Complex Lives: Resiliency of Midlife African American Women Living with HIV/AIDS Serving As Informal Kinship Care Providers

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COMPLEX LIVES: RESILIENCY OF MIDLIFE AFRICAN AMERICAN WOMEN LIVING

WITH HIV/AIDS SERVING AS INFORMAL KINSHIP CARE PROVIDERS

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Abstract

Historically, many midlife African American women have served as kinship care providers for children in the family. These parenting responsibilities present even greater challenges for the increasing and disproportionately high number of African American women in this age group who also are living with HIV/AIDS. Even though there have been technological innovations in treating and managing HIV infection, HIV is the fourth leading cause of death among midlife African American women. Despite the existing research on African American women with HIV/AIDS and on African American kinship caregivers, significant research with a specific focus on resiliency within this population has not been conducted. To fill this gap, using a resiliency model as a conceptual framework, the researcher conducted semi-structured in-depth interviews with a convenience sample of 24 middle-aged African American women with HIV/AIDS who are providing informal kinship care. Implications for policy, research, and practice are provided and suggestions for health care providers and child welfare professionals regarding how to support these women and children through enhanced services and other interventions.

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Chapter 1: Introduction

On July 13, 2010, President Obama introduced the first National HIV/AIDS
Strategy to the public. He vowed to provide 25 million dollars to states that have waiting
lists for their AIDS Drug Assistance Programs, as well as to offer treatment to the
uninsured and underinsured. Specifically, President Obama's plan details a renewed
focus on increasing access to care, with the goals of providing treatment for 85 percent of
people living with HIV/AIDS within three months of their diagnosis, concentrating HIV
prevention efforts at the highest-risk populations (gay and bisexual men as well as
African Americans), and increasing education about the virus, even among communities
with low rates of infection (CDC, 2010b). Even with the Obama Administration's policy
efforts focused on HIV/AIDS in the United States, however, the number of reported cases
of HIV among African Americans—and specifically among African American women—
continues to grow.[1] Among these African American women living with HIV/AIDS, some
also have the additional responsibilities of caring for their kin.

Research Purpose and Specific Aims

The aim of this study was to explore and examine the lives of midlife (between 35
and 65 years of age) African American women living with HIV/AIDS who are providing
care for their grandchildren, nieces, and/or nephews (Erikson, 1950). Using a resiliency
model as a framework to help structure the research questions for this qualitative
description (QD) study, this dissertation aims to create new knowledge about the lives of

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[1] This study recruited women based on their self-identification as African American; as used here, the term
refers to Black American, Afro-American, Afro-Caribbean, and formally American Negro persons.

midlife African American women living with HIV/AIDS who also serve as informal kinship care providers. In addition, the researcher explored with the women their specific encounters with various service providers and how their health status living with HIV/AIDS affected their lives as informal kinship care providers. The researcher hopes that these findings will be useful to various professional, community based, and clinical organizations that work with informal and formal kinship care families as well as to HIV/AIDS service organizations that also provide resources and services to this population. Data gathered from these interviews will also help future clinicians, policy makers, child welfare professionals, and researchers to identify what resources, community supports, and possible future interventions can best assist these women.

Literature Review

This section presents a review of the literature to provide the foundation for the study's research questions and aims. The literature review includes a discussion of the following areas: current incidence of HIV/AIDS in the U.S. among African American women, past and current legislation pertaining to kinship care (both informal and formal), and previous research findings on resiliency.

HIV/AIDS & African Americans

Human immunodeficiency virus (HIV) is the virus that eventually leads to the acquired immunodeficiency syndrome (AIDS) in most of the population (CDC, 2010a). AIDS is an infectious disease in which the immune system becomes increasingly weakened and more vulnerable to opportunistic and normally combatable and/or treatable infections. In the African American community in the U.S., HIV/AIDS is a public health crisis (CDC, 2009a). While African Americans comprise only 12% of the total U.S.

population, they continue to account for almost half (44%) of cases at all stages of HIV/AIDS compared with all other races and ethnicities and represent nearly half (48%) of new infections each year (CDC, 2009b). The rate of infection for African American women is 15 times the rate for white women of similar ages (CDC, 2009a). Moreover, in 2007, among African American women between the ages 25 to 44, HIV/AIDS was the 3rd leading cause of death (Kaiser, 2011).

HIV/AIDS & African American women

While the number of new infections per year among African Americans is lower than during its peak in the 1980s, it has continually exceeded the number of new infections among whites since that time (Kaiser, 2011). African American women account for the largest percentage (64 %) of new HIV infections among women (Kaiser, 2011). Statistics from 2009, based on the results from 37 states, indicate that among newly infected HIV+ women, African American women accounted for 64%, while Latinas (18%) and whites (15%) accounted for a smaller proportion of new infections (CDC, 2009b; Kaiser, 2011). At some point in their lifetimes, 1 in 32 African American women will be diagnosed with HIV (CDC, 2009a).

Heterosexual sex remains the most commonly reported mode of HIV transmission among women. Approximately ¾ of the AIDS cases reported in 2005 among African American women (between the ages of 13-65) were related to high-risk sexual contact (i.e. women who engage in unprotected sex with multiple partners or unprotected sex with persons known to have or be at a high risk for HIV infection). These women may be unaware of their partners' sexual risk factors or may have incorrectly assessed them (CDC, 2009a). Some women are intravenous (IV) drug users and/or recovering drug

users who may also have multiple sex partners, including HIV-infected men, bisexual men, and/or IV drug users (Jacobs & Kane, 2009). Other women may be financially dependent on their male partners, putting them at a disadvantage in negotiating condom use (Kwiatkowski & Booth, 2003).

According to Erikson (1950), midlife is a time when men and women are concerned with contributing in some way to society and creating a legacy that outlives them. In this stage of middle adulthood (between the ages of 35-65), many people begin to broaden their focus to care not only about their families but also the wellbeing of all future generations (Lemme, 2005; McQuaide, 2000). Erikson (1950) defines this as "generativity," or the "concern in establishing and guiding the next generation" (p. 267). Studies suggest that women during this life stage can experience personality changes (Newton & Stewart, 2010), as well as marriage, motherhood, and aging (Peterson & Duncan, 2007; Stephens, Franks, Martire, Norton, & Atienza, 2008). Also, according to Im, Lee, Chee, Dormire, & Brown (2010), as well as Palmer, Rosenbert, Wise, Norton, & Adams-Campbell (2003), women in this age group may be: premenopausal (having normal menstrual cycles with monthly periods), menopausal (cessation of menstrual periods) or postmenopausal (women who have not had a menstrual period for at least 12 months).

Many midlife women living with HIV/AIDS experience additional challenges since it is assumed that they are not engaging in sexual activity, while many are in fact sexually active (Altschuler, Katz, & Tynan, 2008; Henderson et al., 2004; Lindau, Leitsch, Lundberg, & Jerome, 2006). Women in this age group may no longer be worried about getting pregnant and could be less likely to expect their partners to use condoms

and practice safe sex. Assumptions of monogamy and/or infrequent sexual activity among midlife women may lead health care providers to believe that education about the risk of HIV is unnecessary (Emlet, Tangenberg, & Siverson, 2002). These assumptions arise from health care providers' personal and/or cultural biases that equate sexual activity with physical attractiveness and stereotypes regarding aging and declining sexual interest (Emlet et al., 2002). More importantly, poor communication regarding sexual health needs can exist between physicians and African American HIV+ women because physicians are sometimes reluctant to discuss sexual activity with midlife and older patients (Lindau et al. 2006).

Like their younger counterparts, many midlife African American women living with HIV/AIDS in the U.S. commonly reside in urban communities that are characterized by poverty, violence, drug use, and poor access to health care (Tangenberg, 2002; Young, Washington, Jerman, & Tak, 2007). HIV positive women come disproportionately from low-income families, with nearly 2/3 (64%) having incomes below $10,000, compared to 41% of HIV positive men (Kaiser, 2010). Heckman, Kochman, Sikkema, and Kalichman (1999) suggest that many midlife African American women living with HIV/AIDS experience racism, ageism, and numerous chronic co-morbid trajectories (i.e. the presence of two of more diseases/disorders in addition to their primary disease; these may include diabetes, hypertension, and obesity). In the U.S., racism can affect an African American woman's ability to seek treatment, receive resources, and establish the supports necessary to living healthy (Collins, 2005).

African American women are also doubly stigmatized because they are branded with both their age as well as their HIV status, experiencing rejection, stereotyping, and

fear of contagion (Emlet, 2006). In a recent study, African American women (*N*=308) who reported HIV discrimination had higher mean scores for stress, suicidal ideation, and depressive symptoms; they were more likely to not seek medical care for HIV/AIDS compared to white women (*N*=58) with HIV/AIDS (Wingood, et al., 2007).Midlife African American women living with HIV/AIDS also may experience co-morbidity trajectories, which may include diabetes, hypertension, obesity, Additionally, some women in their late stages of HIV/AIDS experience dementia, memory loss, and other aspects of impaired cognitive and intellectual functioning (Tangenberg, 2002).

Roles of kinship care providers

Despite all of these complex realities, there are women living with HIV/AIDS who also serve as kinship care providers. Kinship care is the full time care, nurturing, and protection of children by relatives, members of their tribes or clans, or other adults who have a family relationship to a child (CWLA, 2000). This is not a new phenomenon in the African American community, as kinship care has its cultural roots dating back to traditional African societies from which African Americans were forced to migrate (Crumbley & Little, 1997; Hill, 1972; Jimenez, 2006; Sudarkasa, 1997). The stability of the extended family was one of the most central characteristics of African societies that included kinship care (i.e. shared parenting) as a common practice (Jimenez, 2006). Families disrupted by the dislocating effects of the slave trade were forced to adapt by forming alternative family arrangements that included a strong grandparental presence (Goodman & Silverstein, 2006). Patterns of reliance on extended families continued after the Civil War, as African Americans moved north to find employment, leaving children in the care of their relatives (Jimenez, 2006).

As a result of these traditions, today's African American women are more likely to be grandparent caregivers than any other racial and/or ethnic group (Ehrle & Green, 2002), to know others raising grandchildren, and to have been raised themselves by their grandparents (Pruchno, 1999). An estimated 2 million African American children are being raised by their grandparents, aunts and/or uncles, brothers and/or sisters, cousins, and/or others who are not formal relatives (Urban Institute, 2010). Today, African American children are more likely than any other race of children to be in some form of kinship care (Ehrle & Green, 2002; Ruiz & Zhu, 2004).

Kinship care has two common types: formal, and informal or voluntary. The first, formal kinship care, suggests that children are in foster care, but are placed with relatives who receive financial assistance (Geen, 2003). In most instances, these children were removed from their parents' homes because of abuse or neglect, and the court assumes legal responsibility for them, providing services through the child welfare agency (sometimes referred to as child protective services or CPS).

By contrast, with informal (or voluntary) kinship care, the parents ask kin to care for their children either through an explicit arrangement or through abandonment, and the public child welfare agency assumes neither legal custody nor fiscal responsibility for the child (Crumbley & Little, 1997; CWLA, 2000). Today, informal kinship care remains the most common type of kinship care in African American families (Ehrle & Green, 2002; Jimenez, 2006). Whether provided through informal or formal arrangements, kinship care is seen as a culturally sensitive response that respects and maintains the family origins (Crumbley & Little, 1997).

Recent federal kinship care policy changes: Implications for informal African American kinship care providers

The Adoption Assistance and Child Welfare Act of 1980 (P.L. 96-272) required child welfare professionals to make permanency plans for children in care and to evaluate such plans regularly, while also mandating that a child be placed in the most family-like and least restrictive setting possible. This translated into preference being given for a child to be placed with his or her relatives. In reality, by 1997, when Congress passed the Adoption and Safe Families Act (ASFA), almost as many children were in formal kinship care as they were in any other kind of care such as foster care (Pecora et al., 2009). ASFA was the first federal legislation to address kinship care as a potential permanent placement by indicating that "a fit and willing relative" could provide a "planned permanent living arrangement" (Geen, 2003).

Building on this Act, Congress passed the Fostering Connections to Success and Increasing Adoptions Act (H.R. 6893) in 2008. This Act connects and supports relative caregivers, improves outcomes for children in foster care, provides for tribal foster care and adoption access, and provides better incentives for adoption. States are required to identify and contact grandparents and relatives of a child within 30 days after a child is removed from his/her home by child welfare authorities. But more importantly, states are able to waive licensing standards for relatives on a case-by-case basis in order to eliminate obstacles to placing children with their relatives.

This Act also helps relative caregivers become actively involved in the child's care from the beginning by providing kinship guardianship assistance payments under the Title IV-E funds. In the past, approximately a quarter of all children in kinship care families received either a child-only grant or foster care payment (Ehrle & Green, 2002).

Under this Act, children are also automatically eligible for Medicaid and families are eligible for additional services such as the Supplemental Nutrition Assistance Program (formally known as the Food Stamps Program), housing assistance, fuel assistance, and childcare assistance (Children's Defense Fund, 2010). Child welfare legislation such as this assists in preserving family ties, which supports a deep sense of family loyalty (Scannapecio & Jackson, 1996) while at the same time allowing for a continued relationship between the child and his or her family.

Despite the abundance of research on midlife African American women living with HIV/AIDS (CDC, 2009a; 2010a; Erikson 1950; Kaiser, 2011; Newton & Stewart, 2010; Peterson & Duncan, 2007; Stephens et al., 2008) and research on African American women serving as both formal and informal kinship care providers (Ehrle & Green, 2002; Jimenez, 2006; Pruchno, 1999; Ruiz & Zhu, 2004), there has been surprisingly little research on the experiences of African American women living with HIV/AIDS in the U.S. who are also providing kinship care. Consequently, this study offers a closer look at the complex lives of midlife (Erikson, 1950) African American women living with HIV/AIDS who also serve as informal kinship care providers. In these women's lives in particular, midlife is a unique period because, in addition to the realities that come with this stage, these women may also experience challenges related to living with HIV/AIDS and providing informal kinship care. These realities can include marriage, motherhood, aging (e.g., issues related to menopause), experiences of racism, and co-morbid trajectories (heart disease, diabetes, high blood pressure, etc.,), as well as challenges accessing health care (Collins, 2005; Im et al., 2010; Palmer et al., 2003; Peterson & Duncan, 2007; Stephens et al., 2008).

There is a need to design and implement new programming and health care delivery models for this population that address its complexities and range of experiences. As researchers and practitioners, we need a better understanding of how caregiving affects these women's kinship responsibilities and those specific attitudes, beliefs, and perceptions that may influence their preferences and demands for future services. Only in this way can we hope to implement policies and practices that could help to improve their health and wellbeing.

Conceptual Framework

There is some controversy as to whether frameworks should be used in qualitative research and, if so, how; indeed, it is not always clear which frameworks inform particular studies (Corbin & Strauss, 2008). Some qualitative researchers favor approaches that reject the imposition of any theoretical or conceptual frameworks at the onset of their study (Charmaz, 2004; Creswell, 2009). While much qualitative research explicitly attempts to generate new theory, explanations, ideas, and concepts (Creswell, 2009), other qualitative research starts from the idea that theories should be appropriate to what is studied and if the existing theories are not appropriate to the concrete issue or field, they are adapted and new theories are developed (Gibbs, 2007).

In this study, the researcher takes the approach developed by Gibbs (2007), who argues that qualitative research can be guided and framed by pre-existing theories, ideas, and concepts and that they can be adapted, developed, refined or modified throughout the study process. Further, theoretical or conceptual frameworks can be guides for choosing the concepts to be investigated in a study, suggesting research questions, and framing

research findings (Corbin & Strauss, 2008). As a directing influence, theories can ensure that a study will transcend mere description, no matter how rich or compelling.

As part of its conceptual framework, this study examines the existing research on resiliency and proposes an innovative model of resiliency based on the literature. This model serves as a broad explanation for understanding the lives and complexities of midlife African American women living with HIV/AIDS serving as informal kinship care providers. This theoretical/conceptual framework informed the literature review, was lightly applied during the analysis, and was reexamined during the interpretation of the findings; the key was to prevent it from becoming overseer of the study.

To begin, resiliency is defined as the ability to withstand and rebound from adversity; it is therefore an optimistic approach to understanding an individual's experiences (Walsh, 2002). Adversity refers to the experiences, events, or life situations that have the potential to disrupt normative functioning in an individual enough to cause negative outcomes (Riley & Masten, 2005). Hence, resiliency is a process that leads to positive adaptation within the context of adversity (Luthar, 2003).

Models of resiliency have been developed to explain various behaviors and attitudes, using such variables and constructs as risk and protective factors, support systems, family stress, adaptation and adjustment, and psychosocial wellbeing (Greene 2002; McCubbin, Thompson & McCubbin, 1996). Resiliency models have also drawn from the ecological perspective in how various contexts in an individual's environment are conceptualized at different and multiple levels (Bronfenbrenner, 1979). This perspective takes into consideration the influence of contexts such as the recent legislation in child welfare, HIV/AIDS, poverty, drug use, racism, income, access to

health care, cultural differences, ethnic differences, gender, socioeconomic status, parent-child interactions, etc., attending to the various changes over time within the shifting balance of an individual's life. Bronfenbrenner and Morris (1998) call such interactions between the child and his/her caregivers as well as activities that occur relatively regularly over extended periods of time "proximal processes." The interplay between an individual and his/her proximal processes takes the form of interactions between dyads within the individual's activities, routines of daily life, and/or daily stressors.

These proximal processes, along with the ability of HIV+ African American women to access and receive services, have direct implications for parenting, the dynamics of kinship care, and child outcomes. For example, African American women may undertake the role of caregiver out of necessity because of the absence of the child's parents (Kelch-Oliver, 2008) and in response to a "family crisis" such as drug abuse, unemployment, teen pregnancy, divorce, abuse and neglect, incarceration, abandonment, or death (Burton, 1992; Ruiz & Zhu, 2004). Moreover, such necessities and family crises are complex because these women often have the responsibility of caring for their own children who also reside in the home along with their grandchildren, nieces, and/or nephews (Ruiz & Zhu, 2004). These women may also not have the supports of a partner/husband or other family members and may not be receiving financial assistance from social service agencies. Some of these women may also be dealing with the realities of limited incomes or not being able to work because of their health status. Their relationships with their own children or the siblings for whose children they are caring may also be strained by such factors as drug abuse, incarceration, abandonment, abuse and/or neglect (Burton, 1992; Kelch-Oliver, 2008). Furthermore, as previously

mentioned, the realities of living with HIV/AIDS (and other health needs) affect their abilities as caregiver, which further contributes to the complexities of these women's lives.

Similar to these models of resiliency, Saleebey (2009) notes that a strength-based approach focuses on directly assisting clients to achieve their goals in a joint participatory process to enhance social functioning. One of the principles of a strength-based approach is that adversity can be a source of challenge and opportunity. As such, models of resiliency view caregiving as a positive strength in parenting (e.g., by focusing on a person's ability to sustain communication or have a strong involvement with his/her extended family) and in the education of and involvement with caring for their grandchildren (Gibson, 2005). For instance, many in the African American community rely upon their own community and social networks for mutual aid and support (McAdoo, 1998; Schwartz, 2008), and while there are differences in caregiving among racial and ethnic groups, studies report the effects of strong supports and resourcefulness as encouraging evidence for designing interventions to maintain and improve the wellbeing of women caregivers (Music, Warner, Zauszniewski, Wykle, & Standing, 2009).

There have also been studies of various models of resiliency in child welfare policy and kinship care. These models identified protective factors such as child characteristics, family attributes, and aspects of the social environments of children who did well in spite of adversity (Garmezy, 1985). Children with responsive caregivers had a double dose of protective factors because these caregivers helped the children to develop pro-social and cognitive based skills (Riley & Masten, 2005). Caregivers of African American children

residing in kinship care homes have also been investigated to understand how some children succeeded while others did not. The factors that contributed to resiliency among African American children included more structure, clear boundaries, and well-defined roles (Johnson-Garner & Myers, 2003).

Little research has been conducted on the recent Fostering Connections to Success and Increasing Adoptions Act of 2008, which includes provisions for supporting grandparents and other relative caregivers. The majority of research on this act has focused on foster care youth and permanency planning. A national summit was convened in 2010 to address the effective implementation of new opportunities created by the act, specifically concerning the question of how to extend child welfare benefits for youth until the age of 21. A working group developed 56 recommendations for implementing effective plans for permanency of older youth in foster care, improving courts and legal support systems for youth, developing education and employment measures, as well as building resources to provide long term housing and placements for youth (Krinsky & Liebmann, 2011). In California, a study was conducted to examine the costs and benefits of implementing the 2008 law; it estimated that the average cost per youth of extending foster care for two years offsets by approximately $37,948 the costs associated with public assistance utilization when youth cannot or do not remain in care (Courtney, Dorsky, & Peters, 2009). However, little research since the passage of this new act addresses its implications for kinship care providers.

