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HIV Positive African American Women's Lived Experiences and Clinical Outcomes

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2020

Abstract

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Dissertation Submitted in Partial Fulfillment

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Abstract

African American (AA) women are disproportionately affected by HIV/AIDS. The infection rate for AA women continues to increase, and literature lacks information specifically on education for AA women regarding viral suppression at diagnosis. The purpose of the study was to understand the lived experiences of AA women living with HIV in the District of Columbia, particularly how they acquired knowledge of viral suppression. To understand their experiences with antiretroviral medications, viral suppression, discrimination, and stigma, this qualitative study applied a hermeneutic phenomenological approach. The theories of resilience and empowerment were applied. Ten HIV positive AA women living in the District of Columbia were selected through purposeful sampling. Primary data were collected through semistructured open-ended interviews. Clinical data from DC Health/HAHSTA HIV Surveillance system were used to triangulate responses. Participants' self-report showed 80% achieved viral suppression. Study findings indicate that education on the importance of viral suppression was not consistently provided to women at time of HIV diagnosis. Unprotected sex, men returning from prison, and lack of HIV education were named as factors spreading the infection. The consistent factor in HIV survivability for the sample were unfettered access to HIV treatment, availability of antiretroviral medication, self-efficacy, spirituality, and support group. This study promoted social change by identifying precise areas of HIV education for AA women to be incorporated in HIV prevention and treatment interventions.

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Dedication

This dissertation is dedicated to my mother, Theresa Nwazonu Onyekachi, who passed on to Glory, January 3, 2019 after celebrating her 80th birthday on December 25, 2018. My mother lives on!! Thank you, Mama, for the opportunity to be literate, this degree is for you.

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My deepest and sincere gratitude to God, my maker, redeemer, savior, the reason for my being. But for his intervention, I am alive and sane to embark on this great journey. All praise to Jehovah, Yahweh and my personal Lord and Savior, Jesus Christ. I acknowledge my wonderful family who supported me, my loving husband, Chief Nnamdi Olejemeh, my children, Chimnonso, Amanda, Matthew, Amarachi, Ugonna and my wonderful gift of a grandson, Osinachi. Thank you for being there in various capacities; I love you all. To my late father, Peter Onyekachi, may your gentle soul rest in peace. My wonderful brothers, sisters, nieces, nephews, and in-laws—this degree is for all of you. Thank you and God bless you all.

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I am forever grateful to all the organizations and people I did not mention but contributed in some measure to the successful completion of this dissertation.

Table of Contents

List of Tables vi

List of Figures vii

Chapter 1: Introduction to the Study...1

Introduction..1

Background of the Study 7

Problem Statement..15

Purpose of the Study 17

Research Questions...19

Theoretical Foundation 19

Resilience Theory 19

Empowerment Theory 20

Conceptual Framework..21

Nature of the Study 22

Definitions..25

Assumptions...31

Scope and Delimitations 32

Limitations...33

Significance of the Study 35

Summary..37

Chapter 2: Literature Review...38

Introduction..38

Literature Search Strategy....38

Theoretical Foundation....40

Theory and Origin....40

Rationale for Application of Resilience and Empowerment Theory....45

Previous Applications of Theories....46

Literature Review....50

African American Women and HIV/AIDS Epidemics....50

Knowledge of HIV Transmission among African American Women....51

Social Demographics of HIV/AIDS....53

Community Viral Load....54

Treatment of HIV....56

Guidelines for Treating Adults and Adolescents....57

Guidelines for Treating Women: Considerations for ARV in women with HIV....57

HIV Medications: Medication adherence....60

HIV Continuum of Care....63

Viral Suppression and Health Outcomes....66

Stigma as a Barrier to Treatment....69

HIV/AIDS and Health Disparities....70

Summary and Conclusions....72

Chapter 3: Research Method....74

Introduction....74

Research Design and Rationale....75

    - The Study Phenomenon 76
    - Research Tradition 77
  - Role of the Researcher 79
  - Methodology 80
    - Participant Selection Logic 81
    - Purposeful Sampling 81
    - Inclusion Criteria 82
    - Sample Size 83
    - Saturation Point 84
    - Instrumentation 84
    - Recruitment, Participation, and Data Collection Procedures 85
    - Data Analysis Plan 90
  - Issues of Trustworthiness 91
    - Ethical Procedures 93
  - Summary 95
- Chapter 4: Results 96
  - Introduction 96
  - Research Setting 97
  - Demographics 98
  - Data Collection 99
  - Data Analysis 101
  - Evidence of Trustworthiness 103

        Credibility 103

        Transferability.. 104

        Dependability.. 104

        Confirmability.. 105

    Study Results 105

        Research Question 1 106

        Subquestion 1a.. 113

        Subquestion 1b.. 119

        Research Question 2 124

        Research Question 3 129

    Summary...135

Chapter 5: Discussion, Conclusions, and Recommendations...138

    Introduction...138

        Key Findings.. 138

    Interpretation of the Findings..140

        Advancing New Knowledge 140

        Support for Findings of Other Studies 142

        The HIV Care Continuum.. 145

        High Community Viral Load 146

        Increases in HIV Infection Among AA Women...................................... 146

        Gender Is Associated with Increased HIV Infection Risk 147

        Findings in the Context of the Theoretical and/or Conceptual Framework........ 148

        Methodology: A Phenomenological Approach 149

    Limitations of the Study..150

    Recommendations..151

        Future Research 152

    Implications for Positive Social Change..153

    Conclusions..154

References...157

Appendix A: Specific Codes and Themes that Emerged from Data and Quotations from Participants..194

Appendix B: Responses to Question 1a...196

Appendix C: Responses to Question 1b...197

Appendix D: Responses to Question 2 198

Appendix E: Responses to Question 3...199

Appendix F: Permission to Alter Survey Question....................................201

List of Tables

Table 1. Demographics of Participants 99

Table 2. Data for Triangulation from DC Health/HAHSTA 100

Table 3. Women Newly Diagnosed with HIV in 2000 (Ages 35-54) through 2018 101

Table 4. Specific Codebook and Themes from Question 1 106

Table 5. Participants Age, Viral Load and CD4 Count at Time of Diagnosis………… 107

Table 6. Specific Codebook and Themes from Subquestion 1a 109

Table 7. Specific Codebook and Themes from Subquestion 1b……………………… 110

Table 8. Specific Codebook and Themes from Question 2 110

Table 9. Clinical Outcomes of Participants 111

Table 10. Specific Codebooks and Themes from Question 3 112

Table 11. Comparision of HIV Continuum of Care 131

List of Figures

Figure 1. HIV prevalence by race/ethnicity and gender identity, District of Columbia, 2018. 4

Figure 2. 2016 Care dynamics among women living in DC, by selected characteristics. 5

Figure 3. 2018 DC HIV Continuum of care. 64

Figure 4. Care dynamic among HIV cases living in District of Columbia, 2016. 64

Figure 5. 2018 Care dynamics among Ryan White Clients, District of Columbia. 66

Figure 6. Care dynamics among women diagnosed with HIV living in Washington, DC, in 2016 67

Chapter 1: Introduction to the Study

Introduction

Human immunodeficiency virus (HIV) affects millions of people globally. HIV is defined as a retrovirus which attacks the T-lymphocytes cells in the body, destroying the body's defense mechanism against infections (CDC, 2019). The infected person becomes immune compromised, with potential to degenerate into acquired immune deficiency syndrome (AIDS). At this point, the person becomes symptomatic to the HIV infection, with symptoms including, diarrhea, rashes, weakness, and unexplained weight loss. The immune compromised body is then frequently attacked by opportunistic infections such as Pneumocystis Carinii Pneumonia (PCP), fungal infections, syphilis, Hepatitis B, Hepatitis C and Mycobacterium avium complex (MAC), among others (Panel on Opportunistic Infections in HIV-Infected Adults and Adolescents, 2018). HIV virus is transmitted through unprotected sexual intercourse with an infected person, sharing needles and syringes during injection drug use, from mother to child, and transfusing HIV contaminated blood (WHO, 2018b)

In 2017, there were 36.9 million people living with HIV around the world and 35.1 million of them were adults, while 1.8 million were children under the age of 15 (United Nations on AIDS, 2018). According to United Nations, about 940,000 people died of the disease in 2017 and 35.4 million since the disease epidemic began (2018). In the United States, an estimated 1.1 million people have been infected with HIV (Center for Disease Control and Prevention [CDC], 2019a). The CDC also estimates that 38,700 new infections occur yearly (2019a). HIV was first reported in 1981 among men who have sex with men (MSM) in Los Angeles (CDC, 1981). However, in the last 3 decades, the trend in the prevalence of diagnosed HIV infection has changed affecting every demographic: race, ethnicity, age group, males and females (CDC, 2019a). Overall, in 2017, more than 7,000 women were diagnosed with HIV in the United States (CDC, 2019a). Women made up 19% (7,401) of the total 38,739 new HIV diagnoses in 2017 (CDC, 2019b). The CDC further noted that African Americans females make up 13% of the United States female population. However, 59% of all the women infected with HIV in the United States are African American (AA) females (CDC, 2019b). In contrast, Hispanic females make up 17.4% of the female population, but 16% of the disease burden (CDC, 2019b). White females are 61.2% of the female population but have prevalence rate of 20% (CDC, 2019b). There is an overall downward trend for new infections across the United States. This downward trend is not true for all groups, however. The CDC (2016a) reported an increase of HIV infections among 25 to 34 year-olds African American women for the 3 consecutive years of 2012, 2013 and 2014.

In 2014, the number of HIV infections was high among African American females in the United States, at 4,208, compared to Hispanic/Latino females at 1,111 HIV infections and White females at 988 infections during the same year (CDC, 2017). A similar pattern emerged in 2015, with the number of HIV infections for AA females at 4,075, Hispanic/Latino females at 1,052, and White females at 962 infections (CDC, 2017). In 2016, new HIV diagnosis trends based on race and gender remained consistent with AA women engaged in heterosexual contact disproportionately affected at 4,189 HIV infections. White women infected through heterosexual contact were at 1,032 and

Hispanic/Latina women infected through heterosexual contact were at 1,025 infections (CDC, 2017). Skarbinski, et al. (2015), in their analysis, confirmed reduction of HIV transmission rates along the care continuum. However, even in an analysis of reduction rates, their analysis showed increases in new infections among AA women. The steady increase in HIV infection among AA females remains a concern.

New infection in the District of Columbia is consistent with national rate, with AA women being disproportionately affected by HIV/AIDs. In 2011, the HIV prevalence rate in the District of Columbia was above epidemic level at 2.5% and the prevalence rate among AA females was at 2.6% (District of Columbia/Department of Health//HIV/AIDS, Hepatitis, STD and TB Administration [DC/DOH/HAHSTA] Annual report, 2012). In 2018, the overall HIV prevalence rate fell to 1.8% (DC/DOH/HAHSTA, 2017) while prevalence rate among AA women was 1.6%. This exceeded the prevalence rates for Latino and White women which were 0.3% and 0.01% respectively (Figure 1). Put another way, the general population of African American (AA) female in the District is 48.5% but this demographic accounted for 94.3% of new HIV infections in 2018 (DC/DOH/HAHSTA, 2019).

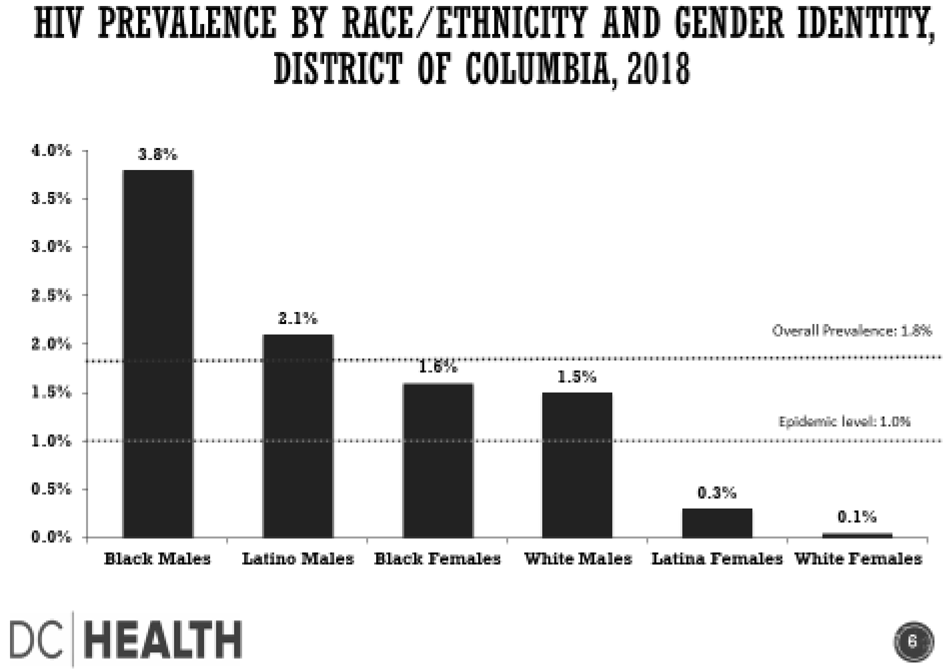
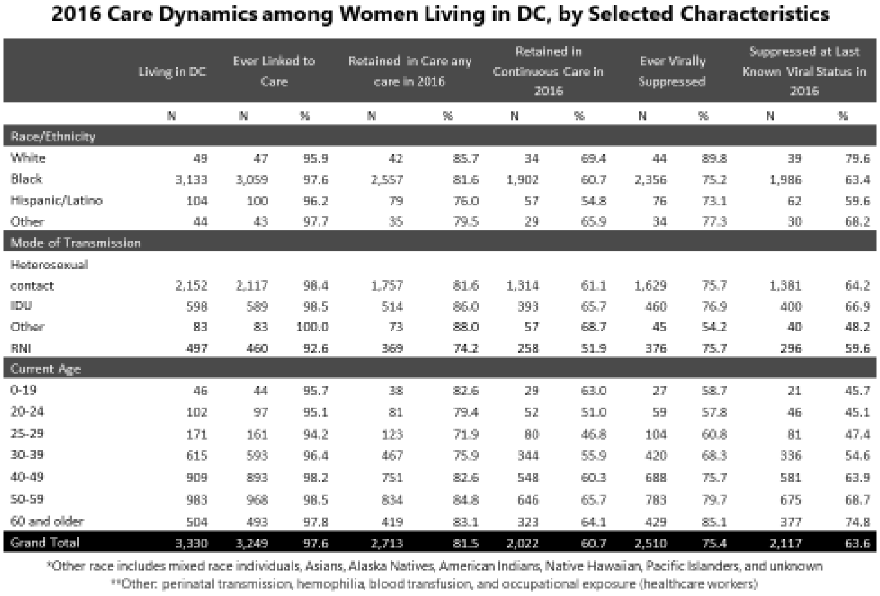


Figure 1. HIV prevalence by race/ethnicity and gender identity, District of Columbia, 2018. From “Annual epidemiology& surveillance report: data through December 2018”, DC/DOH/HAHSTA (2019).

HIV has no cure. As a chronic disease, HIV is treatable with effective active medications. The hallmark clinical benefits of HIV treatment and engaging in HIV care is achieving viral suppression (AIDSinfo, 2019). In this status, the virus is undetectable in the blood and leads to improved health outcomes (Panel on Antiretroviral Guidelines for Adults and Adolescents [DHHS Guideline], 2018). However, adherence to lifelong medications remains a challenge (National Institute of Allergy and Infectious Diseases, 2013). Holstad, Dilorio, & McCarthy (2011) found that low adherence to HIV medication was linked to detectable viral loads, low CD4 count and high risk behaviors for HIV acquisition.

In the 2016 District of Columbia HIV annual report, summarized in Figure 2 below, among AA women living with the disease, 97.5% were linked to care at some point. Amongst which 77.7% are retained in care, 57.7% had more than one medical visit. In the same report, 75.8% were ever virally suppressed while 61.7% were suppressed at last known viral status in the year (DC/DOH/HAHSTA, 2017).



2016 Care Dynamics among Women Living in DC, by Selected Characteristics

	Living in DC	Ever Linked to Care		Retained in Care any care in 2016		Retained in Continuous Care in 2016		Ever Virally Suppressed		Suppressed at Last Known Viral Status in 2016	
	N	N	%	N	%	N	%	N	%	N	%
Race/Ethnicity											
White	49	47	95.9	42	85.7	34	69.4	44	89.8	39	79.6
Black	3,133	3,059	97.6	2,557	81.6	1,902	60.7	2,356	75.2	1,986	63.4
Hispanic/Latino	104	100	96.2	79	76.0	57	54.8	76	73.1	62	59.6
Other	44	43	97.7	35	79.5	29	65.9	34	77.3	30	68.2
Mode of Transmission											
Heterosexual contact	2,152	2,117	98.4	1,757	81.6	1,314	61.1	1,629	75.7	1,381	64.2
IDU	598	589	98.5	514	86.0	393	65.7	460	76.9	400	66.9
Other	83	83	100.0	73	88.0	57	68.7	45	54.2	40	48.2
RNI	497	460	92.6	369	74.2	258	51.9	376	75.7	296	59.6
Current Age											
0-19	46	44	95.7	38	82.6	29	63.0	27	58.7	21	45.7
20-24	102	97	95.1	81	79.4	52	51.0	59	57.8	46	45.1
25-29	171	161	94.2	123	71.9	80	46.8	104	60.8	81	47.4
30-39	615	593	96.4	467	75.9	344	55.9	420	68.3	336	54.6
40-49	909	893	98.2	751	82.6	548	60.3	688	75.7	581	63.9
50-59	983	968	98.5	834	84.8	646	65.7	783	79.7	675	68.7
60 and older	504	493	97.8	419	83.1	323	64.1	429	85.1	377	74.8
Grand Total	3,330	3,249	97.6	2,713	81.5	2,022	60.7	2,510	75.4	2,117	63.6

*Other race includes mixed race individuals, Asians, Alaska Natives, American Indians, Native Hawaiian, Pacific Islanders, and unknown

**Other: perinatal transmission, hemophilia, blood transfusion, and occupational exposure (healthcare workers)

Figure 2. 2016 Care dynamics among women living in DC, by selected characteristics. From “Annual epidemiology & surveillance report: data through December2016” DC/DOH/HAHSTA (2017).

There is little data in the existing body of HIV/AIDS research that focuses on African American women in order to understand their perspectives on viral suppression. This data is critical to create informed interventions that will be effective in reducing the infection rate in this subpopulation and support healthy living with HIV/AIDS. Available literature shows a gap in understanding of viral suppression and its effect on the lived experiences of AA women. It is imperative that women who are HIV positive learn the importance and meaning of viral suppression. The social change in this study is the potential to increase knowledge to prevent HIV transmission and also increase the quality of life for AA women who have the disease.

Available literature shows women of reproductive age (15-49 years) are mostly impacted with HIV (CDC, 2019c, CDC 2018a, DC/DOH/HAHSTA, 2017, World Health Organization, 2006). In 2017, 13% of new HIV diagnoses were among young women ages 13-24 (CDC, 2019c). Eighty six percent of these young women were infected through heterosexual contact. The social implication of HIV among young African American women includes transmission to newborn, known as vertical transmission. This can happen either in the uterus, during birth or while breast feeding (AIDSinfo, 2019b). In addition, HIV infected people suffer stigma, and various forms of discrimination. At the same time, some African American women have been infected at young age and living well with the disease for many years. This study expects to understand the resiliency in African American women infected with HIV that may have contributed to their experiences living and surviving the infection. This study will also attempt to understand the role of empowerment to surviving the infection.

Another potential for social change is using key findings in this study to develop interventions geared towards viral suppression among the African American community. The interventions may be implemented in various clinics to help other HIV positive AA women thrive and live well with the disease. The new knowledge will impact the development and planning of the Mayor’s “Ending the HIV Epidemic Campaign.

Chapter 1 is a synopsis of the epidemiology of HIV and the implication of the disproportionate rate of infection among women, particularly African American women. Specifically, viral load suppression will be discussed as a point of reference among this disproportionately affected population. In this chapter, I include the background of the study, problem statement, purpose of the study, and research questions. Other topics summarized in this chapter included the theoretical framework applied to the study, nature of the study, significance of the study, assumptions, scope and delimitations, and limitations of the study. Some technical terms such as *CD4 count, viral load suppression, vertical transmission, phenomenology,* and *resiliency* are defined to ensure comprehension.

Background of the Study

The United States witnesses approximately 40,000 HIV infections every year (CDC, 2019d). Meanwhile, HIV prevention focuses mainly on MSM in general, and young Black MSM in particular. However, the infection rate among African American females is at 1.9 % of new infections in the District of Columbia (DOH/DC/HAHSTA, 2017) and accounted for 4,189 new infections in 2016 in the United States (CDC, 2017). This has led Haverkos, Chung and Perez (2003) to inquire if there is an HIV epidemic among heterosexuals in the United States, found insidious and underestimated HIV epidemics among AA heterosexual community and recommended immediate mitigation strategies.

Many studies have examined HIV/AIDS surveillance data. Hall, Espinoza, Benbow and Hu (2010) statistically analyzed 2007 data in 12 metropolitan areas and found that 0.3% to 1% of the populations in each area lived with HIV. Researchers report that over the course of the epidemic, the composition of infected population has changed to include more infections among persons of color. This change in the HIV epidemic from white males who have sex with men to AA females is one of the reasons for my research focus. HIV diagnoses for African American females was 4,931 in 2011, 4,666 in 2012, 4,307 in 2013, 4208 in 2014, 4,075 in 2015, and 4,189 in 2016 (CDC, 2017). According to the same report, these number are significantly above the diagnoses of heterosexual African American men. For heterosexual AA men, 2,449 were newly diagnosed in 2011, 2,257 in 2012, 2,059 in 2013, 1,997 in 2014, 2,048 in 2015, and 1,926 in 2016. Diagnoses among Hispanic females were 1,189 in 2011, 1,054 in 2012, 1, 050 in 2013, 1,111 in 2014, 1,052 in 2015 and 1,025 in 2016 (CDC, 2017). Diagnoses among White females in the same years were 1,014 in 2011, 970 in 2012, 913 in 2013, 988 in 2014, 962 in 2015, and 1,032 in 2016. (CDC, 2017).

