

EXPLORING THE LIFE EXPERIENCES OF AFRO-
CARIBBEAN IMMIGRANT WOMEN LIVING WITH HIV:
A PHENOMENOLOGICAL INVESTIGATION

by

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ABSTRACT

Over 35 million individuals across the globe are living with HIV, nearly one-half of who are women (UNAIDS, 2013). In the most affected areas, Sub-Saharan Africa and the Caribbean, women comprise up to 60% of those living with HIV (UNAIDS, 2012a, UNAIDS, 2013). Little research has focused the life experiences of Afro-Caribbean immigrant women living with HIV (for definition of terms, see Appendix A). Prior studies primarily emphasized epidemiological data (Hoffman, Ransome, Adams-Skinner, Leu, & Terzian, 2012), and high risk behaviors and attitudes (Braithwaite & Thomas, 2001; Gillespie-Johnson, 2005; Hoffman et al., 2008; Shedlin et al., 2006).

This phenomenological study explored the life experiences of eight Afro-Caribbean adult immigrant women from the English-speaking Caribbean, living in New York City who were HIV positive. Participants were identified with the assistance of key informants in the Afro-Caribbean community. A semi-structured interview guide facilitated discussion around topics such as immigration status, coping, self-perception, formal and informal support networks. Participants were given a \$25 Metro Card or grocery gift card as a “thank you” for their time. Data were analyzed according to Creswell’s (2007) Simplification of the Stevick-Colaizzi-Keen Method of Phenomenological Analysis created by Moustakas (1994). This entailed bracketing, identification of meaning units and themes, as well as construction of individual textural and structural descriptions. A composite description encapsulated the “essence” of the phenomenon.

These Afro-Caribbean women portrayed specific cultural nuances related to disclosure and the accompanying stigma and discrimination. Maintaining secrecy to ensure the safety of

families who remained in home countries was of utmost importance. The women relied heavily on community support networks facilitated by caseworkers, social workers, and medical professionals. Additionally, they focused on self-care and spirituality. These elements combined, defined their overall experiences.

Social workers can assist in enhancing the quality of life of this population by identifying specific challenges and creating culturally-appropriate and gender-specific interventions, including prevention and education programs. Advocacy should focus on immigration issues and programming specific to immigrant populations. The unique experiences shared by these Afro-Caribbean women living with HIV, supports further investigation with other sub-populations within the group such as with non-English speaking Caribbean, and more recently diagnosed women.

DEDICATION

I dedicate this dissertation to:

God, my Lord and King. Without you NONE of this would be possible. Thank you for entrusting me with this experience. May you be honored by the words on these pages.

The brave women whom I consider 'rock stars' that opened up their lives to me so that they could be placed on the written page. You are truly the heroes, the ones in whom God has placed an incredible trust. Your stories will help those that have yet to tell theirs.

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CONTENTS

ABSTRACT	ii
DEDICATION	iv
ACKNOWLEDGMENTS	v
LIST OF TABLES	x
1. HIV AND AIDS	1
a. Background	2
b. Afro-Caribbean Immigrants and HIV Infection	3
c. Statement of the Problem	4
2. REVIEW OF LITERATURE.....	16
a. The Caribbean Context.....	16
b. The U.S. Context.....	24
c. HIV Prevention Models.....	33
3. METHODOLOGY	37
a. Research Design	37
b. Data Collection.....	42
c. Data Analysis	47
d. IRB Considerations	56
4. RESULTS.....	59
a. Participant Demographics	59
b. Detailed Presentation of Findings	60
c. Composite Textural Description	182

d. Composite Structural Description	194
e. The Essence of Living with HIV for Afro-Caribbean Immigrant Women	197
5. DISCUSSION, CONCLUSIONS, AND RECOMMENDATIONS	199
a. Genesis	199
b. Challenges of Living with HIV	200
c. Coping	203
d. Policy/Immigration Challenges	205
e. Perceived Benefits of Living with HIV	206
f. Life Lessons	207
g. Structural Analysis	208
h. Social Work Implications: Practice and Policy	209
i. Lessons from the Study	220
j. Conclusions	221
REFERENCES	222
APPENDICES	238

LIST OF TABLES

3.1	Summary of Interview Times	46
3.2	Creswell’s Simplification of the Stevick-Colaizzi-Keen Method for Phenomenological Data Analysis	48
3.3	Criteria for Trustworthiness and Rigor in Qualitative Inquiries	54
4.1	Participant Demographic	61
4.2	Individual Textural Themes	184
4.3	Grouping of Individual Textural Themes	186
4.4	Structural Themes	195

CHAPTER 1

HIV AND AIDS

Since its emergence and identification as a viral entity, HIV/AIDS has adversely affected individuals and communities worldwide. According to the United Nations Program on HIV/AIDS (UNAIDS, 2012a), approximately 35 million people were living with HIV. While there has been a steady decline in the incidence of HIV infection and AIDS-related deaths compared to a decade ago, considerable concern remains due to the global prevalence of the infection (UNAIDS, 2013).

Of those infected with HIV/AIDS, women and young girls (aged 15-24) are the most vulnerable groups affected by this pandemic (UNAIDS, 2012b). Women now comprise nearly one-half of all individuals living with HIV worldwide (UNAIDS, 2012b), whereas the percentages were higher for men, particularly gay men (in the U.S) earlier in the history of the infection. Perhaps the greatest impact is occurring for women in Sub-Saharan Africa. This region has the highest HIV rates of infection worldwide, and the ratio of women to young men with HIV is almost 2.5:1 (UNAIDS, 2012b). After Sub-Saharan Africa, the second highest rate for adult HIV prevalence is the Caribbean. In this region, an estimated 280,000 individuals are living with HIV, and women comprise up to 60% of those living with HIV (UNAIDS, 2012b; UNAIDS, 2013). The factors that exacerbate HIV risk in Africa and the Caribbean include gender-based violence (i.e., rape and sexual coercion), political and cultural inequities, domestic violence, inability to achieve financial independence from male partners, and exposure to HIV

promulgated by cultural and societal ideologies of masculinity (UNAIDS, 2013; UNAIDS, 2012b).

Background

In the United States more than one million individuals are living with HIV (Kaiser Family Foundation, March, 2013a). Of all groups infected with HIV, African Americans have the highest incidence and prevalence of this virus in the U.S. (CDC, 2014a). In 2009, nearly half of those living with HIV (44%) were African Americans, which constitutes 12% of the U.S. population (Kaiser Family Foundation, March, 2013b). In addition, African Americans are often diagnosed later and have a greater chance of dying from HIV related infections (Kaiser Family Foundation, March, 2013b).

Twenty-four percent of individuals living with HIV in the United States are women (Kaiser Family Foundation, March, 2013c). In 2010, statistics indicated that among women of all racial and ethnic groups, Black women represented 60 percent of those living with HIV (Kaiser Family Foundation, March, 2013b). The Centers for Disease Control (February, 2013) reported that in 2010, Black women were newly infected at higher rates than their Latina and White counterparts (4 to 5 times and 20 times, respectively) in 2010. In that same year, 64% of all new HIV cases were attributed to Black women (Kaiser Family Foundation, March, 2013b).

In 2009, Black women were also more likely to die from HIV than women of any other racial and ethnic group. Additionally, in this same year, data indicated that for African American men and women (aged 25-44) HIV was one of the leading causes of mortality in this population (Kaiser Family Foundation, March, 2013b). Although rates of new infections among African American women have decreased, concern still remains as African Americans continue to lead in HIV infection rates (Kaiser Family Foundation, 2014). Fullilove (2006) asserted that HIV risk and acquisition among African Americans was due to systemic and personal factors such as

poverty, lack of access to equitable healthcare, stigma associated with HIV, and homosexuality. Understanding these factors may assist in providing a clearer understanding of the disparity between rates of infection among African Americans and other racial and ethnic groups in the U.S.

Afro-Caribbean Immigrants and HIV Infection

In 2010, about 13% of individuals in the United States were foreign-born. Foreign-born individuals are those that are born outside of the U.S. and their dependents cannot claim U.S. citizenship at birth through parentage (Acosta & De La Cruz, 2011).

Many Afro-Caribbean immigrants settle in large metropolitan areas concentrated along the East coast, such as New York and Florida (Thomas, 2012). Data from these states suggest that within this population, there are also sizeable populations of Afro-Caribbean immigrants from the English-speaking Caribbean.

One recent study, based on national HIV/AIDS surveillance data spanning six years (2001-2007), compared rates of HIV infection among U.S. born Blacks and Black immigrants to the U.S. Results suggested that among foreign- born individuals, Black immigrants from the Caribbean, especially females, had a significant risk for HIV infection characterized by heterosexual transmission (Johnson, Hu, & Deane, 2010). The Northeast region of the U.S. followed by the West and Midwest had the highest rates of infection for foreign-born Blacks (Johnson et al., 2010).

Increasing trends of HIV acquisition among foreign-born individuals from the Caribbean have been documented for New York City (New York Department of Health and Mental Hygiene, 2008; Wiewel, 2009). Factors that have contributed to HIV acquisition in this area among Caribbean populations include: engaging in “high risk” sexual behaviors; continuing to

engage in sexual activity with partners from/in their home countries and lack of, or misinformation about HIV transmission (Shedlin et al., 2006; Hoffman et al., 2008).

Changes in legislation that once prohibited immigration and travel of individuals with HIV to the U.S. has recently been rescinded and even more Afro-Caribbean people will likely immigrate to the U.S. to create new lives and obtain care and treatment for HIV infection (CDC, 2009). More information is needed in order to track HIV trends among immigrant groups and to ensure equitable healthcare, especially as it pertains to women.

Statement of the Problem

Other than recording incidence and prevalence of HIV infection, little research has been conducted among Black immigrant sub-populations in the United States about daily life experiences of individuals who are infected. Studies of Afro-Caribbean immigrant populations in the U.S. have focused on, mental health (Jackson et al., 2004; Jones, Cross, & DeFour, 2007; Williams et al., 2007), health (Griffiths, Johnson, Zhang, & Neighbors, 2011), immigration (Foner, 2001; Kasinitz, 1992; Matthews, 2014), well-being (Mahoney, 2004), and identity (Rogers, 2006; Shaw-Taylor & Tuch, 2007). Due to the social construction of race in the U.S. many Black immigrants may be classified as simply “Black”, therefore cultural and ethnic differences pertaining to health and other variables among various Black sub-populations may not be addressed specifically in research (Shaw-Taylor & Tuch, 2007). While some studies have examined Afro-Caribbean immigrants living with HIV (Anderson et al., 2009a; Anderson et al., 2008; Lawson et al., 2006; Stutterheim, Bos, Kesteren et al., 2012; Stutterheim, Bos, Shiripinda et al., 2012) these studies have primarily been conducted with populations outside of the U.S. (U.K, Canada, Netherlands). The few studies that have been conducted in the U.S. highlight immigration status as a barrier to accessing services, cultural barriers, and the role of peer support as a mechanism of support for Caribbean populations living with HIV (Pivnick,

Jacobson, Blank, & Villegas, 2010; Woldehanna, Thomas, & Clarke, 2007). Furthermore, fewer studies have attempted to gain an in-depth understanding of what it is like for Afro-Caribbean immigrants, especially among women (the most vulnerable) to live with HIV.

Study Area and Its Relevance to Social Work

The field of social work offers a unique vantage point for understanding individual experiences from a multi-systemic perspective. More specifically, social work embraces the “person in environment” model (Ashford & LeCroy, 2013 p. 35). This perspective is useful in understanding challenges faced by vulnerable populations and where best to intervene to help resolve problems and improve quality of life. Chang-Muy and Congress (2009) observed that many immigrants face considerable challenges navigating healthcare systems in the U.S. as they are very different from those in their country of origin. Additional factors that further complicate immigrants’ experiences within systems include immigration status, lack of English proficiency, divergent cultural beliefs/traditions, and lack of health insurance coverage. Further, women may not be willing to utilize health care services due to cultural and religious values that may conflict with examinations that focus on intimate areas of the body or necessitate intimate discussions of sexual behavior.

The challenges faced by immigrants highlight the need to abide by the core values as set forth by the National Association of Social Workers (NASW) Code of Ethics (NASW, 2008) of the dignity and worth of the individual, service, competence and social justice. Cultural competence in all aspects of social work policy and practice is essential in work with individuals from different cultural and ethnic backgrounds. Reference to cultural competence can be found in section 1.05 of the Code of Ethics. Social workers are urged to continually increase knowledge and awareness of diverse cultures in order to provide the most appropriate assistance to clients (NASW, 2008). Pardasani, Forge, and Moreno (2010) offered the following definition

of cultural competence, “Cultural competence is a set of behaviors, attitudes, and policies that come together in a system—such as family, agency, or among professionals—that enables that system to work effectively in cross-cultural situations” (p. 82). Social workers who work with immigrant populations with HIV/AIDS must be able to engage individuals by incorporating and honoring cultural differences. This will serve to increase rapport and encourage meaningful dialogue and problem-solving. According to Wheeler and Mahoney (2008), the field of social work should advocate for macro level change, while taking into consideration various systemic and personal influences as it pertains to the health and well-being of Caribbean immigrant populations in the United States. In order to best advocate for Afro-Caribbean women living with HIV, a fuller understanding of their challenges (and triumphs) in daily life is needed. The information generated from this study can inform social workers and other professionals about systemic and micro level that can help or hinder a meaningful quality of life for individuals living with HIV/AIDS.

Researcher Orientation and Experience with the Phenomenon

As a first generation Afro-Caribbean woman born in the United States, I have had the privilege of interacting with two distinct cultures. My parents, Caribbean immigrants from the island of Jamaica, instilled in me a profound respect and appreciation of my Jamaican heritage. During my formative years, I travelled frequently to Jamaica to visit relatives. In my hometown of Hartford, Connecticut, there are many Caribbean businesses and social clubs, as well as individuals from the Caribbean who are very active in both local and state politics.

On our trips to Jamaica, I travelled to different parts of the island and observed the vast differences between individuals in urban and rural areas. I became aware of an unspoken language embedded in the behaviors and very heart of many individuals who surrounded me. I later realized this phenomenon as part of the distinct Jamaican culture. One striking facet of the

culture was the difference in socialization of males and females, and the secrecy that surrounded certain topics such as sexuality and mental illness. This observation prompted me to begin asking myself and my family members questions such as, “Why are women treated differently from men?” I often asked the questions in a juvenile manner, to which my mother would respond, “Yuh too faas” (a phrase in Jamaican dialect meaning inquisitive or nosey). I learned to internalize my questions, but continued seeking answers from observations around me.

During my high school years, I was enrolled in the Upward Bound Program. In this program, students from various backgrounds attended an 8- to 12-week summer instructional session while living on college campuses throughout the State, and preparing for college studies. As part of this program, I was assigned a mentor who kept in contact with me during the school year to chart my academic progress and provide guidance related to college and career planning. I was also able to attend various seminars and programs at the University of Connecticut Medical Center in Farmington, Connecticut. There I met Dr. Boake Plessey, an African American physician who was the director of the Pre-Medical and College Enrichment Programs at the University of Connecticut. In addition, there was another Afro-Caribbean female physician that was closely connected to the program. After attending several of these workshops, I became interested in becoming a physician. After talking with my mentor, she encouraged me to apply for the College Enrichment Program. This was a program in which students attended an 8-week summer intensive course for students that wanted to pursue a medical degree after college. Classes focused on preparing students for college science classes such as chemistry, biology, and physics; providing mentors that were in the medical arena for college students enrolled in this program. I was interested in focusing on individuals with HIV/AIDS and wanted to specialize in infectious diseases. Watching movies such as *The Band Played On* that chronicled the

beginnings of the HIV/AIDS epidemic in the United States, and the movie *Outbreak* that portrayed the work of infectious disease doctors traveling to Africa to work with individuals affected by an Ebola disease epidemic, fuelled my interest further. I spent numerous hours on summer breaks in my parent's basement reading in books about the work of infectious disease doctors. The more I read, the more I thought "this is the life for me." My interest, coupled with the love of travel seemed to be the "perfect fit" for my future career aspiration. By the end of my senior year in High School, I knew that this was the path I wanted to travel. I was accepted to the Pre-Med College Enrichment Program and was assigned to a branch campus of the University of Connecticut near my hometown. I started my freshman year full of zeal and enthusiasm. I enrolled in the standard freshman courses, including Biology and Chemistry. In addition, I enrolled in an Anthropology course through which I became acquainted with the work of Rigoberta Menchu, a Guatemalan woman that was part of an Indian sub-population in Guatemala. Throughout her narrative, she chronicled facets of life such as gender inequities, life in the rural areas, violence at the hands of the government, and fighting against the injustices inflicted upon members of her Indian sub-population in Guatemala. Several of her family members were killed, and she fought the government and documented her life story. Her story fascinated me. As I read through the pages of that book, I wanted to be there. I wanted to help fight injustice. I wanted to make a difference.

Toward the middle of my freshman year, I decided that I wanted to venture into new territory and attend a college away from my home state of Connecticut. I lived in Connecticut all my life and wanted to experience college life at a historically Black college (HBCU). I knew a couple of friends that attended Oakwood College, a small Christian liberal-arts school in Huntsville, Alabama known for its pre-med program. I called and inquired about the program

and was connected with the director of the Biology program. I applied to Oakwood College and formally declared myself a 'pre-med major'. At the age of 19, I was off on a new adventure. I found the studies at Oakwood both challenging and invigorating. It was difficult at first being away from home, but after some time I became acclimated to my new surroundings. I was confident and content with my decision to attend Oakwood College.

Toward the end of my sophomore year, I received a call from my grandmother who informed me that she had been diagnosed with breast cancer. My grandmother was, in my view, a "tower of strength", so I believed there was no need to worry. I was wrong. My grandmother died six months after being diagnosed with breast cancer. I recalled at her funeral how she often complained of pains in her legs and in other areas of her body years prior to her diagnosis. I had urged her to visit her doctor. She tried various herbal remedies and other "cures" utilized in Jamaica to no avail. When the disease continued to progress to stage-4 metastatic breast cancer, we knew the end was in sight. After her death, I remember wondering what she thought about while she was dying, and what her life meant to her in the face of her terminal illness. I was never able to ask her those questions. This event caused me to question how an individual's culture influences personal reactions to illness. In Jamaican culture, discussion of topics such as breast cancer and other illnesses are taboo. After my grandmother's death, I contemplated these issues and reassessed my decision to become a physician. While I was still interested in culture, health, gender inequities, and travel, I felt I was being pulled in a different direction. I always loved writing and throughout my college career had articles published in church magazines, and also published some of my poetry. I was confused about the direction I wanted to pursue. After talking with a career counselor, I contemplated majoring in languages (English and Spanish). At the end of my junior year of college, I officially changed my major to English and Spanish and

retained a minor in Biology. During this time, I also became acquainted with the field of sociology. The following summer, I enrolled in a study abroad program in Spain to complete the requirements for my Spanish degree. I returned and completed my degree in English and graduated in 2002. I knew several individuals that majored in social work at my university and spoke in depth with them; about their plans following graduation and what specific area of social work they wanted to focus on. I discovered that social work incorporated all of my interests! There were many areas of specialty that fell under the umbrella of social work including International Social Work. I applied to the University of Michigan Social Work program and was accepted. Following graduation with my Bachelors in English and Spanish, I matriculated through the social work program in Ann Arbor, Michigan. I learned about family of origin issues, human behavior, policy, and mental health. My eyes were opened to so many of the patterns I saw in my family and in others, but I also saw the unique role that culture plays in how we interact with others and how we perceive our life events. The knowledge that I obtained from my master's degree in social work encompassed all of my passions and enabled me not only to understand the biological basis for disease, but how disease affects individuals with regard to psychosocial factors.

Another event that shaped my interest in exploring the effect of culture on behavior was my experience as a social worker living and practicing in the United Kingdom. After graduating with a master's degree in Social Work, I worked in the field of child protective services for a local authority in London, England. London has a sizable Afro-Caribbean population, and during my time there, I observed many of the cultural patterns I had seen and experienced in Jamaica.

Finally, in 2005 when I returned to the United States, I worked at a local area church in Bloomfield, Connecticut, that served primarily West Indian (Caribbean) and African American

populations. The pastor asked me to help create a group counseling curriculum focusing on depression, family of origin issues, and relationship-building that could be utilized in churches. Throughout this venture, I queried members of the church about counseling, their feelings about engaging in counseling, and what role they felt the faith-based community had in offering these types of services. Many members expressed concern at having their “business” repeated by members of the church. However, as rapport and assurances of confidentiality were addressed, members perceived group-work as non-threatening and began to participate in various activities. This experience provided me with insight as to how to work directly with Caribbean populations. For example, I became aware of the difficulties culturally-diverse populations may have, disclosing personal information about serious medical or mental health issues to those that could potentially cause harm to them. In addition, it taught me the importance of listening to, and respecting what individuals have to say about their discomfort in seeking mental health services. Furthermore, I learned that faith-based organizations might play an important role in dispelling myths surrounding mental health services. They do so by focusing on congregants’ spiritual needs, providing specific faith-based services such as spiritual counseling, and linking clients to community resources when applicable.

Three years after working at the church, I moved back to Alabama, and decided to enroll in the Ph.D. Program in Social Work at the University of Alabama. After assessing my personal and professional goals, I decided that continuing academic studies in the field of social work would assist me in developing research skills and provide me with specialized training to enter the world of academia. I knew that I wanted to explore health and Afro-Caribbean communities. After discussing my interests with mentors and friends, I realized that I wanted to return to my primary interest of infectious diseases—mainly HIV—but wanted to explore this phenomenon

from a person-centered, holistic perspective. I became interested and intrigued with exploring the cultural, social, and systemic problems that many Caribbean immigrants, particularly women, encounter.

Obtaining entrée into the Afro-Caribbean community in the New York Metropolitan area was a three-year effort. After the first year of doctoral studies and review of the literature relevant to this population, I discovered a study conducted by an Afro-Caribbean researcher who conducted an investigation of Black Caribbean men who have sex with men (MSMs) living with HIV in the New York Metro area. I contacted this researcher and arranged a meeting with her. Upon our meeting, she discussed her interest in research with Caribbean MSMs. I was then able to ask her various questions about her methodology, current studies, and future research trajectory. I also found that information could be gathered from agencies providing services for individuals living with HIV in the New York Metropolitan area. I was able to identify several agencies that provided services to immigrant populations, specifically African and Caribbean immigrants with HIV. Afterwards I contacted these agencies by phone or email. These providers were able to provide insight about working with Caribbean immigrant populations, discuss the feasibility of future research with Afro-Caribbean immigrant women living with HIV, and how to network and make contact with providers/community leaders that could assist me in fleshing out ideas.

In January 2009, I contacted an agency in which the director for HIV/AIDS services was a Caribbean woman. She informed me that on the previous day, she attended a seminar that focused on the epidemiological trends of Caribbean populations with HIV/AIDS in New York. She forwarded me the presentation to me along with the name of the lead epidemiologist. I contacted the epidemiologist regarding my interest in Afro-Caribbean populations living with

HIV. Upon hearing of my interest, we spoke and subsequently arranged a face-to-face meeting. She asked me to send an email stating my interests and she corresponded with colleagues in the New York City area that she felt might be willing to speak with me. Two individuals responded to her email. One of the individuals that responded asked the epidemiologist to forward her contact information to me. I contacted her and learned that she was an Afro-Caribbean immigrant woman, who that the time of our communication was an active member of the New York City HIV Prevention Planning Group (PPG), a practicing social worker and had experiences working in various capacities with individuals living with HIV, and was an active member in the Caribbean community. The PPG is comprised of a select group of professionals, practitioners, and local government and community representatives with an interest in decreasing rates of HIV transmission with an emphasis on prevention. The group also has other foci such as criminal justice, women and children, and immigrant populations. She was appointed to the branch of the prevention group that focused on immigrant populations. Shortly after I began communicating with this contact person, I was referred to her colleague, also an Afro-Caribbean woman with experience working with women and young girls infected with HIV. The two contacts served as key informants for my preliminary research in the topic area. Patton (2002) identified key informants as “people who are particularly knowledgeable about the inquiry setting and articulate about their knowledge-people whose insights can prove particularly useful in helping an observer understand what is happening and why” (pp. 321). Key informants assist in helping gain access to a community that may otherwise be closed to the researcher. Contact with these two key informants proved invaluable as I was able to ask questions about their experiences working with Afro-Caribbean populations, learn the pitfalls, hone my area of interest and gain a deeper appreciation for vulnerable populations. In May 2009, one of the key

informants informed me of a meeting she had with some HIV positive Caribbean women, from which she shared some of the ideas I had expressed previously. At this point, I asked the second key informant about her views of the feasibility of conducting a pilot study with these women in order to ascertain their views about the research process and what research methods would prove fruitful for a larger-scale study. She informed that she felt the women would be responsive. After obtaining IRB approval (see Appendix B), the preliminary study was conducted in June 2009. This study informed the primary aims and the methodology selected for my dissertation.

My cultural heritage, education, and life experiences have all contributed to my interest in this research area. While I previously had no interaction with women who were infected with HIV, my questions about the intersection of gender, culture, sexuality, disease, and stigma have all merged to form my interest in Afro-Caribbean immigrant women with HIV. I am aware that due to my cultural heritage, it may be easy to infer or project my assumptions about Caribbean culture into this investigation. Through the process of bracketing, I attempted to remain transparent and to document my continued experiences with the phenomenon. This study is not my study; it belongs to the women who chose to participate and were brave enough to share their life experiences with me. My position as the researcher was to allow them to share; to accurately represent their words and ideas; and to remain accountable, ethical, and transparent

Purpose of the Study

While several studies have explored various aspects of HIV/AIDS as they pertain to African American women (Ferguson, Quinn, Eng, & Sandwowski, 2006; Gilbert & Wright, 2003; Moneyham, Sowell, Seals, & Demi, 2000; Shambley-Ebron & Boyle, 2006; Owens, 2003), few studies have explored the experiences of Black female immigrant sub-populations in the United States, such as those from the English-speaking Caribbean. Furthermore, due to racial/ethnic disparities in the U.S., many Afro-Caribbean individuals may be classified as

African American and thereby not account for cultural nuances, epidemiologic differences, and factors impacting HIV acquisition. Similarly, Shedlin et al. (2006) stated that “In most public health data, race is used as a proxy for ethnicity making it difficult to estimate the prevalence of HIV among West Indian immigrants” (p. 48).

The purpose of this study was to explore the lived experiences of Afro-Caribbean immigrant women living with HIV/AIDS in the U.S. Through the use of a qualitative phenomenological approach, the following questions were explored:

What are the lived experiences of Afro-Caribbean immigrant women with HIV?

How do Afro-Caribbean immigrant women access and maintain relationship with informal (family, friends) and formal (healthcare, community) support systems?

How do culturally attributed meanings of HIV/AIDS and immigration status impact coping and self-perception of Afro-Caribbean immigrant women living with HIV?

CHAPTER 2

REVIEW OF LITERATURE

This chapter will provide a more in-depth review of the literature as it pertains to Afro-Caribbean immigrant women living with HIV in the U.S. First a brief review of the geographical landscape of the Caribbean is provided, followed by the context of HIV risk in the Caribbean. The history of Caribbean immigration to the U.S. is briefly outlined as well as the specific federal policies that have affected immigration and access to resources for this population. More specific to HIV is an epidemiological view of HIV in Black Caribbean populations in the U.S., followed by a review of the literature as it pertains to HIV risk and gaps in the literature leading to a discussion of the conceptualization and rationale for the current study.

The Caribbean Context

After Sub-Saharan Africa, the Caribbean is the second most adversely affected area of HIV prevalence in the world (UNAIDS, 2012a). To begin to understand this phenomenon, a clear picture of the geography and history of the Caribbean region is helpful. Matthews (2014) defined the Caribbean as, “an archipelago of islands that stretch from the tip of Florida to the coast of South America” (p. 23). Although this geographic region includes individuals with various linguistic, religious, and ethnic backgrounds, many islands have a shared historical and cultural background due to former colonial rule by European powers (Figueroa, 2008; Matthews, 2014; Voelker, 2001).

Islands in the Caribbean are often delineated by their linguistic heritage. The French-speaking Caribbean islands include: Haiti, Guadeloupe, St. Martin, and St. Barthelemy. The

Dutch-speaking islands include: Aruba, Bonaire, Curacao, Saint Eustatius, Saba, and Suriname. The English-speaking islands include: Jamaica, Trinidad and Tobago, Guyana, Barbados, Bahamas, Bermuda, Antigua and Barbuda, Anguilla, the Cayman Islands, St. Lucia, Montserrat, St. Kitts and Nevis, Grenada, the British Virgin Islands, Turks and Caicos and St. Vincent and the Grenadines. Finally, the Spanish-speaking islands include: Dominican Republic, Cuba, and Puerto Rico. (Hoffman et al, 2012; Inciardi, Syvertsen, & Surrat, 2005; Matthews, 2014).

HIV in the Caribbean

Estimates indicated that there were approximately 250,000 individuals living with HIV in the Caribbean at the end of 2012 (UNAIDS, 2013), with an adult (aged 15-45) HIV prevalence of 1.1%. There has been a decrease in rates of HIV prevalence in this region, however, inter-island variation does exist (USAID, 2011). HIV epidemics are often categorized as generalized, concentrated, or low-level (UNAIDS, 2013c). Generalized epidemics are those in which a disease can be found and is maintained in the general population (UNAIDS, 2013c). Concentrated epidemics are those in which the rate of a given disease is low throughout the general population but high in vulnerable populations such as sex workers, MSMs. Throughout the Caribbean both generalized and concentrated epidemics are present.

The incidence of HIV in the Caribbean has decreased since the early years of the epidemic; however, certain island nations exhibit high rates of HIV infection. According to the United States Agency for International Development (2011), HIV prevalence is highest in Bahamas (3.1%) followed by Haiti (1.9%), Jamaica (1.7%), Barbados (1.4%), Trinidad and Tobago (1.2%), Guyana (1.2%), and the Dominican Republic (0.9%). In these countries, concentrated epidemics such as those in MSMs and female sex workers (FSWs) have serious public health implications as they add to HIV the number of new infections within the general population. For example, in 2010, it was estimated that HIV prevalence in MSM populations in

Jamaica, the Bahamas, and Trinidad and Tobago were as high as 32%, 25.6%, and 20.4%, respectively. Estimates from Jamaica in 2012 showed an increase in HIV prevalence to 38% (UNAIDS, 2012c). These statistics are indicative of the stigma and discrimination faced by MSM populations throughout the Caribbean. Many Caribbean nations maintain sodomy laws that are punitive in nature and hinder HIV prevention efforts and collection of meaningful data on the preferences and sexual behaviors of this population (Bournre, South-Bourne, & Francis, 2010; UNAIDS, 2010a; USAID, 2011).

Female sex workers are also at high risk for HIV. This is most evident in Haiti and the Dominican Republic where HIV prevalence among FSWs is between 3.2% and 5.3% in 2010 (USAID, 2011). Kempadoo (2004) and Padilla, Guilamo-Ramos, Bouris & Reyes (2010), suggested that commercial sex work has fuelled the HIV epidemic and also the economies of many islands in the Caribbean. Tourism provides economic growth to many small island nations, however, it also perpetuates sexual labor and disease transmission by individuals who may engage in risky sexual behavior in which neither party knows the sexual history of the other.

Epidemiology and risk in Caribbean women.

Globally, women comprise approximately 52% of those living with HIV (Kaiser Family Foundation, October, 2013). In the Caribbean, surveillance data has suggested that the number of women and young girls living with HIV surpasses that of their male counterparts at a higher rate (52%-60%) (UNAIDS, 2010b; UNAIDS, 2012b). The HIV epidemic in the Caribbean is predominantly characterized by heterosexual transmission (USAID, 2013) and of particular concern are young women aged 15-24. Women, especially young girls, by virtue of their physiological make-up are more vulnerable to HIV acquisition due to mucosal changes and underdeveloped vaginal tissue that is easier to tear, thus increasing the chances of infected blood and semen penetrating these areas (Quinn & Overbaugh, 2005; Türmen, 2003; UNAIDS, 2013).

Women are also vulnerable to rape, intimate partner violence, social isolation, and lack of access to reproductive services (UNAIDS, 2013; USAID, 2011).

Social constructions of gender and sexual behavior also affect women's ability to refuse sexual advances from their spouses or partners. For example, a study conducted by Amnesty International (2006) outlined a culture of pervasive violence against females that is entrenched in legal and social fabric of Jamaica. In a national study of knowledge, attitudes, and beliefs about HIV/AIDS among individuals aged 15-49 in Jamaica, showed that risk taking behaviors of both males and females declined as compared to previous studies of this age group, however, risk taking behaviors such as transactional sex, defined as, "the exchange of gifts or money for sex" (p.8) and low condom use put individuals, especially females at risk for HIV acquisition. Males and females did report engaging in concurrent relationships (Hope Enterprises, 2008).

Concurrent relationships for females may be due to economic constraints, such as poverty and relational ideologies that dictate that men should provide financially for their female partners (Le Franc et al., 1996). This economic dependence on males may also increase the risk of HIV acquisition (UNAIDS, 2013).

Chevannes (2001) asserted that males in the Caribbean are often taught that engaging in several sexual relationships concurrently is proof of masculinity. In their study of adolescent attitudes and beliefs related to HIV/AIDS, Hutchinson et al. (2007) found that females received messages that encouraged them to remain chaste, however, if they were singled out by affluent older men to engage in sexual relationships, doing so would provide them with several benefits such as monetary payment, protection, and goods for their family members. In such cases, young women were encouraged to engage in these relationships, especially if these families live in impoverished areas. Sexual abuse was also identified as a possible factor for increased HIV risk.

One study (Jones et al., 2009) explored child sexual abuse in six Eastern Caribbean islands. The study identified many attitudes and beliefs about children and their roles in these given societies. Male interviewees commented that they felt that menarche signaled womanhood and therefore girls that reached this stage of puberty were seen as viable sexual partners. A number of ecological factors were identified, including poverty, familial discord, and lack of parental protection. In addition, mothers that had a series of sexual partners giving access to the homes in which young girls live was also seen as a risk for sexual abuse in children. Furthermore, the authors maintain that while sexual abuse occurs to young males, young girls were more likely to be the victims of abuse. As stated previously, in some Caribbean nations cultural mores support various types of violence against women (UNAIDS, 2013).

Women and young girls face considerable challenges in the Caribbean with regard to HIV risk due to cultural and gender norms, attitudes, beliefs and behaviors. These studies have elucidated factors that contribute to women's HIV risk in the Caribbean. Since there are sizeable populations of individuals from the English-speaking Caribbean in the U.S., it is important to explore the context of risk in the U.S. among the Caribbean immigrant population.

Characteristics of the foreign-born population.

The United States, with its vast geographic expanse, was home to approximately 40 million foreign-born individuals as of 2010 (Grieco et al., 2012). As previously defined, foreign-born individuals are those who were born outside of the U.S. and its territories and cannot claim U.S. citizenship by parentage (Acosta & De la Cruz, 2011). Foreign-born populations in the U.S. are also designated by several legal categorizations such as “naturalized citizens, lawful permanent residents, temporary migrants (such as foreign students), humanitarian migrants (refugees), and undocumented migrants” (Grieco et al., 2012, p. 1). More recent populations of immigrants tend to be younger (18-44 years of age) and are well-educated. They most often

settle in the Northeast or West Coast of the U.S., primarily New York City and California (Grieco et al., 2012). In 2010, of those with legal residency, European, Asian, and Caribbean-born individuals had higher rates of obtaining U.S. citizenship than those from Latin American countries (Grieco et al., 2012). Younger males (18-44) immigrated with a higher frequency than their female counterparts. However, females from the Caribbean and South America migrated to the U.S. with greater frequency than males from these regions (Grieco et al., 2012). Foreign-born males had high rates of engagement in the U.S. workforce as compared with native-born males (79% and 68% respectively). Native-born women had higher engagement in the workforce. Among Caribbean immigrants, females represented approximately 50% of the workforce (Grieco et al., 2012).

Caribbean immigration to the United States.

The previous statistics indicate that the foreign-born population of the U.S. is diverse. Since the focus of this current research was English-speaking Afro-Caribbean populations, a discussion of Caribbean immigration to the U.S. is warranted. According the U.S. Census (Grieco et al., 2012), 49% of 3.4 million Caribbean immigrants to the U.S. were of African descent.

Caribbean immigrants have had a presence in the U.S. dating back to the colonial era. The vast majority of Caribbean immigrants who voluntarily emigrated to the U.S. came in 1965 due to radical changes in U.S. immigration policy that encouraged the immigration of larger numbers of non-European populations to the U.S. (Thomas, 2012). Caribbean immigration to the U.S. is typically broken into three time periods in the 20th century: the early 1920s, between 1930 and 1965, and post 1965 to the present day (Foner, 2001; Matthews, 2014).

A large influx of Caribbean immigrants came to the U.S. after the Hart-Cellar Act of 1965 was passed (Kasinitz, 1992; Matthews, 2014; Thomas, 2012). This legislation eliminated

the former system of immigration that limited the number of non-European individuals permitted to enter the U.S. and focused on sponsorship of non-immigrant family members by family members that became U.S. residents or naturalized citizens (Foner, 2001; Kasinitz, 1992; Matthews, 2014; Shaw-Tuch & Taylor, 2007). Scholars have noted that significant social upheavals were occurring in the U.S. and in many Caribbean island nations during the 1960s (Foner, 2001; Kasinitz, 1992). In the U.S., a history of segregation and violence toward Blacks in the U.S. culminated in the Civil Rights Act of 1965 in which Blacks were granted many civil liberties that were once denied them (Hope-Franklin & Moss, 2008). At that same time, many Caribbean island nations were also gaining independence from colonial powers, which spurred on immigration by Caribbeans to the U.S. to seek economic and educational opportunities because of the turbulence and uncertainty involved in the changeover (Kasinitz, 1992; Matthews, 2014). Subsequent legislation, such as the Immigrant Reform and Control Act of 1986, continued to encourage immigration by granting illegal populations the ability to become naturalized citizens (Kandel, 2011). Many Caribbean immigrants who arrived in the U.S. post-1965 migrated to large urban centers; however, New York City was the epicenter for Caribbean migration (Foner, 2005). Due to the former waves of immigration, newly arrived Caribbean immigrants had access to firmly established cultural enclaves, increased opportunities for educational advancement and open labor markets. Friends and family that emigrated previously served as support networks that provided useful guidance on how to navigate the landscape of the U.S. (Foner, 2005; Kasinitz, 1992).

In the early 20th century, Caribbean immigrants represented a large proportion of Blacks in the U.S. in the years leading up to the 1930s (Crowder & Tedrow, 2001, as cited in Matthews, 2014). During a 29-year span (1980-2009), the Black Caribbean population increased by 1.2

million individuals. During 2008-2009, 49% of all immigrants from the Caribbean were of Black racial composition. Those from the countries of Jamaica, Trinidad and Tobago, Barbados, and Grenada accounted for 53% of Black individuals from the Anglophone Caribbean (Thomas, 2012). Jamaicans and Haitians comprised the majority of Black immigrants in ten U.S. metropolitan areas from 1990-2000 (Logan & Deane, 2003).

Afro-Caribbean Women and Immigration to the United States

Afro-Caribbean women were active participants in all three waves of migration previously mentioned (Spooner, 2013). Because of often low level of education or few economic opportunities in their home countries, many women Afro-Caribbean women found jobs in relatively low-paying jobs in the domestic sector such as nannies or providing other personal care (Foner, 2001; Spooner, 2013). Once procured, these jobs provided income that some of which was sent by these women to assist families back in their home countries (Spooner, 2013). Women often migrate alone and may spend several years abroad before they are able to sponsor other family members, including children, to join them in the United States. Afro-Caribbean women often rely on social networks to link them with jobs and other sources of support (Best-Cummings & Gildner, 2004; Spooner, 2013). If a woman is not part of these networks, the potential for negative psychosocial consequences exists, such as isolation and depression. These may negatively affect physical and mental health, especially for undocumented women because they additionally may fear discovery of their immigration status (Best-Cummings & Gildner, 2004; Williams et al., 2007).

Afro-Caribbean Immigrant Women and HIV

While literature exists on the state of women living with HIV in the Caribbean, the literature about this population in the U.S. primarily focuses on HIV risk. Such studies do provide relevant information about factors related to immigration and cultural beliefs that may

increase risk in this population (Hope Enterprises, 2008; Hutchinson et al., 2007; Kempadoo, 2004; UNAIDS, 2013; USAID, 2011). In a study of newly emigrated Jamaican immigrant women to the U.S., Gillespie-Johnson (2008) suggested that cultural ideologies that relegate sex and sexuality to “taboo” subjects may impede women from discussing preventive efforts, such as condom use and safe sex practices with sexual partners. In addition, the stigma and secrecy surrounding HIV in Caribbean communities may encourage belief in myths related to HIV acquisition and decrease belief in susceptibility. Also women’s religious beliefs that deemed HIV acquisition as punishment for immoral behavior may inhibit women from seeking treatment. Braithwaite & Thomas (2001) compared the attitudes about HIV among African American and Afro-Caribbean college women found that African American women were better able to communicate with their partners about safe sex practices than their Caribbean counterparts. Another study found that Caribbean-born women, though knowledgeable about HIV transmission, did not engage in safe sex practices compared to their counterparts that were born in the United States (Thompson, 2011). These studies highlighted the phenomenon that knowledge of HIV risks do not translate into a change in sex practices.

The U.S. Context

Epidemiology of HIV: African Americans

Despite recent decreases in HIV incidence, African Americans remain most severely affected by the HIV/AIDS epidemic in the U.S. (Kaiser Family Foundation, March, 2013b). In 2010, African Americans were infected at a rate eight times that of Whites and in the same year, 44% of new HIV cases in the U.S. was attributed to African Americans (Kaiser Family Foundation, March, 2013b). African American males, lead in HIV infection for all males regardless of race/ethnicity. In 2010, African American women also had higher new infection rates than their Latina and White counterparts [29%, 14%, and 11% respectively] (Kaiser Family

Foundation, March, 2013b). In addition, African American women ages 25-44 continued to experience the fourth highest incidence of death due to HIV in 2009.

In 2010, 72% of new HIV infections in Black males was attributed to sexual contact with other males (Kaiser Family Foundation, March, 2013b). As previously noted, many Caribbean immigrants tend to settle along the East Coast of the U.S.; with a large proportion settling in New York City (Thomas, 2012). In New York State, Black males (42%) and females (63%) comprised the majority of newly-diagnosed HIV cases in 2010 (New York State Department of Health, 2012). Black male MSMs accounted for approximately 50% of new diagnoses for those aged 15-24 and approximately 25% in those 25 years of age and older as compared to White counterparts (14% and 36%, respectively) (New York State Department of Health, 2012). The majority of newly-diagnosed African American women were infected through heterosexual transmission. Black women were newly-diagnosed at a rate six times higher than their White counterparts (approximately 10%) (New York State Department of Health, 2012). Rates of HIV infection were also high among African Americans overall and for Black immigrant sub-populations in New York City and are consistent with the national data (Kaiser Family Foundation, March, 2013b; New York State Department of Health, 2012).

Afro-Caribbean immigrants and HIV.

Approximately 845,000 individuals from the Caribbean resided in the New York Metropolitan area in 2011 (New York Department of Planning 2011). People from Jamaica (169,235) and Trinidad and Tobago (87,635) are the leading countries of origin for English-speaking Caribbean foreign-born individuals. Other Anglophone Caribbean communities with sizeable populations included Barbados (23,798), Grenada (17,613), and St. Vincent and the Grenadines (12,542). Many Caribbean enclaves exist in the New York Metropolitan and are located in the East Flatbush area of Brooklyn, Crown Heights, and Jamaica, Queens (Shedlin et

al., 2006). These ethnic enclaves of Caribbean immigrants in New York City appear to provide a sense of solidarity (Foner, 2001).

There remains a concern within Caribbean populations regarding HIV risk and acquisition in the U.S. Caribbean-born persons comprised the largest proportion of foreign born persons newly-diagnosed with HIV in New York City (38%). New cases of HIV infection among this population were concentrated in East Flatbush Brooklyn (37%) (New York City Department of Health and Mental Hygiene, 2013a). In 2012, among those foreign-born from the Anglophone Caribbean, individuals from Jamaica, Guyana, and Trinidad and Tobago were the groups most frequently diagnosed (numbered 84, 38, 29 cases, respectively). Caribbean males accounted for the largest proportion of new diagnoses among foreign-born MSMs (27%) in 2012 (New York City Department of Health and Mental Health, 2014b). In the same year, females from the Caribbean accounted for 52% of new HIV cases among foreign-born females (New York Department of Mental Health and Hygiene, 2014c).

HIV risk for Afro-Caribbean immigrant populations in New York City may be exacerbated by cultural and gender-specific norms. For example, Hoffman and colleagues (2008) explored the HIV knowledge, attitudes, and behaviors of native-born Blacks and those from the English-speaking Caribbean. Although they had lower levels of risk behaviors than their native counterparts, results indicated that Caribbean-born females did not believe that they could induce their sexual partners to engage in safe sex practices and health screenings. Caribbean men in this sample reported that they would be less likely to disclose to partners a diagnosis of a sexually transmitted disease. Another study highlighted increased access to a wider net of sexual partners, inability to achieve economic independence, low perception of susceptibility of HIV infection and undocumented immigration status may place women at higher risk for HIV acquisition

(Shedlin et al., 2006). Hoffman and colleagues (2012) also cited that New York City provided a wider array of sexual partners may increase HIV risk and that knowledge of safe sex practices (i.e. condom use) did not necessarily translate into incorporating these behaviors with sex partners. Targeted HIV preventive efforts with attention to cultural beliefs and sexual behaviors are needed with this population.

Race/Ethnicity.

A national study that assessed HIV infection among native-born Blacks and Black immigrant populations over a six-year span (2001-2007) indicated that Caribbean people had higher rates of infection than their African American counterparts; with heterosexual transmission as the main mode of infection for foreign-born Blacks, which warranted further investigation (Johnson et al., 2010). While this study began to address a gap in the literature about Black sub-populations, there is concern that arbitrary racial categorizations make it difficult to track and understand HIV infection in the Black immigrant population. Racial categorization in the U.S. has long been used as a means to separate individuals (Hope-Franklin & Moss, 2008). Legally- sanctioned mistreatment of Blacks in the U.S. persisted well into the twentieth century. The Civil Rights Act abolished the former system of segregation, however various forms of racism and still separate Whites from Blacks in the U.S. (Hope-Franklin & Moss, 2008). Several studies have focused on the systemic divide between races in access to health care and the overall health of African Americans (Braithwaite & Thomas, 2001; LaVeist & Wallace, 2000; Williams & Jackson, 2005). These differences are known as health disparities. Dressler, Oths, and Gravalee (2005) define health disparities as, “differences in morbidity, mortality, and access to health care among population groups defined by factors such as socioeconomic status, gender, residence, and especially race or ethnicity” (p.232). African Americans have higher rates of disparities for a number of health conditions such as; HIV,

tuberculosis and hepatitis and heart disease (CDC, 2010). Literature regarding immigrant populations suggest that some immigrants may prove to be healthier than their native-born counterparts, however over time they may become unhealthier (Gree, Kobayashi, & Prus, 2003; Gushulak, 2007; Singh & Miller, 2004). Afro-Caribbean immigrants with HIV may be underrepresented in research literature due to being classified as “Black”, therefore exposed to mechanisms that place them at risk to be overlooked (Shedlin et al., 2006). Although some literature cites that Afro-Caribbean immigrants, particularly those from the English-speaking Caribbean often fare better than their African American counterparts due to being classified as “model minorities” (Shaw-Taylor, 2007, p. 4), they like other immigrant populations may face stigma and discrimination due to their “minority” status in the U.S. For Afro-Caribbean female immigrants, interaction with the health care system, especially as it pertains to HIV, may prove daunting and they may rely on more holistic or traditional remedies before seeking medical advice (Gillespie-Johnson, 2005; Wheeler & Mahoney, 2008). Research has documented that many African Americans in the U.S. have a mistrust of the medical establishment due to a long standing history of racial inequities (Brandon, Issac, & LaVeist, 2005; Bogart & Thorburn, 2005; Corbie-Smith, Thomas, & St. George, 2002). Afro-Caribbean immigrants may possess some of the same fears due to an inability to navigate the systemic barriers to health care in the U.S. (Wheeler & Mahoney, 2008).