The majority of kinship care providers are still not receiving services or financial assistance through the child welfare system—benefits that could assist in their caregiving needs (Kelch-Oliver, 2008). Moreover, the majority of research with African American

women and other vulnerable groups continues to focus primarily on weaknesses such as health care disparities, poverty, discrimination, lack of education, and so on (Boyd-Franklin, 2002; Collins, 2005). This concentration of research fails to acknowledge or provide a perspective that focuses on the positive aspects of their lives. While there is an abundance of research on HIV/AIDS among African Americans, including HIV+ African American women, much of this has not emphasized the complexities of caregiving or kinship care in particular.

Resiliency Model

With hopes of conceptualizing the complex lives of midlife African American women who are both living with HIV/AIDS and serving as informal kinship care providers, this dissertation uses a model of resiliency with four dimensions: protective factors, risk factors, social supports, and coping. Subsequent sections will address each of these dimensions, while a table summarizing the model can be found in Appendix A.

This model of resiliency serves as a valuable conceptual map for supporting, strengthening, and understanding these women. This model moves away from viewing African American women through a deficit lens as pathological, being distressed, having challenges, or in need of assistance, to a positive premise that views women as resilient and able to overcome adversities in their lives. It emphasizes their strengths, inner resources, and how they learned to adapt and adjust to their circumstances. It affirms and engages these women "with respect and compassion for their struggles," and it enables "efforts … to enhance and bring out the best in their lives" (Walsh, 2002,   p. 130).

Protective factors

Examples of protective factors in this resiliency model include situations and/or

conditions that help individuals, reduce risk, and enhance adaptation (Greene, Cohen, Gonzalez, & Lee, 2009). Protective factors can also act as a "buffer" to the negative consequences associated with an individual's situations and/or conditions, which can predict a positive situation in the context of adversity (Masten & Reed, 2002). They can also help to determine the likelihood of other protective factors at another point in time (Masten & Reed, 2002). These protective factors include individual characteristics such as an easy-going temperament, intellectual and scholastic competence, and a positive self-concept, as well as environmental characteristics such as the degree of social supports available (Lemme, 2005; Werner, 2005). Among African Americans in particular, strong familial ties, the extended family, racial socialization, religion and/or spirituality serve as factors protective of their wellbeing. The church is also a protective factor in African American communities because many African Americans consider their church families as role models and even healers of their emotional distress (Brown, 2008; Boyd-Franklin, 2003; Weinberg & Simoni, 2003). HIV+ African American women in particular describe a renewed faith and deeper connection with a higher power as a source of power and strength.

Other protective factors among midlife African American women living with HIV/AIDS and serving as informal kinship care providers include: the accessibility and availability of health and social service resources (e.g., AIDS service organizations, social service agencies, food pantry, and antiviral medications), good health, and interests in the education of their grandchildren, nieces, and/or nephews. More importantly, research has shown that protective factors have made it possible for an individual to overcome adversity (Werner, 2005). In this instance, resiliency is inferred when risk or

adversity is high enough to pose a significant threat, yet positive outcomes are still observed (Riley & Masten, 2005).

Risk factors

The protective factors discussed in the preceding section mitigate the effects of exposures to risk factors that increase the likelihood of problematic outcomes occurring (Riley & Masten, 2005). For midlife African American women who are informal kinship care providers and also living with HIV/AIDS, risk factors can include stressful life events or circumstances such as caring for their own children, their relatives' children, fear of death, limited income, unemployment, poverty, racism, discrimination, unsafe living conditions, poor health, and inability to access resources (e.g., schools, health care, social services, child care). These women may also be single, without spouses or other familial support. In one study, a grandmother providing informal kinship care had originally been financially stable prior to caring for her grandchild, but later ended up losing her job and her financial standing (Bundy-Fazioli & Law, 2005). Other risk factors include community violence if the neighborhood where a woman resides generates fear and fosters a diminished sense of trust and safety among its inhabitants (Greene, 2002). In addition, some women may be continually engaging in risky sexual behaviors and/or are recovering drug users (CDC, 2009a; Kwiatkowski & Booth, 2003), which can also affect their risk and resiliency in caring for their grandchildren, nieces, and/or nephews.

Poor communication with physicians can be another risk factor. Moreover, women may overlook their own health care needs to maintain caregiving responsibilities ((Lindau et al., 2006; Tangenberg, 2002). They may have fears for their future wellbeing because their own health status is unknown or they may fear the possibility that their

health could negatively affect their future as a care provider. More importantly, the sheer

realization that these women are HIV+ and have other health issues (e.g., diabetes, heart

disease, hypertension, depression, anxiety, etc.) in addition to their caregiving

responsibilities is a risk factor and can adversely affect how they access health care or

other services for their grandchildren, nieces, and/or nephews. Conceivably, an African

American woman living with HIV/AIDS may not live long enough or be physically able

to raise a child long-term.

Risk and protective factors have descriptive utility for explaining resiliency and for

identifying both positive and negative outcomes (Pecora et al., 2009). Examining the

susceptibility to risk also aids in understanding which patterns decrease or increase a

woman's risk. Understanding an individual's resiliency requires knowing which factors

might prevent expected negative outcomes or promote positive outcomes. Further, it is

critical to be able to recognize the markers of both protective factors and risk factors,

which may manifest at different levels of resilient adaptation, such as in an individual's

social supports or in how he/she copes in light of particular experiences.

Social supports

As another dimension of the resiliency model, social supports play a crucial role in

mediating protective and risk factors and in conceptualizing an individual's resiliency

from its multiple influences at the neighborhood, family, and community levels

(Bronfenbrenner, 1979; McCubbin & McCubbin, 1993). Social supports consist of

helpful mutual communication and trust in which individuals feel validated in their

current situation. They can also serve as buffers or mediators in crisis situations. Social

supports can be either informal or formal. Informal social supports include family

members, friends, and church members, while formal social supports include social service agencies, schools, churches, and private or governmental agencies.

The role of social supports has also been widely studied among kinship families (Crumbley & Little, 1997; McCubbin & McCubbin, 1993). Research has indicated that African American kinship care providers in particular rely on social supports to meet their basic needs, to deal with family issues or crises, and to help with childcare (Johnson-Garner & Meyers, 2003). For many African Americans, family, community, and church serve as the core social supports. Social supports are also associated with better mental health among grandmothers in particular who are primary caregivers (Gerard, Landry-Meyer, & Roe, 2006), and a lack of social supports in grandmother caregiving can result in stress, strain, and depressive symptoms (Music et al., 2009). Research has also shown that individuals who relied on sources of social support within their families and communities decreased the number of stressful life events they subsequently encountered, with the result that new opportunities opened up for them (Werner, 2005). Finally, community supports through social networks (e.g., church/faith based organizations, social service agencies, AIDS service organizations) also empower individuals to become problem solvers, decision makers, and committed leaders in the future (Brennan, 2008; Gerard et al., 2006).

Coping

Coping functions as a critical dimension in this resiliency model, which defines it as a process in which individuals react by trying to understand disruptive, stressful, or challenging life events and by considering how they can learn from those experiences (Richardson, Neiger, Jensen, & Kumpfer, 1990). Research on coping is strongly

associated with the regulation of emotion, especially distress. (Folkman & Moskowitz, 2004). The process and certain kinds of coping strategies can be associated with poor mental health outcomes, positive outcomes (seeking supports), and sometimes neither. These associations often depend on characteristics of the stressful encounter that prompts the need for coping (Folkman & Moskowitz, 2004). This process may lead individuals to seek out social supports for guidance and clarification as to how they might go about coping with their situation.

Among midlife African American women living with HIV/AIDS, studies indicate that spirituality, along with participation in support groups and community based organizations, helps in coping with the challenges of living with HIV/AIDS (Tufts, Wessell, & Kearney, 2010). Another study among African American women caregivers found that African American women perceived their activities as achievements that transformed them into testaments of strength and resiliency (Matthews, 2000). They understood caregiving as an activity that supported their sense of competence and provided them with motivation and a positive way of coping.

Many African American women living with HIV/AIDS initially agreed to care for their grandchildren, nieces, and/or nephews due to a "crisis" (Billingsley, 1992; Burton, 1992; Ruiz & Zhu, 2004). Both health care providers, including physicians and AIDS service workers, and child welfare professionals are positioned to play crucial supporting roles for these women. These providers assist women in seeking additional services and resources (e.g., education, housing, health care) while addressing what has been working successfully in their lives.

Accessing service delivery systems, not to mention maintaining ongoing

involvement with such systems, is much more complicated for kinship caregivers than for

parents because these caregivers, the majority of whom are informal, do not have full

legal custody of a child to negotiate with court systems, child advocates, and/or child

welfare systems in order to obtain services such as education and health care for that

child (Crumbley & Little, 1997). These kinship caregivers may need assistance in

obtaining temporary custody or guardianship to access health care, education, or to

prevent the sudden retrieval of the child by a parent who cannot care for the child

(CWLA, 2000). It is also likely these kinship caregivers may also need day care,

individual and family therapy, respite care, and assistance in obtaining other resources

and services such as legal assistance and housing assistance. Because these caregivers are

not part of the formal child welfare system, they are not automatically eligible for such

services (CWLA, 2000).

In addition, these women in particular may or may not want to disclose their

feelings about living with HIV/AIDS and how to process and "take on" the new role of

caregiving. This role may strain these women's relationships with their own children,

brothers, or sisters, and the process of adjusting to caregiving itself might also cause

uneasiness, causing further challenges in coping with their situations. In conclusion,

while this resiliency model encompasses these four dimensions, various social supports,

protective factors (e.g., strong familial ties and supports, religion/spirituality,

neighborhood), and risk factors (e.g., health, health care providers) can influence how

these women cope, and assessing which dimensions are most critical and applicable to

these women's individual experiences is a complex process. Moreover, using this

resiliency model, this qualitative dissertation draws on an emerging conceptual approach

based on the literature in working out how to understand the lives and experiences of this population of women. This dissertation examines the following questions:

Research Questions

- How does the provision of informal kinship care impact the social, financial, legal, psychosocial, and health needs of midlife African American women living with HIV/AIDS?

- How do these informal kinship care providers define resiliency, and how do their HIV/AIDS related health concerns affect their caregiving responsibilities and their daily lives?

- How have their kinship responsibilities, attitudes, beliefs, and perceptions facilitated and/or impeded their preferences and demand for future services (e.g., health care, child welfare, housing, etc.)?

Chapter 2: Methodology

Human Subjects Review

The researcher received Institutional Review Board (IRB) approval for this study

through Boston College on April 23, 2010 and was approved for continual approval until

2013. Protocols submitted to IRB specified how women were identified, recruited, their

right to informed consent (see Appendix E), and their right to refuse participation in the

interview at any point in time. In this study, special consideration was also given to

several issues: care that each woman's medical confidentiality would be absolutely

protected to the fullest extent of law and the refusal of any woman recruited for the study

was respected, therefore, only women who met criteria and actively consented to

voluntary participation were included in the study. Women were given $10.00 in cash for

the one time interview as a token of appreciation for participation. This amount was

based on a community standard after consulting with staff at WCAC on previous research

studies women had participated in. To lesson discomfort during the interview, women

were told they could "opt-out" at anytime with no penalty and would be given $5.00

(cash) for their research reimbursement. None of the woman during the interview asked

to withdraw from the interview prematurely. This compensation was approved by the

IRB and funded by the Fahs-Beck Fund for Research and Experimentation and the Jane

B. Aron NASW Foundation Doctoral Fellowship.

Due to the personal nature of this study and the very sensitive questions that were

addressed which may have caused some women distress, a list of local mental health,

child welfare, community, and health resources were provided for each woman at the end

of the interview. To protect women's anonymity and confidentiality, digital recordings, verbatim transcriptions, written interpretations, and reports were stored without any identifiers on a restricted server in a password-protected folder. Detailed informed consent procedures, letter from Women of Color AIDS Council/Women Connecting Affecting Change (WCAC)/Multicultural AIDS Coalition, and confidentiality protections are described in the protocol of the Boston College IRB application.

Research Design

Qualitative research designs are distinguished by their flexibility, while frequently weaving back and forth between research questions, data collection, and data analysis (Padgett, 2008). Particularly, in these types of design, the researcher may formulate specific aims, change or amend the research questions during the study, seek new participants to interview, or pose new questions to the existing research participants. As such, the basis of qualitative research lies in accessing experiences and interactions, as well as in documenting what occurs in the participants' natural contexts in a way that gives room to their individual particularities (Gibbs, 2007).

Specifically, this study employed a qualitative description (QD) design (Sandelowski, 2000; Sandelowski, 2010; Sullivan-Bolyai, Bova, & Harper, 2005) to answer the research questions and achieve the research aims. QD is a distinct method of naturalistic inquiry that uses low inference interpretation to present the facts using everyday language (Sandelowski, 2000). In particular, it provides a rich description of the experience/event/process in easily understood language, giving it potential for direct translation to pressing health care issues by providing clear information about the various ways to improve care. A QD approach also provides "rich subject information regarding

health-related concerns and issues," as well as a means for identifying "critical

information for crafting new or refining existing interventions and for furthering program

development" (Sullivan-Bolyai et al., 2005, p. 129). This approach differentiates from the

other more common approaches to qualitative research (phenomenology, grounded

theory, ethnography) in that it seeks to strictly adhere to the description of the

"interpretation that is low-inference" (Sandelowski, 2000, p. 335).

This study is also embedded within a an interpretive paradigm, seeking to

discover each woman's "reality" and experiences as she sees them (Denzin & Lincoln,

2000).

> Qualitative researchers approach their studies with a certain paradigm or
> worldview, a basic set of beliefs of assumptions that guide their inquiries. These
> assumptions are related to the nature of reality (the ontology issue), the
> relationship of the researcher to that being researched (the epistemological issue),
> the role of the values in the study (the axiological issues) and the process of
> research (the methodological issue). (Creswell, 1998, p. 74)

Since qualitative research is fundamentally interpretive (also known as the hermeneutic

tradition which is based on the idea that social meaning is created during interaction), this

dissertation departs from the traditional positivist/post positivist paradigm. This

dissertation seeks to understand subjectively, not objectively, and to make meaning of

each woman's story (Hesse-Biber & Leavy, 2004). Specifically, this study is rooted in a

constructivist paradigm (formally known as the naturalistic paradigm), which considers

multiple and sometimes conflicting social realities (ontological premise) and an

epistemology (the relationship of the researcher to that being researched) that is

subjective (Guba & Lincoln, 2004; Lincoln & Guba, 1985).

Study Population

This study uses the term "African American" to refer to Black American, Afro-American, and persons formerly referred to as American Negro persons. While other names are used to describe this population of participants, this study recruited women based on their self-identification as midlife African American women, even though it may be possible that these women have ancestors who were Caribbean, African, Central and/or South American. All twenty-four participants self-identified as African American women. Twenty were permanent residents/citizens of the U.S. living in the greater Boston, MA area. Four of the women were African women who resided in the greater Boston area, originating from the following countries: Ethiopia, Cameroon, Kenya, and Nigeria. All four of these women were in the process of becoming legal citizens (seeking asylum status) and discussed briefly their immigration status during the interview process. Further, all four of these women self-identified themselves as African American.

In addition, because midlife is a critical stage in a woman's life, membership in this demographic was central to sample selection, recruitment criteria, and to determine eligibility for this dissertation study. As previously mentioned, women during this stage of adulthood experience marriage, motherhood, and aging (Newton & Stewart, 2010, Peterson & Duncan, 2007; Stephens et al., 2008). Further, all women participants had a blood (biological relative) kin for whom they were caring for in the home. Women that were caring for their grandchildren, nieces and/or nephews that were not their biological relatives were excluded from participation.

The following were the selection criteria used for participation in the study:

- African American women living with HIV/AIDS residing in the greater Boston area

- Self-reported as living with HIV/AIDS

- English-speaking

- Between 30-65 years of age

- Informal caregivers of their grandchildren, nieces, and/or nephews (biological kin only)

In particular, five specific non-probability sampling methods were used. First, to ensure credibility and trustworthiness of this research with the community of African American women living with HIV/AIDS in the Boston metropolitan area, recruitment began at Women of Color AIDS Council, Inc./Women Connecting Affecting Change/Multicultural AIDS Coalition (WCAC), a drop-in center in Dorchester, MA serving women of color living with HIV/AIDS in the greater Boston area. The researcher had multiple meetings with the director to explain the process and rationale for the study. The researcher also did a short presentation of what the research would entail with staff at WCAC. WCAC was encouraged from the beginning to be engaged in the research and offer suggestions about how best to recruit eligible women. The researcher also was involved in a previous study with a Boston College Nursing Professor on a similar related research project with HIV+ women of color. These examples of assurances and approval by "program gatekeepers" (Padgett, 2008, p. 55) at WCAC provided a confidential space to serve as a "host" location for potential women to be interviewed on site. "Program gatekeepers" at WCAC agreed to announce the study to potential women who utilize their agency and who met study criteria. Program gatekeepers informed women that their participation would be voluntary, and their decision regarding participation would not affect the continuing services provided at WCAC. If a woman was interested in the study,

she was instructed to phone the researcher at which time basic questions were asked to ensure eligibility by the researcher. A confidential phone line and voice mail was used for screening purposes of this study. After the phone screening interview was complete, and if the woman met the criteria to participate, a mutually agreed upon in person interview was scheduled.

Secondly, a "serial selection of sample unit" (i.e. each unit is defined as a person) was utilized (Lincoln & Guba, 1985), and once each woman was selected and interviewed, other women were contacted to extend and also aid in the recruitment of other women. The researcher recruited women according to the pre-determined criteria mentioned above, which is also known as purposive sampling. Thirdly, a particular type of purposive sampling (snowball sampling) also aided in the recruitment of these women; i.e. women were asked to share information about the study with other women they knew who also potentially met the criteria and who, in turn, could contact the researcher. Snowball sampling strategy targets a particular group of people when the desired population for the study is rare, hidden, very difficult to locate, recruit, and/or not easily accessible by researcher. This was a particular helpful sampling strategy for this study. Most women after the interview agreed to share the study with other women they knew who met the criteria. Many women voluntarily asked for flyers of the study (Appendix D) at the end of the interview, which was especially helpful for recruiting other potential women who may have been eligible.

Fourth, recruitment included the assistance of "program gatekeepers" at WCAC and other organizations that serve this population of women through the distribution of flyers at various HIV/AIDS service organizations, community based health clinics,

hospitals, or any site where potential women could be found in the greater Boston area.

Lastly, the researcher made a couple of guest presentations at regular support group

meetings for HIV+ women and grandparenting/caregiving support groups (with prior

approval from "program gatekeepers") in the greater Boston area to describe the study

and invite participation. Within all these non-probability sampling strategies, women had

the option of being interviewed at a location that was convenient for them.

Interviewing Locations

All interviews were conducted within a 25-mile radius of Boston, MA. After a

potential woman was contacted and had been determined to meet the inclusion criteria,

she was given the option of choosing a location that was convenient for her. As

mentioned previously, locations of the interviews included various agencies (e.g., AIDS

service organizations, community based health clinics, hospitals), coffee shops, parks,

and the women's homes. Overall, this method of maximum variation sampling provided

the rich, thick, description of qualitative data needed to answer the research questions and

meet the specific aims of this dissertation study. Privacy, convenience, and

confidentiality were central in determining an agreed upon location for the interview.

After consent was obtained, six interviews were conducted at public parks in Boston,

Somerville, and Cambridge, MA, five interviews were conducted at the women's homes

(two in Boston, two in Cambridge, and one Quincy, MA), three were completed at

McDonald's restaurants in Roxbury, MA (two at the same location and one at another

location), three were completed at community based HIV/AIDS organizations in Boston,

MA, (Dimock Community Health HIV/AIDS clinic, WCAC, and AIDS Action), two

were completed in cars (one interview was in the woman's and the other in the

researcher's car) due to the inability to find parking in the agreed upon interview area, two were completed at Boston Medical Center, two were completed at coffee shops (one at Dunkin Donuts in Somerville, MA, and one at a local coffee shop in Cambridge, MA), and one was completed at a private room at Boston College O'Neill Library. With the exception of the woman interviewed at Boston College (she was reimbursed round trip MBTA fare of $4.00 per her request), no other woman was reimbursed travel costs to meet for the interview.