Hall et al. (2013) found that 857,276 persons with HIV in the United States had not achieved viral suppression, which is the key outcome of HIV treatment and subsequent reduction in transmission. Lanier et al. (2013) used surveillance data on HIV positive AA women in the District of Columbia to explore sociocultural correlates for HIV progression to AIDS. Among 3,050 women with complete data in this study, 59.4% had progressed to AIDS and, at their most recent medical visit, 36.4% had a CD4 count <200 cells; 18.8% of the participants progressed to AIDS within 12 months of diagnosis. The researchers found no relationship for progressing to AIDS with poverty, educational level, or census tract. In this analysis, 25% of women did not have the typical risk factors for acquisition of HIV except that 50% reported heterosexual sex. While African American women made up 48.5% of the estimated population of the District of Columbia in 2015, they accounted for 94.1% of all female HIV cases living in the District in 2016 (DC/DOH/HAHSTA, 2017).

Lending credence to the high need for this study is the analysis by Nwangwu-Ike, Hermandez, An, Huang, and Hall (2015) that shows HIV diagnosis is decreasing among females, but the highest rate remains for African American females. For African American women, acquiring higher education did not result in a decrease in AIDS cases (Horton, 2013). Epidemiological patterns showed African American females ages 15-35 years were still vulnerable to AIDS death but at a reduced rate. Most importantly, disparities exist in viral suppression for African Americans and younger females (Hall et al, 2013; Nwangwu-Ike et al., 2015; Gray, et al., 2013). Virally suppressed HIV infected persons are less likely to transmit HIV (Skarbinski, et al., 2015). Viral suppression reflects the result of a viral load test (i.e., the level of HIV in a person's body is very low [<200 copies/ml] or undetectable). Suppressed viral load improves the health of the person living with HIV, increases survival, and reduces risk of transmitting HIV (AIDSinfo, 2019).

Researchers have examined problems of nondisclosure of HIV status among low literacy populations to ascertain if there are potential risks or protective factors for HIV prevention and sexual behaviors. Polansky, Teti, Chengappa, and Aaron (2015) noted that 79% of women in a monogamous committed relationship disclosed to partners, compared to only 43% of women with multiple partners. In this study, none of the women with multiple nonprimary partners disclosed HIV status. Self-disclosure of HIV status was positively associated with closeness and commitment among low-income urban African American women.

When disclosure of HIV status increases, transmission decreases, and stigma also reduces (Heggeness, Brandt, Paulus, Lemaire & Zvolensky, 2017). Stigma is regarded as a major barrier that prohibits HIV positive persons from seeking care and receiving the benefits of HIV treatment. According to Buseh and Stevens (2007), African American women experience stigma socially, internally, and externally. Stigma also has deep roots in gender, race, ethnicity, class, sexuality, and culture, and continues to be seen as a great impediment to reducing HIV transmission (Valdiserri, 2002). Reducing stigma should be incorporated in many educational programs. A study by Coleman, Tate, Gaddist and White (2016) in a faith-based community noted lower HIV related stigma among females, people who had a higher education, people who knew someone with HIV/AIDS, and people who knew a gay person. Black churches have embarked on numerous health related outreach programs among the black community but stigma in black churches continues to affect the conduct of HIV related health activities (Pryor, Gaddist, & Johnson-Arnold, 2015).

Another significant predictor of HIV infection is acquisition of sexually transmitted diseases. High rates of sexually transmitted diseases offer some explanation for increased incidences of HIV (Reif, Geonnotti & Whetten, 2006; Kanekar & Sharma, 2009), as STD compromises the integrity of the sexual tract for easier acquisition of the virus during nonprotective sex. In 2016 in the District of Columbia, 8,569 people were diagnosed with Chlamydia, 3,797 gonorrhea diagnoses and 181 Syphilis were recorded (DC/DOH/HAHSTA, 2017).

As HIV continues to affect communities, especially the African American community, treatment of HIV is assessed using the continuum of care. The care continuum is a system currently used to assess and measure the efficacy of HIV treatment from the early initiation of diagnosis through a continuum of five steps. The steps of care include the number of people diagnosed, linked to care, engaged in care, prescribed antiretroviral medication, and virally suppressed (CDC, 2017). In the District of Columbia, the continuum of care begins with the number of HIV cases diagnosed and living in the District, time person was linked to care, retained in any care, and virally suppressed. Reduction in infection is one of the benefits of adhering to antiretroviral medication. An observational study conducted by Rodger et. al (2016) supported the importance of HIV treatment. The study included 1238 HIV discordant MSM and heterosexual couples to observe HIV transmission during condomless sex. The HIV positive partner was virally suppressed and on antiretroviral medication. Although, the study reported 10 HIV transmissions among the MSM couples and one in a heterosexual couple, none of the transmission was phylogenetically linked, therefore, the couple transmission was zero for the study. In other words, the discordant couple did not acquired HIV through their partners. Furthermore, the research findings of this study corroborate the results of the randomized control trial known as HIV Prevention Trials Network (HPTN052) in which HIV infection was reduced by 96% if an HIV positive partner is taking and adhering to antiretroviral medication (Cohen, McCarley, & Gamble, 2011).

HIV treatment therefore works as prevention of HIV transmission. This supports the fact that when infected people engage early in treatment, they receive the full benefit of treatment through use of antiretroviral medication. Anyone who tests positive must be treated immediately as poor engagement might decrease the benefit of highly effective antiretroviral medication (Cohen et al., 2012; Gardner, McLees, Stenier, Rio, & Burman, 2011). Antiretroviral medications have been very effective in the treatment of HIV and are also highly effective in HIV prevention.

HIV is transmitted by an infected person. Therefore, initiatives to target uninfected persons with antiretrovirals to prevent acquisition of HIV from infected person is critical to reducing infection. Uninfected individuals at risk for HIV can take pre-exposure prophylaxis (PrEP) to reduce risk of infection (CDC, 2019e). Efficacy in prevention of HIV by taking a daily antiretroviral medication called Truvada has shown promise. Baeten et al. (2014) demonstrated that a single antiretroviral medication, Tenofovir or Truvada (Emtricitabine plus Tenofovir), both provided high protection against acquisition of HIV-1 in heterosexual men and women as a pre-exposure prophylaxis. Radzio, et al. (2012) modeled the benefit of 2 weekly doses of Truvada for repeated exposures in Rhesus Macaques monkeys. The six animals that received Truvada remained SHIV negative demonstrating that vaginal and systemic levels of Truvada was protective against infection. The model showed effectiveness in prevention of vaginal transmission which might be a possibility for a simplified regimen for HIV prevention for women. In a meta-analysis of seven randomized controlled trials involving 14,804 individuals, Jiang et al. (2014) showed that PrEP was effective in reducing new HIV infection among populations at a high risk of infection. According to CDC (2019e), taking one PrEP pill a day reduced infection through sex by 90% and through injection drug use by 70%. The use of additional preventive measures with PrEP adds more preventive value.

PrEP is a successful method for reducing HIV infection risks in men and women. When prescribed, PrEP is entirely within a woman's control to use for prevention of HIV in comparison to a condom. However, Truvada as a PrEP medication is underutilized among women at risk for HIV infection (Aaron et al., 2018). Some of the systemic barriers to PrEP access are that medical providers do not offer it without insurance, lack of awareness among young men who have sex with men, and individual barriers (Bauermeister, Meanley, Pingel, Soler, & Harper, 2013; Ojikutu, et al., 2018). Although the referenced study was conducted among young men who have sex with men, it holds same for AA women. Due to the efficacy of PrEP as a prevention tool, PrEP needs to be discussed and encouraged among AA women as an important intervention and to reduce disparities.

Adherence to HIV antiretroviral medications is critical to their effectiveness as they must be taken as prescribed. In a systematic review and meta-analysis, nonadherence was associated with forgetfulness, travel, change of routine, desire to avoid side effects, pill burden, secrecy due to stigma, alcohol use, and lack of food (Shubber et al., 2016). In another study, a sample of AA women living with HIV were asked to identify roles that their providers played in enhancing their adherence to PrEP use. They identified good provider-patient relationship, holistic patient care, good patient education, effort to model adherence, and motivation as very important to adherence (Okoro & Odedina, 2016). Peer education was also mentioned as a medication adherence enhancer (Okoro & Odedina, 2016).

To ensure that women adhere to a treatment regimen, many medical providers agree women should be assessed for readiness for antiretroviral medication before writing a prescription to avoid development of resistance to medication. Smith et al. (2013) assessed 288 HIV positive patients for readiness skills in relation to antiretroviral therapy (ART). Their study used a structured survey that covered self-reported information, motivation, and behavioral skills specific to retention in pre-ART HIV care. Eligible participants were 18 years and older, newly entering into care, and ineligible for ART (CD4 > 200cell/mm3). Seventy five percent of patients in the sample were women. The findings identified eight information deficits, eight motivation deficits, and eight behavioral deficits. The researchers argued that HIV positive patients could benefit from facilitated social support, further education about the immune system, additional social motivation to build positive attitudes, and increased positive interactions with medical staff. The study also found that self-efficacy might be related to viral suppression and subsequent positive health outcomes.

Unfortunately, high functioning or self-declared commitment does not necessarily translate into medication adherence for better health outcomes. In a randomized intervention program for women being released from prison, high confidence and expectations of ability to manage disease prior to their release for prison did not materialize postrelease (Haley et al., 2014). Some of the reasons identified included substance use, relapse, stressful life experiences, and stigma.

There are no studies that focus on women's lived experiences with HIV infection and their understanding of viral suppression. In addition, there is no research on young black women's perspectives on living with HIV, barriers and challenges to medication adherence, and their views on HIV within the black community. No research has applied self-efficacy as a construct of empowerment theory and resilience to understand viral suppression and adherence to antiretroviral medication among AA women in the District of Columbia. Yet, it is paramount to understand the vulnerability of this population to HIV infection and their own understandings of the epidemic. Study findings can be applied to interventions across the spectrum of age and ethnicity both in the affected and infected to stem the tide of HIV infection in the study population.

Problem Statement

African American females account for 94.3% of new HIV infections among women in the District of Columbia (DC/DOH/HAHSTA, 2017). African American non-Hispanic women are nine times more likely to be infected with HIV/AIDS than any other race or ethnicity (Sionean et al., 2014). Thus, understanding the vulnerability of this population to HIV infection is essential to public health. Efforts to study this phenomenon have taken different directions. In the realm of social determinants, Hatcher et al. (2012) observed that women with high and moderate negotiating power with their sexual partners were less likely to engage in risky behavior than those with low negotiating power. Others have studied the effects of low levels of education on HIV infection (Melton, 2014), the shortage of available partners for college educated AA women (Newsome, Airhihenbuwa & Snipes, 2014), and the role of multiple sexual partners and prior sexually transmitted diseases (Norwood, 2011). Buseh and Stevens (2007) made an effort to understand how HIV positive women respond to stigma as a barrier to care and how women engage family or peer support and become advocates to fight stigma. Pollini, Blanco, Crump and Zuniga (2011) confirmed that isolation and stigma are important barriers to engaging in HIV medical care among persons of color. The possibility of a connection between adherence, sexual risk, viral load, and HIV infected women prescribed ART has also been investigated (Holstad, Dilorio, & McCarthy, 2011). With about 30 antiretroviral medications now available, being HIV positive has been transformed from a death sentence to manageable infection (Chen et al., 2013). However, while the overall infection rate has been decreasing in the U.S., that has not been the case for AA women.

There remains a lack of information on AA women’s knowledge and understanding of viral suppression. Consequently, resulting survival rates, reduction of risk of transmission, and improved health outcomes at diagnosis is lacking for this population. Taking antiretroviral medication is known to reduce the viral load in the blood, leading to a competent immune system when viral suppression is achieved (Cohen, McCauley & Gamble, 2012). Achieving viral suppression is key to reducing HIV infection as it ensures a reduction of the community level viral load. According to Brawner (2014), community viral load is a population marker of infectivity of people living in a geosocial area. Decreased community viral load and increased HIV testing are associated with reduction in new HIV infections (Das et al., 2010). Viral suppression reflects the result of a viral load test in which the level of HIV in a person's body is very low (<200 copies/ml) or undetectable (Cohen, McCauley & Gamble, 2012; Pollini et al., 2011). Unfortunately, a younger age is associated with late initiation of care after diagnosis and a longer time to achieve viral suppression (Pollini et al., 2011; Eshleman, et al., 2017). There is a gap in an understanding of viral suppression and its effect on the lived experiences of AA women. This study added to the literature by describing HIV+ AA women's understanding of viral suppression and how it affects their lives and relationships.

Purpose of the Study

The purpose of this study was to increase understanding of HIV infection and viral suppression from the perspectives of young AA women living with HIV. The study used a phenomenological approach to uncover the lived experiences of HIV positive AA women and viral suppression, including how HIV positive individuals are discriminated against in the community and experience strong stigma from family and friends, as reported by Buseh and Stevens (2007). Another aspect of this study was to use a feminist lens to understand black women's unequal position in relation to HIV infection. In pursuance to understand the lived experience, it is important to understand increases of HIV infection among this group through the lens of empowerment theory.

Under empowerment theory, women are asked to identify the source of disenfranchisement internally and take charge of their life decisions. As articulated, empowerment theory posits that entering into the world of the abused or oppressed helps to empathize and understand their needs. Empowerment is the process utilized to enhance the personal, interpersonal, and political power of an individual to ensure better life outcomes (Turner & Maschi, 2015). In this theory, the participants know better. My study findings support gender as the basic framework that conditions women to an increased risk of HIV infection. In an analysis of HIV/AIDS disease burden among AA women, Brawner (2014) proposed a gender responsive model as an initial step to dialogue and examination of HIV/AIDS as a social issue. Issues of gender roles and socialization may have to be explored more to understand the HIV vulnerability among African American women. One in 32 AA women may be diagnosed with HIV in her lifetime (CDC, 2014), making geo-behavior critical. Geo-behavior basically refers to where one lives, what one does and with whom, which all link to vulnerability to HIV infection (Brawner, 2014). In addition, my study findings contributed knowledge and understanding of power relationships, social constructs and social positions concerning HIV infection.

Furthermore, understanding experiences of women as it pertains to their clinical status, especially achieving viral suppression, is vital to ending HIV infection among women. Ensuring viral suppression through antiretroviral medication is a prelude to the end of HIV/AIDS (United Nations AIDS, 2014). Examining the lives of this group of women provided an opportunity to learn how they experience the disease, what prevention methods may be most effective, and how their experiences link to achieving viral suppression.

Research Questions

Three main questions drove the direction of the study.

Research Question 1: What is the lived experience of AA women with HIV/AIDS in DC?

Subquestion 1a: What are their daily routines of medication adherence?

Subquestion 1b: What challenges constitute stigma and discrimination that they face in daily living?

Research Question 2: How do HIV positive women describe/explain viral suppression?

Research Question 3: How do HIV positive women explain/describe the high rate of HIV infection among AA in the District?

Theoretical Foundation

For this study, I used two theories as foundational. The first theory was resilience theory. I used this theory to understand platform of positive- strength, protective factors and adaptive abilities that people with adversity develop instead of a focus on the deficits. The second theory was empowerment theory, applied to better understand how empowerment can aid to overcome trauma and adversity. In this section, I briefly describe each theory and why I used them for this study.

Resilience Theory

According to Luthar, Cicchetti, and Becker (2000), resilience is a “construct connoting the maintenance of positive adaptation by individuals despite experiences of significant adversity” (p 543). In an argument on the most applicable definition of resilience, Panter-Brick asserted that resilience is not a one-time achievement but sustained over time as it harnesses resources along the continuum of care (Southwick et al., 2014).

Resilience has no agreed upon definition but emerged from the field of psychology and Freud's assumptions that early negative experiences in life produces an adult with psychopathology. Garmezy, a clinical psychologist, looked at resilience in two disciplines, psychoanalysis and development. The researcher looked at the underlying reasons for the differences in outcomes of these two groups of schizophrenic patients. One group is competent, as demonstrated in the lives of the stable patients who are married, have children, and keep jobs (Rolf, 1999). They still experience schizophrenic episodes, but they recover with shorter stays in hospitals and were integrated into their community. The other group had longer stays, up to 13 years or more in institutions. The differences in outcomes of these two groups formed the premise and need to study the underlying difference in these patients, with a focus on areas such as cognitive skills, motivation, and protective factors (Harlow, 2009).

Empowerment Theory

A second theory applied in this study is empowerment theory. In this theory, women living under a patriarchal social system are subservient to men, lacking privileges that their male counterparts enjoy (Maier, 2016). Empowerment theory posits that entering the world of the abused or oppressed helps in empathizing and understanding their needs if the researcher themselves is not in the abused or oppressed group. Empowerment is the process utilized to enhance the personal, interpersonal, and political power of an individual to ensure better life outcomes (Turner & Maschi, 2015). In this theory, the impacted population knows better. Empowerment theory turns inwards for women to identify the source of disenfranchisement internally and take charge of their life decisions.

In this study, resiliency theory was studied with respect to empowerment theory. As AA women, vulnerability to HIV is not determined entirely by engaging in risky behavior but can also include geo-behavior. Thus, it is important to better understand how empowerment can aid to overcome trauma and adversity, as well as initially connecting with and moving along the continuum of HIV care.

Conceptual Framework

My study employed the resilience construct from developmental and social variables. This was more of how nurture shapes nature. There were questions of home disciplines and family culture to learn when adaptive capacity or behaviors were acquired or developed. My study tried to understand resilience on the platform of positive-strength, protective factors and adaptive abilities instead of a focus on the deficits. Although Rutter (2013) states that findings from studies that incorporated resilience may not translate into clear prevention and treatment ideas because of the dynamic views of different individuals to adversities, it can provide some positive leads to research.

What are the factors that may contribute to this resilience? An additional method used in the study included the creation of a time life trajectory. A sample of AA women was chosen to create their time life trajectories. From qualitative interviews, I collected data and created timeline beginning from when HIV infection was first diagnosed to indicating experiences along the continuum of HIV care. According to Yates and Masten (2014), a resilience concept guided study allows the researcher to emphasize competence and successful adaptation to overcoming negative challenges.

Research designed with a combination of resiliency and empowerment theories will provide information, motivation, behavioral skills, self-efficacy, social interaction that is useful in exploring the lived experiences of African American women. Semi structured interview questions were constructed using resilience and empowerment, self-efficacy, and social variables to ascertain or construct the meaning of HIV infection as unique to each individual participant. The focus was on strength (either innate or built from family interactions), overcoming adversity, staying on medication, and achieving positive health outcomes.

Nature of the Study

This qualitative study applied a phenomenological approach. Open-ended questions were used to conduct in-depth interviews of 10 women. The interviews were recorded, and audio materials transcribed. This approach has philosophical implications and tends to reduce individual experiences to a description of the meaning of the phenomenon: “what” the people experienced and “how” they experienced it (Creswell, 2013).

This study also used triangulation to validate and verify information obtained from the women interviewed by drawing on clinical outcome information of viral suppression from the DC Health HIV database. Triangulation according to Rudestam and Newton (2015) is getting information from different sources as a way to corroborate evidence. HIV clinical indicators, CD4 count and viral load were extracted from District of Columbia Health (DC Health) HIV Surveillance System. CD4 count and viral load of sample of AA women who tested HIV positive across some years, 2000, 2010, 2015 and 2018 were extracted and used as data and information triangulation.

This led to a deeper understanding of the phenomena. This qualitative approach allowed HIV positive AA women to describe their own lived experience with HIV/AIDS, discuss these clinical outcomes, and share with others. Edmund Husserl and Martin Heidegger are the two main authors of phenomenology as a qualitative approach. This methodology hinges on the assumption that reality consists of phenomena, as understood in the conscious. The uniqueness of individuals and how different individuals attribute meaning to similar life experiences and how a phenomenon is understood is also referred to as interpretive phenomenology (Burkholder, Cox, & Crawford, [Eds.], 2016; Rudestam & Newton, 2015; Kelly, n.d.). A phenomenological study identified participants from among individuals who have the relevant lived experiences in order to understand the experiences to make meaning to others. The results or findings can further be developed to influence policies and practices.

In this phenomenological study, the experiences of the participants were interpreted using the hermeneutic loop. The hermeneutic loop originated from the Greek god Hermes, known to be a messenger. It is used in the discipline of philosophy to explore and interrogate experiences. As a cyclical loop, the hermeneutic loop lends credence that to understand the whole, it can only be understood by understanding the influences of the different parts (Harris, 2015). This also means that any misinterpretation of a part will distort the meaning of the whole. Each person’s experience was different and has meaning only to that person. As such, in analysis of the data, each experience was understood as all the parts are joined together to bring out the meaning of the whole experience. To understand the meaning of the HIV experience of a participant, the cycle starts with a question about the event (HIV infection), and sorts through actions or speech that surrounded the event. The next part of the process led to what the participants did with the phenomenon (HIV infection), which corresponds to engagement with the part in the hermeneutic loop and reflects the challenges that trigger actions and feedback. The next part was to understand or reinterpret the challenges which lead to understanding the whole - living with HIV disease. The loop showed interrelationships within the parts and influences the parts to understanding the whole.

