape recording interviews for my own information. No one else besides me will ever listen to the interview tape and I will erase it immediately after I type it up into written format. Nothing that could identify you will be included in what I type. Everything you share with me will be kept very strictly private and confidential and I will not use your name on anything. Each participant will receive a \$25 gift card for your time. Does this sound like something that you might be interested in participating in?

#### 2. Prescreening Questions

Okay. 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.

Screening Interview Questions	Participant must answer the following for eligibility
1. How old are you?	21 years old or older
2. How would you describe your race and ethnic background?	White or African American/Black (Probe for any Hispanic heritage)
3. What year did you test HIV-positive?	At least two years ago
4. How many children do you have?	One or more
5. What are their ages?	At least one 18 years old or younger
6. Where do they live?	With participant at least half-time

#### 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.

## **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**

I plan to record our conversation so that I do not have to take notes and so that I can get your complete answer. Otherwise the interview will take a really long time. However, no one besides me will ever listen to the tape and I will erase it within a week. Is this okay with you?

### **7. Assure Interviewee of Confidentiality**

Please feel free to speak openly with me. Maintaining your privacy is the most important thing to me and anything you say during this interview will be kept *very strictly* private and 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.)
- c. How would you describe your sexual orientation? (Probe for straight, lesbian/gay, bisexual...)
- 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 have any type of insurance or other healthcare coverage for yourself? What about for the other members of your family?
- h. Do you currently or have you in the past received any type of financial assistance, like SSI, food stamps, Section 8, Medicaid, or Hoosier Healthwise? (Probe for how long ago if not currently receiving assistance.)
- i. What is your marital or partnership status? (Probe for married, separated, living with someone, in a long-term partnership, divorced, never married, or single.)
- j. How many children do you have? (Probe for ages and residence.)  
(If more than one child) Do your children have the same father?  
  
What is his/their race and ethnic background?
- k. Were any of your children born after you tested HIV-positive?  
If so, was the pregnancy planned?  
  
Are your children your birth children, adopted, stepchildren...?
- l. What is your child(ren)'s HIV status?
- m. Do you know the(ir) father's HIV status?  
(If he is HIV-positive) How is his health?
- n. Where is/are the father(s) now?

- o. What year did you test HIV-positive?
- p. How do you think you became infected with HIV?
- q. To your knowledge, have you ever been diagnosed with AIDS?
- r. Have you ever had an opportunistic infection?
- s. Are you currently taking any HIV medications (like AZT, Sustiva, Kaletra, or Atripla)?
- t. What is the lowest that your CD4 count has ever gone?
- u. What is your current CD4 count and viral load count?
- v. 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. 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, some questions may be sensitive for you. 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?

#### **General questions about mothering experiences**

- a. First of all, can you describe your experiences as a mother with HIV?  
*Prompt: Can you tell me more about that?*
- b. Can you describe the hardest part, if any, of raising children while having HIV?
- c. Have you had any negative experiences happen to you or your children that are related to your HIV status? If so, what happened?
- d. Can you describe any positive experiences?

#### **Questions about strategies and resources**

- e. Have you found any strategies that are particularly helpful to you when you are having a particularly difficult time with being a mother?  
*Prompt: Talking to other women? Spirituality? Exercise? Alcohol/drugs? Sleep? Writing?*
- f. How does the children's father(s) help or not help you with the children?  
How so? What does he do that is helpful or not helpful?
- g. 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?

- h. Other than people, what helps you most in dealing with HIV while raising children? Have any organizations or websites been helpful? How did they help?

**Questions about your children**

- i. How much do you think HIV affects your relationship with your child(ren)? How so?
- j. How did you decide whether (or not) to tell your children your HIV status? If no, are you planning to tell them in the future?  
  
What exactly did (will) you tell them?  
  
Do you have any regrets about your choices?
- k. Have you disclosed your HIV status to anyone involved in your children's lives, such as teachers, babysitters/childcare providers, coaches, counselors, other relatives, godparents?  
  
How did you decide whether or not to tell them?  
  
How did that go?  
  
Any regrets?
- l. Can you describe any concerns that you may have had for yourself as a mother or for your children that are related to your HIV status? (other than disclosure concerns)  
*Prompt: Types of concerns like health or medical, school, HIV transmission, relationships, parenting, end of life, financial, etc.*
- m. To what extent do you feel comfortable asking others to help you with the children? What kinds of things do you feel comfortable asking for help with? What, if any, things are left out?
- n. The kind of care-giving that happens between mothers and their children can be a two-way street. Do your children do anything to help you? What in particular do they do to be helpful?