Measurement and Data Collection: Interviews, Field Notes, and Observations

The data collection period for this dissertation spanned 16 months from April 2010 to August 2011. Single interviews were conducted with each of these women. The three main sources of data for this study included interviews, field notes/memos, and observations. The first data source were interviews which lasted anywhere from approximately 40 minutes to 1 ½ hours, during which the researcher observed verbal and non-verbal behaviors, acting primarily as a listener. Responses were auto recorded (digital voice recorder, microcassette recorder) as well as recorded through written notes (i.e. notes written on the paper copy of the interview protocol). There were a few instances at which the digital voice recorder had to be stopped during the interview and restarted, due to the participants receiving phone calls. At each instance, the woman answered her phone and the digital voice recorder was briefly stopped and turned back on once the phone call concluded. Other interruptions included background noise (e.g., sirens, children playing, loud wind) and location disruptions (music playing in the coffee shop, people talking in the background), which prompted the digital voice recorder to stop and then start again. During the interview, the researcher also systematically

recorded observations of each woman interviewed, the interview setting, and the reactions/responses to the interview questions.

In-depth interviews

The interviews followed a semi-structured format; that is, specific questions were asked related to the study aims (see Appendix F), but the majority of questions were unstructured and open-ended. The use of open-ended questions allowed for women to share their stories without feeling constrained by the questions. This format also allowed the researcher flexibility to frame the discussion without constraining the responses too much (Creswell, 2009).

The interview questions were developed through a combination of information derived from the literature, the researcher's own personal experiences working with persons living with HIV/AIDS abroad and in the U.S., and guidance from the researcher's dissertation chair, Dr. Ruth McRoy, along with her dissertation committee members, Dr. Rosanna DeMarco and Dr. Margaret Lombe. Achieving a balance of questions that allowed for a variety of responses was central.

Prior to the interview, a consent form (Appendix E) approved by IRB was reviewed with the participants, outlining confidentiality and each woman's rights. Once the consent forms were considered and signed, the interview began with a series of questions concerning background information such as age, years of education, employment status, type of health insurance, number of people in the home, how long they have been diagnosed with HIV, etc. During this first phase of interviewing, questions were pre-planned, followed by open-ended questions, allowing for dialogue to flow naturally. Also, during the interview process, the researcher did not insist upon

asking specific questions in a specific order but allowed for the flow of the conversation to dictate the questions asked and those omitted, as well as the order of the questions.

Field notes

The researcher utilized a field notebook during all stages of entry to the field, as well as during interviews, to document observations from each woman interviewed, and she utilized this field notebook throughout the analytic process. Specifically, the field notebook was used to record and describe critical observations about such things as facial expressions and body language, as well as comments derived from the interviews. The field notebook also served to record the researcher's own experiences and thoughts during the research process: what the researcher did that day; where, why and how it was done, with dates; the researcher's reading list for the day, contact summaries about people, events, or situations; what data was collected, what the researcher thought or felt in the field and in the analysis process; particular achievements, dead ends, or surprises (Miles & Huberman, 1994). These notes helped to identify themes and patterns, as well as to define and add dimensions to the data.

Observations

During the interviews, the researcher divided field notes into three parts— physical, psychological, and behavioral—to aid in the documentation of observations. Physically, the researcher observed that the majority of women appeared strong and healthy. The researcher only saw two women who had open sores and rashes on their skin, as these may have been signs of physical changes that occur among persons living with HIV/AIDS (PLWHA) or other unknown ailment. One woman had open needle marks on both arms indicating she may have been actively using IV drugs; however, this

was not confirmed during the interview process. At the end of this interview, this woman did say that she had relapsed again due to an unhealthy relationship with her boyfriend but did not acknowledge in details what type of drugs she was using.

The researcher also recorded psychological and behavioral observations during the interviews. The majority of the women seemed comfortable in their willingness to speak openly, often disclosing their experiences and sharing their story without any hesitation or apprehension. Other observations include moodiness, anger, irritability, laughter, ease, and comfort. One woman in particular was especially irritable and said at the end of the interview, "It seems like you are trying to find something wrong, it's not you, it's the interview questions." Another woman became increasingly tearful, admitting that her own children and niece she was caring for still do not know her HIV status.

Other observations were related to the location of the interview. In public places, (coffee shops, hospital), a few women became easily distracted during the interview process and were not always about sure what questions were being asked. During one interview, one woman, said "hi" to a person who had come into Dunkin Donuts. Then, she realized she did not know the person and apologized but forgot the question directed at her from the interviewer. There were also loud audio distractions that disrupted the interview process, such as music playing in the coffee shops and announcements made over the intercom at the hospital. During these instances, the field notebook became a critical record of the research process, aiding in the analysis of the emerging data (Emerson, Fretz, & Shaw, 1995). More importantly, it assisted in the documentation of various behavioral and physical changes observed during the interview process.

Sample Size

In qualitative research, sample size considerations are directed at different assumptions than in quantitative research (Padgett, 2008). In particular, the emphasis is on flexibility and depth rather than on mathematical probabilities and external validity (Padgett, 2008). Because of this fundamental concern with quality over quantity, the sample size was not predetermined prior to the study, but was determined instead when saturation was reached, that is, when no new information was forthcoming (Padgett, 2008). For this study, saturation was reached with 24 participants.

Reflexivity of Researcher

The researcher has a critical part in the research process, including her own personal presence as the researcher and her experiences in the field, which is known as the *reflexivity* or the role or member of the field under study (Gibbs, 2007). This reflexivity is also described as a systematic reflection on the researcher's role in the study and how that role shapes the study, as well as on the researcher's own personal biography (Creswell, 2009). This introspection and acknowledgement of biases, values, and interests (Creswell, 2009) is crucial to the processes of taking field notes, recruitment, data collection, and analysis.

During this study, reflexivity played an integral role during the interview, after the interview, and in the analysis phase. The researcher paid careful attention to what happened during each interview and to her own actions, questions, and reflections on that day. After each interview, the researcher journaled her thoughts about how the interview went, interesting responses the woman made, notes for improvements for future interviews, and non verbal and verbal behaviors observed. During this journaling process,

the researcher did her best to interpret what was being heard, as well as seek clarity and a deeper understanding from each woman interviewed (Creswell, 2009; Gibbs, 2007; Padgett, 2008).

During the consent phase, the majority of participants also asked about the researcher's own education, background, and experiences working in their population. The researcher felt comfortable sharing she had worked in child welfare and with HIV/AIDS clients in the past. More importantly, she wondered if her prior practice experience reassured the women that it was "ok" to discuss their true feelings. Did the women trust her and were they honest because she had experience? This may have influenced the degree and level of comfort women had in sharing. In some instances, women wanted to know the use of their story and asked the researcher, "Who would get the information? Or "what's the purpose of this?" Some women may have been afraid that their participation and responses would be misused in some way. Other women shared their frustration with past research studies they were involved in because they felt the person who interviewed them, was "distant" or "not interested" in them. The researcher wondered in what types of research these women had participated in the past. Was the role of the researcher to be more detached and objective, as in most quantitative research? Did the researchers only interact with them in the form of a questionnaire of some sort?

The researcher also wondered how her own ethnicity might have helped or hindered her ability to gain access to this population. As an African American woman herself, the researcher speculated how much that might have helped in recruitment and the credibility of her research. While race and/or racism questions were not explicitly

mentioned or discussed during the interview process, the researcher believes her own

ethnicity as African American assisted her during the process of recruitment and in her

ability to encourage women to share the study with other women. More so, she suspects

that these women may have been more honest and forthcoming to her because they knew

she also shared their same ethnicity and could relate on some level to their experience.

These examples of reflexivity were documented in the field notes after each interview.

Data Analysis Procedures

For data analysis, this study employed an ongoing process approach involving

continual reflection on the data from observations, interviews, "thick descriptions," and

the field notebook, as well as ongoing methodological reflections on the reflexivity of the

researcher and peer debriefing from committee members and another doctoral student.

This entailed a concurrent process of gathering data, making interpretations, and writing

notes. In this type of data analysis plan, understanding the lives and complexities of

midlife African American women living with HIV/AIDS serving as informal kinship care

providers continued to be developed during the process of research (Gibbs, 2007).

This dissertation uses Creswell's (2009) data analysis process. The first step of

this process involved organizing and preparing the interviews for analysis (e.g.,

transcribing interviews, typing field notes, sorting and arranging the data into different

types depending on the sources of information). In particular, the researcher and an

assistant transcribed all interview data verbatim . Within each line-by-line transcription

typed, the researcher and research assistant reviewed how each woman described her life,

context, and the situation she experienced. The average transcription consisted of fifteen

pages of text. This process helped to identify unique concepts about the social, financial,

legal, psychosocial, and health needs for which these women living with HIV/AIDS provide as informal kinship care providers for their grandchildren, nieces, and/or nephews. Concurrently, the use of multiple data was employed to include data triangulation (i.e. use of more than one data source to include observations, field notes, interviews) and theory triangulation (i.e. use of multiple theories, resiliency, risk and protective factors, coping, social supports) to assess how the previous studies were similar and or dissimilar to this study.

In step 2, the researcher read through all of the transcribed data, observations, and field notes in order to begin obtaining a general sense of the information and to reflect on its overall meaning. After reviewing all of the materials, the researcher then reviewed each verbatim transcript and individually created a database of information, both socio-demographic (i.e., age, race, education, income) and medical (i.e. time since diagnosis, disease status), to purposively understand similarities and/or differences in each woman's unique background (Appendix G).

Step 3 involved a detailed analysis and coding process. Coding is a fundamental process that entails identifying one or more passages of text that exemplify some thematic idea and linking them with a code (thematic idea) (Gibbs, 2007). This involved taking text data collected during data collection, segmenting sentences (or paragraphs), and labeling these categories with a term. Codes were based on attributes of the study (demographic information), topics of past literature, on a larger theoretical perspective in the research (resiliency model), and ones that were not anticipated at the beginning of the study. Coding data entailed a long and thorough process that lasted over two months. A thematic codebook was created in a complex, iterative, and detailed process.

Systematically, the definitions of each code were written in the thematic codebook as they were created to be sure they were being applied the same way every time.

HyperResearch (a specific qualitative data analysis (QDA) computer program) was used to organize transcripts according to each code. Computer programs such as HyperResearch increase "methodological awareness" (Seale, 2002, p. 108) because the researcher has a record of his or her interviews, memos, field notes, etc. They are also useful because they create an "audit trail" (Lincoln & Guba, 1985) or record of the researcher's work that is available and easily accessible. The use of QDA programs also allows researchers to quickly locate and retrieve useful quotations and multiple perspectives in a category or theme (Creswell, 2009). More importantly, QDA programs contribute to creativity in that the researcher is able to try out different views of the data, looking at relationships without having to spend a lot of time retrieving and organizing data (Corbin & Strauss, 2008). Most QDA programs allow for meaningful data chunks to be identified, retrieved, isolated, grouped and regrouped for analysis, as well as for categories and/or codes names to be entered, later changed, and/or deleted at the discretion of the researcher.

HyperResearch in particular can search for key categories, themes, words or phrases, making it easy to analyze data in different ways. Once the material is entered as a text file it is given a "case" in which the computer program can highlight codes. Another useful feature of HyperResearch is the Code List, which contains all the codes in the study which may be deleted, copied, or renamed (Hesse-Biber, 2004). Codes developed on HyperResearch were concrete and directly related to each interview conducted. The researcher viewed the potential codes more than once, hoping to gain

insights possibly leading to the development of new categories or, alternatively, to their collapse. (Rossman & Rallis, 2003).

To ensure rigor and enhance the accuracy in this study during this coding process (see Appendix C), the researcher's dissertation chair (Dr. Ruth McRoy) was involved. This allowed for both the researcher and the dissertation chair to review the transcripts and codes and ask questions with each other so that the account resonated with other people than only the researcher (Creswell, 2009). In addition, the dissertation chair or "peer reviewer" provided "peer debriefing" through verbal and written feedback about the study, identifying possible areas of oversight. As this was being done, the researcher and the peer reviewer retrieved similarly coded text and compared how it varied across or within cases (i.e. interviews) and how it was coded in different ways (Gibbs, 2007). Particularly, this served to generate questions that "pertain to substantive, methodological, legal, ethical, or any relevant matters" pertinent to the study (Lincoln & Guba, 1985, p. 308). Once common codes across interviews were noted, both the researcher and the peer reviewer reviewed whether they were supported by individual texts and whether they offered a clear description found in the text. The rationale for looking across interviews is not to produce generalizability but to improve interpretive vision (Leong & Austin, 2006). By reviewing both within and across interviews, the researcher and the peer reviewer were able to consider diverse experiences and to recognize how one situation resembles another (Leong & Austin, 2006).

During the initial coding process, another doctoral candidate at Boston College in the Department of Sociology also met with the researcher once a week for two months. During this process, both doctoral students provided guidance and support in completing

their dissertations. While this doctoral student was not involved in analyzing or coding

for this dissertation, he had previously used HyperResearch and was very familiar with

the software. He provided much needed qualitative reference materials to help in the

coding and analytic process. He was also available to assist the researcher with basic

questions about how to create codes and utilize functions of the software. The researcher

was also able to contact the software developers of HyperResearch, both of whom are

from Boston College and made themselves available by e-mail or phone, with specific

coding and analysis questions or other concerns during this initial phase of analysis.

The next two steps, 4 and 5, entail using the coding process to generate categories

and themes for analysis, the most salient of which appear in the findings. This study's

themes were qualitatively descriptive (QD), employing multiple perspectives from the

women, supported by various quotations as listed in the findings section. More

importantly, to ensure anonymity, the researcher did her best to choose quotes that would

not reveal the identity of any of the women. In keeping with QD, a low inference

approach to interpreting data helped the researcher describe a more natural and contextual

depiction (Sandelowski, 2000). This low inference approach in coding first began with

attribute coding. This is usually done at the beginning of a qualitative research study on

basic descriptive information such as the field work setting, participant characteristics,

demographics, time frame, and other variables of interest (Saldana, 2009). This

information appears in Appendix G. Then, a more detailed coding process within

interviews and across interviews of attributed codes was developed. This process led to

the advancement of categories into themes in the narrative and findings section. This two-

fold step included multiple perspectives of women that required revisiting each interview

more than once in order to provide a detailed discussion of the several themes that emerged.

The sixth and final step involves making an interpretation (meaning) of each interview. These meanings include the researcher's personal interpretation, or low level inference (Sandelowski, 2010), the women's experiences, new questions raised during the interview, and future questions to be asked. "Interpretation means attaching significance to what was said, making sense of findings, offering explanations, drawing conclusions, extrapolating lessons, making inferences, considering meanings, and otherwise imposing order" (Patton, 2002, p. 480). This moves thematic analysis to a higher level of integration and synthesis as the researcher finds meaning beyond the specifics of the data (Rossman & Rallis, 2003). Conducting analyses by looking across cases for commonalities, differences, and preliminary themes related to the research questions is the final analysis step. This study analyzed interpretations of how these women defined resiliency, how they accessed services for their caregiving and health needs, and how their kinship responsibilities, attitudes, beliefs, and perceptions facilitated and/or impeded their demand for services.

Moreover, through these above outlined steps, this dissertation aims to ensure trustworthiness and rigor of findings by presenting both negative and discrepant information (Lincoln & Guba, 1985). Once the study is complete, the researcher hopes to ensure that the conclusions and findings exhibited validity and trustworthiness (see Appendix C) from the standpoint of each woman and the researcher (Creswell, 2009; Lincoln & Guba, 1985). It is further the researcher's goal to share the dissertation findings with professionals (e.g., health care providers, child welfare workers, therapists,

counselors, academics, etc.) and consumers in order to provide concrete future steps to better assist this population.

Chapter 3: Findings

This dissertation set out to examine the lives of midlife African American women living with HIV/AIDS and their informal kinship caregiving experiences with their grandchildren, nieces, or nephews. To accomplish this task, the researcher conducted lengthy, in-depth, semi-structured interviews with these women in which they shared their personal experiences. Guided questions, listed in Appendix F, were used to assist the conversation, and interviews were conversational and dialogic in nature. Interviews were completed in environments that provided safety, convenience, and confidentiality, in an attempt to make women as comfortable as possible with revealing and sharing personal information about living with HIV/AIDS and caring for their kin. The QDA program HyperResearch was then used to organize, code, and analyze all of the data. Coding of interviews started as soon as the transcription was complete. Using the HyperResearch software, verbatim transcripts were converted to text files and examined to create lists of codes.

This chapter presents descriptive characteristics of each woman interviewed (age, marital status, occupation, etc.), followed by the analysis and identification of major themes related to each research question. In drawing themes out of the data, the chapter retains as much of the raw qualitative responses as possible in order to maintain the authenticity of the testimonies of women. Direct quotes are used where appropriate; these were not edited for grammatical precision, although repetition or filler words were removed to ensure clarity and readability. Finally, a summary of findings assesses the utility and relevance of the resiliency model that guided the study.

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Descriptive Characteristics of Women Participants

      Midlife African American women living with HIV/AIDS

      Twenty-four midlife heterosexual women who self identified as African

American living with HIV/AIDS serving as informal kinship care providers, and were

residing in the greater Boston, MA (Roxbury, Dorchester, Quincy, Cambridge, and

Somerville) participated in one individual semi-structured interview. The women ranged

in age from 33 to 64 with a mean age of 49 (*SD* = 8.19). Slightly more than half (*N*=13;

54.1%) of the women were single; three (12.5%) were widowed, three (12.5%) separated,

and three (12.5%) divorced. Only two women (8.3%) were married (see Table 2).[2] All

twenty-four women self-identified as African American, with four having immigrated to

the U.S. from countries in Africa (Ethiopia, Kenya, Cameroon, and Nigeria). Because all

four of these women self-identified as African American, even though they immigrated to

the U.S., their stories are included in this study. These four reported incomes below

$10,000, and all but one (a Nigerian woman who is caring for her grandson and two

granddaughters) were caring for their nieces or nephews. Two of the three aunts

completed at least two years of college, while the grandmother did not complete high

school (she stopped at 11th grade). All four of these women from Africa had resided in

the Boston metropolitan area for a relatively short time (less than two years), and they all

hoped to remain in the U.S. and become citizens.

      Years of education, employment status, & yearly income

      The majority (*N*=19; 79.1%) of women interviewed had completed high school

and more than half (*N*=15; 62.5%) completed at least one year of college, with one (4%)

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[2] All tables appear in Appendix G.

having completed a master's degree, and another (4%) having completed a bachelor's degree. Of the remaining women who did not complete high school, two (8.3%) had their General Equivalency Degree (GED), four (16.6%) attended high school until the 11th grade, and one (4%) attended high school until the 10th grade. However, while the majority of women completed at least one year of college; half (*N*=12; 50%) had incomes of less than $10,000 a year with only eight (33.3%) having incomes between $10,000-$20,000, and four (16.6%) having incomes between $20,000-$50,000 (see Table 2).

The majority of women were also unemployed (*N*=19; 79.1%) and receiving SSI/SSDI (*N*=14; 58.3%), with the exceptions of two (8.3%) who were in the process of applying for SSI, six (25%) who were ineligible due to their employment status (working either part time or full time as a peer advocate, HIV para leader, HIV case manager), and four (16.6%) who were not U.S. citizens. So, while the majority of women (*N*=15; 62.5%) completed at least one year of college, more than half were not working (*N*=19; 79.1%), were on SSI/SSDI (*N*=14; 58.3%), and had incomes below $10,000 (*N*=12; 50%).

Year of HIV/AIDS diagnosis

The year of HIV/AIDS diagnosis among women ranged from as far back as 1982 to as recent as 2008 (*M*=1995; *SD* = 6.43), spanning a total of almost 30 years living with the virus among the twenty four women. The year of their diagnosis was almost evenly split between grandmothers and aunts during both decades, 1982-1990 and 1991-2000 (see Table 3). More grandmothers (*N*=5; 38.7%) than aunts (*N*=4; 36.3%) contracted the virus from 1982-1990. Between 1991 and 2000, slightly more grandmothers (*N*=6; 46.1%) than aunts (*N*=4; 36.3%) contracted the virus. Women diagnosed from 2001-2008

accounted for the fewest participants, with only three aunts (27.2%) and two grandmothers (15.4%). The woman living with HIV/AIDS the longest, a grandmother diagnosed in 1982, was also the only woman who contracted the virus through a blood transfusion.

> I'm on dialysis today and I'm still scared of needles, but, I remember the kid's father was an IV drug user, and I remember he had told me when he was incarcerated, I didn't shoot needles but he did.