Having a philosophical basis, phenomenological inquiry discusses a phenomenon as a search for wisdom. Judgments about reality are suspended and there is an angle of intentionality of consciousness, as reality is perceived within the individual and the meaning of the experience, phenomenology also allows for the inner essence, internal subjective experiences, to be explored. In this method of inquiry, information of individual’s cognitive processing structure, which is a conscious experience, is involved (Percy, Kostere & Kostere, 2015). Therefore, making meaning of living with HIV infection, and understanding what the structure of participants cognitive processing of the experience was key to phenomenological study. Hence phenomenology investigates the pre reflective conscious experiencing of an event (Percy, Kostere & Kostere, 2015, p.77)

All qualitative data were analyzed manually. First there was a manual transcription of all interviews recorded by Microsoft word voice recorder. There was a careful reading of the transcribed interviews line by line and sentence by sentence, re-reading of all transcripts creating themes and memos.

Definitions

The following are operational definitions of technical terms used in this study.

Human Immunodeficiency Virus (HIV): This is a virus that attacks T-lymphocytes cells in the body, destroying the body's defense against infections. Once the T-cells are attacked by HIV, the immune system becomes deficient and does not work properly (CDC, 2019, HIV.gov, 2019).

CD4 cell count (T-cell): This is a type of white blood cell for which the HIV virus has great affinity. HIV reduces the number of CD4 cells (T cells) in the body. A normal, healthy range for CD4 cells is about 500-1,500 (CDC, 2018e).

Viral load: This is a test to measure the amount (copies) of HIV genetic materials in one milliliter (ml) of blood. The central treatment goal of HIV medication is to reduce the amount of virus in the blood to the lowest measurable or detectable by the technology used. HIV RNA can be detectable up to < 20 copies/ml of blood. (NAM Publication, 2018, CDC, 2017e, 2018e)).

Acquired Immunodeficiency Syndrome (AIDS): When the CD4 count drops below 200 as result of advanced HIV disease, a person is diagnosed with AIDS. This damage to the immune system makes it increasingly difficult for the body to fight off infections and some other diseases (CDC, 2018b).

Opportunistic Infections (OIs): These are infections that occur more frequently and are more severe in individuals with weakened immune systems, including people with HIV. Opportunistic infections take advantage of a very weak immune system to cause infections in the immunocompromised person. Opportunistic infections include Pneumocystis carinii Pneumonia (PCP), Candidiasis (fungal infections), Mycobacterium avium complex (MAC), toxoplasmosis, cytomegalovirus (CMV) infection, varicella-zoster virus (VZV) infection, cryptococcal infection, histoplasmosis, Hepatitis B, Hepatitis C, bacterial respiratory diseases, bacterial enteric diseases, syphilis, Human papillomavirus, and others (Panel on Opportunistic Infections in HIV-Infected Adults and Adolescents, 2018).

Antiretroviral Therapy (ART): This therapy is characterized by the use of HIV medication to treat HIV infection. There are six classes of highly effective antiretroviral drugs, namely: nucleoside reverse transcriptase inhibitors (NRTIs), non-nucleoside reverse transcriptase inhibitors (NNRTIs), protease inhibitors (PI), integrase inhibitors (INSTIs), fusion inhibitors (FIs) and chemokine receptor antagonists (CCR5 antagonists) (AIDSinfo, 2019a). The general recommendation for HIV treatment is a combination of at least three antiretroviral medications from at least two classes of drugs.

Viral Suppression: Viral suppression reflects the result of a viral load test, i.e., when the level of HIV in a person’s body is very low (<200 copies/ml) or undetectable. Suppressed viral load improves the health of the person living with HIV, increases survival and reduces the risk of transmitting HIV (DHHS Guideline, 2018). The key goal of ART is to achieve and maintain durable viral suppression. Thus, the most important use of viral load testing is to monitor the effectiveness of therapy after initiation of ART.

HIV Treatment: This involves adhering to treatment regimen/guidelines including using antiretroviral medications that slow disease progression. Treatment adherence increases the likelihood that the infected person will live out a normal life free from disease complications.

Treatment Guidelines: This is guidance from the U.S. Department of Health and Human Services that recommends how an HIV positive person should be treated with ART, when to start treatment, what to use, and how to monitor and ensure positive health outcomes are achieved (AIDSinfo, 2019).

Treatment Adherence: This includes initiating care with an HIV provider (linkage to care), regularly attending appointments (retention in care), and adherence to antiretroviral therapy (ART). The concept of a “continuum of care” has been used to describe the process of HIV testing, linkage to HIV care, initiation of ART, adherence to treatment, retention in care, and virologic suppression (CDC, 2018b).

HIV Testing: An HIV test detects if there is HIV genetic material present in a person. Three types of testing are available: antibody tests, combination tests (antibody/antigen tests), and nucleic acid tests (NATs). Antibody tests detect HIV antibodies in blood and the mouth’s mucosal membrane. HIV antibodies develop 3 to 12 weeks in readiness to fight the virus once the body is infected. Combination tests (antibody/antigen tests) detect both HIV antibodies and HIV antigens in blood. This type of testing detects infection before antibodies form as it takes about 2 to 6weeks to detect antigens. NATs detect HIV in the blood 7 to 28 days after infection (AIDSinfo, 2018). The Centers for Disease Control and Prevention (CDC) recommends universal testing for people aged 13 to 64 years old and more often for people who engage in high HIV risk activity. High-risk behaviors include unprotected sex (sex without a condom) with someone who is HIV positive or whose HIV status you don't know; having sex with many partners; and injecting drugs and sharing needles, syringes, or other drug equipment with others. CDC also recommends that all pregnant women be tested for HIV early in pregnancy (AIDSinfo, 2018).

HIV prevalence: This refers to the number of persons living with HIV at a given time and is used in epidemiology to estimate the probability that a person selected at random from a population will have the disease. CDC reports prevalence as the number of persons living with HIV infection in a given population at a given time where a prevalence rate is calculated per 100,000 people (CDC, 2016, CDC, 2017).

HIV incidence: This is defined as the number of newly HIV infected persons in a specific time period. An HIV incidence rate is in turn generated by dividing the estimated number of newly infected people at a specific period by the number of people at risk (CDC, 2016).

Pre-exposure prophylaxis (or PrEP): This refers to any medication taken by a person who does not have HIV to lower the risk of infection. The person must be adherent to the medication and take as directed (CDC, 2019g). Baeten, et al. (2014) demonstrated that Tenofovir alone and a combination of Emtricitabine plus tenofovir for pre-exposure prophylaxis both provided high protection for acquisition of HIV-1 in heterosexual men and women.

Stigma: A mark of disgrace related to someone's circumstances either due to incarceration, disease, mental health or something else that a society looks down on. Usually the negative belief is unfair and affects the health of the person who stigmatized. HIV stigma affects testing, engagement, and staying in HIV care, leading to more infections (Berger, Ferrans & Lashley, 2001; Valdiserri, 2002).

Health disparity: The greater occurrence of a disease in a particular population is known as health disparity, which might be observed according to gender, race, education or even geographical location (CDC, 2014). Health disparity is also defined as a particular health difference between groups that could be socially, economically or environmentally engineered (HealthyPeople.gov, 2019).

Non-disclosure: The failure to reveal information about one's health. Many HIV infected individuals prefer not to inform their sexual partners or intimate friends about their HIV status due to fear of stigmatization and other social reasons. The prevalence of non-disclosure is three times higher among black African heterosexual men who have sex with men (MSM; Daskalopoulou, et al., 2017).

Vertical transmission: This refers to HIV transmission from an HIV-infected mother to her child during pregnancy, labor and delivery, or breastfeeding (through breast milk) (AIDSinfo, 2018b)

Heterosexual transmission: Heterosexual transmission of HIV is considered to have occurred when someone infected with HIV denies any other risk factors except sexual contact with the opposite sex who is infected with HIV (Haverkos, Chung & Perez, 2003).

Phenomenology: Derived from philosophy, it is a method of inquiry that studies appearances instead of reality. It is the study of experiences, how they are experienced, structures of the experiences as subject to the person's point of view. Experiences that can be studied through a phenomenological approach include imagination, thought, emotion, desire, volition, and action (Mastin, 2009; Percy, Kostere & Kostere, 2015)).

Feminism: The advocacy of equality for women's rights as part of efforts to correct the powerlessness, domination and oppression of women by another gender in the social, political, and economic arenas (Turner & Maschi, 2015).

Empowerment: According to Rahman (2013), empowerment includes the processes that lead people to perceive themselves as able and entitled to make decisions and involves undoing negative social construction so that people come to see themselves as having the capacity and the right to act and influence decisions. Empowerment can be defined within three dimensions. One is personal—the development of a sense of self, individual confidence, and capacity, along with undoing the defects of internalized oppression. Second is the rational dimension, which consists of developing the ability to negotiate and influence the nature of a relationship and decisions made within it. The third dimension is collective, which includes involvement in political structures, but might also cover collective action based on cooperation rather than competition (Rahman, 2013). Empowerment enables women to take control of their lives to achieve a set of goals and demands to actualize a change in social structures detrimental to their lives.

Self-Efficacy: This is a belief in an individual's ability to succeed in specific situations or accomplish a task. An individual's sense of self-efficacy can play a major role in how they approach goals, tasks, and challenges, and in their capability to attain designated types of performance (Artino, 2012).

Collective efficacy: This refers to the ability of members of a community to control the behavior of individuals and groups in the community. It describes what group members are willing to do to improve their lives. Collective efficacy is the willingness to intervene and the capacity for informal social control as members collectively agree on what is acceptable behavior and reinforce it among themselves (Higgins & Hunt, 2016).

Assumptions

One assumption associated with this study is that participants are eager to share their stories and truthfully recant events in their lives. However, accurately sharing life stories might be difficult as time has elapsed and sometimes recall of information might be hard. To mitigate against this assumption, participants were asked the same question in different ways, to try to elicit information to answer the research questions. Another assumption is thinking that women of the age criteria were willing to open up about their sexual activities and because the researcher is AA, that participants were comfortable and willing to share their stories. That participants who previously consented to participate will follow through to complete the session is another assumption. No one was forced to participate. To address this last assumption, all interviews were conducted in a relaxed environment. I reinforced to participant that the study was done in good faith and was respectful if a participant refused to answer a question or felt uncomfortable in any way.

Scope and Delimitations

Positive health outcomes during HIV antiretroviral therapy are characterized by progressive reduction of the HIV virus in the blood (Eshleman et al., 2017). The undetectable level and sustained viral load suppression denotes positive outcomes. This means at this stage of disease, comorbidities are reduced (Granich et al., 2015) and symptoms of the disease are almost nonexistent as an HIV positive individual lives a normal life span as any other non-HIV positive person (CDC, 2016b, CDC, 2019a). It is important that this information be shared with HIV positive women at the time of entry into care. Education on the benefits of viral suppression is key as it may become the motivation for retention, engagement, and adherence to care and treatment. Miedema, Maxwell, and Aggleton (2011) emphasized that education is needed and might be central to increasing young people's awareness and reducing vulnerability to HIV acquisition. A search of the literature did not result in any articles where such education was the foundation of the information provided to HIV positive African American women. In a study of urban AA in the South, Klein, Sterk and Elifson (2016) found Athat only 43% of the participants had knowledge of HIV infection and transmission, and the authors recommended establishing HIV educational and intervention programs for AA adults at risk for infection. Some young HIV-positive parents (born with HIV) largely agreed that being a role model for their children was a motivation to pursue education and employment, while fear of discrimination hindered disclosure of status (Fair, Allen, Trexler, & D'Angelo, 2017; Valdiserri, 2002).

The specific focus of this study is HIV+ AA women's understanding of viral load, viral suppression, and transmission at diagnosis and along the continuum of care. It is important to document AA women's perceptions about HIV knowledge and their experiences at diagnosis and in HIV care. It is also pertinent to know when women knew about all the benefits of viral load suppression and how such knowledge may or may not have influenced adherence to care. The findings result in an understanding of how to improve women's experiences upon diagnosis and engagement in care. This study focused on heterosexual AA women living with HIV. The research study was conducted in the District of Columbia where there was access to the population. The results of the research is limited and not representative of all HIV positive women living in the District of Columbia. Excluded from the HIV positive AA in this study are those who are not heterosexual. Other excluded groups are women who are outside of the age being studied or had never been on antiretroviral medication.

Limitations

One limitation of this study is the validation of information from participants. Describing one's lived experience necessitates a good strategy to ensure accurate information is obtained. Patton (2015) discussed four types of triangulation of data that could help reduce this issue, namely triangulation of qualitative sources, mixed triangulation, analytical triangulation, and theory/perspective triangulation. Substantial information can be obtained through triangulation of the different sources of information and crosschecking against theories and multiple sources of data. According to Carter, Byrant-Lukosius, DiCenso, Blythe and Neville (2014), data source triangulation ensures that information collected from multiple sources are used for validation of information collected to have a different perspective of the data. Triangulation helps to make sense of any inconsistent or conflicting data (Patton, 2015). The data was triangulated by including interviews against documents, data from the DC Department of Health, and viral load and CD4 count tests were triangulated against interview documents. Other methods for assessing the quality of the data include conducting peer review, for example, passing the information through peers who acted as fact checkers against other external sources or through peer debriefing (Creswell, 2013).

The findings in this study are not generalizable outside of my study sample and the District of Columbia area. It is typical for a phenomenological study to not necessarily be generalizable, though they nonetheless offer in-depth exploration of a topic. Another major limitation in this qualitative inquiry is my bias as researcher. Validation of this research plan started from ensuring that researcher bias and prejudice about people with HIV who are not engaged in care (Aziz & Smith, 2011) and other prejudices was discussed to allow for objectivity of data. Creswell (2013) called it clarifying researcher bias, where the researcher makes known experiences and prejudices that may affect the credibility of the results ahead of time.

Another limitation included my potential for asking leading questions which may suggest answers to participants. Further, there is the limitation of the power relationship between the researcher and the participants. One caution in any phenomenological research approach was to ensure that the interviewer did not influence the contents of a participant’s description. My knowledge of HIV/AIDS must not affect participants’ actual experience by making sure that questions were crafted objectively.

Significance of the Study

Guidelines from the National HIV/AIDS Strategy, United States Department of Health and Human Services (DHHS), and other national policies for HIV treatment have provided benchmarks and made milestones in the treatment of the disease. There are very effective antiretroviral medications now available that are nontoxic in contrast to the first generation medications, all working towards good quality treatment for HIV (DHHS Guideline, 2018). However, conspicuously missing in research are women’s lived experiences with HIV and how such experiences may facilitate infection when viral suppression is not achieved. At the same time, the United States alone sees at least 40,000 new infections yearly and high prevalence among women of childbearing age (CDC, 2018c). For 3 consecutive years (2012, 2013 and 2014) when new infections showed a downward trend, there continued to be spikes in infections in the 25 to 34 age group (CDC, 2019f). One study that targeted young HIV positive parents (who perinatally acquired HIV) noted that the parents’ motivation to be role models to their children led to pursuit of education and employment (Fair, Allen, Trexler, & D’Angelo, 2017). This was done with the hope to protect their children from discrimination and stigma. Yet, the same parents were found to be afraid to disclose HIV status to their children for fear of stigma. The infection rate continues to decline in the United States, and although mother-to-child infection has drastically fallen, in 2016, 73 infants were born with the disease (CDC, 2018).

This study has significant impact in addressing health disparities in the study population. According to Meyer, Yoon, and Kaufmann (2013), health disparities exist when differences in health outcomes are seen among different populations. The importance of health disparities in public health discourse includes burden of diseases among particular populations compared to others, lack of access to care and specialty care, and low socioeconomic status (Meyer, et al., 2013). Provision of quality care varies depending on the population and part of the country, and differences in cost of care also exist. In their analysis, Johnson et al. (2013) discussed the characteristics of people with HIV diseases in an effort to portray the disparities that exist in the lives of those with this infection and in their use of antiretroviral medication for treatment. The expert panel on the treatment guidelines noted that one of the goals of HIV treatment is achievement of viral suppression at least 8 to 24 weeks on antiretroviral therapy and having improved CD4 count (DHHS Guideline, 2018).

Another positive social change was in the advancement of HIV/AIDS research, treatment, and prevention. Moreover, this study provided information that align with the 90-90-90 initiative newly adopted by many nations to end AIDS by 2020 (United Nations AIDS, 2014). The 90-90-90 initiative is intended to spur more focused efforts in countries' progress in helping people living with HIV access treatment, get diagnosed, and achieve viral suppression and positive health outcomes (International Association of Providers in AIDS Care [IAPAC], 2015). The end of HIV/AIDS is contingent upon diagnosing all infected persons and providing access to antiretroviral medication to ensure viral suppression. HIV treatment is very important in ending the HIV epidemic, normalizing survival, preventing HIV-related illnesses, averting AIDS related deaths, preventing new infections, and saving money (United Nations AIDS, 2014). The 90-90-90 initiative aims to have 90% of all people living with HIV know their HIV status, have 90% of all people so diagnosed receive sustained antiretroviral therapy, and have 90% receiving such therapy achieve viral suppression (United Nations AIDS, 2014).

Summary

I discussed the epidemiological synopsis of the HIV/AIDS infection in the District of Columbia, the United States, and the world as a whole in chapter 1. The background information and the disproportionate infection among AA women. This chapter also included knowledge of viral load suppression among AA women as a reference to improved health outcome. Other topics summarized in this chapter included the study’s theoretical framework, nature, assumptions, scope, delimitations, limitations, and significance.

Chapter 2 provides information on the literature review conducted for this study to establish relevance of the problem. Chapter 3 restates the research questions and the central concepts used to design the study and the reason for their selection. Chapter 4 presents information on the demographics of the participants, the setting, data collection, analysis, and evidence of trustworthiness. The last chapter, Chapter 5, will provide an interpretation of the findings, a discussion on limitations, recommendations, an exploration of implication, and conclusions of the study.

Chapter 2: Literature Review

Introduction

The HIV epidemic in AA communities, especially AA women, continues to attract attention. The public health implications of the epidemic and the recognition of continued health disparities have led to some targeted interventions. Unfortunately, the CDC (2019f) continues to record high rates of HIV infection, with the most recent annual estimate being 40,000 new HIV infections in the United States in 2015. AA are disproportionately affected. AA non-Hispanic women are 9 times more likely to be infected with HIV/AIDS than any other race/ethnicity (Sionean et al., 2014).

Several studies have identified possible factors associated with the disproportionate burden of HIV in AA women. Hatcher, Kumbakumba, Tsai and Dworkin (2012) noted that the ability to have sexual negotiating power with partners may reduce the infection rate. Low levels of education have also been shown to be associated with HIV infection (Melton, 2014) while Newsome, Airhihenbuwa, and Snipes' (2014) results indicated that a lack of college-educated partners is a contributing factor to HIV infection among AA women. The role of stigma as a barrier to care has also been studied to determine how it fuels infection (Buseh & Stevens, 2008; Pollini, Blanco, Crump and Zuniga, 2011)

Literature Search Strategy

In an effort to identify relevant sources in order to study this issue in greater depth, I conducted multiple library searches using different databases. CINAHL Plus included the full text of many of the articles reviewed. Through ProQuest, the

Dissertation & Theses @ Walden University database was accessed to search for additional articles. Other databases searched included PubMed, NCBI, Mendeley Library, STAT!Ref, Essential Evidence Plus POEMS, Walden University Academic Search Complete, and SAGE. In addition, high level searches were conducted on the World Health Organization and CDC websites. Newer articles relevant to research, including those possibly published after I conducted the initial literature searches, were received via email through subscriptions to CAB Direct; Research Gate; the *New England Journal of Medicine Journal Watch HIV/AIDS;* the Health and Medicine Division of the National Academies of Science, Engineering, and Medicine; *AIDS Patient Care and STDs*; and *AIDS Research and Treatment*. Some of the identifiers and key words used for the search included *women* AND *HIV/AIDS; African American* AND *HIV/AIDS; risky sexual behaviors; public health education; HIV prevention health promotion; HIV testing; HIV epidemiology; HIV mortality; HIV* AND *condom use; poverty* AND *women; depression* AND *HIV/AIDS; District of Columbia* AND *HIV/AIDS; resilience theory; empowerment* AND *women; marginalization* AND *women; social support* AND *HIV/AIDS; HIV/AIDS health literacy; sexually transmitted diseases; HIV stigma; phenomenology; hermeneutics;* AND *reproductive health;* and *barriers to disclosure* AND *HIV status.* In the search for relevant peer review articles, I also signed up with the National Library of Medicine (NLM) at the National Institute of Health (NIH) to have relevant articles emailed directly to the researcher. Although I ended up not using the request system, it was valuable to have this resource available, if needed.

Theoretical Foundation

Theory and Origin

Two main theoretical concepts guide this study: resilience theory and feminist/empowerment theory. Resilience theory is derived from two areas of study—namely, child psychiatry and developmental psychology (Vernon, 2004). A resilience-guided study allowed me to emphasize competence and the successful adaptation to overcome negative challenges. And empowerment theory posits that empowered people take action necessary to create social and personal behavioral change. Proponents of empowerment theory have developed theory constructs to apply at the individual, organizational, and community levels. The two theories are expounded below.

Resilience theory.

The school of thought emerged from Freud's assumptions that early negative experiences in life produce an adult with psychopathology. Expert researchers such as Michael Rutter, Norman Garmezy, and Eliot Rodnick applied this assumption in their study of child psychiatry and development (Harlow, 2009; Rolf, 1999; Vernon, 2004). Many scholars have defined resiliency theory, a fairly new research theory and approach, in different ways depending on the approach or issue under investigation. In the United States, the clinical psychologist Norman Garmezy, who helped develop the theory, examined resilience in two disciplines: psychoanalysis and development. Garmezy studied resilience to understand what he and his colleague identified as a distinction between "process" chronic schizophrenic and a "reactive" stable schizophrenic (Rolf, 1999). The researchers explored the underlying reasons for the differences in outcomes of these two groups of patients. They found that one group was competent, as demonstrated in the lives of the stable patients who were married, had children, and maintained their jobs. Members of this group still experienced schizophrenic episodes, but they recovered with shorter stays in hospital and are integrated into their community. The other group had longer stays in institutions, lasting 13 years or more. The differences in outcomes of these two groups formed the premise and need to study the underlying differences in these patients, with a focus on areas such as cognitive skills, motivation, and certain protective factors (Harlow, 2009).