Immigration status.

Immigration status may be correlated with intimate partner violence (IPV) and thereby increase HIV risk. Also having unprotected sex in order to procure a desirable immigration status may be occurring as well (Raj & Silverman, 2002; Shedlin et al., 2006). Immigrants may be categorized by different designations, for example: “naturalized citizens, lawful permanent residents, temporary migrants (such as foreign students), humanitarian migrants (refugees) and

undocumented migrants” (Grieco et al., 2012, p. 1). The particular designation dictates eligibility for a variety of services, including health and social service programs (Jimenez, 2010).

Immigrant populations were adversely affected by two laws enacted under the Clinton Administration: the Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA) and the Illegal Immigration Reform and Immigrant Responsibility Act (IIRIRA) (Fix & Passel, 2002). The PRWORA abolished the former system of welfare in the U.S. by replacing Aid to Families with Dependent Children (AFDC); and replaced it with Temporary Assistance for Needy Families (TANF). TANF was meant to provide temporary assistance to eligible low income children and their families whereas the previous model provided assistance indefinitely (Jimenez, 2010). For legal immigrant populations, the PRWORA also limited access to benefits, such as Medicaid and other means-tested programming, to five years for those who arrived in the United States after August 22, 1996 (Chang-Muy & Congress, 2009). Individuals who lived in the U.S. prior to this date were able to obtain benefits at the discretion of the state where they lived. In addition to time limits, families receiving benefits were required to participate in work training programs and encouraged to find employment (Schoen, 1996). Sponsors of legal immigrants were required to provide financial support for their family members until they met the five-year time limit of eligibility for services (Fix & Passel, 2002). Due to fear and confusion about immigration laws, many legal and undocumented immigrants do not have health coverage (Chang-Muy & Congress, 2009). Since a key feature of this act allowed states to decide how to allocate funding for medical care, some states did choose to use funds to allow immigrant populations to access Medicaid and child care benefits (Chang-Muy & Congress, 2009).

The IIRIRA was enacted shortly after the PRWORA. For undocumented immigrants, the IIRIRA placed sanctions on access to healthcare and other social services. Undocumented immigrants were only allowed access to healthcare services in emergency situations. In addition, strict regulations were dictated deportation of individuals who were found to be in the U.S. illegally, were in the country on expired visas, or had been convicted of a crime (Hagan, Rodrigues, Capps, & Kabiri, 2005). A few years after enacted of this law, immigrant populations were found less likely to have health insurance than previously and that they overall do not understand certain facets of the U.S. healthcare system. Clarke (2004) argued that for Caribbean immigrants these laws had negative effects as basic safety net benefits such as food stamps for families that were already struggling to survive were eliminated. Furthermore, deportation separated families; often leaving one parent in the U.S. responsible for providing care for their families at home. Deportation not only placed strains on separated families, but deportees frequently experienced negative health outcomes after they returned to their countries of origin (Clarke, 2004).

Passed in 1990, the Ryan White Care Act provides “the third largest source of federal funding for HIV care in the U.S. after Medicare and Medicaid” (Kaiser Family Foundation, March, 2013d, p. 1). Under the auspices of the United States Congress, the Department of Health and Human Services and the Health Resources and Services Administration, funds allocated by these governmental agencies were to provide services to individuals living with HIV and their families. Some of the services provided include; HIV testing and prevention services, prenatal and infant care, dental, emergency medical, and mental health treatment. The Program is divided into five “parts” that focus on different aspects of care for families and HIV positive individuals (Kaiser Family Foundation, March, 2013d, p.1). Part A provides funds in the form of grants for

geographic regions or “eligible metropolitan areas” (EMAs) that have 2,000 more individuals diagnosed with HIV and AIDS (Kaiser Family Foundation, March, 2013d, p.1). For those areas awarded monies, a Ryan White Planning council must be created in order to assess the allocation of resources for that geographic area. Under Part B of the program, individuals living with HIV may receive assistance for antiretroviral medications under the AIDS Drug Assistance Program (ADAP). Part C provides services for individuals that have been recently diagnosed with HIV and it provides post-diagnosis support services. In addition, funds are provided for agencies or clinics that administer services to improve current or future services they wish to provide. Part D focuses on providing holistic family-based care for those infected with HIV. These services include “outreach, prevention, primary and specialty medical care and psychosocial services” (Kaiser Family Foundation, March, 2013d, p. 2). Part F provides funding for research (Special Programs of National Significance) with disadvantaged populations living with HIV in order to foster creation of knowledge and programming that focuses on populations with special needs (Kaiser Family Foundation, March, 2013d). One such study was conducted with Afro-Caribbean immigrants living in New York and Florida across multiple sites to assess the role of peer-support for individuals living with HIV (Woldehanna et al., 2007). Also, this section of the program provides dental care, and training for individuals that are engaged in direct practice with those infected and funding for programs that address the needs of minority populations infected with HIV.

Each state may administer the programs in ways that correspond to the unique needs for that state. According to the New York Department of Mental Health and Hygiene, the Ryan White Program provides, “health, housing, mental health, services for alcohol and other drug users, social services including case management, testing, nutrition and other HIV services”

(NYDOHMH website, 2014). In New York, both undocumented and legal immigrants may receive care under this Act (Bachrach, 2013).

Coping and Stigma

For individuals living with HIV, coping with the diagnosis can prove to be challenging. Several studies have addressed various aspects of coping for populations living with HIV (Folkman & Moskowitz, 2000; McCain & Grambling, 1992; Sikkema, Kochman, DiFranceisco, Kelly, & Hoffman, 2003). In Afro-Caribbean populations, coping mechanisms employed by persons living with HIV/AIDS may be related to the stigma associated with the cultural perceptions about HIV present in many Caribbean communities (Stutterheim, Bos, Shiripinda et al., 2012). Goffman (1963) defined stigma as, “an attribute that is deeply discrediting” (p. 3). Furthermore, the stigmatized individual is always seen in terms of social constructs that deem the individual as defective in some way. In one study, stigma related to HIV in Jamaica was found to stem from the belief that acquisition was linked to homosexuality, cultural beliefs about gender, and sexual behaviors (Carr, 2003). In another study, participants expressed sympathy toward women (if not sex workers) who acquired HIV. Stereotypes about female roles in society may still perpetuate blame on the woman (de Bruyn, 1993, as cited in Norman, Carr & Jimenez, 2006). This finding was further confirmed in a study conducted by Stutterheim, Bos, Shiripinda et al. (2012) that revealed stigma in African and Afro-Caribbean communities may be affected by notions that HIV is highly communicable and acquisition of HIV occurs because of deviation from societal norms, especially for females and gay men. Of interventions to address coping with the stigma faced, individuals in Caribbean communities employed cognitive and problem-focused strategies to cope with living with HIV (Stutterheim, Bos, Shiripinda et al., 2012).

HIV Prevention Models

Theory is an intrinsic component for many health behavior models (Fishbein, 2000; National Cancer Institute, 2005). Health behavior models assist in understanding factors that drive human behavior. Various HIV prevention modalities have been used across populations and racial/ethnic groups (Airhihenbuwa & Webster, 2004; Gomez, Hernandez, Fiageles, 1999; Feldman, O'Hara, Baboo, Chitalu, & Lu, 1997; Organista, Carillo, Ayala, 2004; Yep, 1993). DiClemente and Pertersen (1994) in their work on HIV prevention cite the Health Belief Model, Theory of Reasoned Action, Social Learning Theory, and Diffusion Theory as efficacious model for HIV prevention across various racial, ethnic and gendered groups. For African American populations HIV prevention is important due to the disproportionate impact HIV has on this community. However, Wheeler, Hadden, Lewis, Van Sluytman and Parchment (as cited in Poindexter, 2010) assert that common models HIV prevention may not prove effective with marginalized individuals such as sub-populations within the African American community as most models focus on micro-level factors instead of taking into account the complex nuances associated with sexuality and sexual behavior in these populations. With regard to Afro-Caribbean populations Voisin, Baptiste, Martinez & Henderson (2006) explored implementing an HIV prevention program among 15-24 year olds in Trinidad and Tobago. This effort was a collaborative effort between researchers, community agencies and adolescents and their families. The authors contend that a systemic perspective can impact individual adolescent behavior with regard to HIV risk. Another study focused on female injection drug users (IDU) in the U.S. Virgin Islands (Surratt & Inciardi, 2005). This intervention model utilized the Health Belief Model and an Empowerment Model. Key informants were utilized to reach the members of this population. Peer support was advocated as a means to reduce HIV risk this female sub-population. In the U.S. a study with Caribbean populations living with HIV cautiously propose

using peer models and faith-based organizations (i.e. churches) due to the stigma associated with HIV and the possible negative outcomes that may arise if HIV status is disclosed to members of the Caribbean community (Woldehanna et al., 2007). Yet another study of Caribbean immigrants in New York found that micro, mezzo, and macro level factors served as barriers to access and utilization of healthcare services especially for undocumented immigrants (Pivnick et al., 2010). This study also suggested that due to the various factors that mitigated access to services, the Social Ecological Framework would provide a lens through which these factors could be more readily understood and explored.

Social Ecological Model

Bronfenbrenner's (1979) Ecological model also posits that an individual should be understood within the context of systems. This perspective was originally conceptualized as a mechanism to assess child development, however since its creation; many have used this model in various disciplines to explore systemic factors (Robinson, 2008; Lewis, 2012; McDonald, 2006; McQuaid, 2005). In addition, it has been used in understanding factors related to sexually transmitted infection risk and infection (DiClemente, Salazar, Crosby, & Rosenthal, 2005; Green, Frey, & Derlega, 2002).

This model encompasses four interrelated systems that act upon each other. At the micro and mezzo levels interpersonal, relational, and community-level influences are considered (i.e. individual health, gender, familial relationships, an individual's neighborhood, knowledge, attitudes and beliefs) (National Cancer Institute, 2005, p. 11). The next level, the exosystem is comprised of organizations, individuals or entities that may not exist in the individual sphere, but nonetheless may have an influence on the individual. (National Cancer Institute, 2005). Lastly, the macrosystem is the wider sphere that influences the individual. Culture, policy, and government are examples of macro level factors (National Cancer Institute, 2005). The Social

Ecological Model is similar in nature to a phenomenological approach in that it allows for an individual to be viewed in light of their given environment and focuses on understanding the complex phenomenon that impact an individual both directly and indirectly. The studies presented that focus on Caribbean populations and HIV risk demonstrates that risk occurs on the various levels explicated by Bronfenbrenner (1979).

Gaps in the Literature and Current Study

Much of the literature in the U.S. focuses on HIV risk for Afro-Caribbean immigrant populations. Risk factors for Afro-Caribbean women in the U.S. include increased access to sexual partners in the New York City metropolitan area (Shedlin et al., 2006), low perceived ability to negotiate condom use with sexual partners (Hoffman & colleagues, 2008), low perceived susceptibility to acquiring HIV (Gillespie-Johnson, 2005); cultural ideologies that inhibit Caribbean individuals from talking about sex (Gillespie-Johnson, 2005), immigration status and intimate partner violence (Raj & Silverman, 2002), immigration status and reduced access to benefits due to immigrant legislation (Chang-Muy & Congress, 2009) and stigma associated with HIV in many Caribbean islands (Anderson et al., 2010; Archibald, 2010; Carr, 2003; Aggleton, Parker, & Maluwa, 2003; Norman et al. 2006; Stutterheim, Bos, Kesteren et al., 2012). The few studies that have focused on those living with HIV (Pivnick et al., 2010; Woledehanna, Thomas, & Clarke, 2007) have indicated that more research needs to be undertaken to understand the life experiences of Afro-Caribbean immigrant women living with HIV in the U.S. This review of the literature indicated gaps in the areas life after diagnosis, immigration status, coping, ties with formal and informal services and self-perception.

Currently, we do not have a complete picture regarding what life is like for these women living with HIV. In 2009, a preliminary study was conducted in order to determine how best to investigate this phenomenon. After obtaining permission to conduct the study from the

University of Alabama Institutional Review Board (IRB), a discussion group was convened with five HIV positive Afro-Caribbean immigrant women in New York City with the assistance of two Afro-Caribbean women who were considered key informants. The purpose of this discussion group was to explore their views about research and what they felt were the best research practices to utilize in work with this population. The group session was audio-recorded and lasted approximately one and one-half hours. *NVivo8* software was used to store and code data. Results from the study indicated that the women felt that factors such as immigration status, length of time since diagnosis and culture may affect a woman's willingness to speak about her experiences living with HIV. In addition, they felt that a variety of methods should be used and that "one size does not fit all." Three of the participants had previously been involved in research studies. Some indicated that they felt researchers obtained information but had very little contact with participants afterward. Furthermore, one participant noted that research should be a collaborative effort between researchers and those infected, and that women should have a say in what types of research is being conducted. She indicated that community advisory boards are effective in achieving this goal. Informal networks also proved to be an important aspect of living with HIV and of participation in research. Participants also noted that researchers should be sensitive to the stigma surrounding HIV in Caribbean communities. These results, review of previous studies (Anderson et al, 2009b; Anderson et al., 2009a; Perry, 1997; Norman et al. 2006), interaction with key informants (the two that assisted in this study and previous persons that were contacted during the two years prior to the study) and life experiences assisted the researcher in formulating questions and conceptualizing a dissertation study that would add to the knowledge about Afro-Caribbean immigrant women from the English-speaking Caribbean infected with HIV.

CHAPTER 3

METHODOLOGY

The purpose of this research study was to explore the lived experiences of Afro-Caribbean immigrant women living with HIV/AIDS. This chapter explicates the research design and rationale for the method used to conduct this study, theoretical framework, sampling procedures, recruitment, data analysis, and steps taken to ensure rigor and trustworthiness.

Research Design

In order to facilitate a deeper understanding of the experiences of this sample population, a qualitative phenomenological research design was used. There are various types of methods that constitute a qualitative design (i.e., Grounded theory, case study, narrative), and these methods have many common characteristics. Moustakas (1994) identified the unifying qualities of qualitative design as:

1. Recognizing the value of qualitative designs and methodologies, studies of human experiences that are not approachable through quantitative approaches;
2. Focus on the wholeness of experience rather than solely on its objects or parts;
3. Search for meanings and essences of experience rather than measurements and explanations;
4. Obtain descriptions of experience through first person accounts in informal and formal conversations and interviews;
5. Regard the data of experience as imperative in understanding human behavior and evidence for scientific investigations;

6. Formulate questions and problems that reflect the interest, involvement, and personal commitment of the researcher;

7. View experience and behavior as integrated and inseparable relationship of subject and object and of parts and whole (p. 21).

Of the methods that constitute a qualitative design, phenomenology proved to be the approach best suited for this study.

Phenomenological approach.

A phenomenological approach allows the researcher to explore the meanings that individuals attribute to their lived experience (Marshall & Rossman, 2006; Moustakas, 1994). Van Maanen (1990) asserted: “the meaning of lived experiences is usually hidden or veiled” (p. 27); therefore, the phenomenological approach seeks to uncover the “hidden meaning” or essence of a phenomenon.

The philosophy of phenomenology was developed in the early 19th century beginning with Franz Brentano (Speigelberg, 1982). It was later expanded by the German mathematician and philosopher Edmund Husserl, a student of Brentano, who is often credited with phenomenology (Kockelmans, 1967). Phenomenology seeks to describe how individuals experience the world in which they live. People are often aware of what they are experiencing—and their conscious response to it.

The ways in which a person experiences and thinks about his or her experience is at the heart of phenomenology. Hence, the concept of *intentionality*, or the focus of one’s consciousness on an object, that is to say, the ways in which we view or think about a thing or its meaning, is a key feature of Husserlian phenomenology (Kockelmans, 1967, p. 34). Another core tenant is *phenomenological reduction* or bracketing, which asserts that an individual can identify

his or her own biases, feelings, or assumptions in order to view the world or phenomenon from a new vantage point and explicating the essence of the phenomenon (Dowling, 2007; Kockelmans, 1967). From this philosophy, the science and method of phenomenology has grown.

A phenomenological approach explores individuals in their own environment and allows individuals to describe their experiences from a unique vantage point (Creswell, 2007). The researcher acts as an observer and interpreter while aiming to minimize bias and look at the phenomenon afresh (Moustakas, 1994; Priest, 2002). Phenomenology is also utilized when there is limited information about a topical area that other research designs have not addressed (Creswell, 2007). Due to the paucity of literature with the population in this current study, a phenomenological approach provided a holistic and in-depth approach for exploration of this topical area. Guided by a semi-structured interview guide, in-depth interviews were used to explore the phenomenon and data were analyzed according to Creswell's (2007) Simplification of the Stevick-Colazzi-Keen Method of Phenomenological analysis, created by Moustakas (1994).

Pilot study.

In preparation for this study, this author conducted a pilot study in July 2009. The study explored the thoughts and feelings of Afro-Caribbean immigrant women living with HIV/AIDS about participation in research as well as what research methodologies they deemed best to conduct with this population. A focus group was conducted with five HIV infected Afro-Caribbean immigrant women in New York City. While these women did not advocate for one particular methodology, they affirmed that in research "one size does not fit all." The women also stated that they felt members of the research community often "speak for them" instead of allowing them to speak for themselves. They advocated for the use of community-based research

that would allow Afro-Caribbean women to have a voice regarding the types of research conducted with this population.

Participants also asserted that factors related to immigration status, time since HIV diagnosis, and comfort with speaking out about their status might affect whether women would participate in research. Anderson and colleagues (2009a) posited that in Afro-Caribbean communities the stigma associated with HIV and mistrust of researchers are potential barriers for engagement in research. These authors also advocated for the use of community advisory groups comprised of Afro-Caribbean professionals to assist in recruitment and to advise researchers of potential pitfalls. The pilot study conducted by this researcher yielded similar recommendations for engagement of this population.

Recruitment and Sampling Procedures

Recruitment for the study occurred between November, 2011 and February, 2012. Key informants who assisted me with the pilot study provided a list of approximately 20 potential community recruiters who would be able to identify potential participants for the study. Several of these recruiters were also members of the New York City HIV Prevention Planning Group (PPG) who worked in various community agencies throughout the New York City area, and provided services to those living with HIV. The potential community recruiters were contacted by phone or email to make initial introductions, build rapport, discuss the purpose of the study, and confirm their interest in assisting me with the recruitment of Afro-Caribbean immigrant women for the study. Most potential recruiters responded to me by email. Upon my arrival in New York, potential recruiters were contacted once again, and face-to-face meetings were arranged to re-introduce myself and to answer any questions they had about the study. If potential recruiters felt they could not be of assistance to me, they provided the names and contact information of others in their network that could.

Study participants were recruited by a total of six community recruiters. Community recruiters were provided with recruitment flyers (Appendix B) to post on bulletin boards in strategic locations of clinics and community centers, or to give to potential study participants. Community recruiters also invited me to attend various formal and informal meetings to discuss the study and distribute flyers to potential participants, which increased the visibility of the study.

Potential study participants identified by the community recruiters contacted me directly (information contained in the flyer) or gave verbal permission to the recruiter to give their information to me. Individuals that expressed interest in the study were contacted by me to review the study purpose, inclusion criteria, and answer any further questions they had. Once it was determined that the potential participants met inclusion criteria, a date and time was arranged to conduct the interview. Community recruiters reported they sometimes faced difficulty in reconnecting with individuals that had expressed interest. Throughout the study, recruiters alerted me to three individuals that formerly expressed interest, but due to those individuals' lack of follow-up, the recruiters continued to identify other women for the study.

Purposive and snowball sampling were used to identify eight Afro-Caribbean immigrant women aged 27-57 living with HIV. Six of the eight participants were obtained by the community recruiters and the remaining two were identified by one of the six participants (snowball). Purposive sampling permitted me to choose individuals who had experienced the phenomenon (Hesse-Biber & Leavy, 2011), and snowball sampling facilitated engagement of other women who experienced the phenomenon by utilizing the "personal networks" of current survey participants (Hesse-Biber & Leavy, 2011, p. 47). Polkinghorne (1989) suggested that 5 to 25 individuals represent an adequate sample for a phenomenological inquiry (as cited in

Creswell, 2007); and so this study is consistent with this recommendation. Due to the nature of the phenomenological method and the data generated from it, a small study sample allowed the researcher the ability to obtain detailed descriptions of the life experiences of participants (Van Manen, 1990). Eligible participants were 19 years of age or older, self-identified as an Afro-Caribbean immigrant woman from an English-speaking Caribbean island and living with HIV.

Both recruitment and interviews were terminated when saturation was reached.

Saturation or redundancy is the process whereby the information obtained from participants becomes redundant, such that no new information is forthcoming (Hesse-Biber & Leavy, 2011; Lincoln & Guba, 1985). In this study, redundancy in thematic elements of the interviews occurred at the sixth participant; however interviews with the remaining two participants had been scheduled and were conducted. These served to further confirm thematic elements discovered in the previous interviews. The themes of good care, stigma, genesis, relationship and immigration challenges emerged clearly from the voices of the study participants (see Chapter 4).

Data Collection

Location of Interviews

One of the recruiters assisted in obtaining a venue at a local health clinic for interviews to be conducted, however, most participants did not feel comfortable meeting at this location. Consequently, four of the eight participants asked for the interview to be conducted in their homes. Of the remaining interviews, two were conducted at the participants' place of work, and the other two were held at different local health clinics.

Interview Guide and In-depth interviewing

In-depth interviewing is an approach that is used to capture detailed descriptions of the life experiences of participants that display the various contexts, emotions, and events that surround them (Hesse-Biber & Leavy, 2011). Marshall and Rossman (2006) asserted that in a phenomenological study, in-depth interviews “rest on the assumption that there is a structure and essence to shared experiences that can be narrated” (p. 104). According to Guion, Diehl, and McDonald (2011) in-depth interviews consist of “open-ended questions, semi-structured format, understanding and interpretation and recording of responses” (p.1). Following these steps I utilized a semi-structured participant interview guide (Appendix C) that contained open-ended questions aimed at eliciting information from each participant about their unique life experiences. Questions for the interview guide were constructed by review of existing literature (Anderson et al., 2009b; Anderson et al., 2009a; Perry, 1997; Norman et al. 2006), consultation with key informants, and information from the pilot study. Along with using the questions in the interview guide, I remained flexible allowing for new questions to emerge, be removed, or modified as appropriate during each interview. Throughout the interview process, participants sometimes answered multiple questions contained on the interview guide while discussing another topical area. This allowed for a free flow of conversation and permitted the participant to discuss the topical area at her own pace. The interview guide and additional questions were able to elicit information about these women’s experiences on several domains including their personal, cultural, social, and relational perspectives. The information obtained through in-depth interviews, is classified by Hesse-Biber & Leavy (2011) as “knowledge-producing conversation(s)” (p.105).

One of the main goals of in-depth interviewing is to provide “thick description.” Thick description “captures the thoughts and feelings of participants as well as the often complex web

of relationships among them” (Ponterotto, 2006, p.543). I attempted to capture these “relational aspects of the participants’ lives. Several “relational descriptions” were given by the women in this study. Relational descriptions are “those that bring relationship alive” (Ponterotto, 2006, p.544) and were captured throughout the study, such as when participants described the relationships they had with their families, care providers, or community agencies; and the relationship between participants and the two cultural paradigms as modeled in the U.S. and Caribbean contexts. In addition, some descriptions based on in-depth interviews can be classified as biographical, that is to say the events the participants described, were at a certain time-period in their lives that held significance for them (Ponterotto, 2006). The participants provided this narrative—about their lives pre- and post-diagnosis—throughout their interviews. While the interview guide and the interview process seeks to “gain rich qualitative data on a particular subject from the perspective of selected individuals” (Hesse-Biber & Leavy, 2011, p. 95), several factors may impinge on the nature of the information provided such as the degree of comfort the participant has with the subject matter, issues related to availability and their understanding of the questions asked (Marshall & Rossman, 2006). During the course of the interview, if a participant did not understand a question, I re-phrased the question in order to clarify it. I also attempted to provide a comfortable and safe environment that encouraged them to share their stories; paying particular attention to verbal and physical cues (i.e. body language) displayed by participants to gauge their comfort/discomfort, and determine if further exploration about a certain topic would be appropriate (Marshall & Rossman, 2006; Hesse-Biber & Leavy, 2011; Patton, 2002).

Epoche, Journaling, and Memos

As previously described, the practice of epoche allows the researcher to set aside any bias or predetermined ideas in an effort to experience the phenomenon afresh (Moustakas, 1994).

Prior to conducting an interview, the researcher wrote about her experiences in an attempt to bracket her experience. Journaling also assisted the researcher in navigating the context of the environment (New York City) and how the environment may have impacted study participants. Memos were written before and after data analysis of each participant as a way to keep a running log of decisions made regarding coding, thematic elements, textural descriptions, and structural descriptions.

Interviews

As can be seen in Table 3.1, interview times ranged from Approximately 34 minutes to one hour and 47 minutes. Interviews were conducted were conducted in participants' homes, work places and at participant-identified local area clinics. Participants discussed their life experiences in interviews. Variation in the length of interviews, particularly the shorter ones, may have been due to the fact that these particular participants were recruited for the study through snowball sampling and may not have been as familiar with the research process in general, or may have been more interested in doing a "favor" for the friend who asked them about participating, than about contributing to a professional's knowledge about their experiences. It is also possible that they may have been interested solely for the incentive provided to participants.

For each participant, the researcher explained the purpose of the study as well as risks and benefits, and obtained signed copies of the informed consent form (Appendix B). Each participant was given a copy of the informed consent form, the researcher's contact information, and a list of community resources (Appendix D). Permission to audio record interviews was obtained from participants. Additionally, participants were asked to sign a form that they consented to be re-contacted for member checking and to review findings. The researcher was furnished with information of the participants' choosing about how best to re-contact them. Each

participant was informed of her rights and that she could withdraw from the study at any time without penalty.

Table 3.1

Summary of Interview Times

Participant	Interview Length
Betty	1:47:19
Empress	1:18:39
Faith	1:10:08
Flor	52:59
Charlene	52:17
Simone	48:14
Starr	33:36
Julie	33:52

To protect confidentiality the researcher asked each participant to choose a pseudonym. After the pseudonym was chosen, each participant was referred to by this name throughout the interview. In appreciation for their time, participants were given an incentive of either a MetroCard (a subway voucher) or a PathMark (a local grocery store) gift card; both were valued at \$25.00. Upon completion of the aforementioned process, the researcher queried each participant to ascertain if she understood all of the information provided and if she had any questions prior to commencement of the interview. The interview guide contained open-ended questions, which allowed participants to elaborate and describe their experiences (Hesse-Biber &

Leavy, 2011). Once the interview process was completed, all interviews were transcribed by the researcher.

Demographic Information

At the beginning of the interview, participants were informed that the researcher would collect demographic information (Appendix E). Most demographic information was collected during the interview. Any information that was not addressed during the interview was collected at the end of the interview. Demographic data included participant age, relational status, length of time living with HIV, income, country of birth, length of time in the U.S., number of individuals living in the home, length of time receiving antiretroviral therapy, and insurance status. These questions provided important overall composite background information for the participants.

Field Notes

Immediately after each interview, the researcher used field notes (Appendix F) to capture key observations made (e.g., body language, facial expressions, feelings) during the interview. Since the setting for each interview was different, completing field notes immediately upon terminating the interview was challenging at times. Regardless, every effort was made to engage in this practice directly after the interview. Findings of previous studies indicate that field notes assist by reminding the researcher of the context in which the interview was conducted (Berg, 2009; Taylor & Bodgan, 1998).

Data Analysis

Data were analyzed according to Creswell's (2007) Simplification of the Stevick-Colaizzi-Keen Method of Phenomenological Analysis, created by Moustakas (1994), as seen in Table 3.2.

Table 3.2

Creswell's Simplification of the Stevick-Colaizzi-Keen Method for Phenomenological Data Analysis

Method of Analysis	
1.	The researcher engages in epoche (bracketing).
2.	A list of significant statements is developed.
a.	The researcher identifies specific statements that are relevant to the participant's experience.
b.	The researcher lists all the statements that are deemed relevant to the phenomenon. All statements are given equal value. This process is called horizontalization.
c.	A list of non-repeating, non-overlapping statements is listed.
3.	Significant statements (meaning units) are grouped together and listed under a theme.
4.	Meaning units and themes are used to construct a textural description. This description tells "what" the participant experienced. Verbatim examples are to be used.
5.	Next, the research reviews the textural description to ascertain what structures underlie the textural description. This description is the "how" of the participants' experiences. Moustakas (1994) listed these as: "relation to self, relation to time, space, bodily concerns, causality, and relation to others" (p. 99).
6.	Finally, a composite description of the phenomenon was formulated from the textural and structural descriptions. The composite description represented the essence of the phenomenon for the participants.

Source: Creswell (2007, p. 159). *Qualitative inquiry & research design: Choosing among the five approaches*.

After reviewing various types of qualitative data analyses (Chambers, 2009; Lacking, 2007; DeGroat, 2008; Chicoine, 2003), this researcher felt that, due to the nature of the study, Creswell's Simplification of the Stevick-Colaizzi-Keen Method would allow for a thorough analysis and explication of the experiences of the participants.

Creswell (2007) argued that this method provides “systematic steps in the data analysis procedure and guidelines for assembling the textural and structural descriptions” (p. 60). In the first step, I “bracketed” my experiences prior to engaging with the data (written transcripts and audio taped interviews). In the second step, I read through the transcripts several times while listening to the digital recording as a way to review the material again for errors. Every statement expressed was given equal weight. This process is called horizontalization (Moustakas, 1994).

The third step called for the selection of significant statements. In order to arrive at the significant statements I listened again to the digital recording. While listening to the recording track, changes were used in Word in order to document words and phrases that caught the my attention. I then reflected on the notations and words in track changes and also wrote memos (procedural notes) that detailed why these words or phrases were chosen. I then listened once again to the audio recording. While doing so, colored “post-it” notes for each participant were posted on a white board for review, to record words and phrases. When all interviews were completed by this method, I reflected on all of the words and phrases that encompassed participants’ experiences. A table was created that listed the words and phrases for each participant. Subsequently, I was able to go back to the written transcripts and highlight sentences that were essential to understanding the experience of each participant.

From this process I was able to complete the third step of choosing significant statements (meaning units). Each of these statements was non-repeating, non-overlapping that reflected important aspects of the participant experience. Once meaning units were established, themes began to emerge. All meaning units were clustered under an emergent theme. The themes and significant statements were then used to formulate a textural description.

Moustakas (1994) described textural descriptions as “what” the participants’ experience. This description includes verbatim examples. After the textural descriptions were formulated, the structural description was written. A structural description utilizes what Moustakas (1994) referred to as, “imaginative variation” (p. 99). In this step I thought about different perspectives from which the experience could be viewed. The assumption of this step is that there may be different interpretations or understandings of an individual’s experience; however, Moutakas listed different structures that may underlie experience including the “structure of time, space, bodily concerns, materiality, causality, relation to self, or relation to others” (p. 99). These structures are “intimately connected with the essences and meaning of an experience” (p. 99). After the structural description was formulated for each participant, the composite description was written utilizing the textural and structural descriptions. The composite descriptions explicated the essence of the lived experience for the group as a whole. I then created tables that identified the major themes that emerged from the data as well as the prominent structural themes.

Much has been written about issues of trustworthiness and rigor, both of which are critically important in qualitative studies. Due to the inductive nature of qualitative research and its reliance on data generated from sources such as interviews, field notes, and memos, being able to account for measures taken to ensure rigor are vital (Marshall & Rossman, 2006).

In their seminal work Lincoln and Guba (1985) assigned distinct terminology for issues of trustworthiness and rigor in qualitative research. The authors listed four facets of rigor: “credibility, transferability, dependability, and confirmability” (p. 300). Credibility in qualitative inquiries denotes how the researcher has accounted for the various viewpoints or realities that may be present in an investigation. It also addresses how one knows that the materials presented

are in fact, “credible.” As previously stated, qualitative research seeks to explore phenomenon from the perspective of the individual being researched and what it means to him or her (Van Maanen, 1990). Key informants provided the researcher with knowledge of working with Afro-Caribbean populations infected with HIV. This information allowed the researcher to think about the difficulties that she may have encountered in the field. In addition, many of the key informants and community recruiters were available for follow-up consultation, which allowed for continued/ongoing engagement with them. The researcher also engaged in peer debriefing with an experienced qualitative researcher not involved with the study. During this process, the researcher presented her analysis of the study (codes, significant statements, development of themes, etc.). Memos and journal entries were reviewed and discussed in light of how the researcher made decisions about how the data was presented. Meetings took place on a weekly basis so the peer debriefer could monitor the evolution of the analytic process.

The researcher also engaged in member checking with participants. The researcher made attempts to re-contact participants with the contact information given to the researcher during the study in order for them to assess the validity of the findings. Five out of the eight participants contact information was no longer valid (i.e. changed telephone number). The researcher made contact with two participants at which time the researcher re-introduced herself and asked if they were willing to engage in the member check process. Once permission was granted, the researcher sent “test emails” to the participants. Once they confirmed that the email account was correct, the researcher forwarded a member check document that included the purpose of the study, demographic information, summary of general findings and then their individual findings. Each document was password protected. The researcher provided participants with the password. One participant followed through and read the document and informed the researcher that the

conclusions drawn and results accurately depicted her experience living with HIV. The researcher attempted on several occasions to re-contact the second participant but was not able to do so. In addition, field notes, journal entries and memos were used to capture data for personal insights of the researcher and procedural notes. Field notes were also used record observation and insights after each interview that would assist the researcher in remember the context of setting, important words/phrases, and lessons learned.

Transferability is the ability of the findings of the study to be transferred to another context (Lincoln & Guba, 1985). This idea is not one of generalization as in quantitative designs, where a researcher indicates that the results of the study based on quantifiable facts can be generalized to other populations, but more that the descriptions of the phenomenon provided may allow another person to infer that the results may be applied to another study. The participants provided detailed descriptions about several aspects of their life experiences living with HIV. For example, many of the participants spoke about their lives prior to HIV and then finding out about their diagnosis. Some descriptions evoked strong emotions as they recounted their experiences. Many of the participants also described the stigma and discrimination that HIV positive individuals encountered in the Caribbean. In one instance, the idea of being treated like a “leper” was described by one participant. In other instances, participants detailed their lives prior to contracting HIV. For example, Betty spoke about her constant fear of finding out if she was infected with HIV, following a test in her home country that indicated that she *may* be positive. She took a follow-up test, but did not go back for the results. This pattern continued even after arriving in the United States. From the time of her first test, to the time she definitively found out she was HIV positive approximately 6 years elapsed. During this time, she struggled with the possibility that she may be HIV positive. In another instance, Flor described her process in

deciding to take charge of her treatment for HIV by “looking in the mirror” (Chapter 4). According to Lincoln and Guba (1985), transferability is determined by those that read the accounts of the individuals that have experienced the phenomenon under study. As such, the descriptions provided the “what” and “how” of each participant’s experience (Moustakas, 1994). These descriptions assist the reader in understanding the context and meanings that are given to their life experience (Moustakas, 1994; Van Manen, 1990). These descriptions in addition to the method of analysis chosen, which utilized both textural and structural descriptions and the development of themes, assist the reader in being able to identify the common threads of each participant’s experience. The descriptions make it possible for the readers to assess the level of transferability of experiences of these women to other studies and contexts.

The researcher’s conclusions and quality of findings as indicated in dependability were addressed by having an audit trail assessed by the researcher’s dissertation committee chair and the aforementioned experienced qualitative researcher.

Confirmability assesses the soundness of the conclusions drawn in the data. It asks “whether the findings of the study could be confirmed by another” (Marshall & Rossman, 2006, p. 203). In order to account for this, I consulted with an experienced qualitative researcher on a weekly basis to review the memos (detailed descriptions of how I arrived at significant statements and themes), textural and structural descriptions and the composite description of the participants’ experiences and discuss the research process as it unfolded. Feedback was given in person and through email communication. My dissertation chair also provided feedback about the aforementioned materials as well (Hesse-Biber & Leavy, 2011; Lincoln & Guba, 1985). I remained reflexive by bracketing my experiences through journaling about the personal insights

gained from the study and how the researcher was experiencing the phenomenon. Table 3.3 lists the steps I took in order to address issues of credibility and trustworthiness in this study.

Table 3.3

Criteria for Trustworthiness and Rigor in Qualitative Inquiries

Criteria	Steps Taken
1. Credibility	<ul style="list-style-type: none"> • Use of key informants knowledgeable about cultural nuances and experience working with population • Continued/ongoing engagement with key informants in New York Metro area (Lincoln & Guba, 1985, p. 302) • Peer debriefing (Padgett, Matthew, & Conte, in Padgett, 2004) • Member Checking • Field Notes (Berg, 2009; Taylor & Bodgan, 1998)
2. Transferability	<ul style="list-style-type: none"> • Rich, thick, descriptions (Lincoln & Guba, 1985 p. 328)
3. Dependability	<ul style="list-style-type: none"> • Journaling about how decisions were made about coding and results (Audit Trail) (Padgett, 2004) • Bracketing
4. Confirmability	<ul style="list-style-type: none"> • Journaling (Padgett, 2004) • Audit Trail (Lincoln & Guba, 1985) • Memos (Hesse-Biber & Leavy, 2011) • Code Book • Listing of how codes and subsequent themes were created • Reflexivity (Krefting, 1991) • Peer examination (Krefting, 1991)

From (Lincoln & Guba, 1985)

Study Limitations and Strengths

As previously mentioned, the stigma associated with HIV in many Caribbean communities is severe (Aggleton et al., 2003). As such, some participants may not have felt comfortable disclosing certain information during the interview process. However, due to the gap in the literature with regard to this population, the information provided by participants will

assist in forming a holistic picture of issues related to living with HIV/AIDS for Afro-Caribbean immigrant women in the United States.

Another limitation of this study was that it only elicited information from Afro-Caribbean immigrant women from the English-speaking Caribbean. Due to the cultural and linguistic diversity of the Caribbean region, this current study was a starting point and may not represent the experiences of individuals from non-English speaking Caribbean populations. Furthermore, the women selected for participation in this study lived in the New York City area. This may be a limitation in that the experiences of women from the New York City area may vary from those in other geographic locations in the United States due to region-specific factors (e.g., immigration policies, access to resources for documented/undocumented immigrants, budgetary constraints of the city/state).

Another limitation observed was that the shorter interviews by the participants obtained through snowball sampling may have been due to several factors such as comfort of the participants, time constraints of the women, and possible participation in the study due to “doing a favor for a friend.” I attempted to address these issues by scheduling interviews at a time and place deemed comfortable for each participant, answering questions related to the study or as they arose, and using probes to elicit more information from participants. Although, as mentioned previously, all questions were not asked in the interviews because in many instances participants would answer questions naturally during the flow of conversation or based on a stream of consciousness. The richness of the responses may have been impacted by the aforementioned factors. However it is important to note that even in the shortest interviews, the information provided by the participants resulted in information congruent with the thematic elements observed in the other six interviews. Despite the aforementioned limitations, the

scarcity of existing literature regarding the experiences of this population denoted the need for research. Furthermore, the method chosen to undertake this inquiry provided detailed accounts of the lives and experiences of Afro-Caribbean women. These descriptions may provide information that will assist in the creation of policies, interventions, and provision of culturally-competent practices for this population.

IRB Considerations

The application to conduct the study was approved by the University of Alabama IRB (see Appendix B). All documents pertinent to the study were kept under the strict supervision of the researcher. Digital information (i.e., Word documents, digital recordings) was kept on the researcher's personal computer and was password protected. All hard copies of information, such as transcripts, were kept in a locked, secured file cabinet.

After verbal consent was given, face-to-face meetings were arranged in which the researcher discussed the purpose of the study and reviewed the informed consent with each participant. Once the participant indicated that she understood the information presented to her, she signed the informed consent as evidence that she understood the purpose, confidentiality, risks and benefits, voluntariness of participation, and her right to refuse or withdraw for the study at any time without penalty.

Participants also signed a consent form indicating that they agreed for the interviews to be audiotaped. An additional consent form was signed that gave the researcher permission to re-contact participants for member checking. This consent also allowed the researcher to provide results of the study to participant if they indicated a preference for receiving them. Participants were given a copy of the informed consent to keep for their records, including contact numbers if they had any additional questions or concerns about their participation in the study at some point in the future. Two participants declined copies of the informed consent document due to

concerns about family members finding paperwork that was connected to a study about HIV/AIDS.

A digital recorder was used to audio record each interview. Following each interview, audio recordings were downloaded onto the researcher's computer and placed in a password protected file.

Member Checking

All participants consented to be re-contacted in order for the researcher to engage in member checking. Each participant provided their contact information at the time of consent for this process. After analysis of the data, the researcher attempted to contact participants with the information provided. One of the eight participants provided feedback. The remaining participants were not able to be reached due to a change in contact information or not responding to attempts to contact them. A document that re-stated the purpose of the study (Appendix H), the major findings of the study, and a narrative of the findings for the individual participant was constructed. To ensure confidentiality, the researcher sent a test email to participants to ensure that the email address was correct. Following this, a password was sent to the participants for access to their own specific "member check document." Subsequently, the document was sent for the participant's review. A meeting day/time was then set with the researcher for a phone call to review the document and obtain feedback concerning the accuracy of the lived experience of the participant. Each participant reported that they thought that the researcher described their experiences of living with HIV accurately. One participant stated that she felt that a significant part of living with HIV was how one thinks about the situation. She stated, "If you keep thinking the way you think you can't live. You won't change." She also noted that many Afro-Caribbean immigrant women live in fear because they don't have good support networks. She encouraged the researcher to continue to conduct studies with this population.

Potential Risks and Benefits to Society and Participants

While most studies present risks and benefits, this researcher anticipated that there would be minimal risks for participants. However, due to the sensitive nature of the topical area, the researcher provided a list of local area support and counseling services for each participant in the event that they required assistance in processing distressing emotions as a result of study-related questions. To promote the well-being of these individuals, each participant was informed that she could terminate the interview due to any form of distress, and the researcher would resume the interview at a later date. Since confidentiality was paramount to this study, the researcher asked each client to choose a pseudonym (false name) to protect her identity. Two of the eight participants declined to choose a pseudonym. Therefore, in order to protect participant integrity, the researcher changed the names these individuals provided.

As noted by Moustakas (1994), researcher bias is an important factor to consider in qualitative research. To make sure that these women's stories were accurately reflected, the researcher bracketed her experiences. Bracketing allowed the researcher to set aside her assumptions and to learn to see participant experiences with new eyes. The risk of researcher bias was minimized by frequent memos and peer debriefing.

Due to the lack of literature pertaining to Afro-Caribbean immigrant women with HIV/AIDS, this study provides an important commentary about the life experiences of this population. Additionally, each woman was able to tell her story from a unique vantage point. This study may be transferable to other populations, provide information about recruitment of vulnerable populations, and assist in developing culturally-sensitive approaches for immigrant populations living with HIV/AIDS.

CHAPTER 4

RESULTS

The previous chapter focused on the research methodology used in the study. Data collection strategies and measures taken to ensure rigor were described and limitations of the study findings based on methodology and ethical considerations in conducting the study were discussed. This Chapter will present the data along with synthesis of findings for identification of the major themes of the study.

As stated previously, this phenomenological investigation explored the lived experiences of Afro-Caribbean immigrant women living with HIV/AIDS. Data collected in this study was analyzed using Creswell's (2007) Simplification of the Stevick-Coliazzi-Keen for Phenomenological Analysis created by Moustakas (1994). This method provided a step-by-step guide for focusing on epoche (bracketing), horizontalization of the data, and development of individual textural descriptions, individual structural descriptions and a composite description of all of the participants' experiences (Moustakas, 1994, p. 122).

Through the process, the "essence" of each participant's experience of living with HIV/AIDS was extracted. This chapter will provide data for understanding the experience for each individual and also for developing overall themes that describe the experience of the phenomenon for this group of women.

Participant Demographics

The eight participants in this study ranged from 27-57 years of age. As seen in Table 4.1 the countries of origin for the participants were Jamaica, Trinidad & Tobago and Barbados. This

demographic is similar to the foreign-born Caribbean populations in New York City where among those from the English-speaking Caribbean, Jamaicans and Trinidadians populations represent the majority of individuals from the English-speaking Caribbean. Seven of the participants contracted HIV through heterosexual transmission and one through a work-related incident. At the time of interview, five participants were single and not involved in a significant relationship. Two of the participants indicated that they were engaged, one was married, one was widowed, and the other five participants indicated that they were single and not involved in significant relationships at the time of interview. The length of time of participants' had lived in the U.S. ranged from 4-50 years. Most participants were insured and had a primary care physician. Table 4.1 displays demographics for each participant.

Detailed Presentation of Findings

The following sections will detail the results according to the steps outlined in the Stevick-Colazzi-Keen Method. These steps include identification of meaning units (statements that are relevant to understanding the participants' experience) and grouping of significant statements under emergent themes specific to each participant's experience. After these individual results are presented, the group textural and structural themes and a composite description that signifies the essence of the phenomenon are presented.

Meaning Units-Betty

1. ...I knew it was a disease. Sexually transmitted, um and there was a lot of talk about um mosquito bites or whatever
2. I mean...I...I knew of it but I never really thought much about it
3. I never really consider...I didn't put it...put much consideration about it.
4. When I got tested and then they said um that my test came back positive- um it was shocking, but then like 3 days later, they came back um, the person came back to my house and said that you know there was...something went wrong with the testing wasn't done properly.

