

“I DON’T WANNA BURDEN NOBODY” EXPERIENCES LIVING WITH HIV
AMONG AFRICAN AMERICAN FEMALES IN RURAL SOUTH CENTRAL
GEORGIA

by

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(Under the Direction of Su-I Hou)

ABSTRACT

The purpose of this study is to examine the experiences of African American females living with HIV in the rural Deep South. Using grounded theory methods 17 HIV positive females 22-44 years attending a Ryan White Clinic in rural South Central Georgia were interviewed. Participants were asked to describe how they found out they were positive, and what their life has been like since finding out their positive status.

Interviews were initially coded using ATLAS.ti 5.2 statistical software, where 247 open codes were generated. Data reduction occurred during the next phase of coding during the focused coding process, where 8 main codes emerged with 24 different themes. The codes are as followed: 1) Finding out, 2) Life Circumstances, 3) Dealing with the news, 4) Coping with life, 5) Disclosure issues, 6) Small town living, 7) Views of the body and 8) Choosing life. Approximately half of the participants found out they were positive while simultaneously finding out they were pregnant, or during routine testing during pregnancy. All of the participants were infected by their husband, fiancée, long-term boyfriend, or a casual sexual partner that they knew for most of their life.

Upon finding out their results approximately half contemplated or attempted suicide and all of the women went into some form of depression. A large portion of the study (68%) had been involved in abuse or intimate partner violence in their lifetime which may have increased their susceptibility to becoming infected with HIV. Additionally, although many women disclosed their status to their current sexual partners and family members, most did not disclose to their children for fear of burdening them with their illness. There were also expressions of the lack of confidentiality and quality of HIV-related care due to living in a small town. Methods of coping and living with the virus included increased strength and dependency on God, family support, and the desire to support their children. Implications for practice and research include developing more effective treatment and care for HIV positive persons living in rural areas, creating better support systems for children with parents living with HIV and examining the relationship between trauma and risk of HIV infection.

INDEX WORDS: HIV/AIDS, African American females, Rural Deep South, Grounded Theory

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DEDICATION

To the women in South Central Georgia. Thank you so much for sharing your stories, your lives and your homes to me, a complete stranger, who merely came in and said hello, pressed her tape recorder and let you lead the way as you shared your voice with me. Your strength, dedication, resiliency and love for your children have moved me, and touched my life. You have risen through so many obstacles thrown your way and still you remain strong, beautiful, powerful-strong Black woman. Your strength and optimism is inspirational, and will continue to live on in my heart.

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I could not do this without God, because it is He who gives me strength, started me through this process, stayed by my side during this journey, and is jumping for joy with me at the finish line. Thank you to Dr. Su-I Hou for believing in me and still having faith in me even during some of my toughest times. To my committee I thank you for your wisdom and guidance, and special thanks to Dr. Marsha Davis who agreed to be on my dissertation committee. To all the ladies in South Central Georgia at the Ryan White Clinic you are amazing and I could not have done this without you and your hospitality. Thank you for everything you have done for me. Finally, I would be remiss without acknowledging all the countless hours of support I have received from family and friends. They may not completely understand what I'm doing, but they know that I'm doing something important. All that matters is that I have their love and support, and without it I would not have gotten through this. Thank you so much to everyone, it is truly appreciated and I love you all.

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CHAPTER 1

INTRODUCTION

Statement of the Problem

The AIDS epidemic is rampant in the state of Georgia. The state ranks seventh in the nation among US states with the highest cumulative AIDS cases and eighth among states with the highest AIDS rates. African Americans in Georgia continue to be disproportionately affected by HIV/AIDS. In Georgia, through 2005, African Americans accounted for 76% of new AIDS cases, but only account for 29% of the state's population. The AIDS rate for African Americans in Georgia (36 cases per 100,000) was nine times higher than the rates for Whites (4 cases per 100,000). African American females who reside in the state of Georgia are continuing to become infected with HIV. Out of the women living with HIV/AIDS in this state, 84% are African American females. In 2002 AIDS was the leading cause of death among African American women 20-44 years old (Georgia Department of Human Resources, 2007). Among infected women, 45% reported becoming infected through intercourse with a sexual partner. Most (71%) reported not knowing that their partner was infected with HIV. A smaller percentage of women (23%) reported becoming infected from needles through drug use, and the rest were reported as unknown (Georgia Department of Human Resources, 2006).

African American females who reside in rural areas in Georgia are at an increased risk of becoming infected with HIV/AIDS. The epidemic in the state is shifting towards rural populations and small towns and cities. Since December 2004, 29% of men

diagnosed with AIDS, 43% of women diagnosed with AIDS, and 47% of children living with AIDS were living outside of the 20-county metropolitan area at the time of their AIDS diagnosis (Georgia Department of Human Resources, 2006). Due to the increasing rates of infection among women in rural areas and small towns, further knowledge is needed of rural African American women living with HIV/AIDS. Better understanding of their experience will help in learning ways HIV is spread, and access and barriers to receiving HIV-related services.

Through 2005 in Georgia, four health districts had the highest number of HIV/AIDS incidence and prevalence rates in the state. Table one illustrates the rates of these four districts:

Table 1.1 HIV/AIDS Rates of Selected Health Districts in Georgia, through 2005

Health District	City size	HIV incidence	AIDS incidence	HIV prevalence (per 100,000)	AIDS prevalence (per 100,000)
Fulton	LM	60.2	40.9	230	791
DeKalb	LM	32.7	21.3	163	389
South Central	NM	17.6	5.6	189	151
East Central Augusta	MS	18.0	9.0	130	219

Note. LM-Large Metropolitan, MS-Mid-size Metropolitan, NM-Nonmetropolitan
 From "Women and AIDS in Georgia," by Georgia Department of Human Resources, 2006. Accessed 12/17/07 at http://dhr.georgia.gov/DHR/DHR_FactSheets/Women.rev.pdf

There are high rates of HIV/AIDS incidence and prevalence in both large and mid-size metropolitan areas in Georgia (Fulton, DeKalb and East Central Augusta Health districts). South Central Health District is a rural area, whose HIV prevalence is higher than DeKalb county, a large metropolitan area, as well as the East Central Augusta region, which is a mid-size metropolitan area. These rates are especially alarming

because of the smaller size and rural classification of the South Central District, who has the highest HIV/AIDS prevalence and incidence rates of among rural communities in the state of Georgia.

Even though there is a high incidence of HIV in South Central Georgia, there were only a few published studies that focused on women living with HIV in this region of Georgia. This study fills a gap in the paucity of research focusing on HIV/AIDS in South Central, Georgia. It can also help in gaining insight of the different needs of PLWHAS and barriers to care and receiving preventive services in rural communities in Georgia, in order to better serve African Americans in this area.

Background and Significance

HIV/AIDS in the Deep South

Within the Southern region of the US, the majority of HIV/AIDS cases are concentrated in the Deep South where nearly 70% of new HIV/AIDS cases occur in this area. Six Southern states have been classified as the Deep South: Alabama, Georgia, Louisiana, Mississippi, North Carolina and South Carolina. The Deep South is historically defined as Southern states that promoted slavery, and the economic base was cotton (Whetten and Reif, 2006). Reif et al. state that these six states also share several other different characteristics: 1) a population density less than 200 people per square mile; 2) an African American population greater than 20%; 3) African Americans constituting 70% or more of new AIDS cases and 4) more than 33% of women having been newly diagnosed with AIDS. Additionally, the majority of these states has the highest teen pregnancy rates and STI infections, and only allows abstinence-based sexuality education in the schools (Reif et al., 2006). All six of these states are among

the top 15 states nationally with the highest AIDS death rates per 100,000 per population, and since 2001 have had the highest number of AIDS-related deaths. On average, the Deep South has a higher concentration of African Americans (29.2%) living in this region, compared to the 13% that make up the US population (Reif, 2006). Within the Deep South African American females make up a large portion of newly reported AIDS cases (63%), with the majority of these females reporting becoming infected through heterosexual contact (Centers for Disease Control, 2007d).

There were substantial increases of AIDS cases in the Deep South from 2000-2003, especially compared to other regions in the US that were experiencing stable rates or small increases in new AIDS cases (Reif et al., 2006). Additionally these cases were more concentrated among African Americans, African American women and rural residents. Also, other STIs (Sexually Transmitted Infections) such as syphilis and gonorrhea disproportionately affect African Americans in the South, indicating an epidemiologic pattern of risk behaviors associated with the infection of HIV/AIDS (Aral, 2006; Hall et al., 2005; and Whetten and Reif, 2006).

The Spread of HIV in the Deep South

A growing amount of research has investigated factors facilitating the transmission of HIV among African American females in the Deep South. The Deep South is the only region in the US that has a history of slavery coupled with institutionalized segregation and the implementation of Jim Crow Laws. These distinct characteristics separate this region from other regions in the US. Furthermore, O'Leary et al. (2006) found that among HIV and STI positive African Americans in the South alcohol and drug addictions and depression were not a major risk factor for the HIV

epidemic in the South. Consequently, African Americans in this region actually had a significantly lower risk of alcohol and drug disorders than the rest of the US (O'Leary et al., 2006). These results indicate that the spread of HIV among African Americans in this region may be due more to behaviors and cultural factors, rather than substance abuse.

For example, Adimora et al. identified the high prevalence of concurrent sex partners that typically occur among their samples of African Americans in the rural Deep South (Adimora et al., 2005, 2006a, 2006b). African Americans in the South have also been found to have shared sexual networks, which increases the risk of infection when one person in that network is HIV positive, and sexual partners are shared due to concurrent partners (Rothenberg, 2000).

Another explanation for the high prevalence of concurrent sexual partners among African American females has been the low Black male/female ratio. This shortage of available Black males makes it easier for Black males to have concurrent sex partners and cheat on their female partners because of the female's fear of losing that male partner, and the inability of finding a new one. This low ratio also limits the bargaining power that Black females have in negotiating safer sex with a male partner. A female may be more likely to acquiesce to their partner's request not to use condoms, in order to maintain a relationship with that partner (Jones-DeWeever, 2005, Timmons and Sowell, 1999). Females have to decide between either their relationship or their health. Farley (2006) also argues that the history of slavery and racial segregation in the South also influences the spread of HIV and contributes to this low ratio. He mentioned that among low income African Americans in the South chronic joblessness leads to an increase of crime, which leads to drug use, which increases the amount of incarcerated Black males,

which then contributes to the low Black male/female ratio. This ratio causes a reduction in “marriage men”, men women view as viable suitors to marry. These factors then lead to higher casual sexual relationships and the growth of concurrent sexual relationships (Farley, 2006).

Additionally, the “down-lo” phenomenon, a term used to describe gay or bisexual Black men who have sex with both males and females (MSM and MSMW) but do not disclose this to their sexual partners also put African American women at risk of HIV. The stigma around homosexuality, especially within the Black Church has also been shown to contribute to the down low phenomenon, as well as overall AIDS related stigma (Baker, 1999, Fullilove & Fullilove, 1999, Genrich & Bratwaite, 2005). There is also greater stigma of HIV among African Americans in the South, which makes it harder for women to get tested, and inquire how to reduce their risk (Reif, 2006, Thomas 2006). This is compounded by the strong presence of the African American church and silence around homosexuality and HIV prevention for non married church members (Adimora et al., 2003).

HIV in the rural Deep South

The Deep South is a region consisting of a combination of large metropolitan, mid-size metropolitan and rural populations. The classification of a metropolitan area by the CDC is a population per 100,000 of 500,000 or greater, midsize metropolitan area is 500,000-50,000 and a nonmetropolitan or rural area is a population of 50,000 or less (Centers for Disease Control, 2001). Studies have shown that rural populations may have their own characteristics that may facilitate the spread of HIV in this area. Some of the characteristics of rural populations are lack of transportation and mobility to healthcare

services, high rates of poverty and lack of job mobility, and lack of confidentiality (Castaneda, 2000, Adimora et al., 2006a). This lack of access to services may facilitate the spread of HIV, as well as the lack of confidentiality in receiving HIV services. Additionally, Thomas (1999) also asserts that in rural Southern populations, the decline in the agriculture industry and deep segregation in this area, also contributes to lack of job mobility, and education, contributing to the lack of HIV/AIDS knowledge in this region. Many people who were diagnosed with HIV in the South never left the area, because of lack of mobility (Agee, 2006). Additionally, Brown (2003) concluded that in addition to the racism and historical discrimination in rural Southern areas, incarceration rates among African Americans and the lack of available Black men also contribute to the spread of HIV among African American women. These intersecting factors in rural populations contribute to the spread of HIV. An increased understanding of these factors can help create infrastructures that can help reduce the incidence and spread of HIV.

Purpose of the Study

The purpose of this study is to understand the experience of African American females living with HIV in South Central, Georgia. The following questions aim to explore these factors:

- 1) How did women living with HIV in rural South Central Georgia discover that they were infected with HIV?
- 2) What are the life experiences of women living with HIV in rural South Central Georgia?

Study Significance

This study is significant because it provides further understanding of the experience of African American females living with HIV/AIDS which can contribute in the development of HIV-related services for rural African American females in high-risk rural populations. The study also provides insight in the creation of effective HIV prevention programs for rural communities. Effective prevention programs, coupled with comprehensive services for PLWHAS can help reduce the transmission of HIV in South Central Georgia as well as other rural populations. Understanding the available resources as well as the factors endemic to South Central Georgia that influence the transmission of HIV can aid in strengthening its HIV services, and reducing the HIV risk of its residents.

There is also delayed HIV diagnosis among individuals in the Deep South, which not only facilitates the transmission of HIV, but also affects treatment and care of HIV positive individuals. Approximately 30-40% of infected individuals receive a concurrent HIV/AIDS diagnosis, which limits the effects of medication that can improve their quality of life. Some of the barriers of diagnosis and delayed care in the South are being low income, and lack of insurance, rural residence and being African American, and an African American female (Krawczyk et al, 2006). Examining these potential barriers to access and care among HIV positive women will also help to improve HIV-related care and HIV testing and prevention programs.

CHAPTER 2

REVIEW OF LITERATURE

The purpose of this study is to understand the experiences of African American females living with HIV in South Central Georgia. Due to limitations in the literature there is some overlap in the studies. Many studies sample participants from the South and the Deep South and combine findings from both regions in the results session. Additionally, other studies combine urban and rural areas when examining factors in the South; therefore studies that solely focusing on rural areas are indicated, while other studies may combine rural and urban samples. It is important to include studies that focus on the South and rural South, because rural HIV positive residents often access services in urban Southern areas. This chapter is divided into the following components: the epidemiology of HIV/AIDS in the Deep South; factors that facilitate the spread of HIV among African American females in the South; the experiences of African American women living with HIV/AIDS in the South; and narratives of African American women living with HIV/AIDS in the South.

Epidemiology of HIV/AIDS in the Rural Deep South

Since the mid-1980's, more AIDS cases have been reported each year in the South than in any other region of the United States. From 1996-2000 PLWHAS in the South accounted for 39% of cases in the US, and in 1996 there were nearly four to five times as many rural AIDS cases in the South compared to any other region in the US (Fleming et al., 2006, Rural Center for AIDS/STD Prevention, 2002). Furthermore, in

the Deep South, from 2000-2003 the number of newly reported AIDS cases increased by 35.6%, verses a 4.0% increase in other Southern states, and a 5.2% increase nationally (excluding Deep South states) and have largely been among African Americans (Whetten & Reif, 2006).

Additionally, there are other demographic factors that may facilitate the transmission of HIV in the rural South. Migration patterns of PLWHAS in the rural South have been examined, and several studies have noted that as much as 30-36% of HIV positive individuals who report becoming infected with HIV in metropolitan areas return to their rural roots for family support (Rural Center for AIDS/STD Prevention, 2002; Quian et al., 2006; Whetten & Reif, 2006). In a study of rural behaviors, people living in rural Southern areas were about 70% less likely than people living in urban populations to report a change in their sexual behavior because of AIDS (Rural Center for AIDS/STD Prevention, 2002). They did not perceive themselves at risk of HIV/AIDS, and did not see a need to modify their behaviors. These findings support another study examining the epidemiology of HIV/AIDS in women in the South that among PLWHAS in the rural South, 24% of women and 36% of men reported still engaging in risky sex after they found out their positive HIV/AIDS diagnoses (Fleming et al., 2006).

Finally, the use of crack cocaine may also be associated with HIV infection, especially among rural African Americans (Quian et al., 2006). Fleming et al. noted that among PLWHAS 42% of men, and 37% of women reported exchanging sex for crack cocaine, or money to buy drugs and/or alcohol (Fleming et al., 2006). These are HIV risk behaviors. The use of non-injection drugs may also contribute to the prevalence of HIV in the South, particularly in rural areas, where PLWHAS who use drugs are less like to

report injection drug use. When there is no further examination of their substance use, their risk exposure as a drug user is not fully explored (Whetten and Reif, 2006).

Factors Facilitating HIV among African American Females in the South *Sexual Networks*

Several studies have focused on social networks and concurrent partners and how this facilitates the transmission of HIV. Adimora et al. has conducted several studies that have focused on African Americans in North Carolina. In a study conducted in 2003, Adimora et al. investigated concurrent sexual partners among African Americans in the rural south. The study found that 53% of men and 41% of women had concurrent partners in the past 5 years. These respondents were more likely to be unmarried, incarcerated or younger men. In another study using the same database, Adimora et al. (2003) examined concurrent partners among African Americans who recently reported testing positive for HIV. A high percentage of this population (86%) reported not using condoms more than 10 times with their past sexual partner. The amount of concurrent partners increased for females with a history incarceration and lack of high school education. Having concurrent partners was also associated with crack use, binge alcohol drinking and the exchange of sex for drugs. The black male/female sex ratio was also cited.

Additionally, Adimora and Schoenbach (2005) compared the differences in sexual networks of Black and White populations and found that African Americans were more likely to have core sexual networks and share partners, mainly due to the sexual segregation of African Americans. In a study from 2006 Adimora et al. (2006b) also conducted a review of studies that focused on sexual networks and SES status in the

South. Their review found that concurrent partners were more common among African Americans in other study population. Concurrent partners were also more associated with partners on crack, incarceration and those who had cheating partners. Although these results were similar to their study, the studies that they reviewed were not all Southern cities, majority African American population, and also included a city in another country. The inclusion criteria were not stated, and the reasons for including these different populations were unclear.

An earlier study by Thomas et al. (1999) mirrors some of the results from Adimora studies. This study examined behaviors that facilitated the spread of HIV and other STIs among rural African Americans, more than half of the men in the sample of 660 clinic patients reported having multiple sex partners in the past three months, while women were nearly half as likely as men to have multiple sex partners. Condom non-use was the main factor facilitating the spread of HIV and other STIs. Only seven percent of women reported using a condom every time with their main partner, although condom use with casual partners was more highly reported. Correlates of non-condom use included being younger than 25, living with their partner, and social norms that did not support condom use (Thomas et al, 1999). This study however was limited to low-income rural residents of one county in North Carolina.

A prospective longitudinal study by Rothenberg (2000) further examines social networks by examining the sexual networks and behavioral risks of people in the same sexual networks. Findings were similar to some of Adimora et al.'s studies. Core people identified as "seeds" were first contacted who revealed their sexual networks, and interviews were conducted using a snowball effect three times at 6-month intervals. The

study aimed to configure these different sexual networks, examine where risky behaviors took place, and note the changes that occurred within each structure. The study found that 13% of the 228 participants were HIV positive, and 3 people seroconverted to HIV positive status. There was a high frequency of sexual contact within the networks, and multiple networks engaged in risky behaviors. There were also several males who identified same-sex behavior, but did not identify as gay. Overall drug and alcohol use in this population was high and could heavily influence recall bias.