However, researchers have not yet established a single authoritative definition of resilience as experts formulate definitions from differing approaches. In a panel discussion during a conference of the International Society for Traumatic Stress Studies in 2013, various experts agreed that resilience is a complex construct leading to different definitions depending on the area of reasoning (Southwick et al., 2014). In a summary of all definitions generated during this conference, Southwick et al. noted resilience as the ability to bend but not break, bounce back, and perhaps even grow in adverse life experiences. Resilience is a “construct connoting the maintenance of positive adaptation by individuals despite experiences of significant adversity” (Luthar, Cicchetti, & Becker, 2000, p. 543). Other interesting definitions included “stable trajectory of healthy functioning after an adverse trauma,” “capacity of a dynamic system to adapt successfully,” and a “process to harness resources to sustain well-being” (Southwick et al., 2014). In her argument on the most applicable definition, Dr. Catherine Panter-Brick asserted that resilience is not a one-time achievement but sustained over time as it harnesses resources along the continuum of care (Southwick et al., 2014).

Scholars study resilience theory from different approaches. Determinants of resilience are viewed through genetic, epigenetic, developmental, demographic, cultural, economic, and social perspectives (Southwick et al., 2014). Jackson and Miller (2014) used an ecological approach, where a resiliency-enhancing approach was integrated into an ecological model to explore AA women's interactions with the environment, individuals, the community, and society when describing inequities in education, value of education and self-efficacy, commitment, mentoring, and faith and spirituality. The authors further examined resilience in relation to inequities in education, faith and spirituality, self-efficacy, and the need for mentors.

I applied resiliency theory with respect to empowerment theory in this study. AA women's vulnerability to HIV had not been entirely determined by their engagement in risky behavior; it included geo-behavior, which basically refers to where one lives, what one does, and with whom—all of which link to vulnerability to HIV infection (Brawner, 2014). Thus, it was important to develop a deeper understanding of how empowerment aided in overcoming trauma and adversity as well as initially connecting with and moving along the continuum of HIV care.

Feminist/empowerment theory.

A second theory applied in this study is feminism/empowerment theory. Feminism is a socio and political construct that tries to observe the interaction of gender to power relations (Perkins & Zimmerman, 1995). Th empowerment theory posits that entering into the world of the abused or oppressed helps empathize and understand their needs. Empowerment is the process utilized to enhance the personal, interpersonal, and political power of an individual to ensure better life outcomes (Turner & Maschi (2015). According to this theory, the impacted population knows better.

Although the debate about whether empowerment is an outcome or a process rages on (Carr, 2003; Luthar et al., 2000; Perkins & Zimmerman, 1995; Sadan, 2004), this study followed the process approach, which implied that women in this study experienced a personal transformation at some point, with a consciounesses powerful enough to seek and engage in care. Carr (2003) called such an empowering action conscientization, which is necessary to create social and personal behavioral change. However, Rahman (2013) advised caution to ensure that empowerment does not manifest as an exclusionary bias against men—an adversarial orientation and subversive logic that may threaten harmony in the home—as conscientization that excludes men is dangerous. Gender empowerment should be inclusive of all and be a matter of a change of values. This line of thought was explored and considered when empowerment theory was applied.

Empowerment ensures that thoughts and beliefs about self-changes and the image of self are enhanced—namely, that an empowered person wields his or her own power and is motivated to move in the right direction toward a defined positive goal. Moran (2015) clearly depicted the application of feminist theory as empowerment by exploring the self through therapy, looking at uncertainty in normal responses to oppression without a traditional assessment, while exploring upbringing, family life, and religious affiliation.

Moran (2015) further emphasized that the strength of the client is hyperbolic, which means reaction to adversity may be exaggerated. The client is an expert on his or her own life, with exploring a range of possibilities and making informed decisions as to whether to change a behavior or not remaining the right decision. In this study, the feminist/empowerment approach functioned as a lens for understanding women's unequal position to HIV and resilience in the presence of HIV infection. In particular, it used a gender lens that involved studying power relationships, social position, and women's experiences with HIV infection. According to Turner and Maschi (2015), working with feminist theories with marginalized and oppressed women led to a better understanding, assessment, and ultimately intervention strategies to address the gender powerlessness experienced.

The empowering process and outcomes differ depending on the individual and population under study. Perkins and Zimmerman (1995) asserted that, when it comes to individual empowerment, the process could include participation in a community organization; meanwhile, at the organizational level, empowerment might include collective decision-making and collective action. Individual or intrapersonal empowerment can be described as consisting of beliefs, attitudes, competencies, self-determination, and efficacy. Other discourses have interpreted intrapersonal empowerment as the enabling of individuals to achieve personal goals through interaction with others, thereby making room for both personal motivation and collective action (Perkins & Zimmerman, 1995).

Rationale for Application of Resilience and Empowerment Theory

I employed the resilience construct from developmental and social variables in order to demonstrate how nurture shapes nature. This included questions of home disciplines and family culture to determine when adaptive capacity or behaviors were acquired or developed. Gonzales (2003) applied resilience theory in three attributes or concepts: risk factors, protective factors, and resilient child. My aim was to seek to understand resilience on a positive platform—namely, strength, protective factors, and adaptive abilities—instead of a focus on the deficits. Although Rutter (2013) explained that findings from studies that incorporated resilience may not translate into clear prevention and treatment ideas because of the dynamic views of different individuals to adversities, they can provide some positive leads to research.

I also looked at the evolution that transpired from such an adverse event as the time of HIV diagnosis to favorable adjustment when AA women are engaged in care and virally suppressed. Some of the infections happened in the 1980s, when the women were as young as 22 years old and no medication was available, but still exist in 2019. A metric of resilience for these women are that the virus reached an undetectable level in their blood. The researcher explored the factors that may contribute to this resilience. In the framework of epigenetics, resilience could be gene mediated due to phenotypically expressed skills that could withstand trauma and adverse events (Southwick et al., 2014). Thus, as children grow up, there might be some interpersonal role modeling by parents or family members that contributes to the children's development of resilience (Fritz, de Graaff, Caisley, van Harmelen, & Wilkinson, 2018; Rosenberg, Baker, Syrjala, Back, &

Wolfe, 2013). Although discussions of epigenetics are gaining ground in efforts to learn about resilience, it is beyond the scope of this study.

An additional method used in this study was the creation of a time–life trajectory. A sample of AA women were chosen to create their time–life trajectory. Using qualitative interviews, the researcher collected data and created timelines, beginning from when the HIV infection was first diagnosed, to indicate experiences along the continuum of HIV care. According to Yates, Tyrell, and Masten (2014), a resilience concept-guided study allowed the researcher to emphasize competence and successful adaptation in overcoming negative challenges. Research designed with a combination of resiliency and empowerment theories provided information useful for exploring the lived experiences of HIV-positive AA women.

Previous Applications of Theories

Fritz et al.’s (2018) study about childhood adversity and mental health in young people found a relationship between some resilience factors and increased likelihood of psychopathology. The researchers categorized resilience factors into three levels: individual, family, and community levels. Some of the resilience factors studied at the individual level included distress tolerance, cognitive reappraisal, self-efficacy, behavioral reward reactivity, emotional reward reactivity, mental flexibility, protective self-cognition, and socialization. At the family level, Fritz et al. (2018) included positive parenting, family cohesion, adolescent-and-father communication, adolescent-and-mother communication, extended family support, positive family climate, immediate family support, and quality of the parent–child relationship. Community-level resilience factors included social support and friend support (Fritz et al., 2018). Although some of the resilience factors moderated and mediated mental health after childhood adversity, the authors noted that resilience factors should be studied as a complex system, not in isolation from one another. A study by Christman and McClellan (2012) asked women in academia to explain personality traits responsible for or affecting their successful academic pursuit and resilience in the face of challenges. The authors found a “middle space” that tends to break gender role assumptions in leadership to chart new boundaries.

In another study, Washington (2008) applied resilience as hope to female adolescents in an alternate school program who contextualized their negative experiences into success stories. In their study, they recommended gender-specific programming efforts to provide a forum and space for impacted females to at least contribute to the discourse. Findings from the studies discussed thus far have further confirmed that resilience is not static, but moves along the continuum of different timeframes, conditions, and capacities to adjust to an adverse event. As patient education continues to evolve, there is an expectation that patients will actively participate and advocate for themselves, illustrating and depicting empowered patients. Fumagalli, Radelli, Lettieri, Bertele, and Masella (2015) described three areas where empowerment theory has been used. First, as a participative behavior where psychologists defined it as a form of intrinsic motivation to perform tasks (Huang, Shi, Zhang & Cheung, 2006). Secondly, in research as an interactive process through which people experience personal and social change that enabled them to take actions that positively affected their life (Lord & Hutchison, 1993), and thirdly, as an emergent state of adaptability to difficulty and challenges. Bowers, Kreutzer, Cannon-Browers, and Lamb (2017) discussed some emergent states as the second order of positive emotions, self-efficacy, and positive affect.

When researchers applied empowerment theory to reproductive experiences over the life course, they found a strong determinant of the current state of empowerment as one that emerges immediately after marriage (Lee-Rife, 2010). According to Lee-Rife's (2010) study conducted in India, incorporating influences of prior life events, such as abortions, stillbirths, and miscarriages, shape a woman's current state of empowerment and became one factor that lowered violence in marriage.

The concept of empowerment has also been applied in the primary prevention of HIV/AIDS and has been proven effective in many CDC-funded interventions (Beeker, Guenther-Grey, & Raj, 1998). In Pinto, Rahman, and Williams' (2014) study, women in prison with limited re-entry knowledge participated in 12 one-hour program sessions embedded with empowering information. At the end of the sessions, the women reported being empowered on parental rights, housing, and employment. They also had better advocacy skills that benefited them individually and their community (Pinto et al., 2014). In another study where women were given the power to use photo or pictures to illustrate their empowered status, participants showed increased self-esteem, critical thinking skills, and control over life challenges and HIV; they also had increased access to resources that improved health choices and behavior (Teti, Pichon, Kabel, Farnan, & Binson, 2013). In her discussion about empowerment in healthcare settings, Funnell (2016) described moving away from the traditional patient education to an empowerment-based approach. This involves developing educational sessions that encourage the reflection of one’s life, boost self-management efforts, and improve problem-solving skills and engagement in clinical care, which helps make behavioral health changes. Schuler and Nazneen (2018) identified education as an example of an empowerment-based platform where changes in gender roles resulted in a reduction of married women experiencing intimate partner violence. Women were able to take new forms of employment and contribute financially to the household.

Although HIV infection is decreasing in the United States (CDC, 2019a), its associated stigma does not seem to be dissipating. Discussion on the how such high infectivity rates affected the lives of AA women living with the disease is imperative. Rice et al. (2018) found that women mentioned multiple interrelated social determinants of health that continued to perpetuate stigma, such as gender, race, and income level. Continued HIV stigma may exacerbate health disparities and engagement in HIV care.

Engaging HIV-positive women in empowering discussions helped build self-esteem, leading to the recognition of inner strength. This might result in acquiring strategies to survive the disease and perhaps knowledge of what resources to access in order to improve one’s health. People facing adversities who pursue a purpose can develop a sense of meaning in life that promotes psychological health with lower levels of depression (Du, Li, Chi, Zhao, & Zhao, 2017). In addition, I posed questions to HIV positive women about their life experiences in general. Listening and learning about their experiences and challenges, along with how these challenges were overcome or are still being worked through and provided some clarity on the women’s lived experiences.

According to Yates, Tyrell and Masten (2014), a resilience-guided study allowed the researcher to emphasize competence and the successful adaptation to overcome negative challenges. Therefore, the theories of resilience and empowerment are particularly suited for this study.

Literature Review

HIV is on epidemic level in the United States and disproportionately affects AA women. The epidemiology of HIV in the District of Columbia continues to see a rise of new infections among AA women. However, HIV viral suppression leads to positive health outcomes especially for women on antiretroviral medications. The search for relevant literature that adequately discussed HIV viral suppression and infection was thoroughly researched using different relevant key variables.

African American Women and HIV/AIDS Epidemics

When more than 1% of a population has HIV, the CDC defines it as an epidemic (CDC, 2017b). At the onset of HIV in the 1980s, there was a steady increase in infections until the advent of effective medications in the 1990s, from nucleoside reverse transcriptase inhibitors (NRTIs) such as Zidovudine (AZT) and non-nucleotide reverse transcriptase inhibitors (NNRTIs) to protease inhibitors (PIs). HIV prevention has primarily focused on gay men, targeting mainly young black men who have sex with men. However, a marginalized group might be being neglected: young African American females. Haverkos, Chung, and Perez (2003) confirmed the HIV epidemic among heterosexuals by showing the greatest percentage increases in this population over time. In 2016, AA females accounted for 11% of all HIV diagnoses (CDC, 2019h) and 595 of all new female HIV diagnoses in 2017 (CDC, 2019b). Skarbinski et al. (2015) found a reduction in HIV transmission rates along the care continuum, yet between 2012 and 2014, AA women 25–34 years old continued to see spikes in infections (CDC, 2016b). Among all HIV-infected females living in the District of Columbia, AA females accounted for 92.5% of new infections in 2015 (District of Columbia Department of Health, HIV/AIDS, Hepatitis, STD and TB Administration [DC/DOH/HAHSTA], 2016), a percentage that increased to 94.1% in 2016 (DC/DOH/HAHSTA, 2017). In 2018, of the 12,322 HIV cases living in the DC EMA, black women accounts for 22% of the cases (DC/DOH/HAHSTA, 2019).

In Washington, DC, non-Hispanic AA females have the highest rate of infection among all women, having more than 6 times and nearly 50 times greater prevalence rates compared to women of Hispanic origin and White women, respectively (DC/DOH/HAHSTA, 2017). HIV infection among heterosexual Black females in 2016 was 1.6% (see Figure 1), exceeding the 1% threshold of a generalized epidemic as defined by the CDC.

Knowledge of HIV Transmission among African American Women

Transmission of HIV occurs primarily through unprotected sex, infected semen or vaginal fluid during heterosexual sexual contact, and mother-to-child transmission either in the womb or during breast feeding (Drayton & Grant, 2017; CDC, 2018a,). HIV can also be transmitted through the sharing of contaminated drug paraphernalia (Skarbinski et al., 2015). Skarbinsk et al. (2015) found that most HIV transmission (58%) occurs through men who have sex with men, particularly among those between 35 and 44 years old. Although heterosexually acquired HIV among women was found to be much lower, at 1.6%, there was no analysis of race and ethnicity in their study.

Klein, Sterk and Elifson (2016) discovered that HIV knowledge was especially low among older adults in the urban AA South, especially among older adults who have low educational levels and no personal knowledge of someone with HIV/AIDS. Henderson et al. (2004) also found that older women, regardless of marital status, had limited knowledge of HIV transmission through sex. Although various efforts to raise awareness about HIV continue, Perkins, Stennis, Spriggs, Kwegyir-Afful, and Prather (2014) questioned whether knowledge of HIV transmission is enough to make a difference. In another study conducted in urban historically Black colleges and university (HBCU) settings, AA youths did not perceive themselves as having a high risk of contracting HIV yet engaged in highly risky behavior for contracting the disease (Lindong, Edwards, Dennis, & Fajobi, 2017). Klein et al. (2016) studied both HIV-negative and HIV-positive groups and found that this knowledge was not translated into making less risky choices. Knowledge of HIV also did not deter young girls from engaging in high risk behavior in detention facilities, despite elevated odds of contracting HIV for incarcerated AA (Baillargeon et al., 2017; Raiford, Seth, Fasula, & DiClemente, 2017).

HIV transmission among AA is dependent on not only risky behavior, but also geography. Despite efforts to reduce risk, people located in areas with higher concentrations of HIV-infected people still face a higher vulnerability of infection. This is referred to as geo-behavioral vulnerability to HIV (Brawner, 2014). Education and knowledge of HIV transmission should form the foundation of every HIV education session in order to reduce the acquisition of HIV.

Viral suppression also resulted in positive health outcomes for people living with HIV/AIDS (Cohen, McCarley, & Gamble, 2012), yet there was lack of ample research that incorporated HIV viral suppression as a component of HIV education nor emphasized the need for viral suppression as a precursor to reducing HIV infection.

Social Demographics of HIV/AIDS

African Americans in the District of Columbia accounted for 82% and 94% of new HIV diagnoses among males and females, respectively, from 2004 to 2008 (West-Ojo et al., 2010). The district is divided into eight wards, with Wards 7 and 8 having the highest prevalence of HIV. The majority (89%) of DC residents are 25 years old and above and have at least a high school diploma, with about 53.4% with graduate degrees or higher (DC/DOH, 2014). Although the median household income ($48,078) is above the minimum in other parts of the country, due to the high cost of living and housing in the district, many people live in poverty. In 2012, 14.19% of DC residents lived below the federal poverty level, while 26.91% and 20.95% lived at 150% and 200% of the federal poverty level, respectively (DC/DOH, 2014).

Low income, low education level, and increased poverty tend to be strongly associated with HIV infection. Wards 2, 5, 7, and 8 show the highest number of HIV cases, while more new diagnoses are occurring in Wards 5, 6, and 7 (DC/DOH/HAHTSA, 2017). The picture is the same at the national level. In 2017, 86% of all new infections occurred through heterosexual transmissions—an increase from

2016 (CDC, 2019b). During the same year, 4,189 Black heterosexual women were newly diagnosed, which is a much higher number compared to heterosexual Black men (1,926), White women (1,032), and Hispanic/Latina women (1,025) (CDC, 2017a). A study conducted in Baltimore, Maryland, found that testing for HIV occurred more often among women than men, who reported a higher number of sexual partners and/or were involved in illegal drug trade (Decker et al., 2015), a phenomenon which may cause overrepresentation in diagnosis statistics. Nonetheless, AA women are the new faces of HIV infection in Washington, DC, and in the nation, lagging only slightly behind Black men who have sex with men. The community in which someone lives and socializes becomes a significant factor in HIV acquisition. The higher the measurable amount of HIV virus in any community, the higher the rate of infection, which is usually described as community viral load.

Community Viral Load

The HIV virus is transmitted by people who are HIV positive. This basically means that only people who are infected can transmit the disease. The prevalence of HIV is in part dependent on the ongoing transmission risk fueled by high virus among community members. Miller, Powers, Smith, and Cohen (2013) defined community viral load (CVL) as the aggregation of individuals with a virus in a community. Herbeck and Tanser (2016) defined CVL as the mean of the individual viral load in a particular community. Part of the US National HIV/AIDS Strategy (NHAS) (2015) to end the HIV epidemic includes expanding HIV testing in the community to identify HIV-positive individuals and link them to HIV care and treatment. It also includes increasing the proportion of HIV-positive individuals with undetectable viral loads (HIV.gov, 2011; NHAS, 2015).

According to Brawner (2014), CVL is a population marker of the infectivity of people living in a geosocial area. Decreased community viral load and increased HIV testing are associated with a reduction in new HIV infections (Das, 2012; Das et al., 2010). In one study, more than half of the participants had a high viral load associated with transmission risk (Kranzer, Lawn, Johnson, Bekker, & Wood, 2013). In their study, among the people living with HIV in a South African township, a small proportion had a CD4 count less than 200 while more than half had a high viral load that could benefit from an expansion of antiretroviral therapy (ART) treatment to reduce the virus in the community.

One study of HIV-positive individuals receiving medical care in Washington, DC, highlighted the importance of knowing the CVL. Castel et al. (2012) demonstrated that a reduced CVL is associated with a reduced incidence of HIV. The biomarker of HIV incidence, high CVL, is observed in communities with high poverty and low high school graduate rates (Castel et al., 2012). CVL is used as a marker for treatment of HIV, helping decision-makers target areas of high viral burden and make provisions for enhanced access to care and treatment for such impacted communities. Das (2012) advocated for adequate assessment and measurement of CVL, the establishment of a baseline, modernized surveillance, and the following of CVL trends as a central indicator for success in prevention and care efforts.

Treatment of HIV

HIV is treatable and can be classified as a manageable chronic infection. On April 17, 1998, as a result of the efforts of researchers, clinical providers, patients, the Department of Health and Human Services (HHS), the National Institute for Health (NIH), the Centers for Disease Control and Prevention (CDC), and the Henry J. Kaiser Family Foundation, the first guidelines for treating pediatric HIV infection were published, followed quickly by guidelines for treating adults and adolescents with HIV infection published on April 24, 1998 (Health Resources and Services Administration, n.d.).

The guidelines are often updated in light of new research and treatment findings that might improve the quality of care for people living with HIV (AIDSinfo, 2019a; AIDSinfo, 2019c). The panel of experts responsible for developing and updating the guidelines rate certain recommendations as “A” to indicate strongly recommended practices, “B” for moderately recommended practices, and “C” for optional practices. The ratings rely on evidence-based clinical trials from randomized controlled trials; non-randomized, observational cohort studies with long-term clinical outcomes; and expert opinions. The panel has recently recommended that all individuals with HIV be on ART regardless of their CD4 count, as ART reduces morbidity and mortality (AIDSinfo, 2019a). ART is also recommended for individuals with HIV to prevent HIV transmission. ART should only be deferred for clinical/psychosocial reasons, but otherwise initiated as soon as possible (AIDSinfo, 2019a).