**Questions concerning how being a mother affects how you manage/think of your HIV and vice versa**

- o. Is there anything that you do differently as a mother because of your HIV status?  
*Prompt: Conceal medications from anyone? (Who?) Limit use of AIDS-related health services? Limit your children's social contacts? Limit your own social supports and contacts? Limit your social relationships, such as with other parents?*  
How does use of these strategies affect you, either for better, worse, or some of both?

- p. Can you describe the hardest part, if any, of managing HIV while raising children?
- q. How does being an HIV-positive mom affect your social relationships?
- r. 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?
- s. How do you think being a mother affects how you think of HIV?
- t. How might your experiences of motherhood be different if you didn't have HIV?

**Questions about your thoughts and feelings regarding motherhood**

- u. Many women report feeling strongly encouraged by society and by people in their lives to become mothers. However, many HIV-positive women report feeling strongly *discouraged* from becoming mothers by society and by people in their lives because they are HIV-positive. Have you experienced either of these types of pressures and how so?
- v. Do you think it is ok for HIV+ women to have a child after testing HIV-positive?  
Probe for why she feels this way.
- w. Have your thoughts and feelings changed about being a mother since you tested HIV-positive?  
How so?
- x. What do you see as the minimum responsibilities of motherhood?  
*Prompt:* What is the least that you are supposed to do for your children?
- y. What are some additional qualities of a really good mother?
- z. Do you think that these responsibilities change when the mother is living with HIV/AIDS?  
Do you think they should?
- aa. Do you think other people or society object to HIV-positive women becoming pregnant?  
Probe for why she feels this way.
- bb. Do you think other people or society might object to HIV-positive women raising children?  
Probe for why she feels this way.

**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. Do you think that, in general, White women will answer any of these questions differently than Black women?  
How so?                      *or*                      Why not?
- b. What do you think about the future for you and your children?
  - What do you hope for yourself and your children?
  - What are your fears?
- c. After having had your experiences, do you have any advice to give to another mother with HIV?
- d. Is there anything else you think I should know to better understand the experiences of mothers living with HIV?
- e. Is there anything that I should have asked but didn't?
- f. 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 and resource packet.]

## APPENDIX D: RESEARCH PARTICIPANTS

<i>Name</i>	<i>Age</i>	<i>Race</i>	<i>Number of Children</i>	<i>Marital/ Partnership Status</i>	<i>Years HIV-Positive</i>
Andrea	mid-20s	white	2	partnership	5
Anita	late-30s	African American	1	single	3
Diana	late-50s	African American	4	widowed	17
Georgette	mid-40s	African American	2	single	14
Gloria	early-40s	African American	1	widowed	12
Janet	early-40s	white	3	divorced	4
Jillian	late-30s	white	1	divorced	19
Joy	early-30s	white	2	married	16
Laurel	late-30s	white	2	single	12
Leah	late-30s	white	2	married	6
Linda	late-30s	white	1	married	9
Naomi	late-20s	African American	2	single	9
Nina	mid-20s	white	3	partnership	5
Olivia	early-30s	African American	2	single	8
Rachel	early-30s	white	2	partnership	11
Ruth	mid-50s	African American	3	divorced	12
Tabitha	mid-30s	African American	3	separated	12

*To maintain confidentiality, some details have been altered.*

**Andrea:** A 24-year-old white mother of two small children living with her children's father, she became HIV-positive as the result of a rape that occurred several years prior to our meeting. Andrea had left school in the ninth grade and she worked part-time in a service sector job that she coordinated with her partner's job schedule. At the time of our interview, she had been living with HIV for five years.

**Anita:** A single African American mother in her late thirties. Although not working at the time of our interview, she had had a career in the medical field. She had been living with HIV for three years at the time of our interview.

**Diana:** A widowed African American mother of two adult children and two pre-teen children, she had lost her husband to AIDS several years prior. Diana was also a recovering 20-year heroin addict and former drug dealer. She lived with a number of serious chronic health conditions in addition to HIV/AIDS. She had been living with HIV for 17 years at the time of our interview.

**Georgette:** A single African American mother of one adult daughter and one preschool aged daughter, her education ended in the 7<sup>th</sup> grade, followed by years of sex work, drug use, homelessness, and incarceration. Despite decades of life on the street, she had

retained strong ties with her family. With ten years in recovery from drug addiction, Georgette also served as a mentor to family members and friends still out on the street. She had been living with HIV for 14 years at the time of our interview.

**Gloria:** A widowed African American mother of one HIV-positive child, she had lost her husband to AIDS a few years earlier. She had a college education and worked as a bookkeeper, and she and her son lived with Gloria's mother and stepfather. Her son was home sick from school on the day of our interview, so he intermittently contributed details and insights to the conversation. At the time of our interview, Gloria and her son had been living with HIV for 12 years.