Stigma and Religion

AIDS-related stigma was also shown in the literature to facilitate the spread of HIV in the South, particularly stigma based on religious views. Lichtenstein (2003) found stigma as an impediment to STI treatment in the Deep South among African Americans, thereby influencing the spread of HIV infection. This qualitative study conducted six focus groups in small and large cities in Alabama recruited from public health clinics and colleges and high schools. Women were described as “good” or “bad” depending on their sexual behavior or STI status by both patients and health workers, while male sexual risky behaviors were portrayed in a more acceptable light. Concerns about visibility and confidentiality as well as mistrust of the health system were core themes. Additionally people who were positive with a STI or HIV were considered sexually immoral, and stigma based on religion was also prevalent in the focus groups. Individuals expressed fear in being discovered and judged by their positive STI status. One significant finding in this study is that negative views towards a positive STI individual were expressed among health workers that treat people for STIs, which can definitely pose a barrier for treatment of positive individuals. Litchenstein et al. (2005)

also found in a later study, where over half of the participants were African American regular church goers stating that they would delay treatment or not seek treatment of all if they contracted a STI because of fear and embarrassment. Furthermore, women were more stigmatized if they were infected, even though many felt that men were the ones responsible for spreading STIs.

Elifson et al. (2003) also examined the role of religious views in AIDS-related stigma and interviewed drug-using and non-drug using African American mothers and daughters. The greater the religiosity of the participants on a religiosity scale, the lesser the engagement in risky behaviors. Women who were younger, had lower self-esteem or were abused as a child engaged in riskier sexual behaviors. Also, partner communication was important, where the higher the communication, the decrease in risky behaviors. Also, women who lived with a drug user were more likely to engage in HIV risk behaviors. Interestingly, the study found that even among participants with those demographics who reported higher religiosity engaged in less risky behaviors. The more frequently they attended religious services and believed their religion influenced their behaviors, the less involvement in HIV risk behaviors (Elifson et al., 2003). This study does reveal the influence of religion on African American females in the South; however the results include a large sample of drug users, which may influence participant responses and participation in HIV risky behaviors.

Relationship dynamics

There have also been studies that have focused on different relationship dynamics that may influence the spread of HIV. Whyte et al. (2004) recruited 75 African American women 18-38 years from a STI clinic in Atlanta, Georgia. They found that

there was a moderate correlation between HIV knowledge and practicing safer sex behavior and that as the education level increased, so did the levels of safer sex behavior. Whyte (2005) also developed an instrument to measure HIV risk for low-income African American females residing in the South. Salient factors were personal control and assertive sexual communication with a partner and the insistence on them using condoms. Although this study aimed to create a universal instrument to measure the risk of Southern African American women, it was only tested on low-income women, and designed for a clinical setting. Similar findings emerged in a CDC study who also examined low-income HIV negative and positive African American women in North Carolina. Women from both groups engaged in similar HIV risk behavior, which included financial dependence on male partners, feelings of invincibility, low self-esteem and alcohol and drug use (Centers for Disease Control, 2005).

Male assertiveness and control was also a finding in a study by Bowleg et al. (2004). They conducted a qualitative study with 14 African American women who were both low-income and middle income who were involved in heterosexual relationships with African American males. There were several 'relationship scripts' that were common themes among over half of the population. The women stated that men controlled the relationships and sexual activity, and it was the women's job to sustain the relationship. Therefore, women tolerated more of their partner's behaviors such as being emotionally distant; infidelity; enduring emotional and mental abuse, and putting their partner's sexual needs above their own in order to maintain the relationship. Infidelity was seen as a norm, and many women supported their partner's desire not to use condoms (Bowleg et al., 2004). Although these cultural norms and gender expectations

emerged as factors supportive to engaging in risky sexual behaviors, all of the women in the study were in conflict-ridden relationships, which may increase the engagement in risky behaviors.

Similar findings from the Bowleg et al. study also emerged in a study by Timmons et al. (1999) who conducted focus groups on 19 African American women. Some of the themes of this focus group were that “a man will be a man”, condoning infidelity by males in relationships, and engaging in unprotected sex in order to keep that male partner. This view also contributed to the failure of women to negotiate condom use when their male partner had negative views towards condom use. Women who did feel like they were in monogamous relationships did not feel the need to engage in any HIV preventive practices. Finally, similar to previously cited studies, some women believed because of racism, HIV had been placed in the African American community in order to kill African Americans.

One study asked African American females their perceived risk of HIV infection, in order to further examine the factors that facilitate the spread of HIV. Among women ages 18-29 years old, there was a great amount of perceived risk among women who had been cheated on by their male partner, were involved in drug activities, had a frequency of sex with a paying partner, had lower condom use self-efficacy, reported being more depressed, and had less social support from their main partner. These women also experienced more childhood trauma, and did not perceive religion as being a major influence on their behavior. For the older women in this study, risky drug use behaviors were more relevant risky behaviors (Theall et al., 2003). This study is similar to previous findings of factors that facilitate the spread of HIV. However, the sample was a sub

sample of multigenerational drug users, and did not focus specifically on HIV risk factors.

There were also studies that examined structural factors that influence African American females acquiesce to a male partner's sexually risky desires. Several studies have discussed the low Black male/female ratio (Adimora and Schoenbach, 2002 & 2005; Jones-DeWeever, 2005) and its influence on the transmission of HIV/AIDS. There are less available Black males to every female, and a lower marriage ratio among African Americans. This makes it easier to spread HIV if a female does not insist on condom use with a male partner who does not want to use a condom, because of fear of using their male partner.

Drug use

Forney et al. (1992) conducted a pivotal study examining risk factors among a majority African American female sample, with 25 women from rural Georgia and 35 women from urban Florida who reported using crack-cocaine. A large portion of the sample reported exchanging sex for crack-cocaine, and 12% of respondents reported being HIV positive. Even though the women were knowledgeable about HIV/AIDS, most did not change their risk behaviors except for sometimes suggesting condom use among partners. Interestingly, most of the population did not report Injecting Drug Use (IDU), and the most commonly reported drugs were non-injecting drugs which were crack-cocaine, marijuana and alcohol. The overall results did not find any statistical significance between drug use and sexual risk behaviors among the urban and rural women. One factor of the study that may have affected the results was that the majority

of the women had been tested multiple times for HIV, indicating they may be more knowledge in safer sex behavior practices.

Summary of factors facilitating the spread of HIV among African American females in the South

The most prevalent factors based upon the published data that influence women's infection of HIV are concurrent sexual partners and shared sexual networks. The low Black male/female ratio contributes to shared partners, with females acquiescing to their partner's desire not to use condoms for fear of losing that partner. Other factors include low perceived HIV risk factors, lack of HIV knowledge, and the engagement in the exchange of money for sex. Additionally, in rural cities HIV stigma was higher, particularly around religious views, which can contribute to a reluctance to engage in HIV preventive behaviors.

Experiences of African American Women Living with HIV in the South

This next section looks at ways of HIV transmission, barriers to HIV preventive behaviors, service utilization and the different experiences of African American women living with HIV in the South.

Risky Behaviors and Risk Factors

Some HIV positive women have engaged in risky sexual behaviors. Bedimo et al. (1998) conducted focus groups with 15 HIV positive African American females and their barriers to condom use. The women had no problem with bringing up condom use, yet a large part of the sample reported only using condoms sometimes or not at all because their partners refused to use condoms. Condoms were also rarely used for oral or anal sex because of the lack of pregnancy risk. There was also pain in disclosing to loved

ones, and many women in the group did not acknowledge their HIV/AIDS status. This study does provide insight into the sexual practices of HIV positive women, and included a wide age range of women 16-45 years. This age range may have affected participant responses and the interpretation of their questions, especially among the younger women.

Plowden et al. (2005) also identified other risky behaviors of HIV positive African Americans. They sampled HIV positive African American females and asked factors that influenced risky behaviors. Some participants stated that rejection from their family led to the engagement in sexually promiscuous behavior, and self-fulfilling prophecies. Lack of insurance or health care also influenced risk behavior, and being unable to receive condoms or needle exchange. Finally there was a low level of knowledge about risk behaviors that transmit HIV.

HIV positive substance users were also sampled in a study by Moser et al. (2001). Focus groups were conducted among 24 HIV positive Southern African American females and their concerns and experiences with HIV/AIDS and substance use. Several women indicated that they had struggled with their substance abuse issues, but their HIV diagnosis made them realize they needed to stop using drugs. Fewer women indicated that their substance use escalated upon finding out their diagnosis. Their status also negatively changed their relationship with others as well as increased depression and anger in their life. Barriers to care included access to drug treatment programs that also provided HIV care, lack of financial resources for health care, and difficulty retaining social services. It was also difficult for women to remain off drugs when their environment was surrounded by drug use. Women indicated that their relationship with God helped them cope through their status.

A relationship with God also helped positive women with coping in a study by Woodard and Sowell (2001). In this qualitative study the majority of women believed that God controlled all aspects of their lives, and helped them cope with their HIV status. They sought support from God through praying, fasting, attending church, studying the bible, watching Christian shows and talking to God. God was incorporated into their lives, and they derived strength in everyday activities through their relationship with God. Their relationship with God also helped enhance the medical services they received and their relationship with their provider by believing that everything would be ok with God in control. Interestingly, this study did not examine their relationship with God before their HIV diagnosis and how the relationship may have changed due to their positive status.

Similarly, Parsons et al (2006) looked at the impact of religious beliefs and practices and adherence to medication among 306 HIV positive African Americans and Whites in the South. African Americans were more religious than White Americans, and 15% of participants believed that HIV was a punishment from God, while 27% believed sickness is caused by sin. There was also a difference between the diagnosis and start of medical care among African Americans and Whites. Whites had a shorter gap between their diagnosis and start of care, and more African Americans reported a greater frequency of missed doses and medication. Additionally, the gap between diagnosis and start of care was also shorter among women. Longer medical care was strongly associated with the belief that HIV was not a sin in the eyes of God. Additionally, women who reported greater frequency of church attendance reported less missed doses. Many of the individuals did report injection drug use.

In a study by Shambley-Ebron and Boyle (2006), family and culture was a source of strength and support among ten HIV positive African American women living in the South. In order to cope they drew their strength through cultural traditions such as spirituality and faith in order to get through the daily struggles of living with HIV. Participants in this study also had to be a parent of a HIV positive child. They also felt that being a strong Black female was important in being positive role models to their child and passing on positive cultural traditions.

Domestic violence was also seen as a risk factor for HIV. In another study by Lichtenstein (2005b) domestic violence was the biggest risk factor for HIV positive African American females. Among the 50 women in the study 88% of the females had incidences of domestic violence in their relationship with male partners prior to finding out about being infected. This is a high percentage of HIV positive women who experienced domestic violence, as compared to other studies in the literature. Although domestic violence and HIV infection has been explored in the literature, there should be caution in interpreting their findings. Participants were recruited for a public clinic for HIV positive people who also had adult trauma. The high sampling of domestic violence experiences could be a result of the recruitment site. Although adult trauma is not defined, violence could be one of the experiences of the clients at the clinic.

Sowell et al. (1999) also examined psycho-social components of HIV among positive urban and non-urban African American women in the South. Over half of participants (62%) reported experiencing verbal abuse in the past 6 months and 14% experienced physical abuse. Participants in non-urban areas reported significantly higher levels of verbal abuse than urban participants. Self-esteem and abuse were correlated

with each other. Verbal abuse was correlated with self-esteem and competence, while physical abuse was only significantly correlated with self-esteem. As the abuse increased, self-esteem and competence in oneself decreased. Although these findings do support domestic violence that may be prevalent in HIV positive women, this study did not indicate if the women received abuse from a partner that they were in a relationship with.

Stigma

The relationship between psychological functioning, stigma and disclosure was examined by Clark et al. (2003). AIDS related stigma was compared among infected and non-infected African American females. Multiple regression analysis found that as the level of AIDS related stigma increased, the level of disclosure decreased. Additionally, as stigma increased, the level of psychological function decreased, with the infected women reporting experiencing more stigma than the non-infected women in the study. This study demonstrated further evidence on the impact of stigma on the daily functioning of women living with HIV/AIDS. However, the study did not examine in depth the differences in positive and negative women, in order to further compare their differences.

Similarly, stigma and shame was an impediment to disclosure in a qualitative study by Black and Miles (2003). There were feelings of shame, and being afraid of negative reactions by family, church and social networks. The level of a woman's emotional support determined their decision to disclose, as they calculated the risks for themselves and their family if they disclosed their HIV positive status. Different patterns of disclosure also emerged, secretive disclosures to only a few selected individuals;

selective disorders to people outside of their family; disclosing to the larger community; and not disclosing to anyone (Black and Miles, 2003). Sowell et al. (2003) also found that women had different patterns of deciding whom to disclose to. Disclosure decisions were based on three broad factors: their relationship to that person, the quality of that relationship, and if that person was able to keep their HIV status confidential. These studies build upon existing literature of the processes of disclosure among HIV positive African American females in the South.

Summary of the experiences of African American women living with HIV/AIDS in the South

Issues of coping, stigma and disclosure emerged as salient themes among women living with HIV in the South. Fear of stigmatization by loved ones prevented many from disclosing to their loved ones. Many women were also depressed, reported incidents of low functioning and also felt shame due to their positive status. A strong relationship with God was also cited as a key component in helping with coping and functioning.

Experiences of African American Women Living with HIV in Rural South

This next section focuses on African American female's experiences from the rural South. In a study conducted by the CDC, they found that among positive rural African Americans 65% of women believed that they could not become infected with HIV, with common reasons being the lack of knowledge of how HIV was spread, belief in the negative status of their partner, and that only drug users of men who have sex with men (MSM) could become infected (Centers for Disease control, 1998). The majority of this sample (67%) became infected through sexual contact; however, the majority of the population was low-income.

Another study by Whetten-Goldstein et al. (2001) examined the characteristics of rural HIV positive individuals and their service provider interaction. Of the African American females in the study, 88% had a less than high school education, and were less likely to live with a partner or spouse, but were less likely than men to report substance abuse. Their primary mode of HIV infection was through heterosexual contact. Some of the barriers to receiving care included being excluded from dental care because of their HIV status, not having enough money for prescriptions, transportation issues and difficulty with insurance. Over two-thirds of African Americans in the study did not know where to receive HIV-related services.

Whetten et al. (2004) examined gender differences in the knowledge and perception of HIV resources of HIV positive people in the rural South. Even though the majority of African American women (92%) reported having a regular medical care provider, 38% reported that they were not aware how to find access for needed resources, and 22% did not find local services useful. In fact, women were significantly less likely to know how to access HIV-related services than men. Additionally, when compared to non-African American women, older African American women over 35 were more likely to report services not being helpful. These findings do reveal problems with African American women receiving HIV-related care, which can decrease their quality of life. One weakness of this study however was that the differences between African American and non-African-American females was based on predicted probability samples, and no other statistical comparisons were made.

These results are similar to a study conducted by Troy et al. (2001) who examined the prevention and services for HIV-infected women in the rural South. A large portion

of the African American women in the study may not have received effective prevention counseling before they became infected with HIV. Many of these women also indicated that they were not directed to where they could receive HIV treatment and social services. Furthermore, half of the women were sexually active in the previous month of the study, and 13% were positive for a STI, indicating the need for prevention among women who are already HIV positive. In this study approximately 67% of the women were African American, but the study did not compare the differences between the Black and White women in the study, or examine cultural factors that may influence the use of prevention services among these different groups.

McKinney (1998) also examined the needs of predominately southern rural women living with HIV/AIDS. Some of the factors found to facilitate the spread of HIV was poverty, limited job opportunities, “survival sex”, and substance use and gang membership. Drug use among this population was non-injection drug use, including marijuana, crack cocaine and alcohol. Additionally service providers estimated that the number of women who became infected locally, and non-locally were about the same. There were also a number of women who moved to larger cities, but returned home after developing AIDS-related illnesses.

Also in this study, many of the patients had family members in the area, but indicated that their family members did not provide much support, because of their lack of knowledge of HIV-related services, or the woman’s HIV status. Due to stigma, many women did not reveal their HIV status to their family, nor participated in support groups. Lack of confidentiality was a huge factor in obtaining care, as well as lack of health insurance. The study also found that there were not many specialized AIDS-related

services and clinics, and that primary care providers lacked the training and knowledge in AIDS management. Finally, lack of transportation was also listed as a huge barrier to receiving care. These results mirror findings in another study studying barriers to HIV/AIDS care that sampled case managers. The study found that stigma, lack of transportation, healthcare and trained medical professionals were barriers to receiving care (Reif et al., 2005). Although this study has similar results to HIV positive participants, it was based on the perceptions of HIV/AIDS caseworkers, and there was no analysis if these barriers truly resulted in lack of care for PLWHAS in the rural south.

Another study also examined the demographics of rural HIV positive women. The majority of this population (85%) were unemployed and on Medicaid, and did not feel like they had appropriate resources. Approximately half of the population felt stigmatized, that people were uncomfortable around them, and were ashamed by their HIV status (Sowell et al., 1997). The results of this study are similar to previously cited studies in this section, but are also limited by the large sampling of unemployed participants. It is unclear if the women were employed if they would feel like they had better resources.

In a more recent study Reif et al. (2006) compared the utilization of mental health services among rural or urban HIV positive individuals in the Deep South. Over two-thirds of participants reported some form of psychological distress. When urban and rural comparisons were made, there were no statistical differences in the levels of psychological distress in rural and urban populations. Multivariate analyses did indicate that rural individuals were less likely to report seeing a mental health provider. This

study did not however differentiate between males and females, so it is unclear the levels of distress in African American females.

Moneyham et. al (2005) used multiple regression to study patterns of depressive symptoms in HIV positive women in the rural south. The frequency of HIV symptoms and daily functioning were significantly associated with depression. Having social support was associated with depressive symptoms. The lower perceived social support, the higher the depressive symptoms. Coping strategies were living positively with HIV, managing illness, social support, isolation, withdrawal and avoidance. Women in this study had higher depressive symptoms when compared to general rural women, implying high depression among African American females in this region. It is unsure if the women in this study had depressive symptoms before their HIV diagnosis, since their symptoms were only reviewed for the past 12 months.

In a case-control study of HIV/STI positive African Americans in rural cities of North Carolina several factors were cited in focus groups that helped to facilitate the spread of HIV and other STIs. These included a lack of employment and economic opportunities, and the belief that institutional racism prevented upward mobility and the improvement of one's economic status. Additionally, because of the rural community there was a reported lack of recreational activities which resulted in boredom and an increase in drug use and sexual activity. There was also a higher lack of availability of available African American men for African American women due to drug use, death or drugs, which also increased the engagement in concurrent sexual partners. Additionally, the church was viewed as a focal point in the community, and its viewpoints were influential, as well as isolating to younger generations (Adimora et al., 2001, 2003).

These studies helped gain more insight into the role rural status plays in HIV transmission, however, even though the focus groups were separated by gender, they did not go into detail about these different factors that occurred for males and females.

Older African American females in the rural South also engage in risky sexual behavior and are at risk of HIV infection. A study conducted by Winningham et al. (2004) examined the sexual risk behaviors of African American females ages 50 and over. Of the women who indicated that they were sexually active, 60% engaged in one or more of the following risk factors: having more than one sexual partner in the past 5 years; having sex with a sexual partner they knew were cheating on them; having sex with a male partner who was also having sex with other men; exchanging sex for money or goods, and engaging in sex with someone who was HIV positive. Condom use self-efficacy was significantly higher among women who engaged in low risk sexual behaviors, when compared to women who reported higher sexual risky behaviors. Women who engaged in sexual risk behaviors did not perceive themselves at risk of HIV infection. This study has revealed an understudies risk group for HIV infection by examining older African American females. However, the criteria used to measure sexual risk behaviors were not fully developed. Women who had one or more sexual partner in the past 5 years was classified as a risky behavior, but the number of partners, or time period of their sexual partners was not indicated.

Finally, one study examined HIV infection and incarceration in the South. The study found that there were more HIV and STI positive African American women incarcerated in the rural South than any other region in the US (Hammett and Drachman-Jones, 2006). Although the incidence of HIV among this incarcerated group is low

(approximately 0.6%-7% depending on the state), an increased amount of these cases have occurred in the rural South among African American women (Hammett and Drachman-Jones, 2006). Although this study does introduce another risk group for HIV infection among this population, it was a secondary analysis of prison records which does not indicate a trend in infection rates, and may not be a thorough analysis of the AIDS epidemic among this group.