Guidelines for Treating Adults and Adolescents

The panel's most recent recommendations for effective treatment of HIV include taking three active antiretroviral medications from at least two classes. The most favorable "A" rated recommendation is for one medication from the integrase strand transfer inhibitor (INSTI) class and two medications from the nucleoside reverse transcriptase inhibitor (2NRTIs) class. The combinations of medications rated as "A1" and "A11" are:

- Dolutegravir/abacavir/lamivudine, which is only for patients who are HLA-B*5701-negative (AI), represented as "DTG/ABC/3TC[a] (AI) if HLA-B*5701-negative"
- Dolutegravir plus tenofovir/emtricitabine (AI), represented as "DTG + tenofovir/FTC (AI for both TAF/FTC and TDF/FTC"
- Elvitegravir/cobicistat/tenofovir/emtricitabine (AI), represented as "EVG/c/tenofovir/FTC (AI for both TAF/FTC and TDF/FTC"
- Raltegravir plus tenofovir/emtricitabine (AI for tenofovir disoproxil fumarate, AII for tenofovir alafenamide), represented as "RAL + tenofovir/FTC (AI for TDF/FTC, AII for TAF/FTC" (AIDSinfo, 2019a; DHHS Guidelines, 2018)

Guidelines for Treating Women: Considerations for ARV in women with HIV

Preconception counseling has been included in the DHHS guidelines to improve the health of women before conceiving or to ensure that conception is planned. The importance and benefits of preconception counseling were affirmed by the American College of Obstetricians and Gynecologists (ACOG) committee in September 2005. The goal of such counseling is to reduce the adverse effects suffered by HIV-positive women of childbearing age. Simone et al. (2018) identified five thematic areas that affect preconception counseling and barriers to engaging in clinical care. They conducted their study in seven cities in the United States, with an emphasis on counseling being consistent across providers. Factors that affect engagement in preconception counseling and other care include knowledge and attitude, characteristics of the clinical facility, type of care coordinators, and the ability to access locations when referrals are made to other places.

Extra steps are taken to prescribe the most appropriate antiretroviral (ARV) medication for women of childbearing age, especially during pregnancy. The Food and Drug Administration assigns ARVs and all other drugs to categories that consider whether and how the drugs should be used by pregnant women and women contemplating pregnancy. For a drug to be assigned category A, it must be demonstrated to be safe in pregnancy and pose no risk to a fetus. Unfortunately, no ARV is classified as category A at this time. Category B drugs are those that failed to demonstrate risk during testing on animals but have not been subjected to a controlled study on pregnant women. Category C denotes that animal reproduction studies have been conducted on the drug and revealed an adverse effect on the fetus; although no adequate and well-controlled studies on humans have been conducted yet, the potential benefits of pregnant women using the drug possibly outweigh the potential risks. Some ARVs fall into categories B or C (Jose, Wallace, Anand, & Barlett, 2014).

For category D drugs, studies on human subjects have demonstrated a risk of harm to the fetus, although the drug may still be used during pregnancy if warranted. Efavirenz is a category D drug (Jose et al., 2014). Women in the first trimester of pregnancy should especially avoid Efavirenz (AIDSinfo, 2019d). In their clinical trial, Brogly et al. (2010) found an elevated risk of birth defects in pregnant HIV-positive women who used Efavirenz during the first trimester of pregnancy. Category X shows harm to the fetus during animal studies; these drugs should not be used during pregnancy (Jose et al., 2014).

One medication whose category status is currently challenged is Dolutegravir. Dolutegravir is a first-line regimen for HIV treatment (AIDSinfo, 2019e). However, it has been documented to cause neural birth defects (NTDs) in newborns (AIDSinfo, 2019c; U.S. Food and Drug Administration [FDA], 2018). The use of a Dolutegravir–based regimen for women before 8 weeks of pregnancy is no longer recommended, and if the female was already on Dolutegravir and virally suppressed, a change before 8 weeks of pregnancy is recommended. However, if the patient is already on Dolutegravir and the pregnancy is older than 8 weeks, then no change in medication is recommended (AIDSinfo, 2019e). In the meantime, the FDA has not yet removed Dolutegravir's category B status.

In addition to reducing the risk of transmission, an undetectable viral load during pregnancy reduces the risk of HIV transmission to the unborn child (*in vivo*) and the newborn. Although mother-to-child vertical transmission has drastically fallen in the United States, efforts should be maintained to ensure that young HIV-positive women receive quality care to remain virally suppressed. In this way, children will not be born or infected with HIV. In providing ARV to women of childbearing age, efforts are also being made to ensure that many of the pregnancies are planned by using effective contraceptives. As some ARVs also interact with contraceptives, reducing their efficacy, ARV medication may need to be changed or extra protection may need to be used (Matthews et al., 2017).

HIV Medications: Medication adherence

Evidence for the benefits of taking ARVs as well as the resultant effect of reducing HIV transmission was strengthened by the HPTN 052 randomized clinical trials. Adherence to medication and viral suppression as a result of good adherence revolutionized HIV treatment and gave birth to the slogan “Treatment is Prevention.” In the HPTN 052 clinical trials, HIV infection decreased by 96%, and there was also a reduction in morbidity and mortality. Participants in the clinical trials exhibited 95% medication adherence along with a reduction in HIV transmission to others (Cohen et al., 2012). These findings led researchers to advocate for early diagnosis, the early initiation of ARV, and consequent viral suppression.

An earlier study by Kitahata et al. (2009) found that patients who started ARV immediately had better health outcomes than those who deferred medication. Combined with similar results from population studies, Donnell et al. (2010), Montaner et al. (2010), and Das et al. (2010) demonstrated that an effective strategy to reduce HIV transmission is to prescribe appropriate ARVs to everyone infected with HIV.

Continued medication adherence is especially key to improving health outcomes. Adhering to medication at least 95% of the time has been advocated as best adherence practices (CDC, 2013). Factors influencing adherence to medication may involve internal motivation, circumstances, peers, and provider relationships. For some women, adherence is especially motivated by a desire to stay alive for their children (Islam, Minichiello, & Scott, 2018). Okoro and Odedina (2016), studied factors that influence AA women's care-seeking behaviors and adherence to HIV/AIDS medications. They found that the provider–patient relationship is a great resource that promotes adherence while relationship building influences patients' understanding of the need to adhere to ART. Another study by Nokes et al. (2012) found that enhancing self-efficacy was a predictor of medication adherence. The authors also recommended incorporating self-efficacy into nursing interventions to help adherence. Meanwhile, Bonacci et al. (2016) found that, although ARV adherence also entails refilling prescriptions, refilling prescriptions is a poor predictor that someone is engaged and retained in care. The researchers' findings indicated that non-adherence is associated with non-retention, as patients who do not show up for appointments exhibit an increased risk of dropping out of care. Castel et al. (2016) found that about 83% of people who had ARV adherence in the preceding 7 days were in care, compared to 69% for people out of care.

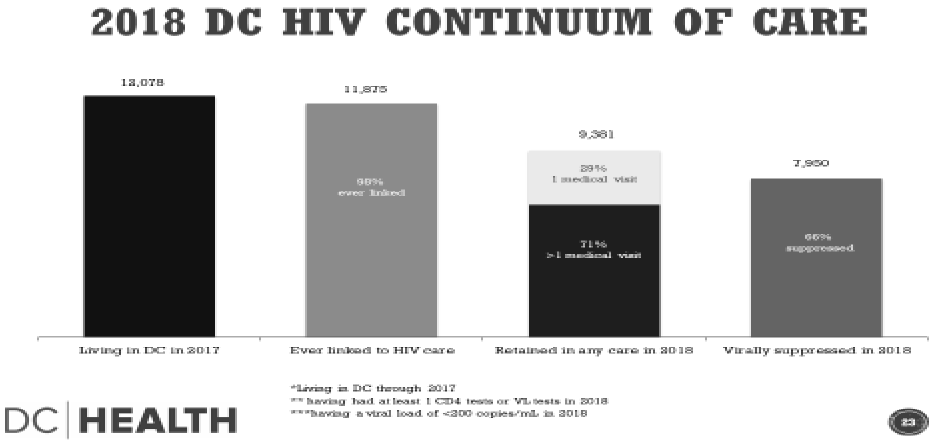
Care providers must analyze adherence on a regular or periodic basis to identify people at risk and have more conversations with patients about the benefits of medication adherence. An analysis of 12 years of United States Medicaid data showed that 57% of patients failed to restart ARV after 18 months of stopping, and many of them were younger females (Zhang, Shireman, Youn, Lee, & Wilson, 2018). Older adults were more likely to be adherent to medical visits and phlebotomy visits and experienced greater levels of viral suppression (Waldrop-Valverde, Guo, Ownby, Rodriguez, & Jones, 2013).

According to Giordano, Jacobson, Mammen, and Moreno-Walton (2017), persons diagnosed with acute HIV infection (AHI) in the emergency room fare better than established HIV patients who also visited the emergency room. Their analysis concluded that persons diagnosed with AHI had better linkage-to-care and greater initiation of ARV, with 35% of the sample experiencing viral suppression within 6 months after the emergency room visit. This better strategy needs to be implemented for all HIV-positive individuals. Nonadherence to medication often leads to low viral suppression. Robertson et al. (2017) performed a comparative analysis of clients who received or did not receive care coordination. Interestingly, in 24 months, the two groups did not show any significant difference in viral suppression. The noted difference was not a result of access to medication as everyone had access, but possibly it was due to adherence instead.

Early diagnosis and engagement in HIV care are associated with not only better health outcomes, but also lower medical costs. According to one study, entry into care within 72 of HIV positive test results led to rapid HIV treatment, faster viral suppression, improved health outcomes, and reduced HIV transmission (Halperin, Butler et al., 2017). Gebo et al.'s (2010) analysis indicated that treating one person with HIV in 2006 in three states in the U.S. was $19,912, with a higher cost for people with low CD4 counts. In 2015, the CDC estimated that it took about $23,000 per year to treat an individual with HIV—an increase of more than three thousand dollars (CDC, 2019i). A lifetime treatment in 2010 was estimated to be $379,668 (CDC, 2019i), while the country sees about 40,000 new infections every year. Economically speaking, a lifetime treatment of HIV is definitely astronomical compared to prevention. Therefore, ensuring that transmission does not happen should be the priority. Adhering to medication and engagement in HIV treatment reduces the virus in the system, which reduces infectivity. As treatment amounts to prevention, ensuring that HIV-positive individuals are diagnosed early and put on treatments seems to be reasonable and logical.

HIV Continuum of Care

The continuum of care is currently used to assess and measure the efficacy of HIV treatment from the early stage of diagnosis of the disease through a continuum of steps until there are improved health outcomes characterized by viral suppression. According to the Department of Health in the District of Columbia, the continuum of care begins with the number of HIV cases diagnosed for residents in the district, followed by the time linked to care, engaged in care, prescribed ARV, and virally suppressed. In 2017, 12,078 people with HIV diagnoses were living in Washington, DC. Of these, 98% were ever linked to HIV care (11, 875), with 29% having sporadic care (only 1 medical visit) and 71% in continuous care (more than one medical visit); 7, 950 (66%) were virally suppressed (DC/DOH/HAHSTA, 2019). Improvement in health outcome is obvious from 2016 to 2018 with a viral suppression rate of 63% to 66% respectively.



*Living in DC through 2017
** having had at least 1 CD4 tests or VL tests in 2018
***having a viral load of <200 copies/mL in 2018

Figure 3. 2018 DC HIV Continuum of care. From “Annual epidemiology report,” by DC/DOH/HAHSTA (2019).

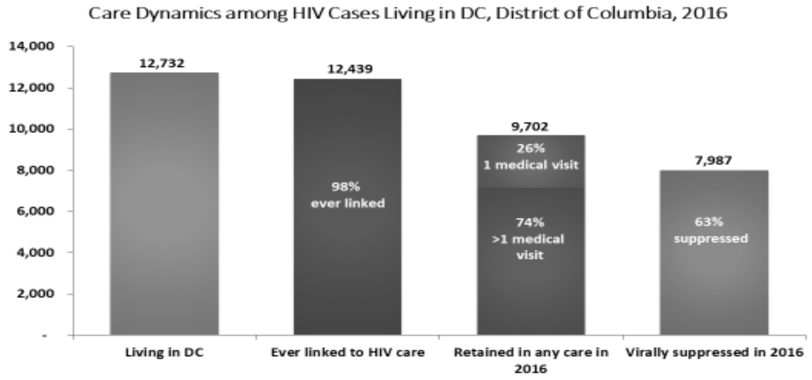


Figure 4. Care dynamic among HIV cases living in District of Columbia, 2016. From “Annual Epidemiology and Surveillance Report 2017,” by DC/DOH/HAHSTA (2017).

The District of Columbia fares better than the nation as a whole when it comes to viral suppression. According to CDC data, only 49% of the 1.1 million persons with HIV in the U.S. achieved viral suppression in 2014 (CDC, 2017a), which increased to 51% in 2017(CDC, 2019a).

Yet a look at the performance of specifically the Ryan White program in Washington, DC, reveals the possibility of even better health outcomes. The Ryan White HIV/AIDS Treatment Extension Act of 2009 was created in 1990 to provide a system of services that helps persons living with HIV in the United States to achieve improved health status (Health Resources and Services Administration, 2016). Grants are awarded to sub-recipients to develop comprehensive services for individuals living with HIV and help optimize health. The array of services ranges from outpatient ambulatory health services, dental services, mental health, substance abuse, medical case management, food bank, and home delivered meals to psychosocial services, respite care, childcare, and others. The various funding parts A, A (MAI), B, B (MAI), C, D, and F of the Ryan White Act integrate to ensure the provision of optimal health for various populations who are eligible. The person must live within the region or geographic area and meet income qualifications (Health Resources and Services Administration, 2016).

By December 2018, 4,229 persons with HIV living in the city were also Ryan White clients, while 73% (3,090) of Ryan White clients were in continuous care (i.e., at least 2 viral loads reported 90 days apart). Of that number, 95% (4,003) were prescribed antiretroviral therapy (ART) and 80% were virally suppressed (DC/DOH/HAHSTA, 2019). The 2018 Ryan White data shows a substantially higher success rate compared to the 66% viral suppression in Washington, DC, as a whole in the same year (see Figure 5).

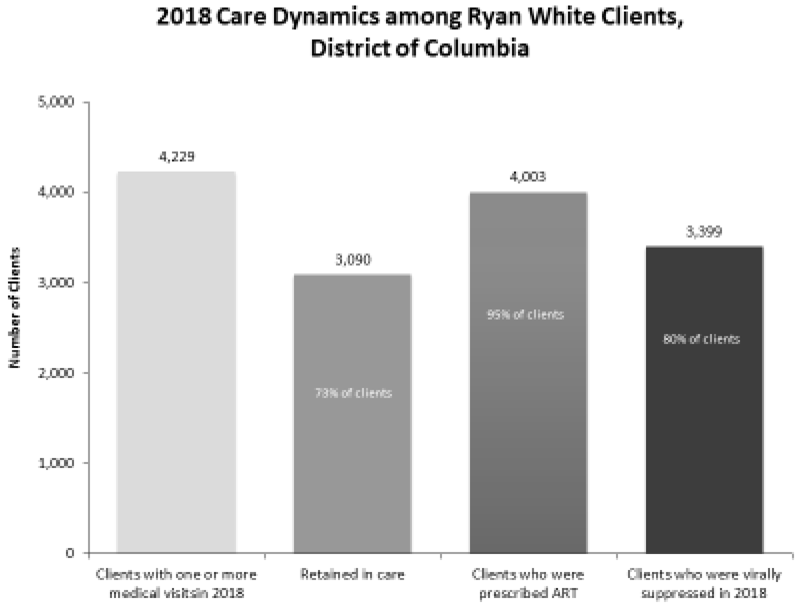


Figure 5. 2018 Care dynamics among Ryan White Clients, District of Columbia. From "Annual Epidemiology and Surveillance Report," By DC/DOH/HAHSTA (2019)

Viral Suppression and Health Outcomes

Viral suppression reflects the result of a viral load test in which the level of HIV in a person's body is very low (<200 copies/ml) or undetectable (Cohen et al., 2012; Pollini et al., 2011). Suppressed viral load improves the health of the person living with HIV, increases survival, and reduces the risk of transmitting HIV (AIDSinfo, 2019a). Virally suppressed HIV-infected persons are less likely to transmit HIV (Skarbinski et al., 2015). Thus, the goal of treatment is to achieve viral suppression, where the virus is undetectable in the blood, there is an increased CD4 count, and there are improved health outcomes (AIDSinfo, 2019a).

Women who are HIV positive should learn the importance and meaning of viral suppression for their own well-being and as a means to reduce transmission. To understand HIV infection within the AA community, it is necessary to understand African American women's knowledge of viral suppression at diagnosis and during the continuum of care. In 2016, viral suppression among women in Washington, DC, was low at 64%. Figure 6 shows that at least 25% of HIV-positive women in the district do not consistently engage in HIV treatment to achieve viral suppression.

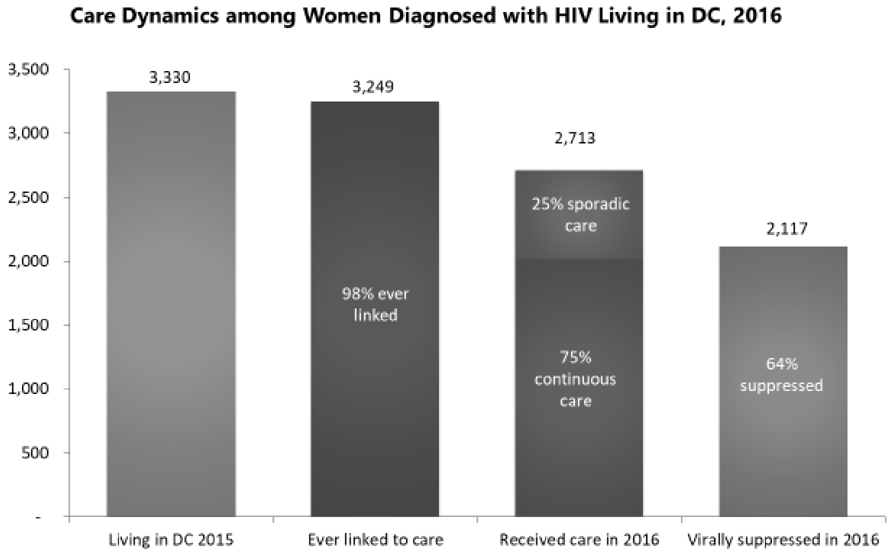


Figure 6. Care dynamics among women diagnosed with HIV living in Washington, DC, in 2016. From "Annual Epidemiology and Surveillance Report," by DC/DOH/HAHSTA (2017).

Although viral suppression is the gold standard for the goal of HIV treatment, it does not necessarily remove the harmful effects of viral attacks on the immune system. HIV infection is characterized by increased immune activation even in people with a suppressed viral load (Malherbe et al., 2014). However, a long interruption in treatment often leads to increased immune activation and negatively affected health (Musinguzi, 2018). In addition to improved health outcomes, viral suppression is associated with a decrease of new HIV cases (Montaner et al., 2010). Viral suppression is also a component of reduced community viral load, which in turn reduces new infections (Das et al., 2010). Yet as important as this is as an indicator of positive health outcomes, Black people are less likely to be virally suppressed. African Americans are less likely to have controlled viral load and medication adherence and more likely to have more comorbidities than Whites (Vaughan-Sarrazin et al., 2018). This scenario results in non-retention, which is a hallmark of disengagement in care and increased inflammation.

Positive health outcomes, according to Parrish (2012), include being alive and having a state of well-functioning mental, physical, and social being, while negative outcomes are death, illness, and a lack of wellness. Viral suppression leads to positive health outcomes for people who are HIV positive, including women. Various studies have shown that, when the HIV virus is reduced to undetectable levels (viral suppression) in an infected person, there is a non-transmission of the virus, even with condomless sex (Cohen, McCarley, & Gamble, 2011; Rodger et al., 2016; World Health Organization [WHO], 2018a). There is no evidence that individuals who have achieved and maintained undetectable levels of the virus transmit HIV to their sexual partners. This knowledge is fueling the campaign known as U (undetectable) = U (Un-transmittable) as a key strategy to ending HIV infection.

Stigma as a Barrier to Treatment

Stigma is defined as a mark of disgrace related to someone’s circumstances due to incarceration, disease, mental health, or something else that a society looks down on. Usually the negative belief is unfair and may affect the health of the individual. HIV stigma negatively affects testing, engagement with, and staying in HIV care, which in turn leads to more infections (Valdiserri, 2002; Nyota, 2017). Stigma is regarded as a major barrier that affects HIV-positive persons from seeking care and receiving the benefits of HIV treatment. Stigma leads to a negative self-image that can prevent individuals from seeking treatment and can delay treatment. Studies have found an association between stigma and reduced initiation of antiretroviral medication, low retention in care, and non-adherence (Logie et al., 2018; Sangaramoorthy, Jamison, & Dyer, 2017).

According to Buseh and Stevens (2008), African American women experience stigma socially, internally, and externally. Stigma has deep roots in gender, race, ethnicity, class, sexuality, and culture and will continue to be seen as a great impediment to reducing HIV transmission (Valdiserri, 2002, Nyota, 2017). Reducing stigma should be incorporated into many educational programs. Coleman, Tate, Gaddist, and White’s (2016) study in a faith-based community found lower HIV-related stigma among females who have higher education, know someone with HIV/AIDS, and/or know a gay person. Black churches have embarked on numerous health-related outreach programs in the Black community, but stigma in Black churches continues to affect the provision of HIV-related health activities (Pryor, Gaddist, & Johnson-Arnold, 2015).