So, it may be possible this woman contracted the virus from her previous partner even though she believes she contracted the virus through a blood transfusion. However, it was unclear from the interview if she was with her partner at the time she was diagnosed.

Although it is difficult to know how these women contracted the virus, CDC statistics suggest that the majority of women contract the virus through heterosexual sex (CDC, 2010a), and this is also consistent among the women in this study (N=18; 75%). Three (12.5%) of these women also said they were IV drug users at the time of their initial diagnosis, so they were unsure if they contracted HIV/AIDS through heterosexual sex or IV drug use. In addition, two (8.3%) other women reported that their husbands/partners were IV drug users, so, while they may have had unprotected sex with their husbands/partners who were IV drug users, they were not sure if they contracted the virus because of their husband's/partner's IV drug use or because they engaged in unprotected sex.

Among the women who contracted HIV/AIDS heterosexual sex, three (12.5%) were adamant in their stories that they were sexual assault victims. In particular, these women (two aunts and one grandmother) shared their vivid stories with great intensity. One, a 47 year old grandmother diagnosed in 1995, said:

> I know it was [rape] because I had never been an IV drug user and I never had unprotected sex before. Even when I was using drugs and alcohol, I've never. I refused to engage in unprotected sex for the simple fact the 1st time I was raped was before my daughter was born. I didn't know about HIV and AIDS then. I was just very protected of me. No hat no honey.

Another woman, now 45, described her rape in 1997 and how she felt completely alone

when she discovered she was HIV+:

> It was emotionally upsetting, and at the time I did find out I had HIV, I was living out in western Mass in Greenfield, Mass. I didn't have my family or anyone out there, I was alone basically, it was hard, it was a hard thing. I didn't want to believe it at first that I had it and I like blamed myself for a long time, but, I had a really good doctor down there that really supported me and helped connect me to an agency called Tapestry Health Systems and I had a really good case manager there.

One of the aunts from Africa, now 52 and diagnosed in 2003, tells a different story:

> I was a strong politician back home, so, I was locked up in the jail and then one man wanted to help me to make me go home while the other people were being tortured So, he he he (she pauses). To me, I believe he was trying to help me out of jail and put me in a place and actually go home, you know? I should go back. But he took me very far. I don't even know where they took me. He said the only way I could go home (silence) since I don't have money. So, I went to the hospital and I told my sister and she arranged and they said I was HIV, I don't know. I was suppose to die. At that time, everybody who had HIV died. I almost died. I almost thought of taking away my life. Yeah. (wind blows). I had a wonderful doctor talking to me: "It's not the end of the world; the only thing that will keep you long is take my medication." They advised me, they advised me to take my medication. Look at me, I'm still fine. I heard that the other one died just two months ago. The other one died, a year back. It's not HIV that killed them, they died of other illness.

Finally, a couple of women (*N*=2; 8.3%) said they contracted the virus through IV drug

use. One of these women said:

> I was actually using so there was really no reaction, I was like, ok, you know what I mean? You know, I was using so there really wasn't a reaction, I was sad, mad, and all that other stuff. I think, I mean, I think by catching HIV it even made me use more cause it made me.

Substance abuse history

After women shared how they contracted the virus, some discussed their substance abuse involvement. In fact, almost half of the women (*N*=10; 41.6%) also had substance abuse histories (see Table 3). Slightly more grandmothers (*N*=6; 60%) than aunts (*N*=4; 40%) reported a current or past substance abuse history. There was also a range of substance use. Two women (20%), one grandmother and one aunt, admitted to previous IV drug use, while the remaining eight women (80%) admitted to smoking crack cocaine, taking pills, or drinking alcohol. One grandmother revealed that she was an IV drug user during her pregnancy and had gone to a methadone clinic for almost twenty years, but she now said that she no longer used drugs (she is caring for her 1 year old granddaughter and 21 year old daughter). When she described finding out that she was HIV+, she was relieved to report that her child was not HIV+.

Another woman admitted to "being clean" for as little as 9 months and currently going to a methadone clinic (she is caring for her 1 year old grandson, 14 year old son, and 21 year old daughter), while another woman said that she has been sober since 1988, and that she takes part in NA/AA meetings and drug addiction support groups (she is caring for her grandchildren ages 8, 6, and 5, along with her 21 year old daughter and 27 year old son). One grandmother described in particular how she maintains her sobriety (she's caring for 2 year old grandson):

> I've been clean for seven years. About seven years. I don't even want to think about drugs. Even if I do do drugs, I have a bad heart, I go to a lot of groups, women groups I love those. They make my day. Actually, I go to one today and I go to one Saturday. Next Tuesday, I go to three, one in Cambridge, one in Dimock and then WCAC on Blue Hill Ave, Sistah Powah. I went there first time last month. Awesome, oh my God.

The woman who admitted to using drugs most recently is caring for her 16 year old

granddaughter; she said:

> Right now, it may be almost two weeks now. Because, I allowed this fool back in
> my life, come to my house. Sometimes, I'm glad to see him, so, when he comes
> into the house, I like the moment. And, I be in my bedroom and he'd be in the
> kitchen walked in the kitchen, he be doing his thing and, I get caught up. Cause, I
> was good for a while, because I kept him out of my life, out of my house. I think I
> have to do that again. Cause, I mean, I was trusting him not to bring that in cause
> he know I don't. Cause, he stay in the kitchen, cause he know, I stay in one room.
> All of sudden, the smell started going through, I was like, "oh no."

Another woman described how her life has changed since staying clean:

> I don't sit here with you on my own. If I told you I sit here with you on my own,
> your 10 dollars [the token of appreciation given at the end of the interview] would
> be out here getting a package. I'm gonna tell you the truth. I will go get a bottle of
> Irish Royals and a 5.00 hit cause they got them out there still and I still know how
> to get it. That's what your 10 dollars would do. I'm keeping it real with you.

Indeed, there was a vast range of sobriety among the women. An equally

interesting finding revealed that women with a history of substance use contracted

HIV/AIDS earlier than the other women who denied a substance abuse history. For

example, women who had a history of substance use contracted the virus as early as

1982, 1990, 1991, 1995, and 1993 while only one woman with a history of substance use

contracted the virus in 2001.

Comparison of kin caregiver relationships by age, race, and marital status

There were some noticeable differences and similarities between kin caregivers

based upon their relationship to the child (aunt or grandmother). In this study, there were

about the same numbers of aunts (*N*=11; 45.8%) and grandmothers (*N*=13; 54.1%)

interviewed (see Table 2). As previously mentioned, while all of the women self-

identified as African American, four were originally from Africa. Of these, three were

aunts (from Ethiopia, Kenya, and Cameroon) and one was a grandmother (from Nigeria).

Two of these women (those from Ethiopia and Kenya) were also among the youngest in the study (ages 36 and 37). Not surprisingly, the youngest women in the study were all aunts in their thirties (ages 33, 34, and 37); overall, aunts' median age (46) was slightly younger than grandmothers' (52).

There were few differences between the aunts' and grandmothers' marital statuses. As previously mentioned, most of the women (*N*=13; 54.1%) were single, equally split between aunts (*N*=7; 29.6%) and grandmothers (*N*=6; 25%). Of the three women who were divorced, two were aunts and the other a grandmother. Two grandmothers were widowed or separated, while only one aunt was widowed or separated. Lastly, the only two married women in this study were the grandmothers to the children for whom they are providing kinship care.

Total income

Half of the women (*N*=12; 50%) had incomes less than $10,000 a year, and this income bracket was evenly split among aunts (*N*=6; 25%) and grandmothers (*N*=6; 25%). While eight (33%) out of the twenty-four women's yearly incomes were between $10-$20,000, there were slightly more grandmothers (*N*=5; 20.8%) than aunts (*N*=3; 12.5%) in this category. In the next category of income, four women (16.6%), two grandmothers and two aunts, reported incomes between $20,000-$50,000 (see Table 2). By marital status, single women still earned more than the two married women and dominated all three categories, making single women the highest earning group in this study (see Table 5).

Years of education

There were clear differences in yearly income among grandmothers and aunts who had more education. Overall, the majority of aunts and grandmothers completed at least one year of college (*N*=15; 62.5%). The highest earning women in this study included an aunt (*N*=1; 4%) earning $39,000 and a grandmother (*N*=1; 4%) earning between $40,000 and $50,000 (see Table 2). In these instances, the aunt was separated from her spouse and the grandmother was single. Not surprisingly, these were the most educated women in the study, having earned a bachelor's degree and a master's degree. Overall, aunts were also more educated than grandmothers, with all of them (*N*=11; 100%) having completed at least high school, while several grandmothers (*N*=5; 20.8%) had not completed high school. It is encouraging to note, however, that most of the women in this study had at least 1 year of college (*N*=15; 62.5%), and these included about the same number of grandmothers (*N*=6; 25%) as aunts (*N*=9; 37.5%). The significance of the amount of education and income among both aunts and grandmothers was quite interesting considering that, while more aunts had completed more post-secondary education, aunts still received about the same amount of income as the grandmothers who had not completed high school or continued on to pursue a post-secondary education (see Table 2).

SSI/SSDI

Receipt of income from SSI/SSDI also differed notably among grandmothers and aunts. In this study, SSI/SSDI was counted as the women's total income. Fourteen out of twenty-four (58.3%) women received SSI/SSDI, with more grandmothers (*N*=9; 37.5%) receiving assistance than aunts (*N*=5; 20.8%). Surprisingly, only two women received

SSDI (a grandmother and an aunt). The interviews did not probe into these women's reasons for receiving SSDI and not SSI. It should be noted, however, that the grandmother who received SSDI and SSI reported that she was disabled and retired, while the aunt reported SSDI as the only income she received. She later told the interviewer that she has an autistic son. While the interviewer did not directly ask about the circumstances under which this woman received SSDI, it may be plausible that this was due to her son's illness. Another equally interesting finding was that both of these women had incomes above $10,000 (aunt's income is $15,600, and the grandmother's income was $19,000). This indicates there is income variability among women who receive SSI/SSDI.

Still, it is noteworthy that while half of all the women in this study (*N*=12; 50%) were making less than $10,000, and more than half (*N*=14; 58.3%) received SSI/SSDI, the majority (*N*=15; 62.5%) had at least completed one year of college. This suggests that while education was important to these women, their incomes remained low. Economic hardship was common among these women considering that the median income in Boston is $59,579 (City-data Boston, MA, 2011). Among single parent (female headed) families with children younger than age 18 in Massachusetts, the median annual family income is $28,125, and among married-couple families with children younger than age 18, the median annual family income is $103, 225 (NACCRA, 2011), which is still considerably higher than the incomes for the sample of women interviewed for this study.

While the overall number of women working in this study was low (*N*=5; 20.8%), the two women (an aunt and a grandmother) who worked full time had a bachelor's and master's degree respectively and were among the most educated women in the study. The

three women who worked part time had low incomes (e.g., $11,000, <$10,000, $22-$30,000). What could explain this? The researcher examined the total years of education among the three women who worked part time. The lone grandmother and one of the aunts who worked part time received earnings of $11,000 and $22-$30,000 respectively and had completed one year of college, while the other aunt whose income was less than $10,000 only had her GED. This signifies that the two women with more education had slightly higher incomes than the woman who only completed her GED. Other examples that support these findings include a grandmother with an annual income of $19,000 who had completed two years of college and an aunt with an annual income between $22-$30,000 who had also completed some college.

These findings are consistent with literature suggesting that the more education a person has, the higher his or her income is likely to be. These findings are not consistent, however, with literature that suggests that the family income of married couples is higher than that of single-headed households. As previously indicated, the single women in this study earned more than the married women (see Table 5). Moreover, single women (the largest group) cared for more children in their households than any other group of women despite their low incomes (see Table 6). No information was provided on the income of the two married women's husbands.

Grandmothers caring for grandchildren versus aunts caring for nieces and nephews

Another interesting demographic finding among aunts and grandmothers in this study were the differences between grandmothers caring for the children of their sons or daughters and aunts caring for the children of their sisters or brothers (see Table 4). In this study, only a few women were caring for children of their sons or brothers. An

overwhelmingly majority of the women were caring for the children of their daughters or sisters. Specifically, grandmothers caring for their daughters' children (*N*=11; 45.8%) heavily outnumbered the grandmothers caring for their sons' children (*N*=2; 8.3%). Similarly, among aunts, the majority (*N*=9; 81.1%) were caring for their sisters' children, while only two (18.1%) were caring for their brothers' children. The aunts from Africa (Kenya, Cameroon, Ethiopia) were all caring for their sisters' children, while the grandmother from Nigeria was caring for her daughter's children.

Gender and age of children receiving informal kinship care

Surprisingly, grandmothers were more likely to care for boys (*N*=9; 69.2%), which was not the case among aunts, who were primarily caring for girls *(N*=6; 54.5%). There were only a couple of instances (*N*=2; 18.1%) where aunts were caring for their nephews. In three instances (27.2%), aunts were caring for more than one of their nieces and nephews. Similarly, among the grandmothers, two (15.4%) were caring for only their granddaughters, and two grandmothers (15.4%) were caring for more than one grandchild (see Table 4).

Caring for elementary aged children was much more common than middle school or high school aged children among both grandmothers and aunts. Among grandmothers, the majority of the grandchildren were between the ages of 0-5 (*N*=8*)* and 6-10 (*N*=8), with only a couple instances where grandmothers were caring for children older than 11. Among the aunts, the majority of nieces and nephews were between the ages of 0-5 (*N*=5) and 6-10 (*N*=5), with only one teenage child (age 14) being cared for by her aunt. Overall, half of the women (both grandmothers and aunts, *N*=12; 50%) were caring for only one kin. The remaining women were either caring for their own adult children

and/or younger children in the home or had more than one kin for whom they were caring.

Length of time caregiving

The average number of years that women had been informal kinship caregivers for their grandchildren, nieces, and/or nephews also varied. As mentioned, all of these women provided care for their grandchildren, nieces, and/or nephews informally, i.e. without the assistance from public child welfare services (see Appendix D). When asked how long they had been caring for their kin, answers ranged from since the birth of their kin to as little as three weeks. Only grandmothers in this study reported caring for their kin since birth (*N=7*; 53.8%). The average ages of those cared for could be as young as two for one granddaughter who had been cared for by her grandmother since her birth or as old as nine for a grandson who has been cared for since his birth. Even in this group, there were a few instances in which these grandmothers' adult daughters also lived in the home. Among the remaining grandmothers, the length of caregiving was equally split between 6-10 years (*N=2;* 15.4%), 1-5 years, (*N=3*; 23.0%), and <1 year (*N=2*; 15.4%) (see Table 4).

There were clear distinctions between aunts and grandmothers regarding the length of caregiving . While the majority of grandmothers had cared for their grandchildren since birth, aunts had cared for their nephews/nieces for a shorter period of time, with most (*N=7*; 63.6%) reporting 1-5 years, one (9%) less than one year, and another two (18.1%) 6-10 years.

At the time of the interview, all of the women with the exception of two (8.3%) were caring for their kin. These two exceptions were due to one father resurfacing in the

grandson's life and to another father's interest in pursuing custody due to substance abuse

of the mother. While the child's mother in this instance was the daughter of the woman

interviewed, the grandmother supported the decision of the father to be a part of her

grandson's life and for him to pursue custody. She talked openly about her age and

declining ability, due to her health, to be the primary caregiver permanently. This

grandmother reports that her grandson had left less than a year prior to the time of the

interview. The other woman who was not currently caring for her niece and two nephews

reported that caregiving took place "now only on weekends," and that this new

arrangement had been in place for about a year because of her own declining health,

saying, "I'm getting old." Later, she said, "I felt it would be temporary because of my

own health concerns."

Permanent or temporary arrangement

Women were also asked if they thought their current caregiving role was permanent

or temporary. Overall, slightly more women (*N*=13; 54.1%) described the arrangement as

temporary rather than permanent, with more aunts (*N*=7; 63.6%) than grandmothers

(*N*=6; 46.1%) reporting a temporary arrangement (see Table 4). More interesting,

however, was that more grandmothers (*N*=7; 53.8%) than aunts (*N*=3; 27.3%) said that

the arrangement was permanent. This may explain why some of the grandmothers

reported caring for their grandchildren since birth. Regardless if they viewed the

arrangement as permanent or temporary, women overwhelmingly discussed how they

embraced and accepted their role as informal kinship care providers. They described how

important their grandchildren, nieces, and/or nephews were to them and how much they

loved them. One grandmother in particular stated:

> They are really close to me, I mean they're really close to me, they'll come to me before they'll come to her [referring to their mother] and ask for a hot dog, whatever they want, they'll always come to me.

Another woman said, "Whenever my grandchild needed help, I would be there. We played computer games; he would come and stay with me. I took him to school."

Informal kinship care providers parenting their own children

All twenty-four women except for one (the aunt from Ethiopia) had their own children. This suggests that almost every midlife African American woman living with HIV/AIDS serving as an informal kinship care provider in this study has also had the dual role of caring for her own children at some point in her life in addition to her relatives' children.

Indeed, almost half of the women (N=11; 46%) also cared for their own children in the home. The interview process revealed a vast range in the ages of these children (see Table 4). There were women caring for their adult children (between the ages of 18-28) and other women caring for their children under the age of 18 (between the ages of 10-17). In a couple of instances, women were caring for their minor children and their adult children in addition to their grandchildren, nieces, or nephews (between the ages of 14-28).

Overall, more grandmothers (N=8; 72.3%) than aunts (N=3; 27.2%) were caring for their own children. Specifically, the majority of grandmothers (N=6; 75%) cared for their adult children, while no aunts did. Among aunts, only two cared for their own children under the age of 18. This was similar to grandmothers; in this category, only one reported caring for her own child under the age of 18. In a couple of instances (N=2; 12.5%), women (one grandmother and one aunt) cared for their adult children, as well as

their own child under the age of 18, and their kin. In these instances, these women shared that it was a positive experience: they felt that the relationship with their own children and their niece and/or grandchild was "good" because, according to one aunt, "They got along." And, the majority of these women who cared for their own children (*N=6*; 54.5%) were single, with one (9%) reporting being separated, another one (9%) divorced, and two (18.1%) married.

Reasons for caregiving

The participants were also asked directly what led to their caregiving role. The most frequently mentioned reason (*N=13*; 54.1%) for children coming to live with their grandmother or aunt was because they (grandmother/aunt) were offering some "financial assistance" or "help" to the parent (see Table 4). This answer was evenly split between grandmothers (*N=7*; 53.8%) and aunts (*N=6*; 54.4%). Women openly discussed their reasons for offering financial assistance/help because their relative lacked housing, expressed interest in going back to school, or was incarcerated. One woman said:

> My sister in law, she has a little too much on her plate right now, she has four other kids plus she has her father too—he's ill—who she took care of 2 years ago, and the baby was just a little too much for her. So she would come over and stay on the weekends and then she wouldn't want to go home. So we just decided that she would come and stay with me. And she would go see her mother and everything on Saturdays. She come back on Sunday. So she just basically stayed with me all the time now.

In another instance, a grandmother said:

> My daughter is in a shelter now, my baby girl and um, her two boys. She was staying with me until she got in a shelter. You know? And, I told her that I can only do so much, you got to get up and help mommy. You got to do what you need to do for you and your boys because God forbid if something was to happen to me what are you going to do? So I put her in a shelter yesterday. But her two boys is at Brockton, but she's been with me for a while: it was kind of stressful cause my two daughters and then her two kids and my grandson, but my grandson go to camp soon—it was the two little ones running around the house.

Another grandmother said:

> My daughter's going to school and working different hours. And I said, "Just bring him here." Sometimes, she might bring him here but she's all over the place. She's trying to figure out what she wants to do. She wants to work, she do not want to work. She wants to go to school. But now, she started going to school. She started getting back in school now. So I have him more than the rest.

Another grandmother shared that her daughter's boyfriend's incarceration as the main reason:

> Um, their baby's father was incarcerated, and, they lost their apartment, and so, it was a no brainer, you know what I mean? No brainer. My mom is elderly, and, she—my daughter—wanted to go and stay with her, you know, grandma will let her get away with murder and mommy won't, and make her more accountable than my mother will, like I said, my mother's elderly, she's ill herself so, um…

> Interviewer: And your mom lives here in the area too?

> No, my mom lives out of state, yeah, but um, and my mother told her, she says there's no way, you might as well go live with your mom, you know, suck it up with your mom, it will get better so.

An aunt describes her brother needing support:

> Yes, his wife died, and that was the only child he had anyway. I'd say about two years now. And so we're all HIV positive.

> Interviewer: Who is HIV positive?