Summary of the experiences of African American women living with HIV in the rural South

Some of the experiences living with HIV among rural Southern women were the same as those residing in urban cities. However, there were some different experiences for positive women in rural areas. Many reported not knowing how to access HIV related services, and cited a lack of transportation as a barrier to obtaining services. Additionally, there was a lack of mental health care facilities, and many reported being in psychological distress. More women also reported feeling stigma and ashamed that they were HIV positive.

Narratives of African American Women Living with HIV

This last section focuses on studies that collected the narratives of African American women living with HIV in order to understand their lived experience. Of studies that did collect the narratives of this population, many were focused on how they felt when becoming infected with HIV, or issues around stigma and disclosure. The studies also tended to be mixed ethnic populations and did not focus on African Americans (Baumgartner, 2002; Brashers et al., 1999, 2004; Ciambrone, 2001; Hackl, 1997; Mosack et al., 2005; Orgins, 2003; Stevens and Doerr, 1997). Barroso and Powell-

Cope (2000) did conduct a metasynthesis of the qualitative research of PLWHAS. They found overall that this population tried to find meaning within the context of HIV/AIDS, by finding human connectedness with others, focusing on the self, negotiating health care, and dealing with stigma. This analysis though comprehensive included multiethnic populations, males and females, and different regions in the US. It is not endemic to African American females in the South.

Of the studies found focusing on the narratives of African American females, very few were focused in the rural South. Bletzer (2007) focused on an African American male and female in the rural south living with HIV. Both individuals constructed a stress-free life, in order to avoid stressors that may trigger their illness, which was the use of crack cocaine. Yet, the female in the study did reduce her drug use as she continued to accept her HIV status. She also recognized the need to change her life, and the importance of family support. This study allowed a glimpse into the life of rural HIV positive African Americans. However, it was analyzed using Becker's disruption narrative theory, which placed their experience into very specific preexisting categories, instead of eliciting participant generated categories. This analytic method limits the overall narrative as well as sampling only drug users.

A very recent study used a grounded theory approach to study the experience of HIV positive African American females in the rural South. Of the 10 participants, all of the women became infected by a male sexual partner, and seven of the women were involved in long-term relationships with their partner who infected them. Only three of the participants engaged in crack-cocaine use and survival sex exchange. The rest of the women considered themselves low-risk. Reasons for lack of condom use included the

desire for intimacy, trying to conceive, trust in their partners, and lack of HIV/AIDS knowledge. There were also influences of gender and power around condom use, with condoms being used as a form of protection only if the man asserted that they use them (Mallory, 2008). Participants in the sample however, were enrolled in a previously larger study, and their responses may have been biased due to previous study participation. Finally, the women as with most of the rural studies were sampled from North Carolina, and this study was conducted in 1999, still indicating a gap in recent studies among HIV positive rural African American females.

Two other studies focused on the narratives of HIV positive African American females, although they did not reside in the South. Russell and Smith (1999) sampled five African American women and provided a holistic view by asking them to describe their experience as Black women living with HIV. Several different themes emerged from the data: violence, such as molestation and homicide, addiction; HIV knowledge, and how having this knowledge did not prevent them from becoming infected; Uncertainty and not knowing when they were going to die; Secrecy surrounding their lives, Survival, and the need to protect their children. This study was one of the first to study the lived experience of African American women living with HIV, but may be biased because the women were recruited from a clinic.

In a more recent study a sub-sample of HIV positive African American women were sampled using a repeated qualitative narrative interview design in a 2-year longitudinal study. Several of the women suffered from external and internal stigma, and lived with the despair of being shunned by others. However, they did not let stigma take control of their life, and resisted stigma through family support and spiritual guidance,

facing their illness head on, disclosing during selected time periods, and regarding stigma as ignorance. Also, many of the participants decided to become advocates for others in order to help deal with stigma (Buseh and Stevens, 2006). This study however, was taken from a larger study, of multiethnic groups, and did not focus on the cultural experience of African American females.

Summary of narratives of African American women living with HIV/AIDS

The amount of studies focused on the narratives of HIV positive African American females in the South are limited. Most of the studies included women from different regions in the United States. Of the few studies that focused on women in the South, they found that most of the infected women considered themselves low risk, had a lack of HIV transmission knowledge, and did not use condoms with their partners because of the desire for intimacy. Additionally for some their positive status helped them change their life.

Summary of Literature Review

Summary of existing studies and gaps in the literature

There has been a review of studies that examine the factors that facilitate the spread of HIV among African American females in the South, and African American women living with HIV. Some of the factors that facilitate the spread of HIV among this population are the practice of shared sexual networks and concurrent partners, the low black male/female ratio, the down low phenomenon, AIDS related stigma, the influence of the Black Church, lack of knowledge and education and poor transportation. However, although many of these studies sampled African Americans, they did not always focus on African American females. HIV and rural health in the context of the

African American female experience has been largely ignored. For example, in studies looking at migration patterns of HIV individuals, the focus primarily has focused on the demographic patterns of males instead of females. This is important in deciphering the demographic patterns among African American females that may increase their risk of HIV infection. African American females in the Deep South, especially the rural South are at highest risk of HIV infection, yet this population is largely understudied. Usually it is in the context of African American males and females, instead of solely focusing on African American females living with HIV.

Furthermore, the majority of studies sampling African American rural females are low-income women. Although rural areas have high rates of poverty and unemployment, there have been few studies that included a broader range of African American women from diverse income levels. Because of sampling, the research is slanted towards low-income African American women as the face of HIV/AIDS. Low-income women may have issues that may not be similar to women who live above the poverty line, which may reveal other factors that facilitate the spread of HIV among this population. This group may be more likely to engage in other high-risk sexual behaviors such as exchanging sex for money or food in order to generate income. These are factors that may not be prevalent in women who live above the poverty line. Also, the majority of studies that have sampled HIV positive rural African American females have resided in North Carolina. Each state has their own issues they face that may influence the transmission of HIV/AIDS. There needs to be more comprehensive research conducted in the Southern region, and examine similar trends and differences in order to deepen our understanding of HIV/AIDS among women in this population. This understanding also

helps in designing not only culturally tailored interventions, but regionally-tailored care and interventions designed specifically for different populations. In South Central Georgia, the HIV incidence is higher than large metropolitan counties, indicating a large problem with HIV in this area. The problems that this region faces may not be the same as other rural African American females in other Deep South states. This knowledge can help build upon the lack of interventions for rural African Americans.

Finally there is a lack of studies that focus on the cultural factors that may facilitate the spread of HIV among African American women. These factors are crucial in the development of culturally tailored interventions that may decrease the risk of infection among African American females. Cross-sectional data does not deeply examine these factors, and studies with small samples of African American females do not explore these factors in depth. There is little qualitative knowledge of the experience of HIV positive African American women living with HIV/AIDS in the rural South, and it is imperative to gain more insight of their experience. Most of the research in this population has been cross-sectional data, and subset data taken from larger studies. Increased knowledge in the experience this group can help in the improvement of services and improve the quality of life for this population. This is especially pertinent because of the barriers rural communities face, and understanding the individual, social-cultural and structural factors that facilitate the spread of HIV among African American females can help reduce the AIDS epidemic among African Americans in the South. This current study can help to fill paucity in the literature by increasing our understanding of rural African American females living with HIV.

CHAPTER 3

METHODOLOGY

The literature review of previous studies indicates that African American females in the Deep South are at a high risk of becoming infected with HIV. This is especially pertinent for African American females who reside in South Central, Georgia and the need for increased knowledge of women living with HIV. The follow chapter presents the methodology used for this study. It is organized in the following manner: Research questions and design, researcher subjectivities, description of sample population, data collection procedures, approval to conduct research and data analysis procedures.

Research Questions

The purpose of this study is to understand the experience of African American women living with HIV in rural South Central Georgia. The following research questions aim to explore their experience:

- 1) How did women living with HIV in rural South Central Georgia discover that they were infected with HIV?
- 2) What are the life experiences of women living with HIV in rural South Central Georgia?

Research Design

The research design for this study is a qualitative study utilizing grounded theory methods. The basic purpose of a qualitative study is to learn about a social phenomenon. In qualitative research, the researcher tries to find meaning in human life, and constructs knowledge through human interaction (Rossman and Rallis, 2003). Qualitative studies construct knowledge by gathering rich data using methodologies such as interviews, focus groups and photo elicitation. These forms of data collection aid in gaining a deeper understanding of the issues being studied. Quantitative studies use numbers to quantify different phenomena, and often use large data sets. This type of research design does not aim to find human meaning in the data, and does not require the deeper interaction with participants that qualitative research requires (Esterberg, 2002).

In this study I want to learn about the experiences of living with HIV among African American females in South Central Georgia. A qualitative research design allows for a deeper understanding of their experience than a quantitative study. Because of the paucity of research focusing on this population grounded theory methods will be employed in order to collect and analyze this data. Grounded theory is the process of staying involved with the data during data collection and analysis. It involves staying within the data, by developing codes and categories that have emerged from the data, instead of using preexisting categories. Additionally, grounded theory helps me to preserve the participant's voice by staying grounded in the data. Charmaz (2006) states that "generality emerges from the analytic process rather than as a prescribed goal for it" (p. 181). Theory is developed during data analysis, using the constant comparative method, which involves making comparisons between the data during the analysis

(Glaser and Strauss, 1967). Memo-writing is a crucial component in using grounded theory, where notes are taken during the data collection process to elaborate on categories and identify relationships and gaps (Charmaz, 2006). A theory is then constructed staying within the data, in order to explain the social phenomenon. Using grounded theory enables me to inductively collect data in a more open-ended manner, which is especially important in this understudied Southern region.

Charmaz (2006) also agrees with Glaser and Strauss (1967) that there is flexibility in the Grounded Theory process. She presents a model for using grounded theory which consists of gathering rich data; coding; memo-writing; theoretical sampling, saturating and sorting, and the construction of a theory. Gathering rich data is the data collection methods that the researcher decides to use. In this study, ‘intensive interviewing’ was used by conducting individual in-depth interviews with study participants. Charmaz (2006) states that intensive interviewing is “an interview in directed conversation that permits an in-depth exploration of a particular topic or experience” (p. 25). In this form of interviewing, the interviewer has the participant “describe and reflect upon his or her experiences...and the interviewer is there to listen, to observe with sensitivity and to encourage the person to respond” (pgs. 26-27). The primary role of the researcher is to let the participant reflect on his or her experience.

Charmaz recommends using a few open-ended questions to elicit responses, and then focus the interview questions based on the participant’s story. In this study, two open-ended questions were asked to the participants: 1) Describe to me how you found out you were infected with HIV and the circumstances surrounding that situation, and 2) Tell me what life has been like for you since being diagnosed with HIV. During the

interview process, I asked participants to elaborate on statements, clarify responses and asked about their thoughts, feelings and actions. In addition to tape recording their conversations, I also took notes. These notes also aided in me being able to recapture participant's main ideas for clarification. Due to the sensitive nature of the topic, some of the women cried during the interview. Adopting an intensive interview method of listening with sensitivity, I stopped the interview and allowed participants to cry, or express how they were feeling talking about the topic. Some participants wanted to continue with the interview through their tears, and felt good being about to talk to someone else and have someone listen to them. Using grounded theory allowed me to stay within the data and ask questions according to participant responses.

Cultural traditions

Qualitative studies also require direct contact with participants and gathering data on how they make meaning in different social issues. Banks-Wallace (2002) asserts that African American oral traditions need to be considered for the development of qualitative research. Stories are used to make sense of human behavior, and within an African American cultural context, traditional values, historical settings, language and style are embedded within these stories. These oral stories can be told in the form of a narrative, dialogue or discussion. The researcher needs to look at the cultural norms that are told in these stories and understand the intersecting factors, and their impact. By capturing the voices of African American females and asking for their stories, this study also follows this traditional oral tradition. A qualitative research design allows me to not only interact with my participants, but capture their voices, and examine how cultural values and traditions may influence HIV infection.

In collecting the narratives of African American females, it is important to ensure that their voices are captured, because the oral narrative can also be used as a form of power in capturing the experiences of women. Etter-Lewis (1991) asserts that traditional narrative texts have ignored the experiences of African American women, whose narratives are often characterized by “the intersection of race, gender and social class with language, history and culture” (p.43). It is important in analyzing narratives of Black women to capture their individual form and style, and to look at speech patterns that may provide more insight into their lives. This also enables me to more closely examine cultural influences that may present itself in focusing on their narratives in this manner. In analyzing the data in this study, attention will be given to language use and structure, cultural idioms and other patterns that may reveal their individual experience. In this study it is particularly important to capture the voices of the participants, because as HIV positive women they are often marginalized, invalidated and ignored. As African American females, this marginalization is exemplified. In attending to the data in this matter, the goal is to ensure that their experiences are heard and documented, and their stories are captured in their own voice.

Researcher Subjectivities

In qualitative research, because the researcher is constantly learning and making meaning, she/he is exposed to their own subjectivities that may influence their overall interpretation of the data (Esterberg, 2002). There are several subjectivities that I have when approaching this research study. First and foremost is my dedication in reducing the spread of HIV/AIDS among African Americans. As an African American the devastating effect it has had on my community has been close to my heart. I have been

involved in this field for over 14 years, and prevention remains my passion. With that passion comes the belief that everyone has a right to have access to proper prevention services and care, and social support that enables them to engage in HIV preventive practices. No one living with HIV/AIDS should be stigmatized, shunned or discarded, and has a right to medication and proper care to ensure their quality of life. These beliefs have helped shaped my desire to ensure that people living with HIV/AIDS are treated with dignity and respect, and that the engagement of HIV preventive practices does not result in individuals being ostracized.

Furthermore, I am also an African American female. This makes me feel a personal connection with my sample population because I identify with them as Black women. Although I am not living with HIV, I feel like I share similar cultural values with my sample population. Furthermore, I am a resident of the Deep South, and know other African American females who engage in HIV risky behaviors, as well as women living with HIV/AIDS. This could affect my interaction with participants, however because of my extensive experience interviewing and implementing research studies with other African American females, I interpret this more as a strength than a weakness of my study.

Banks (1998) refers to this phenomenon as positionality, which are the different positions the researcher brings when interacting with their sample population, especially when they are socialized by race, class, gender and culture. Banks presents four positions: “Indigenous-insider” is one who endorses the unique values, perspectives, behaviors, beliefs and knowledge of his or her indigenous community and can speak with authority about it. The “Indigenous-outsider” is one who has experienced high levels of

cultural assimilation from a different culture, but is still connected with the indigenous community. An “External-insider” rejects his or her indigenous community and endorses another culture to become an adopted insider. Finally, the “External-outsider” is socialized within a community different from the one that he or she is doing research (Banks, 1998).

Based upon these definitions, my positionality is an “indigenous-outsider.” I grew up half of my life in the Deep South, and I know much of the culture, customs and values of this region. My roots are in the South, and much of my family resides in the Deep South, and I would spend summers in these states, strengthening my ties to this community. This intimate knowledge makes me an insider with my population. Yet, because I did not grow up in the rural South I do not have extensive experience and knowledge of the conditions that this region faces. Also for some of the participants my education level may also be a hindrance. These factors situate me as an outsider with my population.

Although my subjectivities can bias my data collection, analysis and interpretation; my passion to prevent the spread of HIV guides me in being neutral in collecting data from my participants. The exploratory structure of my study focuses on capturing the participants’ voice, which takes precedent over my biases. It is important to hear in their own words of their lives as HIV positive African American females. Additionally, because of my qualitative research experience and training, I embrace and apply an open-minded approach to research and the data collection process.

Sample Population

Description of the South Central Health District

Interviews took place in a Ryan White Clinic that serves persons living with HIV and AIDS in the South Central Health District. This health district serves 10 surrounding rural counties in the South Central region of Georgia. These counties are located in the middle of the state of Georgia, approximately 2.5-3.5 hours south of Atlanta, Georgia and 1.5-2.5 hours north of Savannah, Georgia. All counties are located right off of interstate 1-16 and provides easy access to Savannah and Atlanta. Figure 3.1 highlights the area the South Central Health District serves.



Figure 3.1 Map of South Central Health District

Demographics of the South Central Health District Counties

In this study participants were sampled from three different counties. Table 3.1 shows the demographics of these three counties served by the South Central Health District. The counties listed are a pseudonym for the names of the actual counties.

Table 3.1 Demographics of resident counties of participants

Description	Merrigold County	Sachron County	Penny County
Total Population	47, 316	19,700	12,353
African American	35%	30%	26%
White American	64%	69%	73%
Teen pregnancy rate	83.3 per 1,000	86.6 per 1,000	43.7 per 1,000
Median household income	\$33,188	\$28,310	\$35,869
Unemployment rate	5.0%	4.0%	5.3%
People below poverty line	18%	19.5%	15%

The majority of participants were sampled from the largest county, Merrigold County, which also houses the Ryan White Clinic. The three counties have an average even distribution of African American and White populations. Sachron County has the lowest median household income and the highest percentage of people living below the poverty line. Teen pregnancy rates are high in Merrigold and Sachron County.

Ryan White Clinic Demographics

The South Central Health District 5-1 serves 10 surrounding rural counties. The health department also operates as a Ryan White Clinic. All of the patients who attend the Ryan White clinic are either at or below poverty level. Although there are no exact figures on the demographics of patients seen at this clinic, about 60% are males, and 40% are females. The majority of these patients (80%) are African American, and (20%) are White American. The clinic sees on average 8-10 patients a day two times a month. Some of the patients are also sent to a physician at the hospital, which lessens the traffic of patients seen at the clinic R. Bowman (personal communication, March 7, 2008).

Data Collection Procedures

Participant Sample

Participants were recruited using a convenience sample of HIV positive African American patients 20-45 years who attend a Ryan White Clinic in the South Central Health District. This age range was selected because the majority of new HIV cases among African American women in Georgia is between the ages of 15-44 years old. The director of preventive services who oversees HIV education and case management of clients living with HIV/AIDS recruited participants for the study. Women were invited to participate if they were African American females; between the ages of 20-45 years old and living with HIV or AIDS for at least 1 year. Women meeting those criteria were identified by staff at the clinic and were invited to participate in the study. Eighteen women agreed to participate in the study and were interviewed at the clinic or at their home. Participants were offered a \$20 gift card as an incentive for their participation. One interview could not be used because at the end of the interview she revealed that she had only been living with the virus for 6 months and did not meet the criteria for the study. Therefore, the study includes 17 women living with HIV.

The interviews lasted between 1.5-2 hours, with the average time being 1.75 hours. The women were informed of the general content of the study and consent was obtained before they were interviewed. All interviews were audio-taped and transcribed. The audio-tapes, transcripts and consent forms will remain in a locked and secure room in order to protect the confidentiality of the participants. Participants were given a pseudonym during their interview and the majority of pseudonyms were selected by

them. No identifying information will be used in participant transcripts or recording of the data. Once the study is over, all interview tapes will be destroyed.

Due to using grounded theory methods of data collection, the interview guide was loosely structured in order to stay grounded within the data. Two broad open-ended questions were asked in order to illicit responses from the participants. Further questions were asked according to the responses during the interviews. Table 3.2 illustrates the interview guide protocol, and the accompanying research question.

Table 3.2: Interview guide protocol

Research question	Interview question or prompt
How did women living with HIV in rural South Central Georgia discover they were infected with HIV?	Tell me about how you found out you were HIV positive and the circumstances surrounding that situation.
What are the life experiences of women living with HIV in rural South Central Georgia?	Describe to me what life has been like for you since finding out your HIV positive status.

Approval to Conduct Research

Approval to conduct research for this study was granted by the University of Georgia's Institutional Review Board (IRB) for one year in June 2008, project number: 2008-10845-0.

Data Analysis

Coding is crucial to grounded theory, and conducting data analysis. Charmaz states that coding "generates the bones of your analysis" (p. 45). There were two phases of coding: initial open coding, and a more selective and focused coding. Initial coding helps the researcher begin to form ideas about the data, and then focused coding involves sorting large amounts of coding and employing the constant comparative method.

Grounded theorists typically use line-by-line coding during this initial phase which gives each line a code or incident to incident coding. During the coding process memo-writing also occurs. Memo-writing are thoughts and ideas of the researcher that may emerge during the coding of the data. It helps with organizing categories, connecting thoughts and ideas and identify gaps in data collection.