AA women who experience such barriers as stigma, denials, and depression and who lack a support network may be able to mitigate these issues by obtaining resources from their healthcare provider (Petralia, 2016). According to Stewart, Hong, and Powell (2018), multifaceted intervention approaches may provide relief and improve the HIV continuum of care. AA churches can facilitate interventions to reduce stigma, get involved in providing a social support network, provide HIV education, act as agents that link HIV-positive women to care, and provide support groups. AA experience stigma in both the community and healthcare settings. Therefore, there is a need to understand the interactions of all these issues as they apply to AA women with HIV in Washington, DC. Logie et al. (2018) observed that stigma has a negative influence on the initiation and use of HIV medications among women living in Canada.

Any intervention that could eliminate or reduce stigma may increase adherence to treatment and medication and thus improve health outcomes. I had planned this study towards understanding AA women's lived HIV experiences during such challenges. The review of existing literature did not identify any research on AA women's HIV timeline and resilience.

HIV/AIDS and Health Disparities

The CDC (2014) defined health disparity as the greater occurrence of a disease in a particular population. It might occur in association with gender, race, education, or even geographical location (CDC, 2018d). Health disparity is also defined as a particular health difference between groups, which could be socially, economically, or environmentally engineered (CDC, 2018d; HealthyPeople.gov, 2018), and often affects people who have challenges accessing quality healthcare. The various areas in which AA women experience health disparities include viral suppression for AA women infected with HIV (Billioux et al., 2015; Castel et al., 2016; Crepaz, et al., 2016; Hall, Tang, Westfall, & Mugavero, 2013; Nwangwu-Ike, Hermandez, An, Huang, & Hall, 2015; Torian, Xia, & Wiewel, 2014).

Although HIV/AIDS-related deaths continue to decline with effective antiretroviral therapy, the District of Columbia records show that its death rate is higher than the nation's, at 20.4 per 100,000 population versus 2.6 per 100,000 (DC/DOH/HAHSTA, 2017). One of the objectives of the national HIV strategy is to design health programs to reduce disparities in highly affected communities, especially in terms of viral suppression and AIDS death (HIV.gov, n.d.; NHAS, 2015; White House Office of National AIDS Policy, 2016). Washington, DC, is uniquely positioned as a large metropolitan city and the capital of the United States. As such it should be the epitome of health for all its residents. However, in 2016, AA women accounted for 94% of all new HIV cases in the city, an increase from 92.5% in 2015 (DC/DOH/HAHSTA, 2017). Therefore, the need to identify reasons for HIV disparities, especially among AA women in the district, is critical to improve health outcomes in the city.

Geter et al. (2018) found that, although viral suppression increased among HIV-positive women, disparities were observed among racial and ethnic minority women. The researchers underscored the need to study the disparities in HIV treatment, especially among Black women and younger women. They also highlighted the need for gender-based and culturally sensitive interventions.

Summary and Conclusions

HIV/AIDS affects millions of people, with approximately 36.9 million people living with the disease as of 2017 (WHO, 2018b). Women who engage in heterosexual sex are disproportionately affected and, in the United States, AA women are especially affected (CDC, 2019b). The HIV infection rate remains a public health issue as AA women continue to experience increases. Fortunately, HIV treatment has evolved from having no medications to more than 30 active antiretroviral medications. When taken as prescribed, ARV works to reduce the virus in the system, resulting in viral suppression. It has been shown that the virally suppressed person is not infectious and does not transmit HIV to negative partners during times of condomless sex (Skarbinski et al., 2015; WHO, 2018a).

Despite the numerous articles reviewed, no research article or intervention discussed the importance of viral suppression at the time of diagnosis. To achieve viral suppression, one has to be on ARV and adhere to the treatment. In a practical best case scenario, an HIV-infected person who adheres to treatment could achieve viral suppression within 48 weeks and maintain optimal health if other comorbidities do not affect health (AIDSinfo, 2019a; Robertson et al., 2017). The importance of viral suppression and all its positive health implications are known, yet there is a dearth of information on education on viral suppression.

Furthermore, AA women experience stigma in their search for HIV treatment and care. Social stigma of HIV-positive status remains prevalent in society, including in the churches that have otherwise served as refugee for the AA community for hundreds of years. Stigma is a barrier to care and treatment. Stigma impedes the disclosure of HIV status, preventing honesty in relationships and leading to further infections (Avert.org, 2018; Kontomanolis, Michalapoulos, Gkasdaris & Fasoulakis, 2017; Saki, Kermanshahi, Mohammadi & Mohraz, 2015). The stigma and silence that surround HIV is a barrier for the AA community's health and well-being.

The literature has a great deal of information on health disparities experienced by African Americans. AA women, in particular, are disproportionately infected with HIV/AIDS. In Washington, DC, alone, AA women account for 94% of new HIV infections (DC/DOH/HAHSTA, 2017). As the disparities continue, some HIV-positive women are also considered to be living well with the disease. Often infected at an early age, they have lived through time spans of no treatment to effective treatment.

The review of existing literature found that it does not ask or answer questions regarding the characteristics of HIV-positive AA women who have survived decades of infection. To date, no research had ventured to look at the lives of these AA women and their lived experiences with HIV/AIDS, especially their knowledge of viral suppression. Although often infected between 18 and 25 years of age, some AA women are still living today. Their lessons learned should be incorporated into interventions for current younger HIV-infected women. The lessons learned in this study should provide information to help close the gap in the education and counseling on viral suppression at the time of diagnosis and the resultant effect on engaging and remaining in HIV treatment and care. Chapter 3 will delineate all the steps and methods used in designing this study.

Chapter 3: Research Method

Introduction

Learning from the experiences of HIV positive AA women is indeed vital, especially as their experiences relate to achieving viral suppression. Ensuring there is viral suppression when taking antiretroviral medication is an important precursor to ending HIV/AIDS (United Nations AIDS, 2014). Therefore, one of the key purposes of the study was to understand in greater detail how HIV positive AA women gained knowledge of viral suppression at their diagnosis and achieving viral suppression. The insights obtained provided valuable guidance when crafting prevention messages. Another purpose of this study was to increase the understanding of HIV infection and viral suppression from the perspectives of AA women who are living with HIV. The study used a phenomenological approach to uncover the lived experiences of HIV positive AA women and their viral suppression, including how HIV positive individuals are discriminated against in the community and further still can experience strong stigma from family and friends, as reported by Buseh and Stevens (2007). Another aspect of this study was the use of feminist lens to better understand the unequal position of black women in the context of HIV infection.

The study findings supported gender as the basic framework that conditions women for an increased risk of HIV infection. In an analysis of the HIV/AIDS disease burden among AA women, a gender responsive model also furnished useful initial steps for new dialogue and a fresher examination of HIV/AIDS as a social issue (Brawner, 2014). Issues related to gender roles and socialization may also have to be explored to understand the HIV vulnerability of African American women. HIV infection may also reflect geo-behavioral characteristics. In addition, the study findings may contribute more knowledge and understanding of how power relationships, social constructs, and social positions actually impact acquisition of HIV infection.

In Chapter 3, I detail the research design and the rationale including the research questions, phenomenon of study, and the research tradition that informed this study. Most importantly, the rationale for choosing a qualitative phenomenological design is discussed. The role of the researcher is an important part of this discussion. Working in HIV/AIDS for more than 20 years may create a certain bias that I must interrogate to ensure that the study was conducted in a professional manner and vigor applied. A detailed discussion of how researcher bias was managed is also presented.

Another important part of Chapter 3 is my discussion of the selection of the study participants, methods of recruitment, the logic for that selection, the purposeful sampling, inclusion criteria, sample size, and saturation point. Plans for analysis and issues of trustworthiness in a qualitative study are also discussed. Other sections in this chapter include ethical issues and concerns, and how these are managed, including the actual steps for obtaining institutional board review (IRB) approval to conduct the study.

Research Design and Rationale

The three main questions that drove this study are:

Research Question 1: What is the lived experience of African American women with HIV/AIDS in DC?

Subquestion 1a: What are their daily routines of medication adherence?

Subquestion 1b: What challenges constitute stigma and discrimination that they face in daily living?

Research Question 2: How do HIV positive women describe/explain viral suppression?

Research Question 3: How do HIV positive women explain/describe the high rate of HIV infection among African Americans in the District?

The Study Phenomenon

African American females are disproportionately affected by HIV/AIDS in the United States and the District of Columbia in particular. The infection rate continues to increase within this group, even though new infections are decreasing overall across races and ethnicities. One of the hallmarks and clinical benefits of HIV treatment today is achieving viral suppression (AIDSinfo, 2019). Because viral suppression is important, health educators and medical providers must educate newly infected individuals on engaging in medical care, taking medication as prescribed, and achieving viral suppression. Viral suppression means having an undetectable viral load, which according to DHHS guidelines (2018) is when an individual has less than 200 copies of the HIV virus (RNA <200 copies/mL). The knowledge of AA women at diagnosis regarding viral suppression and during the continuum of care will be assessed. Understanding the lived experiences of these women and understanding what they know about the goal of treatment are both important. In addition, the study will look at the increase in HIV infection experienced by this group through the lens of empowerment theory.

Research Tradition

The most appropriate design used in this research is a qualitative study wherein the people experiencing the phenomenon under study were recruited and asked questions. The phenomenology design chosen is appropriate because HIV infection in this instance was studied among HIV positive women who experienced the phenomenon. Phenomenological inquiry also has a philosophical basis (Giorgi, 2017). There are three major phenomenological traditions, namely, transcendental, existential, and hermeneutic (Moustakes, 1994; Kafle, 2011). Transcendental phenomenology is the original form postulated by Husserl with the premise that experiences will have to transcend to reality (Sheehan, 2014; Moustakes, 1994). For this philosophical concept/focus, the researcher will suspend personal experiences and knowledge of the studied phenomenon so as to understand the "lived" experiences of the participants. Personal opinion is suspended, and the phenomenon is instead strictly and descriptively presented. However, challenges that are inherent in this school of thought is the practicability of suspending personal opinion using bracketing and epoche (Kafle, 2011). Transcendental phenomenology demands the suspension of judgment about reality and includes an actual intentionality of consciousness (Percy, Kostere & Kostere, 2015,). The existential phenomenology school of thought argues that only an engaged individual will see the world and rejects the idea that a researcher should suspend personal experience in order to be effective in carrying out such research. (Kafle, 2011).

The third tradition is known as hermeneutic phenomenology. This school of thought was presented by Heidegger and is described as a deviation from Husserl.

Heidegger simply posits that suspending personal opinion is difficult, and there should rather be an interpretation of the descriptive. A hermeneutic phenomenological approach is applied in this particular study and seen in two ways. The first stage was to make sense of what a participant is experiencing and the second stage is to interpret those experiences critically (Taylor, 2015). According to Mjorud, Engedal, Rosvik, and Kirkevoid (2017), interpreting the transcriptions of interviews of participants emphasized the hermeneutic aspect of the methodology. This school of thought considers the researcher to be a signpost that points to understanding the phenomenon during the study so as to ensure and enhance the knowledge of the essence and meaning that has been experienced by the participants (Kafle, 2011).

In this study, the hermeneutic approach allowed the researcher to understand the participant's inner essence, their internal subjective experiences, and at the same time, make sense of the phenomenon (Subramoney, 2015; Taylor, 2015). In this case, the phenomenon is actually living with HIV/AIDS. Also, for this method of research, participants' own cognitive processing structures are also involved. It becomes a conscious experience to understand the reason for the phenomenon (Percy, Kostere & Kostere, 2015). This methodology hinges on the assumption that reality consists of certain phenomena as understood by a person's consciousness. The uniqueness of individuals affects the way they process information, how different individuals will attribute meaning to similar life experiences, and how the phenomenon is ultimately understood by the person (Burkholder, Cox, & Crawford, (Eds.), 2016; Rudestam & Newton, 2015; Kelly, n.d.). These processes are called interpretive phenomenology.

A study guided by interpretive phenomenology identified the participants who have the relevant lived experiences in order to utilize those experiences and their meanings for further development of effective policies for practice. Information obtained using this approach was subjective. However, it does provide in-depth understanding as the individual experiences and meaning of the phenomenon are described in terms of “what” the people experienced and “how” they experienced it. (Creswell, 2013; Crosby, DiClemente, & Salazar, 2006).

Role of the Researcher

An interpretive (hermeneutics) phenomenology approach was applied to this study. Interpretive phenomenology often involves four steps: Bracketing, intuiting, analyzing, and describing. This process means that the researcher must remove all preconceived ideas about HIV among AA women so as to investigate and collect an unbiased dataset and separate what is known of the phenomenon from the pure phenomenon (Van Manen, 1990). During the intuition/intuitive stage, the researcher focuses directly on the phenomenon and the meaning ascribed to it by those who have experienced it, while still continuing to analyze the data until its essence is obtained. Researchers are immersed in the phenomenon and must analyze it using open, axial, and selective coding, categorizing the data into themes until an identifiable essence is obtained (Tavallaei & Talib, 2010). The end stage or end process involves producing a description or definition of the phenomenon being studied. A phenomenological approach studies conscious lived experiences without theories or objective reality, but rather according to how the people who are the participants in the study constructed their meaning of the experience.

As the primary data collection instrument, I disclosed personal biases and assumptions (Creswell, 2014). I have worked on HIV/AIDS issues for more than twenty years. Therefore, as a researcher, I acknowledged my personal bias, beliefs, and values and stated them upfront. This process was needed to understand the perceptions and assumptions that I bring to the table **(**Janesick, 2011). The strategy of reflexivity was utilized to enhance credibility (Draper & Swift, 2010). It was my role as the researcher to ensure that the method of data collection was appropriate and can answer the central question of the study. Researchers' techniques and strategies for sampling was very critical and important in all qualitative studies.

I do not provide clinical care to HIV positive women in the District of Columbia, thereby reducing the concerns about a power relations conflict. As a project officer, the majority of my duties related to project design, technical assistance, and organizational compliance with Federal and State public health laws. Due to the demographics and characteristics of the population of this particular study, I intend to provide incentives for transportation and lunch. These facilitated participants' travel to the interview location. Smart-trip cards ($5.00) and a $25 for lunch was provided, with a total cost of $30 dollars for each participant.

Methodology

Most times, identifying a relevant research method is a difficult task. The most applicable tool must be geared towards obtaining the right information to answer the research question. In this qualitative study, the right participants who have experienced the phenomenon must be identified and sampled.

Participant Selection Logic

HIV positive AA women residing in the District of Columbia are the population that was studied. Participants have lived with HIV for more than 10 years. These are generation X’ers who were born between 1960 and 1980. It is the generation that witnessed the onset of the HIV epidemic, lived through the early days when there was no treatment, but only comfort measures available when people died. The generation also witnessed and lived through the era of thirty different types of effective antiretroviral medication being developed with a consequent improved longevity.

Purposeful Sampling

Purposeful sampling targets a pre-existing group and usually depends on the research question (Crosby, DiClemente & Salazar, 2006). The most practical and best strategy for this particular phenomenological approach is to use group-characteristics sampling, and specifically search for maximum variation (heterogeneity sampling). The purposeful sampling technique selects a wide range of cases to gain good variation in the dimension of interest with two purposes in mind. The intention was to document diversity and also important common patterns across that diversity. Patton (2015), however, noted a problem with this type of sampling, as it is often difficult to select a sample that is representative enough of the population. This issue might lead to having a sample that is homogeneous and not heterogeneous. At the same time, Patton suggested ways to maximize the diversity, namely, by constructing criteria selected from different sites and locations. In order to have a representative sample of the women who have a specific phenomenon, purposeful sampling was the most appropriate way to ensure that only members of the targeted group were selected.

Inclusion Criteria

The following were eligibility criteria for all participants included in this study. All participants were:

- HIV positive,
- African American women,
- Between 35 and 60 years old,
- Reside in the District of Columbia,
- Lived with HIV for 10 years or more, and
- Attending one of the Ryan White funded medical care clinics.

Participants came from already known clinics providing HIV care. Each participant provided self-reported clinical information and demographic information used to confirm that criteria were met. Another strategy applied in this study was triangulation of data. Clinical outcomes for HIV positive AA women were extracted from DC Health/HAHSTA Surveillance system. The data was used to triangulate information obtained from the in-depth interviews during the primary data collection. The researcher obtained approval from the DC Institutional Review Board for Public Health (IRBPH) for permission to use the secondary data already in its system for effective data triangulation.

Sample Size

According to Draper and Swift (2010), qualitative research looks for theoretical generalization instead of empirical generalization and does not require a large sample size to accomplish that goal. Small numbers from a rich source of information are ideal. Sample size is an essential part of designing any study, and according to Buckholder (n.d.), a researcher must ensure that the essential components are contained in the sample. Choosing the sample size in qualitative research was a challenge and does not need power calculations, which are usually linked to quantitative research design (Buckholder, n.d.). The golden rule is to have a sample that is large enough to obtain answers to the research question and not so large as to hinder successful in-depth analysis (Draper & Swift, 2010). A sample size should emerge within a framework of clearly stated aims, approach, and goals, and also be dependent on the resources available (Luborsky & Rubinstein, 1995). According to Patton (2015), 6-10 participants are an ideal number for a proper phenomenological qualitative interview size.

In this study, a sample of 10 HIV positive AA women were drawn from the District of Columbia. Ryan White programs already serving these women were approached. Many of the organizations provide outpatient ambulatory health services and medical case management to residents. The main organizations that serve the majority of the AA minority population in DC were approached and agreed to participate in the study.

Saturation Point

The strategy for this study meant that I started interviewing as soon as IRB approval was obtained. Each interview was analyzed, as more interviews were being conducted. This snowball type of analysis continued until no new information was obtained from new interviews. This was the saturation point when interviewing stopped (Kumar, 2005). Saturation is accepted in qualitative research, but its operationalization depends on the methodology. Saunders et al. (2018) identified four distinct ways of operationalization to ensure that further data collection and analysis does not yield any new information. They concluded that a saturation point should be consistent with the research question. This study conducted 10 in-depth interviews. However, I monitored for saturation point for data collection and analysis. I continued to interview and analyze until no new information was identified and further data collection and analyses did not contribute new information and are thus more interview was not necessary.

Instrumentation

This is the process of identifying research tool that could specifically be used to gather data in this qualitative study. There are different types of tools available for use. The most common tool applied here is the semi-structured interview protocol. Another instrument applied include aggregated clinical data from DC Health used for triangulation which is a way to corroborate that information received from participants are accurate

Interview protocol.

I developed the interview questions and protocol for the study. Constructs selected from resilience theory and empowerment theory were utilized to design the interview questions. Jacob and Furgerson (2012) suggested that interviewers ask questions in a particular order with easy questions asked before more difficult ones. The interview protocol was also flexible enough, so it can be revised on the spot when something interesting but not part of the script emerged. I used a script to start and end each interview. An expert panel and peers earlier validated the interview questions. The questions were also distributed to three expert researchers for their input on the content. This process was to ensure that the questions exactly result in gathering answers to the noted research questions. Another validity strategy to determine ease of comprehension was to administer the questions to peers also.

Recruitment, Participation, and Data Collection Procedures

Solicitation to participate was advertising on fliers and brochures. These were made available at different organizations that receive money from Ryan White funds to serve people who are HIV positive. Information about the researcher and her contact phone number were included on the fliers. Another strategy for recruitment was through medical providers who shared the study opportunity with their patients and contacted me about any willing participant. On a personal level, I approached patients who have publicly shared their HIV status that met my study criteria and ask for their participation. DC HIV Planning Commission on HIV/AIDS was approached with the flier to distribute to their contacts for interested participants to contact me.

Data collection method.

Usually, a research interview is a logical sequence that is actively utilized in the research process. A nine-step interview process, as itemized by Creswell (2013), includes the use of open-ended questions that are focused on the central phenomenon being studied. Interview is an art of conversing used to obtain information (Patton (2015) and also an exchange of conversation between two or more people. Types of interviews include responsive interviewing, creative interviewing, active interviewing, portraiture, and reflective interviewing. Alshenqeeti (2014) defined the process as one that encourages interviewees to answer questions correctly. All interviews in this study were conducted one-on-one and audio recorded with appropriate equipment. The interview protocol validated by experts guided the discussions.

Other strategies of good interview skills included identifying quiet location where a participant felt comfortable and safe, then administering and obtaining consent from the interviewee. The interviews were conducted in quiet safe rooms at clinics where participants receive clinical care. Only one interview was conducted in a private office space. The researcher actively listened during the interview process, was courteous and respectful, and ensured that the participant’s time was respected (Jacob & Furgerson, 2012). Participants signed the consent to take part in the study. This consent form included formal permission to record the interview and all needed information regarding ethical issues.

Primary data collected through interviews.

Data was collected from participants in the District of Columbia by using interview questions that followed well scripted protocol. I interviewed participants individually. The interview responses were audio recorded and later transcribed. This was a one-time, 60- 90 minutes in-depth interview with each participant. The interviews were completed within six weeks of the first interview. The first interview was conducted on September 10 and last interview was October 22, 2019. This ensured that the data was collected within the same timeframe so as to reduce any effects of adverse weather, political developments, or other events that may influence any responses. Completing the data collection within six weeks ensured that the data also remained relevant within the same timeframe. Participants availability were accommodated as the interview sessions were scheduled. Data was collected using open-ended interview questions that were audio-recorded and then transcribed.

During the interview, participants were asked to recall medical information for the timeline that relates to them. For example, if they were diagnosed in 1990, the participant was asked to recall their CD4 count at diagnosis, current CD4 count, viral load at diagnosis, current viral load, the first medication regimen they started, current medication, when they became engaged in HIV care, and any other pertinent information relevant to their lived experience. All these responses formed the bulk of the data that was analyzed and validated through data gathered from DC Health during the triangulation processes.

Data for triangulation.