> She is too, my niece and I am, I mean her father is. And, I am and she is.

In this instance, this aunt, her brother, and her niece all were HIV+ and while this aunt's sister-in-law recently died, she decided to be proactive and help her brother raise his daughter. They all share a common bond of living with the virus. This was the only case in this study in which the aunt, her brother, and kin (a niece who is 9 years old) all have HIV/AIDS.

The second most common reason these women (grandmothers, $N=3$, 23%; and aunts, $N=3$, 27.2%) cared for their kin was drug use by their relative. One grandmother

said, "His mother, she got into her little drug activity so that's the reason why I stepped

in." Similarly, an aunt said:

> I know my sister has a problem. Now, substance abuse is a problem. She's an
> addict. I'm in recovery so I know what an addict is like so, 15 years got over it.
> She's still struggling. So, I don't knock her. I don't like it, so, we have I guess a
> love hate relationship. I'm upset that my sister can't get herself together. I know
> that um, not all women just because you give birth can be a mother. It really takes
> a lot of responsibility, a lot of commitment, and some people, men and women,
> just don't have that commitment or don't want to deal with it. And, she doesn't
> want to deal with it. She makes me angry at times.

Finally, the remaining women cited behavioral issues/special needs of the child

($N=2$; 8.3%), health of niece as poor ($N=1$; 4%), and health of grandmother ($N=1$; 4%)

as reasons they for care for their kin (see Table 4). As one grandmother said:

> Because my granddaughter, she's got like, lately, it's been almost a year before I
> got her. She'd been having trouble in school, fighting and all that. Now, she's on
> probation and if she gets into anymore trouble, she's going to have to do a year in
> DSS. They'll put her in the home with kids who have behavioral problems. She's
> been after me for the longest to come and stay with, so I decided to let her come
> and get into school. Maybe to see if there's any difference in her attitude.

Legal guardianship

All of the women except two (8.3%) did not have legal guardianship or

assistance from the courts to help care for their kin. When asked specifically about legal

guardianship, only one woman (a grandmother) was in the process of gaining permanent

legal guardianship for her grandson. This woman was particularly informed about the

process and talked openly about her encounters with the legal system (attending court

regularly) and receiving support from her daughter to pursue legal guardianship of her

grandson. She described her daughter as supporting the arrangement and voluntarily

"giving up parental rights." In this instance, this grandmother cites her daughter's long

history of substance abuse as grounds for her to care for her grandson.

The other woman had attempted to pursue legal guardianship for her niece but was unsuccessful due to her past assault and battery charge (although she claims the charges were never brought to court). The courts told her she was ineligible for legal guardianship and that such charges remain on a person's record for 7 years. Similarly, when the researcher asked about the Fostering Connections to Success and Increasing Adoptions Act of 2008, none of the women had heard of it or knew anything about what it entails. A few women said they received some TANF benefits because of caregiving but none of them knew about this recent federal legislation to support their caregiving needs. In fact, one woman thought she had to put her niece into foster care to receive additional services.

> Do I have to open up a DSS case? Cause, I called them and said, "How can I get financial help with her?" Cause I mean I know plenty of people who have foster kids—ok, she's not in foster care because my uncle took legal guardianship. We went to court and they said, "Well, if you do this, then, we would have to open a cause." When my uncle took her she was about 8 months old, he just took legal guardianship, so does that mean the DSS case was over when he took legal guardianship? So, now if I go back and open that up, DSS would come in, now do she go into foster home until they decide she's mine? It's crazy.

Housing

Not surprisingly, none of the women—regardless of education, marital status or age—owned a home, lived in a townhouse, or had co-op housing. A variety of factors could explain this finding, such as the high cost of living and Boston's being a densely populated area. All of the women (*N*=24; 100%) lived in apartments and rented some type of section 8 housing. Section 8 housing ranged from 100% subsidized to 30% subsidized. A few interesting section 8 housing options included one woman (4%) residing in a section 8 sheltered care plus apartment. This woman had been caring for her niece for about 11 months:

I was in a shelter for 11 months waiting for a section 8. So section 8 didn't come through, but very few programs have this shelter care plus, and they can place clients out of the shelter and least put them in a home setting with their family, you know?

Other housing options included four (16.6%) women residing in a HIV/AIDS home for women and their children that is completely subsidized. The only requirement for women is that they pay electricity and heat. In one of the interviews, the interviewer asked, "Is it completely subsidized?"—to which the woman replied, "Yes. And, we have this building and, we also have another building on um ----Street."

One grandmother recently moved into a section 8 elderly housing unit for disabled adults through the Housing Authority, which took her a total of 12 ½ years to secure. The sole purpose of moving into this housing unit according to the grandmother was to provide more space to care for her grandson. Previously, this grandmother lived in a one bedroom apartment, which in her words was "quite overcrowded" and difficult because of her disability (she is unable to walk).

Maybe because I applied for a wheelchair accessible because I have leg issues and back issues that I knew I was eventually going to need a chair so that might be why it took me awhile, elderly care don't move unless they pass away. It's not like people move around but because I'm in a chair it also made it, you know it was a priority, you don't get that many units I think there's like four in my building, there's like 53 units it my apartment, It took me 12 1/2 years because once I move, I didn't want to move again. And, I truly hate moving, I didn't want to have to worry about moving again so 12 years. I was like, I was happy for myself you know, cause somebody had to wait because I knew it took me so long.

Even amidst waiting 12 ½ years to secure a larger apartment and having a disability, this grandmother still was able to take on the primary caretaker role of her grandson and remain positive.

Summary

Overall, the twenty-four participants in this study lead diverse, complex, yet interesting lives. They vary in their experiences of caregiving, age, education, housing, and health, including in how they contracted the virus and the years they have been living with it. Even though the participants are all midlife African American women living with HIV/AIDS and serving as informal kinship care providers, many different factors play into their complex lives. Some women care for multiple children that include their own children who are adults as well as their children under the age of 18, while other women only care for their nieces, nephews, and/or grandchildren. In addition, reasons for caregiving focused more on helping their sister/brother/daughter/son financially, due to lack of housing or going back to school than on substance abuse or behavioral/health issues of kin. While literature suggests that informal kinship caregiving often results from a crisis (Billingsley, 1992; Burton, 1992; Ruiz & Zhu, 2004), these women focus more on their abilities to help their sister/daughter/son/brother through a situation than on the crises that led to their becoming primary caregivers. However, despite these realities, there were slightly more women who reported their current arrangements as temporary than permanent, with only grandmothers reporting their arrangements as permanent.

The length of time caregiving also varied. The majority of grandmothers had cared for their grandchildren their entire lives. These grandchildren may be as young as less than a year old to as old as 14, and the average length of time these women had been providing care varied from the birth of their kin to less than one year. Most of these women are single, fall below the Massachusetts poverty line, and also live well below the median income for Boston, MA, even though the majority completed at least one year of college. Clearly, the kinship care responsibilities of these women represent economic

hardships. More surprising was the variation in how long these women had been living with the virus, as well as the fact that close to half of them also had a history of substance use.

Chapter 4: Discussion

This chapter provides an explanation of the qualitative description (QD) approach (Sandelowski, 2000). It presents themes emerging from the data, retaining as much of the raw qualitative responses as possible in order to maintain the authenticity of these women's testimonies. Using the QD approach, the themes are presented in relation by the numbered research questions. The chapter also presents outlying issues, which may include responses by one or two women. Each woman was given a pseudonym that was used during the interview and in all documents to ensure confidentiality.

Descriptive themes that emerged from data

Consistent with within case and across care approaches to qualitative data analysis (Ayers, Kavanaugh, & Knafl, 2003), the researcher compared significant statements from the women that related to the three main research questions: (1) how does the provision of informal kinship care impact the social, financial, legal, psychosocial, and health needs of African American women living with HIV/AIDS; (2) how do these informal kinship care providers define resiliency and how do their HIV/AIDS related health concerns affect their caregiving responsibilities and their daily lives; and (3) how have their kinship responsibilities, attitudes, beliefs, and perceptions facilitated and/or impeded their preferences and demand for future services, e.g., health care, child welfare, housing, etc.? These questions guided the researcher through a detailed process of analyzing the data.

After the thematic analysis was conducted, six descriptive themes emerged from the qualitative interviews that provided understanding to the three research questions mentioned above: (1) negative attitudes toward child welfare agencies and resources, (2)

extensive social/psychosocial support, (3) proactive federal support, (4) access to health care services and adherence, (5) belief in better options (6) benefits of HIV/AIDS status. Theme 1 captures research question 3, specifically addressing how their attitudes and beliefs have impeded their demand for services. Themes 2, 3, and 4 address research question 1, outlining the social/psychosocial benefits of caregiving and living with HIV/AIDS. Themes 5 and 6 respond to research question 2, addressing how these women define resiliency and their views of living with HIV/AIDS.

Theme 1: Negative attitudes toward child welfare agencies and resources

While the majority of women knew how to access services and navigate the many resources that were available to them due to their HIV/AIDS, they had overwhelmingly negative responses when asked about the kinship care services or child welfare resources they access. These experiences shed some light on the continual need for more education and resources that should focus on how to strengthen services for kinship care families through the public child welfare system, both in Massachusetts and nationally. While many of the women reported negative attitudes and beliefs about the child welfare system, they did seek out services through other avenues and organizations. In some instances, women had previously dealt with the public child welfare system. Grace said:

> Yep, and here they are at my front door, like we're sitting here now, filling out paperwork, questioning me of how I can go and get a detox and why I need to do this and told her you need to kiss my cause I'm not doing that anymore. You will not separate this family. I will not allow you to separate this family.

Grace later said:

> Instead of keeping the family together, they want to separate you. They don't want to find out how and how to keep this family together. They just want to separate.

Tanesha said:

> I don't like Department of Social Service because for one, I had them in my life in the past. Two, they don't really help to assist you in anything. As far as for example, let's say they were in my life, and let's say, for example, I didn't have any food or whatever, they have a tendency of saying, "Well, if you can't provide things for her, then, we should come in and take her." I have, I've gone though that with them. They are not a very helpful agency to families and like in keeping families together and stuff like that. That's my own personal experience. Then, if they find out certain things about you, then, it gets thrown up in your face. Stuff like that. I just don't want to go through that.

Jody said:

> They're nosey, they're scandalous, they're sneaky. Sometimes, damn, they ask you too many questions.

Ronda said:

> I don't know what they're doing, they're either not checking out that foster home right or they're not working on to the issues where those kids are at mentally, I guess they're doing their job, I'll probably do it a lot different because I raised my niece and she was in the system and so when I went down to the Department of Social Services, they said "usually you'll get this much money." I said, "listen this is my niece, I don't care about the money, I want to make sure she's ok, it's not the money, I could take care of her, and she's staying with me, I don't want no money!" But, a lot of people seem to do things with these kids because they want the money.

One woman who did not have any personal experiences with child welfare recently,

discussed in length her previous experience with child welfare:

> I remember years ago, years ago, when the checks come on the 1st and the 15th Lord ham mercy. You couldn't have no man in your house, no man's name on your doorbell or on your own apartment. Now listen, and you had to hide appliances and stuff. I mean it was terrible. Oh Lord, and then, it got better when years went on and they was giving out 3 checks on the 1st, the 15th, and then on the 3rd month you get money for furniture or any extra thing. They don't do that no more so they cut that out. They use to give you school clothes, money; they don't give that no more. They done cut that out. When you had your baby, and you got on welfare, they gave you everything. They gave you, they paid for your apartment, they gave you furniture, they gave you a washer and dryer. They don't do that no more. So, you know, I just feel sorry for a young woman whose going for that? What do you call it TAF?

> Interviewer: TANF; it used to be called AFDC.

> Yeah, and thank that she's gonna live on welfare. You can forget it. When a child gets a year to 5 years old, she's gotta get a job. So, you might as well have a job before you even start it. So, I'm saying it's weird, ain't it weird? It's done gone from sugar, my mother said from sugar to shit and I hate to say it like that. But, that's what it's done.

Overall, this overarching theme suggests that many more policy and training efforts need to be focused on child welfare and programs to support kinship care providers in Massachusetts.

Theme 2: Extensive social/psychosocial support

For the majority of women, their involvement in the community and in various organizations is a part of their life and facilitates how they access social and psychosocial support services. Socially, many of these women live engaging and busy lifestyles. In fact, each woman interviewed was able to name multiple community and federal agencies they accessed for their health and kinship care needs. The majority of these agencies provide extensive social and psychosocial support and are community based agencies. Examples include Cambridge Cares about AIDS, which recently merged with AIDS Action; Boston Living Center; Dimock Community Health Center; and Women of Color AIDS Council (WCAC). These various agencies all serve People Living with HIV/AIDS (PLWHA) in the greater Boston area and are critical supports that these women access for multiple services in relation to their caregiving and HIV/AIDS needs. Women also described in detail the various services each organization offers and the types of programs, support groups, case management services, etc. that are readily available if they need them. Even among women who work, their social lives also relate to their professional lives and influence how they seek social and psychosocial support. For

example, Kate, a grandmother who works part time and is caring for her 10 year

grandson, said:

> Well, I lead a women support group and I also lead a recovery support group [for substance abusers], and I also lead a expression group where you express how you feeling and whatcha ya feeling and we do some good life skills around the expressions. And our women's women group is very, we got a closed group cause these women come on a regular, so, it's big and basically it's productive because they are really into the topic and it's pretty good for the women, they look forward to coming.

> Their involvement in social and psychosocial support was also clearly evident in

church and/or spiritual activities. For the majority of the women, they shared how their

belief in a higher power helped facilitate their kinship and health care needs as well as

their social and psychosocial support.

> Megan said, "Spirituality I am grounded, I definitely believe in God, you know,

there is a purpose for me being here and, um, I believe in a higher power."

Carol said:

> I call my pastor and he lets me know, get up, go read the Bible, go jogging, do something but get yourself out of the house. So, I walk. I walk every morning from 5:30 to 6. Me and my cousin. She's my prayer partner, I tell her everything. She's in charge of Radiology at ------. So when I have questions about my HIV, I pick up the phone and call her. She helps me; she guides me to what I need to get through.

She later said:

> My thought is God has watched over me all this time, he's not going to take me away from my kids. I rely on him for everything, he gets me through the day, he gets me through the moment when all else fails, he's there for me.

Helen said:

> I go to -------Church and sometime when they have volunteer opportunities I take part. Like last year we had a picnic at Boston Common and I helped to serve food. This week there is what they call child's week so I went for one day to play with the kids as their mother go to some form of training they had.

Grace said:

> Between God sending people in my life, strong powerful people like my counselors, my peers, my case managers, I wouldn't be anything without these people. I ask for help quickly cause I knew it couldn't have been done by myself.

These examples all indicate how extensive social and psychosocial support services encompass these women's lives. More so, they described in detail how these support services provide resources and what ways they are able to navigate the process of living with HIV/AIDS and caring for their grandchildren, nieces, and/or nephews. In particular, all the agencies they accessed for social/psychosocial—with the exception of their church/spiritual needs—are due to their HIV/AIDS status and not because of their caregiving/kinship care needs.

Theme 3: Proactive federal support

As previously mentioned, more than half of these women (N=13; 54%) received social security income (SSI) and/or social security disability insurance (SSDI; N=3; 12.5%). Under SSI, payments are made on the basis of financial need, whereas SSDI payments are for persons who are physically restricted in their ability to be employed because of some type of disability. The amount of SSI/SSDI ranged considerably among women with the average amount under $800 a month. In this study, half of the women (N=12; 50%) had completed some college education and still received financial assistance from the federal government. Even among the remaining women who did not receive SSI/SSDI at the time of interview, three (12.5%) were in the process of applying for SSI/SSDI, two (8.3%) were working in a full or part time job and were ineligible for SSI/SSDI benefits, and the four (16.6%) originally from Africa did not receive SSI/SSDI because they were also ineligible. Also, the majority of the women who received food

stamps (*N*=18; 75%) reported that it was because they were caregivers to their own

children/kin and because their income was low. There were a few women (*N*=5; 20%)

who also received Temporary Assistance Needy Families (TANF) benefits due to their

caregiving. Mary, who cares for her 12 year old niece, 27 year old son, 19 year old son,

and 14 year old daughter, said:

> Well, for me because of my status, it's the only reason why I can get money.
> Because I'm positive. If I wasn't positive, I wouldn't get TANF, because I work.

This suggests that the majority of women are knowledgeable about what types of federal

financial services they are eligible for due to their diagnosis, health care and/or personal

lifestyle needs.

Theme 4: Access to health care services and adherence

Access to health care services and coverage remains a contested topic in current

social welfare policies today, even after the Affordable Health Care for America Act

(H.R. 3962) passed and President Obama vowed to support HIV/AIDS treatment and

prevention efforts domestically with the development of the National HIV/AIDS Strategy

(NHAS) in 2010. In this study, all of the women received some type of health insurance,

the most common (*N*=13; 54%) being MassHealth, otherwise known as Medicaid.

MassHealth provides comprehensive health care services that include HIV/AIDS

medication, physician appointments, case management services, etc. Other types of state

health insurance these women had included: Neighborhood Health Plan (*N*=3; 12.5%),

and Boston Medical Center Health Net (*N*=1; 4%), which are both managed-care

organizations for MassHealth members. In addition to all twenty-four women having

some type of health insurance, five (21%) also had Medicare insurance along with their

MassHealth insurance, which pays for prescriptions and other medical expenses. Jane said:

> Yes, I have Medicare primary, and Medicaid as my back up. Well, it's MassHealth: Neighborhood Health Plan. It's my HMO under MassHealth and I'm in a special program under NHP called CMA Community Medical Management and they do, I have a visiting nurse from her. They do transportation, social work, mental health issues.

The four women (16.6%) who were originally from Africa, along with one (4%) other woman, who reported working part time, were the only women who had private insurance, in all cases Blue Cross Blue Shield of Massachusetts. One of these women stated, "I go to Boston Medical, there is a free care program and we have Blue Cross Blue Shield and they do co-payment for the HIV medication." The women stated there was a free health care program for PLWHA who have no health insurance at Boston Medical Center.

Still, while all of the women had health insurance, they accessed additional health care providers in addition to their primary care doctors, including specialty care physicians such as infectious disease doctors or cardiologists. In many instances, women had multiple health care providers at various agencies. Many of these agencies were the same community based agencies that work with PLWHA (Dimock, AIDS Action, and Boston Living Center) that they accessed for social and psychosocial support. Women talked openly about their ability to navigate their health care services and were particularly informed about the process, discussing the various case management services, counseling, therapy, and social service resources. Carol, who cares for her 10 year old niece, 16 year old son, 14 year old son, and 12 year old daughter who is a cancer survivor (ovarian and appendix) with sickle cell anemia and diabetes said:

> They know me too well, very well. I have a wonderful relationship with them. I

can talk to them about anything. They don't hold any punches back with me. My diabetic doctor, she tells me what I need to know, no matter how harsh it is. My counselor down at Roxbury Comp is working with me now to be able to sit down and talk to my kids because I'm in this mindset that I don't have to tell them. I'm not at a stage of my illness where they have to take care of me; I'm able to take of it on my own so why worry them with something they do not have to worry about.

Many of these organizations also provide resources to their kin in addition to their own health care needs. Patricia, who cares for her two-year-old grandson, said:

Yes, Boston Living Center they help with the grandkids, they help me get him into summer camp and they also help me get my other ones into overnight camp.

Interviewer: so they help provide the funds for that, so it's free?

Yeah, they do Christmas parties for them; they give them little vouchers to get what they want for Christmas. They help a lot. And, then, with the Living Center they have me connected to Nutrition Works and Nutrition Works, they give you a bag of meat, fresh vegetables, fresh fruit, juice, eggs, milk twice a week. They do that for us, so. It's good.

Interviewer: Nutrition Works you said? So, it's like a food pantry?

Uh huh, it's a food pantry for people who are HIV+.

As for their caregiving responsibilities, women explained that their kin also receive MassHealth insurance. There was no instance in which women said that their health care services negatively impacted their caregiving responsibilities. When describing her family's doctor, Candace said:

I love her, I absolutely adore her because she doesn't tell me what to do, we sit down and we discuss a plan together. Yeah, she asks me what I think would work and she takes it into consideration. She goes and she does her research and she'll come back to me you know as soon as she can. And, I mean like I said I don't disillusion myself I know she's swamped. There's a whole lot of people with this illness beside myself.

Ronda said:

Well, this is a new doctor I have, my primary care doctor, but she's been in my life since I was diagnosed and it's very good, you know I mean very good, I like to no, not joke around but I like to see people happy, smiling. So we have that

connection. And when it's time to get serious, we get serious, and I can't allow myself to be serious all the time because then, I'll just be a mess. I like to think I have a nice sense of humor.