Initial coding was done using ATLAS.ti 5.2 to help with data coding, analysis and management. I coded each individual transcript using the incident to incident technique, which closely follows line-by-line coding, but instead of giving each line a code, coding is done by the incidents that emerge in the data. Using ATLAS.ti I went through each transcript and gave different incidents different codes. During this process I also wrote memos that gave me more ideas about the categories that started to emerge. During this first coding phase I came up with 247 different codes that were saved in ATLAS.ti. Some of the codes included broad codes such as “Daily life”, “Dating”, “Relationship with God”, “Pregnant and Positive”, “Sexual Relations”, “The church and HIV” and “Small town drama.” There were several overlapping codes in each transcript. Some of the most common codes were: Bisexuality, Coping, Daily Life, Drug Use, Family Disclosure, Finding out Status, HIV Knowledge, Love, Partner Disclosure, Pregnant and Positive, Relationship with Children, Relationship with God, Sexual Relations and Stigma.

After this initial coding phase, I began to do focused coding manually in order narrow down my codes and place the data into more selective categories. First I reviewed my memos in order to recap the different themes that I noticed had emerged within the data. Next, staying grounded in the data I narrowed down the different codes

and placed them into prevalent categories that emerged across the transcripts. During this phase I also used the constant comparative methods introduced by Glaser and Strauss (1967), where I compared all of the transcripts for similarities and differences. This process also allowed me to develop more selective categories, and place the data into these different groups. The process resulted in 8 codes and 24 different themes. Table 3.3 lists the major codes and themes.

Table 3.3: Major codes and themes

Code	Theme	Meaning
Finding Out		Find out about HIV status
	What about my baby?	Being pregnant and positive
	Locked up for life	Find out about HIV status while incarcerated
	The killing secret	Wanting to kill partner
Life circumstances		Situations influencing HIV infection
	Looking for love in all the wrong places	Incidents of abuse
	Woman to woman	Bisexuality
	Open wounds	Physical abuse
Dealing with the news		Initial reactions to HIV status
	Killing me softly	Thoughts of suicide
	Relax, God's in control	Relying on God
Coping with life		Coping with living with HIV
	I never would have Made it	Reliance on God to cope
	Take me to another place	Substance use
	Out of sight, out of mind	Denial and avoidance
	HIV saved my life	Positive life changes
Disclosure issues		Disclosing status to others
	Don't wanna be a burden	Keeping status to oneself
	Don't worry momma	Disclosure to children
	We are family	Disclosure to family members
	What about your friends	Disclosure to friends
	For better or for worse	Disclosure to romantic partners
Small town living		Living with HIV in small rural towns
	Party at the clinic	Lack of clinic confidentiality
	Horror in the hospital	Lack of hospital care
	News at eleven	Lack of privacy
Views of the body		Changes in relationship with the body

	In sickness and in health	Health issues
	Letting go	Not caring about appearance
	Spoiled goods	Negative body changes of HIV
Choosing life		Life with HIV
	One day at a time	Living positively

Summary of Chapter

For this study a qualitative design will be employed, using grounded theory in order to learn about women's experience living with HIV. The total sample size included 17 African American women living with HIV. Through focused coding 8 major codes and 24 thematic categories were identified using the constant-comparative method of grounded theory.

CHAPTER 4

RESULTS

The purpose of this study was to understand the experiences of African American women living with HIV in South Central, GA. Two research questions were developed in order to better understand their experience: 1) How did women living with HIV in rural South Central Georgia discover that they were infected with HIV? 2) What are the life experiences of women living with HIV in rural South Central Georgia?

This chapter presents the findings of this study. In this study 17 women were interviewed from the South Central Health District in Georgia. Using grounded theory methods, open-ended questions were asked of the participants: 1) Tell me about how you found out you were HIV positive and the circumstances surrounding that situation, and 2) describe to me what life has been like for you since finding out your HIV positive status. Utilizing the constant-comparative method through focused coding, 14 main thematic categories emerged from the data. The following presents these findings.

Participant demographics

All of the participants were African American females between the ages of 20-44. The mean age was 33 years old. All of the participants had a household income level below or at poverty level, and most had an educational level of high school. The majority of participants had children (only one participant did not have any children), were not married and had been living with HIV for either 1-4 years or 5-9 years. Most of the women were infected by their current sexual partner, who were either their boyfriend, husband or fiancée. One of the participants was

infected by another female. Table 4.1 is a description of each of the participants. All of the participants were receiving care from the Ryan White Clinic in the South Central Health District.

Table 4.1: Participant demographics

Name of participant	Age	# of years with HIV	Household Income	Education Level	# of children	Relationship status	Mode of infection
Dee	44	10+ years	\$20,000-30,000	Some college	3	Married	Husband
Tracey	34	5-9 years	\$20,000-30,000	Technical Certificate	2	Single	Father of Child
Shay	42	1-4 years	\$0-10,000	Technical Certificate	3	Divorced	Fiancée
Keisha	30	1-4 years	\$0-10,000	Some high School	1	Single w/ partner	Female Friend
Kim	34	1-4 years	\$0-10,000	High School	2& currently pregnant	Engaged	Male Friend
Shonda	22	5-9 years	\$10,000-20,000	High School	0	Single	Male Friend
Simone	43	10+ years	\$0-10,000	Some College	2	Married	Boyfriend
Tisha	27	5-9 years	\$0-10,000	Some high school	2	Single w/ partner	Boyfriend
Treasure	22	5-9 years	\$0-10,000	High school	3& currently pregnant	Single w/ partner	Boyfriend
Michelle	28	1-4 years	\$0-10,000	Technical Certificate	1	Single	Male Friend
Lisa	38	1-4 years	\$10,000-20,000	Some high School	3	Single	Family Member
Diamond	27	5-9 years	\$0-10,000	Some high School	1	Married	Boyfriend
Honey	38	10+ years	\$0-10,000	Some College	2	Single w/ partner	Boyfriend
Nicole	44	10+ years	\$0-10,000	Some high School	1	Single w/ partner	Boyfriend
LaToya	22	1-4 years	\$0-10,000	Some high School	3	Single	Older Boyfriend
Kaya	36	5-9 years	\$0-10,000	Some College	2	Single w/ partner	Boyfriend
Tina	31	10+ years	\$0-10,000	High School	3	Single	Boyfriend

Findings from the interviews

The following data presents the 14 general themes that resulted across the participant interviews.

Research question #1: How did women living with HIV in rural South Central Georgia discover that they were infected with HIV?

My first question to participants in order to answer this research question was: Describe to me how you found out you were infected with HIV, and the circumstances surrounding that situation. Women answered this question by revealing how they felt when they first heard about their status. The circumstances for them included events influencing their infection, and initial confrontation with the partner they believe infected them

Finding Out

What about my baby?

Approximately half of the participants (53%) found out their HIV status at the same time they found out they were pregnant or during their pregnancy. Michelle was pregnant and went to the doctor's office in order to find out the sex of her child. She explains that the doctor asked her to come into her office and sit down:

She was like I have something to tell you, and I was like I hope it's a girl and she was like no, it's about your HIV test and I was like huh? And she was like ma'm you're CDC thing came back that you're HIV positive. I said you gotta do this over, you're mistaken, you got the wrong one. And so she was like no, we're going to retest you, we're going to make sure, and she did another one and the Western Blot came out positive also...the

doctor call you in and say look ma'am you have AIDS, you have HIV,
you're going to die soon, what I'm supposed to do?

Michelle thought that she was going to hear what sex her child was, but instead was informed that she was HIV positive. She felt like her life had become to an abrupt end because of the information that she just received. When she heard this news she stated that she went through three different emotions:

I wanted to kill him first off. Second off I felt like taking my own life and third off I said that wouldn't be fair to my baby. The only thing I gotta do is just do what I have to do to make my baby safe while I'm carrying this child. But it was heard and I went through a lot. It was like it was the end of the world, which it was... I felt like [he] ended my life. There's no more me, there's nothing to do for my kids now that I'm dying.

Michelle felt like not only was her life over, but now she could not care or provide for her children. Her children now had their mother taken away from them. What kept her from killing herself was the fact that she was pregnant and wanted to provide the best care possible for her unborn child. She said at first she thought "Oh God I have to get an abortion, this child do not deserve this", but she realized she did not believe in abortion and instead decided to focus on giving her child the best care possible.

LaToya was also devastated when she found her HIV status during her pregnancy, especially when her son ended up being HIV positive as well. This startling discovery also let her into a deep depression that led to multiple suicide attempts:

I felt down, I cried a lot, I'd just go to my room, shut myself in my room, won't come out for like 1 or 2 days. I stayed a lot...just sit there and just

gaze out the window. It was a hard situation at first, but I finally got through it. At one point I did try to attempt to commit suicide. I took like 50 something Tylenol PM. My momma called the paramedics, and they got me to the hospital just in time. They had to pump all that and put some kind of tube in my stomach. The second time I tried to do it again because I felt helpless. I feel like it was my fault for my son having it. At that time that's what I felt so I attempted it again. I was trying to stab myself but my step daddy took the knife from me.

LaToya was led to attempt suicide twice. The first time was when she found out about her HIV status during her pregnancy, and the second attempt was when she began to contemplate her son's positive status. The second attempt was more violent as she was gripped with depression and guilt because her child now had to live with HIV.

Nicole was also gripped with despair and fear for her unborn child when she found out her status. Nicole states:

I was pregnant when I went back to get my check up and everything and they tested me then, and they told me that and I was like oh my God, and I worried about my baby, I was like ok, because one I used to do crack and that's terrible, but I gave it up and I turned my life around. I was under depression for awhile because I didn't accept it. I didn't want to live, I really didn't want to live, and I then I locked up in the room for about a week, wouldn't eat nothing...then I was more concerned about my baby.

Nicole admitted at she was more worried about her child's health than her own HIV status when she first found out her status. She was using crack before she found out she

was pregnant, and decided to quit her addiction cold turkey when she found out she was pregnant and HIV positive. Once the realization of her own health status dawned on her, she slipped into a state of depression. Refocusing on her son's health helped bring her out of her status as well as what she calls a "praying grandmother."

Like LaToya, Nicole's son also tested HIV positive after he was born. However, even though he tested positive initially, upon subsequent retests he's tested negative for the past 17 years. She reveals how she felt about his HIV tests:

The doctor gave me some kind of hope when he told me he could pass it through his bowel movement, and that was a hope for me and I kept on praying too. I kept on getting him tested and eventually it was over, and I told him I wanted him to get tested all the time. And he turned out fine.

My baby he thick, he play football, he wrestle, he get out of school next year, he graduate.

In the beginning she was worried he would permanently be HIV positive, but held on to hope once the doctor informed her that it could pass through her child through his bowel movement. She was relieved that her son continued to test negative, and is healthy and living a good life. She encourages him to continue to get tested as a means of taking control of his own life, and always knowing his own status.

Honey on the other hand, wanted to abort her child when she found out she was pregnant and HIV positive, instead of trying to kill herself. She went in to get birth control, concurrently had swollen lymph nodes. Her doctor gave her an HIV test and a pregnancy test and that's when she found out about her status:

Maybe two weeks after I found out I was HIV positive, I also found out I was pregnant with my youngest daughter. I was so young and terrified...I wanted to get rid of that baby because I was afraid that she'd be born with the virus. It went through my mind that my baby would be born sick, and at the time I was working in the shelter for abused and abandoned kids so I was working with kids who was born with the virus, and I didn't want my baby to have to go through that. But I prayed regularly asking God to help my baby be healthy and I could be the best mom I could be for the baby. By the grace of God she wasn't [born with the virus] and she came and she's here and I'm really happy.

Honey had experience working with children infected with HIV and did not want her child to live their life coping with the virus. To her, having an abortion was a better alternative than the possibility of her child having HIV. She was so determined to get an abortion that the father of her child, who also infected her locked her in the house for about 2 months in order to stop her from getting an abortion. Honey states when he did that I "really thought he loved me too, he said I'm gonna always have a reason to be in your life, and now I know we gonna be together...whenever I would need to go anywhere he would be right there with me." Even though she was determined to get an abortion, he tried to make it impossible to do so. She even stated that the house they stayed in "it had bars, and it was like you can't even sneak out the window..." She was trapped in the house living with the thoughts of the possibility of her child being HIV positive.

Tisha thought her life was going to end immediately when she found out she was positive during the birth of her daughter. She said that she:

Felt like it was the end of the world, I just wanted to die. I was scared to go to sleep at night because if I went to sleep I was scared that I wouldn't wake back up. It was true. I took 2 or 3 more tests after that. I was scared, I was scared. I used to say how could this happen to me, because it don't happen to people like me. I wasn't out there, I got it from my little girl's daddy and that really hurts me.

Tisha was afraid to sleep at night because she thought that she would not wake up. She believed that being diagnosed with HIV meant automatic death. She took multiple tests because she was in denial, hoping that her status was a mistake and that she could wake up from the nightmare that had now become her life.

Although her daughter tested negative for HIV, she had other health problems that Tisha believes may have been a result of her own HIV positive status: "she got hearing loss in both of her ears, and she kinda slow and stuff and I got to thinking maybe this sickness got to her while I was carrying her." Her daughter was diagnosed with hearing problems and has to wear a hearing aid. She also processes slower than other people. Tisha believed that the virus inside her spread to her daughter and made her develop these health problems.

In contrast to the other women, Tina really did not know much about HIV when she was told that she was positive during her pregnancy. She stated that:

I had went in for my doctor's appointment [when I was pregnant] and they went in and I did the test and they just blurted it out in front of my momma and them. I didn't really get no prenatal care with my daughter, because after I got pregnant with her and they found out I was HIV positive, I was on my daddy's insurance

they dropped me. I didn't really get prenatal care, because I had pre-term labor.

At the time I was young, I didn't really know what it was. Then when I got to the hospital they put me with a case manager. They put me on meds and everything, and as I was getting older and living with it, that's how I found out more about it, because I stayed in them studies.

Tina was not sure what it meant to be HIV positive when she was told her status, and did not know what the implications meant for her child during her pregnancy. She took the initiative to learn more about the virus through reading and following different HIV/AIDS related studies.

Locked up for life

A few of the participants found out about their status while incarcerated in jail or while in mandated drug treatment facilities. Simone was in a mandatory drug treatment facility that she was ordered to be in so she could regain custody of her children as she fought her addiction to crack. She describes the day she checked into the facility and received an HIV test:

I did a drug program at the mental health, and they asked did I want to take a test and I told them yeah, because I know that I just had took a test before I came and it came up negative. I took a test here at the mental health and it was positive and I was like oh my God. I had her to do another one. Sometimes I just see it and am like how in the hell, but I don't know. He ain't never tell me that he had it. Sometimes I think about it, and then my anger, because I'm like my life is getting cut short.

Sometimes I deal with it, and then sometimes I just go into my little mood, the depressing mood.

Simone was surprised that she tested positive for HIV since she just had a test and it was negative. She believed that the man that she had been with for years never told her about his positive status. She had a mixture of depression and anger upon hearing the news.

Shay also found out about her status in a drug treatment facility and felt like she was going crazy when she found out her fiancée infected her:

My fiancé gave me this and when I found out I had it I called him on the phone. He said 'damn', just very calm...'I always said if I caught anything...fuck it, we got it.' I'm on the phone and I said huh wait? Wait a damn minute hold on. Whoah! I talked to myself at that mental health place. I was shedding tears having a fit, they thought they were gonna have to send me off. What's embarrassing is that I stood and sat there on that commode and I said wait a minute, this bitch is too calm. This mutherfo sitting here like it ain't nothing. Somewhere down the line this mutherfucker here gonna pay for my life he done took from me where I could be happy one day and he took my happiness away. He took all, and all with me and that's a hurting thing when you take something like that. It's like he done wrote my death trap. I'm already dead. He was too calm. So I'm like this bitch had this shit and he didn't tell me. How in the hell you gonna sit here and kill somebody up here cuz somebody done killed you? Bitch living somewhere else now, but I'm sitting here having to deal with the consequences of being with that man.

She felt betrayed by her fiancée because of his calm response, leading her to believe that he knew that he was HIV positive, and could pass it to her. She felt like the person she was going to marry took her life away from her, and that hurt her to the core. He gave her news that forever changed her life, and now she had to live with the consequences of this decision.

Diamond was in jail when she found out about her positive status, although she suspected she may have been positive 9 years ago because her previous partner had died of AIDS; something she did not find out until he died:

I had got locked up [for aggravated assault on current husband] in diagnostics you have to go through the medical, they test you for everything. They call you back in the room that's when they told me. I was hurt. I knew it, but didn't know it. I didn't want to hear it. I knew it because my partner, he was positive, and then I felt like I probably was. His momma, the whole family they knew and they didn't tell me. I knew for most of my life. I called home and told my momma, I just told her I was sick. She's a nurse, she was hurt too, she said just pray.

Diamond was not in complete shock about her status because her previous partner had died of AIDS. She had been in denial about her status and was afraid to get tested because she was scared to face the fact that she may be positive. Finally hearing her status hurt her, and was the reality call that she had dreaded hearing.

The killing secret

Participants had different feelings when it came to confronting their partner who they believe infected them. Many immediately felt like they wanted to kill that sexual

partner when they found out their positive status. Kim told her family of her intentions when she found out her status:

My cousins and them say I know if you go over there you're gonna kill him. I told them I said if I ever seem him I might try to do my best to kill him and that's what was going through my mind all the time. She said if we go to his house they would stop me because they know what I'm gonna do. They don't want me nowhere over there. I don't go over there cuz if I see him I'm gonna either try to run over him, or there is going to be something that I'm going to do. I feel like he done took my life away from me, but I ain't fin to go do that cuz I'd be serving the time from what I did to him. I try to be calm and I try to keep a certain mood as much as I can cuz if I sit in the house I think about it I get depressed. I get frustrated and I try not to even think about it.

Kim felt so hurt and enraged that she felt like she wanted to kill the person who infected her. One of the only things keeping her from killing him was the fact that she could be facing jail time. The threat of jail time also stopped Shonda from acting on her feelings as she says "I wanted to kill him [when I first found out], but wasn't nothing I could do about it, if I killed him I would be in prison so I just said don't worry about it." Tisha adds "when I first found out I just wanted to kill him, but I think if I killed him I would not have gotten away with it." In the middle of their anger rationality took over as they reflected on the consequences of their actions.

Keisha felt the same way about the female who infected her, but her belief in God helped her from acting on her feelings. She stated "you know sometime when you want

to kill a person and you like damn I feel like hurting her, but I say naw I'm gonna let God handle that I ain't gonna worry about that." Keisha also wanted to kill the person who infected her, but instead chose to let God act on her anger and betrayal.

Treasure also thought a lot about killing the person she believes infected her and states "I even had hits out on him, but when I found out he was in a halfway house I realized I have to pay for that. Regardless if somebody else do it or not I have to pay for that as far as it being on my conscience." She didn't want killing him to be on her conscience, and knew that killing him would not take the virus away from her. She further describes why she had such murderous thoughts go through her head:

When I heard that, when I say I literally lost my mind, I felt like killing him. I was a young girl and then I was like I basically just pissed in the water trying to have a relationship, trusting somebody, after going through all the stuff that I went through, finally trusting somebody and then it's like my life is over. I felt like he knew it at the beginning but didn't tell me. I felt like it should have been a choice that I made instead, if I loved him that much and I really wanted to be with him that would of been a choice that I made, not just somebody just taking it from me. I think that's one thing everybody is entitled to, just making decisions and that decision I didn't have a choice in making. I felt like you knew this, you should of told me before we went to bed together. You should have told me, regardless of what. And then when I wanted to use rubbers and stuff he didn't want to use them, and had that comeback if you love me, you'll do

it. So I did it thinking that it was love, but it was more, it felt like since I got it, I'll just give it to anybody, and I felt just real hurt by it.

Treasure felt like her life was taken away by the man she loved. She believed that he knew he was HIV positive, and knew that he could infect her. He took away her power to decide if she wanted to take the risk by having unprotected him because of his positive status. She felt like she was in love and that he loved her, which is why he didn't want to use condoms. It hurt her that he deceived her, especially after her troubled past. When she finally opened up and trusted again, that trust was broken, and led to her rage and frustration of wanting to kill him.