Table 4.1

Participant Demographic

	Betty	Charlene	Simone	Flor	Julie	Faith	Empress	Starr
Age	37	47	27	29	49	42	57	43
Relational Status	Single	Single	Engaged	Engaged	Single	Married	Single	Single
Household Income	0-9999	0-9999	0-9999	0-9999	0-9999	10-19999	40-49,999	0-9999
Number In Home	2	2	4	10	3	3	1	2
Length of Time in U.S.	4 yrs	20+ yrs. (34 yrs.)	15 yrs.	20+ yrs.	15 yrs.	8-11 yrs.	50 yrs.	12-15 yrs. (13 yrs.)
Living with HIV	2-15 yrs Multiple tests;	24 yrs.	8-11 yrs.	8-11 yrs.	7 yrs. (2004)	4-7 yrs. (5 yrs.) (2006)	12-15 yrs. (Aug. 1996)	7 yrs. (2004)
Birthplace	Jamaica	Trinidad	Trinidad	Barbados	Jamaica	Tobago	Jamaica	Jamaica
Children	2	3	3	0	4	6	2	1
Currently on ARVs	No.	Yes	Yes	Yes	No	Yes	Yes	Yes
ARV Duration	-	15 yrs.	6 yrs.	8-11 yrs.	-	4-7 yrs.	12+ yrs.	7 yrs.
Insured/Type	ADAP	Medicaid	ADAP Medicaid	Medicaid AmidaCare	ADAP	Yes/ADAP	Yes	Yes/ADAP
Primary Care Physician	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Hospitalized in last 6 months?	No	No	No	No	Yes (not HIV related)	No	Yes (not HIV related)	No

Note. ADAP = AIDS Assistance Drug Program ; ARV = Antiretroviral Therapy

5. When I got tested and then they said um that my test came back positive- um it was shocking, but then like 3 days later, they came back um, the person came back to my house and said that you know there was...something went wrong with the testing wasn't done properly.
6. Because I just thought that since they didn't come back at that time I figured that since they didn't come back to my house that I was okay (pause). So I just went on with my daily living and just normal...just whatever- just working, just doing whatever and just never paid it anymore mind.
7. I just started to think about a lot of things when it just got real bad back home [Jamaica] and you know economically, and you know...you kinda come here and just got used to a lot of things and a lot of changes and it's just better and um you just said "ok" you wanna make a try and see, you know?
8. Then you have a lot of friends who did it before you so, but then um you know you figure your're gonna make a try you know to stay here...
9. ...then I -you know was thinking about living with somebody and um, I decided that if I'm gonna live with this person and um you know I need to know what you know cause if I'm gonna live with this person and um (pause) I thought that to get married you know whatever do the medical I always thought that was gonna be a problem so I had it in the back of my mind but I never really thought much about it but it was just...it was still there.
10. So that's when I went to a clinic in Florida and did a test and um and I still never went back for the results because I did the test...(thinking) I think it took me a couple months before I went back for the results and when I did went back for the results, you know that is when I really heard that yes you're positive and yes- I guess that's when it really hit me.
11. And that's when I was like "Ok" I really have this thing.
12. Then it's like I just started thinking you know get panicked- I was like "Ok" I need to get out of this relationship that I'm in because you know if you put marriage on the table with somebody who you don't tell your status then they're going- it gonna come a point when they're gonna say ok time for us to- you know you saying you wanna use protection and it's like what "Why are we using it?"
13. So it's like and I don't know probably this person would react to you, you know so I said "Ok" I just got fearful (pause) because I mean throughout my life I mean I'm not gonna say that my life was normal. I mean...I don't know normal for me, but not for somebody else but normal for me was growing up was I mean I was in a lot of abusive relationships (pause) whether it was physical abuse, verbal abuse...
14. I'd overstayed my visa I wasn't able to work anymore so cause you know (pause) and then I said, "ok" I need to do something? Do I go back knowing that I have this disease? And treatment back home there's no treatment -there is nothing you know...You.. you literally go into an isolation and you just like be there until you just wither away and then at some point everybody would guess or assume that that's what's going on

15. Everybody knows everybody so if you walk into this room and they look in your file or they look in your docket or whatever they call it and it's gonna get to that person and that person and that person until you know by the time you get home everybody knows
16. You're looked at different, you're treated different not even just you- your whole family is treated you know...like, like (in frustration) Ugh...I don't even know what the word is but you are treated like nothing.
17. How you don't have papers...how do you go to the hospital? How do you get...and she tell me, "Just go over there and they'll still look at you just um, I'll write you a letter saying you know that you...that I...that you stay here- you just want a proof of address or whatever and they'll whatever but I went there with the intention of getting on the birth control so that's what I told her I needed...you know to go on birth control
18. I'm not gonna say having this disease is not bad but I don't know for me it's like if I didn't have this disease I don't think I would be able to survive here. (Pause)
19. I wouldn't be able to afford rent even though where I live now is not my ideal place and um I get...I'm gettin help.
20. Cause I'm undocumented... I wouldn't be able to... I can't work as how I want to work.
21. And...it... I mean the only drawback is that I don't have my papers- which I do and um cause I really...sometimes I wish that I could...I do wanna go home but not go home to stay
22. And I want my papers cause I wanna go.. I mean maybe I can go to school or...you know finish school or get a good job or something
23. So you know cause my thing was even though you could have a child I just don't wanna put that risk on any...(trying to express self)... you know I don't wanna put it on a child
24. ... I mean to get the help I have to like divulge so much information you know about myself that it's ridiculous... it's like every three months you gotta go do paperwork and you gotta...they question you about this and that and everything and it...I'm such a private person that by the time I get outta the meetin I'm like so overwhelmed because they ask you everything and it's you know- in order to get the help you have to tell these people everything (with emphasis) about your everyday...you know your whole...UGH (with frustration)
25. ...it's just a lot and I'm just a very private person and I just feel like you lose a lot of yourself because you have to be gettin help from these people and you know it's like you ...you... can't say no... you can't really tell them "that's none of your business"-or you know cause then you won't get the help
26. Nobody...my kids...my family...Nobody knows. Nobody...nobody knows... I haven't told a soul. So you know...it's hard

27. so yeah, so I'm just not a very open person when it becomes to certain things. Cause I keep...you know... keeping this secret too cause I mean...like I...the only people that know about my status are my doctor, social workers, you know nurse...whoever at the hospitalwhoever at groups that I go to that are for people with HIV- that's it
28. ...And part of the reason why I haven't told anybody is because (pause)...I don't know...it's just...I... I don't know what... people have this- this bad thinking about people with HIV...like they are not aware about certain things, um..(crying)...
29. I didn't see it or whatever but when I moved out I got a phone call saying that they found this piece of paper and it was...it said whatever on it and um I can't believe you were here living with us and you were cooking the food and you were playing with the kids and knowing you were infected...(Pause, crying)
30. But she was like "Oh you didn't tell me? And you were here and you were this and that and you were...you know...I'm like- What's cookin' food? And, and playing with kids have to do with anything? I mean you know like, so it's like... I... I just had to get outta there. I had to really just get outta there.
31. So like I said it's been over a year I haven't spoken to her and I'm just so glad that I got outta there and I just isolated myself from her...
32. ...I don't know if she read the paper tore off and I didn't see it or whatever but when I moved out I got a phone call saying that they found this piece of paper and it was...it said whatever on it and um I can't believe you were here living with us and you were cooking the food and you were playing with the kids and knowing you were infected...(Pause, crying)
33. I said, "You know what?" "I need to get away from...from her...from everybody that I used to be around cause I don't know who she's gonna tell what so I just need to separate myself, but (sniffles- crying).
34. They started me out with ATRIPLA and um they put me in this...they had me goin' to this...they had me goin' to this...to take part in this research study which they you know... I said, "Okay sure."
35. It's like... I...I don't really have family here so they were like...it was just...you, you get that sense of they wanted you. When I went there I was treated very special (pause)...you know I got in, I didn't have to wait...I didn't. You know?
36. I wouldn't be in there for hours. I'd get anything gone like if, if I said I had an earache or toothache I'd go from one...they checked out like full...the whole nine....like anything I want done, I'd get it done and um it just...it just made me feel good
37. I feel like- you know...not sayin' it's the best care that I get, but at least I'm gettin' it
38. Because it's not like I can just go out and get in a relationship for the fun of it because- I can't. Because my fear if I stick to- if I get into a relationship with somebody and I don't tell

them which it's not right but yet I don't know if I do tell them- what are they gonna say or what are they gonna do?

39. So I have a lota fear about that and like I said once ...once you've been abused or...or you know, it's hard
40. The thing is I don't want a relationship with them because some of them they are either recovering drug addict, alcoholic, um, they look sick (noise of people yelling in the background downstairs) not sayin' I'm discriminating
41. Some of them that I've spoken to they don't even take their medication. Some of them don't- it's like...ugh [with disgust] you look at them and you just- I mean if I didn't have HIV I would not even be in the same circle with them
42. So I'm just...I'm just tryin' right now to do me whatever little jobs I can get, um save whatever little money I can because of the...and then at the end of the day I have my kids to take care of . I have my family back home to take care of and I gotta take care of me.
43. I know sometimes I go to the doctor and it's one thing after another- if it's not HIV its high cholesterol then its um, uh (pause) its takin' this pill for that and that pill for that and then sometimes the, the, the pills cause even right now I'm trying to get off the pills I'm takin' for this its puttin' me in a weird place
44. Cause sometimes the dreams are very disturbing- just very disturbing. Like the other night I dreamt that I told somebody about my status and they were burnin' me alive!
45. So, I...so...ugh {exasperated, sniffles} but and especially this time of year like Christmas...yeah...you kinda get really (pause) I don't know...like you really miss home
46. I mean she kinda maybe knows a little but- like the pills and whatever and all that stuff but cause she knows that I take this pills and I'm always going to doctor I'm always whatever, whatever but I mean she may- I mean she's not stupid, she's 21 , so she's not stupid but...she ask me and I just got to the point where I just told her I'm not ready...its nothing like ...its nothing- I just told her its nothing where I'm gonna drop down and die tomorrow or whatever but I'm not ready to tell you whatever is goin' on with me
47. And then to know that she's there and I'm here...nah! I would prefer to let them know when I can...when I'm able to like go back and like if I support myself with my papers and whatever go back and I can sit them down and say you know this is what is goin' on and yeah...I'll tell them, because they will see that I'm doin' fine
48. And I don't want them to think, "Ooohhh! She's gonna die tomorrow!" "Ooooh no! She's gonna this" "Ooohhh, she's gonna that!" And yeah, so yeah, so I don't...that' the one...that's all they gonna fret about and my mom....my mom is like seventy something years old you know she has you know high blood pressure or whatever so...ooohhh! Nah. (sniffles)
49. So (sniffles) um, I just don't want to dump anything more on my mom and she has to dealin' with that right now

50. So, you know I just...I'm just tryin to be strong for me, for my kids and just cause you know when I found out the first thing...first thing that came to mind, I mean ...when I found...when I first tested in 96 my kids were like six and two years old (pause) so I was like... I honestly thought that I was gonna die
51. But they just don't have nobody but me, you know I'm like (sniffles) I just...that was the first thought that came to mind so it's like from ever since it's like I just got so motivated to like just be workin' workin' just to make sure that they are okay that they are, you know-good.
52. And it's like here in America it's like people are just so busy going about they don't have no time to really be all up in your business.
53. So it's easy to...to be unseen or just you know ...just, I mean...to me nobody's up in my business cause nobody knows me.
54. People would like be lookin at you, like you know-treatin' you different.
55. They...they talk behind your back um they would just you know- everything.
56. And then they would start, you know like look at every person that you've ever spoken to and if you go to, like if you go to this shop to do your hair or if, if you um it's like they would just start to...separating themselves from you so it's like you...yeah
57. Cause even if they said they're your friend soon as they heard you know even if it's true or not they would just like...cause they would think that that's like the worst thing that could ever happen to you.
58. So it's not just me.
59. I'm not sayin' that I feel comforted in a way but in a way I just say you know what at least I know my status and I'm dealin' with it.
60. Nobody wants to ever think that they have HIV or and they don't even say HIV they say AIDS
61. That's... that's the one thing that they say AIDS...they say you have AIDS. It's not even HIV, its AIDS. Cause they don't understand...they don't know the difference or it's that they don't know the difference or they just don't care to know the difference.
62. ... I would say, "Oh I have this friend that you know, she's positive but she's still- I still talk to her she's a nice lady" and they be like, "You talk to her!" I would...I wouldn't talk to her!" And "Those people!" and I'm like- "those people!"
63. Yeah. Cause I have my doctor's number in my phone. I can call him anytime. Even though I'm not a part of the study anymore you know, he, he's very nice. Trust me. He's...He...I really like my doctor- He, I talk to him about just about anything

64. I can talk to him about anything and he will listen
65. So it like you know sometimes like I said you know if I'm overwhelmed or I'm havin' a bad day or , or um you know whatever I go in, it's not just to me it's not just a visit or to go get blood work or whatever, we just talk
66. Even though I'm HASA eligible cause I got the letter stating that I am eligible but because I'm undocumented I cannot get their services
67. A little thing, but I go to other pantries so food... food is not an issue for me. The food I'm supposed to eat; now that's another issue. Cause you know I have cholesterol whatever so they say don't eat this, don't eat that you can't eat this you can't eat that so 90% of the stuff that I get at the pantry I cannot eat it.
68. I mean I don't do nails, I mean like hair- I love doing hair...like hair but it's so expensive. Like going...like New York is very expensive going to hair shop! Shoot! To get my hair done, like maybe a hundred dollars or more and it's like I don't have that money!!
69. I don't have friends so I don't have a lot of people here so it's not like I have friends coming over that you know hang out or whatever so it does get kind of lonely so my comfort is my phone or you know when I had the internet was the computer, which you know even bought my daughter laptop which surprisingly you know I'm surprised we get wireless
70. So, um you know so I'm you know it's like you – you really – people would say, “You can't do so much for your family” but they don't understand it's hard to say that you're not supposed to help your family or they will tell you um, “you can't help your sister or your brother or your mother or whatever because {Woman yelling in the background below} they're grown or they should help themselves” No you don't tell me that because...no to me that's like when you're telling me that it's like I'm not even listening to you.
71. ... I'm gonna help my family whether it's my brother, sister, niece, nephew
72. I don't know my strength is just. It's like you just gotta dig deep and find your inner strength and whatever strength you have left inside of you- cause you just tell yourself that you just gotta push on you gotta um persevere through all of this, you gotta, there's no giving up
73. You know there's no giving up, cause if you give up its like who's gonna take care of you know your family, your kids, your whatever.
74. People would say if you have it you're gonna this and you're gonna that and if you get you know lonely or depressed whatever you're gonna turn to the bottle or you're gonna...nah. Nope.
75. ...they need to get educated...like learn...learn about your...your disease-whatever it is that you have cause even if you have HI V or you have HIV plus high blood pressure or HIV and whatever else you have learn about it
76. To me it's a lot about education like gettin' out...getting' a lot of knowledge

77. ... I don't know it's a strong belief in God and everything and I pray a lot
78. I talk to somebody. Nobody's spoken back which is good {laughing}
79. So yeah, I tell people yeah being illegal doesn't stop you from goin' home it's just that you won't be able to come back
80. A lot of African people and they get...everytime I go to group I hear, "Oh this person went back to Africa cause they got their green card." And I'm like "what about me?" "What about us?"
81. Nobody in the group who is from the Caribbean-there's this lady there that I met she said she's been goin' there... I mean she's been here for years cause she has...I guess she's been here over ten years and she up to now she hasn't gotten her papers
82. I've been to every lawyer- I've been to every um legal aid everything cause (sniffles) and they said basically that I'm not eligible or it makes no sense to put my case to a...to the immigration
83. But there is poverty um...there is a lot of stigma. There is um...there's just the same issues but it may not be as a lot as Africa but um like I said they get ...they get...whatever.
84. ok I'm here in the Bronx and if I had friends in you know like ...it only takes a phone call and whoever knows me or knows somebody back home they would say, "oh she has whatever and you're treated the same way. You're treated the same way....
85. ...they will say, "Oh she used to sleep with that man or – or she used to sleep with that man, or that man used to- used to talk to her and then everybody you know it's like ...its...yeah...or even if you used to just talk to that person maybe nothing physical but then everybody is gonna just start assuming that you know...so it's like you're treated like a um, like back in the day, like a leper.

Individual Textural Themes-Betty

Knowledge of HIV.

1. ...I knew it was a disease. Sexually transmitted, um and there was a lot of talk about um mosquito bites or whatever
2. I mean...I...I knew of it but I never really thought much about it
3. I never really consider...I didn't put it...put much consideration about it.

Finding out.

1. When I got tested and then they said um that my test came back positive- um it was shocking, but then like 3 days later, they came back um, the person came back to my house and said that you know there was...something went wrong with the testing wasn't done properly.
2. Because I just thought that since they didn't come back at that time I figured that since they didn't come back to my house that I was okay (pause). So I just went on with my daily living and just normal...just whatever- just working, just doing whatever and just never paid it anymore mind.
3. So that's when I went to a clinic in Florida and did a test and um and I still never went back for the results because I did the test...(thinking) I think it took me a couple months before I went back for the results and when I did went back for the results, you know that is when I really heard that yes you're positive and yes- I guess that's when it really hit me.
4. ...And that's when I was like "Ok" I really have this thing.

Stigma (cultural).

1. Everybody knows everybody so if you walk into this room and they look in your file or they look in your docket or whatever they call it and it's gonna get to that person and that person and that person until you know by the time you get home everybody knows
2. You're looked at different, you're treated different not even just you- your whole family is treated you know...like, like (in frustration) Ugh...I don't even know what the word is but you are treated like nothing.
3. ...They will say, "Oh she used to sleep with that man or she used to sleep with that man, or that man used to- used to talk to her and then everybody you know it's like ...its...yeah...or even if you used to just talk to that person maybe nothing physical but then everybody is gonna just start assuming that you know...
4. ...So it's like you're treated like a um, like back in the day-like a leper.
5. They...they talk behind your back um they would just you know- everything.
6. And then they would start, you know like look at every person that you've ever spoken to and if you go to, like if you go to this shop to do your hair or if, if you um it's like they would just start to...separating themselves from you so it's like you.
7. Cause even if they said they're your friend soon as they heard you know even if it's true or not they would just like...cause they would think that that's like the worst thing that could ever happen to you

8. That's... that's the one thing that they say AIDS...they say you have AIDS. It's not even HIV, its AIDS. Cause they don't understand...they don't know the difference or it's that they don't know the difference or they just don't care to know the difference.
9. ... I would say, "Oh I have this friend that you know, she's positive but she's still- I still talk to her she's a nice lady" and they be like, "You talk to her!" I would...I wouldn't talk to her!" And "Those people!" and I'm like- "those people!"

Coping [secrecy].

1. Nobody...my kids...my family...Nobody knows. Nobody...nobody knows... I haven't told a soul. So you know...it's hard
2. So yeah, so I'm just not a very open person when it becomes to certain things. Cause I keep...you know... keeping this secret too cause I mean...like I...the only people that know about my status are my doctor, social workers, you know nurse...whoever at the hospitalwhoever at groups that I go to that are for people with HIV- that's it
3. ..And part of the reason why I haven't told anybody is because (pause)...I don't know...it's just...I... I don't know what... people have this- this bad thinking about people with HIV...like they are not aware about certain things, um..(crying)...

Immigration challenges.

1. Cause I'm undocumented... I wouldn't be able to- I can't work as how I want to work.
2. And I want my papers cause I wanna go-I mean maybe I can go to school or...you know finish school or get a good job or something
3. Even though I'm HASA eligible cause I got the letter stating that I am eligible but because I'm undocumented I cannot get their services
4. So yeah, I tell people yeah being illegal doesn't stop you from goin' home it's just that you won't be able to come back.
5. A lot of African people and they get...every time I go to group I hear, "Oh this person went back to Africa cause they got their green card." And I'm like "what about me?" "What about us?"
6. Nobody in the group who is from the Caribbean-there's this lady there that I met she said she's been goin' there... I mean she's been here for years cause she has...I guess she's been here over ten years and she up to now she hasn't gotten her papers.
7. I've been to every lawyer- I've been to every um legal aid everything cause (sniffles) and they said basically that I'm not eligible or it makes no sense to put my case to a...to the immigration

8. But there is poverty um...there is a lot of stigma. There is um...there's just the same issues but it may not be as a lot as Africa but um like I said they get ...they get...whatever.

Loss of privacy.

1. ... I mean to get the help I have to like divulge so much information you know about myself that it's ridiculous... it's like every three months you gotta go do paperwork and you gotta...they question you about this and that and everything and it...I'm such a private person that by the time I get outta the meetin I'm like so overwhelmed because they ask you everything and it's you know- in order to get the help you have to tell these people everything (with emphasis) about your everyday...you know your whole...UGH (with frustration)
2. ...it's just a lot and I'm just a very private person and I just feel like you lose a lot of yourself because you have to be gettin help from these people and you know it's like you ...you... can't say no... you can't really tell them "that's none of your business"-or you know cause then you won't get the help

Under the radar.

1. And it's like here in America it's like people are just so busy going about they don't have no time to really be all up in your business.
2. So it's easy to...to be unseen or just you know ...just, I mean...to me nobody's up in my business cause nobody knows me.
3. New York is the best place to be because you are undocumented you can pretty much get lost in the mix.
4. ...Its big here. Like I live here and I don't even know my neighbors and I've been here over a year.

Coping [self-care].

1. I mean I don't do nails, I mean like hair- I love doing hair...like hair but it's so expensive. Like going...like New York is very expensive going to hair shop! Shoot! To get my hair done, like maybe a hundred dollars or more and it's like I don't have that money!!
2. I don't have friends so I don't have a lot of people here so it's not like I have friends coming over that you know hang out or whatever so it does get kind of lonely so my comfort is my phone or you know when I had the internet was the computer, which you know even bought my daughter laptop which surprisingly you know I'm surprised we get wireless

Good care [medical family].

1. Cause I have my doctor's number in my phone. I can call him anytime.
2. I can talk to him about anything and he will listen
3. So it like you know sometimes like I said you know if I'm overwhelmed or I'm havin' a bad day or , or um you know whatever I go in, it's not just to me it's not just a visit or to go get blood work or whatever, we just talk.
4. It's like... I...I don't really have family here so they were like...it was just...you, you get that sense of they wanted you. When I went there I was treated very special (pause)...you know I got in, I didn't have to wait: I didn't. You know?
5. I wouldn't be in there for hours. I'd get anything gone like if, if I said I had an earache or toothache I'd go from one...they checked out like full...the whole nine...like anything I want done, I'd get it done and um it just...it just made me feel good
6. I feel like- you know...not sayin' it's the best care that I get, but at least I'm gettin' it

Relationship challenges [intimate].

1. Because it's not like I can just go out and get in a relationship for the fun of it because- I can't...
2. ...If I get into a relationship with somebody and I don't tell them, which it's not right, but yet I don't know if I do tell them- what are they gonna say or what are they gonna do?
3. So I have a lot of fear about that and like I said once ...once you've been abused or...or you know, it's hard
4. The thing is I don't want a relationship with them because some of them [men]. They are either recovering drug addict, alcoholic, um, they look sick. Not sayin' I'm discriminating
5. Some of them that I've spoken to, they don't even take their medication. Some of them don't- it's like...ugh. You look at them and you just- I mean if I didn't have HIV I would not even be in the same circle with them
6. So it's like and I don't know probably this person would react to you, you know so I said "Ok" I just got fearful (pause) because I mean throughout my life I mean I'm not gonna say that my life was normal. Normal for me was growing up I mean I was in a lot of abusive relationships (pause) whether it was physical abuse, verbal abuse...
7. It's very hard and like I said, I spoken to a lot of men friends, whether it be sexually or just somebody casually and I would say to them like, "What would you do if...?" And the

answers I get from them- I would be like hell no. I would not tell them anything just because of the way they answer.

Relationship challenges [friendship/betrayal].

1. I didn't see it or whatever but when I moved out I got a phone call saying that they found this piece of paper and it was...it said whatever on it and um I can't believe you were here living with us and you were cooking the food and you were playing with the kids and knowing you were infected...(Pause, crying)
2. But she was like "Oh you didn't tell me? And you were here and you were this and that and you were...you know...I'm like- What's cookin' food? And, and playing with kids have to do with anything? I mean you know like, so it's like... I... I just had to get outta there. I had to really just get outta there.
3. So like I said it's been over a year I haven't spoken to her and I'm just so glad that I got outta there and I just isolated myself from her...
4. ...I don't know if she read the paper tore off and I didn't see it or whatever but when I moved out I got a phone call saying that they found this piece of paper and it was...it said whatever on it and um I can't believe you were here living with us and you were cooking the food and you were playing with the kids and knowing you were infected...(Pause, crying)

Coping [strength].

1. I don't know my strength is just. It's like you just gotta dig deep and find your inner strength and whatever strength you have left inside of you- cause you just tell yourself that you just gotta push on you gotta um persevere through all of this, you gotta, there's no giving up
2. You know there's no giving up, cause if you give up its like who's gonna take care of you know your family, your kids, your whatever.
3. People would say if you have it you're gonna this and you're gonna that and if you get you know lonely or depressed whatever you're gonna turn to the bottle or you're gonna...nah. Nope.
4. ... I don't know it's a strong belief in God and everything and I pray a lot

Familial responsibility.

1. ... I'm gonna help my family whether it's my brother, sister, niece, nephew

2. So, um you know so I'm you know it's like you – you really – people would say, “You can't do so much for your family” but they don't understand it's hard to say that you're not supposed to help your family...
3. So I'm just...I'm just tryin' right now to do me whatever little jobs I can get, um save whatever little money I can because of the...and then at the end of the day I have my kids to take care of . I have my family back home to take care of and I gotta take care of me.
4. You know there's no giving up, cause if you give up its like who's gonna take care of, you know your family, your kids, your whatever.
5. But they just don't have nobody but me, you know I'm like (sniffles) I just...that was the first thought that came to mind so it's like from ever since it's like I just got so motivated to like just be workin' workin' just to make sure that they are okay that they are, you know, good.

Coping [secrecy-family].

1. I mean she [daughter] kinda maybe knows a little but-, like the pills and whatever and all that stuff but cause she knows that I take this pills and I'm always going to doctor I'm always whatever, whatever but I mean she may- I mean she's not stupid, she's 21 , so she's not stupid but...she ask me and I just got to the point where I just told her I'm not ready...its nothing like ...its nothing- I just told her it's nothing where I'm gonna drop down and die tomorrow or whatever but I'm not ready to tell you whatever is goin' on with me
2. And then to know that she's [participant's mother] there and I'm here...nah! I would prefer to let them know when I can...when I'm able to like go back and like if I support myself with my papers and whatever go back and I can sit them down and say you know this is what is goin' on and yeah...I'll tell them, because they will see that I'm doin' fine.
3. And I don't want them to think, “Ooohhh! She's gonna die tomorrow!” “Ooooh no! She's gonna this” “Ooohhh, she's gonna that!”
4. So (sniffles) um, I just don't want to dump anything more on my mom and she has to dealin' with that right now

Individual Textural Description-Betty

Betty's interview took place on a crisp winter evening. Her apartment was a small unit with a narrow long hallway. The walls were a beige color and we sat on couches facing each other with the noise of the city street occasionally streaming. Betty was a Jamaican woman with a caring and expressive manner. She often had tears running down during the interview when she

described her experiences living with HIV. At the time of this interview Betty had resided in the U.S. for approximately four years. She estimated that she had been living with HIV for 2-15 years.

The themes that emerged for Betty were, *Pre- HIV, knowledge of HIV, finding out, stigma, coping [secrecy, secrecy-family] immigration challenges, loss of privacy, under the radar, taking care, good care, relationship challenges (intimate), relationship challenges [friends-betrayal], coping [secrecy-family], coping[strength] and familial responsibility.*

The first theme that emerged was *Pre- HIV*. Betty's narrative commenced with a description of her life before her HIV diagnosis as "normal" and "regular." She indicated that she was "just working." The second theme that emerged was knowledge of HIV. This participant indicated that she knew that HIV was transmitted through sexual intercourse but that it was never really a relevant part of her life. She also believed that there were lots of misperceptions about HIV and how it was acquired. She recounted that her knowledge of HIV was mainly obtained by what others said about it and what the media portrayed. Also, "there was a lot of talk about like common about mosquito bites or whether... um...being gay...or um...you hear all those stuff until, you know, stories kept changing and you hear it through music or you hear it through commercials or whatever." In the third theme, *finding out*, Betty spoke about being diagnosed in her country of origin and the "shock" she experienced. However, she was told that "something went wrong with the testing." After she tested again, she did not go back for her results and "figured that since they didn't come back to my house that I was okay." Related to the way that Betty never gave much thought to HIV before being diagnosed, she shared that after her second testing, she "went on with her daily living." However, after immigrating to the United States and getting involved in a romantic relationship, she began to question her status because the results

were not known from the previous testing. She decided to have another test and this time she stated that she did not return to the health clinic for a couple of months. When she was told that she was positive, she expressed her beginning acceptance of the diagnosis, “I guess that’s when it really hit me” “and that’s when I was like okay, I really have this thing.”

The fourth theme that emerged for Betty was *stigma*. This participant expressed that the stigma in her home country was so profound that “you’re looked at as different, you’re treated different.” She compared the treatment of those that are HIV positive to the biblical analogy of being treated “like a leper.” The consequences of being HIV positive did not just extend to the individual, but to their family as well. People were labeled and outcast because “they would think that that’s like the worst thing that could ever happen to you” and that, “they would talk behind your back”. In addition, Betty said that people in her country are scared to seek services if they are HIV positive because “everybody knows everybody so if you walk into this room and they look in your file or they look in your docket or whatever they call it and its gonna get to this person and that person until you know by the time you get home, everybody knows.” Betty also felt that the stigma associated with HIV is due to misperception and ignorance. She stated, “It’s not even HIV, its AIDS. ‘Cause they don’t understand...they don’t know the difference or they just don’t care to know the difference.” In addition, Betty related that a close friend of hers found out she was HIV positive when her medication was delivered to her friend’s home when she was out an errand. In shock and disbelief Betty was accused of “cooking the food and playing with the kids knowing you were infected.” The pain of that incident stayed with the participant as she continued to share her story.

The fifth theme *secrecy* is related to the previous theme of *stigma* because for those that are infected and initially-diagnosed in either their home country or in the U.S., secrecy was seen

as essential for well-being and security in the community. Betty related, “Nobody knows. I haven’t told a soul.” She indicated the intense fear she felt and rationale for keeping her status a secret was because “people have this-this bad thinking about people with HIV.” “The only people that know about my status are my doctor, social workers, you know, the nurse... whoever at the hospital.” She believed it was acceptable for these individuals to know because they made her feel “special” and like they “wanted you.” She felt that she got “good care” and highlighted the fact that she could reach out to her doctor and “talk to him about anything”. This indicated a good level of comfort and support received from the medical and professional staff she had encountered since being diagnosed with HIV.

The sixth theme that emerged was *loss of privacy*. It seemed paradoxical considering the two themes of *secrecy* and *stigma*. Betty spoke about having to “divulge so much information about myself [to the health professionals] that it’s ridiculous.” She reported that this was a necessity because “in order to get the help you have to tell these people everything” and that “you lose a lot of yourself because you have to be gettin’ help from these people.” While Betty reported that interfacing with the care system yielded positive benefits, it also caused her to give up privacy.

Under the radar was a theme that related to both Betty’s geographic location as well as her desire to remain anonymous. She indicated that she could be “unseen” in her neighborhood because “nobody knows her.” An example given was, “like I live here and I don’t even know my neighbors and I’ve been here for over a year in this building. I come and I go- you understand?”

The next theme, *immigration challenges* emerged as Betty talked about her frustration because she was “undocumented”. “I can’t work as how I want to work.” She tried to find out about how to change her immigration status and was simply told she is not “eligible” The

inequity between Caribbean people and other groups of people that seemed to be able to procure their citizenship status faster became evident to her. Betty also discussed the option of getting married to obtain citizenship, but that was not a feasible option for her, as she did not want to marry just to obtain legal status.

In chronicling her *relationship challenges (intimate)*, she indicated that relationships are hard for her because of her HIV status. She says, “It’s not like I can go out and get into a relationship for the fun of it because I can’t.” In addition, the fear of disclosure to a partner and their reaction was in the forefront of her mind because she wondered “what are they gonna say? Or what are they gonna do?” She tested this out by asking males in her life about what their reaction would be if someone they were interested in dating were to disclose that they were HIV positive. “I spoken to a lot of men friends, whether it be sexually or just somebody casually and I would say to them like, ‘What would you do if...?’ And the answers I get from them- I would be like ‘hell no’. I would not tell them anything just because of the way they answer.” This fear was compounded by Betty’s admission of being “abused” while she was growing up. She stated “...because I mean throughout my life I mean, I’m not gonna say that my life was normal. I mean, I don’t know normal for me, but not for somebody else, but normal for me was growing up was I mean, I was in a lot of abusive relationships whether it was physical abuse, verbal abuse. Um, all of those things and it never came from my parents. It was more like men that I’ve you know come in contact with so I was always fearful of what um a man would do, you know?” Betty also noted that there are challenges in trying to date someone that is also HIV positive- “The thing is I don’t want a relationship with them because some of them [men].. They are either a recovering drug addict, alcoholic, um, they look sick. Not sayin’ I’m discriminating.” At

one point Betty said she engaged in online dating; however she stopped because, “like it’s nothing but weirdoes on the internet-perverts, um users, whatever the word is, it’s all there.”

Three themes could be extracted from Betty’s experience related to coping. The first theme of *coping* related to the challenge of not disclosing her HIV is status to family members. For Betty, it appeared that she did not want to burden her family and cause undue stress. For example, she said, “I just don’t want to dump anything more on my mom and she has to dealin’ with that right now.” Although most of her family lived abroad, Betty reported that she has not even told her daughter, who lives with her, that she is HIV positive, “I mean she’s not stupid, she’s 21 , so she’s not stupid but...she ask me and I just got to the point where I just told her I’m not ready...its nothing like ...its nothing; I just told her it’s nothing where I’m gonna drop down and die tomorrow or whatever but I’m not ready to tell you whatever is goin’ on with me.” Secrecy was something that Betty considered a way to cope, not only with those family members not nearby but also for those close, and who could be a potential support, as well. The burden that Betty believed would be harmful to family (possibly negative health consequences related to the worry/stress related to the disclosure) and fear of the reactions prevented disclosure. The second theme of coping was related to “strength “and Betty’s internal resources that allow her to cope with living with HIV. She used words such as “digging deep”, “inner strength”, and “push” to describe how she used her strength on a daily basis. She believed that taking care of her family motivated her to stay strong and to find a way cope with her condition.

The final theme related to coping was related to self-care Betty recounted some of her methods for engaging in self-care. While B indicated that it is too expensive to go out and eat or engage in “other social activities”, she indicated that she “does her hair” and “watches DVDs” as a way to take care of herself.

Individual Structural Description-Betty

The structures that underlie this participant's experience are: *relation to self, relation to others, and space.*

Betty's relation to self appears to be dominated by fear and a profound sense of loss. In her description of her early childhood, she stated that she was "abused" and that "I was always being abused in some way or the other" and it was "never from family but from men." She was reluctant to share more about her "abuse". It appears likely that Betty's self-concept has been affected by her "abuse" and her HIV status. Another facet of Betty's relation to self is that her physical body now houses an ideological construct. In her culture, those that are infected with HIV are seen as "lepers" as she indicated in her narrative. It seems that she believed that if she did acknowledge that she was infected with HIV she would take on a feared "place" in her country's society for which she was not prepared.

Relationships have proved challenging for Betty. Although Betty still engages in relationship with her family and extended family, these relationships have been altered by her diagnosis and non-disclosure. She cannot share her inner world of stress and struggles living as an HIV positive woman living abroad especially with her mother. In essence, Betty has had to compartmentalize her "inner landscape" in order to survive. Even her closest relationship, with her daughter, she has done this. However, Betty's relationships with her doctors have been much more "open". She felt "wanted" and "very special." These close relationships appear to have had a profound effect on her. They are relationships that evoke warmth and trust. In a way it appears that Betty experiences these relationships as a source of strength that she was not able to procure from her family. Since she has no family that she can speak with openly about her diagnosis, she uses the health care team to confide in and to obtain information about problems related to her diagnosis and overall mental and physical health care. This participant also

attends support groups and gains access to a wider community of those that are facing the same struggles. Although she is able to access these services, she also describes attempting to obtain assistance as “too much” at times. This concept of “too much” translates to Betty’s intimate relationships as well. Betty appears to experience intimate relationships as dangerous. She laments the loss of her ability to engage in meaningful relationships due to fear of the reaction of an intimate partner upon disclosing her diagnosis.

With regard to the structure of *space*, Betty’s experiences interfacing with the medical system in the United States have been portrayed in a positive light. The physical and geographical space she occupies allows her to experience a system of care that would not otherwise be accessible. Residing in NYC provides the opportunity for greater acceptance; even outside of her immediate neighborhood and the Caribbean community. This openness has allowed Betty to receive needed health care and introduced her to a different philosophy on life, that those who are HIV positive will be treated with respect and dignity. However, in this same geographic space, the oppressive culture of the Caribbean community is still evident in terms of the stigma that she experienced in her home country. This stigmatization of those who are HIV positive forces Betty to continue to live in secrecy, thus compounding her disconnection with the Caribbean community, but fostering connection with the medical community that appears to be her only social support.

Betty has also experienced hardship in terms of trying to obtain a legal status in the U.S. She was told she is not “eligible” to change her status and that “sometimes I just block out whatever they’re [immigration lawyers] sayin....” In addition, she cannot work and have all the rights of someone that has a legal immigration status. This has a profound effect not only relative to her life and well-being, but also that of her daughter. Her ability to more effectively

provide for her family in her home country with monetary assistance would be greater.

Throughout her narrative, Betty provided details about her experiences living with HIV with much anguish. At times during the interview she sobbed profusely in describing her hardships in living each day. On one hand, the policies that govern the geographic region in which she lives, provides her with support regarding her medical and daily needs; however governmental policies limit Betty from obtaining a legal permanent status. This fact impedes her from living and creating the type of life she would like to have for herself and her children.

Meaning Units-Charlene

1. It was AIDS and death back then.
2. Well my first set of emotions was after the initial shock it was like destructive behaviors cause I figured I was dying back then.
3. So I realized that I wasn't...it was more pain you know like tryna die than just getting myself together and living so that was the process you know. With that came denial and anger and resentment, shame- you know all that type of stuff but within those years of being destructive and going through those feelings, I climbed out of that...
4. I've founded a non-profit that we do a lot of community services...
5. Right now I'm studying for my clinical drug counselor certification. I have a Masters.
6. I pretty much do support groups for newly diagnosed people
7. ...I was afraid that I was going to be shunned but when I told my family actually they started spoiling me too much... You know my family embraced me nonetheless but everyone is not that lucky.
8. I keep my medical appointments, um I mediate. I exercise. I try to eat right (Laughing).
9. I have incorporated a lot of health attitudes since then [HIV diagnosis]. First I had to get the healthier attitude and then the behaviors followed.
10. ...I've always been an advocate and an activist. I've always been out there so you know for me I'm the type of person who always go after things...
11. ...There's a lot of good services you know in this country. I wouldn't want to be positive and live in any other city but New York you know because in New York we get certain entitlements that you can't get any place else, so it's a good thing, the medical care and stuff like that you know.

12. I wanna wipe my own ass! I don't want to be so sick that I'm in a pamper and depending on someone to wipe my ass. So in order to be healthy enough to my own ass I got take care of myself.
13. I have been in a study...It's been like 15 years right? So they see me twice a year.
14. ...In the Caribbean it's still very shameful to be- to have HIV or to be seen in the village or town you from and know that a person is HIV positive.
15. I gotta say I'm glad that I'm HIV positive in New York and not in Trinidad.
16. People in New York have more tolerance, but in the Caribbean culture everything is so strict. They see in this tunnel vision that it can make a person life miserable.
17. My heart breaks for people who are positive in the Caribbean and I'll say women because I'm a woman and I am biased for women who are positive in the Caribbean you know?
18. I used to feel like damaged goods. Like I'm scarred- damaged, you know like the Red Scarlet thing and this is what HIV does when a female become positive. It makes them feel like they are damaged goods-garbage to throw away because nobody is gonna want them.
19. I'm still learning to love myself one day at a time.
20. ...This is the first time in my life that I am single for a year and it still could pop up- that fear of meeting somebody new to tell them you're positive if they gonna reject you, right?
21. I do workshops because I try to empower them [women] with having a better quality of life and also learning how to love themselves and how to disclose instead of keeping the secret.
22. I think the body is beautiful you know? I mean if I had a bangin' body and I was 20 years old I take nice pictures. I like to wear negligee stuff under because it makes you feel beautiful and all that stuff. When you HIV positive it makes you feel dirty. In the beginning it takes all that from you so when they [women] start to love themselves, and growing and accepting the virus for what it is and whatever then I'm able to love all of me again, you know? But it takes a lot of work.
23. I don't have a Caribbean community in my life. I just have you know, good women in my life of different nationalities or whatever, including Caribbean.
24. I was brought up to know, people expect me to see me do good.
25. I've never been sick a day in my life with HIV, so it's not, "Oh, I got HIV!" Woe to me!" It's about owning what you have and knowing that you have to take better care of yourself.
26. I would really say that being brought up in a stable environment is what helps me keep it together.

27. I always wanted somebody to do a dissertation on the welfare and social security system...when we're grouped together in this lower income bracket
28. I'm trying to plan ahead and get the education I need to give me what I need to live a sustained, fruitful life.
29. Nobody knew anything about it [HIV], but you know um that's why I went through my destructive behaviors and all that crazy stuff because that's all it was back then- a death sentence, you know? So there was no support. I eventually found support three years later.
30. ...My higher power guided me to information where I get a procedure done.
31. ...I do go to um a 12-step program, you know um and um I keep myself busy.
32. You know it's like um, I'm a very spiritual person...

Individual Textural Themes-Charlene

Pre- HIV.

1. So my life was pretty much around that time was hang out, party, drink, a little weed. Stuff like that...

Knowledge of HIV.

1. Nothing. Nothing at all. When I was diagnosed all they had was AZT. They didn't even have medication for it and when people had HIV it was like-there was not HIV. It was AIDS and death back then.

Finding out.

1. So I was diagnosed when I was 23 and prior to that it was just um, I had a son. I was in sch...I just came out of high school a little while before that and I mean I was diagnosed at 23 but the doctor said I had to have been infected at 19 because of the count [CD4 cells].
2. I used to drink a lot and party a lot, mess with some you know, substances and stuff like that so I went into a treatment program to straighten myself up and that's when I found out.

Coping [post-diagnosis].

1. Well my first set of emotions was after the initial shock it was like destructive behaviors cause I figured I was dying back then. You had this thing you were gonna die. So I left the treatment program after nine months and I um continued just to just party and drink and get high and waiting to die. But a year passed and I wasn't dead. Another year passed, another year pass and I wasn't dead and I was like daaaaammnnn! [laughing] So I realized that I wasn't...it was more pain you know like tryna die than just getting myself together and living so that was the process you know. With that came denial and anger and resentment,

shame- you know all that type of stuff but within those years of being destructive and going through those feelings, I climbed out of that so...

Stigma (cultural).

1. ...But in the Caribbean it's still very shameful to be- to have HIV or to be seen in the village or town you from and know that a person is HIV positive. A lot of shoo, shoo and talk, talk, talk and you know it can make your life miserable, you know.
2. People in New York have more tolerance, but in the Caribbean culture everything is so strict. They see in this tunnel vision that it can make a person life miserable.
3. My heart breaks for people who are positive in the Caribbean and I'll say women because I'm a woman and I am biased for women who are positive in the Caribbean you know?

Support [post- diagnosis- family].

1. ...I was afraid that I was going to be shunned but when I told my family actually they started spoiling me too much... You know my family embraced me nonetheless but everyone is not that lucky.

Support [post-diagnosis-systemic].

1. Nobody knew anything about it [HIV], but you know um that's why I went through my destructive behaviors and all that crazy stuff because that's all it was back then- a death sentence, you know? So there was no support. I eventually found support three years later.

Self-care.

1. I'm still learning to love myself one day at a time.
2. I keep my medical appointments, um I mediate. I exercise. I try to eat right (Laughing).
3. I have incorporated a lot of health attitudes since then [HIV diagnosis]. First I had to get the healthier attitude and then the behaviors followed.

Self-care [motivation].

1. I wanna wipe my own ass! I don't want to be so sick that I'm in a pamper and depending on someone to wipe my ass. So in order to be healthy enough to my own ass I got take care of myself.

Turning it around [empowerment].

1. I've founded a non-profit that we do a lot of community services...
2. I do workshops because I try to empower them [women] with having a better quality of life and also learning how to love themselves and how to disclose instead of keeping the secret.

3. ...I've always been an advocate and an activist. I've always been out there so you know, um, so for me you know, I'm the type of person who always go after things...

Relationship challenges [intimate].

1. I mean even though I was married to a negative man for 14 years- my daughter's father and then I was in a relationship after I got divorced for 8-9 years with a negative man, this is the first time in my life that I am single for a year and it still could pop up- that fear of meeting somebody new to tell them you're positive if they gonna reject you, right?
2. ...Cause I feel disclosing- if I'm dating somebody and I'm startin' to like them I want to disclose before I like you too much, you know? Because if I like you too much and I spend too much time with you and then you reject me, I'm a mess, but if I disclose to you when my heart is not really all in there, I can move on. I'll feel bad yes, but I can move on.

Self-perception [upbringing].

1. My bringing up. You know um, even though um my upbringing wasn't huggy, huggy kissy, kissy, and it was more of a disciplinarian brining up, excuse me, I was brought up to know that I'm supposed to be somebody. I was brought up to know you know, um people expect to see me do good.

Self-perception [HIV].

1. I used to feel like damaged goods. Like I'm scarred- damaged, you know like the Red Scarlet thing and this is what HIV does when a female become positive. It makes them feel like they are damaged goods-garbage to throw away because nobody is gonna want them.
2. I think the body is beautiful you know? I mean if I had a bangin' body and I was 20 years old I take nice pictures. I like to wear negligee stuff under because it makes you feel beautiful and all that stuff. When you HIV positive it makes you feel dirty. In the beginning it takes all that from you so when they [women] start to love themselves, and growing and accepting the virus for what it is and whatever then I'm able to love all of me again, you know? But it takes a lot of work.

Good care.

1. ...There's a lot of good services you know in this country. I wouldn't want to be positive and live in any other city but New York you know because in New York we get certain entitlements that you can't get any place else...so it's a good thing, the medical care and stuff like that you know.

Systemic challenges [the cage].

1. I always wanted somebody to do a dissertation on the welfare and social security system lower income because you ask me what is my thing for the future and it has to do with the

constant fight to get out of this iron cage that we still in when we're grouped in the lower income bracket.

Spirituality.

1. My higher power guided me to information where I get a procedure done.
2. ...I do go to um a 12-step program, you know um and um I keep myself busy.
3. You know it's like um, I'm a very spiritual person...

Individual Textural Description-Charlene

In a car on a busy New York City street, Charlene, who at the time of interview had been living in the U.S. for 34 years and living with the HIV virus for 24 years, told me her story. She described her experience living with HIV in the "early years" of the epidemic and her evolution as an individual.

Charlene's narrative produced the themes Pre-HIV, knowledge of HIV, finding out, coping, stigma, support, self-care, turning it around, relationship challenges, self-perception, good care and systemic challenges and spirituality.

The first emergent theme, *Pre-HIV*, captures the participant's life prior to her diagnosis. Charlene indicated that her life revolved around school (she was a recent high school graduate) and the pursuit of having fun. She stated, "my life was pretty much around that time was hang out, party, drink, a little weed-stuff like that..." In the next theme, *knowledge of HIV*, she indicated that she was diagnosed very early in the AIDS epidemic and had no knowledge of the HIV virus. This is highlighted in the following quote, "[I knew} Nothing. Nothing at all. When I was diagnosed all they had was AZT. They didn't even have medication for it and when people had HIV it was like-there was no HIV. It was AIDS and death back then." She entered a substance abuse treatment center because of her chronic drug abuse at that time and while in the drug treatment program, the participant was told she was HIV positive. She chronicles her

finding out stating, “I used to drink a lot and party a lot, mess with some you know, substances and stuff like that so I went into a treatment program to straighten myself up and that’s when I found out.” She added, “...so I was diagnosed when I was 23 and prior to that it was just, um, I had a son. I was in school. I just came out of high school a little while before that and I mean I was diagnosed at 23, but the doctor said I had to have been infected at 19 because of the count [CD4 cells].” According to the participant, the diagnosis set her on a path that led her life out of control. The next theme coping [*post-diagnosis*] highlights her “shock” and then “destructive behaviors” in response to the diagnosis. Earlier, the participant indicated her limited knowledge and the perception about the HIV virus as a death sentence, and so figured she was dying back then.” Therefore, she “continued just to party and drink and get high and waiting to die.” However, after continuing this behavior, Charlene realized that she was not dying and that she needed to make adjustments in her life to successfully cope with living with HIV. She chronicled this turning point by remarking, “So I realized I wasn’t- it was more pain you know, like tryna die than just getting myself together and living so that was the process you know?” She also added that there was a cycle of emotions that accompanied her diagnosis, “With that came denial and anger and resentment, shame...you know, all that type of stuff but within those years of being destructive and going through those feelings, I climbed out that of that so...”

Charlene commented that her primary support system after her diagnosis was her family. In the identified theme of *support [post diagnosis-family]* she recounted her fear of disclosure to her family by stating, “I was afraid that I was going to be shunned but when I told my family, but actually they started spoiling me too much. You know my family embraced me nonetheless, but everyone is not that lucky.” While her family provided support for her, she indicated that support on systemic level took a longer time to obtain due to limited knowledge of HIV and AIDS on the

community/societal level, “Nobody knew anything about it [HIV], but you know um that’s why I went through my destructive behaviors and all that crazy stuff because that’s all it was back then—a death sentence you know? So there was no support. I eventually found support three years later.”