Most of the challenges associated with these women's health care stem from changes in primary care doctors or lack of time to talk or interact with their physicians during visits. Megan said:

> They don't give you the time, you know what I mean, and, I don't know. You know, you can see I'm a very personable person. I don't want my doctor to just like throw like numbers at me or like, I just don't want to hear about my blood results. I want her to hear me and what I'm going through, period. You know, you know what I'm saying? The open communication isn't good. I'm just not comfortable with that. But, she has a big caseload but that's not my concern and, I'm processing it, but I will be changing primary care medical care and there's several options. I don't have to and I think more importantly is, I'm use to having a doctor that when I gets sick, it's not so much being well, but when I get sick, I want a doctor that I want to feel comfortable with pick up the phone knowing that I get her or she will return my calls and this doctor don't, she works with a team of doctors, so, the only time I get to see her talk to her is at visits, you know, and I'm not comfortable with that.

Not surprisingly, because these are midlife women, many had other health conditions in addition to their HIV/AIDS diagnosis, creating needs for additional health care services. These conditions include arthritis/osteoarthritis (N=6; 25%), high blood pressure (N=5; 20%), hepatitis C (N=5; 20%), cancer survivor (lung, thyroid, breast, ovarian) (N=4; 16%), diabetes (N=3; 12.5%), asthma (N=2; 8.3%), congestive heart failure (N=2; 8.3%), depression (N=2; 8.3%), kidney failure (N=1; 4%), and sickle cell anemia/sickle cell traits (N=2; 8.3%). Carol, 49, who cares for her own children under the age of 18 along with her niece, said:

> I been diagnosed with diabetes back in 2003. I have hypertension. But, I've gotten better. I don't scream and holler at my kids anymore, I've learned how to just sit back and take my medicine, take time out for me, and um, my kids, they got chores, they come in, they do their chores, they do their homework, then, they can go hang out.

Women explained that they were able to manage despite having other health care problems. Sylvia's story was especially moving because she shared how her life after cancer and knee replacement has helped her sobriety:

> Yeah, I wore it out to the fullest. Where now, I have had the full knee replacement, I had breast cancer, the left breast removed, where I had reconstructive surgery. So, with all that, after that, who the hell wants to go back out there? (She laughs) This keeps me from relapsing; do you hear what I'm saying? Yeah, God first and foremost. That was the scariest thing in my life when they told me I had breast cancer.

Ronda too, tells a similar experience:

> I'm also a cancer survivor, lung cancer in my left lung, it's in remission now.

> Interviewer: did you smoke?

> Yep, yes, I do, I know, I know, not as much though, you know, I'm also a recovering addict, so you know I dealt with a lot. I mean I don't drink anymore but I can't do everything at one time, you know, I've slowed down with my cigarettes tremendously, cause I was smoking like 2 packs a day.

> They also described seeing other specialty doctors for these needs regularly.

While the majority of these women (N=18; 75%) were taking their antiviral medications, they were also taking additional medications (heart medications, insulin, HBP+ medications, anti-depressants, etc.) in conjunction with their anti-viral medications suggesting they were proactive in seeking care and treatment. All of these women were adherent to their anti-viral medications except for one woman who chose instead to utilize homeopathic treatment. Megan, who was adamant about her medications, said:

> I'm adherent to my medication, you know what I'm saying, I, I, I'm real, which wasn't always the case but I mean now, 25 years of living with this disease I'm more focused now than ever, you know age gots a lot to do with it, I'm more mature, more knowledgeable and more connected I ah, I don't have the um, I've been working through the issues I use to have.

Theme 5: Belief in better options

Women were also asked to describe their lives today and how their health status living with HIV/AIDS affects their caregiving responsibilities and their daily lives (research question #2). In responses ranging from the general to the very specific, women overwhelmingly reported their ability to bounce back from their adversities in a positive way that emphasized their strengths and inner resources. Describing what resiliency meant for them and for their family included a broad range of ways they took control of their situation. These ways emphasized the women's strengths, inner resources, and beliefs that they have options.

In particular, when describing the process of finding new housing or locating other options to best meet their caregiving needs, women overwhelmingly described the situation in a positive manner. They discussed taking proactive steps to secure resources and additional funds to provide for themselves, their grandchildren, nieces, nephews, and, in some cases, also their own children who were living in the home. For example, the majority of women (N=19; 79%) felt that their current housing arrangement provided "adequate space." Of the remaining four (16%) who believed their housing arrangement was "overcrowded," two were in the process of moving into a larger place. In both of these instances, women talked openly their plans to move and about how they were able to secure a larger space for their family. Most of the women (N=11; 45.8%) live in only two bedroom apartments, followed by eight women (33.3%) in three bedroom apartments, four (16.6%) in one bedroom apartments, and one (4%) in a four bedroom apartment. Moreover, these women explained how they were able to help themselves and their family, demonstrating a resiliency defined by a process in which they continue to work towards improved circumstances. One woman stated:

I was granted my section 8 because the majority of the building is metropolitan housing, and it's only two units in the building that have Boston Housing—which is me and the other lady on the first floor—so we were able to get our section 8 to move, so I'm moving up on Bolden Ave.

While section 8 housing apartments were the only living arrangements for these women, some women found other ways to take control of their housing needs and make changes that would best benefit them. For example, four women resided in subsidized housing family arrangements because of their HIV/AIDS status through a program at Dimock Community Health Center in Roxbury, MA.

You have to go through Dimock Community Health Center through a lady name Miss ---, she's in charge of the program, or you have to be in women's transitional home, which, women have to be HIV positive or they need to be affected with the virus and they have to have children to be able to live there.

Other housing options included an adult/disabled subsidized housing apartment. It took one woman Jane, twelve years to secure this apartment, but she was adamant that she wanted to have more space to care for her grandson (her previous home was only a one-bedroom) and to accommodate her disability. Another woman, Helen (from Kenya) lives in a Young Men's Christian Association (YMCA) building that is almost completely subsidized (90%) and paid for by Cambridge Cares About AIDS because she is HIV+. She explains:

They call it single room occupancy.

Interviewer: And you rent?

Yes

Interviewer: And about how much is the rent?

Less than ten dollars a month.

She later clarifies:

Cambridge Care About Aids, they are the ones who actually supporting me in

housing; that is why I am in this place today. Cambridge Cares helps me in getting food, they give us food vouchers, I think it's every six months—things have changed since the budget cuts, we used to get them every other month, then. We have this nutrition supplement here, Ensure; we get it every month.

Another woman, Mary lives in a section-8 Shelter Care plus apartment:

I was in a shelter for 11 months waiting for a section 8, so, section 8 didn't come through but very few programs have this Shelter Care Plus and they can place clients out of the shelter and least put them in a home setting with their family.

Women also discussed in lengthy detail the plethora of agencies in the greater Boston area that provide resources for PLWHA. For example, one community based agency in particular (Cambridge Cares About AIDS) provides fuel vouchers in the winter in addition to subsidized housing for HIV/AIDS clients. In three separate instances (12.5%), women described how they benefited from fuel vouchers to help pay for their heat in the winter. One of these women, Megan, said:

Well, we get—AIDS Actions was funded and they were able to give us and help us with our utility bills for the past few years, and they gave us six hundred a year fuel assistance per year through Aids Action, five hundred per year through ABCD. So, we get a lot of help with AIDS Action. Isn't that wonderful? This is a special fund that they have, AIDS Action has, they have been doing that for the past three or four years.

Some of these same women also reported receiving vouchers to buy clothing at thrift stores or household items at Bed Bath & Beyond, going to food pantries to help offset the cost of groceries, and getting legal assistance to help with a health care proxy or living will because of their HIV/AIDS status. Helen shares her experience:

Cambridge Cares gets donations from Bed Bath & Beyond, so every month we are given an opportunity to select what we want, and most of my beddings you can see here and some of my household I have gotten through Cambridge Cares.

Surprisingly, some agencies also provide self-care management for their clients. Patricia said: "And, then, I go to um, get massages through Boston Living Center, I've got to get back into that, get massages and acupuncture." In a few instances, cab vouchers from

AIDS Action were also available for women to be transported to their counseling/health related appointments. Jenny described in detail the various vouchers and resources she accessed through one agency in particular, Cambridge Cares about AIDS:

> Cambridge Cares is more actively involved with, like I said with food vouchers, they help around housing too, like if you have needs around furniture in food, clothing, you know what I mean, they help you with personal needs, and also they have caseworkers on hand, If they can't help you, they refer you. And, they have some great support groups, they have a housing support group, they have an expressions support group, which you do arts and crafts, women's group, recovery group.

Similar to Jenny, Jane said:

> I use like the pantries in the area to make sure that my house has always has food in it, I have, like I said, I have medical transportation and I get that subsidized through AIDS Action. So, if I need to go to anything HIV related, doctors, psychologists, whatever, they pay for me to get there cause I'm a ride recipient, They just put money in my account and I go where I need to go, so I have that, I have delivered foods, I have a pharmacy that brings my medicine right to my door, yeah, they're in Boston but when I moved out here, and I ask them, is it fine for you to deliver my meds here and they said, "yeah, that's fine", so they FED EX me all my meds, so, I have a lot of resources, to keep me comfortable.

Mary said:

> So, if their wasn't programs like AIDS Action or Cambridge Cares where I could get gift cards once every 6 months to help me out especially for the holidays, I mean, I really struggle a lot, you know? I do, I struggle. I mean, I'm living check to check to make ends meet. They don't even know about my niece but because I have my two kids and myself they give me 70 dollars and gift cards so I'll get that for Christmas usually Thanksgiving and 70 dollars and that's my Thanksgiving meal and I usually can get a turkey from AIDS Action or Dimock so Thanksgiving my meal is given to me. You know what I mean? So, I make a good, you know, and I appreciate that cause that's a big time in the month that my family all comes together and we'll all here so, I only utilize that for Thanksgiving. Christmas, because that gives me that for Thanksgiving I can put that money away for Christmas.

These women also displayed resiliency through their participation in Consumer Advisory Boards (CABs). Four of the women (16%) mentioned that they were active in CABs. These CABs are an opportunity for PLWHA to become involved at the federal,

state, and local levels to effect change in their lives. While these organizations may have

varying missions and goals, CABs generally try to present community perspectives, in

these instances related to HIV/AIDS. CABs also assist various service providers to

develop strategies for measuring risk behavior and tactics for achieving community

support for future biomedical and behavioral studies (CAB Fenway Health, 2011). CAB

members can include representatives of AIDS service organizations, consumers, the

medical field, science, business, publishing, health administration, information

technology, and academics. Women in this study reported their involvement in CABs

because of their HIV/AIDS status and because they offered the voice for PLWHA.

Women in this study belong to CABs including Whittier Street, Saint Right, Justice

Resource Institute (JRI), and Community Research Initiative (CRI). Megan said:

> I'm on practically every agency I'm involved with, I'm on their board, so, if I feel
> there are anything changes, believe me, I speak on it. You know, so I'm actively
> involved that way so I can't really, you have, you have grievances, or whatever,
> you have negative about thoughts for changes you need to get involved. Just get
> involved, make it happened. Don't just talk about it. And you know and that's in
> the positive way because actually it's just my way of giving back. I mean the
> blessings are just unbelievable, they just been pouring in. I travel all over, you
> know: consumer advisory boards I'm on, they send me every other month to a
> different state or whatever and we speak and it's just awesome, awesome. It
> seems you know how people are living with this disease in different parts of the
> country you know it's amazing and the services that we're getting here opposed to
> other places, we're one of the best places to be medically cause I wanted to move
> out of Massachusetts but Massachusetts has the best, the best medical care, the
> most services around HIV, yeah, yeah.

Support groups also serve as a way for these women to describe their lives living

with the virus and caring for their grandchildren, nieces, or nephews, as well as their

beliefs in better options for their futures. Some women attended retreats as part of their

involvement in support groups, volunteering their time to make items, serve food, etc.

Jody said:

It's my second family, I would suggest anybody who have HIV and want help, go to ---. It's support. You get support, you get good information. I don't know what I would do without it. That's my life. I can't wait to every second Monday to go. Only time I don't go, if I'm sick or something happen. Even in the wintertime, I hop on the train and bus and go.

Helen said:

Cambridge Cares has gotten a peers spot where we have support groups, we have a women's group. There is a housing group. There is a drop in center at Cambridge Cares where you can go and relax, there is TV, computer where you can access internet and there is a phone where you can make calls, there is coffee all day long and tea and snacking then, once a month they have a luncheon and every Wednesdays once a week there's a breakfast, they have little trips every now and then where people go and just have fun.

Grace said:

That's where I go on every other Tuesday our women support we have. We change our places sometimes we have at Boston Living Center and sometimes it's over here. I get my support from the women that I facilitate and they get support from me. So, we get support from each other. And, most of the women we do have are HIV positive. So, it's a blessing for me to know I am not alone in this. I'm not. There are those that have a problem disclosing their status but there are those that do not have a problem. And, that's ok. I'm fine with that. Cause it took me a long time to say I am HIV positive.

All of the agencies women discussed were related to their HIV/AIDS diagnosis.

Some agencies also served to provide counseling, therapy, and case management

services. Carol said:

They know me too well, very well. I have a wonderful relationship with them. I can talk to them about anything. They don't hold any punches back with me. My diabetic doctor, she tells me what I need to know, no matter how harsh it is. My counselor down at Roxbury Comp is working with me now to be able to sit down and talk to my kids because I'm in this mindset that I don't have to tell them. I'm not at a stage of my illness where they have to take care of me; I'm able to take of it on my own so why worry them with something they do not have to worry about.

In thinking of their futures, these women wanted to achieve something oriented

towards making positive changes in their lives and for the future of their kin. They

viewed it in terms of their social supports and how they cope, in ways that emphasize

their own personal journeys and their own views of resiliency that made sense for them,

their futures and their children/kin. One woman said:

> My main goal was not to get a job, my main goal was to go back to school and get my GED. That was my first priority. That became now my third priority. My first priority now is to get to work every morning. Because I was on disability and I was fine taking disability. But after a while disability got uncomfortable because I was bored. Waiting for a nothing check watching TV and not having anything to do was not what I signed up for.

Mary said:

> I go to school in the evenings. I'm getting ready to get my LADC [Licensed Alcohol and Drug Counselor], do you know what that is?
>
> Interviewer: Yep.
>
> So, I'm doing that at UMass because you one thing with my niece being there, um she's company for my daughter, you know cause my son they go out. They do their own thing. They make sure my daughter's ok, but if they go out the house and they stay out all night, they stay out all night, but if my daughter comes home from school, she would normally be alone until I come home. But, if my niece being there, it would have each other so they have each other. I bought bunk beds for them to share a room together, so now they help each other with homework and stuff. So, it's good for them and it's good for my niece too because my niece doesn't have siblings that she can bond with but she has her cousin and they're really close now.

Grace said:

> All I worry is about my children. I don't worry about what my other family members know and care, I don't and my mom is ok with me. Even though she has a slight touch of Alzheimer's she knows who I am. She knows I am her daughter. And, I'm the crazy one in the bunch with uh, six living children and thirty odd something grandchildren. Like I said, my four children and my four grand children, I am more on point with them.

Theme 6: Benefits of HIV/AIDS status

HIV/AIDS status and the resulting ability to navigate and access services for

caregiving forms a central part of how these women understand their kinship

responsibilities, attitudes, beliefs, and perceptions for future services. Women discussed

openly what they receive because of their HIV/AIDS status and how their status provides

them with better resources and benefits than someone that does not live with the virus.

They are often frank and to the point, sharing the realities of what they have been able to

access due to their HIV/AIDS status. Their kinship responsibilities were secondary to

how they receive or access services. Everything about their situations related to their

kinship responsibilities, attitudes, or beliefs and perceptions were accessed because they

were living with HIV/AIDS. Ruth said:

> I probably get more help from my circumstances because I have HIV, more help than just if I was a single black mother without this condition. So, it's almost with my condition I get these like little gifts, and I get these little things. I mean, it's almost sad to say that, like because like I see the difference between me and my sister. Like she got her own kids and I got my kids. But, I see the things that I get and she's like, "oh, can I get that?" but she can't cause she don't have HIV. You know what I'm saying? So, mainly with benefits, and with the HIV I get more benefits. So, it's almost like, it's a good thing. It is what it is. And, I'm gonna take full advantage of it. I mean, I don't want to take advantage of it. It's there for me, why not use it?

Mary said:

> Dimock, they'll give me ten dollars bus pass a month, so that helps me out cause I usually give it to them [her children and niece] for the weekends when they go out and that helps me. You know anything that I can get, you know that I don't have to come out of my pocket you know, that can kind of put away for something else. I try to utilize, pretty much that's it. Dimock did help me when I moved, gave me 150 dollars for the movers so that helped and if like my light bill gets really high, they'll give me at least 200 dollars towards my light bill. You know and sometimes, I won't pay it because I know they'll give it to me anyways and that's more stuff that we could do. So, but, that's because of my status, you know and I feel bad about people who are in my position who don't have that access. You know what I mean? It's gotta be hard.

She later said:

> Well, for me because of my status, it's the only reason why I can get money. Because I'm positive, if I wasn't positive, I wouldn't get TANF, because I work. And again, they are only giving it to me for my daughter, now, I could add my niece but again that would bring complications financially for my sister. So, me and my sister keep bumping heads, what are you gonna do? What are you gonna do? You know, I'm taking care of her, well, I can always give you the money, I can go buy all the stuff, so that's what my sister go through.

Similarly, Megan said:

> As far as the services, I utilize everything that's available to me that's and not in an negative way, you know, like I said I give too, but you know, my feeling is if you don't participate, you know, don't use these services, I'm an advocate around getting people involved, so each agency I use for different reasons, you know, but I get my needs met.

Ronda said:

> Well of course Boston Medical, and Dimock Health Clinic because I do my support groups there for HIV and it's all women, my peers, services I get there, I can get a bus pass if I need it, you know, and mainly support from other women from Dimock, the women's center. They helped me a lot I go there, you can go through the Living Center, they do computer classes, jewelry classes, they have a food pantry which helps, they have a lot of support groups there but they're mostly like for gay and bisexual so, I don't really do my support groups there but I go through and they have lunch every day and then on Mondays and Wednesdays they have a dinner. So, if I'm hungry. What else? AIDS Action helps me with like housing if I need help with my fuel assistance, or if legal if I had any legal problems I can access all that through them, I have a lot of support groups there too, that I do.

Other women benefit financially from sharing their experiences of living with

HIV/AIDS to others. In some instances, women traveled outside of Massachusetts to

share their stories. Hannah said:

> I was getting paid 500 dollars for like 40 minutes and that included questions and answers. Twice, once up here and then I went to New York in Brooklyn, as a matter of fact… they'd put me up in a hotel. I had lobster, I had my son and his fiancé come out and hang out with me. I mean, it was just really nice.

Megan said:

> I travel all over you know, they send me every other month to a different state or whatever and we speak and it's just awesome, awesome. It seems you know how people are living with this disease in different parts of the country you know it's amazing and the services that we're getting here opposed to other places, we're one of the best places to be medically cause I wanted to move out of Massachusetts but Massachusetts has the best, the best medical care, the most services around HIV, yeah, yeah.

Summary

Overall, these themes present descriptive information about why midlife African American women living with HIV/AIDS who serve as informal kinship care providers access some services and not others in caring for their grandchildren, nieces, and/or nephews. The first research question—how does the provision of informal kinship care impact the social, financial, legal, psychosocial, and health needs of midlife African American women living with HIV/AIDS?—elicited themes including information about these women's extensive social/psychosocial support networks for services. These sources of support include their roles in their churches, their relationships with their pastors, their belief in God, and community based agencies. For others, their social/psychosocial support centers on both their personal and professional lives. Another salient theme is their ability to be proactive in seeking federal support for their HIV/AIDS and caregiving needs. All of the women are living in some type of subsidized housing and many also receive food stamps, TANF, and SSI/SSDI. Others are able to receive daycare assistance and some live in apartments that are completely subsidized because of their HIV status. Women discussed openly their ability to seek out resources from federal sources and how they utilize an array of health care services.

Their ability to access health care services and adhere to their health care needs is also a central theme. All of the women have some type of health insurance, and all but one are receiving and adhering to their anti-viral medications. For others, their resiliency could clearly be seen because in addition to their HIV status they also have other health issues and utilize additional health care providers for their care. Some of the older women receive Medicare in addition to MassHealth (i.e., Medicaid). Even the women who immigrated from Africa have free comprehensive health insurance coverage and are able

to access multiple health care providers and services for their caregiving needs. These women openly shared their ability to navigate an array of services successfully to meet their health care and caregiving needs.