Honey however, didn't feel anger towards her partner and admits when she found out:

I didn't go anywhere, I went straight to him. I just found out, and he was like no you not, and I was like I had to get it from you because I haven't been with anybody else, I don't sleep with other people, it's you. And of course he denied it, but I knew deep down inside that he was lying. He never had me fooled once I found out about it but I was so over it still and so infatuated that I thought we would be together until one day something went on and girl he still a ho. I never told this to anybody, but Ima let loose. I wasn't happy but I said wow, maybe now we'll be together forever. I really thought me and that man would be together knowing that we was both HIV positive. I thought you don't want to spread it to nobody, and it's just the two of us, but it didn't work that way.

Although she wasn't happy with him, Honey felt like they would be together forever because they were both positive. She was so in love with him, she created what she called "a fairytale picture" and knew that they would live happily ever after. HIV would be the bond that kept them together, rather than break them apart.

Shay had views similar to Honey. Once she got over the initial anger she felt towards her partner she decided to stay with her partner and says "I felt like with me having HIV why not stay with the one who gave it to me? Ain't no reason for me to go nowhere else. Who else gonna want me?" She felt like nobody else could love her because of her status, so she should just stay with the one who infected her.

Life circumstances

Looking for love in all the wrong places

As the women shared their stories, some of them reflected on how some of their experiences with abuse may have led to negative partner selections which in hindsight may have increased their risk of becoming infected with HIV. A large percentage of the sample (68%) had been involved in some type of abusive relationship or experienced abuse over their lifetime before finding out their status. These forms of abuse include: physical, mental and verbal abuse; rape, statutory rape and molestation.

LaToya had been through a series of abusive relationships. At the age of 10 she had sex with a 32 year old male who ended up impregnating her. When her mother found out about she states "all hell broke loose and she had him locked up for statutory rape, even though I did consent to [having sex]. He told the judge well she consented to it but the judge was like I don't give a damn if she consented to it, she's a minor and he went to jail." LaToya did not see it as statutory rape, admitting that ever since she was 9 years old

she wanted to have a baby “just to see how it would feel”, but she didn’t know “that I was gonna get none that quick.”

LaToya believes what really changed her views on the opposite sex was when her stepfather molested and raped her continuously for 2 years:

He was drinking bad. He would just constantly drink that whole day, next day he’d do the same thing [to me] day after day, it would never fail. I told my momma and she didn’t believe me. I’d just wake up at about 2 or 3 o’clock in the morning and got nothing on, just as naked and sore as a jackbird. He admitted to her in front of the police ‘yeah bitch I did rape your daughter’ and they got him on child molestation charges. She didn’t want to press charges, he got out and she took him back and the same thing again. I felt low for awhile, not knowing that somebody my momma loved would really do that to her children he called his own. She claimed she was so in love with him, that’s the only reason why she took him back. So I just told my momma it would be best if I got out. She said you ain’t got to leave, he ain’t gonna bother you. I said momma every time you leave me here with this bastard he’ll do it. The last time he raped me she actually caught him. He was locked up again for child molestation. When he got out they gave him 15 years probation and he had to pay a 5,000 fine. He ain’t never pay it or anything cause he got kilt. God don’t like ugly.

LaToya felt betrayed on several levels. She was abused for years by the man that she loved and trusted like a father. What further hurt her was when she told her mother, and

her mother did not believe her. She felt very low because she felt like that not only was she being violated by her stepfather, but she didn't have her mother's love as well. The betrayal was worse when he did admit he raped her in front of her mother, and her mother still took him back. It took her mother catching him in the act to finally expel him from their home.

That incident really changed her outlook on men. She says "I don't too much trust men like that, not the way I trusted my step daddy not to hurt me and he did. That's really the only thang that got to me, because he told my momma I would never do anything to hurt your daughter, I love her as if she was in my home." She felt like the man who was supposed to love and protect her violated her trust. She went through dating not really trusting men completely, and felt like she continuously got violated by men, including the one who infected her with the virus:

I don't look at dating quite the same as I did before. I'm not gonna say that all men are dogs, but some of them are, especially the ones that know they got something and not man enough to tell you. I don't hate what they did to me, but still I regret what they did to me and the way they went about doing it. They lied to me.

LaToya felt like she continued to be violated by men she thought she trusted, and it began with her stepfather. Now, she looks at men warily, looking for love and a man that she can trust.

Woman to woman

Michelle was also raped when she was younger by her mother's ex boyfriend, and experienced the same disbelief from her mother that LaToya did:

An incident happened where her ex, an old man raped me and I told her and she was in denial about it, and I held that against her for a long time and I had to go through counseling to forgive for upholding this man. I was nine and she said no you're just imagining it, that was something that you want...I went to the doctor and they said I was raped and she felt that I was nothing, that I was a low life and allowed him to do it and it was my fault. So they put him in jail, she went and bonded him out.

Michelle was also raped by her mother's boyfriend, and her mother did not believe her. Her mother also stayed with her boyfriend, and didn't end the relationship until he got caught molesting her again by her grandmother. Michelle's molestation led her to be with women and identify with being bisexual as she admits:

I was bisexual, then I thought God, what in the world was I doing, this is not right, so therefore I'm not fin to do it. I just said Lord what in the world am I doing, this is not right, and I was like please take this away from me, I can not deal with this, this is wrong in your eyes and I'm trying to be right...but I did feel safer being around a woman, I didn't feel safe being around a man, I hated a man.

Michelle felt that if she was a woman she wouldn't get hurt the same way that her mother's boyfriend hurt her. Being with a woman was a way of protection, where she could feel safe. Another female would not hurt her the same way that a man would. Although she hated the fact that she was with a woman sexually, she'd rather deal with that guilt and shame instead of leaving herself vulnerable being with a man. When she was finally with a man she said that "I was shaking to death, I didn't know what to do, I

was like oh my God.” It took her awhile to learn how to be with a man again, and even then she was afraid. This fear has influenced her partner selection.

Treasure was also raped when she was younger. When asked I asked her to describe how she found out about her status her response was:

When I was 10 I was raped and then again when I was 12. Then I got to be a hot pants because I didn’t care no more cuz I felt like it was me against the world basically. Not only that I started trying to have feelings for a guy and this one guy-I would do anything for him. He wanted me to sleep around with different people. I did it because I thought that was love and years later I was a hot pants. I would probably do anything just to have a man to feel protected. And my dad wasn’t there so now I feel that it was more that I was looking for a father figure than just somebody to sleep with. I was more into being fast and looking for love that really wasn’t.

Treasure’s rapes changed her outlook on men, and led her to do anything for a man on her quest for love. This led to the involvement in other relationships that she realized were unhealthy. Like LaToya, Treasure was also led to women after being raped, due to fear and lack of trust of men:

It got to the point where I didn’t like men at all, I was just disgusted with men, then I stated dealing with women. A lot of women open, they open to talking...men, they always keep things closed up, hid and basically from you. The things you should know and need to know you don’t know until the last minute and I think that was the most hurting part about it. The way a woman treat you it’s very good. I was loving it because I ain’t never had

no man or nobody cater to me like that and she was basically doing something that I wanted my man to do so I got to feeling comfortable like that and didn't want nobody to know. Then it got to a point where it got out of hand, and I didn't like it. I wanted to be with another female just to see if that's what I wanted.

Treasure was also led to women because she was disgusted by men, and would rather deal with a woman than a man. She felt like men hid things from you and hurt you, and a woman gave her the love and attention that she had been craving. Women were open and honest and she didn't have to worry about being betrayed with a woman. A female served as a sanctuary from all the wrong that men did to her. She felt good being with a woman, but she was still ashamed, because ultimately she felt like it was wrong.

Keisha was also raped when she was younger and also felt betrayed by her mother. She revealed that "I was 12 years old I got raped and she sold me for drugs basically. I don't even talk to her period. [I told her] 'you sold me for dope and you looked the other way when someone raped me. Why should I talk to you?' I don't speak to her, I don't even look at her." Keisha's mother is addicted to crack and sold her daughter to another man to have sex with in exchange for drugs. Keisha's way of coping with this was to shun her mother and try to live her own life. She did not develop a hatred and distrust for men like Treasure and LaToya expressed, but did admit to becoming bisexual later in life.

Open wounds

Both Tina and Simone were in physically, verbally and mentally abusive relationships. Both of their partners were also the ones who they believe infected them

with the virus. Simone admits “I had been with him for 14 years, it was an abusive relationship. I got scars from knives and extension cords. He was [also] shooting up and cheating. One night he was doing crack and tied me up and made me smoke it. When I decided to leave him he laughed in my face.” Simone’s partner not only physically abused her, but also forced her to do crack which helped to start her crack addiction. He also cheated on her during their relationship, which is how she believes she became infected. She was only able to escape him after he passed away.

Tina’s relationship with the one who infected her was also physically abusive. She states ” he was too violent, I was in an abusive relationship, and during the last end I got tired of it and I just beat his behind with a crate and I just left him. It was a cycle because I grew up in it, but I broke my cycle.” Her abusive partner was also the one who infected her. Tina was able to break the abusive cycle that she had witnessed when she was younger, and became a part of by fighting back. After she fought back and left her partner she stated that she developed an independence that she didn’t have before. This new independence was her way of healing from an abusive relationship.

Dealing with the news

Killing me softly

Upon finding out, many of the participants went through a range of emotions when they learned about their status. Most of the participants were devastated when they first found out about their status, and several women expressed the desire to kill themselves. Shonda states:

When I first found out about it I tried to kill myself. I wanted to walk home, but they wouldn’t let me walk home cuz I was already mad so they

dropped me off home, and when I got home I tried to take an overdose of some kind of pills sitting at home. My momma was coming in from work and I was in my room crying and she asked me what was going on so I told her but everything is ok now.

Simone also had similar thoughts of killing herself and states “to be honest with you, I just felt like driving off a cliff, because I’m like that’s it, my life is over, whatever it is I want to do, it’s over.” She wanted to end her life, because she felt like the life that she had was taken away.

Keisha isolated herself and tried to kill herself by starving herself. She states:

I came home and I laid propped up in my room for about a week. I just cried and cried and cried. I kept asking why, why it had to happen to me. If I can go back in time it would of never happened. I would of never messed with her, I would of never talked to her, pretty much I would of stopped talking to a woman since I found that out that day. I mean cuz it hurt, it hurt because I’d look at it on TV and I’d be like I’d never get that, but now, and all this don’t you never say what you never can get...I brought dope and was smoking all night, and for some reason it didn’t work. I tried to starve myself, for about 2 weeks but that didn’t work.

Keisha was so devastated that she tried to kill herself multiple times. First she tried by going back on crack and tried to smoke enough crack to kill herself. When that did not work, she tried to kill herself by not eating and refusing food. She even stop bathing, in order to let herself just wither away. It was only when her child came to her and her partner’s mother helped her that she started to eat again and develop new hope and a better outlook on life.

Shay also felt like hearing about her positive status killed her and living everyday with the virus pains her:

I thought it was the end of the world. It's like one foot on the banana peel, and the other foot at the end of the grave. It's devastating. I still have not been able to accept it, and when I found out it like to literally and mentally kill me. Self-worth wasn't about nothing, I felt low self-esteem already and this here made it worse than anything, so it's like my life is shit. It's nothing else I could do. I'm self-conscious about having this disease. It hurts everyday wishing that you didn't have it, and it's like damn, you never know when it's going to become full-blown. You never know when this medicine is going to keep working for me, I don't know what changes I'll have to go through with my life. I got screwed.

Shay was devastated when she found out she was HIV positive, and felt hurt each day. Because of the way low way she was feeling, she felt like she wanted to commit suicide as well and stated:

I done tried to commit suicide a whole bunch of times and shit too. I thought about it, but I never went through with it, so what the hell for? Hell I'm tired and I might as well go ahead and live with it the best way that I know how, it ain't worth that. Hell if Magic Johnson can live like that so can I. I'm not dead yet.

Shay wanted to commit suicide because she felt like her life was over once she was diagnosed with HIV. However, once she tried she realized that she had to learn to live with her status she changed her outlook on living with the virus.

Treasure also felt like killing herself in moments of anguish and despair and admitted to having several thoughts of committing suicide:

It makes me sick, it makes me real sick to my stomach, because sometimes when you wake up you don't want to be waking up. You're just like I wish I wouldn't of woke up today, I just want to sleep my life away. You start having suicide thoughts, real bad suicide thoughts. I've even came close to drinking Clorox, I came close to like taking pills, like a whole bottle of Ibuprofen. I came close to doing a lot of harmful things to myself, but I had to think, the Lord blessed me with my kids. I had to think if I did something to myself how it would hurt them. At the time I was fin to take the pills [my son] came in and said momma what you doing. I was just crying and he said momma don't cry, and he just stayed there watching me so I was like it ain't worth it, it ain't worth it. I had this little voice in my head saying do it, don't nobody give a fuck about you, just do it, nobody don't care. I was like my heart was saying that baby care, think about your baby, he's standing right here looking at you. I know that will hurt for me to take my life, and I don't want to do that.

Her son helped save her life by walking in on her, before she swallowed the bottle of pills, and his presence stopped her from completing the act. The love for her children helped motivate her to keep on living so she could be there for them as their mother.

Kim also felt like committing suicide, and her children also helped save her life and says "when I found out I just wanted to get in front of a car and just kill myself. I said well I got two kids I got to take care of and I can't have that." She was also

motivated to live by her children, and wanting to be there as their mother. Her children gave her strength and support and the will to live in order to provide for them.

Relax, God's in control

Shay also felt like God was in control of her life, and had the final say on whether she lived or died. She stated that her belief in God also kept her from trying to commit suicide again and continues: "I'm not dead yet, I don't claim it anyway. They say I got it, but God didn't say I got it. Look, I ain't got nothing, that's how I deal with it I don't have nothing, I just hold on." Leaning on God has also helped to keep her through living with her status. She doesn't really have to claim being sick or that she's dying because God didn't tell her she was dying. Her dependency on God has helped her cope with dealing with her status, and her belief that He was watching over her.

Kaya also demonstrated her belief in God keeping her healthy when she found out her status and when her doctor stated that her HIV numbers were undetectable. Her doctor was trying to understand how her numbers got so low so quickly, and she shares:

[He said] I don't understand and I said it's not meant for you to understand, I'm not dependent on man. I said cause God gonna do whatever he say he gonna do, he's gonna take care of it. He's like well that's good you got faith, that's good. I said yeah cause if you don't got faith, then you don't got nothing.

Kaya believed that God will keep her healthy and kept her numbers low. Her faith has helped to sustain her and keep her uplifted and optimistic about her status. This is similar to Shay's sentiment who also believes that God has the final say in deciding if she dies

from being HIV positive. These beliefs have helped them to cope with hearing their positive status.

Research question #2: What are the life experiences of women living with HIV in rural South Central Georgia?

For all of the women in the study their lives have changed since being HIV positive. This includes the views of themselves, relationships with others, and their overall outlook on life.

Coping with life

I never would have made it

God was present in initial reactions to hearing one's HIV status, as well as helping many of the women cope with living with HIV. In addition to believing that God was in control, many of the women renewed and strengthen their relationship with God as a means of healing and coping with everyday life.

Tisha relies on God to help get her through daily living:

Sometimes I have bad days and I start praying and I feel so much better. People that have been sick they shouldn't let it get them down. I thank like when you worry about it that's what make you go down quicker. I thank that people shouldn't really worry about nothing and they should just take one day at a time and do whatever God has in store for you and it will happen. Don't worry about it, cuz that's the only thing that get you by. I pray all the time. I pray about everything, my health, my strength and all that, my kids, stuff like that. I pray to God for waking me up in the morning and for allowing me to see another day cuz somebody ain't make

it over. Just to get up and go about my daily activities and don't worry about it, don't think about it unless you really have too. So coming out and not really thinking about it, that's what gets me by everyday.

Tisha's relationship with God keeps her going, and keeps her hopeful and optimistic. She prays about everything in her life and this keeps her from worrying. She believes that sometimes people who are sick die more from stressing about it than from the disease itself. Her continued prayers to God helps to motivate and energize her.

Dee agrees that faith in God is what helps her to cope with the virus and live each day. Faith is imperative to living with this virus:

If someone say don't take a spirituality they do need to reevaluate that, because it do take a spirituality. As far as spirituality there were times that my husband and my children would just have to get around my bed and just pray me up out of that bed. I mean you definitely gotta have a spirituality of some sort. And the one thing that I don't take for granted is giving him the praise from everyday that he let's me see. Because I outlived my siblings and my parents, that's something to have a spirituality about. So it's hard.

Dee believes that her faith and spirituality has kept her alive for this long living with the virus. She has been living with the virus for 20 years and has out lived not only her parents, but some of her siblings as well. She is grateful for the life that God has continued to give her each day.

Michelle has relied on God as well and shared how she leaned on him when she was very sick and thought she was going to die:

They told me I had double pneumonia, something about my heart flutter and that my viral load had dropped to where I needed help right then and there. They had to put me on the life support thing. They said that if I wouldn't of came in that night, the next morning they don't think I would have been living. I didn't have an ounce of blood in me, they had to give me a blood transfusion. They had to pump my medicine to me, they had to give me so many antibiotics, just to build my immune system up because my immune system had completely shut down and I was like God and I was pregnant with her. I was like Lord what am I going to do, and He just pulled me through, He really pulled me through.

Michelle prayed to God to be able to overcome her illness and that her daughter would be kept safe. After she made it through the episode, she credited God as the reason for her overcoming her illness. Without God she never would have survived.

Treasure also accredits God for keeping her healthy:

I have faith and the faith that I have I haven't been sick. It's like when I went to the doctor and it was undetectable it just let me know that God answer's prayers no matter what. I don't have to take no everyday medicine which I thank God for. And all I can say I just live everyday to it's fullest. I just thank God, it could be worse, it's not. I could be sick with this virus but I'm not. I'm sick from other things, but not the virus. It's sad, it's very sad but I just thank God I could be worse, as I said before. I just take one day at a time and keep my faith in God and trust in believing him and everything is fine.

Treasure believes that without God she would not be as healthy as she is. God is the one that keeps her from getting sick and keeps her healthy each day. She is able to live life each day to the fullest because he keeps her healthy and whole.

Honey also agrees with Treasure's views and admits that "God has brought me this far and he's gonna carry me this far through." Similarly, Tina feels that without God she would not have lived her life this far with the virus, especially as a survivor of an abusive relationship:

I could have been done been dead, but He keep on sparing my life for some reason, so that's why I'm doing the things that I'm doing now to change my life, because I could have been dead. When my health was getting worse when I was in that relationship, he could have took me.

When he used to beat me up so bad, my life could have been taken. It's for some reason he keep on sparing my life, and I ain't taking it for a joke no more. That's why I'm doing the things that I'm doing now.

God kept sparing Tina's life and keeping her safe. She was beat several times within inches of her life by her partner, but she managed to continue to stay alive. God has protected her when she was being abused, and has kept her healthy while living with the virus for over 10 years. Her life has become dedicated to living for God, so she could honor Him the same way he has honored her.

Lisa has also changed her life since finding out she was living with the virus in order to strengthen her relationship with God:

I started getting better and better with God about going to church and I go to Bible study and stuff like that. I learn a little bit more. I haven't clung

to God not really, for about a year and a half all the way. I'd say about 6 months completely cuz see I was real sick. God is the head of my life and everything else. I'm confident in God about everything now. Cuz sometimes when you get sick you don't know when you get sick. When you feel bad you don't know when you feeling bad. When you can't get up and walk and stuff like that get you. When I turn to God anything is possible, anything. When I turn to God people talk about me and saying bad things about me I don't worry bout it. I walk off. God will work it out.

After she got sick she decided to give her life completely to God, which meant trusting him completely with her health and well-being. Once she did that she felt an inner peace inside her, and nothing bothered her. God was in control of her health and her destiny and it stopped her from worrying about anything.