Another source of data for this study came from the District of Columbia Health Department (DC Health). Clinical records, specifically viral loads, CD4 counts, of African American women who meet the criteria for the study were extracted from the Department’s surveillance database. The system is highly protected with physical locks and electronic passwords. Anyone accessing the information was directed to a locked room to extract the information, and no identifying information leaves the room. For this study, there was no protected health information from the system and the surveillance team pulled the aggregated data for triangulation for the researcher.

Clinical data on the participants was used to triangulate and validate the interview responses. Patton (2015) noted that triangulation is a relevant method for confirming consistency in the results. The time series data extracted were newly diagnosed AA women diagnosed in 2000, and their clinical data in 2000, 2010, 2015 and 2018. This process helped to identify for patterns of viral suppression and engagement in care for participants, and supports the clinical picture used to validate the interviews. The information from this objective data also support some of the self-reported responses. Most of the information collected by the Department of Health came through State Laboratories and the mandated infectious diseases reporting system. The instrument used by medical laboratories and medical facilities to report infectious diseases were already validated and used nationally. Therefore, there was no need to validate any secondary data from the department.

Follow-up plan if few participants were recruited.

In the event that I was not able to recruit 8- 10 participants, I was to solicit the help of the Ryan White Consumer Advisory Council of DC Health, which met periodically. Another alternative strategy was to attend some of the support group meetings hosted by various organizations, so I could explain to their attendees the need for the study, the benefits for AA women, and the inclusion of incentives that covered transportation and lunch. A last resort measure to ensure that I recruited the number of women needed would have been to increase the age gap being studied to include older AA women. All these contingency measures were not implemented because I recruited the exact number of participants that I needed and stopped.

Debriefing, exit process, and follow-up interviews.

After each interview, each participant was debriefed on the next processes of the study and thanked for their participation. The researcher reiterated the benefits of the study and the commitment that the participant will receive a copy of the study when completed. In addition, an incentive package was provided to each participant. Each participant will also be notified on how she had contributed to social change through their act of participation. Part of the debriefing process included providing the researcher’s contact information to the participants. Participants willingness to come back during data analysis if further clarification was needed for any interview responses was solicited and confirmed.

Data Analysis Plan

Data was analyzed and grouped into specific research questions and how each question was answered. As the interview questions were designed with various research questions in mind, the collection of information was grouped in the same format. There were groups of responses on lived experiences related to self-efficacy, resiliency, empowerment, stigma, HIV as a gender issue, medication, and treatment adherence. Another group included the women's experiences and knowledge of viral suppression at diagnosis and along their continuum of care. Clinical data for the women was arranged in tables to reflect clinical outcomes in a time series that runs from diagnosis to 2018. There were tables of descriptive statistics on the demographics of the participants.

In this phenomenological research, data was managed by hand coding. Coding is a process of combining and analyzing data into categories or themes, to increase the ease of information retrieval at a later stage for comparison (Taylor & Gibbs, 2010, Adu, 2013). While a code can represent a phrase or word that pulls the meaning of each bit of data. It is important, therefore, that the process is done as thoroughly as possible. Although interviews generated lot of data, thorough reading of the transcripts several times helped to reduce codes into a manageable number without missing important information. Creswell (2013) advised a good approach is to start lean and broaden later. Gibbs (2010) discussed many ways to approach coding, namely, line by line, sentence by sentence, several paragraphs together, paragraph by paragraph, and whole document coding. This process helped the researcher to be thorough in coding and all subsequent analysis. After all the information was collated, the most significant comments were grouped into relevant recurring statements and themes. Then, I wrote a textual description of the participants' experiences, along with a structural description or the context of each experience. The two write-ups were then be merged for a composite description of the participants' experiences of HIV disease. The analysis included examining the diversity of the sample. Each case was unique, as the researcher looked for common patterns or traits that unify even in diversity except that all of the cases were HIV positive. There was no discrepant case encountered.

Issues of Trustworthiness

Clinical data on the AA women in this study were used to triangulate the qualitative data collected. Patton (2015) and Creswell (2014) proposed that qualitative researchers used the concept of reflexivity, which advises researchers to be conscious of their biases, values, and experiences in order to write and communicate more objectively. The credibility of data and the findings in any research is key. This focus propels researchers to put solid strategies in place to ensure that all data is credible, validated, and trustworthy. Creswell (2014) discussed various methods used for ensuring credibility, such as ensuring that codes are cross checked, checking transcripts for errors, and performing useful triangulations.

Triangulation of data enhances the building and integrating of many sources to validate the information collected during interviews. Four types of data triangulation will help ensure the validity and credibility of data, namely, triangulation of qualitative sources, mixed triangulation, analytical triangulation, and the theory/perspective triangulation (Patton, 2015. In this study, analytical triangulation was conducted. Data from DC Health was crosschecked with medical information obtained during the interviews. Triangulation helped the researcher make sense of any inconsistent or conflicting data. Another method for ensuring trustworthiness was peer review. This aspect involved passing the information through peers who acted as fact checkers and through peer debriefings (Creswell, 2014). In addition, this study methodology is reproducible, as all the steps for data collection were clearly elucidated. I kept a journal of the daily and weekly activities being carried out during data collection, interviews, and communications to ensure accurate information was obtained. Peer support was also utilized to discuss the credibility of the information obtained.

Another action taken to ensure trustworthiness of the collected data was checking the transcripts of the recorded interviews and identifying alternative words for the ones provided. I also engage in member checking, which Hadi and Closs (2016) described as a form of ongoing validation. This was informally with the participants and during the interpretation of the collected information. No participants were contacted further to verify the information that they provided during their personal interviews.

In addition, I used reflexive writing, which basically means putting my feelings in control to enable a full objective analysis void of any bias to be produced. This focus was needed especially during the interpretation of the findings. Hadi and Closs (2016) advised that researcher apply the same critical analysis to the researcher’s own knowledge of the field of study or the phenomenon being studied.

Ethical Procedures

This study required the use and collection of very sensitive information where confidentiality is important. Participants meet the inclusion criteria, consented to participation, and signed a confidentiality form. The protocols followed in this study was clearly documented to enable future researchers clearly follow the steps used in this research and potentially use them.

Research on HIV/AIDS always has unique ethical and legal aspects to consider. Due to the nature of the disease and the stigmatization of the community associated with the infection, many HIV positive persons do not disclose their status. It is also illegal and against HIPAA rules to conduct research and disclose someone’s medical status without consent. All participants signed consent forms. The contents of the study/analysis was explained in detail to participants before signatures were obtained. Moreover, in this qualitative research, ahead of the data collection, all legal and ethical issues were discussed with each participant along with the strategies to mitigate any issue discussed.

Two Institutional Review Board (IRB) agreements were obtained for undertaking this study. IRB approval number from Walden University is 08-29-19-0450160 while DC Health IRB approval number is IRBPH # 2019-18. Approval by each institutional review board was obtained as required for research with human subjects. A brief description of the study proposal was also submitted to the DC Health Institutional Review Board (IRB) as the data for triangulation was collected from the DC Health surveillance system. The methodology was itemized to ensure that it posed no harm to any of the participants.

After gaining IRB approval from both institutions, the study started and there was no change in the proposed methodology that needed correction or amendment.

In addition to the ethical issues mentioned above, bias was another key problem that was seriously considered. Bias is the tendency to bring prejudice and subjectivity into the research process that may affect the findings and/or make answering the research questions questionable or impossible (Pannucci & Wilkins, 2010). This issue can be introduced at any point in the data collection. In such a case, the researcher must be able to set aside personal assumptions about AA women and HIV infection, set aside societal moral codes, and be fully open to new ideas.

I ensured that any information provided by participants was treated as confidential unless required by law for disclosure. I also respected all privacy laws and followed the code of ethics of the health education profession (Fertman & Allensworth, 2017). To ensure cultural appropriateness and acceptability, all effort was made to respect each participant’s religious beliefs, socioeconomic status, family style, and values. (Fertman & Allensworth, 2017).

All participants were given clear information on the voluntary nature of participation and their ability to withdraw at any time from the study. There was no coercion to participate. All the data collected were stored in a locked cabinet and electronic information password protected. The use of a $30 incentive for transportation and lunch was explained to all participants. This modest fund was to help and assist the participants’ ability to take a metro train or bus to the location of the interview and by no means a payment for their participation. And participants were also informed that receiving these incentives did not bind them, as any withdrawal from the study can still be exercised even after an interview had been completed.

Summary

An interpretive (hermeneutics) phenomenology approach was applied to study the lived experiences of HIV positive AA women who reside in the District of Columbia. Study of the members of this population, particularly due to their HIV status and the use of their patient health information and records, necessitates the review and approval of the Walden University IRB and the DC Health IRB. Collection of data was twofold through an interview instrument that I developed and used secondary data from DC Health. The interview questions were reviewed by experts in the field of HIV research, who validated the questions to determine whether they had the capacity to elicit correct information when posed to the participants. Peers reviewed the comprehensibility of the interview questions to ensure they are at a 9th grade reading level. Secondary data on health outcomes was collected from DC Health, primarily for triangulation purposes. The methods of recruitment were carefully considered and outlined, and inclusion criteria elucidated. Data was manually coded, and nodes created When all data had been collected and collated, the related analyses were conducted to look for themes and findings that were then presented in Chapter 4. These results answered the research questions on the resiliency of women and offer further insight into the lived experiences of the women in this study.

Chapter 4: Results

Introduction

In Chapter 4, I describe the results of the interviews that were conducted individually with 10 AA women in the District of Columbia who were HIV positive. Using a phenomenological approach, the purpose of the study was to learn and understand the lived experiences and clinical outcomes of HIV positive AA women with an emphasis on their perspectives related to becoming informed about viral suppression at or after the time of diagnosis. Another component of this study was an examination of how gender contributed to women's vulnerability to HIV infection. Theories of resilience and empowerment were considered in analyzing the responses of the interviewed women who have lived with the disease from reproductive age, often had children, and have dealt with the disease at the same time for 10 years or more.

The open-ended research questions were designed to elicit information on the lived experiences among the study participants. Three main questions drove the direction of the study with additional subquestions.

Research Question 1: What is the lived experience of African American women with HIV/AIDS in DC?

Subquestion 1a: What are their daily routines of medication adherence?

Subquestion 1b: What challenges constitute stigma and discrimination that they face in daily living?

Research Question 2: How do HIV positive women describe/explain viral suppression?

Research Question 3: How do HIV positive women explain/describe the high rate of HIV infection among African Americans in the District?

In this chapter, I discuss the setting of the interviews at the various organizations, including information on who participated. I address the demographics and characteristics of the participants. I also discuss the data collection methods, data analysis, evidence of trustworthiness. Finally, I present the results of the interviews and key findings.

Research Setting

All interviews were conducted in a private and quiet location. Nine interviews took place at community clinics located in the heart of the District. One interview was conducted in Ward 2 in a private office space. The interviews were conducted based on participants' support groups or clinic appointments to ensure it did not infringe on their daily schedule. The participants chose dates and times to schedule the interviews as were convenient for them. The interview dates spanned from September 10 to October 22, 2019. The interview rooms were medical case management offices or small conference rooms which were private. The rooms were very comfortable and quiet, away from the clinic activity. There were also medical case managers across from the hall if needed and clinic was in session if any of the women needed any intervention due to stress during the interview. None of the participants displayed signs of stress requiring intervention. However, two participants became emotional as they recounted their experiences stating that they had not been able to narrate their experiences in a long time and talking about it brought some relief. One of the two participants who became emotional stated that this was her first time in more than 15 years discussing the experience in full and appreciated the opportunity. The voice recorder on my HP computer was placed next to myself and the interviewee to allow for eye contact and acknowledgement during the sessions.

Demographics

The 10 participants are all residents of the District of Columbia, the location for the study. Seventy percent (70%) of the participants were either born in Ward 8, Ward 7, raised in Ward 8 or just moved to Ward 8. Together, Wards 7 and 8 are areas of high HIV/AIDS prevalence in the District of Columbia (District of Columbia Department of Health, HIV/AIDS, Hepatitis, STD and Tuberculosis Administration, 2016). The study was open to any DC resident who was female and matched the other study eligibility criteria, but many of the women who volunteered to speak about their experiences and were interviewed lived in Ward 8. Among the others, one was from Ward 7, one was from Ward 1, and two were from Ward 5 respectively. The location of respondents is important, as findings are relevant to targeting interventions at the heart of HIV infection in the District.

Participant age ranged from the youngest at 39 years old to the oldest at 60 years old. All the women had lived with the infection for 10 years or more. They were all infected during reproductive ages of 22 years up to 45 years and 60% were diagnosed during pregnancy. Among the 10 women, three were married and lived with their spouses. Seven participants reported they were currently single, had never been married, and were not in a committed relationship. Six single participants reported having and raising four to a total of 21 children without a spouse. Half (five) of the participants were employed and had jobs in the healthcare sector counseling other women as peer support and the other half (five) were unemployed. The participants' level of education included no education, 10th grade, high school attempted, high school diploma, some college, to master's degree.

Table 1

Demographics of Participants

Participants	Age	Education	Employment	Marital Status	Ward in DC
1	53	Some College	Employed	Single	8
2	43	High School	Employed	Married	5
3	44	Some College	Employed	Single	5
4	48	No Education	Unemployed	Single	8
5	40	High School	Unemployed	Single	8
6	55	10th Grade	Unemployed	Single	8
7	39	High school	Unemployed	Single	7
8	55	Some College	Unemployed	Single	8
9	43	Associate Degree	Employed	Married	8
10	60	Master's Degree	Own Business	Married	1

Data Collection

Walden University IRB approved an interview protocol of 42 questions. I designed the questions to evince from the study participants answers to the major research questions. Primary data were collected from participants during face-to -face interviews with open-ended questions. The interview sessions lasted from 40 minutes to 60 minutes. The setting appeared to be comfortable for the participants as they individually volunteered answers to every question asked. Each participant was only interviewed once. In addition, participants were asked if the interview could be recorded for ease of transcription. A voice recorder in an HP computer was used to record all interviews and later transcribed verbatim.

Secondary data was collected through the surveillance system of DC Health. DC Health and Walden University IRB approved secondary data for triangulation. Data of newly diagnosed AA women from the years 2000, 2010, 2015 and 2018 were extracted (Table 2). The specific variables were the median viral load at diagnosis, median viral load at the end of each of the years, median CD4 count at diagnosis, and median CD4 at end of the each of the years.

Table 2

Data for triangulation from DC Health/HAHSTA

Variables	2000	2010	2015	2018
African American Women diagnosed with HIV	201	123	108	105
Ages 25 - 34	73			
Ages 35 - 44	77			
Ages 45 - 54	46			
Ages 55 - 60	5			
Median CD4 Count at diagnoses	154.5			
Median Viral load at diagnoses	1205			
Median Viral load at end of year	1205	20	20	20
Median CD4 at end of the year	126	586	646	582

In addition, a cohort of data from all newly diagnosed AA women in 2000, 2010 and 2018, were extracted. The specific variables of the same cohort were median CD4 Count and viral load at end of the years 2010 and 2018. The range in ages of newly diagnosed in year 2000 were also extracted from the surveillance system. The form below was used to extract data from the DC surveillance system for newly diagnosed AA women. The collected information was used to discuss the self-reported narratives collected from face to face interview of participants.

Table 3

Women newly diagnosed in 2000 (Ages 35 – 54) through 2018

Variable	2000	2010	2018
CD4 count end of year	156	586	612
Viral Load end of year	3687	47	46.5

I attempted to use NVivo software to transcribe the recorded interviews. However, after two interview transcriptions, I found that the software output was incomprehensible. The transcriptions were not coherent for both the questions I posed, and the answers participants provided. Thus, I performed a manual transcription, listening to the interviews multiple times and transcribe the recorded interviews verbatim.

Data Analysis

All interviews were recorded using ‘voice recorder’, software program in my HP computer. I transcribed each interview into Microsoft Word. The first step of the data analysis was a careful reading and re-reading of each interview transcript. The intent of this reading and re-reading was to gain an overall idea of the content of the women's responses before proceeding to code the responses.

Coding is a process of combining and analyzing data into categories or themes to increase ease of information retrieval at a later stage for comparison (Taylor & Gibbs, 2010; Adu, 2013). A code represents a phrase or word that pulls the meaning of a data point. It is important therefore that it is done as thoroughly as possible. The approach I took was to read the responses line by line, sentence by sentence, paragraph by paragraph, and then the whole document. Supported by Gibbs (2010), this approach is known as an inductive approach. Thomas (2006) further described it as a process used to "condense extensive and varied raw text data into a brief, summary format" (p. 241). There were no discrepant cases used in the analysis. Specific codes and 18 themes emerged from the data. Appendix A is a is a compilation of the themes and codes including important quotations that emphasized responses from participants. In addition, clinical data of women in DC, generated from DC Health Surveillance system, were arranged in tables in a time series. Data of newly diagnosed AA women from the years 2000, 2010, 2015 and 2018 were extracted (Table 2). Clinical data of the women at time of HIV diagnosis in year 2000 were compared to clinical outcomes in 2010, 2018 and self-reported clinical data from participants. Specific clinical variables from the same cohort were analyzed. Clinical data from surveillance system of newly diagnosed AA women, ages 35-54years, were particularly analyzed because this is the age group mostly affected by HIV in the District (Table 3).

Evidence of Trustworthiness

Participants were interviewed individually, each seated in a comfortable private room. Evidence of trustworthiness comprised of the credibility, transferability, dependability and confirmability of the information collected. The interviews sessions had an introductory section, which explained who I am, the purpose of the interview and if the participants had any reservation in participation. The consent form was signed, and interview conducted. At the end of the semi structured interview, the closing statement contained an appreciation message and incentive given for participation.

Credibility

The credibility of the data was implemented as stated in Chapter 3. Clinical data of HIV positive AA women from DC health were used for triangulation of the qualitative data collected. Triangulation enhances integrating other sources to confirm data collected through interviews. The DC Health surveillance system that houses HIV data for the District of Columbia was used to confirm the self- reported clinical outcomes collected from the participants. I applied the strategy of reflexive writing in this analysis. This meant that my personal feelings were put in control and that enabled objective analysis void of bias. In addition, I confirmed the credibility of the data through cross checking personal notes obtained during the interviews with the audio recorded interview which I transcribed. To avoid ambiguity of information, during the interview, there was reflective affirmation to ensure participant’s information was understood. At the end of the interviews, a summary of responses was read back to participants to ensure they were adequately represented and no misrepresentation.

Transferability

A detailed description of the research method was provided to allow for replicability by other researchers. There was a rich description of the participants' demographics to enable comparison to other population living in the District of Columbia. The data collected was from DC residents. However, the 42 open-ended questions in this study can be used in any setting of HIV infection. The ten women's information on lived experience were collected in very private interview rooms in a clinic and one in office setting. Each face to face meeting lasted more than 40 minutes. This data is specific to AA women in DC but can be generalized to all HIV positive AA women receiving treatment in DC. The information and experience can only be limited to DC residents due to the generosity of the city making HIV treatment accessible to DC residents. The application of the hermeneutic circle in this analysis and triangulation of clinical outcome data from the DC surveillance system makes the findings of this study generalizable to other HIV positive women from other races living in the District.

Dependability

Interviews were transcribed verbatim using Microsoft word. I kept daily and weekly activities during the data collection interviews to ensure correct information was obtained. Each participant was asked the same questions, time given to ensure information obtained was accurate. Participants were also allowed to ask questions before and after the interviews. Clarity was also provided in case where the participant may not understand the words used. Audio recorder provided data used verbatim to avoid recall bias. In addition, each interview was transcribed independently to ensure no information was mixed or credited to the wrong participant. Triangulation of data was conducted. Triangulation also helped to make sense of any inconsistent or conflicting data.

Confirmability

The strategy to ensure confirmability included description of the participants. I searched within the interview transcripts for negative instances that may contradict prior data and these were none. All participants provided information to all 42 questions asked. Each audio-recorded interview was transcribed within 48 hours and corroborated with the interview notes. Triangulation of data was conducted by use of the DC surveillance system and for newly diagnosed AA women in, 2000, 2010, and 2018 (Table 2). The clinical data was consistent with self-reported data from the participants. Another strategy employed here was use of writing memos. This strategy ensure confirmability in qualitative study. All transcripts were read many times, line-by-line, sentence by sentence to ensure that all ideas are from participants.

Study Results

The three main research questions were thoroughly answered through data collected from the 10 participants. The results are presented according to the questions. There was other subquestions that also proffered answers to the research questions. Hermeneutic approach was used for the analysis of the data in understanding the lived HIV experiences. Results of this study was collated from all the responses from the 10 participants who answered 42 open-ended-questions. Eighteen different themes were identified from many codes.

Research Question 1

The first research question was: What are the lived experiences of African American women with HIV/AIDS in DC? Four themes emerged related to this question. These themes are: (a) Theme 1: Diagnosed at reproductive age; (b) Theme 2: Adaptive ability to lived experience; (c) Theme 3: Intense expectations for cure; and (d) Theme 4: Positive strengths that contributes to resilience. The following section addresses each them in turn.

Table 4

Specific codebook and themes from question 1

Question	Theme	Description
Question 1	1.Diagnosed at reproductive age	Infection at age of planning families and future Growing up in a family culture
	2.Adaptative ability to lived experience	Denials of diagnosis Spirituality as strength to survive Self -efficacy
	3.Era of denials and not involved in care	Empowerment Involvement in Support groups Relationships
	4.Positive strengths that contributes to resilience	Receiving the diagnosis and when effects of such diagnosis at the time of diagnosis and subsequently

Theme 1: Diagnosed at reproductive age. The participants were diagnosed during various years, the longest lived experience with a diagnosis made in 1992, and the shortest lived experience with a diagnosis made in 2007. Nine of the women were diagnosed with HIV at ages between 22 to 36 years old and only one was diagnosed at age 45 years. Sixty percent of the participants were diagnosed while pregnant (See Table

5 for age at diagnoses) and 40% diagnosed at sickness. They had gone for prenatal care and got tested for HIV. Participant 5 said that, she was diagnosed at age 23 when pregnant with her 4th child. She went ahead to have 3 more babies and one of her children is HIV positive. The positive baby was born 18 months before the next pregnancy when the diagnosis was made. Participant 4 (diagnosed age -36years) went to a clinic for a pregnancy test and they asked her “do you know you are HIV and pregnant right? Until that moment, she did not know, saying during the interview, “it was really hard, life changing’. Eighty percent (80%) of the participants have children.