Research question two addressed how these kinship care providers define resiliency and how their HIV/AIDS related health problems affect their caregiving responsibilities and their daily lives. The women discussed their beliefs that there are better options for the future and for their kin, as well as the benefits they receive due to their HIV+ status. While the majority of women do not work, they do receive SSI/SSDI. Many of them want to do more for themselves (e.g., get a job, provide a better life for their grandchildren or nieces/nephews). Others commented on the process of finding new housing, and what they needed to do to locate other options to best meet their caregiving and health care needs. These women were taking proactive steps to secure resources and additional funds to provide for themselves, their grandchildren, their nieces, and/or nephews.

In some cases, women also had the added responsibility of caring for their own children who were also living in the home, while others were involved in CABs that provided them the opportunity to share their stories and experiences of living with HIV/AIDS to others. Others talked about how they received money to talk about their experiences in public venues. Women recognized how they receive benefits due to their HIV/AIDS status. They shared their ability to get gift cards for themselves and their grandchildren/nieces/nephews, fuel assistance, utility assistance, daycare assistance, cab vouchers, gift cards for Bed Bath & Beyond, food pantries, and other special perks all because of their HIV/AIDS status. It was interesting to learn that these special benefits

were due to their HIV/AIDS status and not because they are caregivers. The benefits they described were all a positive thing for them and they were aware of how to access and utilize additional benefits if needed.

When they discussed resources for caregiving, they shared negative perspectives of child welfare services. Women overwhelmingly discussed their experiences with child welfare in an unenthusiastic manner. As Carol stated, "They're nosey, scandalous, and sneaky." The women felt that the agency was not helpful to them, and that its purpose was not about supporting or keeping families together.

Finally, the utility and relevance of the resiliency conceptual framework which guided the study should also be highlighted. As previously mentioned, midlife years for women include additional challenges such as marriage, motherhood, aging (e.g., issues related to menopause), racism, co-morbid trajectories (heart disease, diabetes, high blood pressure, etc.,) as well as accessing health care (Peterson & Duncan, 2007; Stephens et al., 2008; Collins, 2005; Palmer et al., 2003; Im et al. 2010). While these are risk factors for many of the women in this study, many protective factors, social supports, and coping mechanisms were also highlighted. This resiliency model provides a way to design and implement programming and health care delivery models for this population that highlights their complexities and experiences. It calls for policy makers, researchers, health care providers, and child welfare workers to recognize and understand how women with multiple complexities, like the participants in this study, are able to overcome significant adversities and challenges in their lives and positively adapt to their circumstances (Luthar, 2003). More importantly, it provides a framework for better conceptualizing how caregiving affects these women's kinship responsibilities as well as

their specific attitudes, beliefs, and perceptions in ways that facilitate, support, enhance, or impede their preferences and demands for future services. In other words, this framework can serve as a tool to help understand in what areas midlife African American women who serve as informal kinship care providers can improve in their health and wellbeing while living with HIV/AIDS in a way that emphasizes their strengths and inner resources. As such, it is a valuable tool in practice and research settings. The next chapter will discuss implications for future research and the limitations of the present study.

Chapter 5: Implications and Recommendations for Future Research

Despite the fact that these women all receive health care benefits and utilize

services for their health care and caregiving needs, the recent prevalence statistics for

HIV+ African Americans are still bleak, and it remains critical for clinicians, child

welfare workers, health care providers, and researchers to assess the needs of this unique

population. HIV/AIDS affects a large number of people, with an estimated 1 million

people in the U.S. infected and one in five (21%) unaware of their infection (CDC, 2010).

While the Obama administration continues to support HIV/AIDS education and research

domestically, this crisis continues to disproportionately affect African Americans

nationwide, compounded by problems in health care delivery (CDC, 2010a). Statistics

from 2009, based on the results from 37 states, indicate that among newly infected HIV+

women, African American women accounted for 64%, while Latinas (18%) and Whites

(15%) accounted for a smaller proportion of new infections (CDC, 2009b; Kaiser, 2011).

According to a recent study, more than 2.6 million grandparents are raising 2.5

million children (Livingston & Parker, 2010). In Massachusetts, among the 1.5 million

children under the age of 18 living in family households in 2000, an estimated 54,000

children (3.5%) lived in a kinship care setting (Mutchler, Gottlieb, Choi, & Bruce, 2002).

Furthermore, as previously mentioned, there has been an abundance of research on

HIV/AIDS in African American communities, as well as on kinship care among African

Americans, but little research addresses these two populations simultaneously.

Systematically, multi-level interventions should be developed at the local, state,

and national levels to specifically address the needs of this population. In particular, child

welfare organizations at all levels need to become aware of these women's lives and their

unique situations in order to help foster collaborative and successful programs that fit their needs. African American children continue to be disproportionately represented in the child welfare system (McRoy, 2005; 2008). The difficulty in identifying causal factors of disproportionality often leads to inaction and consequently to inappropriate uses of resources in child welfare (Cross, 2008). Moreover, many of the women shared negative views of the child welfare system, and many do not access or utilize these services. Additional child welfare training at the national level that addresses the cultural and health differences encompassing this population could prove helpful. Such training would have to target the complex needs of these women, which often exceed those of the majority of kinship care providers and other clients assisted by child welfare professionals.

As such, these trainings could specifically focus on the recent Fostering Connections to Success and Increasing Adoptions Act of 2008. This act connects and supports relative caregivers, seeks to improve outcomes for children in foster care, provides for tribal foster care and adoption access, and provides better incentives for adoption. States are required to identify and contact grandparents and relatives of a child within 30 days after a child is removed from his/her home. More importantly, states are able to waive licensing standards for relatives on a case-by-case basis in order to eliminate obstacles to placing children with their relatives.

By providing kinship guardianship assistance payments under the Title IV-E funds, this act also helps relative caregivers to become actively involved in a child's care from the time such care begins. In the past, approximately a quarter of all children in kinship care families received either a child-only grant or foster care payment (Ehrle & Green,

2002). Children are also automatically eligible for Medicaid. Families are eligible for additional services such as the Supplemental Nutrition Assistance Program (formerly known as the Food Stamps Program), housing assistance, fuel assistance, and childcare assistance (Children's Defense Fund, 2010). Specifically, many of these women would be eligible funds through the Kinship Navigator programs (e.g., Family Connection grants), which can help children living with their relatives gain access to supports and assistance they need, especially since none of the women in this study knew about this legislation.

More kinship care policies along the lines of the 2008 law might also need to be discussed locally and nationally with current recipients to help change the negative attitudes that the majority of the women in this study have towards the child welfare system. Concrete examples would also help to publicize the benefits of this new legislation. While changing overall perspectives about child welfare will most likely be challenging, information dissemination may prove beneficial in facilitating change.

Another area of concern is health care policy. In 2010, President Obama introduced the National HIV/AIDS Strategy (NHAS). This, the first comprehensive HIV/AIDS plan for all Americans, provides clear and measurable targets to be achieved by 2015: (1) reducing new HIV infections, (2) increasing access to care and improving health outcomes for people living with HIV, (3) reducing HIV-related disparities and health inequities, and (4) achieving a more coordinated national response to the HIV epidemic (CDC, 2010b). The Obama Administration vowed to provide 25 million dollars to states that have waiting lists for their AIDS Drug Assistance Programs, and to offer treatment to the uninsured and underinsured. Specifically, by 2015 there should be an increase in the proportion of Ryan White HIV/AIDS Program clients who are in

continuous care (at least 2 visits for routine HIV medical care in 12 months at least 3 months apart) from 73% to 80% and increase the number of Ryan White clients with permanent housing from 82% to 86% (CDC, 2010b). This ambitious National HIV/AIDS strategy requires strong commitment from the federal government, as well as state and local agencies.

Since Massachusetts is currently the only state that has a comprehensive health care system, with the result that everyone in this study has health care coverage, the question remains of what lessons and practices can be replicated in other cities and states across the country that would further support and enhance the needs of this population. Moreover, if such policies exist in other states, could they be replicated in yet other states? The implementation and health care treatment for PLWHA with the passage of the recent Affordable Care Act legislation and Vermont's recent universal health care plan is yet to be known. More information on the specific requirements that provided the four women with comprehensive and free health care treatment from a private insurance coverage (Blue Cross Blue Shield of Massachusetts) may prove helpful for future studies.

Investigation revealed that the Massachusetts HIV Drug Assistance Program (HDAP) pays the Blue Cross Blue Shield of Massachusetts health care premiums for these four women. Designed to provide access to medications to HIV+ clients, HDAP is among the nation's most complete drug assistance programs for people living with HIV. It pays for medications and drug co-pays, private non-group health insurance premiums and premium co-pays, HIV resistance testing (genotype and virtual phenotype lab tests), and post-exposure prophylaxis (PEP) for potential non-occupational exposures to HIV (CRINE, 2011). By law, HDAP is a "payer of last resort"; this means that program

enrollees must show that they have applied to other entitlement programs (e.g., Medicaid/MassHealth, Medicare, etc.) at the time of their HDAP application. Undocumented Massachusetts residents are eligible for HDAP (CRINE, 2011).

Similarly, MassHealth's policy for persons living with HIV/AIDS is comprehensive. MassHealth (i.e., Medicaid) covers health care benefits such as doctor visits, medications, lab tests, mental health services, substance abuse treatment services, hospital stays, dentists, eyeglasses, and smoking cessation services (MassHealth, 2011). To be eligible for MassHealth, monthly incomes must be less than $2,452 for a family of two, less than $3,089 for a family of three, and less than $3,725 for a family of four (MassHealth, 2011). Among the women in this study, all of their incomes met MassHealth's requirements. In addition, MassHealth recipients receive support services through AIDS Action; these include transportation costs to health care providers, childcare, management of daily medications, and case management services. Clearly, the women in this study lived with HIV/AIDS and some had additional health challenges but were able to access multiple health care providers.

Moreover, it is critical for clinicians, child welfare professionals, and health care professionals to be able to apply such findings to their practice. In particular, the health care model in Massachusetts involves using community based HIV/AIDS health agencies to provide comprehensive health care services that include primary care, counseling, case management, etc. More communities throughout the country should provide similar services and perhaps involve women with other community based providers that could lead to "action" prevention programs (DeMarco & Johnsen, 2003). For example, in rural communities or areas that are less educated than Boston, women's ability to access

services may look quite different, and the scope of programs and resources may be much more limited. Future studies that compare such differences and similarities may indicate the scope of services and needs at a national level. Just as the literature suggests that African American women living with HIV/AIDS experience multiple stressors and lack service providers to assist in their needs (Altschuler et al., 2008; Ehrle & Greene, 2002; Newton & Stewart, 2010; Peterson & Duncan, 2007, Pecora et al., 2009), this study indicates that these grandmothers and aunts experience the same stressors even with their HIV/AIDS status but also that they accept their situations, work towards accessing services, and adhere to treatment. These women have a strong social and psychosocial community and are actively involved in a variety of programs and services. Their resiliency reflects a proactive approach to their care. They have a positive outlook on their situation. If a future study were conducted in a rural or different region in the United States where fewer services were available, these women's resiliency might look quite different.

Limitations of study

The present study sheds some light on middle-aged, primarily single, low-income African American women with HIV/AIDS who are raising their kin. It indicates that many of these women believe in a better future despite their complex lives. It is unclear from this study how many of these women's experiences were impacted by their race and/or ethnicity, urban environment, socioeconomic status, or a combination of these factors. It is also unclear if women from different geographical regions in the U.S. would have similar and/or dissimilar experiences. But, since the women were all from Boston, it does explain why these women were able to access and receive such comprehensive

health care services for their HIV/AIDS which may not be the case in many other cities in the U.S.

This dissertation study was also conducted on the assumption that research findings on this population of women in particular could assist future efforts in the design, implementation of programs and policies for this population. Further, it assumed that the women participating in this study had an interest in sharing their knowledge, experiences, attitudes, and beliefs about living with HIV/AIDS and caring for their grandchildren, nieces, or nephews. As such, the participant base consisted solely of midlife African American women living with HIV/AIDS who were also serving as informal kinship care providers. Further, the study included only women in the greater Boston, MA who were recruited with the assistance of a community based HIV/AIDS agency that serves only women of color (homogeneous sample) in the greater Boston, MA area. There was no comparison group with women from other ethnic groups or who live in other regions or, specifically in rural areas within the U.S.

Unfortunately, during the screening process of selecting participants, Latino and/or Hispanic women contacted the researcher in hopes that they, too, could share their stories and experiences of living with HIV/AIDS and providing care for their grandchildren, nieces, or nephews. While this study has provided an opportunity to share the unique lives of midlife African American women living with HIV/AIDS, other women of color were not included. Similar research is needed on other racial and ethnic groups of women in order to gain more insight into cultural differences and much more rich descriptions of similarities and differences of living with HIV/AIDS and the role of caregiving.

The research reimbursement of $10.00 and not requiring women to "show proof" of their HIV status could have enticed women to participate who might have not been HIV+. It is unknown if any of the women participated in the study were not HIV positive.

The research design for this dissertation also posed challenges. As the study progressed, some questions were altered and or omitted, meaning that not all questions were asked to all of the women. For example, some of the women at the onset of the interview described how they were diagnosed with HIV/AIDS and their life living with HIV/AIDS, while others talked more openly at the beginning of the interview their caregiving role. This allowed for the women to dictate the flow of the interview, thus not abiding strictly to the interview protocol. Those that were asked questions were not asked in identical ways and this allowed the women to dictate the tone of the interview. This is nearly always the case in semi-structured interviews, as it is assumed that no participants may find the same experience significant or they may attach different meanings to the same experiences, raising questions of validity. As such, thick descriptions of each women's story allowed for the flow of each interview to be decided upon by the woman and not the interviewer. At the end of each interview, the interviewer allowed for the woman to ask or expand on anything that was not covered in the interview protocol.

The researcher also acknowledges that being an African American woman herself may have hindered efforts to understand issues such as their health care needs, lack of access or challenges in child care, accessing resources in general because these women may assume the researcher already understands these issues. Consequently, being an insider may not yield as much information as that of an outsider. However, being a

person of color (i.e. insider), the researcher may more likely understand the their plight and be more empathetic to their stories than that of an outsider.

In addition, all of the women in this study had the privilege of receiving medication and comprehensive health care services for their HIV status. Massachusetts is the only state with universal health care and thus generalizations of such findings are limited. None of the women discussed difficulties in accessing their antiviral medications, seeking health care providers, and/or case managers for their HIV diagnosis. Further, while it is true that in some states PLWHA wait months to receive care, this is not the case in Massachusetts. Further, the stories and experiences of caseworkers, other family members, health care providers, etc. were not included in this study. Including such stories could further demonstrate the encompassing effects of HIV/AIDS and the systemic needs within kinship care and health policy research. Future research should additionally involve these groups as well as grandfathers or uncles to explore their experiences and provide a deeper understanding of diversity within the family unit.

In the end, this study of midlife African American women living with HIV/AIDS who serve as informal kinship care providers offers findings that contribute not only to social work but also to health care, child welfare, and social policy development. The future outlook of kinship care and the impact of statewide policies on these women are also unknown. Unless more education and training is provided to inform these women, in ways that address their negative experiences with child welfare, what services they could access for their caregiving needs their perceptions will most likely remain the same.

Chapter 6: Conclusions

African American women living with HIV/AIDS continues to be a public health crisis in the U.S. (CDC, 2010a). Among newly affected HIV women, African Americans account for 64%, while Latinas (18%) and whites (15%) account for a smaller proportion of new infections (Kaiser, 2011). Kinship care in African American families continues to be the most common type of caregiving, and economic hardship is common. The goal of this dissertation is to increase the understanding of the complexities that midlife African American women living with HIV/AIDS who serve as informal kinship care providers face in their lives. Women shared important issues in ways that help to better understand the African American community, as discussed in the literature review and supported by the data. These women provided extensive information concerning their lives with HIV, their caregiving needs and experiences, and their resiliency. They exhibited remarkable strength in confronting their challenges. It is critical for social work researchers, child welfare providers, policy makers, and others working with midlife African American women living with HIV/AIDS to understand the complexities that these women experience.

Methodology

Qualitative description (QD) was the primary methodology that guided the activities of the study. This approach encouraged the "rich subject information regarding health-related concerns and issues" as well as a means for "critical information for crafting new or refining existing interventions, and for furthering program development" (Sullivan-Bolyai et al., 2005, p. 129). This approach differs from other more common approaches (phenomenology, grounded theory, ethnography) in that it seeks to strictly

adhere to the description of the "interpretation that is low-inference" (Sandelowski, 2000, p. 335).

Findings and Discussion

The findings present the individual testimonies of the women in their lives regarding their own resiliency living with HIV/AIDS and providing care for their kin. The themes presented are those that expand the understanding and knowledge of the issues reflected in the research questions. The themes emerged from the data. Living with HIV/AIDS while also serving as informal kinship care providers makes these women's lives complex. They provided comprehensive definitions of resiliency, describing how they were able to cope with their circumstances and the processes by which they accessed services. Despite how long they cared for their kin, the circumstances that led to their caregiving roles focused on the supports and positive aspects of their lives. The findings reveal that these women consult multiple health care and community service treatment providers and receive many services due to their HIV/AIDS diagnoses. The results further suggest that these women receive extensive social and psychosocial support that includes health care services, community based services, and federal services. Such services include transportation to medical appointments, visits with physicians (including specialists), fuel assistance, and case management services as well as housing, daycare assistance, and funds to support their caregiving needs (including food vouchers, access to food pantries, clothing for their kin, and gift cards during the holidays).

More importantly, women saw their lives positively and described better futures for themselves and their grandchildren, nieces, and/or nephews. While more than half of the women's incomes were below the poverty line, despite their being educated, they had

made future plans for their caregiving. Many had been living with the virus for many

years and some had other health concerns, but they did not discuss their health status

living with HIV/AIDS and/or their other health issues at length. Instead, they shared how

they were able to access resources and how extensive their support networks were.

Indeed, these women had resiliency.

Moreover, it is critical for researchers, child welfare providers, health care

providers, policy makers, and others working with midlife African American women

living with HIV/AIDS to understand the complexities these women experience. Further,

this dissertation study was undertaken not for the sole purpose of publishing results and

completing a doctoral degree, but rather with the hope of using the findings to improve

the health and wellbeing of these women and to help the service providers who work with

these women gain an improved understanding their daily lives.

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Appendix A: Resiliency Model

Protective Factors	Risk Factors	Social Supports	Coping
Easy-going temperament, intellectual/scholastic competence, positive self-concept	Age, caring for their own children, worries of their own children (incarnation, drugs) caring for their relative's children, lack of familial support	Strong familial ties, friends, community, neighborhood, church	Seeking social supports (family, community, neighborhood, social service agencies/health care providers, religious leaders)
Strong familial ties (support from husband/partner, extended family), racial socialization religion/spirituality/ attending church/prayer	Fear of death, limited income/poverty/ unemployed, experiencing racism and/or discrimination, stigma associated with being HIV+, fear of disclosure	Having a positive, caring relationship with another person(s), agency, organization	Religion/spirituality/ attending church/prayer
Accessibility and availability with AIDS service organizations, health and social service agencies, food pantry, child welfare, etc.	Health care disparities, poor health (e.g., co-morbidity with other chronic health and/or mental health conditions –heart disease, diabetes, hypertension, depression, anxiety), inability to access resources (health care, anti-viral medication, child welfare), poor communication with physicians	Being involved in social network of extended family members, friends, neighbors, church members	Participation in support groups, community based organizations
Good health, interest in grandchildren/nieces/ nephews education	Violence in neighborhood/community, unsafe living conditions, engaging in risky sexual behaviors, substance abuse	Seeking resources in community (social services, health care, therapy/counseling, church, HIV/AIDS organizations, food pantry, child welfare)	Role of health care providers and child welfare professionals in seeking additional resources/services, acceptance of situation/optimism in life/future

Appendix B: Project Timeline

Defend proposal	April 15, 2010
Submission to IRB *Approval of IRB:*	April 2010
Begin data collection:	April 2010
Complete data collection:	August 2011
Complete 1ˢᵗ phase of data analysis:	September 2011
Complete writing *literature review chapter:*	September 2011
Complete data analysis:	October 2011
Complete first draft of dissertation:	November 2011
Defend dissertation:	December 2011

Appendix C: Steps to Ensure Validity/Rigor of Findings

Triangulation	Different data sources (observations, interviews) of information	Theory triangulation- use of multiple theories or perspectives to interpret a single set of data Data triangulation- use of more than one data source (Denzin, 1978)
"Thick description"	Rich, detailed descriptions	Step into the shoes of participants," feeling at "gut level"
Present negative & discrepant information	Discussion of contrary information adds to the credibility of the reader	Ensures trustworthiness, researcher develops sensitivity, empathy, carefulness, respect
Peer debriefing	Dissertation chair & dissertation committee reviews and asks questions about the study	Reduces researcher bias
Reflexivity	Self-awareness, keeping a journal, field notebook, writing frequent memos	Recognize the influence research has on researcher & research is having upon the researcher, reduces bias

Adapted from Creswell (2009). Research design: Qualitative, quantitative, and mixed methods approaches
Guba, E.G. & Lincoln, Y.S. (1989). Fourth generation evaluation. Newbury Park, CA: Sage.
Corbin & Strauss, (2008). Basics of qualitative research 3e.