Diamond also felt like she had to strengthen her relationship with God. She discussed how she saw other people getting sick from AIDS and told her mom "he's dying with it, and he looks bad." She started to worry that it could have become her who would look sick and died, and stated "I just be like one day that's going to be me. It makes me scared, like I know I gotta get myself right with Him. I'm trying to work on my relationship with God, I know I done backslid, but I'm trying." Diamond wants to have a good relationship with God before she passes away. Her seeing other people dying with AIDS made her afraid that she would die without a healthy relationship with God. Her diagnosis was a catalyst for her to strengthen her relationship with God.

Take me to another place

A few of the participants turned to drug use as a way of coping with their status. Four of the women had been former crack users: Shay, Simone, Nicole and Keisha. Keisha admitted that as soon as she found out her status she went back to smoking. She wanted to smoke enough crack to kill herself and said “to be honest I had a shitload of money and I just brought dope and was smoking all night and for some reason it didn’t work. I sat there and I just cried and cried.”

Keisha had been clean for a few years before hearing her status, but once she found out she was HIV positive she started smoking again. This time, she was trying to smoke herself to death, instead of going back to her regular drug use.

Shay used crack again in order to escape the reality of her HIV status:

It took me to the place of heaven, Lord, wherever you wants to lead me. You don’t even have that on your mind. It was like spaced out. Coke, smile, grin, laugh and don’t worry about it. I ain’t saying it ain’t in your conscious mode, it’s gonna be right there, but it just knocks that out of the way so you can feel free of that depression or whatever that is. Tell you the truth it made me more depressed when I came down. Hell I don’t know, I never figured that out. I’m already depressed, I got a bad heart and I got HIV. This is one of the ugliest things black women gotta deal with, and we still gotta walk with our heads up. How in the hell you gonna do something like that? Ain’t no way in hell you can do it. So I’m thinking for a few minutes let me feel a little bit better, do the drugs, let me do the damn drugs.

For Shay doing crack cocaine helped her to forget that she was living with HIV. She was able to escape her everyday reality of living with the virus. Even if it is for a few minutes the drugs helped take her to heaven. She currently still struggles with her drug use, as she tries to continue to cope daily with her status.

In contrast, for Nicole and Simone they shied away from reverting back to using drugs as a coping mechanism. Simone stated that she did not feel like she could return to drugs because she was saved, and instead relies on God to get her through her days. Likewise, Nicole stated that she wasn't tempted to turn to crack because "those two don't mix, that don't mix. You gotta be strong, you gotta be strong." She didn't want to turn back to drug use because of the way that she felt, and stated "I rather have this any day, than to be out there on that dope. I really do, I'm telling you." Nicole feels happier living with HIV coping without drugs than the way she felt when she was on drugs. She takes one day at a time and says "my momma says you don't let nothing bother you and I said why should I?" She lives her life trying not to worry, but instead focuses on being worry free.

Out of sight, out of mind

For some of the women, even after their initial reactions they lived for years in denial about their status as a way of coping. Tina admitted "I was still having sex with people unprotected, I was still in denial." She refused to accept her status and continued to live life like she didn't have the virus. She continued to get pregnant, and described how she lived in denial until she lost her daughter:

I didn't believe it when I had my 10 year old I still didn't believe it. Then
I had a set of twins, I buried my baby when she was 4 months and that's

what did it, that's what did it in 2000. I was just ready to end my life. I just didn't want to live no more, I didn't know how my life was going to be from that point on, I aint know if I was going to be still living today. I had went and I had got one on one counseling and I had got group counseling. If it wasn't from these people from the HIV ward, I probably would have been gone. But I thank God for them people cause I'm still here.

Tina stayed in denial until her daughter died. When it finally hit her that she was HIV positive, and she lost her will to live. Her coping mechanism of denial was gone, and now she was faced with the reality that she could die at any moment and she became depressed. Through counselors at the HIV ward she managed to gain new hope on live, and learn how to live life as a HIV positive woman.

For Kim her form of denial is by not talking about having the virus. This was accentuated by her response to my first question during her interview. When asked how she found out about her status, she talked for awhile about her unborn child, her kids, job search and fiancée and did not talk about her being positive until towards the end of the interview. She discusses why she does not like to talk about her status:

I said if I live to see all my kids and I think that I want to see my grand kids that I would not think about it. As long as the caseworker don't come by I don't get depressed, I don't get frustrated , I be fine. And then she come around and things start back over again. I don't know what to do and I get depressed all over again. I just get in a space when she comes around and its frustrating but I talk to her. A situation that a lot of people

don't understand, they don't want to talk about that all the time cuz you have to go through this mess and you get depressed and it starts to hurt. She can't tell me how to get over everything. When she come round here it don't do noting but depress me more and more and I don't try to be like that, but I can't help it. I don't want to go through all of that.

Kim decided she would live her life caring for her children, and hopefully spending time with her grandkids, and not focus on her positive status. She would rather live this way than become depressed and frustrated because she is living with HIV.

Keisha has similar views:

I'm gonna be honest, to tell you the truth. I ain't wanna hear it. We can go to the store and I could see a sign with something with HIV on it or a commercial and I turn my head, that's what I do. It make me feel bad. I don't want to hear it, I don't want to hear it.

For Keisha, thinking about the virus hurts her and makes her feel bad. She turns away when she sees billboards or signs about HIV because she doesn't want to acknowledge that those signs pertain to her. Her way of coping is to ignore anything HIV-related and act like it does not exist.

HIV saved my life

For others, becoming HIV positive has helped save their life and has enabled them to become a better person. Believing this has enabled them to cope with their status and be at peace with their diagnosis. Nicole says:

[First] it was like I couldn't believe this, that's what was on my mind, naw, not me. But then I said yes me. I stayed in there for about a week or

so, and then I had to shake it off. I said you know God don't make no mistakes, everything he do is for a reason, and that reason was to bring me out them streets and stop smoking that crack. That's what I feel in my heart, he don't make no mistakes. Everything He do is for a reason.

When Nicole was first diagnosed, she was briefly in denial. Then she clung to her relationship with God and realized that God doesn't make mistakes. She believed the reason for her HIV status was to stop her from smoking crack. She admits that "I didn't have a life, honestly I didn't have a life. The only thing I wanted to do was get high all the time. I really didn't have a life." Smoking crack took her life away, and reduced it to nothing. God brought her back to life by creating the circumstances for her to become infected with it. She is able to live more at peace knowing that she could have wasted her life away doing drugs and being in the streets. Instead of HIV being a death sentence, for Nicole her HIV status became a life sentence.

For Michelle HIV also helped to save her life and change her for the better. She believed God allowing her to keep having kids who did not turn out HIV positive exemplified her true calling in life:

I felt like there was a reason behind all this and the reason was to really slow me down. The reason why he allowed me to get this was to slow me down. For me to keep having all these kids was to slow me down even more by saying look you're not only thinking about you, think about others. I thought everything was about me. If I didn't feel right I'd leave or whatnot but I thought everything was about me. My kids, my first two oldest kids my mom have. I thought God was saying think about your

child, think about what you're doing to your body, think about that I done allowed this to happen to you, but by the grace of God your count is so high that it's undetectable but you know it's there. But think about somebody else besides you and that's what I had to realize. It's not all about me it's about my children now.

Prior to becoming infected with HIV, Michelle focused on herself instead of her children. She would hang out with her friends and be in the streets partying. Her mom ended up obtaining custody of her children because she did not want to stay home to take care of them. After she became infected she continued to get pregnant and none of her children ended up testing positive for the virus. This realization made her realize that she was supposed to have HIV in order for her to be a better mother. Now she had to think about her children and take care of them and develop a relationship with them. She realized that her life's focus is not about her, it's about her children.

For both Michelle and Nicole, a relationship with God was also present which helped them cope with their status. They believe that God allowed them to become infected in order to force them to change their life. If he did not allow this to happen they would have destroyed themselves. Becoming HIV positive was the catalyst for them to change their life.

Disclosure Issues

Disclosure was an issue for all of the women. Many went through different triumphs and tribulations as they disclosed to their children, partners, family and friends.

Don't wanna be a burden

A large portion of the women hesitated about disclosing their status to their children. They did not want to hurt them, and wanted them to be able to live and enjoy life without worrying about their mother being sick or dying with HIV. Tracy stated that “I don’t really want to burden nobody else, it’s mine. It’s really my problem ya know? So as long as I take care of myself and do what I’m supposed to do I’m just working and taking care of my kids right now.” Tracy doesn’t want to burden her children with her status or anyone else. She feels like as long as she does what she is supposed to do to take care of her children she does not need to tell them about her health. Her HIV status is her own burden to bear and she does not feel like anyone else needs to share that load with her.

Some of the women do not want to disclose to their children because they know it will hurt them and they wanted them to be able to focus in school. Kim shares about her children: “I still ain’t told them. I don’t know [if I ever will]. I don’t know because I don’t want it to affect them in school because things like that will affect a child in school. I don’t want it to. They alright. Right now while they focusing on school I don’t want to put them through that.” She feels like her children would be too stressed worrying about her and be unable to focus on school.

Simone has similar sentiments and states why she doesn’t want to disclose to her youngest daughter:

My baby girl she pretend like she tough or whatever, but if I get sick she be like oh mom, then she’ll say I can’t go to school and I be like you go to school Ima be alright. Like last time I had surgery because they found

some cancer in the uterus and she was like I'm not going to school and I'm like yeah you go to school, but she be like she worry too much. She 13 and I don't wanna; I just want her to go ahead and finish school.

Simone has other health problems that she has been dealing with, and her daughter worries about her when she gets sick. She knows that her daughter will worry a lot if she told her that she was HIV positive, so she decides not to let her know. Like Kim, she wants her daughter to be able to focus on school without agonizing over the fact that her mother has HIV.

Lisa believes that her children would be more hurt if they knew she had HIV, so she leads them to believe when she gets sick it's due to other health problems:

I don't want them to know about that, they my children. I just never told them. I think it would hurt them, and I don't want them to hurt themselves, I want to protect them. They think I get sick with diabetes.

It's easier for them to handle diabetes.

Her children know that she has diabetes, and she feels like this is easier for them to cope with than her living with HIV. She is afraid that not only would her positive status hurt them, but that her children would try to hurt themselves as well in reaction to that news.

Tina also does the same with her children and says "I don't want to hurt my kids, so I'm gonna keep it to myself...My daughter knows I'm on meds, and she know that I was sick; it was from an accident so I left it at that." She feels better letting her children believe she takes pills due to a car accident, instead of HIV.

Keisha had similar reasons as to why she doesn't want to tell her son about her status:

I don't want to put nobody through no pain like that, how long she gonna live? I just don't want to put nobody through no pain like that. That's why I ain't tell my son. My son think I got cancer because I was in and out the doctor and he was like ma what's wrong with you? You know a child gonna keep wanting to know why you keep going, why you taking all these pills. You know I came and got that mass in my head, so he was like what's wrong with you, and it was like baby I got cancer. That's what my grandmother died with and he saw she lived this long, my momma can live that long time. [He said] oh ok, you take those pills to make you fill better. Yeah, but maybe one day if I stopped taking them pills something will happen to me, so as long as I keep doing that he'll be alright. But if I just dropped down and told him that he'll do bad in school, he'll stop making honor roll, and then he'll try to do something somebody else doing. I can't just drop down and tell him like that and bring his whole world down.

Keisha did not want to cause her son any pain by telling him her HIV status. It was easier for her to tell her son that she had cancer because his grandmother died of cancer. Her son knew that his grandmother lived a long time with cancer, and she wanted him to feel like she would live a long time too. She also felt like if he knew about her HIV status he would be concerned about her health and not be able to focus in school.

Nicole, Kaya and Diamond also didn't want to devastate their children. Nicole says about her son "to me that's been my best friend, and I'm like I can't break his heart like that, I don't wanna break his heart. Maybe when he get older I'll be able to tell him,

but right now I'm just not ready." Her son is not only her child, but also her best friend. She doesn't think that he could handle her status, because it would shatter him and break his heart. Kaya agrees and also says she wouldn't tell her son "I don't think I'll tell him. I think [it might break his heart]. Just the fact to know that it could take me, that'll bother him, so naw I wouldn't tell him, he's a mess." Kaya knew that her son would be wounded if he knew that there was something that could take her life away. She wants to protect him from knowing her status, and keep him from worrying about him. Diamond shares those same views and says about her daughter "I will probably tell her later on, when I have to I will. When I'm on my deathbed I guess. I don't want to tell her because I don't want her to be hurt." She feels like its better not to burden her daughter with her HIV status until she is actually dying of AIDS. These women would rather carry their burden themselves than hurt their children with their HIV positive status.

Don't worry momma

Some of the women disclosed to children, and they received different reactions. Nicole's children were very supportive of her and stated:

My oldest son, said well momma if anything happen to you, you coming where I am, and Ima take care of you. He live in another state. He said I'm gonna take care of you, I said well I hope it don't get to that point. My daughter, she just said well momma, we still love you, we still love you unconditionally, no matter what, and I said well good. They don't ask me no questions about it or anything, but they do ask me about the medicine. They push that.

Her children were accepting, and assured her that they loved her and would take care of her if she got sick. They demonstrated unconditional love for her, and encourage her to take her medication so she can live a good quality of life.

Shay's relationship with her children changed for the better. Because of her struggle with drug use for over half of her life, she had a tumultuous relationship with her children. She confessed that they never really showed their love for her except when they wanted something. Yet, something magical happened when she disclosed her status to them:

It's free will love this time for once in my life, and they know I got HIV. They call me momma. They don't call me Shay. That's just...When I was bad I got sick up there at the hospital first time in my life that child ever kissed me on my forehead and said I love you momma you gotta do something better than this, you can't leave us like this. Now the oldest one can't stand me, but now he come up to me and say momma, use a condom 'dough, and now he call me momma, and that boy 26 years old. So when I tell them I ain't gonna always be here, they say don't talk like that ma, you gonna be here a long time, you ain't got nothing but the virus, and I dare a bitch out here to say something to you or about you too. And don't nobody bother me no more. So I'm doing good.

When Shay disclosed her status to her children, they begun to love and respect her. She never heard them say 'I love you' without having an ulterior motive. She became important to them, and they didn't want to loose her. Her eldest son never had a favorable view of her, but for the first time in her life he kissed her and expressed his

love for her. That changed her life, and also helped her cope with her status. Her relationship with her children has become stronger after she disclosed her status to them.

Michelle's relationship with her children also changed after she revealed her status to them:

Me and my 12 year old we fuss, we argue and bump heads and he's mad at me because he say everyday he wake up he think I'm not going to be breathing. We have kind of got distant. Before this we were real close, but now we're just....He's mad, he's very upset with me, he says 'it's your fault' and he hates me, he think Ima leave him and he don't want that. I tell him well baby if so it's God's will and he says I know, but I'm mad at God. I keep trying to tell him look, don't be mad at God it's my mistake. It was my stupid mistake, my stupid judgment, but know that I love you regardless. And he's like I'm mad at you too because you shouldn't of made the stupid mistake and I'm always going to be mad. He said well who supposed to watch me going down the aisle when I graduate. I say well maybe God will let me live a little bit longer. And he say well I'm just in the 7th grade, you got a long way to go. It's just crazy. But my 13 year old, me and her we are best friends, best friends. She cried and she was mad and then she said you know what momma, I love you regardless. She said whatever the situation may be I love you regardless. I said ok and she said Ima pray for you and I said alright, pray for me.

Michelle's son took it hard when she told him that she was HIV positive. He was so angry with her that he distanced himself from her because he was upset at the possibility

of losing his mother. He is mad at God, because he feels like God allowed this to happen and will take his mother away. The two continue to argue because he can't contain his anger at her becoming infected. He's rejected her, not because he is afraid to be around her due to her status, but because he wants to protect himself when she leaves him. Michelle is not sure how to adjust to his reaction, and just tries to continue to love him. In contrast, her daughter was initially angry and then decided to express her love and support for her mother. Her and her daughter have grown closer and continue to be best friends.

In response to her diagnosis, Michelle has also changed the way that she interacts with children. She revealed that her kids think of her more as their sister than their mother. She explains why she does not mind them thinking that way:

When I'm around them, it's like a parent is supposed to enforce rules, I don't because I feel like I only got one time to live and I don't know when God is going to be like I'm fin to take her life. Before, this sickness I got was real hard. I had [gotten sick] and they had to put me on a breathing machine and that was really scary. I said I'm not gonna be rough, I'm not gonna be tough. I'm going to treat everyday as it being my last day because if I be harsh on them or try to enforce some type of rule on them and then I leave this world they gonna say oh my momma hated me, or my momma didn't like me or something. So I want to spend everyday that I have, that I'm breathing with them, I don't care what they want to do, I'm going to do it regardless. I'm just like a child when I'm around them.

Michelle felt like she was faced with death when she was put on a breathing machine. When that happened she decided to change the way she engaged her children. She used to be a tough disciplinarian, but she decided to change this tactic and let her children feel free to do anything they wanted. It is important to her that they remember her being loving and kind when she passes away instead of harsh and strict. She wants to enjoy each moment with them without them being angry at her, so she can leave a loving memory of herself in their hearts.

Simone's said that her oldest daughter did not act hurt when she disclosed her status. Her daughter said "momma you for real, and I was like yeah. She was like ok. So we've been through sickness, and I told her and that's it, but my baby girl, she don't know." Simone had been through so many other illnesses that her daughter was not totally phased by her HIV status. She felt like they had made it through other illnesses and would make it through HIV.

Honey's daughters don't believe that she's really living with the virus. She says that:

They tell me all the time that they had to make a mistake because I don't look like it; I'm always feeling good and doing good. I always say you don't really know, that's just a persona that I show you all. She said well do you really feel sick sometime, and I say no, not really to tell you the truth but not physically sick, but sometimes it bothers me mentally and emotionally.

Because Honey 'looks' healthy her daughters do not really believe that she has HIV.

They think their mother was not really diagnosed with the virus. Honey tries to explain

to them that living with HIV involves more than just physical deterioration; it can also destroy you mentally.

Honey had decided to disclose to her daughters because her youngest daughter got pregnant, and she did not want her daughter to have to embody the same mistakes she made. Honey reveals “my youngest daughter, she’s quite promiscuous, and it scares me and one of the reasons why I didn’t tell my daughter my status then because I thought she was too young.” She didn’t believe that her daughter was mature enough to hear about her status. Additionally, she didn’t want to hurt her daughter “because for her to know that her mom and her dad had the virus, I just didn’t want to burden her with that. I felt like I had to because that’s a part of being a momma. You have to love and protect and guide and you can guide.” Honey decided to disclose in order to protect her daughter from making bad sexual decisions.

We are family

Women also had mixed responses when they disclosed to family members and friends. Many women did receive love and support from their family when they divulged their status.

Kim says when she told her family:

My whole family was hurt but they support me the best that they can.

They try to keep me comfortable and they see what I have to have or if I need anything, or if I need them to go pay my bills. They very supportive and I like that. At first I felt that I let the family down. They had talked to me and stuff and say girl you ain’t let us down, don’t feel that way and everything. They support me real good.

Kim's family was hurt when they found out, because of what she now had to go through. She felt like she had disappointed her family by becoming infected with HIV. Instead they showed her their support, and try their best to comfort her and supply her with things she may need. LaToya's family also embraced her with open arms and says that her mother still treats her the same "even though she say that I get on her nerves, but she still treat me the same as she treats my other sister. She ain't change nothing, she treat us and love us differently, but equally, that's the best part about it." Her mother does not treat her any differently just because she's positive. She still is loved and respected member of the family.

Nicole's family also reacted positively and didn't treat her any differently when she informed them about her positive status:

My family, they know about it, and they don't hold it against me, they love me, and they don't treat me no different. Most people need to get educated on it because they think you can get it by touching them and all kinds of stupid stuff, but it's not like that. I be around my family and my grandkids you know, it's not like that, they just need to get educated on it, and most people don't want people to know because the way they would treat them.

Nicole's family also treated her the same when she told them her status. She cites education as being key in her family not stigmatizing her. She's even trusted to be around her grandchildren, because they are not afraid of her passing along the virus to other family members.