**Janet:** A white divorced mother of three teenagers, Janet had contracted HIV from her ex-husband. She also described a history of domestic violence and drug and alcohol abuse with her ex-husband. Although on disability at the time of our interview, Janet was actively looking for work and had a history of work as a bookkeeper and administrative assistant. She had been living with HIV for four years.

**Jillian:** A 40-year-old white professional mother of one adopted son, Jillian was divorced and living with her HIV-negative partner. She had contracted HIV as the result of IV drug use during her teens. She had been living with HIV for 19 years at the time of our interview.

**Joy:** A white married stay-at-home mother of two, Joy became HIV-positive thanks to a teenage boyfriend who subsequently died of AIDS. Joy struck me as a woman of profound faith with amazing charisma. After becoming infected with HIV, Joy went on to earn a college degree, get married, and have two children. Blessed with a vivacious and stubborn spirit, Joy asserted, "I'll be damned if I was gonna let the guy who infected me stop me from being a mother." At the time of our interview, Joy had been living with HIV for sixteen years.

**Laurel:** A single white mother living with her two teenage daughters, she relied heavily on her family living close-by. Of all the research participants, Laurel's health was probably the poorest. For the past several years, her health had cycled between manageable chronic illness and grave life-threatening attacks of illness resulting in long-term hospitalization. She had been living with HIV for 12 years, and she had been diagnosed with AIDS.

**Leah:** A white married mother of two, Leah had contracted HIV from her younger child's father six years prior to our interview. After a career of factory work, she had been placed on disability after being diagnosed with PTSD and bipolar disorder. In the few years preceding our interview, she had struggled with depression, several suicide attempts, methamphetamine addiction, and incarceration. Leah also suffered as the result of acute AIDS stigma after the residents of her small town discovered her status.

**Linda:** A white married mother of one elementary-school-aged son, Linda's husband was also HIV-positive. Although Linda and her husband were among the most successfully

middle class of my participants, they clearly struggled under exhausting work schedules. Linda worked over 40 hours a week at her job and her husband worked two jobs, due mainly to their efforts to maintain health care coverage for them both despite their HIV-positive status. Linda had tested positive during a routine prenatal test. At the time of our interview, both Linda and her husband had been living with HIV for nine years.

**Naomi:** An African American mother of one HIV-positive daughter and HIV-negative son, Naomi had contracted HIV from her ex-partner. She was also a survivor of domestic violence. At the time of our interview, she was one of a few remaining residents in a soon-to-be demolished public housing project. She had been living with HIV for nine years.

**Nina:** A white mother of three in her mid-20s, Nina lived with her domestic partner who was also HIV-positive. One child was developmentally disabled. Nina worked part-time in a clerical position. At the time of our interview, Nina and her partner had been living with HIV for five years.

**Olivia:** A single African American mother of two teenage boys, Olivia also intermittently took care of a pre-teen nephew for weeks at a time. Olivia was in a state of crisis on the day of our interview. She and her sons were facing imminent eviction from their apartment, and Olivia had so far been unable to find another apartment that she could afford to rent. Additionally, her car had broken down a month prior to our interview, she lacked the money to pay for repairs, and her apartment was located too far out for her to access the very limited public transportation available in her city. She worked nights as a nursing assistant, although she reported that she was on the verge of losing her job because of her lack of reliable transportation. She reported that her own family could be of no help whatsoever and her sons' fathers had been out of her life "from day one," leaving her to search for resources on her own with the limited help of her care coordinator. She had been living with HIV and largely free of illness for eight years at the time of our interview.

**Rachel:** A white stay-at-home mother of two young children, Rachel lived with her long-time domestic partner, also HIV-positive. Like Linda, Rachel had tested positive during routine prenatal tests during her first pregnancy. Although on disability, she was extremely active in the HIV-positive community. Both Rachel and her partner had been living with HIV for eleven years.

**Ruth:** A single African American mother of three children in her mid-50s, Ruth was also a recovering drug addict who described being extremely active in both the 12-step recovery and the HIV-positive communities. In addition to HIV, she was also living with Hepatitis C and diabetes. She had been living with HIV for 12 years.

**Tabitha:** An African American mother of three girls, Tabitha was separated from her husband at the time of our interview. She was not working at the time of our interview, although she had a number of years of experience in health care. She had been living with HIV for twelve years.



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- 2010 James Luther and Erica Reichert. SAMHSA Minority Substance Abuse and HIV Prevention Initiative Needs Assessment Final Report. Prepared for Luther Consulting, Indianapolis, IN.

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