Other themes emerged that seemed to link the participant’s feelings about being diagnosed with HIV and her evolution as a woman: *self-perception due to HIV* and *self-perception [upbringing]*. In sharing her thoughts about herself, Charlene spoke candidly about the difficulties she had separating her diagnosis from her inner self. She noted, “I used to feel like damaged goods. Like I’m scarred, damaged, you know like the Red Scarlet thing and this is what HIV does when a female becomes positive. It makes them feel like they are damaged goods; garbage to throw away because nobody is gonna want them.” This vivid account of being “singled out” and the illusion to being marked with a “scarlet letter” indicates the shame that Charlene felt while trying to accept her diagnosis. She added that she has an overall sense that “the body is beautiful”, however she describes the psychological and physical implications being diagnosed with HIV has on a woman as follows. “When you [are] HIV positive, it makes you feel dirty.” In addition, she commented that, “In the beginning it [HIV] takes all that from you, so when they [women] start to love themselves, and growing and accepting the virus for what it is and whatever, then I’m able to love all of me again, you know? But it takes a lot of work.” It appeared that the inner work described by the participant came about by a concerted effort toward acceptance of the disease. She also revealed a view of herself that was constructed by her familial upbringing. She stated that, “I was brought up to know that I’m supposed to be somebody.”

In the next theme, *Relationship challenges [intimate]*, Charlene described her intimate relationships with men as mostly long-term and that at the time of interview, “this is the first time in my life that I am single for a year.” She discussed the challenges of disclosing her HIV status to a potential long-term partner in the following way. “Cause I feel disclosing, if I’m dating somebody and I’m startin’ to like them, I want to disclose before ‘I like you too much’. This appears to be done as a protective mechanism from the pain of a broken relationship.. She adds, “Because if I like you too much and I spend too much time with you and then you reject me, I’m a mess, but if I can disclose to you when my heart is not really all in there, I can move on.” The fear of rejection because of HIV status appears to be a very real reality for Charlene.

Charlene provided insight into social construction of HIV in the Caribbean. She noted that, “in the Caribbean it’s still shameful to be- to have HIV or to be seen in the village or town you from and know that a person is HIV positive.” She also indicated that the stigma that accompanies an HIV diagnosis may be more difficult for women than for men in the Caribbean, “My heart breaks for people who are positive in the Caribbean and I’ll say women because I’m a woman and I am biased for women who are positive in the Caribbean you know? She also discussed the differences between the perceptions of HIV in the Caribbean versus in New York City. “People in New York have more tolerance, but in the Caribbean culture everything is so strict. They see in this tunnel vision that it can make a person life miserable.” The Caribbean culture, as described by the Charlene, is restrictive and very condemning, however the U.S. has a greater acceptance of those that are HIV positive and is able to offer health and psychosocial care that may not be found in the Caribbean.

The next theme of *good care* was described clearly by Charlene. The participant spoke about the range of services available to individuals who are HIV positive living in the U.S. The

participant emphasized this point stating, “There’s lots of good services you know in this country. I wouldn’t want to be positive and live in any other city but New York you know? Because in New York we get certain entitlements that you can’t get any place else so it’s a good thing, the medical care and stuff like that.” Even though the participant spoke highly of the entitlements that may be procured by HIV positive individuals, she also presented another side of receiving these benefits. While benefits assist with necessities such as housing and medication, they also impede individuals from procuring jobs that would provide more economic stability.

Charlene spoke at length about the systemic challenges of receiving perceived benefits when the individual is HIV positive, such as housing benefits and SSI (social security insurance). She indicated that although one receives benefits from these sources they are in what she describes as an “iron cage” when they want to work and stop receiving benefits. Often individuals living with HIV or AIDS “cannot get out.” She suggested a need for future research in this area. “I always wanted for somebody to do a dissertation on the welfare and social security system lower income...”

The theme of *self-care* also emerged from this interview. In telling her story, Charlene cited the ways in which she cares of herself. She said she was “learning to love herself one day at a time”, “meditate”, and that she “incorporated a lot of health attitudes.” These behaviors are motivated by the need for the Charlene to maintain her independence and to enjoy her life. She made this point by stating, “I wanna wipe my own ass! I don’t want to be so sick that I’m in a pamper and depending on someone to wipe my ass. So in order to be healthy enough to wipe my own ass I got to take care of myself!” In caring for herself, she has also learned how to assist other women that are HIV positive to care for themselves. The theme of *turning it around*, [empowerment] highlights Charlene’s motivation and entrepreneurial spirit that has come about

as a result of her living with HIV. She is very active in her community and provides education for individuals living with HIV, “I do workshops because I try to empower them [women] with having a better quality of life and also learning how to love themselves and how to disclose instead of keeping the secret.”

The last theme that emerged from this narrative was *spirituality*. This component of Charlene’s life appears to provide her with guidance and support. She noted, “You know um, it’s like I’m a very spiritual person.” This method of “self-work” or reflection seemed to provide a foundation for her understanding of herself and her world.

Individual Structural Description-Charlene

The structures represented in Charlene’s narrative are: relation to self, relation to others and time. Charlene indicated that she had been living with HIV for “24 years” and that when she was diagnosed the only pharmacological option for treatment was AZT. The perception of HIV/AIDS at that time was that if you had the HIV virus, it was equivalent to “AIDS and death.” The time period demarcating “destructive behaviors” engaged in after her diagnosis was told to be about “three years.” These years were marked with “denial, anger, resentment, and shame.” As a reaction to her diagnosis, Charlene began to adapt “destructive behaviors”, however soon learned that the destructive behaviors were maladaptive and did not assist her with learning to live with HIV. Charlene decided to channel her energy into moving forward with her life as an HIV positive woman.

Charlene’s knowledge about the HIV virus and her personal options for her life that have presented and evolved over the course of her “24 years” seemed to provide her with life experiences that enabled her to re-define herself and her life as an HIV positive woman. Initially, Charlene appeared to believe that HIV meant “death” and therefore adapted “destructive behaviors.” In highlighting the *time* (24 years) since living with HIV, she noted that “she was

diagnosed at 23.” That time in Charlene’s life was “pretty much hang out, party, drink , and a little weed.” Before, her life was characterized by carefree living. After being diagnosed however, her world and concept of *time* shifted.

The second structural aspect, *relation to self* is pivotal in that Charlene paints a picture of her life in which her “self” evolves over time. The acceptance of her diagnosis came at the cost of excavating her “inner self.” She described the “self” she experienced in the early years of her diagnosis as “damaged goods”, “damaged-scarred” “garbage to throw away” and “Red Scarlet.” The words are indicative of the perception of the “self” she knew. She also notes, “...when you HIV positive it makes you feel dirty in the beginning.” Part of this perception of self appeared to be grounded in cultural ideologies about individuals that acquire HIV as being “dirty.” I noted the growth in her relation to self as she added, “I’m still learning to love myself one day at a time.” While an HIV positive diagnosis may present challenges to one’s self-perception, Charlene’s honest assessment of her own journey indicated that she has now progressed in her understanding of her evolving “self.” She has not “arrived” as it were, but she continues moving toward a goal of self-love, honesty, and transparency. The self she is constructing, “is trying to plan ahead and get the education I need to give me what I need to live a sustained, fruitful life”, incorporating “healthy attitudes”, and “biased for women who are positive in the Caribbean”, (has a burden for HIV positive Caribbean women) and “spiritual.” She is “a work in progress” with the lived experience of a Caribbean woman diagnosed with HIV from the beginning of the “discovery” of the virus and still living to tell the story of her “self.”

The third structure is *relation to others*. The experience of living with HIV has provided Charlene with a platform to assist others to learn and practice self-love and self-acceptance. She believes wholeheartedly in assisting women to find their own voices and to educate them about

living with HIV. She described herself as an “advocate” and appeared to believe that advocacy for others was important for both her and other women affected by the virus. Charlene, for example stated, “I do a lot of workshops. I pretty much do support groups for newly diagnosed people.” She cited her reasons for relating to others in this way as, “I do workshops because I try to empower them [women] with having a better quality of life and also learning how to love themselves and how do disclose instead of keeping the secret.” This ability to assist others through the acceptance process stems from a deep commitment to pass along life lessons learned to others.

Meaning Units-Starr

1. Oh I always heard that once you have it you gonna die. That’s what I always got in my head- I heard. People said stuff about it, like if you have it you gonna die.
2. They never have anything good to say about it [HIV}
3. This guy get the result and then he went in to like a Caribbean bar and was just tellin’ everybody that he was infected. I was dating that person. And then I said, “You know what? Let me go and check myself.” And then I heard that I get it.
4. It’s like your whole body just like lock down. Like a shock. Then at that moment you pick it up and said, “I can’t lock down like that...”
5. After you deal with it now, you accept it. First you have to deal with it, and then you accept it, and then you try to have it now as a secret.
6. And then you go to the doctor, and after you start visit the doctors and to the clinic it’s not like what you heard about-death like that.
7. I think you get more better treatment with this [HIV} than if you never have it.
8. ...But the only thing is you still have...like you don’t want to tell anybody because you don’t want anybody condemn you because you know people nice to you now.
9. Sometimes you drop word and hear what they say. They say bad things about it, but you don’t say nothing because you know you have it.
10. Cause who you gonna run to? You understand? You can’t run to a friend. You can’t run tell your kids and you can’t run tell a family member.

11. You can tell like a social worker. Dey are the best people with you feel more comfortable because they never like have nothing negative to say about it.
12. Social worker people always have positive things. They try everything to help. You more comfortable to run to them.
13. If you feel you can't deal with yourself, like you feel you gonna go suicide or you gonna kill yourself or something bad, you in in your thinkin' and you don't want to go to that person and say anything cause it gonna be too much blow up. Blow up mean like they gonna say it wasn't them and they might call your name to somebody else and you just don't wanna hear- you just want to stop it right there.
14. But I'm not going to a family member for help.
15. They not gonna want you to drink out of their cup. They wouldn't want you to come to their house. They gonna said, "Oh you come to American and you let this happen to you?" , or "you have sex without condom."
16. You know, you don't want to hear the negative things cause the deal is you have it already so you don't want anybody come with anything different...so you feel more comfortable talkin' to a social worker
17. Like I just deal with it. I just say "Yes, fine. I have it. Fine.
18. Then you said, "okay you gonna go to the doctor and get your pills dem. That's how you deal with it.
19. Like I still find a job. Still associate myself with people same way, still have friends.
20. I'm not gonna hurt myself because that still not gonna help the situation
21. Like you have your family and friends. But at the same time when something come in like that, they still...you don't want to tell them because dey- dey not gonna help you. Dey gonna let it worsen.
22. So when you walkin' people just gonna whisper about you- "Oh that girl have HIV."
23. Even my daughter...dey gonna let my daughter feel very bad too because once the mother have it day gonna feel like, Oh you know her mother have this and day might tear she down.
24. Casue I don't tell her. I don't tell my daughter.
25. I was tryin' to date somebody who have it so we could just laugh about it and make fun about it...
26. You can't just depressed about it so you just turn it into a fun way...
27. I don't have any support

28. But we don't have anybody like in the neighborhood- like anybody we could run to.
29. I'm childcare. I work wid the white people dem and I do child care
30. I like to get my hair done, my nails. You know I play music in the house. I like to keep everything clean.
31. Only when I go to the doctor he remind you why you here, but when you leave and come back out to the world, you don't remember anything about it-like it block from your system.
32. The service is good. Yeah. The service is good. It's um- it's that they deal with. You know the doctors where you go they deal with HIV and um, you know it's good. I never get any you know funniness...
33. You know they treat you like a normal person and the service is good to me.
34. Because you know I want to live. I don't want to die. Cause you know if you not taking the proper things, then things can happen. So I want to live. I want to live for my child. You understand me? I want to still live until, you know the time come.
35. So what happened, the ADAP give you that medicine that you don't have to pay from your pocket and they come and they deliver it to you. So all those things are a blessing to me. And even the little rent, cause you never really know if your body break down, you still need a place to live. So all those things are help to me...
36. The people have this caring and niceness about them-where I go in the hospital
37. They just have this dark side that once you have it, like you're nobody.
38. So I prefer to die. I don't wanna say nothing to none of them. They jus illiterate towards it.
39. We get like platinum treatment here, but in Jamaica now they don't get any treatment so they trying to compare like we are the same. That's why I don't want to go back down there. If I have to go back I would die before I reach back because there because no treatment is not there. It's like when you go back there it's like a death sentence you goin' on under....
40. If they have it {Caribbean people} they will understand it. But even if they don't have it they won't understand it, so I still don't feel comfortable with them.
41. I talk to them normal, but they don't know anything.
42. Because if they know, they gonna scorn you
43. And then you feel like you more when you walkin' everybody just goin' to point at you with they finger and give you that extra look. That would make you feel like you gonna die more than anything else. So it better that you don't let them know.

44. I'm just glad to know that I am in the United States of American and know that somebody will- you can reach out to be here.
45. Try to cling to people...people who have it, who you can talk with
46. Try to take care of yourself. Try to put pride in yourself.
47. Like try to look in the mirror, I'm beautiful. I'm all that." Still do your thing. And try to take care of yourself.
48. You know God in your soul and find friends who even if one of them have it you could have somebody who, and try feel proud of yourself same way.
49. ...You laughing and grinning and you know, you're doin' your thing so right there you can feel that you are strong. And don't feel sorry for yourself.
50. Like you know, I try to do a little exercise. I have a trainer who come in and give me exercise
51. I have a massage person who come in and I have a yoga teacher.
52. You know and if you know there's anything supposed to come out of the blue, you just have to accept it, but right now I'm just a happy child. I try not to think about it.
53. ...I feel like this little young girl. I always tell people I'm 40. I never use you the other number (Laughing)
54. So you just to t a social worker and explain everything cause they have more- dem know how to relax you and tell you good things for you not to worry.
55. I think she know, but I don't tell her. She could know because she use certain word so you can know that she know but I don't tell her.
56. From the start I said the service is good. It's always good because I know what I'm looking for and you get it- like help with the rent, and help with the medicine cause I don't have certain types of paper documents.

Individual Textural Themes-Starr

Pre-HIV.

1. It [life] was good.
2. Yeah, working. You know doin' my thing. It was just good [life].

Knowledge of HIV [pre-diagnosis].

1. Oh, I always hear that once you have it you gonna die. That's what I always got in my head, I heard. People said bad stuff about it, like if you have it you gonna die.

2. Like they [people in her home country] never have anything good to say about it [HIV].

Perceived benefits of living with HIV.

1. I think you get more better treatment with this {HIV} than if you never have it.
2. So what happened, the ADAP give you that medicine that you don't have to pay from your pocket and they come and deliver it to you. So all those things are a blessing to me. And even the little rent, cause you never really know if your body break down, you still need a place to live. So all these things are help to me...

Finding out (HIV diagnosis).

1. This guy get the result and then he went into like a Caribbean bar and was jus tellin' everybody that he was infected and I was dating that person. And then I said, "You know what? Let me go and check myself" and then I heard that I get it [HIV].
2. ...That's why I said, "if he have it, maybe I have it so let me go and check it out."
3. It's like your whole body jus like lock down, like a shock, then at that moment you try to pick it up and said, "I can't lock down like that because you know, you...you don...so you just deal with it.

Finding out [HIV myths].

1. And then you go to the doctor and after you start visit the doctors and go to the clinic, it's not what you hear about...death like that.
2. Like you know the doctors dem nice and the whole system, and how when you take your medicine and you say, "Wow! People have it wrong!" [what it's like to have HIV]
3. Because the way how I did create it, it wasn't like that.

Good care (formal services).

1. The service is good. Yeah. The service is good. It's um- it's that they deal with. You know the doctors where you go they deal with HIV and um, you know it's good. I never get any you know, funniness...
2. You know they treat you like a normal person and the service is good to me.
3. The people have this caring and niceness about them where I go in the hospital.
4. From the start I said the service is good. Its' always good because I know what I'm looking for and you get it- like help with the rent, and help with the medicine cause I don't have certain types of paper documents.
5. So you just go to a social worker and explain everything cause they have more- dem know how to relax you and tell you good things for you not to worry.

6. Social worker people always have positive things. They try everything to help. You more comfortable to run to them.

Stigma (cultural).

1. They never have anything good to say about it [HIV].
2. They not gonna want you to drink out of their cup. They wouldn't want you to come to their house. They gonna said, "Oh you come to America and you let this happen to you?" or "You have sex without condom."
3. So when you walkin' people just gonna whisper about you- "Oh, that girl have HIV."
4. They just have this dark side that once you have it- like you're nobody.
5. ...Because if they know, they gonna scorn you.
6. Oh I always heard that once you have it you gonna die. That's what I always got in my head- I heard. People say stuff about it, like if you have it you gonna die.
7. But you know if they hear you have it now, then, especially Caribbean people- I think they more illiterate towards it because I guess they don't understand.

Stigma (tainted by association).

1. ...Even my daughter...dey gonna let my daughter feel very bad too because once the mother have it- dey gonna feel like, "Oh you know her mother have this sand dey might tear she down."

Coping (strategy).

1. Like I just deal with it. I just say, "Yes fine, I have it. Fine." Then you said, "Okay you gonna to the doctor and get your pills dem." That's how you deal with it. After you deal with it now, you accept it [diagnosis of HIV]. First you have to deal with it, and then you accept it, and then you try to have it now as a secret.

Coping (secrecy).

1. Like you have your family and friends. But at the same time when something like that [HIV] come in like that, they still...you don't want to tell them because dey- dey not gonna help you. Dey gonna let is worsen.
2. If they have it [Caribbean people with HIV], they will understand it. But if they don't have it, they won't understand it, so I still don't feel comfortable with them.
3. ...But the only thing is you still have- like you don't want to tell anybody because you don't want anybody condemn you because you know people are nice to you now.
4. So I prefer to die. I don't wanna say nothing to none of them [Jamaicans]...

5. Sometimes you drop a word and hear what they say. They say bad things about it [HIV] , but you don't say nothing because you know you have it.
6. I talk to them [Caribbean people] normal, but they don't know anything.
7. Cause who you gonna run to? You understand? You can't run to a friend. You can't run tell your kids and you can't run tell a family member.
8. I think she [participant's daughter], but I don't tell her [about HIV status]. She could know because she uses certain words, so you can know that she knows, but I don't tell her.
9. But I'm not goin' to family member for help.

Coping (positive outlook).

1. ...I feel like this young girl. I always tell people I'm 40. I never use the other number...(Laughing)
2. You know if there's anything supposed to come out of the blue, you just have to accept it, but right now I'm just a happy child. I try not to think about it [HIV].
3. Yeah! Yeah! Cause you have to have fun about it[HIV diagnosis], you understand? You can't just depressed about it, so you just turn it into a fun way like, "Oh look at Dr. [] two patient dem in the club like, "Whoo! Whoo!" dancin'!

Coping [self-care].

1. Like you know, I try to do a little exercise. I have a trainer who come in and give me exercise.
2. I have a massage person who come in and I have a yoga teacher.
3. Like try to look in the mirror, "I'm beautiful. I'm all that." Still do your thing and try to take care of yourself.
4. Because you know I want to live. I don't want to die. Cease you know if you not taking the proper things, then things can happen. So I want to live. I want to live for my child. You understand me? I want to still live until-you know the time come.
5. I like to get my hair done, my nails, you know play my music in the house. I like to keep everything clean. These things let me feel happy.
6. ...When I'm home and I'm doing things, you don't remember about the sickness. Only when I go to the doctor he remind you why you are here, but when you leave and come back out to the world, you don't remember about it- like you block it from your system.

Perceived benefits of living with HIV [life/treatment in America].

1. We get like platinum treatment here, but in Jamaica now they don't get any treatment so they trying to compare like we are the same. That's why I don't want to go back down there. If I have to go back I would die before I reach back because there no treatment is not there. It's like when you go back there it's like a death sentence you goin' on under...
2. I'm just glad to know that I am in the United States of America and know that somebody will- you can reach out to be here.

Life lessons [HIV].

1. Try to cling to people...people who have it, who you can talk with.
2. Try to take care of yourself. Try to put pride in yourself.
3. You know with God in your soul and find friends who even if one of them have it you could have somebody who, and try to feel proud of yourself same way.
4. ...You laughin' and grinning and you know, you're doin' your thing so right there you can feel that you are strong. And don't feel sorry for yourself.

Individual Textural Description-Starr

It was in Starr's brightly-colored apartment with comfortable furniture and hard wood floors, that she told me her story. Starr had been living in the United States for about 10 years at the time of her interview.

The themes for that emerged for Starr's interview are *Pre-HIV, knowledge of HIV, finding out, good care, stigma, coping, self-care, relationships, perceived benefits of living with HIV [life/treatment in America] and life lessons [HIV]* .

In the first theme *Pre-HIV*, Starr indicated that life before she was diagnosed was "good" and she was, "workin' and doin my thing." Starr reported that her *knowledge of HIV* prior to her diagnosis was that once you contracted HIV, it was tantamount to death, "Oh, I always hear that once you have it you gonna die. That's what I always got in my head, I heard."

Starr stated that her finding out started when a man she was dating announced to several people that he was HIV positive. "This guy get the result and then he went into like a Caribbean

bar and was jus tellin' everybody that he was infected and I was dating that person." After Y heard this, she went to get tested, "And then I said, "You know what? Let me go and check myself" and then I heard that I get it [HIV]." From her description, her initial reaction to learning she was HIV positive was that of shock. She described this by saying, "it's like your whole body jus like lock down, like a shock, then at that moment you try to pick it up and said, 'I can't lock down like that because you know, you...you don...so you just deal with it.'" The shock was followed by a resolve to "just deal with it." She suggested that after finding out about her diagnosis, she realized that her perceptions of HIV learned in her home country were wrong. She indicated that her prior knowledge was characterized by it being a fatal disease, "Oh, I always hear that once you have it you gonna die. That's what I always got in my head." However, when she went to the health center for services specific for HIV she was educated more regarding the facts of the disease. "And then you go to the doctor and after you start visit the doctors and go to the clinic, it's not what you hear about...death like that." This appeared to be a moment of "awakening" for Starr regarding survival and medical treatment for people that were HIV positive in that she realized that she could live successfully with HIV, unlike many individuals in her home country.

Starr indicated that since her emigration to the United States and subsequent diagnosis, her medical treatment has been good. The doctors and social workers appeared to provide treatment, education and a safe place for this participant. She highlighted this aspect as follows, "They people have this caring and niceness about them where I go in the hospital" and "The service is good. Yeah. The service is good. Its um-it's that they deal with. You know the doctors where you go they deal with HIV and um, you know it's good. I never get any you know, funniness..." She also felt that social workers are integral in her health and well-being, "So you

just go to a social worker and explain everything ‘cause they have more- dem know how to relax you and tell you good things for you not to worry” and “social worker people always have positive things. They try everything to help you. You more comfortable to run to them.” It appeared that even though she is undocumented, she is able to access services that assist her in living with HIV. “Perceived benefits of living with HIV” was illuminated by the following statement, “I think you get better treatment with this [HIV] than if you never have it. Several programs such as ADAP (AIDS Drug Assistance Program) provide benefits to individuals that are living with HIV that cannot afford to pay for medications and other resources. Starr described it in this way, “So what happened, ADAP give you that medicine that you don’t have to pay from your pocket and they come and deliver it to you; so all those things are a blessing to me. And even the little rent, cause you never really know if your body break down, you still need a place to live. So all these things are help to me.” The experience have accessing to health care and related services and being treated as “normal” is in stark contrast to the reactions one would receive in Starr’s home country.

Another theme pertained to overall life and medical treatment in the U.S. Starr recounted feeling that living with HIV here in the U.S. as an Afro-Caribbean woman has been positive in large part due to the medical care she has received. She said, “We get like platinum treatment here, but in Jamaica now they don’t get any treatment so they trying to compare like we are the same. That’s why I don’t want to go back down there. If I have to go back I would die before I reach back there because, no, treatment is not there. It’s like when you go back there it’s like a death sentence you goin’ on under...” This idea that a “death sentence” faces those with HIV in the Caribbean provides an understanding of the challenges that exist.

In chronicling her experiences, Starr indicated that the *stigma* associated with HIV in her home country was very strong and people tended to cast a sense of blame on the one infected. “They not gonna want you to drink out of their cup. They wouldn’t want you to come to their house. They gonna said, “Oh you come to America and you let this happen to you?” or “You have sex without condom.” In addition, Starr offered, “So when you walkin’ people just gonna whisper about you- “Oh, that girl have HIV.” She used words such as; “dark side” and “illiterate” when describing the mentality of Caribbean people toward those with HIV. She recounted that an individual becomes “scorned” when known to be infected. This scorn and scrutiny apparently leads those infected to become secretive and isolate themselves.

Secrecy is a coping mechanism that Starr used in order to survive. Secrecy also extended to her family and those in the Caribbean community that are not infected with HIV due to the stigma associated with HIV. Starr was emphatic about the need for secrecy, “So I prefer to die. I don’t wanna say nothing to none of them [Caribbean people]...” Secrecy is vital because of the personal consequences one might suffer as well as the social ramifications to family members that would result if someone from the Caribbean community finding out. She feels that if a person from the Caribbean is infected they would be much more sympathetic to another person that is infected, “If they have it [Caribbean people with HIV], they will understand it. But if they don’t have it, they won’t understand it, so I still don’t feel comfortable with them.” Disclosing to a member of the Caribbean community may result discriminatory treatment, “But the only thing is you still have, like, you don’t want to tell anybody because you don’t want anybody condemn you because you know people are nice to you now.” Secrecy is upheld even when others from this community speak negatively about those with HIV, “Sometimes you drop a word and hear

what they say. They say bad things about it [HIV], but you don't say nothing because you know you have it.”

Secrecy extends to family members as well. This participant stated that she had not disclosed to her daughter who lives with her. “I think she know [participant's daughter], but I don't tell her [about HIV status]. She could know because she uses certain words, so you can know that she knows, but I don't tell her.” In addition, there appears to be an understanding that after diagnosis as HIV positive, they cannot depend upon family members for support or to disclose their status, “Cause who you gonna run to? You understand? You can't run to a friend. You can't run tell your kids and you can't run tell a family member.” Lack of disclosure to family also seems to serve a protective function as it prevents family members from being stigmatized. This point is illustrated by Starr, “Even my daughter...dey [those in the Caribbean community] gonna let my daughter feel very bad too because once the mother have it- dey gonna feel like, “Oh you know her mother have this and dey might tear she down.”

Starr outlined her coping strategy for living with HIV. “Like I just deal with it. I just say, “Yes fine, I have it. Fine. Then you said, “Okay you gonna to the doctor and get your pills dem.” That's how you deal with it. After you deal with it now, you accept it [diagnosis of HIV]. First you have to deal with it, and then you accept it, and then you try to have it now as a secret.” This three step formula appears to involve acceptance of an HIV diagnosis and self-care, however as aforementioned, secrecy is also vital to coping and living with HIV.

Another method employed by Starr to cope with living with HIV is having a positive outlook. Starr believed that this is a very important aspect of living “fully”. “Yeah! Yeah! Cause you have to have fun about it [HIV diagnosis], you understand? You can't just depressed about it, so you just turn it into a fun way like, “Oh look at Dr. [] two patient dem in the club like,

“Whoop! Whoop!” dancin’!” This carefree attitude is also reflected in the statement, “...I feel like this young girl. I always tell people I’m 40. I never use the other number...(Laughing)” and “You know if there’s anything supposed to come out of the blue, you just have to accept it, but right now I’m just a happy child. I try not to think about it [HIV].”

In terms of self-care, Starr noted that she has several ways in which she practices this. She stated, “Like you know, I try to do a little exercise. I have a trainer who come in and give me exercise.” Self-care for Starr appears to also be fueled by her motivation to care for those that she loves. This is highlighted in the quote, “Because you know I want to live. I don’t want to die. Cause you know if you not taking the proper things, then things can happen. So I want to live. I want to live for my child. You understand me? I want to still live until-you know the time come.” In addition, she appears to link self-perception with self-care. She indicates that positive self-talk can be linked with self-care. “Like try to look in the mirror, “I’m beautiful. I’m all that.” Still do your thing and try to take care of yourself.” Many of Starr’s activities are an integral part of her happiness and self-care, “I like to get my hair done, my nails, you know play my music in the house. In like to keep everything clean. These things let me feel happy.”

A last theme, *life lessons [HIV]*, provides advice for those that are living with a diagnosis of HIV. Starr offers a holistic view of what other women can do to live a fulfilling life. “Try to cling to people, people who have it, who you can talk to.” “You know with God in your soul and friends who even if one of them have it, you could have somebody who...and try to feel proud of yourself same way.” For this participant, it appears as if friendship, self-care and a positive self-concept are important all important facets of living successfully with HIV.

Individual Structural Description-Starr

The structures presented in Starr’s narrative are: relation to *self*, *relation* to others and *space*.

Regarding *relation to self*, Starr has experienced HIV as an entity that is housed in her body, but not in her psyche. She discussed her experiences with accessing health services in the U.S. and described this as “good.” The doctors and other care staff with whom she has interfaced, have treated her with “caring and niceness” and like she is a “normal” person. Due to the care she has received she is able to maintain a healthy and productive life as her body has not “broken down” on her. In her description of self-care, Starr believes that it is important for women to validate themselves by speaking words of affirmation as cited in the following statement. “Like try to look in the mirror, “I’m beautiful. I’m all that.” Still do your thing and try to take care of yourself.” These words appear to indicate that Starr has incorporated these practices in her own life to combat the negative stereotypes that have been displayed upon to those that are HIV positive in the Caribbean community in the U.S. and abroad. It appears that on the deepest level, Starr believes that she is worthy of care and respect.

Starr’s *relation to others*, particularly family and the Caribbean community in the U.S. has been affected by the stigma associated with living with HIV. She indicated that she practices extreme caution in interactions with Caribbean people by stating, “I talk to them [Caribbean people] normal, but they don’t know anything.” Her vehement statement, “So I prefer to die. I don’t wanna say nothing to none of them [Jamaicans}”, indicates that Starr sees her life in jeopardy if someone from this community were to find out. In addition, while Starr does not talk directly about her relationships with her family back in her home country she does denote that they would assign blame to her for her HIV positive status, “...They gonna said, “Oh you come to America and you let this happen to you?” or “You have sex without condom.” Starr also fears for her daughter that in some way her daughter would be “tainted” due to Starr’s positive status. For this reason it seems that she has kept her status a secret from her daughter even though she

suspects that she may know. While this may seem counterproductive as her daughter lives with her, this mechanism provides a certain degree of safety for both of them.

Finally, Starr experiences *space* within the culture of New York and the United States as liberating. The systems and policies that govern her geographic location allow her to have health care and related benefits associated with and because of her HIV positive status. For her, as an undocumented immigrant, these services have provided a lifeline with regard to her overall health and well-being. She states, "I'm just glad to know that I am in the United States of America and know that somebody will- you can reach out to be here." Benefits such as ADAP (mentioned previously), allows Starr to have her medication paid for and delivered to her home. In addition, she is also able to have access to other allied health practitioners such as physical therapists and nutritionists that assist with her care. While other facets of Starr's life may be limited by her immigration status, she has found ways to link with friends in order to live a full life.

Meaning Units-Julie

1. I didn't have a great life. I was abused- not physically, but emotionally by my mom.
2. ...I was laughing because it didn't hit me so much. I was laughing and then is when the doctor came out and the nurse she had um, then the doctor came and out the nurse was talking and then the nurse bring me some chart and tell me I have to come back so, and so because you know I was diagnosed with HIV and whatever and it um, the health inspector gonna call me and a lot of stuff. That's when it really hits me
3. Years passed and I still have...I'm still goin' on. It doesn't bother me like before.
4. I only had one baby father back home in Jamaica and then now I met this guy here in America, so I know when I came here I was clean.
5. I was cryin'. I cry a lot. I was livin' by myself with the little girl and the little body and I find out and most times I sleep a lot.
6. Okay before di...I had a rough time because I was living with my mom and we weren't getting along and um there I met my son father and then now he treat me very good so in the long run we get along. I had a baby for him and after that he died. So after he died not I

went to [] Hospital and there was a lady who she always ask me, “Um, do you want to do a test?” Because she is like 16 years and she be tellin’ me so I said, “let me try it.” So I always did know but I didn’t know what he died from so and he was sick so let me try and it went on, and when I took that test that’s when I found out.

7. At first it was a lot of emotion. I don’t know a lot of different ways of coping. Yeah, I couldn’t bear- I couldn’t cope but then they call um support groups? That’s where my social worker sent me to this support group so then with other women positive like myself so we all talk about it.
8. Well for me I don’t have no family members cause I don’t tell nobody nothing. ...but the two kids here, I spoke to them about it.
9. I try to cope because from I come to church I have one friend in church that I spoke to about it and we talk. So I go to church and I try to cope.
10. I pray and I ask God to help me that I don’t stress because I have family to take of, and you know what? I always say it’s not the end of the world.
11. So women like myself, we can. Some people stressed out and some people cope, but I know I’m coping cause we have to show people out there that HIV is not the end of the world.
12. I told some of my friends out there about it but not family.
13. Because for me, more stuff I stressed out around me like my children them back home and how to support them, how to take care of them and these two kids here as a single mother. I was stress about that, but I don’t stress about the HIV
14. We get an apartment, we get food to some of the program, Pantry bags, MetroCards, support, we cook and eat there. We have fun there so you know it’s not the end of the world.
15. I don’t really have time to stress. Cause if you go stressin’ you just hurtin’ yourself.
16. ...I already know I have it so I’m tryin’ to cope to live with it until the Good Lord take me home because I have four kids to take care of and I want them to see me strong and powerful.
17. If I could say anything to anybody out there, is keep your confidence and live strong, you know.
18. I moved to xxx Hospital because I want better treatment because I know they had a massage therapist and those acupuncture and...I was in a lot of pain causing from arthritis.
19. You don’t have to worry about those because they provide insurance called ADAP so that’s help and with other legal problem like immigration and like those, those are what woman

like myself and those living with HIV or not that stress us sometimes too like immigration problems casue a lot of us including myself need that.

20. We have some well-trained, some good, gorgeous, what you call them now? Our case manager, social worker, therapist and all we have been goin' through we have some lovely people out there who take good care of us when we go to them for care.
21. The people them out there, they are more-more important to me than my own family cause things like these you can't tell your family.
22. They will talk to us and they will say, "come on over. Let's sit down and talk", but you know- so you feel good.
23. I have been seeing a psychiatrist too for stress from breakdown from not seeing my kids them back home. Well once in a while when they call me because sometime I can't get in touch with them because they phones not workin' in the area they live. They have to go into another area. The same area but they have to climb on a hill for the phone to work.
24. My sister is in Jamaica, my brother is here and um my mom die here. My father died, and my son father died. They all died three years apart so I mean one year apart from each other so this year...they all die in a row so that was a lot of stress for me too.
25. For the long run I really need a GED cause even I'm getting' older. I want to become a nurse one day [chuckling] and if I wait until the last day of my life to get that immigration status I'm gonna become a nurse, so that gives me motivation.
26. You know HIV is a hard thing to live with when you have it, especially in Caribbean families. You come from Caribbean or you have Caribbean...in America, it's much easier.
27. You could walk and tell everybody in America, they don't care. Go to Jamaica and cross that border and go to Jamaica sand say, "I have HIV", if you don't mind they beat you to death because it's hard.

Individual Textural Themes-Julie

Knowledge of HIV.

1. I always heard about HIV. People say to you um use protection, use condom. HIV kills people. I mean AIDS, when it turn into AIDS. They were always sayin' they had treatment for it before it turns its treatment for it.

Finding out.

1. Okay before di...I had a rough time because I was living with my mom and we weren't getting along and um there I met my son father and then now he treat me very good so in the long run we get along. I had a baby for him and after that he died. So after he died not I went to the hospital and there was a lady who she always ask me, "Um, do you want to do a test?" Because she is like 16 years and she be tellin' me so I said, "let me try it." So I

always did know but I didn't know what he died from so and he was sick so let me try and it went on, and when I took that test that's when I found out.

2. ...I was laughing because it didn't hit me so much. I was laughing and then is when the doctor came out and the nurse she had um, then the doctor came and out the nurse was talking and then the nurse bring me some chart and tell me I have to come back so, and so because you know I was diagnosed with HIV and whatever and it um, the health inspector gonna call me and a lot of stuff. That's when it really hits me.
3. I only had one baby father back home in Jamaica and then now I met this guy here in America, so I know when I came here I was clean.

Coping [post diagnosis].

1. At first it was a lot of emotion. I don't know a lot of different ways of coping. Yeah, I couldn't bear- I couldn't cope but then they call um support groups? That's where my social worker sent me to this support group so then with other women positive like myself so we all talk about it. Some people stress. Some people cryin'. All of us break down. I cry a lot afterwards I start to ignore and tell them [group members] "why are we cryin'?"
2. I was cryin'. I cry a lot. I was livin' by myself with the little girl and the little body and I find out and most times I sleep a lot.

Coping [secrecy-from family].

1. Well for me I don't have no family members cause I don't tell nobody nothing. ...but the two kids here, I spoke to them about it.
2. The people them out there, they are more-more important to me than my own family cause things like these you can't tell your family. You have to fight some of these cause you know if my family come and know I have HIV they not drinkin' a cup of water [chuckling] and I'm sure if a case manager or somebody come here and they say, "you want a cup of water?" Well you know some of them don't but some will say, "okay give me a bottle or whatever" but for us too we have some being in denial with our families cause they are very different from [long pause] I don't know...the people them that I'm amongst right- I'm around right now.
3. So I know I have two kids here but my sister and my brother they don't know. I have an uncle and three cousins here and they don't know. I don't tell them nothing. We don't even close.

Coping [positive outlook].

1. So women like myself, we can. Some people stressed out and some people cope, but I know I'm coping cause we have to show people out there that HIV is not the end of the world.

Disclosure [friends].

1. ...Because I talk to people, some of my friends about it. I told some of my friends out there about it but not family.
2. I just tell them upfront like that I'm HIV positive and I want you as my friend. Even though you might not have a partner right now or you might have a partner on and off, take tests and I even tell them some of these programs helps, really help us to cope with our everyday life different from HIV.

Disclosure [children].

1. And they said, "Mommy you don't look like you sick." They say I don't look like I'm sick [chuckling]. I say you know what because I'm really not stressing.

Stressors.

1. I have been seeing a psychiatrist too for stress from breakdown from not seeing my kids them back home. Well once in a while when they call me because sometime I can't get in touch with them because they phones not workin' in the area they live. They have to go into another area. The same area but they have to climb on a hill for the phone to work.
2. My sister is in Jamaica, my brother is here and um my mom die here. My father died, and my son father died. They all died three years apart so I mean one year apart from each other so this year...they all die in a row so that was a lot of stress for me too.
3. Because for me, more stuff I stressed out around me like my children them back home and how to support them, how to take care of them and these two kids here as a single mother. I was stress about that, but I don't stress about the HIV.

Motivation.

1. For the long run I really need a GED cause even I'm getting' older. I want to become a nurse one day [chuckling] and if I wait until the last day of my life to get that immigration status I'm gonna become a nurse, so that gives me motivation.
2. My two children the give me, they motivate me, because you know what? If it snow, they are out of here to school. If it rains, they are gone. If it is hot, they are gone. They never stay home. So they motivate me a lot and they love me and I love them.

Coping [spirituality].

1. I pray and I ask God to help me that I don't stress because I have family to take of, and you know what? I always say it's not the end of the world.
2. My church. I never stop goin' to church so we have the, we have- I call the church my family and my programs in the HIV, they are my family because I don't have any family here-only me and the two kids.

Advocacy.

1. Friends and so on, I told them to be careful to take, um use condoms and all of that. Take test. Get tested cause you know it's better for people to know that not to know, yeah..
2. I was on a video [discussing HIV] and they look at me strong.

Life lessons [HIV].

1. If I could say anything to anybody out there, is keep your confidence and live strong, you know.

Good care (formal services).

1. We have some well-trained, some good, gorgeous, what you call them now? Our case manager, social worker, therapist and all we have been goin' through we have some lovely people out there who take good care of us when we go to them for care.
2. They [care staff] will talk to us and they will say, "come on over. Let's sit down and talk", but you know- so you feel good.
3. So if I wanna- Like I'm at home right now, for instant I was so tired takin' all these medications for like the asthma, the arthritis cause I was in a lot of pain and they [care staff] miss me so much and call me my name and say, "what happened to you?" "We haven't seen you" and you feel good when they call you up and you know, the groups, your peers and the workers, everybody be callin' you up to see if you alright.

Perceived benefits of living with HIV.

1. You don't have to worry about those because they provide insurance called ADAP so that's help and with other legal problem like immigration and like those, those are what woman like myself and those living with HIV or not that stress us sometimes too like immigration problems cause a lot of us including myself need that.
2. I moved to the hospital because I want better treatment because I know they had a massage therapist and those acupuncture and...I was in a lot of pain causing from arthritis.
3. We get an apartment, we get food to some of the program, Pantry bags, MetroCards, support, we cook and eat there. We have fun there so you know it's not the end of the world.
4. ...You know I am happy. I- I am change in a way, in different ways. Look at us, we got somewhere to live, we are gettin' Medicaid that we never had before...
5. ...And after you finish group you have like groups. You have management groups, like you have some of those that are working with us, our case workers and all of them, they do groups where we sit down, eat, chat and drink juice, water, tea- they have all of those for us

when we get there so. I don't know if people will find time to stress. Right now if I'm worried, I just call one of them.

6. ...That's why I said I love this thing [HIV] cause I don't have nowhere to go otherwise from school to here to [] where I go to groups and stuff so every year we [the children & participant] have one week off for me and the kids to go for camp which is around HIV. That's HIV camp. So it's a whole bunch of kids, adults, everybody we go there and we have fun. They are some nice people from all over the world volunteer come and support us.

Medication adherence.

1. ...so I don't take medication and maybe if I was takin' medication I would more look stressed out because a lot of the medication you know it's not agree with my body cause I take some different types of medication and most time they make me sick but my doctor told me no that they're going to gonna start put me on medication, but I'm still not worried about it. I try my best not to.

Stigma (cultural).

1. You know HIV is a hard thing to live with when you have it, especially in Caribbean families. You come from Caribbean or you have Caribbean...in America, it's much easier. You could walk and tell everybody in America. They don't care. Go to Jamaica and cross that border and go to Jamaica sand say, "I have HIV", if you don't mind they beat you to death because it's hard. That's why we cannot go to Jamaica to live there with HIV and that's why I think it's good for the law to change so we could get some immigration status that we could get to help ourself here because if we go back home, it's not easy.
2. ...Because as I said, nobody eating from you, nobody drinking from you. You have to be isolated. Nobody cares.

Immigration challenges.

1. For me to seek some kind of service or any kinds of service if somebody doesn't help me, it's mostly health or immigration, right? Scared to go and seek any kinds of services otherwise from goin' to a doctor
2. They also have immigration you know, our case management here, but for our Caribbean women and men we don't have nothing going on for us right now.

Individual Textural Description-Julie

Julie's narrative began in her rather spacious apartment. An elongated hallway and light colored walls dominated the room in which we met for the interview. The interview took place

by a window with the scene below of the train line and individuals bustling about in the cold winter air

The themes that emerged from Julie's narrative were: *pre-HIV, finding out, knowledge of HIV, coping [post diagnosis, secrecy from family, positive outlook], disclosure, stressors, motivation, strength, life lessons-[HIV], good care, perceived benefits of living with HIV and medication adherence.*

The first themes of *finding out* and *pre-HIV* emerged simultaneously as the participant shared experiences of her life prior to her diagnosis. She recalled, "...I had a rough time 'cause I was living with my mom and we weren't getting along and um, there I met my son father and then now he treat me very good so in the long run we get along." This experience with her mother occurred while living in the United States. She also added, "I was abused, not physically but, um, emotionally by my mom." In contrast to her relationship with her mother, the relationship with her son's father proved to be harmonious. However, she noted, "I had a baby for him [her late husband] and after that he died." This loss was confusing for Julie, "...I didn't know what he died form so and he was so sick..." At the urging of a friend, she went and took an HIV test, "...there was a lady who she always ask me, um do you want to do a test?" because she's like 16 years and she be telling me, so I said let me try it." Subsequently she found out she had contracted HIV from her late husband, "...and when I took the test that's when 'I found out. And I found out so I didn't have a great life." She indicated that the first emotion she experienced was "kinda shock" and that she "was laughing because it didn't hit me so much I was laughing..." It appeared that the initial "shock" of discovering she was HIV positive left Julie numb to a certain degree. She described the way in which the care staff disclosed that she was positive, "...then is when the doctor came out and the nurse she had um, then the doctor

came and out the nurse was talking and then the nurse bring me some chart and tell me I have to come back so and so because you know I was diagnosed with HIV and whatever and it um, the health inspector are gonna call me and a lot of stuff. That's when it really hits me." This scene almost appeared to have gone by in a blur for the participant until "it really hits me and I break down and start to cry." Julie indicated that her knowledge of HIV was that 'HIV kills people'. However, she also received information that "there was treatment for it." This information confirmed that there was a way in which to live successfully with HIV.

Sub-themes within a broader theme of coping emerged: *post-diagnosis*, *secrecy from family* and *positive outlook*. Julie recalled that after being diagnosed, she experienced a range of emotions and found it difficult to cope, "I was crying a lot." However, she was linked to support services that seemed to help her come to terms with her diagnosis. "At first it was a lot of emotion. I don't know a lot of different ways of coping. Yeah, I couldn't bear... I couldn't cope, but then they call um support groups? That's where my social worker sent me to this support group so then with other women positive like myself so we all talk about it." With such support, Julie was able to talk about her diagnosis in a safe environment. She was just as quick to point out, however, that speaking to her family in her home country about her diagnosis was not an option, "Well for me I don't have no family members cause I don't tell nobody nothing. ...but the two kids here, I spoke to them about it." Secrecy appears to have been a coping method because allowed for this participant to gain support in her immediate circle without burdening her family with the news of her diagnosis. The third sub-theme, positive outlook, seems to provide a sense of empowerment for Julie. The statement "HIV is not the end of the world" is pivotal in that it indicates a sense of acceptance and peace about the HIV diagnosis. She also indicated that she does not "stress" about being HIV positive. Secrecy from family is also related

to stigma. Julie suggested that in her home country of Jamaica, the stigmatization surrounding those that are HIV positive is pervasive. Individuals are forced to remain “isolated” and “nobody cares.” She further stressed this by telling “nobody eating from you. Nobody drinking from you.” In addition, Julie adds that positive persons may face bodily harm from individuals in her home country. “Go to Jamaica and cross that border and go to Jamaica and say, ‘I have HIV’, and if you don’t mind they beat you to death because it’s hard.” The attitudes toward those that are positive in America are starkly different from attitudes those in the Caribbean. “You could walk and tell everyone in America. They don’t care.”

Throughout her narrative, Julie speaks highly of the health care services she has received in the U.S. She used the terms “well-trained” and “gorgeous” to describe her care team. She indicated that social workers have been an integral part of the support provide and have helped with referrals to community resources, “Our case manager, social worker, therapist and all, we have been goin’ through we have some lovely people out there who take good care of us when we go to them for care.” From the description given by Julie, her care team encourages her to talk through her problems and difficulties and that they make her “feel good.” Those that she feels connected to in a formal setting seem to have taken on a familial role. She highlighted this by discussing the fact that if she misses appointment someone from the care staff or in her support groups calls her to make sure that she is well. The participant cited that there are many *benefits* for those that are HIV positive in New York. Specific examples of benefits derived are ADAP (AIDS Drug Assistance Program), Medicaid, housing benefits and, other forms of social support. These benefits provide not only assistance for mental, physical and emotional needs but they also seem to lead to an improved quality of life and ability to cope for those in the programs. An example of this can be seen in the following statement. “ and after you finish

group you have like groups. You have management groups, like you have some of those that are working with us, our case workers and all of them, they do groups where we sit down, eat, chat and drink juice, water, tea...they have all of those for us when we get there so I don't know if people will find time to stress. Right now if I'm worried, I just call one of them."

In various instances, Julie does speak about *stressors*. When Julie came to the U.S., she left behind other children and family. The stress of being separated from her family has caused her difficulties, "I have been seeing a psychiatrist too for stress from breakdown from not seeing my kids them back home." Moreover a series of losses also had an emotional impact on her,

My sister is in [home country], my brother is here and, um, my mom die here. My father died, and my son father died. They all died three years apart so I mean one year apart from each other so this year...they all die in a row so that was a lot of stress for me too.