For some of the women, lack of HIV knowledge led them to becoming shunned by some family members when their status was disclosed. Michelle recalls an incident with one of her aunts:

She's off the chain. We went to her house for dinner and she's ignorant to the fact of how you can get it. Everybody else eat with me, real forks, plates and stuff. This lady come putting a plastic plate in front of me and a plastic spoon in front of me. And she say you can not pass it to other people like this right here. I said well you're ignorant to the fact if eating behind me can give it to you then you're ignorant and you don't really know. I said soap and water and bleach won't hurt nothing. She said no I just wanna be safe. I said ok then. So I asked for some water, she messed around and gave me some of her real cups for some water. Do you know she threw it in the trash afterward? And I sat down and she cleaned up behind me and I felt very uncomfortable and I felt really bad. So I let her know, you know what, you clean up behind me from when I was sitting down, you threw your stuff away in the trash, you act like I'm just a disease waiting to happen to leech on to you. It don't work like that, but you really hurt my feelings, but it's alright though, uneducated people really don't know. I said it take for you to be in my shoes to understand that you don't got to be so protective with your kids, or you can't play with them, or that you scratch them, or if you bleed you got to protect them. When you get into my shoes then you'll really understand how I

feel. So she was like I'm doing it for my own safety and I said ok then, I will not come back to your house no more, and I haven't been back.

The rest of Michelle's family openly accepted her after she disclosed to them. Her aunt however, still lived in fear and believed that HIV could be transmitted just from Michelle being in her presence. These actions made Michelle feel low and she decided never to return to her home. Dee was also shunned by family members as news of her status spread like wildfire:

When it comes to HIV and AIDS there's a stigma, and you hear people say harsh things. Some of my family and sisters, they kind of ostracize you. One of my aunts can say well you're not in my family but she's one of the aunt's that got such a persuasive way of talking that she can turn all of the family members against you and then you turn to be the black sheep. But I keep telling myself that truth will prevail, truth will prevail, but when it comes to this it doesn't matter. I just started contacting one of my family members on my father's side. They're so mean. I went to my grandmother's funeral and they were so cold. And one thing that I've heard one of my aunts say is 'what's she doing here?' And I'm like you are my mother's sister that was my grandmother. Like you're asking what am I doing here, and then you had your family members sitting here looking at you like a stranger. That gets hard. But through it all I made it.

When Dee's family members found out about her status they ostracized her and disowned her from the family. They treated her with disdain and scorned her because of her status. This moment was very hard for Dee and she cried after she shared this and said it was

really hard for her to be treated so cruel by her family. She expected to be stigmatized by people who didn't know her, but not by her own family members.

Tina fears telling other family members not because of fear of being stigmatized, but because she did not want to hurt them with her news:

I'm just scared to tell my brother that I'm really close to. I can't tell my brother, I can't tell him. I'm afraid of his reaction, he's gonna be hurt, I don't wanna hurt him. I don't want to hurt him. I couldn't even tell my sister, and now I wish I would of and I think about it everyday. I'll let them find out whenever my time is out. I know it's gonna hurt them worse, but I just can't tell them. I think about it all the time. Trust me, I want to tell them but I can't. I can't tell them. I can't tell them. I'm healthy now, so I'll just keep that fact to myself, but I can't tell them. I can't do it.

Tina really struggles with sharing her status with close family members. Although she is wrought with pain living with the virus, she doesn't want to put her family members through pain. Her sister passed away before she could tell her that she was infected. She'd rather live her life as the healthy woman her family knows and tell them about her health when she is sick and dying from AIDS.

What about your friends

Many of the women in this study stated that they had few close friends, and mainly interacted with family members and their children. Some women experienced negative reactions when they disclosed their status to some of their friends. LaToya was completely shunned by her friends and retreated into a pit of despair:

The way my friends treat me now, is different than the way they did beforehand. They used to be over here everyday and we'd just sit here and chill, watch TV, be on the phone, talk about people, but now they don't call me, they don't come by or nothing. [I was feeling lonely]. Very lonely. I used to pay a lot of people to be my friend. I used to give them money to be my friend. It was a lot of people that used to pick on me. I played by myself, and I got tired of playing by myself, and I felt like I was obligated to pay people to be my friend. I'd give them money, give them my lunch tray or the food that my momma fixed me for lunch just so they could be my friend. They take it. They would talk to me, we'd be go outside, we'd play together and then we get back in the classroom around the rest of the people.

LaToya was young when she found out about her HIV status, and was still in high school. News spread in her town about her HIV infection, and her current friends disowned her and stopped interacting with her. She was feeling so lonely that she paid other people to be her friend. This helped her be able to deal with her loneliness and the fact that her friends left her by herself.

Michelle was also scorned by one of her good friends when she told her she was HIV positive:

I started getting treated different for real and one of my bestest friends she just stopped coming around. So I called her and I was like you know why don't you come to my house no more, what's going on with you. She said I'd rather not deal with people of your kind. And I was like what do you

mean, and she was like people like you, and I said ok then I respect that,
I'm gonna give you your space.

Rather than dwell in the pain of rejection, Michelle decided to not be around her anymore and give her space. Their friendship then became severed because of her friend's fear of her HIV status.

Ironically Michelle's friend called her 4 to 5 months later and told her that she was HIV positive and that "I have the same thing you have." Once she heard that news Michelle did not reject her. She responded by saying "Ima friend, regardless of what my situation may be, I'm still going to be your friend, I'm not going to be like you, you shied away from me, but when you needed me you came to me in conference. Me and her we tight, but we ain't tight like we were before." Michelle decided to provide support, even though her friend shunned her only a few months ago. Although Michelle told her friend she'd be a shoulder for her to lean on, she still felt differently towards her because of the reaction to her positive status, their friendship forever changed.

For better or for worse

Participants have also disclosed to their sexual partners. Some partners accepted their status better than they thought they would. For example, Diamond's partner told her "I don't care, we're soul mates already" when she disclosed to him and they got married. Interestingly, some sexual partners didn't believe some of the participants were actually HIV positive when they told them their status. For example, when Kaya told her partner she stated:

He stuck by me. He said ain't nothing wrong with you, they just using you as a guinea pig. They just want to tell you to take some medicine and

they don't even use that medicine. Ain't nothing wrong with you. He talking about it's only wrong with you if you say its wrong. I'm like ok, that may be true but I know what the doctor say. He said well what did God tell you? I say ok, I'm going to leave it alone if that's how you feel. Her partner felt like she didn't really have HIV, only that the hospital was using her as a guinea pig for medical testing. He did not want her to embrace her status, but instead rely on God to release her from her diagnosis.

Similarly, Treasure's boyfriend also suggested that she was merely a carrier and did not really have the virus:

He was like people done hurt you so much, it just seem like you just a carrier and I felt like by me having sex with you, I took a chance by having sex with you unprotected and I knew about your situation but I didn't have anything. It kind of made me feel like well they saying that I have something, I'm going through all this, what is it really? It didn't make me want to go out and sleep with a lot more people or nothing, it just made me wonder why I'm not passing anything? Another guy told me the same thing that I didn't pass anything to him. He went and got checked and he said I didn't pass anything. And I'm like well I guess I'm just a carrier. And I'm like that's odd because people pass this stuff everyday, and then when I go to the doctor and the doctor tell me well baby you fine, you know your just as good as anybody else is.

Her boyfriend feels like Treasure had been hurt so much in life by others that she is just a carrier of HIV but doesn't really have the virus. Therefore, he feels comfortable having

unprotected sex with her, because he feels like she can't transmit anything to him.

Treasure somewhat embraces that theory, because she has engaged in unprotected sex with several other men, and none of them became infected. She also continued to get pregnant by her partner and all of her children have had a negative status. Her theory as only being a carrier was confirmed when she went to the doctor's office and was told her status was undetectable.

Michelle's partner also felt comfortable continuing to engage in unprotected sex with her and decided to remain with her no matter the circumstances:

If it's God's will, it's God's will. He already know what's going to happen before we know what's going to happen. I just hate that you put this right here on me but I'm just gonna stick by you. He stuck by me for a minute and then he got distant, then we came back and got [my daughter]. Thank God she's negative. He's been around, trying to help keep me motivated and just being there for me. He said that we gonna keep trying regardless and if I love you and it's God's Will then I'll get it too cause I love you. I mean it's this guy that I've been with since God knows maybe 5th grade me and him been together. We got a 13 year old, and a 12 year old together. He was like I'm going to stand by you and that's what he did.

Michelle's partner decided that he was going to support her when she told him her status. Furthermore, he decided that because he loved her, he would continue to engage in unprotected sex with her. God had preordained events that happened to them, and if he was supposed to become infected too then he would.

LaToya's boyfriend wanted to continue to have unprotected sex, but she believed that he didn't know how HIV was transmitted:

He was cool with it at first. When I told him I was HIV positive, I told him before we even had sex we could still be together, but we'd just have to use a condom. He didn't wanna do it, he wanted to have sex without a condom, and I wasn't going for that. I don't want nobody to be screwed up because of me. I was like ok, forget it, just leave it like that. Honestly I don't think he thought you could get it He was like well why do I have to use a condom? I said because you'll get it through sexual contact. He was like well can't you get rid of it. I don't wanna mess nobody up with my situation or my problem because he don't wanna use a condom or whatever you gonna do. I mean he still come over here, we still speak, we'll sit here and talk and chill or whatever, but as far as unprotected sex, can't go for that.

Not only did LaToya's partner think that HIV could not be transmitted through sex, but he also believed that there was a cure for HIV and LaToya could just 'get rid of it.' Alarmed by this lack of education she decided to break up with him because he kept insisting on having unprotected sex.

Honey thought that her partner would not accept her, and kept her status a secret. It wasn't until she got sick that she felt compelled to tell him:

When I told him of my HIV status it didn't matter to him. He said it's gonna be alright, I'm here, I'm gonna learn about this, and I'm going to deal with it. He went and got himself some literature, spoke to his doctor

and what not and we've been together. It was about 4 months before I told him. But I told him that I had just found out. But at the time he and I when we had sex it would always be protected. Then when I got sick I really had to tell him. And that's when I told him that I just had found out. I should of told that man, but I just couldn't bring myself to tell him. I just couldn't. And to tell you the truth I think that if I wouldn't of gotten sick I probably wouldn't of told him. But, that took a lot of stress off of me too, because that was like a big, not one elephant, but 3 or 4 elephants on my back that you have to carry. Cuz I would want to tell him, because he was so loving and caring.

Honey's boyfriend embraced her when she disclosed to him. He learned more about the virus, and then decided to stay with her. It was hard for Honey to inform him, and instead of telling him she made sure they used condoms 100% of the time. Although she was afraid at first she was relieved to finally have told him because of his love and concern for her.

Kim was also terrified to let her partner know about her status:

I was scared because I ain't know how he was gonna look at me or how he was gonna take it but then I told him and we both shed tears and he said he still wanna be with me and he still love me and everything and he not gonna stop being with me cause of that and he say he finally found somebody. He say he gonna be there for me and my children. He say because he finally found somebody who could love him the way he love them. He was like he just said that he feel comfortable being with me and

he say people make mistakes. He say he not gonna stop being with me and he still wanna marry me, we gonna get married regardless. He just said he ain't gonna let me go because of that. He made me feel better and everything. I felt a whole lot better when I told him because I got it off my chest. That was stressing me out too but then since I told him it don't bother me no more.

Kim's partner still professed his love for her. Like Diamond he felt like he found his soul mate and wanted to continue to be with her. He knew that she made a mistake and didn't want to punish her for it by leaving her. Her HIV status was not going to make him leave her. Kim's partner's profession of his love helped her cope with her status, and made living with HIV more bearable.

Tisha however, still does not know how to disclose to her partner, and keeps it to herself. She says that he knows "a little bit, I kinda told him bits and pieces but I haven't really told him the actual thing. I be telling him stuff like I could have it but he act like he really don't care." She says that they "use protection all the time whenever we are intimate." She wasn't sure why she could not fully disclose to him, because she didn't think that he would treat her any differently. She merely stated that "It's hard to tell a person that. " Tisha still holds on to the fear that keeps her from telling her partner.

Small town living

For many, living in a small town with HIV provided a lack of confidentiality, and as several women put it "everybody knows everybody's business." This reduction in privacy has made it harder to receive treatment and care and just live in peace with the virus.

Party at the clinic

Shay expresses her dissatisfaction with the amount of privacy she has when she goes to the clinic to receive HIV-related care:

The only thing I hate with having this is having come to an area like this place here cuz everybody here knows who works here and it's very uncomfortable, I don't like it. It pisses me off. There is no privacy in this place at the health office. When they had a place where there wasn't nothing but people like me I felt better. But in a public place and you have to come here that shit pisses you off every time you come here because everybody knows cuz everybody know some type of somebody. They gonna see these same disease people and then they come back again, and then they gonna say this bitch gotta disease, I'm gonna come back here and see she had it.

Because of the small town, everyone comes to the clinic for different health problems.

Within the health clinic is the Ryan White Clinic that serves HIV clients. Shay feels like people still know who is getting treated for HIV, and there still is no privacy. When people see who continuously comes back to receive care, she believes that they spread to others who they believe is positive. This situation angers her because she feels like she can not receive confidential care. Tina also says there is no confidentiality in the clinic because "there's too many people in and out."

Dee agrees with the lack of privacy in the clinic as well. She believes that "people around here talk", and was angered one day when "someone who didn't even know me came up to me and told me something from someone I trusted." That

information reiterated to her how easily information is spread in such a small town. Dee describes how her husband protects her when she goes to receive care at the clinic:

Sometimes when we come here I have the appointment and he sees someone in the lobby area which in some sense that really shouldn't be; you shouldn't be in the same area as everyone else, you should have a separate area or entrance, something like that. But like I say you only work with what you have. Someone would say oh what are you doing here? And he would put the blame on him and say I'm going to see the doctor or something like that. I'm over there looking like it shouldn't have to be that way that he would take the blame on whatever was going on himself just to protect me. But he knows how it is here, this is his hometown.

Her husband takes responsibility for the doctor's appointment when they go to the clinic, thereby reducing the scrutiny placed on Dee. She also acknowledges how rural health clinics don't always have the resources that they should, and there should be a private entrance for HIV positive patients in order to protect their identity.

Kaya also takes steps to protect her identity when she goes to the clinic to receive care:

I don't really like coming out here, because I know a lot of the people that work here, and a lot of people that be in here. The clinic is stereotyped for that anyway. One time they had a building and they was off by themselves, then all of a sudden they brought them back out here. I never like to come to the clinic. I come if I had to, but if I don't have to I won't.

They try to schedule me to come later in the evening or something like that or early in the morning, spacing it out so nobody run into anybody. I be the first one to come, so that way you can do it, then you can go on.

Kaya knows the people who work at the clinic, as well as clients who come there, so she does not want the clinic traffic to see her come in for her appointment. When she schedules appointments she tries to come early in the morning, or at the end of the day in order to avoid the most people possible. Like Shay and Dee she agrees there should be something separate for people who are living with HIV/AIDS.

Horror in the hospital

Some of the women feel like the hospitals in their town don't really care about them and stigmatize them because they have HIV. Michelle says "that hospital over there will let you die. They don't even house people. They just sees you and send you out. That's the butcher over there now. So I definitely go and get help somewhere else." She doesn't feel comfortable going to the hospital to seek care because of the way they treat people. There is a lack of concern for the people that they treat.

Honey affirms that statement and shares when she was hospitalized and thought that she was going to die.

When I was sick one doctor wanted to put me in a hospice. I said oh hell no, I'm going to check myself out of this hospital because I'm not ready to die, I don't feel like I'm close to death. This doctor, he was so crappy. I was telling this man what I was experiencing, and he would just send me back home. No x-rays, he would draw blood but that would be about it, or give him some urine and that would be about it. He didn't look deeper

into it. At this time I was in and out of the hospital, they couldn't tell me what was wrong with me, why I couldn't breathe. I go to the city and in less than 24 hours they tell me I have fluid in my lungs, and they had to perform surgery to get the fluid out of my right lung and that was it. But this doctor, I guess he didn't want to take the time, he didn't care, he didn't have the knowledge, I don't know what it was. But his first thing he did was put me in a hospice and I'm like hell naw, that's not me, let me go. And I just wonder if I didn't have the faith that I have in God I would of just went to the hospice, I would have. And for that reason that's why I go 50 miles round trip to see a doctor, and I don't go to the hospital because I don't trust the hospital. I really don't.

Honey went to receive care because she couldn't breathe and was instead sent to the hospice to die. The doctor who treated her did not try to find out what was causing her not to breathe, and Honey feels that because she was HIV-positive didn't bother. Instead her told her that she was dying, and sent her to die. Once she went to a bigger city to receive care she found out she merely had fluid in her lungs and filed a complaint against the hospital. Because of he way she was treated she doesn't go to the hospital in her town anymore, and would rather drive out of her way in order to receive compassionate care.

Dee also believes that the hospital lacks care and professionalism.

Now in the hospital that's a different thing. My son-in-law's brother was ill and the nurse, I knew her. She had the neighborhood kids in her home and she was telling them about the people in the hospital names that were

ill. I got really angry because I'm like professionals are not being professional and they are also running to find out who has it because they've been trying to find out about me. Someone professional will tell. I was in the hospital a year ago and now I can't even go to get my hair done with my daughter. My neighbor she do hair, because they know somebody who work in the hospital too and they be trying to get it out my daughter saying I heard your mother was in the hospital. I do have more than one thing that can put me in the hospital but the cancer is not what they are worried about. They're worried about that 3 letter word.

Because it's such a small town, the hospital employees usually know the clients who come in and have leaked information about her, which has spread throughout town. Now people are asking her family members if she has HIV. Dee is more outraged that the professionals are leaking information rather than the people who live in town.

News at eleven

Michelle also experienced the ramifications of living in a small town. Her HIV positive status spread like wildfire throughout her town when she had a confrontation with her boyfriend. She hit him in the back of the head with a hoe when they argued about him cheating on her. She describes the incident "[he said] that's why you're dying, that's why you have AIDS and I don't want to be with you. He kept falling behind so the girl had a hoe by her door and hit him in the back with it and then the police broadcasted it in the paper." This incident made the news, and because so many people witnessed the confrontation many people knew they were referring to her. After that was printed Michelle stated that "people in town look at me crazy, and then they go to whispering and

I already know what they're whispering about, this a small town, everybody talk, so I rather just be by myself." Since the news of her status spread, Michelle would rather isolate herself than to deal with people in town.

Shay also felt bad when people found out her HIV status. Her mother told one friend, and that friend told another friend and the news "kept going like the energizer bunny and it never stopped." Eventually her entire neighborhood knew about her status. Shay says that "I still walk with my head down, but I don't bother nobody. They still respect me in a certain sense, but you can hear them talk about you-heh, you know she got that package, or that bitch got that." She can't walk around anywhere in her community without most people talking about her and knowing that she's HIV positive.

In order to avoid being the center of attention in their city, both Lisa and Keisha let people know they have other illnesses in order to avoid people finding out about their HIV status. Lisa says that "everybody knows that I have diabetes", so she doesn't worry about anyone finding out when she gets sick. Keisha says "they know I've been dealing with these tumors" and people think that the tumors on the back of her head were caused by cancer. By highlighting other health problems, they can keep their HIV status private.

Views of the body

In sickness and in health

Interestingly, a large portion of participants (68%) had other existing health issues that they were dealing with. Lisa suffers from diabetes and actually got sick during our interview due a low blood sugar level. Simone also has diabetes, high blood pressure and a bad heart. Shay, Nicole and Keisha are recovering crack addicts. Nicole also has high blood pressure. Shay still goes through withdrawal and has a low attention span. She also has high blood pressure and a heart that functions at 27%. Keisha also has tumors and has

several masses that are on the back of her head. Dee has been dealing with cervical cancer, and has been hospitalized with this illness. Shonda remains in pain from untreated gallstones, and does not have the insurance to pay for an operation to remove them. Treasure has syphilis, juvenile arthritis and suffers from strokes and epilepsy. Currently pregnant, she takes additional medication to help keep her healthy. Tina was involved in a car accident and suffers from muscle spasms that cause swelling and back problems. She too was in discomfort during our interview. For most of them, their other health problems cause them more problems than HIV. As Simone put it “HIV is the least of my worries” as it pertains to her health.