Appendix D: Flyer

Boston College
Understanding the Experiences of African American Women Living with HIV/AIDS
as Informal Kinship Care Providers

If you are an African American Woman living with HIV/AIDS, **who is** also caring for your grandchildren and/or nieces and/or nephews and NOT receiving financial assistance for their care, **we would like to hear about your experiences.**

If you qualify for participation and wish to share your experiences, **You Will Receive Compensation for your time $10.00.** The findings from this study will help others in the future. It is unlikely that you will receive either direct benefit or experience significant risk for participating.

Expectation: All you have to do is to participate in one brief (45 minutes to an hour) interview about your experiences parenting. We are especially interested in learning how your health affects your parenting responsibilities.

How can I set up an interview: If you or anyone you know might be interested in being interviewed, or just want more information on the study, please contact Ms. Charu Stokes at the following address:

Charu Stokes, MSW, PhD student
Boston College Graduate School of Social Work
UUUUstokesca@bc.edu
617-694-9842

Appendix E: Consent Form

Boston College Adult Consent Form

Boston College Graduate School of Social Work
Informed Consent for Participation in Understanding the Experiences of African American Women Living with HIV/AIDS as Informal Kinship Care Providers
Researcher: Charu Stokes

Introduction
- You are being asked to be in a research study of African American women living with HIV/AIDS caring for their grandchild(ren)/niece(s)/nephew(s)
- You were selected as a possible participant because you are of African American woman living with HIV/AIDS and live in the Greater Boston area
- I ask that you read this form and ask any questions that you may have before agreeing to be in the study.

Purpose of Study:
- The purpose of this study is to explore the ways African American women living with HIV/AIDS experience their lives as caregivers for their grandchild(ren)/niece(s)/nephew(s)
- The total number of subjects is expected to be 30 African American women.

Description of the Study Procedures:
- If you agree to be in this study, we would ask you to do the following things: give consent for participation and agree to be interviewed for 45 minutes to one hour total at one time only at Women of Color Aids Council (WCAC) at Dorchester, MA. Both the consent form process and interviews will be conducted at WCAC.

Risks/Discomforts of Being in the Study:
- The study may include risks that are unknown at this time
- Since personal questions are asked
- You may find a question to be emotionally upsetting
- Uncomfortable interactional patterns may develop
- You may also not want to discuss some topics with someone you do not know

Benefits of Being in the Study:

- The purpose of the study is stated above; to explore the experiences of African American women living with HIV/AIDS experience their lives as caregivers for their grandchild(ren)/niece(s)/nephew(s)
- There are no expected benefits of participation in this study.

Payments:
- You will receive $10.00 as a token of appreciation and remuneration for your time.

Costs:
- There is no cost to you to participate in this research study.

Confidentiality:
- The records of this study will be kept private. In any sort of report we may publish, we will not include any information that will make it possible to identify a participant. Research records will be kept in a locked file.
- All electronic information will be coded and secured using a password-protected file. The audiotapes will be accessed only by this researcher and will also be transcribed only by the researcher.
- Access to the records will be limited to the researcher; however, please note that if applicable sponsors or funding agencies regulatory agencies, and the Institutional Review Board and internal Boston College auditors may review the research records.

Voluntary Participation/Withdrawal:
- Your participation is voluntary. If you choose not to participate, it will not affect your current or future relations with the University Women of Color Aids Council (WCAC)/SISTAH POWAH
- You are free to withdraw at any time, for whatever reason and will receive a $5.00 compensation for your time.
- There is no penalty or loss of benefits for not taking part or for stopping your participation.

Dismissal From the Study:
- The researcher may withdraw the participant at any time (i.e. when it is in the participant's best interests, there is a failure to comply with study requirements)

Compensation for Injury:
- If you experience an emergency medical problem or injury as a direct result of your participation in this research, the interview will be immediately stopped for you to be able to address your needs. Referral to mental health resources can be made available if the questions cause emotional distress.

Contacts and Questions:
- The researcher conducting this study is Charu Stokes. For questions or more information concerning this research you may contact her at 617-694-9842 or stokesca@bc.edu.

- If you believe you may have suffered a research related injury, contact Ruth McRoy, PhD, Publishable Paper/Dissertation Chair, at 617-552-4362 or mcroy@bc.edu who will give you further instructions.
- If you have any questions about your rights as a research subject, you may contact: Director, Office for Research Protections, Boston College at 617-552-4778, or irb@bc.edu

Copy of Consent Form:
- You will be given a copy of this form to keep for your records and future reference.

Statement of Consent:
- I have read (or have had read to me) the contents of this consent form and have been encouraged to ask questions. I have received answers to my questions. I give my consent to participate in this study. I have received a copy of this form.

Signatures/Dates

Study Participant (Print Name): _____

Participant's Signature: _____ Date _____

Researcher's Signature: _____ Date _____

Appendix F: Semi-structured Qualitative Interview Guide

Demographics   ID_____

Relative Kinship Family Member

What is your age? ___

Marital Status
Married_____ Divorced____ Widowed____ Single_____ Separated__ Living with
Partner____
Total years of education__ less than high school ____ Completed high school/received
GED__ Attended college____ Completed 2 year degree/vocational program___
Completed 4 year degree____ Completed graduate degree____
Number of children in the household___ and their ages?____
Number of other adults living in household____and their ages?___
Number of rooms in house____
# of bedrooms____
Do you feel overcrowded? ____
What type of neighborhood do you reside in? (urban, suburban, rural?)
How would you describe the level of safety in your neighborhood?

Work Status
Full-Time Employed_____ Part-Time Employed_____ Retired_____
Disabled ____ Unemployed ____Occupation if working_____
___# of other people working in household Are they working? (FT, PT, per diem)

How many health care providers, relatives, or friends give you practical, informational, or
emotional support in helping you living with HIV/AIDS (such as loaning money, taking
care of you if you don't feel well, providing help in an emergency)?_____

On a scale of 1-10, 10 being the most support, circle how much does this group (health
care providers) give you practical, informational, or emotional support?
1   2   3   4   5   6   7   8   9   10

On a scale of 1-10, 10 being the most support, circle how much does this group
(relatives) give you practical, informational, or emotional support?
1   2   3   4   5   6   7   8   9   10

On a scale of 1-10, 10 being the most support, circle how much does this group (friends)
give you practical, informational, or emotional support?
1   2   3   4   5   6   7   8   9   10

Health Care Status
Type of health care
MassHealth__ Private Insurance (BCBS, Aetna) __ Medicare__ Uninsured__

Total Household Income
10,000 or below___ 10,000-20,000___ 20,000-30,000___ 30,000-40,000___40,000-50,000+___

Other Financial Resources
Do you receive Supplemental Security Income (SSI), Supplemental Security Disability Income (SSDI), food stamps, heating assistance, Temporary Assistance to Needy Families (TANF) or any other federal/state/community based assistance (e.g., food emergency from a food pantry, free meals for attending HIV/AIDS support groups, Supplemental Assistance with rent/housing, transportation services, personal care AIDE for chronic health care needs?)

If so, what do you receive and about how much do you receive monthly? ___
Do you also have a regular caseworker? __ (health, counseling, support, HIV/AIDS, housing)
Are you in a counseling/therapeutic relationship with a professional? ___
Case management from a professional? ___
Advanced practice nurse, psychiatrist? __
Where do you access your HIV care?
How often to you see him/her? ___

Living Arrangement
house___ own__ rent__
apartment__condo__ own__ rent__ other__
Total number of relative children you are parenting ____ Male___ Female___
Age ___ Gender___
___ ___
___ ___
Are you also caring for your own birth children? ____
How many children do you have? ____
Are you parenting your daughter's children? Yes___ No___
Are you parenting your son's children? Yes___ No___
What is the age of the children's mother (your daughter?)___
What is the age of the children's father (your son?)____
Has anyone else taken care of these children when they were young? Yes__ No___
If yes, whom? ___
How many years/months have you cared for your grandchildren? ____
Do any of the children you are caring for now have special needs? ____
If so, what are they? (E.g., learning disabled, health care issues, behavioral problems at school, IEP?)

**Qualitative Data Collection Instrument-
Interview Protocol**

Ok, now I am going to ask you a few questions related to your health status as a woman living with HIV/AIDS and your experiences caring for your grandchildren/nieces/nephews.

Health Status

1. When were you diagnosed with HIV/AIDS?

2. How old were you at the time?

3. How did you contract HIV/AIDS? (e.g., prostitution, IV drug user, from spouse/partner, blood transfusion)

4. How did you react to your diagnoses?

5. How would you describe your life today living with HIV/AIDS?

6. What medications are you currently taking?

7. How would you describe your reaction to these medications?

8. Are you taking any other medication regularly?

9. What (if any) other health care issues are you facing? (e.g., diabetes, heart disease, etc.)

10. What types of health services are you utilizing? (e.g., primary care physician, cardiologist, counselor, physical therapist, etc.)

11. Would you say you see your health care service providers regularly? Why or Why not?

12. How would you describe your relationship with your health care providers?

13. How has your health care needs affected your caregiving of your grandchildren/nieces/nephews?

14. What has been successful?

15. What would you like to see changed?

16. What are some of the biggest health care challenges you have faced?

Relationship with Grandchildren/Nieces/Nephews/Own child
1. How long have you been caring for your grandchildren/nieces/nephews?

2. What circumstances led to the child(ren) being placed with you.

3. Would you describe this arrangement as temporary or permanent? Can you explain this more?

4. How would you describe your relationship with your son or daughter? (sister/brother if caring for niece/nephew)

5. Have he/she been supportive of you providing care for their children? Can you tell me about it?

6. If not, what is the relationship like?

7. What is the likelihood they will take the children back? Under what circumstances might this occur?

8. How do you feel about this?

9. What would you like to have happen with the children?

10. What are your biggest concerns about the children, should something happen to you—need more health care, become very ill, etc.?

11. Who will take care of the children if something should happen to you?

12. Has your daughter or son expressed concern about your being able to care for the children due to your health issues?

Impact on Your Life

1. How has your decision to provide kinship care affected you? (e.g., income, future goals, relationship with your children, education, free time, community involvement, independence, financially?

2. Tell me about some of the major challenges? (Probe: financial, time, space, etc.)

3. How about sacrifices?

4. In all, what are your thoughts about being the primary caretaker?

5. Have you explored who would care for these children if you were to become too ill?

6. Have you accessed or explored receiving any child welfare resources?

7. Do you know about resources available to you if you became licensed as a foster parent or became a legal guardian?

8. If yes, what resources in particular? Guardianship subsidies? How this experience been positive? Negative?

9. If not, tell me about your general experience/perceptions with Department of Children and Families (DCF)?

10. What about adopting the child (ren)? Would you consider this option? Or applying and receiving assistance payments?

11. If not, what are some of the challenges and fears you have concerning this?

12. What led to your decision to not access formal services through them?

Identification of Supports/Resources

1. What community resources, individuals, or groups have been helpful for you? (e.g., churches, support groups, other community-based agencies)

2. How have they been helpful?

3. Are there other family members that help?

4. Tell me about these experiences

5. Are there specific ways that individuals, groups, or resources could be more helpful or useful?

6. What would you like to see differently?

I appreciate all the information you have shared with me so far, and before we finish, I would like for offer you the opportunity to share with me any other information you think is important that we did not discuss.

Ok, these are all the questions I have for you. THANK YOU for your participation.

Appendix G: Data

Table 1

Sociodemographic Information by Participant

	Age	Year of HIV/AIDS Diagnosis	Current Relationship Status	Education	Current Work Status	Job	Kin	Total Yearly Income
Interview #1 Jacqueline	49	1990	Single	Master's	Full-time	Case Manager	Granddaughter	40,000-50,000
Interview #2 Erin	34	2004	Single	3 years college	Unemployed	None, but applying for SSI	Niece, nephew	<10,000
Interview #3 Hannah	64	1997	Widowed	3 years college	Self-employed	SSI	Grandson	<10,000
Interview #4 Tanesha	45	1997	Single	1 ½ years college	Unemployed	SSI	Niece	10,000-20,000
Interview #5 Ruth	41	1990	Single	GED	Unemployed	SSI	Niece	<10,000
Interview #6 Candace	47	1995	Widowed	2 years college	Unemployed	None, but applying for SSI	Grandson	<10,000
Interview #7 Abigail	52	2003	Widowed	Graduated HS	Unemployed	None	Niece, nephew	<10,000
Interview #8 Rene	48	2000	Separated	2 years college	Unemployed	SSI	Grandson	<10,000
Interview #9 Jenny	60	1998	Single	1 year college	Unemployed	SSI	Niece	25,000-30,000
Interview #10 Megan	55	1985	Single	2 ½ years college	Part-time	HIV Peer Advocate	Grandniece	11,000
Interview #11 Kate	44	1990	Single	Some college	Part-time	HIV Para-leader	Grandson	22-30,000
Interview #12 Carol	49	2000	Divorced	2 years college	Unemployed	SSI	Niece	<10,000
Interview #13 Rudy	51	2008	Married	2 years college	Unemployed	SSI	Grandson	10,000-20,000
Interview #14 Jody	60	1991	Separated	11 grade	Unemployed	SSI	Granddaughter	<10,000
Interview #15 Patricia	55	1982	Single	Graduated HS	Unemployed	SSI	Grandson	<10,000
Interview #16 Helen	37	1992	Single	2 years college	Unemployed	none	Nieces and nephews	<10,000
Interview #17 Grace	56	1990	Divorced	GED	Part-time	HIV Peer Advocate	Nephew, grandson, granddaughter	<10,000
Interview #18 Lisa	50	1995	Married	11th grade	Unemployed	SSDI	Grandson	11,000-12,000
Interview #19 Linda	42	1993	Single	10th grade	Unemployed	SSI	Grandson	10,000-11,000
Interview #20 Nia	49	2006	Single	11th grade	Unemployed	None, but applying for SSI	Grandson, two granddaughters	<10,000
Interview #21 Beth	33	2001	Single	1 year college	Unemployed	SSDI	Nephew	10,000-20,000
Interview #22 Jane	61	1994	Divorced	2 years college	Disabled & retired	SSI & SSDI	Grandson	19,000+
Interview #23 Ronda	53	2000	Single	11th grade	Unemployed	SSI	Granddaughter, two grandsons	14,400
Interview #24 Mary	48	1996	Separated	Bachelor's	Full-time	HIV Medical Case Manager	Niece	39,000

Table 2

Sociodemographic Information by Kinship Relation

	Aunts	Grandmothers
	Ages 33-60 ($M = 46$, $SD = 9.16$) $N = 11$ N (%)	Ages 42-64 ($M = 52$, $SD = 6.62$) $N = 13$ N (%)
Marital Status		
Single	7 (63.6%)	6 (46.1%)
Married	0 (0.0%)	2 (15.4%)
Divorced	2 (18.1%)	1 (7.6%)
Separated	1 (9.0%)	2 (15.4%)
Widowed	1 (9.0%)	2 (15.4%)
Race		
African American	8 (72.7%)	12 (92.3%)
African (Kenya, Nigeria, Cameroon, Ethiopia)	3 (27.2%)	1 (7.6%)
Education		
Less than high school	0 (0.0%)	5 (38.4%)
High school diploma/GED	2 (18.1%)	2 (15.4%)
Some education beyond high school	7 (63.6%)	6 (46.1%)
College or graduate level degree	2 (18.1%)	0 (0.0%)
Household income		
Less than $10,000	6 (54.5%)	6 (46.1%)
$10,000-$20,000	3 (27.2%)	5 (38.4%)
$20,000-$50,000	2 (18.1%)	2 (15.4%)
Work Status		
Unemployed	8 (72.7%)	11 (84.6%)
Part-time	2 (18.1%)	1 (7.6%)
Full-time	1 (9.0%)	1 (7.6%)
Public Assistance		
SSI/SSDI	5 (45.4%)	9 (69.2%)
None	6 (54.5%)	4 (30.7%)

Table 3

Information Pertaining to HIV+ Diagnosis, by Kinship Relation

	Aunts N = 11 N (%)	Grandmothers N = 13 N (%)
Diagnosis Year	1985-2004 (*M* = 1996, *SD* = 6.06)	1982-2008 (*M* = 1996, *SD* = 7.10)
1982-1990	4 (36.3%)	5 (38.4%)
1991-2000	4 (36.3%)	6 (46.1%)
2001-2008	3 (27.2%)	2 (15.4%)
Mode of Transmission		
Heterosexual sex	7 (63.6%)	8 (61.5%)
IDU	1 (9.1%)	1 (7.6%)
Heterosexual sex or IDU	1 (9.1%)	2 (15.4%)
Rape/sexual assault	2 (18.2%)	1 (7.6%)
Blood transfusion	0 (0.0%)	1 (7.6%)
Substance Abuse History		
None	7 (63.0%)	7 (53.8%)
Crack Cocaine & Alcohol Use	3 (27.2%)	5 (38.4%)
IDU & Alcohol Use	1 (9.1%)	1 (7.6%)

Table 4

Caregiving Information, by Kinship Relation

	Aunts N = 11 N (%)	Grandmothers N = 13 N (%)
Reason for Caregiving		
Offer help/financial assistance	6 (54.5%)	7 (53.8%)
Sister/daughter uses drugs	3 (27.2%)	3 (23.0%)
Behavioral issues/special needs of child	1 (9.0%)	1 (7.6%)
Health of "niece" is failing	1 (9.0%)	0 (0.0%)
Health of Kin poor	0 (0.0%)	1 (7.6%)
Total Years Caregiving		
Child's entire life	0 (0.0%)	7 (53.8%)
6-10 years	2 (18.1%)	2 (15.4%)
1-5 years	7 (63.6%)	3 (23.0%)
< 1 year	1 (9.0%)	2 (15.4%)
Caregiver's Relation to Child(ren)		
Sister's / Daughter's Children	9 (81.8%)	11 (84.6%)
Brother's / Son's Children	2 (18.1%)	2 (15.4%)
Ages of Kin		
0-5	5	8
6-10	5	8
11-16	1	2
Gender of Kin		
Male	2 (18.1%)	9 (69.2%)
Female	6 (54.5%)	2 (15.4%)
Female & Male	3 (27.3%)	2 (15.4%)
Arrangement		
Permanent	3 (27.3%)	7 (53.8%)
Temporary	7 (63.6%)	6 (46.1%)
Unsure	1 (9.0%)	0 (0.0%)
Caring for their Own Children		
None	8 (72.7%)	5 (38.4%)
Children <18	2 (66.6%)	1 (12.5%)
Adult children 18+	0 (0.0%)	6 (75.0%)
Adult children & <18	1 (33.3%)	1 (12.5%)

Table 5

Caregivers' Total Household Income by Marital Status

Total Household Income
N=24

Marital Status	<$10,000	$10-$20,000	$20,000-$50,000
Single	5 (20.8%)	5 (20.8%)	3 (12.5%)
Married	0 (0.0%)	2 (8.3%)	0 (0.0%)
Divorced	2 (8.3%)	1 (4.0%)	0 (0.0%)
Separated	2 (8.3%)	0 (0.0%)	1 (4.0%)
Widowed	3 (12.5%)	0 (0.0%)	0 (0.0%)

Table 6

Caregivers' Total Number of Children by Marital Status

Total Number of Children
N=24

Marital Status	1	2-3	3+
Single	10 (41.6%)	1 (4.0%)	2 (8.3%)
Married	2 (8.3%)	0 (0.0%)	0 (0.0%)
Divorced	2 (12.5%)	1 (4.0%)	(0.0%)
Separated	2 (12.5%)	1(4.0%)	(0.0%)
Widowed	2 (12.5%)	1 (4.0%)	