Although as mentioned before, the benefits Julie has accessed have been able to provide some support, there have been instances in which she has suffered severe emotional distress. However, both the tangible and intangible benefits provided essential resources that helped meet daily needs and cope with other stressors that result from HIV or from her current life situation.

Another facet of Julie's life that seems to provide a sense of well-being is connected to theme of disclosure to children and to friends]. As previously mentioned, Julie has not disclosed the diagnosis to her family in her home country. However, she did say that she did tell her two adolescent children that live with her. She commented that this was not an easy process for her but she felt that it was important. "And they said, "Mommy you don't look like you sick." They say I don't look like I'm sick [chuckling]. I say you know what because I'm really not stressing." Because Julie has an extended network of support in her friends, she has disclosed to some of her friends and found this to be cathartic. "I just tell them [friends] upfront like that I'm HIV positive and I want you as my friend. Even though you might not have a partner right now or you might have a partner on and off, take tests and I even tell them some of these programs helps, really

help us to cope with our everyday life different from HIV.” Disclosure has also provided a platform for Julie to be able to educate friends about HIV and encourage them to engage in self-care practices such as getting tested. Furthermore, it assists her de-mystifying what it is like to live HIV as she is able to share her experience. As a result of disclosing to immediate family and friends, she has been able to take a more active stance in HIV education by engaging with others and spreading awareness particularly in the Caribbean community. She indicated that she has participated in a video about those living with HIV, “I was on a video [discussing HIV] and they look at me strong.”

The concept of strength is illuminated in the next theme of strength (spiritual). In various parts of her narrative, Julie discussed her church attendance and her relationship with God. It seems as if this relationship provides Julie with strength to cope in living with HIV and to care for her family, “I pray and I ask God to help me that I don’t stress because I have family to take of, and you know what? I always say it’s not the end of the world.” A separate theme motivation is also linked with strength. Although Julie has experienced previous setbacks, she explained that she was determined to accomplish her personal goals. She believes that reaching these goals would assist her in living a full and meaningful life. Education is one of these goals, “For the long run I really need a GED cause even I’m getting’ older. I want to become a nurse one day [chuckling] and if I wait until the last day of my life to get that immigration status I’m gonna become a nurse, so that gives me motivation.” Furthermore, her children are an impetus for her to realize her dreams, “My two children they give me-they motivate me, because you know what? If it snow, they are out of here to school. If it rains, they are gone. If it is hot, they are gone. They never stay home. So they motivate me a lot and they love me and I love them.”

Finally, Julie shared life lessons of living with HIV. She had one primary wish for anyone living with HIV, “If I could say anything to anybody out there, is keep your confidence and live strong, you know.”

Individual Structural Description-Julie

Throughout Julie’s narrative the structural elements present are *relation to self, relation to others, time and space*.

Julie’s understanding of herself of an individual living with HIV is demarcated by the period before contracting HIV. She indicates that she was infected by her deceased husband. Prior to meeting him and contracting HIV, she used the word “abused” to describe herself, even though the abuse describe was inflicted on her mother. Further in her narrative, she also uses the word “clean” to describe the state of her body upon coming to the United States. She stated, “I only had one baby father back home in Jamaica and then now I met this guy here in America, so I know when I came here I was clean.” In this context, “clean” appears to signify the relationship between not having HIV and contracting HIV. She implied that contracting HIV has now made her the opposite of “clean.” In essence, HIV has contaminated her body. So her “self” had been diminished in some way. This line of thinking affected Julie profoundly in the early period after being diagnosed. She also used words such as “depressed”, “stress” and “break down” to describe her emotional state after diagnosis. These emotions contributed to her self-perception which became negative. However, through medical and psychological intervention, Julie was able to create a new “self” perception of living with HIV. She has learned not to “stress” and indicates that she is “happy” and there had been “change in a way.” Living with HIV no longer seems to carry the weight it did in the early days, but it more of a vehicle for her to increase her self-awareness to live life fully.

This participant's *relation to others* is an important aspect of her life. Julie explained that in the community, especially her health care and support communities, she feels "good." She experiences her relationship to friends as fellowship, encouragement, and advocacy. To be able education and inform others for Julie is vital because of her own experience. She appears to find joy in doing this. Her relationship with her children also provides her with a sense of purpose and motivation. Although she indicated that caring for them in times past has been difficult, they have accepted her as an HIV positive woman and a compassionate mother. In contrast, her relationships with her extended family, including her other children in her home country are more distant and stressed due to geographical distance and non-disclosure of her HIV status. Non-disclosure serves as a means of protection and avoidance of being stigmatized and "isolated." The participant's relationship with God also provides a foundation for her. She refers to God as "the Good Lord" and experiences a relationship with him by "prayer" and "go in to church." Those at church she calls "family" because "I don't have family here-only me and the two kids." Her relationship with God helps her cope through support and spiritual nourishment.

Space is experienced as a liberating force for Julie. She contrasts the attitudes of those in her home country toward individuals with HIV and those in America. New York City has provided her with the geographic "*space*" (anonymity) to live as a woman without a label so to speak. The space of the hospital and other care facilities have been places of healing and maintenance. The geographic space has also allowed her to develop her internal space and so she does not "cross that border and go to [home country]." Her home country in this context is a space or geography that invites stigmatization and isolation.

The concept of *time* is experienced by this participant as the means by which she has been able to live and process her emotions, obtain assistance and to grieve. She commented that

over a relatively short period of time, she experienced a series of losses in her life in rapid succession. These losses were both a loss of roles (as a daughter and a wife) and a loss of her life as she knew it prior to contracting HIV. Time in the early days after diagnosis appeared to represent a depressed state of being and a kind of “dragging along”. However, with the passage of time, Julie has had the opportunity to grow and to learn more about HIV and herself.

Meaning Units-Faith

1. I came from em, um but in this way-poverty. Married have five kids back home but my husband was the more goin’ out one. I was the one being home taking care of the kids.
2. It was a sad day and because em I was just newly married-newly re-married back here and um I was sick for about two years but didn’t get a diagnose because everything-all the um tests that did was, came back negative. They didn’t know what was goin’ on with me until um I started to you know, get worse and the doctor did you know a particular test and um when it came back positive I was and I got the result my husband was there, my um new husband was there with me and I had was to break the news to him.
3. Yeah, um but I could have pinpoint as to what you know could have just know how I manage to contact it. I knew a lot of things. I saw a lot of things. Never question a lot of things although I knew um which part I was livin’ it was rampant with that [HIV]-infected with that all that virus you know? Em’ I never believe I would be able to get that because I tell myself um even though I know that I believe he would have been safe, you know and um but all that went on between that found out few years later that was the case.
4. Yeah. Because the people that I know that he was movin’ around with, the women um they all dead.
5. ...you know um I think about you know back home in my country once you contact that virus [HIV] you know they see it as a death sentence. It’s just like your life is over...
6. ...And that is one of the most important things that this sickness has done for me-makin’ me start to live for me, stop livin’ for everybody else and start takin’ care of me. It open up my eyes to make me understand that after God, is me.
7. I think HIV gives you the opportunity to reflect back on you, to think about you and to do things that you know is beneficial to you, you know and I have a peace of mind right now because I have a wonderful husband. I have a wonderful two year old. Oh she drive me crazy sometime but you know I still love her and em I get to do things for me that I never used to do for me.
8. You survive this when you have good support that like I have-my husband, my church family. I have my medical family I call them and you good you know could reach out to

any one of them and they are always there for you, you know? It's very important for people with HIV that they get that support, you know and that would help them a lot.

9. I was angry. I was angry. Um, I just wanted to just go back home and kill him [ex-husband]. Because as I tell you where I come from hearin' about that you already have in your mind that you are dead so I was like, you know it doesn't matter if I go take his life first.
10. He was saying, "you know something? I think it's a blessing in disguise. I was like, "How in the name of Jesus you could call HIV a blessing in disguise?"
11. I want the day to when I really sit down and tell them [her daughters] about it that they are educated enough to understand that okay, that that doesn't change me from bein' me.
12. Um, I don't want it to leave a stigma even on this child here [youngest daughter] because she is a product of a mother, you know havin' HIV and was able to bring her into the world and she's negative and back home when a child born um and the mother is HIV, the child is also condemn and it traumatize them...they may view here differently, they may treat her differently because of that-yeah.
13. ...So the only person that know about it [HIV status] right now is my husband, my medical family and myself and the most High God most of all know about it, but besides that I keep it to myself.
14. Right now I go to meetings every month where I met people who are struggling with the same things. So we get to encourage each other. It's a lot of formal support.
15. I am surrounded by a lot of support
16. I have such a positive attitude about the sickness because you know I have people there for me. I have people I could talk to anytime I choose to.
17. The sickness has not changed my um, it has not changed you know the relationship I have with him [husband]. It get even better-it's more it's like he worry about me more than I even worry about myself you know. He wake up in the mornin' and he ask me, "Are you okay?"
18. That makes you understand that if you don't have great support, it is very hard for you to move on and become the person you ought to be. Support is very, very important.
19. When I came to [] and I was diagnose the very next day and there was this caseworker and she took me like a big sister and she cried with me and she said, "it's okay to cry." She said, "You goin' to the hospital and I didn't know anything about any insurance or whatever and what was the best or whatever and she did everything for me until I was able to do it for myself.

20. I get to spend time with me. These are the times I go and do my worship and my devotion and you know I get started with my devotion. Very important for me that I you know, you know connect with a higher source.
21. Yes, and I know that God brought me back for a reason. Really brought be back for a reason and that's why I wake up every mornin', every day thankin' God for me bein' here...
22. But you know, knowin' my doctor and knowin' how the kind of- you know relationship we have, we are very close. He's the godfather for my daughter.
23. And he [participant's doctor] makes sure, I would say that he takes care of me medically. Anything that I need to do, you know need to look at the eye surgery he was-when I had the baby, he was you know come through for me. He would come look for me. He would make sure everything is okay with me. He will make sure that no doctors besides him would you know convincin' me to do things that he don't want me to do. He was always you know um, always interactin' with him in everything that I do. He, you know, he's like a part of my life then.
24. So we have this thing in our house on Sunday we do nothing more than go to the house of the Lord, pray, worship and come back home and we eat and we rest.
25. You know they have this tendency to make you feel as though you already dead already. You just need to you know nail the coffin and put you into the grave and you still breathin'
- 26.
27. I can say this much, there are people who you know works in a medical facility although they know they cannot contract HIV from touchin' a person, you still get that um reaction from them...
28. And although I am HIV positive, we do have HIV positive people in our church but I don't tell them anything about me because I don't know how they gonna receive me if they gonna receive me differently.
29. And what I love about this facility and I tell them that every day, every time I call them I tell them thank you because I know when I came here how I was and how this place has really changed my life, so it's like my medical family...
30. ...I talkin' about the clinic. Since I been here and I think that's why I haven't left, I have met the most sweetest, the most kindest, the most wonderful bunch of people you could think about. They are so caring. They are so thoughtful. They think about everything, everything that is going to better your life.
31. The doctor, he works with you.

32. The caseworker they look out for you. [] is my daughter godmother. She has been there with me from the day I got pregnant till now. She was in every appointment when I was pregnant. She was there in everything. Every ultrasound, she was there for everything.
33. Um, I have great friends you know around me. Great support and I'm just enjoyin' me. I think that's the most important thing. I'm just enjoyin' me.
34. I think when you remain silent it kills you. You wanna die fast from HIV? Keep silent. Don't have any friends. Go into a deep depression. Do all of the things that kills you fast.
35. But I think what you need to do is embrace it. That's what I did. Embrace it, understand it. It's a part of me. There is nothing I can do about that. I will die you know when the time come you know when once you know He wants to bring it to an end. The time gonna come and I already make up my mind for that. When that time come, let, so be it but for this moment, I am just gonna enjoy me. I'm gonna have fun. I'm gonna forget that HIV is on me. Yes, I may you know HIV is in me but it doesn't have me. I done make up my mind I'm gonna enjoy my life.
36. I don't need to be stressin' out about what if, what if but what if...whatever. I just, I just roll with it. That's what I do. I just roll with it. I try not to live a stress- I try to live a stress free life because I think that's the key to my long life. Stress free. Yeah.
37. ...I didn't know how to tell him you know what was goin' on but I just trust my, you know my lil' instinct that tell me tell him the truth. Don't hide it, you know. Let him make his own decision because it's his life. I felt really bad because you know it was my husband. We been having unprotected sex you know and I'm wonderin' you know could I have him contracted it? You know if he did I couldn't live with myself. There was so much guilt playin' on me and then um I told him about while we were walkin' out of the doctor office as we come through the entrance and on the road I told him exactly what the results was and he hug me and said, "You know something? We gonna get through this together" and uh we went home and he said, "If you wanna cry, cry." I knew he was cryin' but he wasn't showin' me that he was cryin' because he was tryin' to stay strong for me...
38. ...When I came to [] I met wonderful people. Wonderful people, wonderful doctors, wonderful nurses, wonderful care, you know care, um case managers and um they work with me to obtain insurance, help me to attain you know whatever programs was necessary to help me even to assist me in getting housing to get to assist me in getting whatever benefits you know, you know that I could locate because of my medical um situation, I couldn't work because you know the medication makes me so sick.
39. Because I educate myself about the sickness, I felt you know, um more stronger. I 'm able to take charge of my life, not fearin' it. Understand? Uh, I know it's there but I don't fear it. I know what I have to do and I do it and I became more confident in myself that you know I could have take the next step in my life to have, have another child which is this baby I have I'm holdin' here.
40. If it's one thing this sickness teaches me –one of the most important things is how valuable I am. If I didn't know it then I know it now because I think it, what I can say is that I got

alotta opportunity to do things and to be what I want to be in this sickness that I would never even think about it if I was sick.

41. And I could tell you a whole long list: go to the beauty salon, do my hair, sometimes I go for a little massage. Yeah right now I'm workin' to lose the weight that I gained with the baby. I was so proud of myself. I told my caseworker, "I lost 7 pounds and feelin' good you know.
42. You know we went on the computer, we went on some websites and I didn't know they had website on these! We went on all kinds of websites dealing with this disease and I started to understand how it works you know and um what I need to do about you know my viral load you know CD4 and what is the CD4 and what is the viral load and you know when it goes under 200 you already into AIDS...
43. I have five daughters age 28 and um and the fifth- I have 6 daughters in all. Um, the baby is three years old and the biggest one is 28 and from 28 to 21 and I haven't told them anything. Reason being is because um the country I come from we call it more third world country and people back home is not as educated and informed as people here and um people may take it the wrong way. It could kinda mess up in a way um how they see you and back home in my country people have still has this um way where they scorn people with HIV and all that has to do with, with knowledge and information or you could say education.
44. I want the day to come when I do really sit down and tell them [family] about it, that they educated enough to understand that okay, that doesn't change me from bein' me.

Individual Textural Themes-Faith

Pre- HIV.

1. I came from em, um but in this way poverty. Married, have five kids back home but my husband was the more goin' out one. I was the one being home taking care of the kids.

Pre-HIV [denial].

1. Yeah, um but I could have pinpoint as to what you know could have just know how I manage to contact it. I knew a lot of things. I saw a lot of things. Never question a lot of things although I knew um which part I was livin' it was rampant with that [HIV]-infected with that all that virus you know? Em' I never believe I would be able to get that because I tell myself um even though I know that I believe he would have been safe, you know and um but all that went on between that found out a few years later that was the case.
2. Yeah, because the people that I know that he was movin' around with [having affairs with], the women um they all dead.

Finding out.

1. It was a sad day and because em' I was just newly married- newly re-married back here and um I was sick for about two years but didn't get diagnose because everything-all the um test that did was came back negative. They didn't know what was goin' on with me until um I started to you know, get worse and the doctor did you know a particular test and um when it came back positive I was and I got the result my husband was there. My um new husband was there with me and I had was to break the news to him.
2. I was angry. I was angry. Um, I just wanted to just go back home and kill him [ex-husband]. Because as I tell you where I come from hearin' about that you already have in your mind that you are dead, so I was like you know it doesn't matter if I go take his life first.

Coping [support].

1. Right now I go to meetings every month where I met people who are struggling with the same things. So we get to encourage each other. It's a lot of formal support.
2. I am surrounded by a lot of support.
3. I have such a positive attitude about the sickness because you know I have people there for me. I have people I could talk to anytime I choose.
4. That makes you understand that if you don't have great support, it is very hard for you to move one and become the person you ought to be. Support is very, very important.

Coping [support-multi-source].

1. You survive this when you have good support like I have- my husband, my church family. I have my medical family I call them and you could you know, reach out to any one of them and they are always there for you, you know. It's very important for people with HIV that they get that support, you know and that would help them a lot.

Good care [medical family].

1. And he [participant's doctor] makes sure I would say that he takes care of me medically. Anything I need to do, you know need to look at the eye surgery he was-when I had the baby, he was you know come through for me. He would come look for me. He would make sure everything is okay with me. He will make sure that no doctors besides him would you know convincin' me to do things that he don't want me to do. He was always you know um, always interactin' with him in everything that I do. He, you know, he's like a part of my life then.
2. And what I love about this facility and I tell them that every day, every time I call them, I tell them thank you because I know when I came here how I was and how this place has really changed my life, so it's like my medical family...

3. The doctor he works with you.
4. ...I talkin' about the clinic. Since I been here and I think that's why I haven't left, I have met the most sweetest, kindest, the most wonderful bunch of people you could think about. They are so caring. They are so thoughtful. They think about everything-everything that is going to better your life.
5. The caseworker they look out for you. [] is my daughter godmother. She has been there with me form the day I got pregnant until now. She was in every appointment when I was pregnant. She was there in everything. Every ultrasound, she was there for everything.
6. When I came to [] and I was diagnose they very next day and there was this caseworker and she took me like a big sister and she cried with me and she said, "it's okay to cry." She said, "You goin' to the hospital and I didn't know anything about any insurance or whatever and that was the best or whatever and she did everything for me until I was able to do it for myself."

Stigma [cultural].

1. ...you know um I think about you know, back in my home country once you contact that virus [HIV] you know they see it as a death sentence. It's just like your life is over.
2. You know they have this tendency to make you feel as though you already dead already. You just need to you know nail the coffin and put you into the grave and you still breathin'.
3. Um, I don't want to leave a stigma on even this child here [youngest daughter] because she is a product of a mother, you know havin' HIV and was able to bring her into the world and she's negative and back home when a child born um and the mother is HIV, the child is also condemn and it traumatize them...they may view her differently, they may treat her differently because of that-yeah.
4. ...The country I come from we call it more third world country and people back home is not educated and informed as people here and um people may take it the wrong way. It could kind mess up in a way um how they see you and back home in my country people still has this um way where they scorn people with HIV and all that has to do with knowledge and information or you could say education.

The blessing of HIV.

1. He [participant's husband] was saying, "you know something? I think it's [HIV] a blessing in disguise." I was like, "How in the name of Jesus you could call HIV a blessing in disguise?"
2. I think HIV gives you the opportunity to reflect back on you, to think about you and to do things that you know is beneficial to you, you know and I have a peace of mind right now because I have a wonderful husband. I have a wonderful two-year-old. Oh she drive me crazy sometime but you know I still lover her and em' I get to do things for me that I never used to do for me.

3. ...And that is one of the most important things that this sickness has done for me-makin' me start to live for me, stop livin' for everybody else and start takin' care of me. It open up my eyes to make me understand that after God, is me.
4. If it's one thing this sickness teaches me-one of the most important things is how valuable I am. If I didn't know it then, I know it now because I think it-what I can say is that I got alotta opportunity to do things and to be what I want to be in this sickness that I would never even think it if I was sick.

Coping [spirituality].

1. I get to spend time with me. These are the times I go and do my worship and my devotion and you know I get started with my devotion. Very important for me that I you know, you know connect with a higher source.
2. So we have this thing in our house on Sunday we do nothing more than go to the house of the Lord, pray, worship, and come back home and we eat and rest.
3. Yes, and I know that God brought me back for a reason. Really brought me back for a reason and that's why I wake up every mornin', every day thankin' God for me bein' here.

Coping [secrecy].

1. I have five daughters age 28 and um the fifth- I have 6 daughters in all U, the baby is three years old and the biggest one is 28 and from 28 to 21 and I haven't told them anything.

Coping [positive outlook].

2. I don't need to be stressin' out about what, what if, but what if...whatever. I just, I just roll with it. That's what I do. I just roll with it. I try not to stress- I try to live a stress free life because I think that's they knew to my long life. Stress free. Yeah.

Coping [education about HIV].

3. Because I educate myself about the sickness, I felt, you know, um more stronger. I'm able to take charge of my life, not fearin' it. Understand? I, I know it's there but I don't fear it. I know what I have to do and I do it and I became more confident in myself that you know I could take the next step in my life to have, have nother child which is this baby I have I'm holdin' right here.
4. You know we [husband and participant] went on the computer. We went to some websites and I didn't know they had website on these! We went on all kinds of websites dealing with this disease and I started to understand how it works you know, and um what I need to do about you know my viral load, you know CD4 and what is the CD4 and what is the viral load and you know when it goes under 200 you already into AIDS ...

Coping [self-care].

1. And I could tell you a whole long list: go to the beauty salon, do my hair, sometimes I go for a little massage. Yeah right now I'm workin' to lose the weight that I gained with the baby. I was so proud of myself. I told my caseworker, "I lost 7 pounds and feelin' good you know?"

Life lessons [HIV].

1. But I think what you need to do is embrace it. That's what I did. Embrace it. Understand it. It's part of me. There is nothing I can do about that. I will die you know when the time come you know when once you know He [God] wants to bring it to an end. The time gonna come and I already make up my mind for that. When the time come, let so be it but for this moment, I am just gonna enjoy me. I'm gonna have fun. I'm gonna forget that HIV is one. Yes, I may you know HIV is in me but it doesn't have me. I done make up my mind I'm gonna enjoy my life.

Individual Textural Description-Faith

My interview with Faith took place in an office space with colored walls. I sat at a desk and Faith on a chair opposite me with her daughter on her lap. This framed the space in Faith's story unfolded before me. At the time of interview Faith was a in her early 40's and had been living in New York City for approximately ten years.

The themes that emerged from her narrative were, *Pre-HIV*, *Finding out*, *Denial*, *Stigma [Cultural]*, *Stigma [Healthcare providers]*, *Coping [Support]*, *Good Care*, *the Blessing of HIV*, and *Life Lessons [HIV]*.

Faith's narrative began with the themes of *Pre-HIV*, and *Finding Out* which emerged simultaneously. Faith indicated that her life before being diagnosed with HIV, when she lived in her home country, was spent in poverty. She was "married, had five kids back home." Her role while there was "being home taking care of the kids" while her husband was the "going out one" implying that he was frequently away from the home and engaged in many sexual relationships outside of his marriage. Her then husband's behavior was not questioned by Faith as she took for granted that her husband's behavior would not affect her, "I never believe I would be able to get

that [HIV] because I tell myself um even though I know that I believe he would have been safe...” She also suggested that she was living in denial about her susceptibility to contracting HIV, “I knew a lot of things. I saw a lot of things. Never question a lot of things although I knew, um, which part I was livin’; it was rampant with that {HIV}...” After Faith immigrated to the United States, she divorced her previous husband from her home country, leaving behind five children and re-married. However, sometime after living in the U.S., she became ill a number of times but the doctors could not come to a consensus as to her malady, “They didn’t know what was goin’ on with me until um I started to get you know worse, and the doctor did you know a particular test and um when it came back positive I was and I got the results my husband was there, my new husband was there with me and I had was to break the news to him.” The participant added that she believes that she contracted HIV in her home country; however she was not diagnosed until she came to the U.S. Faith reported that the day she found out she was infected was a “sad day.” She had to reconcile herself with the fact that she would now have to tell her current husband that she was infected. Following her diagnosis, Faith said that “guilt was playin’ on me” because she was unaware of her status and knew that she had potentially infected her husband. The agony of this disclosure was met with a resolution to inform her husband, “I didn’t know how was to tell him you know what was goin’ on but I just trust my, you know trust my lil’ instinct that tell me to tell him the truth.” Upon reporting her diagnosis, Faith was told by her husband, “You know something? We gonna get through this together” and that “he was cryin’ but wasn’t showin’ me that he was cryin’ because he was tryin’ to stay strong for me...” Faith also shared that she experienced anger because she was infected by her first husband, “I was angry, um I wanted to just go back home [to her home country] and kill him.” She was encouraged by her current husband to “start thinking about you.”

Faith then chronicled a discussion she had with her husband shortly after her diagnosis in which he told her, “‘you know something? I think it’s [HIV] a blessing in disguise.’ I was like, ‘How in the name of Jesus you could call HIV a blessing in disguise?’” At first it appeared that the participant thought that his suggestion was absurd, however when she was farther into her experience living with HIV she observed, “If it’s one thing this sickness teaches me, one of the most important things is how valuable I am. If I didn’t know it then, I know it now because I think it-what I can say is that I got a ‘lotta opportunity to do things and to be what I want to be in this sickness that I would never even think it if I was sick.” In addition, HIV has “open up my eyes to realize that after God comes me.” Prior to her diagnosis, life was about others; however she was afforded the opportunity to begin to focus on self. This newfound introspective stance appeared to be encouraged by the participant’s care team.

Throughout her narrative, Faith reiterated her gratitude toward her “*medical family*”, she stated, “And what I love about this facility and I tell them that every day, every time I call them, I tell them, “thank you” because I know when I came here how I was and how this place has really changed my life, so it’s like my medical family.” This transformation has led to a familial-type bond with both her physician and caseworker, “the caseworker they look out for you. She is my daughter “godmother”. She has been there with me from the day I got pregnant until now. She was in every appointment when I was pregnant. She was there in everything.” It appears that Faith also felt that the care staff also was key in helping her to navigate formal systems, “She said, “you goin’ to the hospital and I didn’t know anything about any insurance or whatever and that was the best or whatever and she did everything for me until I was able to do it for myself.” Faith’s doctor and caseworkers have proven to be an extended family and fill a much needed role of support.

The theme of coping has six sub-themes: *support, support [multi-source], secrecy, positive outlook, stigma, education about HIV, self-care* and *spirituality*. Support is an essential element that is used by Faith in order to cope with living with a diagnosis of HIV. Faith states, “I am surrounded by a lot of support.” As mentioned previously, under the theme of *good care*, Faith maintains a familial relationship with her care staff and she also has support both in the community and in her personal life, “Right now, I go to meetings every month where I meet people who are struggling with the same things, so we get to encourage each other. It’s a lot of formal support.” In addition, she added that there was a need for multiple sources of support, “You survive this [living with HIV] when you have good support like I have: my husband, my church family;...my medical family I call them and you could you know, reach out to any one of them and they are always there for you, you know. It’s very important for people with HIV that they get that support you know? That would help them a lot.” Although Faith receives this support in the United States, she must still hide her diagnosis from family in her home country, “I have five daughters age 28 and um the fifth; I have six daughters in all. The baby is three years old and the biggest one is 28 and from 28 to 21 and I haven’t told them anything. She fears that telling them would change the way that they perceive her. Secrecy may have proven to be stressful in the past, however now Faith has learned to incorporate healthy habits in order to cope. She indicated that having a positive attitude is important. “...I try to live a stress-free life because I think that’s the key to my long life.” In addition, being educated about HIV, assists with alleviating fear about the disease. “I know what I have to do and I do it and I became more confident in myself that you know, I could take the next step in my life to have, have another child which is this baby I have holdin’ right here.” For Faith, having another child was a dream of hers. However, upon learning that she was infected with HIV, she thought she would no

longer be able to have a child. Her doctor informed her that she could have a child that would not be infected if she followed the advice given to her. She was then able to conceive and gave birth to her sixth daughter. Gaining the information she needed helped her to think through what she wanted in her life. Education about pregnancy and being HIV positive assisted her with this process.

Self-care was also an important part of coping for Faith. Going “to the beauty salon” and “do my hair, sometimes I go for a little massage” are all parts of Faith’s self-care regimen. Finally, spirituality appears to be an important part of Faith’s life. She emphasized that when she wakes in the morning, spending time in prayer and meditation with God is important in keeping her grounded. “I get to spend time with me. These are the times I go and do my worship and my devotion and you know I get started with my devotion. Very important for me that I you know, you know connect with a higher source.” For her to “connect” with God is to honor the reason she believes she is still alive. “Yes, and I know that God brought me back for a reason. Really brought me back for a reason and that’s why I wake up every mornin’, every day thankin’ God for me being here.”

While Faith has been able to find support and encouragement here in the U.S., she pointed out that in her home country; people with HIV do not receive good care. The stigma [*cultural*] facilitates and understanding of this stigma. She described the diagnosis of HIV as a “death sentence” and “it’s just like your life is over.” In a very poignant description she says, “You just need to you know nail the coffin and put you into the grave and you still breathin.” Furthermore, stigma will extend to one’s family members in the Caribbean. Faith spoke of not wanting her child to be discriminated against due to her mother’s HIV diagnosis, “Um I don’t want to leave a stigma on even this child here [youngest daughter] because she is a product of

her mother, you know havin' HIV and was able to bring her into the world and she's negative and back home when a child is born um and the mother is HIV, the child is also condemn and it traumatize them...they may view her differently, they may treat her differently because of that-yeah." This tendency to stigmatize those with HIV appears to be a result of a lack of information and education about the virus.

Finally, the last theme of *life lessons living [HIV]* finds Faith making peace with her diagnosis. She offers this view of her journey, "But I think what you need to do is embrace it [HIV diagnosis]. That's what I did. Embrace it. Understand it. It's part of me. There is nothing I can do that. I will die you know when the time come you know, when you know He [God] want to bring it to an end. The time gonna come and I already make up my mind for that. When the time come, let so be it but for this moment, I am just gonna enjoy me." This resolute stance appeared to provide a peace and comfort that leaves has left Faith in an empowered "place" living with HIV.

Individual Structural Description-Faith

The major concepts seen for Faith were: relation to self, relation to others, and space appear to be salient.

In speaking of her life, Pre-HIV Faith reported that she was a housewife while her husband was "the more going out one." Denial of her husband's infidelities appeared to be a common way that Faith coped with her marriage prior to her diagnosis. She said, "I knew a lot of things. I saw a lot of things. Never question a lot of things although I knew um which part I was livin' was rampant with that [HIV]-infected with all that virus. She adds that after her diagnosis she could "pinpoint" when she was infected. This description displays Faith's "*self*" pre-diagnosis as a woman that was not empowered to make changes in her marital relationship. Although she does not speak in detail about the specifics of her marital relationship, she does

indicate that her first husband infected her with HIV. In her home country, the stigma of HIV causes one to be ostracized and labeled, like you should be placed in “the coffin and put you into the grave and you still breathin.” Hence, Faith would have been labeled an outcast in her society. Her inability to “question” and “see a lot of things” indicates that she was seen, but not heard, almost invisible. However, upon her arrival and re-marriage in the United States, Faith’s diagnosis of HIV appears to have shifted her internal and external perceptions of herself. At first, her diagnosis rocked her to the core, because she felt guilt about the fact that she could have potentially infected her current husband because she was unaware of her status. She uses words such as, “fear” “guilt” and “anger” to describe her internal emotions after diagnosis, however as she educated herself about HIV, words such as; “less stress”, “peace of mind”, “livin’ for me”, “valuable” and “important” and “a new person” to describe herself and her state of being. The “self” after HIV was more empowered and peaceful than the “self” prior to HIV which Faith describes as “livin’ for everybody else.” Her multiple sources of support assisted her with forming a new identity, particularly the relationship with her current husband. She has traversed the bridge of death to life to form a new “self.”

Relation to others for Faith occurs in community. She has managed to create a family inclusive of her “medical family.” The space created for her by her family empowers her to “be the person she was meant to be.” Her support groups, relationship with her husband, interaction with her care community and even her relationship with her family in her home country all bridge the gap in creating and maintaining meaningful relationships. Faith’s relationship with God provides her with a sense of peace and purpose. This relationship is important because Faith indicates that she feels that God brought her back after her almost near death experience while being diagnosed with HIV. Her relation to God is one of redemption. She feels that she was

allowed to live for a purpose. Hence, the summation of her relation to others is that her life is given purpose by the interactions that she has and they leave her empowered and able to speak life into someone else's experience.

Finally the structure of space is a key element in this narrative. Faith's internal space has been transformed as she reiterates throughout the interview. She looks at life with a whole new perspective because the work she has done to understand herself and her world, have yielded a ripe harvest. In addition, her geographic space has afforded her the ability to cope effectively. In New York, she has made a home but it also gives her access to resources, the ability to obtain effective health care and the knowledge to grow. Unlike her home country, people with HIV are allowed to live life without fear of reprisals or harm. The *space* in the clinic that she attends is filled with "caring" individuals. Her space at home is occupied by the objects of her affection- her husband and young daughter.

Meaning Units-Empress

1. Um, I did not think that I could get HIV due to the fact that I had the...I come from an upper middle class Caribbean family so we don't carry ourself in the manner that we should contract HIV. I did not...at that time, I was not having- I was not having sex with a man number one which I felt put me not at risk, um I didn't think about vaginal fluids. Um, I didn't think about my partner's health status, whether or not they were either bisexual or heterosexual or curious.
2. Well I'm a lesbian. That's one.
3. I was a terrible child. I had gotten released from prison, I was in New York City and I had never lived in New York City so I was like, "whoa!"
4. Um, the way I got diagnosed was that unfortunately I was defending a colleague and a client went ballistic and had came with a syringe, two pockets full of syringe-filled contaminated blood and in the process of trying not get that client to kill my colleague while waiting for the police to come, I intervened and four of those needles fell into my leg. It was summertime so I had on sandals and it went into my calf and leg. Of course right away I tried to pull them out and one of them ripped open my leg.
5. I started feeling out of sync. You know when your body-and I decided to go back to the doctor and that's when they told me I had Hep C.

6. I was having night sweats very bad. I mean I was swimming in my bed. Um, I had loss of appetite. I was really tired and I'm normally a person that gets up, 5, 6 o'clock in the morning. [Finding out]
7. I knew in my heart of hearts.
8. I really stayed home and locked myself down and I was like, "Oh my God." And I like to be pretty. I like to dress up and I wanted to throw away all my clothes and I just did not want to deal with anything at all.
9. ...I didn't know how I was gonna tell my family especially because my mother um because I had a cousin who was HIV positive and of course they said the person that she was a drug...she took drugs on the side and she must have been doing something she was not supposed to be doing, etc, etc now knowing that her husband had infected her and he committed suicide um so it was a little difficult for me.
10. And then I realized that she [participant's boss] didn't know what I was talking about, so I said, "well boss I'm HIV positive." She goes, "okay so what are you going to do now?" I says, "I really don't know." She says, "Yes you do. You're gonna go to your doctor, you're gonna find out what your T-cell is this is before they had viral loads and all of that. You're gonna find out what your t-cell is and you're gonna follow what your doctor says and nobody's gonna know but if you take care of yourself." She says, "You know this. You teach this." I says, "yeah but this is got me for a loop. It's in my yard now." She says, "I understand that so this is what you have do-you have to dig up the dirt in your yard and you gotta re-plant the flowers and you're gonna be fine."
11. ...but who I first told was my grandmother and grandfather. My grandmother and I are very close. I first told her and she says, "Ok I still love you so what we gon' do about it?"
12. So when I told mama [participant's other grandmother], the old dreadlock she says, "well child you always want to defend somebody even when you was a baby you want to defend somebody. You always want to take care of somebody so you will be fine. When you come I mek you same ganja tea."
13. Even up to today, my mother will not acknowledge that I have HIV. My mother still acts as though I have cancer. You know I've had this cancer for so long chile, should have been dead 10 times over but it's okay if that's what it takes for her to deal with it. [Disclosure-parental denial]
14. ...so but with her daughter, she will not acknowledge the fact that I'm HIV positive because should not have gotten it.
15. That you were going to see a neon sign of my forehead that said I was HIV positive. That I would lose friends um or people within my community that would turn their back on me because I was-because I know about stigma and discrimination. I've worked with it with a variety of my clients. That was one of my concerns, that they would like, "how the hell did you do it? Did you do something to get it?"

16. For a while I was quiet. The only person that knew was my executive director and my father and then afterwards...I told my grandmothers but and my younger sister knew.
17. At that time they [doctors] were saying, "okay you have a year, two years, three years to live. So I was like, "I was going to enjoy it to the fullest. So you know I'm still here and I'm gonna be here much longer because my work is not done yet.
18. At that time they were saying, "Okay you have a year, two years, three years to live" so I was going to enjoy it to the fullest. So you know I'm still here and I'm gonna be here much longer because my work is not done yet.
19. My support after I was diagnosed was a very good friend of mine...She has since passed on. She died of cancer. My other supportive units were my church. Uh, some of the members of my church, not all of them knew. Some of my sister clergy-sister and brother clergy members. Um, there was nobody else for years. I chose not to have anybody else for years. I'm really funny about, well back then I was very funny about-you know when you see people crossing your doorstep? You don't let anybody cross your doorstep. And that's the way I felt. Not everybody is not gonna breach anything closer so immerse myself in educating and myself and learning as much as I possibly can and advocating for women who are HIV positive.
20. I had a Hennessey straight up with Coke on the side [laughing]. I did and I just went ahead and did it [disclosed]. And when I first did it um it felt good. It felt like this thing was lifted off my, not just, you know people says that if feel like a whole weight was lifted off your shoulders. I felt like my skin came off and a new skin came on.
21. I don't know what it was. I stared dancing. This morning when I woke up I didn't have no doubt cause I know the Lord will take care of me. The Lord will provide for me. I just started singing and dancing and we started singing and dancing. It was like something just said, "Whoosa!" And I had a brand new skin and since then I ain't been able to shut my mouth [laughing]!
22. So at that time [beginnings of HIV epidemic] everybody was having unprotected sex. They weren't taking care of their bodies and people...I remember when women were taking coat hangers and heating them up and taking that chance of to pull a fetus out of their body and takin' all kind of soo, soo [herbs] to make the baby come out- same thing with HIV.
23. I know we've done it. We've tried to do any kind of voodoo or whatever it is we had to get it out [HIV] but we got it. It's here. It ain't goin' nowhere till the fovernment say they gon' give it to us. They gon' give it to us secure.
24. It was fear. It was fear of not being respected anymore as an educator. It was fear of people staying away from me. It was fear that maybe they wouldn't have the proper medication and I was gonna die.
25. So we went to all the islands educating women and telling them to take their medications and stuff like that because now we had protease inhibitors and there was a big grant that they had. We were trying to get the numbers regarding Caribbean Americans, um not

Caribbean Americans, Caribbeanites that were positive and what could be done and what we found was basically what we expected- a lot of stigma, discrimination, and silence

26. Not a damn thing! I started to learn about HIV when I was in prison, but honestly, um from 87-88 up until 1995 August or April of 1995, I knew that you can't have sexual contact and you can't use needles and you have to take a test to find out etc.
27. HIV was running rampant and nobody was-it was running rampant within our community and nobody was paying attention to it because within our Caribbean community everybody was dying of cancer. Every one of us had cancer. Every damn one of us had cancer. It was ridiculous. They should have found a cure for cancer.
28. Um, about two years ago I started to take time out where at least once a week I have the "me" time because not every day I can because I have two sets of positions...I do a tub bath for hours. A good two hours until my fingers and toes look like prunes. I light my candles. I'll have a book there. I do not have the phone next to me. I may have a cup of tea. I like going to the sea row whatever, or I'll go to um any place I can be near water.
29. Well, I'm not as stressed as I used to be. I used to be so stressed. Always thinking about a deadline.
30. I don't want to be older!
31. I'm not as strong as I used to be. I used to be able to lift weights. Now I look at my weight and I pick one up and I'm like okay find and they sit there and they watch me like okay one day you gonna pick us up again, but I'm not ready right now.
32. But my strength is gone. Well my strength has diminished-it's not completely gone so I don't like the aging part. If I could stop, I would have stopped at 50.
33. I haven't gotten to the term that I okay, I'm 57 years old. I don't look or feel 57 but I don't think I look 57. Maybe when I wake up I look it. Right now um, I don't want to age. I want to stay where I am. I don't wanna get the aches and pains mmm hmm of what you do when you get older.
34. It was difficult because first of all the doctor I had was not very happy that I did not have sex like normal people. I didn't know what that meant but for what I knew I had to ask him, "What the hell's a normal person?" Well people that have sex with other genders and I was like, "ok so because I don't have sex with a man there's a problem?" So I got rid of him. Um, the other doctor wanted to know why: why I could not I guess be normal or accept whatever he had to tell me regarding HIV so I had a problem with that. [Provider stigma]
35. So I was a pain in the ass and they didn't like me and they kept shifting me all over the place until I got, till I decided ya'll not gonna shift me anymore cause I'm payin' out of pocket here so this is what's gonna happen- we gon' get us a doctor that's gonna be able to be enough for me you know what I'm sayin'?

36. Um and then they called me back and said there was some discrepancy, abnormalities...and I was like it can't be. I'm very health and very strong...
37. So at that time [beginnings of HIV epidemic] everybody was having unprotected sex. They weren't taking care of their bodies and people- I remember when women were taking coat hangers and heating them up and taking that chance of to pull a fetus out of their body and takin' all kind of soo, soo [herbs/potions given by traditional healers] to make the baby come out- same thing with HIV." She also notes, "I know we've done it. We've tried to do any kind of voodoo or whatever it is we had to get it out [HIV] but we got it."
38. My first doctor, I still pray for him cause he just knew that the sky you know, the ground was gonna open up and I was gonna burn in hell , you know? Um, he made me feel less than, you know? First of all you are a lesbian, then you get HIIV! Oh my God ewww! So we had to get rid of him!
39. They [women seeking services for HIV] sneak in there [local agency]. Only the bravest ones will walk in there just as bold as they can but the majority-we have women that live in Staten Island, um that live in Brooklyn, that live in Yonkers because they don't want anybody in their community to know that they are [HIV positive).
40. It's still shh, shh, shh. It should not be that because that's why the women that continue that especially heterosexual women because within the Caribbean community you know that as a woman and you have five men, you're a whore. But if a man have five women, he a don. That concept is still there and that's what's continuing to place our community in danger.
41. ...I started to learn about HIV when NI was in prison...I knew that you can't have sexual contact and you can't use needles and you have to take a test to find out etc and you can't use drugs...
42. They're beat down. My heart bleeds and cries for every Caribbean woman that is not able to stand on her own two feet and says, "I'm HIV positive and what?" She can still bore and raise children. She can still do any type-she can be the President of the United States, but she's not gonna be no more than a heterosexual woman that's infected living in the midst of Crown Heights and nobody's gonna pay attention to because the communities are gonna hold her down.
43. If our culture was a little bit more open and not so machismo ingrained we would have more women empowered to know their health status and once knowing their health status to proceed with taking care of not only themselves but their families and their communities.
44. My faith is so strong sometimes it scares me.
45. Well when I get in there [doctor's office] and the receptionist knows I'm there and she says, "Empress is here." And then you hear him go, "Oh my God!" So that makes me feel good.

46. And that's why I love him [doctor], cause he takes the time. He really, really does. Most places you go to you see a doctor that has 20-30 clients...1, 2, 3, etc., he sits and takes the time to talk to me.
47. Back home they'd kill us. A lot of them. Burn down the house, stone us. I think the only reason they [members of the Caribbean community] don't do it in the United States is because justice is more rapid here.
48. Well prior to last year before President Obama signed the bill no way were you coming in the United States HIV positive! People snuck in here and people didn't say anything but if they government find out you were HIV positive they could deport you because what they were saying is that you were gonna be a burden, hardship on the country. So that's why people that were HIV positive were not allowed for years into the United States until last year. Now there's no worry about that.

Textural Themes-Empress

Pre-HIV.

1. Well I'm a lesbian. That's one.
2. I had gotten released from prison, I was in New York City and I had never lived in New York City so I was like, "whoa!"
3. Um, I did not think that I could get HIV due to the fact that I had the...I come from an upper middle class Caribbean family so we don't carry ourself in the manner that we should contract HIV. [Denial] [Lack of susceptibility]

Pre-HIV [lack of susceptibility].

1. I did not...at that time, I was not having- I was not having sex with a man number one which I felt put me not at risk, um I didn't think about vaginal fluids. Um, I didn't think about my partner's health status, whether or not they were either bisexual or heterosexual or curious.

Knowledge of HIV.

1. ...I started to learn about HIV when NI was in prison...I knew that you can't have sexual contact and you can't use needles and you have to take a test to find out etc. and you can't use drugs...
2. So at that time [beginnings of HIV epidemic] everybody was having unprotected sex. They weren't taking care of their bodies and people- I remember when women were taking coat hangers and heating them up and taking that chance of to pull a fetus out of their body and takin' all kind of soo, soo [herbs/potions given by traditional healers] to make the baby come out- same thing with HIV." She also notes, "I know we've done it. We've tried to do any kind of voodoo or whatever it is we had to get it out [HIV] but we got it.

Finding out.

1. Um, the way I got diagnosed was that unfortunately I was defending a colleague and a client went ballistic and had come with a syringe, two pockets full of syringe-filled contaminated blood and in the process of trying not to get that client to kill my colleague while waiting for the police to come, I intervened and four of those needles fell into my leg. Of course right away I tried to pull them out and one of them ripped open my leg.
2. I knew in my heart of hearts.
3. I started feeling out of sync. You know when your body-and I decided to go back to the doctor and that's when they told me I had Hep C.
4. I was having night sweats very bad. I mean I was swimming in my bed. Um, I had loss of appetite. I was really tired and I'm normally a person that gets up, 5, 6 o'clock in the morning.
5. And uh, when he called, he said, "D I need to talk to you," I knew something was wrong.
6. Um and then they called me back and said there was some discrepancy, abnormalities...and I was like it can't be. I'm very health and very strong...

Finding out [Grieving].

1. I really stayed home and locked myself down and I was like, "Oh my God." And I like to be pretty. I like to dress up and I wanted to throw away all my clothes and I just did not want to deal with anything at all.

Disclosure [close to home].

1. You can tell? You can see it?
2. And then I realized that she didn't know what I was talking about so I said, "Well boss. I'm positive." She goes, "okay so what are you going to do now?" I says, "I really don't know." She says, "Yes you do. You're gonna go to your doctor, you're gonna find out what your T-cell is"- this is before they had viral loads and all of that...and you're gonna follow what your doctor says and nobody's gonna know but if you take care of yourself." She says, "You know this. You teach this." I says, "Yeah but this is got me for a loop. It's in my yard now." She says, "I understand that so this is what you have to do- you have to dig up the dirt in your yard and you gotta re-plant the follower and you're gonna be fine.

Disclosure [familial-acceptance/positive].

1. Well child, you always want to defend somebody even when you was a baby you want to defend somebody. You always want to take care of somebody so you will be fine. When you come I mek you some ganja [marijuana] tea.

2. ...But who I told first was my grandmother and grandfather. My grandmother and I are very close. I first told her and she says, "Ok, I still love you so what we gon' do about it?"

Disclosure [parental denial].

1. Even up to today, my mother will not acknowledge that I have HIV. My mother still acts as though I have cancer. You know I've had this cancer for so long chile, I should have been dead 10 times over, but it's okay if that's what it takes for her to deal with it.
2. "...So, but with her daughter she will not acknowledge the fact that I'm HIV positive because I should not have gotten it.

Disclosure [fear].

1. That you were going to see a neon sign on my forehead that said I was HIV positive. That was one of my concerns that they [clients] would be like, "How the hell did you do it? Did you do something to get it?"
2. It was fear. It was fear of not being respected anymore as an educator. It was fear of people staying away from me. It was fear that maybe they [doctors] wouldn't have the proper medication and I was gonna die.

Disclosure [rebirth].

1. I had a Hennessy straight up with a Coke on the side [laughing]. I did and I just went ahead and did it. And when I first did it, it felt good. It felt like this thing was lifted off of my, not just you know, people says that if feel like a while weight was lifted off of your shoulders. I felt like my seeking came off and a new skin came on.
2. I don't know what it was. I started dancing. This morning when I woke up I didn't have no doubt cause I know the Lord will take care of me. The Lord will provide for me. I just started singing and dancing and we started singing and dancing. It was like something just said, "Whoosa!" And I had a brand new skin and since then I ain't been able to shut my mouth [laughing]!