Letting go

However, for some, their relationship with their body changed as they continue to live with the virus. Lisa admitted “I don’t get stuff like I used to, and get my hair done and stuff. But I’m fin to start back. I fin to start back.” Lisa used to be concerned about having the newest clothes and keeping her hair done. Now, that’s not as important to her anymore, and she feels like she has “let herself go” due to her illness. She’s not as concerned with her outwardly appearance as she used to be.

Spoiled goods

A few women feel like their bodies have been spoiled because of their HIV status. In a sorrowful voice Honey remarks “I feel like it’s tainted, because I can’t give blood. I can’t help anybody in that way, I can’t save a life, I can’t donate an organ. I’m tainted, that’s it.” She feels like her blood and her body is not worth anything because she can’t do anything with it to help others. Her body can never be used for healing, and it will always be marked.

Keisha also feels bad about her body. When she gets sick or injured she tells her partner not to touch her or put any blood on her. Additionally, she also says to everyone in the household “don’t wash my clothes with ya’ll, I’ll wash my clothes by myself, or wash them in some Clorox bleach.” She also makes her partner wash every dish she uses in bleach. She feels like her body is now a vessel that can infect others, and also thinks of herself as tainted. Instead of viewing her body as a way to spread love, it spreads disease. When asked why she felt like she had to isolate herself in this manner she said she wasn’t sure, that “I just don’t want to put that on nobody.” She doesn’t want to take any risks of infecting anyone else.

Both Kaya and Michelle share similar views, and both women stated “I don’t really like to be all around people like that.” Instead they chose to keep their body away from others, in order to decrease their chances of infecting other people. In fact, during our interview Michelle had to cough and felt uncomfortable being in front of me doing so. When I asked her why she felt uncomfortable, she stated that she didn’t want to expose me to anything, even though she knew that HIV could not be spread in that manner. These women now feel more self-conscious about their bodies and their interactions with others, now viewing their bodies differently because they are infected.

Both Diamond and Tisha don’t even view themselves as sexual beings anymore. Tisha is now repelled by sex and admits when it comes to having sex “me and him don’t even sleep together all the time because I don’t even really like doing it anymore cuz that is what got me in the situation that I am in now. If I do it, it’s to satisfy him, but I don’t like to do it.” She now thinks of sex as the means that got her infected, and doesn’t want

to be involved in it anymore. Her sexual desires are absent from her body and she is no longer a sexual being.

Diamond also feels the same and does not have sex with her husband that often as well. She said “it done got old, been there, done that, I’d rather go to the store.” She sees her body entirely different now and no longer has sexual desires. When she does have sex, it’s only to satisfy her husband and she doesn’t enjoy it. She says that “he can’t tell, I get an Oscar.”

Choosing Life

One day at a time

Many of the women explain that they just take each day “one day at a time” and try to live with the status. Most of them are mothers, and just try to take care of their children and do the best that they can do to survive. They have optimism, hope and faith that motivate them to thrive every day. Nicole sends a message out to HIV positive people everywhere and says “the people that have it, they gotta keep the faith and don’t give up. Don’t give up cause it’s not as bad as people make it to be, it’s not as bad.” LaToya says “I’m dealing with it, like I said I just read my Bible day and night and I just take it to God and pray and just leave it there. Let Him deal with it. He can deal with things better than I can. But it really don’t bother me. You just have to take it one step at a time.” She puts it in God’s hands and tries to just enjoy life. Kaya feels the same and says “I’m good, I ain’t going nowhere.” Simone finishes off this viewpoint by saying “ain’t nothing to add, because like I say you take one day at a time and you take what’s thrown at you. If you want life regardless of what it is, you can have it. Don’t let it get to you. Like I say, it’s not the end of the world.” They chose to just live.

CHAPTER 5

DISCUSSION

The goal of this study was to examine the experiences of African American females living with HIV in the rural Deep South. In order to learn more about these experiences, the following research questions were developed: 1) How did women living with HIV in rural South Central Georgia discover that they were infected with HIV? 2) What are the life experiences of women living with HIV in rural South Central Georgia? In order to answer these questions I interviewed 17 African American females who received care at a Ryan White Clinic located in South Central, Georgia. The study was a qualitative study that employed grounded theory methods during data collection and analysis. This chapter discusses the findings and conclusions and recommendations drawn from the study and the implications that they have for further research.

Discussion of findings

Research question #1: How did women living with HIV in rural South Central Georgia discover that they were infected with HIV?

Women were asked how they found out they were infected with HIV, and the circumstances surrounding that situation. Approximately 50% of participants found out that they were HIV positive during pregnancy, during doctor's visits when they first found out they were pregnant, or during routine prenatal care. A large number of participants also found out about their status while incarcerated either in jail, or mandatory drug treatment facilities. Women were not receiving regular HIV testing,

which is congruent with other studies in the literature that have examined HIV testing behaviors among African Americans in the rural South (Thomas, 1999). In rural areas there are limitations such as mobility which impedes access to healthcare that may reduce the frequency of obtaining regular HIV testing (Castaneda, 2000 & Adimora, 2006a).

Women in this study frequently found out their HIV status only during routine medical testing. This may also be due to the silence around of HIV related behaviors that is often prevalent in the South (Reif, 2006 & Thomas, 2006). People are hesitant to participate in HIV-associated risk reduction behaviors for fear of stigma and shame of in participating in sexual activity. What has been absent from the literature is a focus on this phenomenon of women who find out their HIV status during pregnancy. The large number of women simultaneously finding out their status during pregnancy has implications for the need to emphasize routine HIV testing in rural areas.

Many of the women wanted to kill their partners when initially finding out their status. There were mixtures of anger, fear and helplessness as women processed what living with the virus meant and how that changed their relationship with their partner. The majority of women were infected by sexual partners who they were in a monogamous relationship with, which includes being married, engaged, or cohabitating with a long-term partner. Most women knew their partners for many years, with several growing up with their partner living in the same town. Most women were not engaging in risky sexual behaviors, which has also been similar to findings in the literature that have examined modes of infection among HIV positive women. Mallory (2008) found that among a sample of 10 HIV positive women, 7 out of 10 of the women were infected by partners they were in a monogamous relationship with. Therefore, they considered

themselves low risk for HIV infection. Only three of the participants were infected due to other HIV risk factors which were drug use, and exchanging sex for money.

In this study, I also only had 3 participants who had used drugs, but they did not become infected due to drug use behaviors; they were infected by partners who cheated. O'Leary (2006) also found that drug addiction among southern African American females was not a major risk factor for HIV infection. Additionally, in many of the Adimora et al. studies, it was found that rural African Americans have a high incidence of concurrent (shared) sexual partners (Adimora et al. 2005a, 2006b, 2007b). Women in my study were also a part of this shared sexual network that helped lead to them becoming infected with HIV.

Additionally, a few of the women also found that their partners were living an 'undercover lifestyle' and were bisexual. Dee suspected that her husband was, but was "always afraid to ask" and Tisha was "never really quite sure." A few others also suspected their partners may also be having sex with men, but never probed the situation. This unwillingness to discuss impending homosexuality with their partner is also one of the silences around HIV risk behaviors that Reif (2006) and Thomas (2006) discuss that is prevalent among rural African Americans.

Lack of proper HIV transmission knowledge may have also contributed to infection among participants in my study. Although not a major theme, some women did express lack of proper HIV knowledge, which may have led them to also believe that they were low risk for HIV infection. Some of the women in the study believed that HIV was transmitted: by blood only; not through sexual contact; only through drug use; by being promiscuous, by monkeys, and was manufactured by the government who infected

people with it. One participant believed that it was conjured by witchcraft by the partner who infected her. Whyte (2004) also found in a study of Southern African American women that HIV knowledge seemed to be associated with education; the higher the education, the higher the HIV prevention knowledge. Findings from the Whyte study are consistent with the HIV knowledge and education level of participants from this study, where the majority of participants did not graduate from high school.

Besides thinking about killing their partner, women also thought about killing themselves. Many women contemplated suicide, and others did actually attempt to kill themselves. For most, their attempts were thwarted either by their children, or pulling on strength from God to continue living. Several studies have shown that both a strong relationship with God (Woodward & Sowell, 2001; Parsons et al., 2006) and a relationship with their children (Shambley-Ebron & Boyle 2006; Polzer-Casarez & Shandor-Miles 2008) have helped prevent HIV infected mothers from committing suicide.

A very large percentage of participants (68%) had experienced incidents of abuse and violence during their lifetime before finding out they were infected with HIV. This includes rape, statutory rape, molestation and physical, mental and verbal abuse. Lichtenstein (2005b) also found high incidences of domestic violence among her sample of African American females. Some of the women admitted that their experiences with violence may have contributed to their vulnerability of becoming infected with HIV. For some, their experiences influenced their partner choices, and contributed to a cycle of abusive relationships.

The focus on women's HIV risk who have experienced violence has recently emerged in the literature. Studies that have focused on HIV positive women who have experienced intimate partner violence (IPV) have found that IPV can be both a risk factor and consequence of HIV. Being a survivor of violence was found to be a significant risk factor for unprotected sex, as well as partners deliberately forcing women to participate in HIV risky behaviors (Gielen, McDonall, Burke & O'Campo, 2000; Zierler et al., 2000). Additionally, (Wyatt et. al, 2000a) found that compared to HIV negative women, HIV positive women reported more incidents of abuse. Experiences with abuse and intimate partner violence were very prevalent in my study, and this phenomenon occurring among HIV positive women is increasing in the literature.

Interestingly, one factor that has not been prevalent in the literature is HIV positive women who had been abused engaging in bisexual relationships with women. A few of the women in this study, Treasure and Michelle felt more comfortable with women after being abused and pursued relationships with women. They felt safer around women and wanted to protect themselves. Additionally, Keisha was raped when she was a child, and later became bisexual. She also became infected from another woman. Bisexuality as a means of coping among HIV positive women has not been thoroughly explored in the literature.

Research question #2) What are the life experiences of women living with HIV in rural South Central Georgia?

Women were also asked to describe what life has been like for them since finding out about their HIV positive status. Similar to what was stated earlier, a relationship with God continued to help women live and cope with being HIV positive. In this study,

many of the women believed that God kept them healthy, and a common phrase utilized was “I only got it if God says I got it.” They relied on God to keep them positive and healthy. Other methods of coping were also similar to other studies in the literature, which included depression, drug use and denial of one’s status. Moneyham (2005) indicates that HIV functioning is linked to these methods of coping as well as isolation and withdrawal. Some of the participants also isolated themselves as a means of coping.

As time wore on, many of the participants became “used to living with this” and learned how to cope positively with their status. Besides a reliance on God to get them through each day, they developed positive attitudes and outlooks on life. This was done by avoiding stress, and having increased family support. Bletzer (2007) also found that HIV positive women in their sample avoided stressors that may have triggered their illness as a way of functioning.

For some, helping others was also a way of coping and living with their status. Dee expressed the desire to become a “ray of hope” for other women, by living a positive lifestyle. After our interview was completed, she admitted that our session was therapeutic for her and expressed the desire to become a counselor. This was an avenue she never thought about exploring until after becoming HIV positive. Additionally Nicole stated “if something that I say or do can help other women [living with this], then I’m going to do it” after we completed our interview. Being able to provide support for others was also a means of coping.

Furthermore, for some women living with HIV actually helped to save their life and helped them to become a better person. Michelle felt like God allowed her to become HIV positive in order for her to be a better mother to her children. She now has a

different relationship with her children than she did before finding out her status.

Additionally, Nicole and Shay were drug addicts and their HIV status helped them reevaluate their drug use. This notion of seeing HIV more as a positive life change than a negative one was also found in a study by (Siegel, 2000) whose HIV positive participants found growth in the midst of their HIV positive adversity.

Disclosure to loved ones was difficult and also resulted in relationship changes for several participants. HIV disclosure, especially among Southern African Americans may be especially hard, due to the stigma and shame associated with living with in the South (Black & Miles, 2003). In this study, most women found it hardest to disclose to their children, and did not want to burden them with worry of their HIV status. For those who did disclose to their children, some of their children showed love and support, while others distanced themselves from them.

Some friends and family members also shunned and disowned many of the participants, and stigma and fear remained the prevailing reason why members did not want to interact with their HIV positive family members. This secrecy and silence is once again highlighted, and often prevents education around HIV transmission (Reif, 2006).

For the majority of women who disclosed to their current sexual partners, their sexual partners accepted and embraced them. Some partners remarked that they were “soul mates” and still wanted to be with them, and HIV was not going to scare them away. Their partner’s lack of HIV knowledge was also exhibited when women disclosed their status. For example both Treasure and Michelle’s partners stated that they were “just a carrier” of HIV and could not infect anyone. They continued to feel comfortable

engaging in unprotected sex, even after knowing women's positive status. A few other women also had partners who continued to engage in unprotected sex with them, because they did not think HIV could be passed through to them, or that you could not get it through protected sex. This also resulted in pregnancy after HIV disclosure for several of the women. Additionally, Kaya's partner said she did not have the virus, that she was just a victim of government experimentation. He did not believe that HIV truly existed. Although their partners accepted them, there was still some uncertainty about the transmission of HIV.

Disclosure was also hard for women because of the lack of confidentiality due to living in a small town. Many women did not even trust coming to the clinic to receive care, because they believed that people would know that they were infected. This made it harder to live with HIV in a small town, for fear of being treated differently if their status was found out. For some women, when one person found out about their status, their entire community knew, and they were looked upon in disdain. Some of the disclosure of their status to others came from their healthcare workers in the hospital, who often treated them with disdain and did not give them proper care. The lack of confidentiality in rural areas and disdain by health workers has been heavily documented in the literature, and continues to be an issue for rural residents (Adimora et. al. 2006a, Agee, 2006, Lichtenstein, 2003).

For some women, their relationships with their bodies changed. Some viewed their bodies as diseased, and did not want to expose it to others. Honey felt like she was "tainted" and could never give her life to help someone else. Their relationship with their bodies changed as they viewed themselves as the infected. This also resulted in the

abandonment of their appearance, and lack of sexual desires. In a study by Lawless et al (1999), they found that HIV positive women looked at their bodies with guilt because they were plagued with a disease and could not be a nurturer and bringer of life. Their body now represents something new that has been forever changed.

Overall, the majority of women have adopted different methods that have helped them cope with living with their status. Faith in God and a strong spiritual basis was a very strong foundation for all of the women, and has helped them deal with their status as they continue to take one day at a time.

Limitations of the study

Although there were several rich findings in this, there are some limitations to this study. This study was a qualitative study, which limits generalizability to the rest of the population. However, the nature of a qualitative study is to better understand a phenomenon, instead of generalizing to the population. Also, all of the women received care at one clinic, and their perception of services may be biased towards that one clinic. I tried to reduce this possible bias by sampling participants from different counties in order to have a wider range of participants.

Additionally, all but one of the participants were mothers, which did not allow for a broad range of perspectives of women living with HIV. There were however, a diverse range of age groups, which contributed to different viewpoints being represented.

Implications for practice

There are implications for practice for providers who provide services to HIV positive clients in the rural Deep South. As cited previously in the literature, rural populations often lack the resources and services to provide proper healthcare. However,

existing services could be modified in order to improve care. In this study, the lack of HIV knowledge was common for both the women living with HIV and their loved ones. Several studies (Morin et al, 2004, Mitchell et al, 2001, Geibert et al, 2006) talk about the need to increase prevention for positives, and how that is a part of effective care.

Even after becoming positive, some of the women still demonstrated a lack of HIV knowledge. A few participants did not know that two HIV positive people can reinfect one another. Some also believed that HIV could be passed throw the air, clothing or utensils. Also, many of the women continued to participate in unprotected sex with their partners, not fully realizing the implications of engaging in unprotected sex. These views indicate the need for HIV prevention strategies and education to become an integrated part of HIV case management and care. The spread of HIV stops with HIV positive persons, and they can be used as a tool to help reduce the incidence of HIV.

Furthermore, hospital workers and medical professionals need more training and care in working with HIV positive clients. Several women indicated the disdain and poor care that they received when they were treated in the hospitals. Stigma was still prevalent even among professionals, which has also been documented in the literature (Lichtenstein, 2003). Hospital professionals need to be trained more on confidentiality, sensitivity and the skills needed to treat seropositive clients. This training will also help increase the lack of HIV doctors in the area. For example, in Sachron County, the one doctor who treated HIV positive patients died, and no other doctor in the area is willing to provide care for clients. The women have to find a new doctor and travel even further

just to receive proper care. If hospital workers were better equipped to work with PLWHAS, this would increase care options.

Participants also indicated that there was a lack of effective mental health care in their area. Whetten et al. (2008) reported that mental health care needs to become a key ingredient of care when serving HIV positive clients. Many of the women in this study had issues with coping and functioning, and still struggle to live a healthy life. Additionally, many have experienced several incidents of trauma that have never been addressed. This can lead to a continual cycle of involvement in unhealthy relationships Wyatt et al. (2000). Existing HIV caseworkers could also be better trained at providing mental health services.

Many participants also stated that they never saw any prevention messages in their community. Existing health organizations can create more prevention messages and awareness around HIV. This can help increase several needed HIV related services. Routine HIV testing needs to be more emphasized, especially due to the number of women in this study who found out about their status during routine pregnancy care. If there were more visible prevent messages, more people may be willing to get tested regularly.

Additionally, because of the lack of awareness and discussion around HIV, many women were afraid to disclose to others because of the fear of being stigmatized. As Nicole stated, more education can help reduce stigma. HIV education was a key component in her family not fearing being around her when she disclosed to them. This fear of stigma has encouraged some women to disclose to loved ones only when they are on their deathbeds dying of AIDS, instead of while they are living with HIV. If there was

more knowledge of HIV by others, this may contribute to an increase in HIV disclosure. Knowledge of one's HIV status can also aid in reducing the spread of HIV.

Finally, more services need to exist for children who have HIV infected parents. For all of the mothers in the study their relationship with their children were key influences in their decision making process. Many did not tell their children because they did not want to hurt them. If there were better support services for children of HIV positive parents that may ease the burden of fear women don't want to put on their children. Children could also receive mental health services and other forms of support to help them cope with their parents living with HIV.

Implications for research

This study has shown the need to continue research among HIV positive persons living in the rural Deep South. In this study there was a large portion of women who had experienced some form of abuse before becoming infected with HIV. Research needs to continue to focus on the relationship between IPV and trauma and women's vulnerability to becoming infected with HIV. This focus is especially important in the rural Deep South. Treasure was raped and had to see her attacker almost everyday because he lived 3 blocks away from her. Ruralness may make it may be easier for women to encounter their attacker, thereby making their healing process even more traumatic. Due to the lack of services focusing on IPV in rural areas, it is imperative to examine how trauma may increase the risks of HIV infection.

More research focusing on prevention for positives also needs to be developed. There is an apparent lack of HIV transmission knowledge among the women and their sexual partners. Research focusing on the sexual practices of couples in serodiscordant

relationships may be helpful in tailoring messages and interventions that focus on HIV prevention for these types of couples. Also, HIV knowledge in rural towns needs to be better understood, in order to create better prevention activities that can help reduce HIV incidence in this area.

HIV prevention research focusing on rural communities needs to continue. Rural communities lack certain infrastructures that larger cities have in providing HIV-related care. HIV prevention methods can be created using *existing* resources of rural communities, instead of recommendations that continue to be made based on bringing in *new* resources. Once we better understand rural communities we can better tailor prevention messages.

Conclusion

We are now in our 25th year of learning about HIV. We continue to make gains in understanding how the virus works in our bodies, modes of infection and ways of protection, the creation of vaccines and microbicides, understanding risk behaviors of HIV infection and providing care for HIV positive persons. However, even with our increased knowledge, people continually become infected with HIV. Additionally PLWHAS continue to be stigmatized, despite the gains we have made over the decades. The rates of new infections are especially high among African Americans, and continue to increase among African Americans in the rural South. I had the amazing opportunity to learn more about the experiences of living with HIV among African American females in the rural South. The more we continue to learn, the better we will become at creating tools to combat this virus. As we are learning, we need to continue to remember to treat PLWHAS with care, dignity and respect.

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