Support [multi-source].

1. My support after I was diagnosed was a very good friend of mine...she has since passed on. She died of cancer. My other supportive units were my church. Uh, some of the members of my church, not all of them knew-some of my sister clergy-sister and brother clergy members.
2. I have a great support system but like I said, my grandchildren and my grandmothers are my number one support.

Provider stigma.

1. My first doctor, I still pray for him cause he just knew that the sky you know, the ground was gonna open up and I was gonna burn in hell, you know? Um, he made me feel less than, you know? First of all you are a lesbian, and then you get HIV! Oh my God ewwww! So we had to get rid of him.
2. It was difficult because first of all the doctor I had was not very happy that I did not have sex like “normal” people.” I didn’t know what that meant but for what I knew I had to ask him what the hell’s a normal person? Well people that have sex with other genders and I was like, “ok so because I don’t have sex with a man there’s a problem so I got rid of him.
3. So I was a pain in the ass and they didn’t like me and they kept shifting me all over the place until I got, till I decided ya’ll not gonna shift me anymore cause I’m payin’ out of pocket here so this is what’s gonna happen- we gon’ get us a doctor that’s gonna be able to be enough for me, you know what I’m sayin’?

Good care.

1. And that’s why I love him cause he takes the time. He really does. Most places you go to see a doctor that has 20, 30, clients, 1, 2, 3, etc. He sits down and takes the time to talk to me.
2. Well when I get in there [doctor’s office] and the receptionist knows I’m there she says, “D is here”, and then I hear him go, “Oh my God!” So that makes me feel good.

Secrecy.

1. They [women seeking services for HIV] sneak in there. Only the bravest ones will walk in there just as bold as they can but the majority-we have women that live in Staten Island um that live in Brooklyn, that live in Yonkers because they don’t want anybody in their community to know that they are [HIV positive].

Stigma [cultural].

1. Back home they’d kill us...burn down the house-stone us. I think the only reason they [members of the Caribbean community] don’t do it in the United States is because justice is more rapid here.

Cultural denial [HIV].

1. It was running rampant within our community and nobody was paying attention to it because within our Caribbean community everybody was dying of cancer. ...Every damn of us had cancer. It was ridiculous. They should have found a cure for cancer.

Gender based discrimination.

1. It's [HIV] still shh, shh, shh. It shouldn't be that because that's why the women that continue that especially heterosexual women because within the Caribbean community you know that as a woman and you have five men, you're a whore. But if a man have five women, he is don [playboy]! That concept is still there and that's what's continuing to place our community in danger.
2. They're beat down. My heart bleeds and cries for every Caribbean woman that is not able to stand on her own two feet and says, "I'm HIV positive and what?" She can still bore and raise children...but she's not gonna be no more than a heterosexual woman that's infected living in the midst of Crown Heights and nobody's gonna pay attention to because the communities are gonna hold her down.
3. If our culture was a little bit more open and not so machismo ingrained we would have more women empowered to know their health status and once knowing their health status to proceed with taking care of not only themselves but their families and communities.

Advocacy [Caribbean community].

1. So we went to the islands educating women and telling them to take their medications and stuff like that because now we had protease inhibitors and there was a big grant. We were trying to get the numbers of Caribbean Americans, that were positive and what could be done and what we found was basically what we expected- a lot of stigma, discrimination, and silence.
2. I have worked with the Caribbean correctional officers...you know educating them.

Aging.

1. I don't want to be older!
2. I'm not as strong as I used to be. I used to be able to lift weights. Now I look at my weight and I pick one up and I'm like okay find and they sit there and they watch me like okay one day you gonna pick us up again, but I'm not ready right now.
3. But my strength is gone. Well my strength has diminished-it's not completely gone so I don't like the aging part. If I could stop, I would have stopped at 50.
4. I haven't gotten to the term that I okay, I'm 57 years old. I don't look or feel 57 but I don't think I look 57. Maybe when I wake up I look it. Right now um, I don't want to age. I want to stay where I am. I don't wanna get the aches and pains mmm hmm of what you do when you get older.
5. Um, I notice that when I sit down now, my cones, when I have to get up they hurt. They're not-it's a little difficult. Um...I'm just aging.

Self-care.

1. Um, about two years ago I started to take time out where at least once a week I have the “me” time because not every day I can because I have two sets of positions...I do a tub bath for hours. A good two hours until my fingers and toes look like prunes. I light my candles. I’ll have a book there. I do not have the phone next to me. I may have a cup of tea. I like going to the sea row whatever, or I’ll go to um any place I can be near water.
2. Well, I’m not as stressed as I used to be. I used to be so stressed. Always thinking about a deadline.

Spirituality.

1. My faith in God is my number one strength. My faith is so strong sometimes it scares me.

HIV policy.

1. Well prior to last year before President Obama signed the bill no way were you coming in the United States HIV positive! People snuck in here and people didn’t say anything but if they government find out you were HIV positive they could deport you because what they were saying is that you were gonna be a burden, hardship on the country. So that’s why people that were HIV positive were not allowed for years into the United States until last year. Now there’s no worry about that.
2. Now if you’re undocumented this is what you can get. As a person that is HIV positive you can get uh public assistance. Public assistance will pray for some people like say if they have AIDS or they’re you have a lot of symptoms they will get. They will pay their full rent. There are some undocumented that get SSI but they don’t get any good stamps, so you see it’s one or the other.
3. So we don’t have to worry about immigration status now like we once did unless of course you commit a felony and you’re HIV positive or have AIDS and you’re undocumented when you’re done they are gonna send you back not because of your health status but because of the crime you committed.

Purpose.

1. At that time [diagnosis], they [doctors] were saying, “Okay, you have year, two years, three years to live. So I was like, “I was going to enjoy it to the fullest.” So you know I’m still here and I’m goanna be here much longer because my work is not done yet.

Individual Textural Description-Emress

The interview with Emress took place on a brisk winter day in an office building located on a busy New York City street. She has lived in the U.S. over upwards forty years. She seemed

to be a formidable woman with a varied past who had gained a sense of empowerment through living with HIV and she shared her story.

The themes that emerged for this participant were *pre-HIV, lack of susceptibility, finding out, knowledge of HIV, denial, disclosure, coping, aging, provider stigma, secrecy, stigma [cultural], stigma [provider, gender-based discrimination, cultural denial of HIV, good care, advocacy, and policy [HIV]*.

In the theme, *pre-HIV*, Empress told me that, “I had gotten released from prison, I was in New York City and I had never lived in New York City so I was like, “whoa!” This participant appeared to relish the freedom and excitement of the city after her release from prison. She indicated that she was “part of a posse” before her imprisonment but did not expound on her reasons for being incarcerated. She also recounts, “...I was happy-go-lucky...very promiscuous...” Even though this participant highlighted that she was “promiscuous” in her past, she never thought that she was susceptible to contracting HIV.. Empress identified herself as a “lesbian” and that because of this she “was not having sex with a man who I felt put me not at risk” and also she “didn’t think about vaginal fluids” or “...think about my partner’s health status, whether or not they were either bisexual or heterosexual or curious.” In addition, she added that she came “from an upper middle class Caribbean family so we don’t carry ourself in a manner that we should contract HIV.”

Empress stated that she had limited knowledge of what HIV was prior to being diagnosed, “...I started to learn about HIV when I was in prison. I knew that you can’t have sexual contact and you can’t use needles and you have to take a test to find out etc.” Even though the participant had some general knowledge of HIV, it appeared that mechanics of HIV were still unclear to her. Furthermore, the fear and misinformation associated with HIV in the early

eighties, as Empress recalled, caused women to take measures to eliminate HIV from their bodies by using cultural knowledge/methods, “So at that time [beginnings of HIV epidemic] everybody was having unprotected sex. They weren’t taking care of their bodies and people...I remember when women were taking coat hangers and heating them up and taking that chance of to pull a fetus out of their body and takin’ all kind of soo, soo [herbs/potions given by traditional healers] to make the baby come out- same thing with HIV.” She also notes, “I know we’ve done it. We’ve tried to do any kind of voodoo or whatever it is we had to get it out [HIV] but we got it.”

Empress recalled the day she believes she was infected with HIV,

Um, the way I got diagnosed was that unfortunately I was defending a colleague and a client went ballistic and had came with a syringe, two pockets full of syringe-filled contaminated blood and in the process of trying not to get that client to kill my colleague while waiting for the police to come, I intervened and four of those needles fell into my leg.

After the needles implanted themselves into her leg she attempted to remove them, however doing so left a significant wound in her leg. Following this incident, the participant indicated that she consulted with a physician and was given medication. Following testing she was contacted shortly thereafter, “Um and then they called me back and said there was some discrepancy, abnormalities...and I was like it can’t be. I’m very health and very strong...” However, the participant recalled having somatic symptoms that were not normal for her. She said she was “feeling out of sync” and “decided to go back to her doctor. She added, “I having night sweats very bad. I mean I was swimming in my bed. Um, I had loss of appetite. I was really tired and I’m normally a person that gets up, 5, 6 o’clock in the morning.” As mentioned previously, her doctor contacted her, however she avoided going to hear the results of the testing and confessed, “I knew in my heart of hearts.” This “knowing” came as a result of her bodily symptoms but also because, she “was already in this field” meaning because her job at the time

was educating and working with individuals with HIV, she already knew the signs and symptoms of HIV. She told about the moment her physician finally confronted the participant with the news as follows. “And uh, when he called, he said, ‘Empress I need to talk to you,’ I knew something was wrong. “ Following her diagnosis, Empress entered a period of grieving. She described it in this way, “I really stayed home and locked myself down and I was like, “Oh my God.” And I like to be pretty. I like to dress up and I wanted to throw away all my clothes and I just did not want to deal with anything at all.” This grieving caused her to isolate herself, including not going to work.

Empress, subsequently called her supervisor and attempted to quit her job. Her supervisor then asked to meet with her. In McDonald’s restaurant, her supervisor tried to assure her that she would transcend her present situation, to which the participant responded, “You can tell? You can see it?” Bewildered, her boss told Empress that she did not understand her line of questioning. Empress recalled her disclosure to her supervisor in this way, “And then I realized that she didn’t know what I was talking about so I said, “Well boss. I’m positive.” She goes, “okay so what are you going to do now?” I says, “I really don’t know.” She says, “Yes you do. You’re gonna go to your doctor, you’re gonna find out what your T-cell is”...this is before they had viral loads and all of that...and you’re gonna follow what your doctor says and nobody’s gonna know but if you take care of yourself.” She says, “You know this. You teach this.” I says, “Yeah but this is got me for a loop. It’s in my yard now.” She says, “I understand that so this is what you have to do- you have to dig up the dirt in your yard and you gotta re-plant the follower and you’re gonna be fine.” This experience with disclosure appeared to empower Empress so that she could move on to the next phase in disclosure.

Empress, first disclosed to her paternal and maternal grandparents in whom she found acceptance and love, “Ok, I still love you so what we gon’ do about it?” In speaking with her maternal grandmother the response was to her disclosure was, “Well child, you always want to defend somebody even when you was a baby you want to defend somebody. You always want to take care of somebody so you will be fine. When you come I mek you some ganja [marijuana] tea.” However, with disclosure to her mother, she found denial, “Even up to today, my mother will not acknowledge that I have HIV. My mother still acts as though I have cancer. You know I’ve had this cancer for so long chile, I should have been dead 10 times over, but it’s okay if that’s what it takes for her to deal with it.

She rationalized her mother’s reaction by stating, “...So, but with her daughter she will not acknowledge the fact that I’m HIV positive because I should not have gotten it.” It appeared that there is an element of blame that Empress experienced from her mother as a result of her diagnosis.

Empress also recounted what she felt and experienced when she disclosed to her church family and friends and in a professional capacity. As recounted earlier, working in an environment treating and educating those with HIV, the participant reported that coached many people through the process of living with HIV, she experienced fear regarding the perception her clients might and others in the HIV community would have of her if they should learn she was infected with HIV. This fear caused her to think, “That you were going to see a neon sign on my forehead that said I was HIV positive. That was one of my concerns that they [clients] would be like, “How the hell did you do it? Did you do something to get it?” She also stated as reasons for non-disclosure to others, “It was fear. It was fear of not being respected anymore as an educator. It was fear of people staying away from me. It was fear that maybe they [doctors] wouldn’t have

the proper medication and I was gonna die.” Both internal and external fears were related to her concept of disclosure. However, later in her journey of acceptance of the diagnosis, Empress was able to experience disclosure as a rebirth. She recalled the experience telling her church family of her status in a public forum for World AIDS Day, “I had a Hennessy straight up with a Coke on the side. I did and I just went ahead and did it.” The act of disclosing was akin to having, “a brand new skin.” Being able to disclose allowed Empress to experience a wider sense of community and to obtain support.

For Empress, coping with HIV came in the form of a wide support systems, “My support after I was diagnosed was a very good friend of mine...she has since passed on. She died of cancer. My other supportive units were my church. Uh, some of the members of my church, not all of them knew...some of my sister clergy-sister and brother clergy members.” She also cited that her family, more specifically her grandchildren, provide support for her, “I have a great support system but like I said, my grandchildren and my grandmothers are my number one support.” The support system constructed by Empress came as a result of several life experiences with discrimination. In her narrative, instances of a lack of support particularly by the medical establishment were recounted.

The stigma and discrimination encountered by the participant due to her sexual orientation by health care providers were particularly palpable for her. She noted, “My first doctor, I still pray for him cause he just knew that the sky you know, the ground was gonna open up and I was gonna burn in hell, you know? Um, he made me feel less than, you know? First of all you are a lesbian, and then you get HIV! Oh my God ewwww! So we had to get rid of him.” In another instance she recounted, “It was difficult because first of all the doctor I had was not very happy that I did not have sex like “normal” people.” Well people that have sex with other

genders and I was like, “ok so because I don’t have sex with a man there’s a problem so I got rid of him.” Her continual disappointment with trying to obtain a competent healthcare provider led her to a resolution that called for self-advocacy, “So I was a pain in the ass and they didn’t like me and they kept shifting me all over the place until I got, ‘til I decided ya’ll not gonna shift me anymore cause I’m payin’ out of pocket here so this is what’s gonna happen- we gon’ get us a doctor that’s gonna be able to be enough for me, you know what I’m sayin’?” Although obtaining a knowledgeable physician proved challenging, at the time of interview Empress indicated that she found a competent and caring physician.

Of her doctor she says, “And that’s why I love him ‘cause he takes the time. He really does. Most places you go to see a doctor that has 20, 30, clients, 1, 2, 3, etc. He sits down and takes the time to talk to me.” According to Empress, “taking time” consists of reviewing lab work, asking about general health concerns and showing compassion and understanding of her as an individual.

Past and prior experiences have provided a road map for this participant to be able to identify what she needs in a healthcare provider. However, she highlighted that for many HIV positive women in New York City, *good care* is not a reality due to cultural and environmental factors. The themes of *secrecy*, *cultural stigma*, and *gender-based discrimination* address this sentiment. According to Empress, Caribbean women who want to access health care services often have to attend clinics far from their homes due to the fear of being identified by someone they know. “They [women seeking services for HIV] sneak in there. Only the bravest ones will walk in there just as bold as they can but the majority-we have women that live in Staten Island um that live in Brooklyn, that live in Yonkers because they don’t want anybody in their community to know that they are [HIV positive].” This *secrecy* is vital to maintaining a secure

place in their community without the cultural *stigma* attached to being HIV positive, “Back home they’d kill us...burn down the house-stone us. I think the only reason they [members of the Caribbean community] don’t do it in the United States is because justice is more rapid here.” Furthermore, she feels that historically Caribbean people have attempted to disavow the concept of HIV, “...It was running rampant within our community and nobody was paying attention to it because within our Caribbean community everybody was dying of cancer. ...Every damn of us had cancer. It was ridiculous. They should have found a cure for cancer.” This denial of HIV may serve as a protective mechanism dependent on the attitude of the individual. For example, a family member that is having difficulty accepting a diagnosis might use the word “cancer” to continue to reframe or minimize HIV, while another person may use the term “cancer” to silently implicate or condemn an individual with HIV. The *secrecy, cultural stigma, and cultural denial* associated with HIV are also compounded by *gender based discrimination* in Caribbean communities. “It’s [HIV] still shh, shh, shh. It shouldn’t be that because that’s why the women that continue that especially heterosexual women because within the Caribbean community you know that as a woman and you have five men, you’re a whore. But if a man have five women, he is don [playboy]! That concept is still there and that’s what’s continuing to place our community in danger.” Empress believes that women living with HIV are placed in a difficult position. “They’re beat down. My heart bleeds and cries for every Caribbean woman that is not able to stand on her own two feet and says, “I’m HIV positive and what?” She can still bore and raise children...but she’s not gonna be no more than a heterosexual woman that’s infected living in the midst of Crown Heights and nobody’s gonna pay attention to because the communities are gonna hold her down.” This “holding down” of women is also evidenced by the statement, “If our culture was a little bit more open and not so machismo ingrained we would have more

women empowered to know their health status and once knowing their health status to proceed with taking care of not only themselves but their families and communities.” This statement implies that disempowered Caribbean women do not have the resources or in many cases the support to be able to empower themselves and in turn those closest to them. Furthermore, cultural ideologies about masculinity and femininity also define behaviors that are acceptable and unacceptable in Caribbean communities.

Advocacy is closely related to the themes of *secrecy*, *stigma* and *gender-based discrimination*. Because she is a woman living with HIV-in the Caribbean community and working with those infected, Empress related that advocacy for women is vital, hence she has worked on several projects to spread awareness of HIV. “So we went to the islands educating women and telling them to take their medications and stuff like that because now we had protease inhibitors and there was a big grant. We were trying to get the numbers of Caribbean Americans, that were positive and what could be done and what we found was basically what we expected- a lot of stigma, discrimination, and silence.” Empress has also worked with those that have experienced have experienced discrimination due to their sexual orientation and has participated in education at local festivals, including passing out condoms, HIV literature and encouraging people to get tested for HIV. For example she states, “I have worked with the Caribbean correctional officers...you know educating them.” For Empress education and advocacy are important in general, but she feels a strong urge to assist those in the Caribbean community.

Empress reported that she participated in many activities, but also feels the need to relax and disconnect from her busy schedule. She said she has, “me time” and does “a tub bath for hours”, “light candles” and likes to “be near water.” She has also engaged in self-care after she

came to recognize her mental and physical limitations. “Well, I’m not as stressed as I used to be. I used to be so stressed, always thinking about a deadline. Another important aspect of self-care and coping with HIV for Empress is her *spirituality*. Spirituality is a source of support and comfort. Early in the interview, Empress revealed that she is an ordained minister. The ministry has provided a place to continue to develop her spirituality. Empress says of her faith, “My faith in God is my number one strength. My faith is so strong sometimes it scares me.”

Aging was a particularly salient theme for Empress. She spoke of it often throughout her narrative. She emphatically stated, “I don’t want to be older!” This protest against the aging process appeared to be related to the physical limitations she is now experiencing as result of getting older. “I ‘m not as strong as I used to be. I used to be able to lift weights. Now I look at my weights and I pick one up and I’m like okay fine and they sit there and they watch me like okay one day you gonna pick us up again, but I’m not ready right now.” The aging process seemed to have been a concept that has caught her somewhat by surprise. She related, “I haven’t gotten to the term that I okay, I’m 57 years old. Right now I don’t want to age. I want to stay where I am. I don’t wanna get the aches and pains mmm hmm of what you do when you get older.” One area that she thought needed to be addressed more strongly was *policy*. At the time of her interview, she lauded President Obama for addressing a key area of HIV policy, “Well prior to last year, before President Obama sign the bill, no way were you coming in the United States HIV positive. People snuck in here and people didn’t say anything but if the government find out you were HIV positive they could deport you because what they were saying sit aht you were gonann be a burden-hardship on the country. So that’s why people that were HIV positive were not allowed for year into the United States until last year. Now there is no worry about that.” She further expounded that these changes would have a lasting impact on those that were

positive. In addition, she also spoke about the provisions and benefits for undocumented immigrants with HIV/AIDS.

Finally, Empress spoke about many causes that are close to her heart and her journey of being HIV positive. Above, all she feels that her *purpose* is to help those that may be voiceless and to provide real life solutions to problems affecting people living with HIV. Of her purpose she stated, “At that time [diagnosis], they [doctors] were saying, “Okay, you have year, two years, three years to live. So I was like, “I was going to enjoy it to the fullest.” So you know I’m still here and I’m goanna be here much longer because my work is not done yet.”

Individual Structural Description-Empress

The structures that have been identified for this participant are: relation to self, relation to others.

Relation to self for Empress is a concept that has proven to be marked by transformation. Regarding her inner self, Empress used words to describe her life ‘pre-HIV’ such as, “a terrible child”, “former ex-posse member”, “promiscuous”, “upper middle class Caribbean”, “dread”. These words are indicative of her outer “self”, however these descriptions all have inner “self” connotations. Her “self” prior to contracting HIV appears to have been marked by a period of instability and rebellion. She briefly described her time in prison for what appear to be illicit activities. She said, “So you know I had a big “S” [for Superman] on my chest.” This indicated that she felt her “self” was invincible and could do all things. After her diagnosis, her world came to a stunning halt even though she reported that, “I knew in my heart of hearts” indicating that she knew that she was infected with HIV after a workplace incident in which she was injected with contaminated needles. This life event caused her to now evaluate her former life and “self.” “ It’s in my yard now”; indicative of the fact that she worked with those that were HIV positive and now she had to deal with her diagnosis. This role reversal challenged her

previous notions of what it was like to live infected with HIV. Her self-concept was also challenged. “I like to be pretty. I like to dress up and I wanted to throw away all my clothes and I just did not want to deal with anything at all.” She no longer thought of her “self” as “pretty.” However, remnants of the old “self” did seem to converge with the new as she described her growth as a woman. The fighting spirit that she possessed prior to her diagnosis, continues to be evident as she “fights” for others infected with HIV in the form of advocacy and education. Empress’s spiritual “self” inhabits a place in which she felt that her relationship and faith in God was so palpable that it “scared” her. The reality of God and her spiritual life appeared to have contributed to a deep sense of “self” in relation to her higher power. As result she joined the clergy and saw the spiritual “self” and the advocate “self” as both able to affect change while sharing her calling. Finally, her aging “self” acknowledged that she does not like idea of getting older, however she seemed able to begin to formulate an acceptance of her life as she begins to experience health complications, not necessarily from HIV, but from the aging process.

Empress experiences her *relation to others* namely her family as important. The parts of her “self” that were connected with family strengthened and changed. In recounting her experience with disclosure to her grandparents, she reported that the love and respect that they possessed for her remained constant and reinforced the concept of unconditional acceptance. However it seemed that for with her mother, the daughter that she once knew was now infected with a disease that carried with it stigma and judgment. Her “daughter-self” now was not fully-accepted, “so but with her daughter she will not acknowledge that fact that I’m HIV positive because I should not have gotten it.” This idea coincides with a statement made earlier in her narrative, “I come from an upper middle class Caribbean family so we don’t carry ouself in a manner that we should contract HIV.” The collective “our” “selves” did not associate the “self”

with HIV. It appeared that the space that Empress's "daughter-self" inhabits was able to acknowledge that she is still not fully-accepted or understood by her mother. Her work appeared to form the main foundation for her relationship to and with others. She is able to interact with members of the community on both formal and personal levels. She is able to advocate for change on a local and state level and also in the lives of her clients. Empress is so "other"-entered that she has spent the majority of her career focused on others and indeed she indicated that her life will continue to be spent in such a manner.

Meaning Units-Simone

1. All I knew when you get diagnosed or when you do have HIV- you die! That's what I used to hear.
2. This [HIV] is not gonna stop me.
3. I found out um, I was pregnant and I went to the doctor and that's when I found out.
4. I was like, "It's not me! I was 18 years old. Me-NO! Can you do a test over? Maybe ya'll switch blood.
5. I remembered calling him [ex-boyfriend] on the phone and screaming on the phone and he couldn't believe it.
6. So when I came home honestly I wanted to kill myself right cause I'm thinkin' I'm gonna die anyways so why not? And a couple days after that I had to really think and come to terms with it [diagnosis] and read more about it and you know that's why now I realize it's not really...HIV is just a chronic illness to me.
7. I was with him for two years before we had sex and not use a condom and got pregnant and that was the time I found out...
8. ...At the age of 13-14 somewhere around there, my father brought me up here [U.S.] ...but comin' up here in America with an accent kids used to make fun of my accent and stuff so I used to like stand back-be standoffish because I couldn't be the person who I used to be back home.
9. Yeah! I always used to be in charge- I'm like, "Oh, no we're not doing this! We're doing that! And if somebody hit my cousins they would come to me and I would have to go fight them [school peers]. That's how I used to be.
10. When I was pregnant or when I had my son, I can't recall- I think I had my son, I end up leavin' my child father, my first son...I went to a shelter and it had a case manager was

helping me, you know, to get myself together. So I stayed in the shelter for like three months...

11. ...One day I went to my father house to get my paperwork and my social security cause he had everything there and he said, "I need to talk to you." I'm like, "What?" He said, "You HIV positive?"
12. She [participant's step-mother] went in my information and found out. So we did the research. We call who we need to call and found out yes it was her. So they sayin' that she went in my record and see that I was [HIV positive] and she told my father.
13. Um, but my father knows, my boyfriend knows, my auntie knows and that's good enough for me.
14. Like I have a best friend- I won't even tell her.
15. You know what to say and what not to say and you know how people think about certain things and especially people from the islands, they very ignorant when it comes to HIV...
16. My mother, she doesn't know. And I see how my mother acts with people who do have it [HIV]
17. I live my life. I don't think about it, honestly I don't. I get dressed and I go my parties. I do my thing. I enjoy my life. It's-nothing's gonna stop me.
18. That's what I tell the patients here listen, "Live your life. Don't be stressed out. When you bring stress into your life, you bring stress around you, that's when you fall. Get up. Live. Do what you gotta do. The same think I say to everybody, that's what I say to myself.
19. Ok, when I'm stressed, this is just me; I will go and I will take down my curtains and change them. Yeah, when it comes to my house I'm a clean freak. I will change from to-when me and my boyfriend we don't see eye to eye just see me movin' around changing and trust me I'll change my curtains yesterday and you see me change it today. That's just how to calm me down and to yeah. I like, I'll go shopping. That's just my thing when I'm pissed.
20. Well no one here knows my status [at work].
21. ...I'm so freakin' tired of takin' medication. You really get tired of it. You never been on that shit before so now it's like I gotta take it, especially when you start on a new regimen you get sick for like a few...for the first few weeks like either you feel dizzy so you gotta take it at night.
22. I wanna see my kids- you know the funny thing I think that's what it is; I always say my kids have to go to college. I wanna see my kids graduate, I wanna see my kids go to...
23. With my doctor, I could ask him questions-anything I want to ask him. I think when you work at the hospital they respect you more than- this is just my opinion, they respect you more than when you a regular patient.

24. In the islands they know about HIV, some people. Some people illiterate in the islands and they just think like back in the eighties you know? HIV people was dyin' out because they had no medication so they still have that stigma about HIV. You get HIV and you DIE! And you know you have, you start getting skinny, losing weight or they see a lot of scab on your skin, you got HIV.
25. The only thing I do is like where I live, there's a lot of Haitians, um Puerto Ricans, Jamaicans, so like yeah there's a lot of island people so sometimes I'll just pull up my car and I'll just in the summertime play my music sittin' in my care where everybody outside and I'm like, "Yo, ya'll want some condoms?" And I'll just give it to them. And they know me from givin' out condoms...
26. There's a stigma too when it comes to immigration. Why it is when you have HIV as I say, HIV or AIDS, first of all it's hard for them to come to the U.S. Why is that? They comin' for help. Second, why is, let's say I didn't have my papers and I'm here and I get HIV, I'm here and I wanna file for my documents, why it take a longer period? Years than a regular person and doesn't and it take six months to a year. So as I said all of us is human but again it's a stigma.
27. Live your life! That's it. For all you Black women out there! If it's \$20, if it's \$5, treat yourself. And make sure that you have someone that you trust and someone that you know have respect for you even though you and your man, your boyfriend break up, they will have respect that's gonna say, "You know what? I'm not gonna tell nobody [about HIV status] that's her privacy."

Individual Textural Themes-Simone

Pre-HIV.

1. ...At the age of 13-14 somewhere around there, my father brought me up here [U.S.] ...but comin' up here in America with an accent kids used to make fun of my accent and stuff so I used to like stand back-be standoffish because I couldn't be the person who I used to be back home.
2. Yeah! I always used to be in charge- I'm like, "Oh, no we're not doing this! We're doing that! And if somebody hit my cousins they would come to me and I would have to go fight them [school peers]. That's how I used to be.
3. A happy young lady... Whatever I used to do back then, like I'm a very outgoing person.
4. When I was in 9th grade I started running so they used to take me to different states to represent the school."

Knowledge of HIV.

1. All I knew when you get diagnosed or when you do have HIV- you die! That's what I used to hear.

Finding out.

1. I found out um, I was pregnant and I went to the doctor and that's when I found out.
2. I was like, "It's not me! I was 18 years old. Me-NO! Can you do a test over? Maybe ya'll switch blood.
3. I remembered calling him [ex-boyfriend] on the phone and screaming on the phone and he couldn't believe it.
4. So when I came home honestly I wanted to kill myself right cause I'm thinkin' I'm gonna die anyways so why not?
5. I was with him for two years before we had sex and not use a condom and got pregnant and that was the time I found out...

Coping [stress].

1. Ok, when I'm stressed, this is just me; I will go and I will take down my curtains and change them. Yeah, when it comes to my house I'm a clean freak. I will change from to-when me and my boyfriend we don't see eye to eye just see me movin' around changing and trust me I'll change my curtains yesterday and you see me change it today. That's just how to calm me down and to yeah. I like, I'll go shopping. That's just my thing when I'm pissed.

Coping [secrecy].

1. Like I have a best friend- I won't even tell her.
2. My mother, she doesn't know. And I see how my mother acts with people who do have it [HIV].
3. Well no one here knows my status [at work].
4. It's just me. I keep-it's my business. If I choose to tell someone, I will.

Disclosure [forced].

1. She [participant's step-mother] went in my information and found out. So we did the research. We call who we need to call and found out yes it was her. So they sayin' that she went in my record and see that I was [HIV positive] and she told my father.
2. ...One day I sent to my father house to get my paperwork and my social security cause he had everything there and he said, "I need to talk to you." I'm like, "What?" He said, "You HIV positive?"
3. So my father went and tell my grandmother. He told my um aunts, everyone on my father's side they know but they don't the whole- they don't know if it's true or not.

Challenges living with HIV.

1. ...I'm so freakin' tired of takin' medication. You really get tired of it. You never been on that shit before so now it's like I gotta take it, especially when you start on a new regimen you get sick for like a few...for the first few weeks like either you feel dizzy so you gotta take it at night.

Stigma [cultural].

1. You know what to say and what not to say and you know how people think about certain things and especially people from the islands, they very ignorant when it comes to HIV...
2. In the islands they know about HIV, some people. Some people illiterate in the islands and they just think like back in the eighties you know? HIV people was dyin' out because they had no medication so they still have that stigma about HIV. You get HIV and you DIE! And you know you have, you start getting skinny, losing weight or they see a lot of scab on your skin, you got HIV.

Immigration challenges.

1. There's a stigma too when it comes to immigration. Why it is when you have HIV as I say, HIV or AIDS, first of all it's hard for them to come to the U.S. Why is that? They comin' for help. Second, why is, let's say I didn't have my papers and I'm here and I get HIV, I'm here and I wanna file for my documents, why it take a longer period? Years than a regular person and doesn't and it take six months to a year. So as I said all of us is human but again it's a stigma.

Relationship challenges [intimate-getting out].

1. When I was pregnant or when I had my son, I can't recall- I think I had my son, I end up leavin' my child father, my first son...I went to a shelter and it had a case manager was helping me, you know, to get myself together. So I stayed in the shelter for like three months...
2. How my mother used to support me in track and field, my father never used to support me like that. He would come to one or two track meets but not the support that I always wanted. I wanted him to be at all my track meets.

Life lessons [HIV].

1. Live your life! That's it. For all you Black women out there! If it's \$20, if it's \$5, treat yourself. And make sure that you have someone that you trust and someone that you know have respect for you even though you and your man, your boyfriend break up, they will have respect that's gonna say, "You know what? I'm not gonna tell nobody [about HIV status] that's her privacy."

2. That's what I tell the patients here listen, "Live your life. Don't be stressed out. When you bring stress into your life, you bring stress around you, that's when you fall. Get up. Live. Do what you gotta do. The same think I say to everybody, that's what I say to myself.

Individual Textural Description-Simone

In a small office with two chairs and Christmas decorations, Simone, who at the time of interview had been living in the U.S. for fourteen years, shared her journey of living with HIV. As she spoke, her lilting accent punctuated her words. Her locked hair flowed down her back and her bangle bracelets and other accessories displayed her unique sense of style.

The themes that emerged for Simone were pre-HIV, knowledge of HIV, finding out, coping [stress & secrecy], disclosure, challenges living with HIV, stigma, relationship challenges[intimate & familial] and life lessons.

Simone expounded on her life prior to her diagnosis by stating, "...like I'm a very outgoing person" and that she was a "happy young lady." She pointed out that her personality has not changed even though she is now HIV positive. She also spoke about her transition from life in her home country to the U.S. She said that this transition was difficult at first because since she was an adolescent at the time, she had to learn how to integrate to a new school and new culture. This proved challenging for Simone. "My father brought me up here. Um, I started school from 8th grade, but comin' up here in America with an accent kids used to make fun of my accent and stuff so I used to stand back-be standoffish because I couldn't be the person I used to be back home." She described her personality in her home country as "I always used to be in charge. I'm like, "Oh no we're not doing this! We're doing that!" However, after some time in the U.S. her outgoing personality returned and Simone "started opening up" and "picking up their slang here." Her outgoing nature was nurtured through competing in track, "...When I was in 9th grade I started running so they used to take me to different states to represent the school." She also reported that she had "a lot of fans" during her track and field career in high school.

Simone shared that her *knowledge of HIV* came from those around her. “All I knew you get diagnosed or when you do have HIV-you die! That’s what I used to hear.” The notion that HIV led to death made Simone’s diagnosis of HIV even more shocking to her. Simone was mainly focused on her education in high school; however she met her first boyfriend and commenced a relationship. She believed that she contracted HIV from this relationship. “I was with him for two years before we had sex and not use a condom and got pregnant.” While at a visit to her physician during her first pregnancy, she discovered that she was HIV positive. She recounted the experience this way, “And um, went to the doctor I think it was like three months and that’s when I found out.” Upon hearing that she was HIV positive, Simone reported that she was in disbelief, “I was like, “It’s NOT ME!” ...Do it over! IT CAN’T BE ME! I was 18 years old. ME-NO!” When telling me about the confrontation with her boyfriend about her diagnosis, Simone inhaled sharply and closed her eyes and recollected it as follows. “I remember calling him on the phone and screaming over the phone and he couldn’t believe it.” She added that she encountered feeling of despair and thought about committing suicide, “So when I came home honestly I wanted to kill myself right cause I’m thinkin’ I’m gonna die anyways so why not?” When queried further about her then boyfriend’s response to her HIV positive status and how she could have contracted it she replied, “He wasn’t aware. So he say.” The nonchalant attitude her boyfriend displayed coupled with the fact that this was her first serious relationship led Simone to believe that she contracted HIV from her then boyfriend. At some point after her diagnosis, the participant’s relationship with her boyfriend deteriorated and she had to live in a shelter for some time. This part of the narrative led to a theme *relationship challenges*. Simone did not identify specific reasons for her leaving the relationship, however she relayed that she gave birth to her first son while living at the shelter. During her time there she was able to earn money from

braiding hair. He had saved to rent an apartment only to have the money stolen by a trusted friend. However, she was later able to procure an apartment and leave the shelter. In addition to losing her significant intimate relationship, Simone's relationship with her family became somewhat strained. This highlighted a painful chapter in Simone's journey with HIV. Simone indicated that she was not allowed to disclose her status to her family because her step-mother found out her status from her hospital records and told her father. Her step-mother worked at the hospital where Simone was diagnosed. "She [participant's step-mother] went in my information and found out. So we did the research. We call who we need to call and found out yes it was her. So they sayin' that she went in my record and see that I was [HIV positive] and she told my father." She was then later confronted by her father about her status. She reported to her father that she was indeed HIV positive. Her father then disclosed her status to other family members. This forced disclosure did not allow Simone the freedom to be able to disclose to those she chose to. This betrayal by family members added to Simone's need to exercise extreme caution in disclosing her status. *Secrecy* proved to be an important aspect of living with HIV for Simone. She is reluctant to disclose even those that she considers closest to her are not aware of her status. "Like I have a best friend; I won't even tell her." For Simone, knowledge of her HIV status is something that is to be guarded. Her attitude toward secrecy is summed up in the following quote. "It's just me. I keep...it's my business. If I choose to tell someone, I will." Furthermore, concealment of her status extends to family members. Simone said that her mother, who lives in her home country showed discrimination toward those that are infected with HIV, therefore she feels it would be unwise to disclose her status even many years later. "My mother, she doesn't know. And I see how my mother acts with people who do have it [HIV]." Simone correlated the stigma that surrounds HIV in the Caribbean and Caribbean communities in the

U.S. with lack of knowledge or misinformation, “In the islands they know about HIV, some people. Some people illiterate in the islands and they just think like back in the eighties you know? HIV people was dyin’ out because they had no medication so they still have that stigma about HIV. You get HIV and you DIE! And you know you have, you start getting skinny, losing weight or they see a lot of scab on your skin, you got HIV.” From this statement, it is apparent that certain physical symptoms are also associated with and cause alarm that someone may be infected with HIV. In addition, Simone also noted that because of the stigma associated with HIV/AIDS in Caribbean communities, one must be secretive in order to preserve a sense of self and well-being, “You know what to say and what not to say and you know how people think about certain things and especially people from the islands, they very ignorant when it comes to HIV...” Another aspect of *stigma* is captured in this narrative centers on immigrants that reside in the U.S. Simone implied that immigrants that reside in the U.S. that are HIV infected are not granted the same expediency toward obtaining legal immigration status compared with that are not HIV infected. “There’s a stigma too when it comes to immigration. Why it is when you have HIV as I say, HIV or AIDS, first of all it’s hard for them to come to the U.S. Why is that? They comin’ for help. Second, why is, let’s say I didn’t have my papers and I’m here and I get HIV, I’m here and I wanna file for my documents, why it take a longer period? Years than a regular person and doesn’t and it take six months to a year. So as I said all of us is human but again it’s a stigma.”

Simone also discussed challenges in her daily life. Although she is grateful for her life and doesn’t focus on the fact that she is HIV positive, living with HIV does present some hurdles. Simone emphatically spoke about her dislike of having to take antiretrovirals (ARVs) to suppress her viral load, “I’m so freakin’ tired of takin’ medication. You really get tired of it. You

never been on that shit before so now it's like I gotta take it, especially when you start on a new regiment you get sick for a few...for the first few weeks like either you feel dizzy so you gotta take it at night.”

Simone's life centers around her immediate family. Through her role as a mother and fiancée, however, when asked how she takes care of herself, she reported that shopping and keeping her house clean are the major ways in which she deals with stress. “Ok when I 'm stressed, this is just me; I will go and I will take down my curtains and change them. Yeah, when it comes to my house I'm a clean freak. ...I like, I'll go shopping. That just my thing when I'm pissed.” These coping mechanisms have assisted Simone to alleviate negative feelings.

Throughout her journey with HIV, Simone revealed that she has learned many valuable *life lessons*. She shared valuable insight and advice for other women living with HIV. Living life to the fullest is an important aspect of living well for this participant. She states, “live your life!! That's it. For all you Black women out there! If it's \$20, if it's \$5, treat yourself.” As seen in her narrative, Simone also has faced betrayal by those closest to her. She advised women that are HIV positive to surround themselves with people in whom they can confide especially in the context of intimate relationships, “And make sure that you have someone that you trust and someone that you know have respect for you even though you and your man, your boyfriend break up, they will have respect that's gonna say, “You know what? I'm not gonna tell nobody, that's her privacy.” Simone also believes in following her own advice, “...Don't be stressed out. When you bring stress into your life, you bring stress around you that's when you fall. Get up. Live. Do what you gotta do. The same thing I say to everybody, that's what I say to myself.” For Simone, HIV is a journey. She stated, “This [HIV] is not gonna stop me.”

Individual Structural Description-Simone

The two structures that emerged for Simone are relation to self and relation to others. Simone's relation to self was seen as she chronicled her immigration to the U.S. Prior to coming to the U.S., Simone said that she was "a control freak" and was more assertive. However, in the U.S. she initially felt out of place and that other students "made fun of her accent". As time went on she was able to assimilate to the culture and found a new identity. Upon first learning that she was HIV positive, Simone expressed disbelief at the diagnosis, "It CAN'T be me!" This appears to indicate that her diagnosis did not align with her view of herself. Due to the stigma that is attached to those that contract HIV in her home country, a diagnosis of HIV signified that she would now be stigmatized; therefore, HIV may have represented, at the very least, a difficult life and at most, death to Simone. Her diagnosis was the death of the "self" that she knew previously. However, later in her narrative she expressed that she learned to accept her "self" as a person with a diagnosis of HIV. She indicated that "HIV is just a chronic illness to me. It's just like a cold..." This acceptance allowed her to move on and forge a new reality. The self that has emerged is one that is guarded, but has constructed a new life with her family that consists of her fiancée and her sons. Simone's relation to others occurs in a very controlled environment. She is very careful about her inner circle and indicated that her life revolved mostly around her fiancée, children and certain family members. Her job at an agency that assists individuals with health problems, including HIV, places her in a position of helper and educator, however she remains guarded about her own status and details of her personal life. It appeared from her narrative Simone is fulfilled in her role as a mother and fiancée. Her relationships with her nuclear family appear to be somewhat strained. Although she relayed that she had a good relationship with her father, it appeared, from her narrative, that her HIV status was disclosed by her father to other family members. In addition, the betrayal that she encountered when her step-mother discovered

her status by looking at her medical records at the hospital she was employed posed a serious breach in relationship. Furthermore, Simone suggested that even though her mother had been supportive of her in past endeavors, she did not feel comfortable disclosing her status to her because of her mother's attitude toward those infected with HIV. In the context of her intimate relationships, Simone contracted HIV in her first intimate relationship. The tension that appeared to exist on a familial level suggested that Simone has learned that to be careful in the context of interpersonal relationships.

Meaning Units-Flor

1. ...My life was basically like cause I didn't grow up with my father. My father lived in Barbados and my mother brought me and my brother here [U.S.] when I was like five, so it was like my life was on the fast track goin' downhill so to speak, simply because again I didn't grow up with my father so it was like I was basically- you know they say lookin' for love in all the wrong places.
2. So I'm like, "What the hell am I sittin' here talkin' to this lady for about HIV?" I don't care nothin' about this. So then she brought me back in the room and told me that I was positive. So my first instinct was to think naturally is to cry cause I don't know what the hell that shi- I don't know what it was. I was 18 at the time and I still didn't know what it was so my first instinct was to call my sister cause my sister and me is like two peas in a pod.
3. The first thing that came to my mind was death. Because in a way even though I sat and talked to the counselor like in a way that's the first thing that came to my head as she was talkin' to be, like, "Oh my God imma die!" That was the first thing that came to me. So as soon as she told me I started cryin'. I was like, "Oh my gosh!" This can't be true! You lyin'!" I didn't say that to her but these was the emotions that was goin' through my head, "Oh no, you lyin'! She doesn't know what she talkin' about, blah, blah, blah. So I was upset to the point where she told me I had to- they wouldn't let me out of the clinic unless I had somebody to come get me.
4. My first boyfriend was 30 and I was 13. So it was like you know basically tryin' to find that quote un-quote father figure.
5. I think everything I go through in my life stem back from the fact of my father not being in my life.
6. Nothing at all.

7. I'm not sayin' you know that I don't love her for real. I'll always love my mother. She's my mother. I love her unconditionally but it's just like me and her don't have that close bond like that I think that too has an effect on like my childhood and the way that you know I treated men and how I was in and out of relationships and stuff like that.
8. So like at one point in time I was lookin' real bad. I dropped from like 135-140 pounds to like 80-something pounds. When I first came to here [clinic], I had like five T-cells for somethin' like that so I was lookin'. Yeah so I was lookin' BAD and it was not me.
9. I'm sittin' in the car and it was in the mirror, I didn't feel like that person. Like my face was sunken in- my teeth was yellow and hair was like you know that soft curly kind of hair and I was lookin' at that person and I just sat in the car and I just started cryin' and I'm like this isn't me-this is not me even though like I look like I was knockin' on death's door. I honestly didn't believe in myself like not I'm not ready to go. Hell no!
10. I started comin' to the clinic and then I started accessing services like HASA and Social Security and stuff like that and then after I aged out of one program and I went to another program so basically I never had problems sayin', "Oh my God, I gotta find a doctor that caters to HIV positive people or I don't know where to go, who to talk to and stuff like that.
11. I'm always at my appointments and that's one thing I stay on top of my appointments irregardless of whether I'm workin' or not. That's one thing that I don't play with, my appointments and my medication. I take takin' my medication very seriously like that's one thing I don't play with cause I know where I was when I wasn't takin' medication so I'm not tryna go back there at all.
12. I'm a very vocal person, I could open my mouth curse them out, tell them about their self and simply walk away and find somewhere else to go so it's like I never dealin' with the virus. I've never had to deal with like I went somewhere and felt like I was bein' discriminated against or you know like people lookin' down on me because of my virus or you know whatever...
13. I never got the reason as to why HIV is looked down upon like I don't understand it. Like what's the reason? It's just a virus. That's just like you goin' to the doctor and the doctor tellin' you, you have gonorrhea or chlamydia or you have a tumor in your head or somethin' like, that's just it.
14. It's like in Barbados and even here it's looked down upon like, "oh my gosh" like it's frowned upon and it's like I don't-I honestly don't understand why. It's like you go to Barbados and you go tell somebody, "Oh you know, I'm positive. More likely than not it's gon' get passed from one person to another and it's like people gon' start treating you differently. They gon' start talkin' about you, you know? But's it's like for what.
15. It doesn't make you no different from anybody else. The only difference between that and what-the only difference between that and say cancer is okay you can't catch cancer from somebody else buy you could catch HIV from somebody else but in the Caribbean it's something looked down upon and for that reason I think that's why more and more people are getting infected cause it's like-it's like hush-hush secret like, "Oh my God I'm bout to

have sex with this person but I don't want to tell her that I'm positive simply because he might look down upon me or he might go tell my friends or he might go tell my family or you know?

16. But honestly I think that it's through my first boyfriend, the 30 year old... When I found out, I went to him and told him like, "Oh you know I went to the doctor today and they told me that I was positive. So he was like, "Oh yeah?" He was like, "Let's go upstairs." Let's go upstairs? I just told you I was positive and you wanna go have sex? So I'm like, that was the first red flag for me."
17. I'm very big with nails, hair and stuff like that.
18. ...At first when I found out I was positive my mother with the whole church thing she didn't believe in it so at one point in time she told me not to take no medication or anything like that so I was listenin' to her and I wasn't takin' medication for like a year and a half, two years.
19. So my mother was gettin' married... I wanted to be in the wedding so like I couldn't be in the wedding simply because I couldn't stand up or anything like that so you know my mother gon' know my cousins and everybody goin' to get bridesmaid dresses and stuff like that so they left me in the car. I'm sittin' in the car and it was just like I looked in the mirror, the rear view mirror of the car and the person- basically the person that was in the mirror, I didn't really feel like that person. My face was sunken in, my teeth was yellow. ...I just sat in the car
20. You know like some people they will talk to a friend or go through somethin' my shoppin' is my therapy. That's how I ease myself when I'm overly stress or when I'm thinkin' about somethin' or somethin' like that. That's what I do is shop.
21. ...So I'm known in my family to be the one that's always speakin' up so I like, it's good havin' to deal with this virus and bein' vocal. I'm not sayin' that havin' the virus and bein' timid and not sayin' anything is a bad thing. Bein' vocal and havin' this virus can work for you well in ways cause it's like you won't sit down and take anything. You won't just let nobody treat you no kinda way or tell you anything.
22. Don't think that because you have the virus that's it. You can't find a man, your life is over
23. It's [HIV] not a death sentence or it's not somethin' that's stamped on your forehead. Life goes on. You got more life ahead of you.

Individual Textural Themes-Flor

Pre-HIV.

1. ...My life was basically like cause I didn't grow up with my father. My father lived in Barbados and my mother brought me and my brother here [U.S.] when I was like five, so it was like my life was on the fast track goin' downhill so to speak, simply because again I

didn't grow up with my father so it was like I was basically- you know they say lookin' for love in all the wrong places.

2. My first boyfriend was 30 and I was 13. So it was like you know basically tryin' to find that quote un-quote father figure.
3. I think everything I go through in my life stem back from the fact of my father not being in my life.

Finding out.

1. The first thing that came to my mind was death. Because in a way even though I sat and talked to the counselor like in a way that's the first thing that came to my head as she was talkin' to be, like, "Oh my God imma die!" That was the first thing that came to me. So as soon as she told me I started cryin'. I was like, "Oh my gosh!" This can't be true! You lyin'!" I didn't say that to her but these was the emotions that was goin' through my head, "Oh no, you lyin'! She doesn't know what she talkin' about, blah, blah, blah. So I was upset to the point where she told me I had to- they wouldn't let me out of the clinic unless I had somebody to come get me.
2. Before I had took the HIV test I taken a blood test so I'm guessin' like they seen something in my blood that's why when I came back for the next visit she was like, "Oh have you ever taken an HIV test?" And I'm like, "No." I'm like thinkin' it's like a cholesterol test or something. I'm like, "Yeah sure. I'll take one. No problem. Take my blood. I don't care." And when she called me back she was like, you know "Oh I'm gonna send you to a pre, you know the people you talk to when you get your results or whatever.
3. I was sittin' there. She [HIV counselor] was basically tellin' me like about the virus, how you catch and basically like you know about you know the information concerning the virus. I'm sittin' there like "Ok. Like that doesn't apply to me. I really don't care. I'll listen to you but I mean it really doesn't apply to me."
4. But honestly I think that it's through my first boyfriend, the 30 year old... When I found out, I went to him and told him like, "Oh you know I went to the doctor today and they told me that I was positive. So he was like, "Oh yeah?" He was like, "Let's go upstairs." Let's go upstairs? I just told you I was positive and you wanna go have sex? So I'm like, that was the first red flag for me."

Relationship challenges [familial].

1. I'm not sayin' I don't love her for real. I'll always love my mother. She's my mother. I love her unconditionally but it's just like me and her don't have that, that close bond like that and I think that too has an effect on like my childhood and the way that you know I treated men and how I was in and out of relationships and stuff like that.
2. ...I don't want to say that she is negative but she at times -she can't, she never see the picture. She always sees above the picture.

3. She [participant's mother] told me one day you know how West Indian women are, "Oh two queen kyaan live in here and I'm the only queen in her. You need to get out."
4. Even till now like I'm bout to be 30 in July so it's like I can't really, I still don't feel comfortable talkin' to my mother.

Self-perception [looking in the mirror].

1. So my mother was gettin' married...I wanted to be in the wedding so like I cound't be in the wedding simply because I couldn't stand up or anything like that so you know my mother gon' know my cousins and everybody goin' to get bridesmaid dresses and stuff like that so they left me in the car. I'm sittin' in the car and it was just like I looked in the mirror, the rear view mirror of the car and the person- basically the person that was in the mirror, I didn't really feel like that person. My face was sunken in, my teeth was yellow. ...I just sat in the car and I just started cryin' and I'm like this isn't me; this is not me even though like I look like I was knockin' on death's door. I honestly didn't believe in myself. Like not I'm not ready to go. Hell no!
2. So like at one point in time I was lookin' real bad. I dropped from like 135-140 pounds to like 80-something pounds. When I first came to here [clinic], I had like five T-cells for somethin' like that so I was lookin'. Yeah so I was lookin' BAD and it was not me.

Coping [self-care].

1. I'm always at my appointments and that's one thing I stay on top of my appointments irregardless of whether I'm workin' or not. That's one thing that I don't play with, my appointments and my medication. I take takin' my medication very seriously like that's one thing I don't play with cause I know where I was when I wasn't takin' medication so I'm not tryna go back there at all.
2. You know like some people they will talk to a friend or go through somethin' my shoppin' is my therapy. That's how I ease myself when I'm overly stress or when I'm thinkin' about somethin' or somethin' like that. That's what I do is shop.
3. I'm very big with nails, hair and stuff like that.

Self-advocacy.

1. ...So I'm known in my family to be the one that's always speakin' up so I like, it's good havin' to deal with this virus and bein' vocal. I'm not sayin' that havin' the virus and bein' timid and not sayin' anything is a bad thing. Bein' vocal and havin' this virus can work for you well in ways cause it's like you won't sit down and take anything. You won't just let nobody treat you no kinda way or tell you anything.

Good care.

1. ...So I've never had problems accessing help, information or anything.

2. So like in terms of health services I never had a problem, knock on wood.
3. I never had to go through that [discrimination from health care workers], even sometimes like even though they supposed to have but I guess like they [health care providers] are so comfortable with me when they take my blood they don't even some of them don't even put on gloves and they know I have the virus...

Stigma [cultural].

1. It doesn't make you no different from anybody else. The only difference between that and what-the only difference between that and say cancer is okay you can't catch cancer from somebody else buy you could catch HIV from somebody else but in the Caribbean it's something looked down upon and for that reason I think that's why more and more people are getting infected cause it's like-it's like hush hush secret like, "Oh my God I'm bout to have sex with this person but I don't want to tell her that I'm positive simply because he might look down upon me or he might go tell my friends or he might go tell my family or you know?"
2. I never got the reason as to why HIV is looked down upon like I don't understand it. Like what's the reason? It's just a virus. That's just like you goin' to the doctor and the doctor tellin' you, you have gonorrhoea or chlamydia or you have a tumor in your head or somethin' like, that's just it.
3. It's like in Barbados and even here it's looked down upon like, "oh my gosh" like it's frowned upon and it's like I don't-I honestly don't understand why. It's like you go to Barbados and you go tell somebody, "Oh you know, I'm positive. More likely than not it's gon' get passed from one person to another and it's like people gon' start treating you differently. They gon' start talkin' about you, you know? But's it's like for what.

Disclosure [familial reactions].

1. He [participant's brother] ended up punching the radio to the point- so he got upset to the point where he cracked, he punched the radio. The radio cracked and then he ended up walkin' out of the house.
2. ...My mother came home after that and then my sister came with her best friend shortly after that and I told them what happened and then I started cryin'. My sister started cryin' and then my brother walked into the house.

Disclosure [forced].

1. So she told him and he went to Barbados and told my cousin' and my cousin' end up tellin' his mother and so it trickled down that everybody know everybody in the West Indies so it's like that's how everybody in Barbados found out...

Coping [supports].

1. I could count how many friends I have on my one hand. Like I don't associate with a lot of people.
2. I have an older brother but he's like a typical older brother. He's just there...
3. That's one thing I can say about them [participant's family], like they never treated me different. Like throughout the years that I've met other people that are positive like I've heard stories where they go to they family house and they give them plastic plates and plastic cups and stuff. I've never had to experience that...

Life lessons [HIV].

1. Don't think that because you have the virus that's it. You can't find a man, your life is over.
2. It's [HIV] not a death sentence or it's not somethin' that's stamped on your forehead. Life goes on. You got more life ahead of you.

Individual Textural Description-Flor

Within an office building in a private corner at a small table near a water cooler, Flor and I met and she shared her story of living with HIV. Flor seemed to have a well-put-together sense of style and a distinct mixture of New York and Island accent. At the time of interview, Flor had lived in the U.S. for twenty-five years.

The themes that emerged for this participant were *pre-HIV, finding out, relationship challenges (familial), self-perception, coping, self-advocacy, good care, stigma (cultural), disclosure (familial, forced), coping, and life lessons [HIV]*.

Flor began her story by recounting what her life was like *prior to her HIV* diagnosis. She quickly noted that she felt that her life in her “formative” years and into her twenties was negatively impacted by not having her father in the home, “...I didn't grow up with my father so it was like I was basically you know lookin' for love in all the wrong places. To illustrate this point further, she spoke of her first relationship, “My first boyfriend was 30 and I was 13. So it was like you know, basically tryin' to find that quote unquote father figure.” While she did not

go into detail about her first relationship Flor did indicate she believes that she may have contracted HIV from this relationship, "...honestly I think that it's [HIV] through my first boyfriend, the 30 year old...". Flor said that *finding out* that she was HIV positive was very traumatic and she didn't know much about HIV before her diagnosis, "Before I had took the HIV test, I taken a blood test, so I'm guessin' like they seen something in my blood that's why when I came back for the next visit [doctor's] she was like, "Oh have you ever taken an HIV test?" The abnormality in her blood work revealed that Flor was HIV positive. She was counseled by a an HIV counselor/educator but was confused by the information she received, "I was sittin' there. She [HIV counselor] was basically tellin' me like about the virus, how you catch it and basically like you know, the information concerning the virus. I'm sittin' there like, "Ok. Like that doesn't apply to me. I really don't care..." When she was informed after her counseling that she was infected with HIV, Flor reacted with shock. "The first thing that came to my mind was death. Because in a way even though I sat and talked to the counselor like in a ways that's the first thing that came to my head as she was talkin' to me like, "Oh my God imma die!" Her reaction caused much concern among the staff and she had to be escorted home. "So I was upset to the point where she told me I had to, they wouldn't let me out of the clinic unless I had somebody to come get me."

The next theme *disclosure [familial reactions]* chronicles Flor's experience disclosing her status to her family members. The first person this participant told of the diagnosis was her mother. She recounted, "...My mother came home after that and then my sister came with her best friend shortly after that and I told them what happened and then I started cryin'. My sister started crying and then my brother walked into the house." Disclosure to her brother produced a very emotional reaction, "He ended up punching the radio to the point...so he got upset to the

point where he cracked-he punched the radio. The radio cracked and then he ended up walkin' out of the house." In addition to telling her immediate family, Flor's status was also disclosed to her family in the Caribbean by her sister's boyfriend without her consent. "So she told him and he went to [home country] and told my cousin' and my cousin' end up tellin' his mother and so it trickled down that everybody know everybody in the West Indies so it's like that's how everybody in [home country] found out..." Disclosure of one's status in the Caribbean can cause ramifications for the individual and their family.

Flor expressed her dismay over the stigma toward those that are HIV infected and toward HIV as a disease in the Caribbean as follows. "It's like in [home country] and even here it's looked down upon like, "Oh my gosh" like it's frowned upon and it's like I don't, I honestly don't understand why. It's like you go to Barbados and tell somebody, "Oh you know, I'm positive. More likely it's gon' get passed from one person to another and it's like people gon' start treating you differently. They gon' start talkin' about you, you know? But it's like for what?" She also expressed that she feels that, "it's just a virus" and that "it's like a hush-hush secret." This secrecy is the reason Flor thinks that HIV is spreading throughout the Caribbean.

The stigma toward HIV in the Caribbean and in Caribbean communities abroad may have an impact one's self perception. Flor recounted one experience in particular that changed the way she viewed herself that influence the course for her living with HIV. Flor stated that while accompanying her mother and cousin to a store to pick up items for her mother's wedding, she was left in the car because she was "wasting" a condition in which her T-cells were very low characterized by low weight and opportunistic infections related to HIV. At this stage, someone is typically diagnosed with AIDS. At the point in which she is left in the car she said, "I'm sittin' in the car and it was just like I looked in the mirror, the rear view mirror of the car and the person

[and] basically the person that was in the mirror, I didn't really feel like that person. My face was sunken in, my teeth was yellow. ...I just sat in the car and I just started cryin' and I'm like this isn't me; this is not me even though like I look like I was knockin' on death's door. I honestly didn't believe in myself. Like, I'm not ready to go. Hell no!" Flor added that her mother had persuaded her not to adhere to her medical regimen because she believed she could pray and Flor would be healed of HIV. Flor's resolve to live her own life is evidenced in her saying "hello no!"

Flor described, throughout her narrative, the strained relationship with her mother. In describing her relationship with her mother, this participant stated, "Even till now like I'm 'bout to be 30 in July so it's like I can't really, I still don't feel comfortable talkin' to my mother. Flor indicated that she has always been closer to her sister. The difficulties in her relationship with her mother Flor felt was due to culture and personality differences, "I'm not sayin' I don't love her for real. I'll always love my mother. She's my mother. I love her unconditionally but it's just like me and her don't have that close bond like that..." Flor told of a situation in which she was living with her mother and her new husband and her mother asked her to leave her home. "She [participant's mother] told me one day you know how [home country] women are, "Oh two queen kyaan live in here and I'm the only queen in her. You need to get out." Although Flor indicated that she loves her mother, this relationship has proven to be stressful for her.

The theme of *self-advocacy* describes Flor's "tenacious" spirit. She thinks that her personality allows her to advocate for herself because she is not afraid to speak out against things that she feels are wrong, "So I'm known in my family to be the one that's always speakin' up..." In addition, she feels that being infected with HIV can provide a platform for others to speak out. "Bein' vocal and havin' this virus can work for you well in ways cause it's like you won't sit down and take anything. You won't just let nobody treat you no kinda way or tell you anything."

This character trait has also served Flor well in finding and accessing services related to her HIV status.

Flor's overall experience with the health care system relative to her HIV status was positive. Flor narrated that throughout her time living with HIV, she never had any negative experiences in accessing services, "So like in terms of health services I never had a problem, knock on wood." She was able to link with services at an area clinic especially for those living with HIV. She described her experiences with care staff that were truly interested in her well-being. She indicated that while she heard stories of people that had negative experiences, she was grateful that she was never exposed to uncaring staff. She recounted, "I never had to go through that [discrimination from health care workers], even sometimes like even though they supposed to have but I guess like they [health care providers] are so comfortable with me when they take my blood they don't even some of them don't even put on gloves and they know I have the virus..."

Coping through self-care seemed to help maintain a good quality of health for Flor. She indicated that she felt that part of taking care of herself includes attending her appointments and adhering to her medication regimen, "I'm always at my appointments and that's one thing I stay on top of my appointments irregardless of whether I'm workin' or not. That's one thing that I don't play with, my appointments and my medication. I take takin' my medication very seriously like that's one thing I don't play with cause I know where I was when I wasn't takin' medication so I'm not tryna go back there at all." In addition, Flor described shopping and grooming as important facets of her regimen of self-care. Another method of coping for Flor involved her *support* systems. Even though Flor stated earlier in her narrative that she had a conflictual relationship with her mother, she still depends upon her family for support. She also added that

her family never judged or treatment her differently after her diagnosis, “That’s one thing I can say about them [participant’s family], like they never treated me different.” This has proven to be a source of support to her. Flor also highlighted that her fiancée was also a source of support for her.

Finally, Flor spoke about the life lessons she has learned through her experience living with HIV. The idea that life is not over because one acquires HIV is important, “It’s [HIV] not a death sentence or it’s not somethin’ that’s stamped on your forehead. Life goes on. You got more life ahead of you.” The idea of longevity and living life well are key factors in this participant’s success in living with HIV.

Individual Structural Description-Flor

The structures that emerged from Flor’s narrative are: *relation to self* and *relation to others*.

It was evident that Flor’s *relation to self* (self-perception) has been influence by experiences she had in childhood/adolescence. Very early in her discourse, she stated, “...I didn’t grow up with my father so it was like I was basically-you know they say lookin’ for love in all the wrong places.” This insight appears to have formed the image of the “self” that Flor adapted. Her immature “little” girl “self” related to men that were much older than her as a means of protection and love/intimacy to fulfill basic human needs. Following her diagnosis, Flor underwent a transformation. In a poignant description of looking at herself in a mirror while she was exhibiting bodily symptoms of a low T-cell count she stated, “I just started cryin’ and I’m like this isn’t me...” The “self” that Flor described while looking in the mirror was not the “self” that she wished for herself The “self” that was revealed during the interview was assertive and willing to “take chances” as a result of her previous experiences. Flor has learned to advocate for herself in a number of arenas especially as it pertains to self-care.

The majority of Flor's narrative centers around her *relation to others*, her family. She commented that her relationship with her mother was strained and distant, "...she's my mother and I love her unconditionally but it's just like me and her don't have that-that close bond like that and I think that too has an effect on like my childhood..." The lack of a maternal bond caused Flor to cleave more to her sister. This relationship is described as "close." She also added, within the first five minutes of her interview that her father was not present in her life and she feels that she was "looking for love" in the older men that she dated. She used the words, "not stable", to describe her family experience and revealed this with visible uneasiness. The foundational structure of family did not provide Flor with a safe place and thus it appears that she sought to create her own space with friends and intimate relationships. Her intimate relationships were also characterized by instability. Her first relationship commenced at the age of 13 with a man 17 years her senior. Although not certain, Flor feels that she may have contracted HIV from this partner. At the time of interview, Flor was engaged and her current relationship appeared to be stable and fulfilling. It appeared that through her relationship challenges with others, Flor has learned to be self-reliant.

Composite Textural Description

In this study the textural themes of *genesis, challenges of living with HIV, coping, perceived benefits of living with HIV, policy and immigration challenges, and life lessons* emerged as the major textural themes of these participants. Tables 4.2 and 4.3 display the individual textural themes and how each theme was coalesced to from groups or clusters.

Each woman shared what life was like prior to contracting HIV (pre-HIV), what their knowledge of HIV was prior to acquiring it and how they found out they were HIV positive (finding out). These three initial themes formed the major theme of genesis. The theme represents "beginnings." Most of the participants said that their knowledge of HIV was colored

by cultural ideologies pertaining to the HIV virus and those that contracted it. Most characterized HIV in the following ways: “a death sentence” (Starr), “you get it and you die” (Simone). The association of HIV with death was strong throughout these narratives. Many participants expressed shock or disbelief upon learning that they were HIV positive due to denial or feeling that they were not at risk. Most notably, Faith explained that, “I never believe I would be able to get that [HIV] because I tell myself um even though I know that I believe he would have been safe...” In a similar vein, Empress indicated that she felt that she was not susceptible to contracting HIV because she “was not having sex with a man who I felt put me not at risk.” For Simone, hearing that she was HIV positive also came as a shock because she was only sexually-active with one partner. This was echoed in Flor’s narrative as well. For some participants, finding out definitively about being infected was a long process. For Betty, this was because of denial about the possibility of being HIV positive. She was initially diagnosed in her home country, however, due to an error in the testing procedure, it was suggested that she come back for another test. Because of this, she could put off the acknowledgement that she was HIV positive. She did get tested again, but never went back for the results. This pattern continued as she tested at least two more times after immigrating to the U. S. She finally learned that she was indeed HIV positive. Charlene reacted to finding out her status with “denial and anger and resentment, shame-you know all that type of stuff” and Starr described it as a physical response in which “it’s like your whole body just like lock down, like a shock...” Julie expressed a similar idea of shock All the participants were able to describe their emotional response to the initial diagnosis with the HIV virus.

Table 4.2

Individual Textural Themes

	Betty	Faith	Empress	Starr	Simone	Charlene	Flor	Julie
Pre-HIV	X	X	X	X	X	X	X	X
Knowledge of HIV	X	X	X	X	X	X	X	X
Finding Out	X	X	X	X	X	X	X	X
Coping	X	X	-	X	X	-	-	X
Disclosure	X	X	-	X	-	-	-	X
Relationship Challenges	X	-	-	X	X	X	X	-
Good Care	X	X	X	X	X	X	X	X
Immigration Challenges	X	-	-	X	X	-	-	X
Stigma	X	X	X	X	X	X	X	X
Self-Perception	-	-	-	-	-	X	X	-
Life Lessons [HIV]	-	-	-	X	X	-	X	X
Spirituality	-	-	X	-	-	X	-	X
Perceived Benefits of Living with HIV	-	-	-	X	-	-	-	X
Support	X	X(coping as well)	X	-	-	X	-	-
Self-Care	X	X	X	X(coping)	X	X	X	-
Stressors	-	-	-	-	-	-	-	X
Motivation	-	-	-	-	-	-	-	-
Advocacy & Self-Advocacy	-	-	X	-	-	-	X	X
Medication Adherence	X	-	-	-	-	-	-	X
The Blessing of HIV	X	-	-	-	-	-	-	-
Resolution	X	-	-	-	-	-	-	-
Provider Stigma	-	-	X	-	-	-	-	-
Gender Based Discrimination	-	-	X	-	-	-	-	-

Table 4.2 – *Continued*

	Betty	Faith	Empress	Starr	Simone	Charlene	Flor	Julie
Cultural Denial [HIV]	-	-	X	-	-	-	-	-
Aging	-	-	X	-	-	-	-	-
HIV Policy	-	-	X	-	X	-	-	-
Purpose	-	-	-	-	-	-	-	-
Challenges Living with HIV	-	-	-	-	X	-	-	-
Under the Radar	X	-	-	-	-	-	-	-
Loss of Privacy	X	-	-	-	-	-	-	-
Turning it Around	-	-	-	-	-	X	-	-
Systemic Challenges	-	-	-	-	-	X	-	-

Throughout this study, each participant highlighted challenges associated with living with HIV. Several challenges were described in detail by the participants. One of the common challenges seen was how to handle disclosure of their diagnosis to family and friends. The process of disclosure for Julie was precipitated by the illnesses that occurred after diagnosis. Participation in support groups gave her the inner strength to be able to disclose her status to her children who were living with her. She was relieved that her experience of disclosure with her children was a positive one; even though they may not have totally understood the situation they said, “Mommy you don’t look like you sick.” She encountered love and acceptance from her children. For Empress, disclosure to family members was met with both acceptance and resistance. Her grandparents played a significant role in her upbringing and, according to her description, seemed to act as parental figures. Both sets of grandparents accepted her diagnosis

Table 4.3

Grouping of Individual Textural Themes

Group	Individual Textural Themes
Genesis	Finding Out Knowledge of HIV Pre-HIV
Challenges [HIV]	Disclosure Relationship Challenges Stigma [Cultural] Stigma [Community] Provider Stigma Cultural Denial [HIV] Gender Based Discrimination Stressors Medication Adherence Systemic Challenges Familial Responsibility
Coping	Coping Positive Outlook Secrecy Self-Care Spirituality Support Self-Perception
Policy/Immigration Challenges	HIV Policy Immigration Challenges
Perceived Benefits of living with HIV	Perceived Benefits of Living with HIV Good Care Life/Treatment in America The Blessing of HIV
Life Lessons	Advocacy & Self-Advocacy Life Lessons [HIV]

and expressed their support. However her mother would not acknowledge her HIV status and instead cast blame on her. Empress illustrated this point by stating, "...She will not acknowledge the fact that I'm HIV positive because I should not have gotten it." Disclosure to her supervisor was met with acceptance as with her grandparents. Her position as a clergy member and a

lesbian seemed to influence what it meant to live with the HIV virus. The act of disclosing to her church family and others gave her “a brand new skin.” This re-birth allowed Empress to live more freely with her status. Flor and Simone described the difficulty and betrayal that accompanied having others disclose their statuses without their permission. For Simone, whose step-mother disclosed her status to her father; it did not give her the freedom to disclose in her own time and way. The same was true of Flor. She indicated that others in her social network disclosed her status to her fiancée. However, she did not seem to feel as strongly about it as Simone did. For others in this study namely Betty, Starr, Faith and Julie, disclosure to wider family and friends was not done at all because of potential ramifications (maltreatment) that could affect them and their families. They did not want to unnecessarily burden their families, especially those who remained in the Caribbean and wanted not harm to face them.

Relationship challenges for this sample proved to be a salient theme. For some, engaging in intimate relationships proved difficult to navigate due to the fear of rejection by an intimate partner after disclosure. In speaking about intimate relationships, Charlene explained, “I want to disclose before I like you too much, you know.” Betty also offered insight into her thought process when deciding whether or not she should disclose to a potential intimate partner, “What are they gonna say? Or what are they gonna do?” For Betty this was very important because she had faced abuse and rejection in her childhood and in prior relationships; therefore the rejection of an intimate partner could amplify the pain from previous experiences. Simone also chronicled that after being infected with HIV, she fled to a shelter from her then boyfriend while pregnant with her first child. Flor spoke about the challenges she faced in her interpersonal relationship with her first boyfriend from whom she believes she contracted HIV as well as a strained

relationship with her mother. Relationships formed a very integral part of the experiences of these women.

Another important facet of living with HIV for these participants was *stigma*. Stigma was mentioned by eight participants. The experience of stigma for those living with HIV is very palpable in Caribbean communities. Betty explained cultural ideologies surrounding HIV by stating, “You’re looked at different. You’re treated different. Not even just you, your whole family is treated you know like...but you are treated like nothing.” She also described those that are infected with HIV being treated like “lepers” and that they “go into an isolation.” Julie further described the stigma family members may attribute to one that is HIV positive, “...If my family come and know that I have HIV they not drinkin’ a cup of water.” This sentiment was echoed by Simone who relayed that an individual would be “scorned” by their family. There is a very real sense of danger for those that are HIV positive in the Caribbean context. Empress stated, “Back home they’d kill us...burn down the house...stone us.” Julie also added, “...If you don’t mind they beat you to death...” In one instance Empress described the stigma place on them by the community also caused so much fear that women are afraid to access services where they live for fear that someone will recognize them, “They [women seeking services for HIV] sneak in there. Only the bravest ones will walk in there just as bold as they can but the majority- we have women that live in Staten Island um that live in Brooklyn, that live in Yonkers because they don’t want anybody in their community to know that they are [HIV positive].” It seemed that cultural beliefs and behaviors toward HIV and people infected with HIV influenced these women’s lives on a daily basis. To a large degree it governed who they associated with and how they viewed themselves. Provider stigma was also present. Two participants noted experiences in which they felt they were being discriminated against due to their HIV positive status. However,

most participants in this sample spoke about good care they had received since their diagnosis. There may be some differences in the attitudes of providers, thus underscoring the reluctance to accept a diagnosis or receive treatment (at least initially). Experiences that were related to stigma included one from Faith who noted that the nurses did not adhere to proper medical protocol with regard to cleaning her the birth of her daughter.. She was left on her own for hours without adequate medical care. Empress's experience with provider stigma was felt through the generalizations made and stigma felt toward LGBTQ communities. The fact the she is a lesbian and contracted HIV exposed her to scorn by some in the medical community.

Cultural denial of HIV was also another individual textural theme that emerged. Empress spoke at length about the fact that stigma is often directed toward those that are HIV positive in the Caribbean, however those in the Caribbean community often mask or completely ignore the reality of HIV. This denial may serve as a coping mechanism so as not to associate with anyone that is HIV positive or to devalue those with HIV so as to act as if they do not exist. The denial may take the form of "code switching"; using a phrase to identify those with HIV but not directly coming out and saying that an individual has HIV.

The next cluster of themes under the group coping include: secrecy, positive outlook, self-care, spirituality and support. This fear of stigma and being isolated within the community led many of the participants to keep their status a secret from family members, especially those in their home countries. In addition, some kept their status a secret from their children. Betty and Starr both had daughters that were living with them at the time of interview. They would not disclose their status to their daughters even though they hinted at the fact that they had indications that both of their children knew. Faith echoed this sentiment by indicating that she did not disclose her status to her children in her home country. While Julie did disclose to her

children that lived with her, she did not disclose to her distant relatives. Simone, after an experience in which her status was disclosed to family by her step-mother indicated that she had a best friend, but would not even disclose to her due to her former experience. Secrecy proved to be a challenge of living with HIV, but was also important for these participants' well-being.

Although many of the women in this study did not speak directly about the concept of self-perception, some did. The most striking example of awareness of self-perception was Flor's description of herself as she described living with HIV over the years. She indicated that she looked into a mirror at a particularly unhealthy point and did not recognize herself. Up to that point, it appeared that her view of herself was mainly influenced by her mother's dictates about the treatment she should follow. She decided that she would no longer take her mother's advice to not take her antiretroviral medication (ARVs), but would fight to be well and become the person she wanted to be. Charlene also described her process of defining herself by indicating that she when she contracted HIV, she felt like "damaged goods" and "dirty." Both of these women struggled with images of themselves, but managed to see themselves differently due to formal and informal support they received.

Support was also an important aspect of coping for those involved in this study. Support could include family, as described by the participants as blood relations. However many of the women in talking about their health care team of doctors, nurses, and social workers were likened to family members. Individuals they met in support groups were also relied upon. All of these supports allowed the women to cope with living with HIV.

Spirituality was also seen as contributing to the ability to cope with their illness. A majority of the participants stated a belief in a "higher power" or that "God" was important to them. Attending church, praying and meditating were practices used as a means to connect with

God, themselves and others and seemed to provide a sense of security and an opportunity for catharsis. For example, Empress became a clergy member in her chosen religious tradition. This connection allowed her access to a wider community with similar beliefs and values. This community would then be a form of support for her after she disclosed her status. Spirituality provided these participants a platform from which to assess their choices and lead them to see their life circumstance in a different perspective and to provide a firm foundation. Spirituality for some was empowering and an important dynamic in their lives.

These women were active in self-care after they were able to understand their diagnosis and accept the need for treatment and lifestyle changes necessary for well-being. Since all of the women in this sample were able to access formal services, they could participate in health care services, physical training, and massage therapy. Charlene recounted that she engaged in self-care (attending her appointments) because she “wanted to wipe her own ass.” She connected self-care with independence. Even though she struggled with certain facets of her health, such as maintaining a healthy diet, she believed that self-care now would impact her health in future years. Other participants expressed that going shopping, keeping a clean home, and taking care of others was a means of taking care of themselves. For all of these women, self-care was an important part of their lives because it allowed them to focus on others in their lives, alleviate stress and continue their own health practices.

Three of the participants spoke about the importance of having a positive outlook as a means of coping. The reality of living with HIV may cause feelings of self-pity or symptoms of depression, however they chose instead to look at their lives in a positive manner. HIV was only one part of their being. Julie said that at first she thought of HIV as a “death sentence” but then came to realize that having HIV is “not the end of the world.” For Starr having a positive outlook

means that she is able to focus more on living life and having fun than to focus on the fact that she has HIV, "...You can't be depressed about it." Faith also indicated that having a positive outlook is the key to longevity.

The next cluster of themes (HIV policy and immigration challenges) illuminate the participants' struggles with navigating the system in terms of immigration. Four participants described their experiences as they attempted to understand the U.S. immigration policies that directly or indirectly affect individuals with HIV. For Betty, Starr, Faith and Simone immigration policy was particularly salient for them. Three of these four participants noted that obtaining legal immigration presented a challenge due to various codes in immigration laws that dictate time lengths, undocumented status and having an HIV positive diagnosis. Laws in the U.S. were recently changed (2010) so that people that are HIV positive could immigrate to the U.S. Prior to 2010, those that were HIV positive could not immigrate to the United States. These women felt that immigration laws favored those from certain parts of Africa since they were able to obtain refugee status under the premise that if they returned to their home countries in Africa they would face persecution or even death. Betty remarked that individuals from the Caribbean that are diagnosed with HIV faced the same dangers; however they are not given the opportunity to file under a refugee designation due to limited awareness of this issue in the Caribbean. Simone believed that those with HIV were subject to longer waiting periods to obtain legal status. These insights provide a glimpse into the difficulties that other Caribbean immigrants, particularly those that are undocumented, may encounter in their efforts to obtain citizenship. Another challenge related to immigration issues noted by the women in this study was the inability of some of the participants to earn adequate wages and provide for their families. Most women in

this sample that were undocumented tried numerous times to obtain assistance so that they could become naturalized citizens but were often dismissed totally or told to come back at a later date.

The themes under the heading ‘perceived benefits of living with HIV’ (good care, life/treatment in America, the blessing of HIV) emerged from the experiences related about access and adequacy of medical and other formal care services. The women were grateful for the formal care they received in the U.S. in particular because they likely would not be able to obtain such services in their home countries. All of the participants spoke of their interactions with health care team members with warmth. Many felt that the doctors and social workers in particular provided a kind of care and compassion akin with that of family. These relationships proved to be more important to them than merely as medical providers. These individuals were often seen as providing a way to cope with the pressures of living with HIV. For example, participants said:

“And that’s why I love him. He sits, “What’s goin’ on today? How are you feeling?” (Empress)
“I can talk to him about anything and he will listen.” (Betty). “You know, they treat you like a normal person and the service is good to me.” (Starr). “...Again I gotta say I’m glad I’m HIV positive in New York and not in Trinidad.” (Charlene).

These examples reveal that the participants felt that the level and manner of care that they received is vital to their well-being. In addition, one participant mentioned that she didn’t believe that she would be able to survive the way she has in the U.S. if she did not have HIV and able to receive specialized services. Another participant described that she felt that acquiring HIV was a blessing because she was now able to see that her life prior to HIV was focused on others instead of self. Even though she almost died from an opportunistic infection, she felt that her experiences have made her a better person.

The last cluster of themes life lessons, including life lessons and advocacy/self-advocacy focuses on the lessons learned that helped in their lives since being diagnosed with HIV. For many of the participants engaged in advocacy and it became a way of life. Empress and Charlene were most active in this activity. Charlene believed that part of her mission in life was to educate and advocate those that are infected as well as those that are not and may be at high risk for becoming HIV positive. She founded a company that focuses on the ‘arts’ as a way of doing this. In addition, she facilitates support groups. For Empress, passing out condoms and educating the Caribbean community has become her specific focus both through her agency and her individual efforts. She also provides education to faith communities about HIV/AIDS as well. Empress spoke in detail about being infected with HIV and “speaking up.” Although she noted that she naturally possesses an outgoing personality, she believed that having the experience of living with HIV, can bolster her credibility and make her more able to give voice to those that do not have one. Simone, spoke about “really living” with HIV. She believed that some women think that after a diagnosis of HIV that their lives are over. Simone embrace the thinking that life is to be lived and that HIV is just a small part of life. Faith took this sentiment even further by suggesting that HIV was in essence the beginning of her life. She really learned how to appreciate her family, her faith community and her life after her diagnosis. Simone expressed that she was resolved to not let HIV “rob” her of her “best” days.

Composite Structural Description

In assessing the structural themes for this group as a whole, the structures of relation to self, relation to others, time and space emerged (see Table 4.4). All eight participants’ *relation to self*, proved to be an important structure. For most of the women, living with HIV started with their lives prior to HIV and what their lives were in the aftermath of their diagnosis. At the time of interview, they were able to share their current “selves” with me. From their stories, comes the

Table 4.4

Structural Themes

	Betty	Charlene	Starr	Julie	Faith	Empress	Simone	Flor
Relation to Self	X	X	X	X	X	X	X	X
Relation to Others	X	X	X	X	X	X	X	X
Time	-	X	-	X	-	-	-	-
Space	X	-	X	X	-	-	-	-

realization that the “self” for these participants is constantly evolving. Many described similar to make meaning of their diagnosis in terms of them as individual beings. Each woman made sense of the “selves” that they formerly knew and learned to accept the “selves” that were emerging; some with more difficulty than others. Charlene aptly captured the essence of this concept by stating, “I am learning to love myself one day at a time.” She also added, “it takes a lot of work.” The evolution of self for this sample did often involve “digging deep” as Betty indicated. It is an active process of looking back and looking forward in order to create something new.

Relation to others was experienced for many of the participants as relationships with their immediate families and their health care staff. These women felt as though they were treated with dignity and respect despite the fact that they were HIV positive. This treatment went against what they felt those in their home countries experienced due to the stigma and discrimination leveled at those that are HIV positive. They were valued for who they were and not labeled. Because of this treatment many of the women were able to venture out and form new relationships with the understanding that they would not be discriminated against. Julie recounted how participation in support groups allowed her and to experience herself differently because of her relationships with others. Many of the women knew that they could not disclose

to relatives in their home countries, but they could share their experiences living with HIV with others who could “understand” their circumstances. Faith and Simone’s immediate family were to a large degree their major support systems, and Faith noted that such support helps one to live successfully with HIV. She highlighted that secrecy is the antithesis of connection with others, “You wanna die fast from HIV? Keep silent. Don’t have any friends. Go into a deep depression. Do all of the things that kills you fast.” Another important aspect to this structural theme is that most of the women, even though they stated having support this may have been limited by careful scrutiny regarding whom they could trust. Even though most of these participants were connected to support groups and some had familial involvement they knew that they had to keep silent in some areas of their lives. For example, Simone learned through her experience that she would need to keep her status and connection with others at a minimum. She explained, I have a best friend and I wouldn’t even tell her.” She was content with her immediate family knowing and even though at the time of interview she worked at an agency that assisted those living with HIV, she would only disclose to certain clients. This “selectivity” appeared to be a hallmark of relating to others for Simone.

The structure of time was important for Charlene and Julie. Charlene was diagnosed at a time when medical advances were few and there was not as much hope as there is currently for those infected. In relating her narrative, time appeared to be a significant structure of her, as living at the beginning of the epidemic and thriving in her current state provided her with a chance to observe her growth at a time when she had marked herself as “dead.” For Julie, time was also important because it provided an emotional catharsis. She had experiences with grief and loss due to deaths of loved ones and her own subsequent diagnosis with HIV that left her depressed and feeling alone. However after being she came to terms with her diagnosis, she was

able to obtain support and in time was able to view the events as stepping stones to emotional growth. Time afforded her this opportunity.

The structure of space was important for most of the participants, but markedly so for Betty, Starr, and Julie). These women reported that they were undocumented. For these women living in New York City provided them with opportunities for care and growth that would not have been afforded to them in their home countries (or perhaps in smaller communities in the U.S.). In addition, they were also able to grow in their own individual spaces. Personal development characterized their experiences living with HIV. They were able to do this in spite of the constant fear that they may have to return to countries where they will be ostracized and may even face death. The space they occupied represented by their homes, doctors' offices, churches and their neighborhoods provided them with freedom, access to care and the ability to live as individuals that are able to define their own lives within a larger context.

The Essence of Living with HIV for Afro-Caribbean Immigrant Women

For the women who participated in this study, living with HIV has been a process of self-formation, re-invention and continual meaning making. The process ebbs and flows depending on the various situations that may occur in their lives. Living with HIV is only part of their story. Learning to piece together the various facets of their lives is a work in progress. While many of these women have created meaningful lives, some of them live in fear of the “what if.” For the women who had an undocumented immigration status, their stories have coalesced into the fabric of the United States. They all however had immigrated to the U.S. for various reasons and were at different stages of understanding and acceptance the HIV virus. They know that if they cannot stay in the United States, their lives will be markedly different in their home countries from the ones they live now. They do not seem to live in fear of the possibility of return. The immigrant

experience for these women has different meanings for each of these women. The fact that they are women, immigrants and part of a sub-population of Black women in the U.S. has not deterred these participants from attempting to create the lives they desire.

The resilience seen in these women was revealed in the ability to find ways to be able to reach out to others in meaningful ways and to re-create their survival stories. The life lessons learned have allowed them to pass through valleys of grief, loss, shame and guilt. While some of these emotions likely will always be present, they have learned to cope and to move forward with the support from formal and informal support networks and knowledge about themselves that they have gained throughout their respective journeys.

The cultural context in which these participants were lived seemed to significantly influence all aspects of living with HIV.. They have chronicled that in most Caribbean communities, HIV is seen as a “death sentence” .In their home countries, people with HIV are “scorned” and “shunned” from community life. Also, they often live in fear of physical harm within their own home and when interacting with community members. However, in their thinking and through their actions these women have been able to develop their own unique meaning of the illness in their lives. The legacy of this group of women is one of strength and dignity in the face of what appeared to be insurmountable odds. It is indeed is the “blessing of HIV.”

CHAPTER 5

DISCUSSION, CONCLUSIONS, AND RECOMMENDATIONS

This chapter provides further discussion of the results presented in the previous chapter. While some studies have explored some aspects of Afro-Caribbean immigrant populations living with HIV, they have been conducted outside of the U.S. (Anderson et al., 2008; Anderson et al., 2009a; Lawson et.al., 2006; Stutterheim, Bos, Kesteren et al., 2012; Stutterheim, Bos, Shiripinda et al., 2012). This phenomenological study of eight Afro-Caribbean immigrant women living with HIV in the New York Metropolitan area addressed the lack of attention in the research literature to understanding the life experiences of this population. The major themes identified from the interviews with these women were: *genesis*; *challenges of living with HIV*; *coping*; *perceived benefits of living with HIV*; and *life lessons*. Social work practice, policy and future research implications are suggested based on these findings.

Genesis

A diagnosis of HIV for many of the women in this study was met with “shock.” While many of the women knew some information about modes of transmission of HIV, some did not believe they were susceptible to contracting the virus. In some cases, a lack of knowledge of HIV prior to diagnosis exacerbated their reactions and beliefs that HIV was a “death sentence.” Most of the participants’ reactions appeared to be based on things they heard about HIV in their countries of origin. It appeared that there was a perception that they were not at risk of acquiring HIV mainly due to denial of their partner’s sexual relationships with others or lack of knowledge of HIV transmission routes. Gillespie-Johnson (2005) highlighted this low perception of risk

with newly immigrated Jamaican women. Carr (2003) and Gillespie-Johnson (2005) speculated that for women, HIV acquisition may be associated with immoral behavior; so if they didn't engage in immoral behavior, then it was not possible to contract HIV. Some women in the study did have some prior knowledge of HIV, however, they may not have engaged in safe sex practices. This finding corroborated results from Braithwaite and Thomas (2001), Hoffman et al. (2012), and Hoffman and colleagues (2008) who studied HIV knowledge, attitudes, and beliefs of Caribbean populations in the U.S. They concluded that knowledge of HIV did not necessarily translate into safe sex practices with partners.

Challenges of Living with HIV

The experience of stigma and discrimination emerged as a critical component of the lived experiences of the participants in this study. Some evidence of stigma toward persons that are living with HIV/AIDS can be found in the literature (Varas-Diaz, Serrano-Garcia, & Toro-Alfonso, 2005; Skinner & Mfecane, 2004; Genberg et al. 2009; Mawar, Sahay, Pandit & Mahajan, 2005). Studies have been conducted about attitudes and stigma toward those with HIV in the Caribbean (Aggleton et al., 2003; Norman & Carr, 2003; Norman et al. 2006; Hines, 2012) and in Caribbean communities abroad (Sutterhheim et al., 2012; Anderson et al., 2008).

Stigma also appeared to be something that was internalized by some of the participants. She recounted, "So it's like you're treated like a um, like back in the day-like a leper." One participant compared cultural differences regarding the stigma associated with HIV and the treatment of individuals with HIV in the U.S. and in the Caribbean, "You could walk and tell everybody in America [that you are HIV positive], they don't care. Go to Jamaica and cross that border and say, "I have HIV", if you don't mind they beat you to death". Another suggested that the "leper" status that one is given indicated the level of ostracization in the community and that this affects the person infected as well as family members. These results concur with common

conceptions of stigma. Goffman (1963) defined stigma as, “an attribute that is deeply discrediting” (p.3) and stated that the stigmatized individual is always seen in terms of social constructs that deem that the individual is defective in some way. The stigma faced in Caribbean communities associated with HIV appeared to be a primary reason that some of the women in this study did not disclose their HIV status among those in their community (Caribbean in the U.S.). The stigma experienced by some women because they were HIV positive may also lead to feelings of shame (Duffy, 2005; Lawson et.al., 2006). From a social work perspective, Brown (2007, 2010, and 2012) investigated the phenomenon of shame, wholehearted living and vulnerability. She believed that shame functions as a barrier to social connection with others. She defined shame as, “an intensely painful feeling or experience of believing we are flawed and therefore unworthy of acceptance or belonging” (Brown, 2006, p. 43). Furthermore, she argued that for women, shame functions along three different domains: what a woman should be, who she should be, and how she should be (p. 45). This gendered construct is socially-defined. Based on the data collected from this study, the women identified HIV as a social construction that delineated those that are accepted from those that are not.

Anderson and colleagues (2008) reported similar results with regard to this concept of non-acceptance and ostracization among Caribbean individuals living with HIV in the UK. Stutterheim, Bos, Shiripinda et al. (2012) also identified culturally-based ideologies rooted in blame, sexuality and bodily manifestations of HIV (i.e. weight loss) as perpetuating stigma and discrimination in Caribbean communities in the Netherlands.

Some participants also expressed challenges related to intimate relationships and having an HIV positive status. One participant noted that she was afraid to tell her partner about her status because of fears that the relationship might be terminated or she would face physical

violence. Another participant commented about the difficulty associated with deciding whether to tell an intimate partner because she did not want to be rejected after investing emotional energy in the relationship. These findings revealed that women utilized several different mechanisms that assisted them in the decision making process about how and when to disclose their status and to which individuals; similar to previous studies (Moneyham, Seals, Sowell, Cohen & Guillory, 1996; Sowell, Seals, Phillips & Julious, 2003).

Two participants tied the concepts of stigma and discrimination together when discussing experiences with service providers. Provider stigma has been examined in a variety of settings as it pertains to those living with HIV (Kinsler, Wong, Sayles, Davis & Cunningham, 2007; Valdisseri, 2002; Li, Wu, Wu, Zhaoc, Jia & Yan, 2007). For one participant, the experience with provider stigma occurred because of her HIV positive status, but was compounded because of her sexual orientation. LGBTQ persons from minority communities may face significant challenges in accessing quality services related to their HIV status due to this double stigma (Wilson & Yoshikawa as cited in Meyer & Northridge, 2007). In addition, research conducted about provider stigma in the Caribbean cited that cultural attitudes may often prevail over technical knowledge of HIV and its acquisition (Abell, Rutledge, McCann & Padmore, 2007; Massiah et al., 2004; Rutledge, Abell, Padmore & McCann, 2009).

Grief and loss were salient for the women in this study. Each woman went through her own process of grieving in order to make sense an HIV positive diagnosis. One participant experienced a heightened level of grief and loss related to possible denial of her diagnosis. She was tested several times after her arrival in the U.S. (knowing that it was likely she was HIV positive) without going back for test results. At the time of interview, she appeared to struggle with how to live with HIV and move forward. She denied the possibility of a HIV positive status

for many months before she was even able to go to the clinic to get tested and ultimately retrieve the results. Each participant moved through a process of grief unique to their experience of diagnosis and incorporation of HIV into their lives.

Adherence to strict medication regimens is often a problem among those living with HIV. Two participants recounted that medication adherence and the side effects were challenging for them. Literature widely recognizes the importance and challenge of medication adherence for those living with HIV (Catz, Kelly, Bogart, Benotsch & McAuliffe, 2000; Kumarasamy et al., 2005; Ramirez-Garcia & Cote, 2003; Roberts & Mann, 2000). Rintamaki, Davis, Skripkauskas, Bennet & Wolf (2005) indicated that for individuals diagnosed with HIV that are concerned about the stigma associated with being HIV positive, medication adherence may be even more difficult. Given the seriousness of stigma associated with HIV in Caribbean communities, Afro-Caribbean immigrant women may lapse in adherence by not attending clinic appointments because they fear encountering someone they know. In turn, missing appointments and needed treatment puts them at a greater risk for increased CD4+ counts and higher viral loads that could lead to various opportunistic illnesses.

Coping

Many of the women identified coping mechanisms such as; shopping, taking baths, spending time with family, secrecy and spirituality. Secrecy was found to be related specifically to coping with living with HIV, however other strategies utilized by participants may or may not be directly related, but with coping with daily lives in general. This information about coping provides information about the experiences that contribute to their lives in general. For most of the women, secrecy was vital to their ability to cope living with HIV. It also served as a way of protecting themselves and family members from the stigma of being associated with someone

that was HIV positive. One way that secrecy is manifested is in the selective manner in which disclosure is handled.

This same phenomenon was also found by both Anderson et al. (2009a) and Stutterheim et al. (2011) from their studies conducted in Afro-Caribbean immigrant communities. This form of selective disclosure was employed as a coping mechanism due to fear of being stigmatized or the effect the disclosure will have on family members. For some participants, disclosure of their status was done by others, such as some family members. This stripping away of their ability to decide whom and when to disclose likely caused even more reluctance to disclose to others.

Spirituality was also brought up during the interviews as an important part of the lives of some participants. It appeared to provide “grounding” and support their ability to cope with living with HIV and daily life in general. Literature supports that spirituality is an important component of life for many living with HIV (Coleman & Holzemer, 1999; Coton et al., 2006; Simoni, Martone & Kerwin, 2002).

Stigma and secrecy were also related to self-concept and coping with HIV. Shame, brought on by the internalization of stigma associated with an HIV positive status, can prove detrimental to one’s self-concept. However the women in this study that experienced shame as a result of culturally-based social constructions of HIV, were able to form a new self-concept. They created links with formal and informal networks in order to manage daily life. Previous research showed that women with HIV often struggled with self-concept (Lather & Smithies, 1997) and that self-concept evolves over time and through various life experiences.

Utilizing various forms of support for these women also emerged as another important aspect of coping with HIV. Formal support such as through interactions with medical clinics (physicians, social workers, case workers), and support groups served as integral factors in the

ability to cope living with HIV. This seems particularly important for undocumented women in the study. Doctors, caseworkers, and support groups provided a positive form of support because they had disclosed their status to very few outside of these formal structures. Because of the fear of being stigmatized, many were unable to tell their families and thus rely on them for support. Some informal networks such as; church groups, friends and family were mentioned as an integral part in addressing the emotional and psychological challenges associated with living with HIV. Support networks are necessary for positive coping with living with HIV (Freidland, Renwick, & McColl, 1996).

Participants in the study identified several self-care strategies used such as; shopping, cleaning the house, personal grooming (i.e. getting manicures and pedicures), spending time with family, medication adherence and attending clinic appointments. Self-care provided a way for participants, especially those with families, to disconnect from the pressures of daily life and unwind. Previous studies have explored various facets of self-care in women living with HIV or AIDS (Chou, Holzemer, Portillo, Carmen & Slaughter, 2004; Grant & Welsh, 2005; Kemppainen et al., 2003; Sowell et al., 1997). Self-care, in some instances, may prove difficult depending on the resources available to an individual (Leenerts, 1998). In this study, many of the women, especially those that were undocumented reported some self-care strategies that were based on the services they were able to receive from primary providers, social workers and other health care professionals. For example, one participant received in-home physical therapy and massage as a means of self-care. In addition, those that were mothers may have felt a stronger impetus for engaging in self-care practices (Shambley-Ebron & Boyle, 2006).

Policy/Immigration Challenges

Participants also shared that they faced challenges related to immigration policies. Among these challenges, immigration status appeared to be significant concern for Afro-

Caribbean women, especially those that were undocumented at the time of interview. Being able to work and be integrated fully into society was discussed as dependent upon immigration status. However, regardless of status, most of these women were still able to obtain medical care and other services such as housing benefits (payment of some or all of rent). Many immigrant populations also face challenges navigating the healthcare system in the U.S. due to systemic and cultural differences. Furthermore, undocumented immigrants may be afraid to access services because of fear of being asked about their immigration status (show documentation) or concern about deportation. Undocumented status impeded meaningful engagement with health services especially as it pertained to women in Afro-Caribbean communities (Pivnick et al., 2010). In addition, immigration laws such as the Personal Responsibility and Work Opportunity Act (PRWORA) and the Illegal Immigrant Reform and Immigrant Responsibility Act (IIRIRA), both passed in 1996, curtailed access to many benefits for legal immigrants placed more punitive measures on illegal immigrants (Fix & Passel, 2002; Jimenez, 2010; Schoen, 1996). Some participants reported that they had tried on several occasions to change their immigration status and were told by attorneys that they would not be able to do so.

Furthermore, while the benefits participants received were reported to be helpful, this is much less than if they were able to work full-time jobs. In addition to supporting themselves and their immediate families in the U.S., they wanted to be able to provide monetary support to their families in their home countries but were not able to contribute in the way they would have liked because of their immigration status.

Perceived Benefits of Living with HIV

All of the participants spoke in some way about the “good care” they received in the medical community; even those who were undocumented. According to the participants, physicians provided information about medication management and the physiological effects of

the medication regimens relative to the progression of HIV. The participants also reported that the physicians gave them “support”. These aspects demonstrated that perceived “good” medical care and trust or feeling of “family” was often formed between providers and these women. For the participants that were undocumented, such support proved even more salient because of the nature of their immigration status in the United States and fear of discovery. In addition, many women were able to work with social workers and case managers to navigate systemic barriers in order to receive the formal services needed. These professionals helped in concrete ways such as shepherding medical information needed for Medicaid, ADAP (Assistance Drug Program) and housing benefit applications. However, the women more often spoke about the “intangibles” provided that helped them cope with living with HIV.

Life Lessons

Participants shared life lessons they learned as a result of living with HIV. Many of them reported that they felt that because they were infected with HIV that they know vastly more about the disease and thus were better able to take care of themselves and their families. In addition, advocacy and self-advocacy were skill sets that were learned. For example, one participant had been employed working with those living with HIV at the time of her diagnosis. She shared that she became more involved in working specifically with the Afro-Caribbean community after her diagnosis. Another felt that her contribution was to advocate for others that were diagnosed so that they could find needed services. Yet another indicated that learning how to advocate for oneself was empowering as it taught her how to be assertive. Most participants spoke about how they viewed HIV as a “death sentence” when they were first diagnosed, but subsequently believed that they would be able to lead full, healthy lives if they took care of themselves. One participant said that the biggest life lesson, one that she would pass on to other

Afro-Caribbean immigrant women living with HIV would be to “live your life”. Many of the women ultimately viewed HIV as part of their life journey in life, not the end of it.

Structural Analysis

The method chosen for this study utilized structural descriptions in which the process of imaginative variation is used to capture the essence of the lived experiences of these women. According to Moustakas (1994) capturing essences are based on “universal structures that precipitate feelings and thoughts with reference to the phenomenon such as the structure of time, space, bodily concerns, materiality causality, relation to self or relation to others” (pp. 99). The most prominent structures that emerged in this study were relation to self, relation to others, time and space. These structures are supported also by in Bronfenbrenner’s (1979) Social Ecological Model.

Results from this study suggested that each participant utilized a multi-level approach to living with HIV. On the micro and mezzo levels, each woman was able to physically care for herself by taking antiretroviral medications that would suppress the HIV virus that increased their ability to maintain the health and wellness of their body. Among those who described it as important, spirituality provided individual level support through a connection with a power/source higher than themselves. Family support, when present, enhanced the everyday experiences of these women as it provided a buffer against general life and HIV-related stressors such as adherence to medication, periodic illness and depression. The definition of “family” for some participants included doctors, nurses, social workers, case workers and support groups. An example of this is when one participant described her relationship with her doctor and others on the health care team, “...every time I call them, I tell them, ‘thank you’ because I know when I came here how I was and how this place has really changed my life, so it’s like my medical family.” In addition, another participant commented that the care staff functioned as a family to

her, "...they are more-more important to me than my own family cause things like these you can't tell your family." Resources to help with basic needs were secured through work with caseworkers and social workers in micro-level relationships. Exosystem level entities such as clinics, legal aid, food pantries and schools (for their children and themselves) provided additional support to the women in this study. Finally on the macro level, participants were able to access services and re-define themselves due to the broader cultural context and policies of the New York state and the U.S. Challenges were faced within their local Caribbean communities in New York, but most felt successful in choices made to keep their status a secret if they wanted to do so that they were able to maintain their "standing" in the community. The intersection of these two cultures provides both challenges and benefits for each participant.

Social Work Implications: Practice and Policy

Social work is defined and maintains its uniqueness because of the focus on individuals in the context of their social environment (Ashford & LeCroy, 2013). As individuals experience the world, many factors may impinge on their quality of life. Along with these potentially detrimental factors, strengths can be identified from each individual experience. From a social work perspective, the current study can inform social workers about the factors that affect the quality of life of these women living with HIV. Some of the challenges identified in this study were related to issues of gender, acceptance, immigration, and membership in a minority sub-population. Strengths of these women were related to maintaining a healthy lifestyle and changes in life perspectives and worldviews.

Social workers can design programs that enhance the quality of life for Afro-Caribbean immigrant women living with HIV. Many participants spoke of the support they obtained from formal and informal supports. Support groups provided a haven for the women in this study to learn coping skills, talk about their various life experiences, obtain more education about facets

of living with HIV such as medication adherence, and to share concerns. The important role of support groups in the lives of these women support the need for culturally-sensitive and gender-based peer-led groups that take into consideration the high levels of stigma associated with HIV in Caribbean communities both in the U.S. and abroad. In a study that assessed a peer-support model for Afro-Caribbean populations living with HIV in the U.S., highlighted the difficulties of recruitment and retention of HIV positive peer mentors due to fear of one's status becoming known in the community (Woldehanna et al., 2007). Peer-led support groups with this population should emphasize confidentiality by the peer group leader, especially if that person was HIV positive along with the attendees. Group leaders may be of Afro-Caribbean origin or social workers trained peer group facilitators of Afro-Caribbean origin may provide the advantage of a cultural connection. Educational self-help groups can also facilitate education and discussion around topics such as disclosure, self-care, immigration status or assistance, stigma, and relationship challenges; with those that are from a similar cultural background. Although some programs do exist that target females of color living with HIV, such as WILLOW (Women Involved in Life Learning from Other Women), educational curricula can be expanded to incorporate specific challenges immigrant women may face, such as undocumented immigration, status, and self-perception. Programs that take into consideration the aforementioned factors will also take into consideration the racial and ethnic differences of Afro-Caribbean immigrant communities. Researchers have highlighted that many Caribbean immigrant groups are well-represented in the New York Metropolitan area (Foner, 2001; Kasinitz, 1992; Shaw-Tuch & Taylor, 2007). However, due to racial categorization, the unique needs of Afro-Caribbean populations with HIV may not be accounted for in programs specifically designed for African American populations. While many similarities do exist between these two groups, there are

differences with regard to the severity of stigma for individuals living with HIV from Caribbean backgrounds (Norman et al. 2006) and the perception of Afro-Caribbeans viewing themselves as a “minority” group. Many individuals that come from the Caribbean are unaccustomed to the racial stratification that exists in the U.S., as in many instances they are the majority population in their country of origin (Shaw-Taylor, 2007, as cited in Shaw-Taylor & Tuch, 2007).

Therefore, programs that address the unique cultural aspects of Afro-Caribbean immigrants may prove to be effective for those living with HIV.

Another primary avenue for intervention with this population is psycho-educational. Brown’s (2006) theory-based shame resilience curriculum may prove useful in assisting women in identifying “shame triggers” and providing a means of effectively coping with stigma for Afro-Caribbean immigrant women. Shame for some of these participants was due to a history of abuse. This was mentioned by one participant who did not elaborate on what type of abuse she faced, but she indicated that the abuse impacted how she perceived herself and how she engaged in intimate relationships. Sexual abuse in childhood may negatively impact future relationships, health and may lead women to be re-victimized (Dong, Anda, Dube, Giles & Felitti; West, Williams, & Siegel, 2000; Hillis, Anda, Felitti, & Marchbanks, 2001). Shedlin et al. (2006) also cited in their study of HIV risk among immigrant populations in New York City that in Caribbean populations both women and men reported previous childhood abuse. For social workers, assisting women to process the events may positively affect relationships and increase awareness of risk factors for abuse that they still may be exposed to in the community.

Social workers have an important role in advocacy and policy development for those who belong to vulnerable populations (Chang-Muy & Congress, 2009). Four of the eight participants spoke explicitly about the need for advocacy for Afro-Caribbean immigrant women’s access to

health and social services. For example, Faith stated that many women she has encountered “don’t even have insurance and it’s hard for them to live”; implying that they are not able to receive health care needed. Federal policies, such as the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PRWORA) and the Illegal Immigration Reform and Immigrant Responsibility Act of 1996 (IIRIRA), curtailed access to benefits for immigrant populations. These policies granted states the right to allocate funding for programming for low income and immigrant individuals and families as they saw fit (Jimenez, 2010). As a result, clinics, faith-based organizations and various community centers could create programs they believe are needed (within financial constraints), and designate which populations access those services. Local agencies can also advocate for populations they deem the most vulnerable in an effort to ensure that they are able to provide equitable services. The passage of the Patient Protection and Affordable Care Act (PPCA; 111-148) aims to provide equitable care for more Americans by decreasing the costs of health insurance thereby increasing the number of individuals that will be able to afford quality healthcare coverage (Kaiser Family Foundation, March, 2013d). In addition, the program seeks to expand Medicaid. Most participants in this study received benefits from AIDS Drug Assistance Program, which is under Part B of the Ryan White Program (Kaiser Family Foundation, March, 2013d). All participants of the Ryan White Program must also be enrolled in Medicaid program. Although it is too soon to tell how the PPCA will affect funding various Ryan White Programs, many women in this study stressed the fact that they depended heavily on the support they received from various social programs. In addition, legislation that rescinded the ban on immigration of those infected with HIV to the U.S. may mean that more immigrants come to the U.S. for treatment and services. This is important in that will create new pathways for research into how the new wave of immigrants living with HIV

coming to the U.S. are able to cope and access services related to their HIV positive status. Social workers can empower members of vulnerable populations by providing them with pertinent information and service provision (Chang-Muy & Congress, 2009; Poindexter, 2010). Social workers can and should be at the front of these efforts.

Community-based participatory research (CBPR) can also serve as a method of empowerment and legislative change. In this model, Afro-Caribbean immigrant populations living with HIV can have a say in what types of research is conducted and on what topical areas. The findings from such research can inform policymakers and other stakeholders regarding the most pivotal issues in this community. For example, the preliminary study conducted by this researcher yielded commentary from participants that CBPR and community advisory boards (CABs) provided the community with “a voice.”

The women in this study also identified spirituality as an important facet of living with HIV. It emerged as sub-theme of coping. For Empress, Charlene, and Faith; spirituality was an important component to living successfully with HIV. Within their religious communities, they found support and fellowship. Koenig (2001, as cited in Taylor, Chatters, & Jackson, 2009) asserted that socially-constructed ideas of spirituality and religion have evolved over time. Religion focuses on adherence to a particular set of tenants in relation to a specific organized faith community or denomination whereas spirituality focuses on relationship with a higher being. This involves actions in which individuals construct their own view of a force outside themselves and seek to answer existential questions about life and human existence. (Koenig, 2001 as cited in Taylor, Chatters, & Jackson, 2009). In their study of spirituality among Afro-Caribbean and African American populations in the U.S. Taylor, Chatters, & Jackson (2009) stated that few studies exist that explore spirituality among Afro-Caribbean populations in the

U.S. They argued that religious and spiritual traditions are complex and are varied within this population. For example, the authors discussed the practice of African-based spiritual traditions such as Orisha and Santeria, not mainstream religious traditions, but are often practiced by small sub-sets of individuals, and are subject to stigma.

Based on the importance of religion and spirituality expressed by participants in this study, faith-based programs, especially those that serve predominantly Caribbean populations, should take into account the varied spiritual and religious traditions. Prior to engaging in and designing specific programs based in churches, education of clergy and laypersons who would shepherd these programs should take place and include topics such as; modes of HIV transmission, importance of confidentiality, the role of stigma and discrimination, and linking congregants to community resources. In addition, as set forth by the NASW Code of Ethics, Section 1.05 (2008), social workers should engage in culturally-competent practice with regard to understanding the importance of individual spiritual and cultural practices and how they impact the quality of life for Afro-Caribbean immigrant populations in the U.S.

The primary strength of this study was found in the qualitative method selected for the study. The information obtained from the interviews provided a glimpse into the experiences of these women living with HIV, including an intimately-portrayed knowledge of the strengths and challenges faced in everyday life. The sample for this study was purposive and small, as was appropriate for this methodology. Participants were recruited through several methods; primary recruitment sites included two community health clinics in the neighborhoods identified with a high number of Caribbean immigrants. These was a strength of the study in that these women had previously disclosed their HIV status and were able to share their views fairly freely during the interviews. However, it was also a limitation as the study did not capture the views of those

who were not able to access health services and concerns. The fears and coping may be very different than those of the women interviewed. The overall recruitment strategy was sensitive to the issues of stigma and discrimination that is pervasive in the Caribbean community with respect to HIV. Furthermore, the sample was drawn from among Afro-Caribbean immigrant women from the English-speaking Caribbean area of the New York metropolitan area.

The wide variation in interview lengths may be seen as a limitation as well. Time constraints were a factor for many of the participants as many in the sample had various obligations such as, child care, work, and attending classes. In some instances, transportation issues (missed or delay in train schedules) also played a role in scheduling of interviews. The researcher made sure to work with participants to identify a date and time that worked best for their schedules. Any unforeseen circumstances were dealt with as they came up. In addition, the researcher always extended the opportunity for a follow-up interview, if the participants deemed it necessary. Two of the eight participants that were recruited via snowball sampling, interestingly proved to be the shortest in length. It may be viewed by some that since these did not yield a similar volume of information producing longer interviews, that an in-depth aspect was missing. Even though the researcher thoroughly explained the study purpose, and expectations of participation, these participants may not have been briefed by the person “in network” that recruited them about certain aspects of the study to the participants’ understanding. Furthermore, they may have approached the interview process as doing a “favor” for a friend.

While this study had limitations, it represents an important contribution to the study of Afro-Caribbean immigrant populations living with HIV. The women in this study were identified by community recruiters that worked closely with various populations living with HIV and were able to provide guidance and vital information to the researcher about cultural nuances

associated with this sub-group of Black immigrants living in the New York Metro area. Participants represented Caribbean island nations that are well-represented among the demographic of Caribbean immigrants living in this area.

Future research with Afro-Caribbean immigrant populations in the U.S. should focus on the diversity within the population, such as with those that are from the Francophone, Spanish, or Dutch-speaking Caribbean. This would offer more breadth of experiences across Afro-Caribbean communities. In addition, across islands, inter-island diversity also extends to other racial and ethnic groups. For example, to date, few studies have explored HIV among Indo-Caribbean immigrant populations in the U.S. Exploration of other ethnic/racial immigrant groups in the U.S. can provide useful information as to how populations differ with regard to HIV risk and acquisition, and lived experiences.

As previously mentioned, culture was a pervasive construct in the lives of this sample of women. They highlighted cultural norms that focused on stigmatization of individuals living with HIV. The construct of culture is complex and encompasses many facets of human life. Tylor (1958) offers the following definition of culture, “it is that complex whole which includes knowledge, belief, art, morals, law, customs, and any other capabilities and habits acquired by man as a member of society” (p. 3). For the women in this study, their knowledge of HIV prior to diagnosis was partly based on educational campaigns and word of mouth knowledge; however HIV was seen as “death” and “scorn.” Individuals with HIV were treated like “nothing.” For these participants, their cultural understanding of HIV led them to view it as a “death sentence.” However, as Starr recounted, after she was diagnosed and learned about how to manage and live with HIV, she realized many of the perceptions she had of HIV in the Caribbean were not true and it was not a “death sentence.” In context of the Caribbean culture, participants utilized

secrecy as a form of empowerment. Many of the participants spoke of not disclosing their status to family members in their home countries and some also chose not to disclose to members of the Caribbean community in New York City unless they were also HIV positive. The cultural norms of the U.S., more specifically New York City, facilitated an increased understanding of HIV; the ability to access services related to their HIV status, and to be seen as “normal.” However, New York City is unique in that Caribbean individuals have set up various cultural enclaves that perpetuate the cultural heritage of their home countries unlike other areas in the U.S. (Foner, 2001; Kasinitz, 1992). It is against this cultural backdrop that the women in this study live with HIV. While the notion of secrecy as a form of empowerment may seem contradictory, these women have learned to effectively navigate two different cultural contexts. In New York City, they were able to find individuals (health professionals and support group members) with whom they felt comfortable discussing HIV status; believing that would maintain their “secret” while offering them resources and friendship, but they also knew that to disclose within the Caribbean community may invite judgment and stigma. Many women felt that they needed to protect themselves and their families while simultaneously forging out a life for themselves where they experienced a feeling of acceptance. Based on the finding of secrecy as a form of empowerment, future research could focus on what Afro-Caribbean people believed were the ramifications for their families and themselves when they disclosed to their families abroad.

The stigma associated with LGBTQ populations in Caribbean communities has also impeded research with these populations. Empress highlighted personal experiences of discrimination by healthcare providers due to a combination of her sexual orientation and being HIV positive. Although some studies exist regarding Caribbean MSMs (Bourne, Wedderburn,

Rogers, Tureski & Cushnie, 2012; Carr, 2003; White & Carr, 2005), little is known about lesbian or transgender populations in the Caribbean. LGBTQ communities in the U.S. face considerable challenges in accessing services due to discrimination and stigma (Wilson & Yoshikawa as cited in Meyer & Northridge, 2007). Research in the U.S. with Afro-Caribbean lesbian and transgender populations may prove effective in understanding more about this minority sub-population within Caribbean communities.

Another area for future research may relate to the length of time individuals have been living with HIV. At the time of the interviews, two of the participants had been living with HIV for 24 and 15 years respectively (Charlene and Empress). Charlene recounted that when she was diagnosed, there were very few options for treatment for those living with HIV and little community support. Empress also stressed the fact that she was growing older and did not want to “age.” These two aspects may suggest that exploring the experiences of those that are aging with an HIV positive status, may shed light on the various challenges associated with living with HIV over time. In addition, data suggests that HIV infection is increasing among individuals aged 50 and over, especially in those 50-54 years of age (CDC, June, 2013). Blacks in this age-range were diagnosed at a much higher rate than their White and Latino counterparts (CDC, February, 2013). This suggests that exploring the experience of HIV among older Caribbean immigrants that have been diagnosed at a later age, may prove useful in understanding how older adults navigate living with HIV.

Two participants spoke about concealing their diagnosis from their young adult children (Betty and Starr) in an effort to shield them from harm due to stigma or discrimination. This finding suggests a need for more research in assessing how young adults with an HIV infected parent cope with learning of their parent’s status among Caribbean cultures. In addition, research

with young adults who were infected with HIV through perinatal transmission might also assist in providing a clearer picture of how these individuals cope with living with HIV, and how it affects parent-child relationships.

Young adults (aged 13-24) also have increased risk for acquiring HIV both in the U.S. and the Caribbean (UNAIDS, 2013; CDC, February, 2014b). Youth in this age range comprised 26% of new infections in 2010, with Black youth accounting for the majority (57%) of new infections among youth in this same year (CDC, February, 2014b). While some research has been conducted on HIV attitudes, beliefs, and behaviors among adolescent Afro-Caribbean females with HIV risk, (Archibald, 2007; Archibald, 2010); conducting research concerning HIV risk behaviors with young Afro-Caribbean females with an HIV infected parent could provide insight as to how these young women conceptualize risk, and if they engage in risky sexual behaviors. In addition, it would be important to assess family responses they experienced after contracting HIV. Conducting research among Caribbean youth and young adults (second generation and immigrated) with an HIV infected parent will provide useful information about how youth conceptualize HIV risk. Archibald (2011) conducted a study of Caribbean-born and native-born adolescent females of Caribbean ancestry in Florida. Results indicated that many young females projected some level of stigma toward individuals with HIV based on cultural ideologies about persons living with HIV. Some of these beliefs may be influenced by religious beliefs that suggest that a person may contract HIV as means to test allegiance to God. Some participants also noted the lack of information about sex from parents. Although these studies explored attitudes and stigma, the young women were not children of parents infected with HIV. This suggests that more research needs to be conducted among this population.

Results from this study indicated that the participants were able to effectively access and navigate health systems in New York with the assistance of caseworkers, doctors, and social workers. However, this may not be the case for other Caribbean immigrant women, especially those that are undocumented (Chang-Muy & Congress, 2009; Pivnick et al., 2010). Future research should focus on exploring the experiences of those that are not as well-connected to services or providers.

Lessons from the Study

“They will never speak to you.” “You want to research what?” “Wow. Good luck with that!” “We just don’t talk about those things.” These words represented the opinions of several individuals that I spoke with in the early days of formulating this study; many of whom were my Afro-Caribbean peers. What I learned from those statements was that we often fear that which we do not know. Through this phenomenological investigation an opportunity was provided that opened a person’s life journey to another’s interpretation. As I talked with the women in the study, I learned the power of resilience. The women illuminated the challenges they faced in their daily lives, such as not being able to work and provide adequately for themselves and their families. Both documented and undocumented women in this sample were able to access the necessary treatment they needed. I realized after speaking with these women that all Caribbean women were not able to access these services so readily. Utilizing key informants taught me about the importance of making sure that a researcher is as informed as possible prior conducting research with a vulnerable population. Stigma and discrimination proved to be powerful concepts for the majority of the women in the study. On one hand, the women in this study were able to create productive and meaningful lives for themselves in the U.S. On the other hand, they remained guarded about disclosing their status to members of the Caribbean community and their families for fear of being ostracized. These two realities in some ways seemed

contradictory, but vital for their survival and well-being. The life lessons these participants shared have implications for women that are newly diagnosed as well as those that have been living with HIV for some time. They indicated that with support and guidance, women can overcome the obstacles they face related to living with HIV. However without support, women may not fare as well.

Conclusions

Despite an increased interest in Afro-Caribbean immigrant populations living with HIV (Anderson et al., 2008; Anderson et al., 2009a; Lawson et.al., 2006; Stutterheim, Bos, Kesteren et al., 2012; Stutterheim, Bos, Shiripinda et al., 2012), little information exists about the unique experience of Afro-Caribbean immigrant women living with HIV, especially those in the New York Metropolitan Area. In addition, Black women in the U.S. lead among all other racial/ethnic groups with regard to HIV prevalence and incidence (Kaiser Family Foundation, March, 2013c).

This study represents an attempt to fill the in research about Black immigrant sub-populations in the U.S. The qualitative phenomenological design elicited information from eight Afro-Caribbean females about their life experiences living with HIV. The previous studies that focused exclusively on this population in the U.S. (Pivnick et al., 2010; Woldehanna et al, 2007) used qualitative and quantitative perspectives however did not address the overall life experiences, self-care, self-perception and coping mechanism utilized by this population and how it affects the daily lives of women who are infected with HIV. This study can help social workers, healthcare professionals, stakeholders and those in the social sciences understand various aspects of life for Afro-Caribbean immigrant women living with HIV so that interventions can be targeted to resolve problems that these women identify as important. The need for further research and culturally-competent, gender-specific approaches to working with this population in order to maximize quality of life is evident.

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APPENDICES

Appendix A

Definition of Relevant Terms

African American: Individuals in the United States of African descent. For the purpose of this document, this term was used for individuals born in the U.S. and not for immigrant populations of African descent.

Afro-Caribbean immigrant: An immigrant from the Caribbean of African descent that has migrated to the United States.

Black: Individuals in the United States of African descent. It may be used throughout this document interchangeably with African American or Caribbean (i.e., Black Caribbean).

AIDS (Acquired Immune Deficiency Syndrome): AIDS is the sequelae of HIV. AIDS may develop after an individual's CD4 +T count drops below 200/mm. Retrieved from http://www.cdc.gov/hiv/pdf/statistics_recommendations_terms.pdf

Coding: According to Bloor and Wood (2006), coding refers to “the activity where a researcher applies meaning to raw data by assigning key words or phrases. These key words act as signposts to themes within the data” (p. 101).

Culture: “Culture or civilization, taken in its broad ethnographic sense, is that complex whole which includes knowledge, belief, art, morals, law, custom, and any other capabilities and habits acquired by man as a member of society” (Tylor, 1958, p.3).

Epoche: A Greek term meaning “to refrain from judgment, to abstain from or stay away from the everyday ordinary ways of perceiving things” (Moustakas, 1994, p. 33). This is a key tenant of transcendental phenomenology.

Essence: “that which is common or universal, the condition or quality without which a thing would not be what it is” (Husserl, 1931, p. 43, as cited in Moustakas, 1994). In

transcendental phenomenology, the essence of a phenomenon is derived from the composite description of the participants' experiences.

HIV (Human Immunodeficiency Virus): HIV is defined as: "The precursor to AIDS. There are two subtypes of HIV- HIV-1 and HIV-2. HIV attacks an individual's CD4 +T cells (specific type of white blood cell that fights off viruses). In healthy individuals, a CD4 + T count ranging from 800/mm³ and 1200/mm³ is considered adequate. A person is diagnosed with HIV when their CD4 +T count falls below 200/mm³ at which time and individual is immune-compromised and may become susceptible to developing AIDS." (CDC, 2010)

HIV prevalence: According to the CDC (2013), HIV prevalence represents "the number of persons living with HIV disease at a given time regardless of the time of infection, whether the person has received a diagnosis (aware of infection) or the stage of HIV disease." Retrieved from http://www.cdc.gov/hiv/pdf/statistics_recommendations_terms.pdf

HIV incidence: "the estimated number of persons newly infected with HIV during a specified time period." (CDC, 2013) Retrieved from http://www.cdc.gov/hiv/pdf/statistics_recommendations_terms.pdf

Horizontalization: the process in which the researcher reads each statement in a transcript and assigns each statement the same value. Each statement is seen as a new "horizon" of the experience of the individual (Moustakas, 1994, p. 95).

Meaning units (invariant horizons): Non-repeating, non-overlapping statements chosen from the process of horizontalization that represent the experience of the phenomenon under investigation. Meaning units are clustered together under an emergent theme. them (Moustakas, 1994, p.122).

Intentionality of consciousness: An idea developed by Edmund Husserl which asserted that human consciousness always has as its aim, an object (Spiegelberg & Schumann, 1982).

Phenomenology: A branch of qualitative inquiry that “aims to describe, understand and interpret the meanings of experiences of human life” (Bloor & Wood, 2006). Phenomenology is often associated with Edmund Husserl and is both a philosophy and a method of analysis in the social sciences (Bloor & Wood, 2006; Spiegelberg & Schumann, 1982).

Structural description: A process in which a written description is formulated that encompasses the structural and environmental influences that affect how an individual experiences a phenomenon (Creswell, 2007; Moustakas, 1994).

Textural description: In the Stevick-Colaizzi-Keen Method of Analysis (Moustakas, 1994), textual description is a written description of *what* participants experience in relation to a phenomenon. The textural description emerges from the process of horizontalization and clustering of themes.

Appendix B

IRB Approval and Consent Documents

October 27, 2011

Office for Research
Institutional Review Board for the
Protection of Human Subjects

THE UNIVERSITY OF
ALABAMA
R E S E A R C H

Krista Cooper, MSW
School of Social Work
The University of Alabama
Box 870314

Re: IRB# 11-OR-315-ME: "Experiences of Afro-Caribbean Women
Living with HIV/AIDS: A Phenomenological Investigation"

Dear Ms. Cooper:

The University of Alabama Institutional Review Board has granted approval for your proposed research.

Your application has been given expedited approval according to 45 CFR part 46. The requested waiver of written documentation of informed consent has been granted. Approval has been given under expedited review category 7 as outlined below:

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

Your application will expire on October 26, 2012. If the study continues beyond that date, you must complete the IRB Renewal Application. If you modify the application, please complete the Modification of an Approved Protocol form. Changes in this study cannot be initiated without IRB approval, except when necessary to eliminate apparent immediate hazards to participants. When the study closes, please complete the Request for Study Closure form.

Should you need to submit any further correspondence regarding this application, please include the assigned IRB application number.

Good luck with your research.

Sincerely,



Stuart Usdan, Ph.D.
Chair, Non-Medical IRB
The University of Alabama

358 Rose Administration Building
Box 870127
Tuscaloosa, Alabama 35487-0127
Phone (205) 348-8461
Fax (205) 348-7189
TOLL FREE (877) 820-3066

Research Study for HIV/AIDS

Investigator: Krista Cooper, MSW—The University of Alabama



The purpose of this study is understand the experiences of Afro-Caribbean immigrant women living with HIV/AIDS.

To be in the study you must be:

- An Afro-Caribbean immigrant woman from the English-speaking Caribbean
- 19 years of age or older
- Living with HIV/AIDS

You will be asked to participate in an interview lasting one to two hours in a private, convenient location.

Each participant will a \$25 gift card to PathMark or a \$25 MetroCard.



If you are interested in this opportunity to share your experiences, please contact Krista Cooper at 914-309-9523 or caribbeanwomenstudy@gmail.com

UA IRB Approved Document
Approval date: 10/27/2011
Expiration date: 10/26/2012

THE UNIVERSITY OF ALABAMA
HUMAN RESEARCH PROTECTION PROGRAM

UNIVERSITY OF ALABAMA INSTITUTIONAL REVIEW BOARD

Title of Research: Experiences of Afro-Caribbean Immigrant Women Living with HIV/AIDS:
A Phenomenological Investigation

Investigator(s): Krista Cooper, MSW

IRB Approval #:

OSP #:

Sponsor: Ellen L. Csikai, Ph.D.

You are asked to participate in a research study.

The name of this study is: Experiences of Afro-Caribbean Immigrant Women Living with HIV:
A Phenomenological Investigation

This study is being done by Krista Cooper, MSW

Ms. Cooper is a Ph.D. student at the University of Alabama and Dr. Ellen L. Csikai a professor and Ms. Cooper's Dissertation Committee Chair at the School of Social Work-The University of Alabama.

What is the purpose of this study—what is it trying to learn?

The purpose of this study is to learn from Afro-Caribbean women about their experiences living with HIV. This study seeks to explore the various factors that contribute to your overall experience living with HIV.

Why this is study important—what good will the results do?

Currently, there are very few studies that focus on Afro-Caribbean immigrants with HIV in the United States. It is hoped that this study will provide more information about the lives and experiences Afro-Caribbean women infected with HIV. The results of this study may provide important information for policy makers, social workers/community practitioners and others that work with Caribbean populations about better ways to conduct research, write policy, and provide services to this population.

UNIVERSITY OF ALABAMA IRB
CONSENT FORM APPROVED 10/27/2011
EXPIRATION DATE 10/26/2012

Why have I been asked to be in this study?

You are being asked to participate in this study because you are an Afro-Caribbean immigrant woman from the English-speaking Caribbean, are 19 years of age or older, and living with HIV. Your participation in this study and unique experiences can assist researchers in better understanding the experiences of Caribbean women with HIV.

How many other people will be in this study?

Besides you, this study seeks to interview up to nineteen (19) other women.

What will we be asked to do in this study?

If you agree to participate in this study you will take part in an individual interview with the researcher. This interviewer will ask questions related to your experiences living with HIV. In addition, you will be asked general questions about yourself such as; your age, what Caribbean island you are from and so on. This information is just to help form an overall picture of those that have chosen to participate in this study. You will be asked to provide consent to the researcher to audio record your interview. Only the researcher and her academic advisor will have access to your recorded and transcribed responses. Furthermore, in order to ensure that your experiences are accurately described, if you consent, you *may* be re-contacted by the researcher to review the major findings of this study.

How much time will I spend being in this study?

The individual interview is expected to last 1-2 hours. This is just an estimate. It may take more or less time depending on the flow of conversation and what you choose to share with the researcher.

Will being in this study cost us anything?

There are no costs associated with this study. The main cost to you is the time you will spend during the interview process.

What are the benefits of being in this study?

There are no direct individual benefits to being in this study. You will receive a summary of the major findings of this study. The results of this study could lead to a better understanding of the needs of women in similar circumstances and inform intervention and programs designed for women living with HIV that can further benefit individuals and the community. In addition, if you consent, you *may* be re-contacted by the researcher in order to review the major findings of this study to assist with data analysis and to ensure that your experiences are described accurately.

Will I be paid for being in the study?

Each participant will receive a \$25 gift card to PathMark or a MetroCard of the same amount for participating in this study. More importantly it is hoped that participation in this study will provide an opportunity for you to share your experiences.

UNIVERSITY OF ALABAMA IRB
CONSENT FORM APPROVED: 10/27/2011
EXPIRATION DATE: 10/26/2012

What are the risks (dangers or harms) to me if I am in this study?

This research involves no physical risk and minimal emotional risk. During the course of the interview, reflecting on certain experiences may evoke some strong emotional responses. You will be provided a list of counseling/mental health or health services in the greater New York area. If you should feel uncomfortable at any time throughout the interview, please alert the researcher and the interview **will be stopped** so that your concerns may be addressed. If, after your concerns are addressed, you feel comfortable continuing with the interview- the interview will proceed. If not, the meeting can be rescheduled for another time. As mentioned previously, a community resource list will be provided to you. **It is important that you remember, you may withdraw your participation in the research study AT ANY TIME WITHOUT PENALTY.** If you choose to participate in this study, you **DO NOT** have to answer any questions that you feel uncomfortable with during the course of the interview.

How will my privacy be protected?

Your privacy and level of comfort is very important and vital to this study. To ensure privacy, the interview will be conducted at a location in which there will be limited access to the location (meaning only the researcher and the participant will have access to the room). The interview will be audio recorded, with your consent so that the researcher will be able to review the information presented in the interview. The information gathered during each interview will be used for research purposes. The audio taped material will be transcribed (or typed) in order to analyze the material. All audio recordings will be transcribed (typed) by the researcher. Only the researcher and her academic advisor will have access to materials associated with the study.

How will my confidentiality be protected?

The information gathered from this interview will be used for research purposes only. The audio material from the interviews will be kept confidential. It will be downloaded from the digital recorder to the researcher's personal laptop. The files on the researcher's personal computer may only be accessed by a password known only to the researcher. In order to protect your identity, a pseudonym (false name) will be used throughout the interview and in the written transcripts. Any information that may identify your real name will not be used in any written reports. In addition, all written transcripts and other materials associated with the study will be kept in a locked file cabinet accessible only to the researcher. The findings from this study will be used for the researcher's dissertation (the final study done for the researcher's graduate degree), and for research purposes (conference presentations and journal publications). Any information used for the above purposes will not contain any identifying information. When no longer needed for research or academic purposes, the audio recordings and transcripts (typed material from the audio recordings) will be erased/ destroyed.

Do we have to be in this study?

Your participation in this study is entirely voluntary. You may choose not to participate in this study or withdraw from the study at any time without penalty.

UNIVERSITY OF ALABAMA IRB
CONSENT FORM APPROVED: 10/27/2011
EXPIRATION DATE: 10/26/2012

If we don't want to be in the study, are there other choices?

If you do not wish to participate in this study, you may refuse to participate. Your time is greatly appreciated.

What if we have questions, suggestions, concerns, or complaints?

If you should have questions about the study at any time during or afterwards, please feel free to ask them. Additionally, after this meeting, if you have any further concerns or questions, please feel free to contact me, Krista Cooper, MSW at (615) 483-6133 or Dr. Ellen L. Csikai, the researcher's academic advisor at the University of Alabama, at (205) 348-4447 .

If you have questions, concerns, or complaints about your rights as a participant in this research study, you may contact Ms. Tanta Myles, the Research Compliance Officer at UA, at 205-348-8461 or toll-free at 1-877-820-3066. You may also ask questions, make suggestions, or file complaints and concerns through the IRB Outreach website at http://osp.ua.edu/site/PRCO_Welcome.html or email us at participantoutreach@bama.ua.edu. After you participate, you are encouraged to complete the survey for research participants that is online at the outreach website or you may ask the investigator for a copy of it and mail it to the University Office for Research Compliance, Box 870127, 358 Rose Administration Building, Tuscaloosa, AL 35487-0127.

What else do we need to know?

You do not give up any of your legal rights by signing this consent form.

You will be given a copy of this consent form to keep. Save it in case you want to review it later or you decide to contact the investigator or the university about the study.

The University of Alabama Institutional Review Board (IRB) is the committee that protects the rights of people in research studies. The IRB may review study records from time to time to be sure that people in research studies are being treated fairly and the study is being carried out as planned.

UNIVERSITY OF ALABAMA IRB
CONSENT FORM APPROVED: 10/27/2011
EXPIRATION DATE: 10/26/2012

Appendix C

Participant Interview Guide

Experiences of Afro-Caribbean Immigrant Women Living with HIV/AIDS

- 1) Describe for me what life was like prior to your diagnosis.
- 2) What did you know about HIV/AIDS before you were diagnosed?
- 3) Please tell me how you found out/discovered you were infected with HIV/AIDS.
- 4) Please tell me about the emotions you experienced upon first learning you were infected with HIV/AIDS.
- 5) Please tell me what a typical day consists of for you. What is your routine?
- 6) What were the support(s) you had after her diagnosis?
 - What support(s) do you currently have?
- 7) Please share with me what your experience has been with regard to disclosing your status with you family or friends?
 - If you have not disclosed, what are the barriers to disclosure?
- 8) Have your relationships with family and/or friends changed since your diagnosis? How so?
- 9) Describe for me what practices you engage in to care for yourself.
 - How do you believe self-care impacts your well-being?
- 10) Please tell me about your experiences with accessing services related to your HIV/AIDS diagnosis (This can include health care, legal services, community services, etc).
- 11) What issues are important to you when you seek services?
- 12) What has been the biggest deterrent or motivator for you to seek health services?

- 13) When you seek services related to your diagnosis, please elaborate on what would make you feel validated or understood by a service care provider?
- 14) Please tell me about an experience where you received care that you thought addressed your needs as an Afro-Caribbean woman diagnosed with HIV/AIDS, and an experience that did not address your needs. What were the main differences?
- 15) Explain how you think that HIV/AIDS is perceived in the Caribbean.
- 16) Describe what interaction(s) have with the Caribbean community since your diagnosis.
- 17) As an Afro-Caribbean woman, what do you believe are your strengths that allow you to cope with this illness?\
- 18) Please share concerns you have about the future.
- 19) What advice or suggestions do you want to share with other Afro-Caribbean women diagnosed with HIV/AIDS who may be struggling with managing their diagnosis?

Appendix D

HIV & AIDS Resources

Resource List

Union Settlement Mental Health Services

2089 Third Ave.

New York, NY 10029

(212) 828-6144

<http://www.unionsettlement.org/ieversion....html>

Non-profit outpatient mental health clinic providing individual, group, couples, and family psychotherapy; HIV/AIDS counseling; geriatric mental health services; and children's blended case management for children ages 5-18.

Metropolitan Hospital Center

Community Support Services

1900 Second Ave.

Third Floor

New York, NY 10029

(212) 423- 7109

www.nyc.gov/html/hhc/html/facilities/metropolitan.shtml

William F. Ryan Community Health Center

110 W. 97th St.

New York, NY 10025

http://www.ryancenter.org/rc_home.htm

Non-profit community health center offering individuals of all ages medical, dental, and support services, including HIV/AIDS counseling, testing, and treatment; health information; social services; substance abuse treatment; mental health care; and adolescent health services.

Ryan Center Annex

801 Amsterdam Ave.

Lower Level

New York, NY

10025

(212) 760-7200

http://www.ryancenter.org/rc_services.htm#7

Non-profit outpatient mental health center offering individuals of all ages psychiatric care, specializing in the treatment of those affected by HIV/AIDS; the center is also a local WIC enrollment and services site.

Center for Comprehensive Health Practice-Primary Care Center
1900 Second Ave.
9th Floor
New York, NY 10029
(212) 360-7893

<http://www.cchphealthcare.org/index.html>

Non-profit health center providing individuals of all ages with primary and specialty medical care and mental health treatment.

Caribbean American Family Health Center
3414 Church Ave.
Brooklyn, NY 11203
(718) 940-9425 Appointments/24-hour advice hotline

<http://www.lmcmc.com/OurFacilities/Luthe...ican/>

Monday through Friday, 8 a.m. - 8 p.m.

Saturday, 8:30 a.m. - 4:30 p.m.

Walk-in Services from 8 a.m. - 6 p.m.

Non-profit health center providing primary and specialty medical services and dental care for patients of all ages, with a focus on the Caribbean-American community.

HIV Center for Women and Children
SUNY Downstate Medical Center
450 Clarkson Ave.
Box 1240
Brooklyn, NY 11203
(718) 270-3745

<http://www.hivcenter.org>

Mon, Tues & Fri, 9am-5pm

Wed, 9am-8pm

Thurs, 1:30pm-5pm

Non-profit center providing HIV-infected individuals of all ages with primary care, specialty referrals, nutritional education and counseling, treatment education, buddy services, case management, acupuncture, buprenorphine treatment (for opioid addiction), HIV clinical trials, behavioral health services, HIV counseling and testing, inpatient HIV services and research programs at the STAR Health Center of University Hospital of Brooklyn.

Kings County Hospital Center-Center for Hope
541 Clarkson Ave.
Building, 4th Floor

Brooklyn, NY
11203
(718) 245-2800

<http://www.nyc.gov/html/hhc/kchc/html/se...shtml>

Public outpatient HIV/AIDS treatment center providing adults (ages 18+) with primary and specialty medical care, testing and pre-/post-test counseling, psychological counseling, case management, treatment education, and support groups.

Mon, 11am-7pm HIV Clinic
Tues-Fri, 8:30am-5pm

Walk in services for HIV Clinic: Tues & Fri: 11:30 am, Wed:
8:30 am

Clinic services are not available Wednesday mornings or
Friday evenings.

Caribbean Women's Health Association
3512 Church Ave.
Brooklyn, NY 11203
(718) 826- 2942
(718) 940-9505
(718) 940-9501
<http://cwha.org/index.php>

Community Healthcare Network
Caribbean House Health Center
1167 Nostrand Ave.
Brooklyn, NY 11225
(718) 778-0198
<http://www.chnyc.org/locations/ch/>

Non-profit health center providing individuals of all ages with primary and specialty medical care, mental health services, and case management.

Mon, Wed, Thurs & Fri, 9am-5pm
Tues, 12pm-8pm

Immigration Advocacy Services

Appendix E

Demographic Information

Experiences of Afro-Caribbean Immigrant Women Living with HIV/AIDS

Name (Pseudonym): _____

Age: _____

Relational Status:

1. Single ____
2. Separated ____
3. Divorced ____
4. Common Law ____
5. Widowed ____
6. Other ____

Yearly Household Income:

1. \$0-9,999
2. \$10,000-19,999
3. \$20,000-29,999
4. \$30,000-39,999
5. \$40,000-49,999
6. \$50,000-59,999
7. Other _____

Length of Time Living with HIV/AIDS:

1. 0-9 months
2. 1-3 yrs
3. 4-7 yrs
4. 8-11 yrs
5. 12-15 yrs
6. 16-19 yrs
7. 20+ yrs
8. Other _____

Length of Time Residing in the United States:

1. 0-9 months
2. 1-3 yrs
3. 4-7 yrs
4. 8-11 yrs
5. 12-15 yrs
6. 16-19 yrs
7. 20+ yrs
8. Other _____

Number of individuals in the home:

1. 1-2 ____
2. 3-4 ____
3. 5 + ____

Country of Birth: _____

Do you have children?

Yes _____

No _____

If yes, how many? _____

Are you currently receiving HAART (ARV) treatment?

Yes _____

No _____

How long have you received HAART (ARV) treatment?

1. 0-9 months _____

2. 1-3 yrs _____

3. 4-7 yrs _____

4. 8-11 yrs _____

5. 12-15 yrs _____

6. 16-19 yrs _____

7. 20+ yrs _____

8. Other _____

Do you have Health Insurance? If yes, what type?

Yes _____ Type _____

No _____

Do you have a regular physician? If yes, please indicate what type.

Yes _____

No _____

Private Practice _____

Clinic _____

Appendix F

Field Note Form

Experiences of Afro-Caribbean Immigrant Women Living with HIV/AIDS

Interview Participant: _____

Scheduled Interview Date: _____

Time Interview Commenced: _____

Time of Termination of Interview: _____

Location of the Interview: _____

Feelings before the interview:

Feelings after the interview:

Distinct Observations (Location, Colors, Scents, etc.):

Pivotal Points in the Interview:

Lessons Learned:

*(Adapted from Berg, 2009 & Taylor & Bodgan, 1998)

Appendix G

Member Checking Document

The Experiences of Afro-Caribbean Immigrant Women Living with HIV:

Purpose:

Participants:

Interviews:

Major Findings of the Study:

Individual Findings (Participant Pseudonym):