Table 5

Participants’ Age, Viral Load and CD4 Count at time of diagnosis

Participants	Current Age (years)	Age (years) at Diagnosis	CD4 Count at Diagnosis	Viral load at Diagnosis
Cases\\PARTICIPANT 1	53	33	150	500000
Cases\\PARTICIPANT 2	43	22	150	1000000
Cases\\PARTICIPANT 3	44	30	132	950000
Cases\\PARTICIPANT 4	48	36	150	500000
Cases\\PARTICIPANT 5	40	23	69	1000000
Cases\\PARTICIPANT 6	55	45	3	1000000
Cases\\PARTICIPANT 7	39	23	5	1000000
Cases\\PARTICIPANT 8	55	28	150	1000000
Cases\\PARTICIPANT 9	43	25	2	1000000
Cases\\PARTICIPANT 10	60	34	215	1000000

Participant 7 (diagnosed at 23years) stated she was losing so much weight and could not hold any food and experienced constant blackouts. She decided to go a clinic where she was diagnosed with HIV. According to her, “my health deteriorates very bad, my mother took me to the hospital… the hospital did not disclose to my mother, I explained everything to her’. The age of diagnoses for all the participants were at a reproductive age ranging from 22 to 45 years. Many of them were at the period of life when they are planning their future when their diagnoses were received. However, 100% of the participants discussed the effects of the diagnoses, initial denials, empowerment, resilience, and the point of turnaround to embrace the diagnosis and learn to live with the disease.

Theme 2: Adaptive ability to lived experience. Many of the participants were not raised in a two- parents households, 50% were raised only by their mothers, who they said were very strong and stood by them through the experience, 20% were homeless and going from one foster home to another while growing up, 10% (1) was raised by a grandmother and an older sister. The other 20% had relationships with both mother and father in the same household.

For the 80% that had a mother, grandmother and parents in the home, they described the positive influence of their backgrounds on surviving HIV. Participant 1 stated “my mom kept telling me that I have a purpose to live”. According to Participant 2, “I was slow to learn… special aid, born drug addicted baby, and was not going to make it…I did not know that I was on special aid in school. My grandmother said you are not slow or stupid, it is that you learn different than others”. Upbringing and family culture where the participant grew up had some influence on how they have dealt with the experiences living with the disease. Some participants had negative influences while growing up in the home, such as drug addicted parents, drug addicted single mothers, lived in abusive foster homes, but developed adaptive ability which helped to turn around all the negative influences somewhere in the HIV journey.

For some participants, the point of behavior change, turnaround and decision to survive HIV was dramatic while others achieved it slowly. However, at the initial time of HIV diagnoses, denial was more at the forefront for 80% of the women.

Theme 3: Era of denials and not involved in care. Many of the women described a period of denial after the diagnosis. Out of fear, anger and bewilderment, 60% of the participants denied the diagnosis and went on with their lives as if nothing happened. The ones diagnosed during sickness, once they felt better, or those diagnosed during pregnancy, once babies were born, disengaged from receiving treatment. Participant 6 said, “I immediately went into denial, did not believe it, I had no feeling”. Participant 7 also said, “I was in denial at time of diagnosis and wanted to kill everybody… I never had issue accessing care, just not interested, in denial”. It took some of the participants sometimes, up to years and Participant 2 specifically stated that it took her about 10 to 15 years after diagnosis to get involved in treatment. According to Participant 10, “there was nothing to live for, no history, gonna die anyway…did drugs heavily for 4 years”. At this denial era, the participants were not involved in HIV treatment, which meant, there was increased HIV virus in their community, which may lead to more infections among their sexual partners.

Theme 4: Positive strengths that contributes to resilience. Theme 4 tapped into strengths that related to resilience. I grouped these strengths into subthemes. The subthemes are decision to survive and thrive, drawing on spirituality for strength, involvement in support groups, and identifying other supportive relationships.

Subtheme 4a: Decision to survive and thrive. There was resilience embedded in all the responses from the participants. After the initial stage of denial, 100% of the participants although still struggling with some individual difficulties, decided to thrive and live with HIV. Participant 8 stated “different things were going on in my mind, how am I going to raise them, take care of me, provide, all by myself… the father is not there on regular basis to help with day to day, so I went through different changes’… I found peace in my chaos”. Some of the survival and resilience statements among the women included, a decision to live for the children’s sake. For example, Participant 2 shared “have two kids to live for, that stayed in my mind, keep my mindset”. Others stated, “my kids, its mine kids, I don’t want to just die for anybody to raise them…sick, tired, I’ve got to get off my butts, they depend on me to do everything… it is not for me, it is for them (Participant 5) and ‘the children are the motivation to stay alive (Participant 7). For some, the sheer decision to stay alive and not allow HIV to define who they are motivated their interest to engage in HIV treatment.

Subtheme 4b: Spirituality as strength for survival on the lived HIV journey. Spirituality plays a vital role in the lived experienced of AA HIV positive women. One of the survival hallmarks is having a relationship with a higher being, often called God. The women discussed improving their ability to manage their HIV status through praying to

God and having the will to take control and live. Participant 9 was very adamant about how God told her that she was going to leave her profession to tell others about the disease. She started speaking publicly about the disease in seminars and among young girls. Living with HIV was also described as an emotional and spiritual journey. “God has kept me going... he is my healer, keep positive attitude, keep my eyes on the prize, I will be fine, that what I hold onto” (Participant 4).

“When I got pregnant with my 3rd child, I went back to church where I started from… when I got myself together in the church that helped me to really digest and grasp” (Participant 8). There was deep rooted relationship with spiritual leader, who functioned as role father model that influenced one of the women. One participant decided to stop using drugs that God had things better for her. To the extent that Participant 4, will have to pray for the medicine to work before taking her daily antiretroviral medication. She stated, “Everyday say a prayer, God let this medicine work, God is good”. In all, there is a belief among the participants, that on a daily living, involving God will make the HIV experience better.

Subtheme 4c: Involvement in support group. Among the keys to living well with HIV was engagement in support groups. All the participants mentioned support groups as a life saver. Forty percent of the participants are also engaged as peer educators in various support groups. According to Participant 1, her support group “is a safe place to vent, cry, disseminate information, give each other encouragement”. Having a place and people one can relate with without fear of being judged was seen as a critical need for the women. Some women do not have families, so instead being in a support group becomes a key factor to surviving. Participant 10 stated “I got involved in many support groups and is better”. ‘This is a disease that cripples you, not just physically but mentally, if you are not built for it and don’t have a support system, this is another key factor you have to have a support system in place in case anything in life happens, what type of support system do you have? That’s the lot of life” (Participant 8). Some called for mental health support groups, self-esteem groups, more psychiatrists, including setting up HIV hotlines to assist newly infected people navigate the health system to get help.

Subtheme 4d: Positive relationships. A gender issue raised was the role of men in the lives of women after the infection. Some of the participants were able to find love again. Among those that found love, whether the men were HIV positive or negative, they have been a source of strength in the lived HIV experience. They are not judged by their new partners and some because of the role of the men in their lives, have been shielded from stigma. In one participant, the spouse was instrumental in her stopping a life of prostitution and drugs, According to her, “Plus the dude told me, I come for you a lot but I am not coming back no more because you act like you don’t want nothing better and I said Oh Oh, I slapped myself up… I said, girl snap out of it, I decided am gonna live right, gonna do my part… I met a guy who seemed to care more about me than I cared for myself, but I met him in my addiction and prostitution…that my husband, so he takes good care of me. We have been married 22 years” (Participant 10). Participant 4 met her spouse, who is HIV negative and states, “God is good, I found a man that loves me, he encourages me to take my medication, he encourages me to keep positive attitude, there is life after HIV, really is”. And for participant 9, her HIV negative husband has been the strength she needed to survive the disease. He also publicly acknowledges his HIV positive wife further reducing her stigma and shame. “My husband had a T-shirt which reads ‘my mate is beautifully made regardless of the HIV’… my husband is God’s gift, celebrated 18years of marriage” (Participant 9). Participant 2 acknowledges never experienced stigma because her husband in also positive and they work things together at home ensuring that their children stays HIV negative. Forty percent (40%) of the participants have positive relationships with their spouses and boyfriend, who provide emotional strength and support.

Subquestion 1a

Subquestion 1a asked, what are their daily routines in relation to medication adherence? Four themes emerged related to this question. These themes are: (a) Theme 5: Importance of daily medication adherence; (b) Theme 6: Unfettered access to good HIV treatment; (c) Theme 7: Intense expectations for cure; and (d) Theme 8: Conscientization-personal transformation to engage in HIV care. The following section addresses each them in turn.

Table 6

Specific codebook and themes from subquestion 1a

Question	Theme	Description
Subquestion 1a	5. Importance of daily medication adherence	Individualized uniqueness in taking medication The need for a cure
	6.Unfettered access to good HIV care treatment	Good access to HIV care in District of Columbia The need to survive and not die
	7.Intense expectation for cure of HIV	Daily routines of medication adherence Access to treatment Satisfaction with care
	8.Conscientization-personal transformation to engage in HIV care	

Theme 5: Importance of daily medication adherence. The women understood the importance of taking antiretroviral medications on a daily basis. They built individual skills to ensure adherence. Eighty percent are virally suppressed for many years while twenty percent have achieved viral suppression sometime in the journey but currently not suppressed. Among the ten women interviewed, each had a unique way of describing the daily routine of taking antiretroviral medications. Not taking medication was likened to abandoning children in the subway. According to Participant 5, “It is like leaving your children in the subway and get off, anyone of them dies, you die”, I take it every day just to live for them. I may miss sometimes but I get back to it”. Taking medication daily has become part of life, either taking it in the morning or before bed. Some of the women who take medication once a day profess how easy and convenient it is to be consistent and take just one pill a day. The simplification of HIV medication was a vital factor to

living well with the disease especially for women who were infected when there was little to no medication. According to Participant 3 “Biktarvy once a day, that’s all”. “One time a day with food, I take it in the afternoon, I don’t miss it. Because I take other heart medicines” (Participant 2), “I take the medicine every night at 9pm, all the time, if the medicine don’t work, it’s out of my control, I don’t have control of anything. The only thing I have control is taking it” (Participant 4). “They are in bubble pack, Triumeq once a day with food… prefers to take it in the morning as can forget in evening’ (Participant 10). According to Participant 8, a perfect reminder is to put the medication by the pillow in the bedroom “It is by my pillow where I can see it before I sleep”. I see it, grab it and take it. If not in my face, I will forget, it is not intentional, if you have a busy life like mine”.

However, taking medication is still a challenge for all the women. This is not necessarily because the participants do not understand the importance, rather because of other life challenges. Participant 10 has a swallowing problem and Participant 7 can’t take pills, shots including cough medicine and she was wondering, “if they make a patch, all medicine in one into a patch. They have patches for cigarette, why can’t they make a patch for HIV”.

Despite all challenges in medication adherence, medical providers and other health workers who care for the participants play vital role in encouraging adherence. Participant 2 stated “the way the medical provider treated me, she gave me the push, no excuses, your numbers are good, but you have other health issues”. According to her, the provider made her own her care by recommending to “call it your name”. Then

Participant 2 stated that “mine is cocktail”. Using such names made her feel comfortable taking the medications and she no longer refers to them as medication but as a cocktail. Participant 6 was encouraged by her medical provider to join research study where she was treated with utmost respect, became part of the research family, which played vital positive role in her being adherent to treatment and medication.

Theme 6: Unfettered access to good HIV treatment. All of the 10 women interviewed are satisfied with access to care and the care they receive in District of Columbia. It was unanimous that some places that do not specialize in HIV treatment did not do a good job, but wherever they were next referred after being diagnosed provided great HIV care. One of the participants made the statement that “DC is a good place for HIV treatment…no matter what you have you will never be turned away in DC” (Participant 1). Their experiences with HIV treatment in the District of Columbia has been very positive. According to participant 6, “I did not have problem accessing care, I am engaged in the hospital that diagnosed me, I have been here all these years”. Other statements confirming good HIV treatment and access to care in DC include, “I have always had good care” (Participant 5), “I never had issue accessing care, just not interested, in denial” (Participant 7) and Participant 9 stated “I am 103% satisfied, Father, Son and Holy Ghost.”

However, Participant 8 discussed things that might be missing or lacking in DC HIV care. According to her “DC don’t have services that really meet anything for people like us and when they do, they have different types of rules and guidelines that you have to cross all the “t” and dots all the “I”, I got my own wagon but you have to jump all these hoops just to get some help". She said this with particular reference to financial help. "Right now, its financial challenges, when I tried to get disability, it's like pulling teeth, that is the struggle right there. They want you to be close to death before they give you anything. I can close up and lie and say I am mental and get it" Participant 8). Participant 9 put it succinctly: "From what I understand, some people play the mental health card just to get a check". However, Participant 10 summarized the discussion and put it in a different perspective: "We are well and now we are looking for something to complain about… because people are mad that they are not paying for their house anymore. Because you live longer than they expected you to, where do you think the money go come from?". The participants agreed that the District of Columbia provide adequate access to HIV treatment, but HIV positive women have other pressing issues that equally need to be addressed in addition to HIV

Theme 7. Intense expectations for cure. One of the findings in this study is during the interviews; some of the participants conveyed a desire for a cure to be developed for HIV. Some of the women expressed a desire to be cured and look forward to when they could stop taking antiretroviral medications. The women made statements such as: "One day, there will be a cure…even though it did not have a cure, I could still live a long healthy life with medications and things of that nature" (Participant 6). Participant 7 wanted to know if there was a medication to cure HIV, "do you think they already have a cure, they need a cure". Another participant expressed satisfaction with the care she received but still need to be cured, "I am satisfied with care but I wanna be cured, can they cure us"? (Participant 10). Researches in HIV have continued but there are no news of HIV cure yet and that is a concern for some of the women that believe that HIV cure should be discovered sooner than later.

Theme 8: Conscientization-personal transformation to engage in HIV care. All the participants discussed times of denial and powerlessness as well as reaching an empowered status. They attributed their empowered status to taking active role in learning about the disease, getting involved in support groups, and linking up with other women, churches, and other avenues to get information. Participant 9 stated, “I learned about HIV, viral load, CD4”. Participant 9 speaks publicly about the disease in seminars and recall an incident at a Walmart store with her supportive HIV negative status husband. She stated that she wore a T-shirt written “I am HIV challenged, make sure you are not”, while at same time, her husband wore had a T-shirt that read, “My mate is beautifully made regardless of the HIV”. Many of the customers and staff at Walmart stare at them. Another participant stated “I found these things by myself, I pitched around to find anything that would educate me” (Participant 4). She reflected that, “through HIV, I became empowered’ and Participant 3 stated that, “I advocate for myself, asks for medicine ahead of time just in case they are needed”. Participant 6 said, “this thing wont beat me, I will beat it, I did my part and still doing my part, I am a survivor, being here is a testimony that I have survived the disease…I have come a long way, as long as am taking my medicine, my virus is suppressed, I can’t stop”. One common denominator among the women was coming to a point, when the reality of living with the disease was conscientized and the personal transformation to be involved in care occurred.

Subquestion 1b

Subquestion 1b asked: What constitutes stigma and discrimination faced on daily living? Three themes emerged related to this question. These themes are: (a) Theme 9: Negative effects of HIV stigma on HIV Disclosures; (b) Theme 10: Stigma, self - stigma/blame and engagement in care; and (c) Theme 11: Challenges in the ‘lived’ HIV journey. The following section addresses each them in turn.

Table 7

Specific codebook and themes from subquestion 1b

Question	Theme	Description
Question 1b	9.Negative effects of HIV stigma on disclosures	Ignorance, fear of the unknown, uneducated, gossiping, false rumor and hearsay
	10.Stigma, Self-stigma/Blame and engagement in care	Complications of the disease Financial challenges Taking medications daily Swallowing difficulties
	11.Challenges in the ‘lived’ HIV journey	Challenges that constitute stigma and discrimination

Theme 9: Negative effects of HIV stigma on HIV Disclosures. According to participants, stigma and discrimination include ignorance, fear of the unknown, lack of education, gossip, the spreading of false rumors and hearsay. One hundred percent (100%) of the women acknowledge the presence of stigma in the community. Half of them reported having never experienced stigma personally but that they have heard other women discuss stigma and personal journeys in their support groups. The participants think ignorance and being uneducated about the disease is a major factor propelling the

stigma and discrimination. To the extent that a mother would not accept food from her HIV positive daughter because she was HIV positive but when a second daughter (Participant 3) became positive, the mother had learned a lot about the disease and treated the second daughter better than the first. Meanwhile, the second daughter was fearful about disclosing because of the mistreatment she witnessed against her sister. But all the participants have a very defiant attitude towards people propagating stigma. According to participant 5, "it is on them…it is their rumor and ignorance and has nothing to do with me". Other experiences with stigma and discrimination are summarized in the statements below:

- When you tell anyone that you have HIV, the first question they ask is how did you contract it, nobody asks how you contract diabetes or other diseases (Participant 1)
- I don't face stigma on a daily basis, there is too much stigma around, stigma has to be broken, know your status is not enough, you must do more than that, that's why I am in the field am working with young women, when I come across them, I share my story to give hope' (Participant 3)
- There is so much stigma with HIV than any other disease…if they come to me, I will ask them what they got, who are you to judge me, what you got? (Participant 6)
- Now, I don't care, work in the hospital, has never affected my job… it took a minute to get there ...now judge me all you want, if I get it, you can get it too. (Participant 7)

Stigma is a barrier to some of the participants acknowledging the disease within their families or in a public space. Stigma affects disclosures for some of the women while others speak publicly about their diagnosis and will not be bordered about who is aware of the status or not. The participants during individual interviews acknowledged that stigma must stop for HIV infection to decrease.

Theme 10: Stigma, Self -Stigma/Blame and engagement in care. Among the lived experiences, that the women shared was stigma, self-stigma/blame and overcoming them to engage in HIV care. Self-stigma/blame was expressed as in part being aware and having heard about HIV but not thinking that she herself would ever become infected. Anger against self and self-blame became a barrier initially to engage in treatment. According to Participant 1, “it took me a longtime to forgive myself, the shame of it…it is bad enough that outside world to shame you, it is worst, personal shame”.

However, some of the participants devise measures to deal with stigma. Amongst them is keep a circle of other AA women especially in peer support groups. Some participants are prepared to defend themselves if disrespected or ignore the attacker. Participant 5 stated “I don’t argue with them, whatever you think, run with yourself, it does not matter, and they might be messed up themselves’. Participant 6 affirmed that there was a lot of stigma in society in general, though not among healthcare providers. She added, “if they come to me, I will ask them what they got, who are you to judge me, what you got?”. The Participants became empowered to challenge anything that may be an expression of stigma in their daily living. Participant 9 shared an experience she had while providing education to young women about HIV disease. She stated

> Recently, I was invited to give a talk in one of my mentor's shop in a live program. I am speaking to a lot of girls. I told them that I was HIV challenged, I call it HIV challenged, told them to be careful as young girls. One of the ladies stood up. 'I am taking my daughter out of here, coming here and boasting as if HIV is a beautiful thing'. I was in shock; I was messed up and held my hand. Before I could put it down, two other ladies stood up, I am not a part of this, you people are dangerous to us who are normal.

According to Participant 9, in the live meeting, she asked the group if anyone wanted to leave because she must complete her task. And she said,

> Before I continue, does anyone wants to leave because these ones want to stay in their mindset, I am here to let you know we have medications, they start out with one pill and now we have more than twenty.

According to this participant, in her eighteen years of living with the disease she had experienced stigma only about three times. All participants in this study expressed full engagement in HIV care despite the stigma in the community.

Theme 11: Challenges in the 'lived' HIV journey. For many of the participants, there are difficulties faced on a daily basis. Although all participants expressed positive attitudes towards dealing and living with the disease, they unanimously agreed that there are difficulties in the journey that is unique to HIV. Participant 4 stated, "living with HIV is really hard, life changing…this is disease that cripples you not just physically but mentally… the mental aspect of HIV is bigger than the physical, the mental and the physical needs to go together". For Participant 8, it "triggers feelings of depression" and

Participant 6 expressed having, “mental health problems, depression…had bouts of depressing modes”.

Another challenge is taking medication. The newest antiretroviral medications have less intense side effects and are easier to take, especially the one-a-day pills. No matter how simplified the regimen might be, some participants continues to have problems physically swallowing the medication. “Not great at taking medicine, because the pills are huge, they stuck in my throat” (Participant 10). Participant 7 would prefer the medication to be patch. “They have patches for cigarette why can’t they make a patch for HIV?”. Participant 5 has been struggling with medication adherence and expressed frustration stating, “the only issue was to adjust to taking medications daily, taking the medicine is the greatest challenge, I forget to take them many times, not taking them”.

Despite having a positive attitude towards dealing with the effects of the disease on daily living, the women reflected on the devastation that the HIV diagnosis has had on their lives. “You don’t die with HIV but all the complications that comes with it, now I understand, that’s the scary part”, (Participant 4). It is a life-altering event, often resulting in starting life afresh with new friends as old ones disappears. There are basic housing and financial challenges that are on top of dealing with an HIV diagnosis, especially in DC with its rising housing costs and overall high cost of living. Many of the interviewed participants are single (70%), with children (80%). Half of the interviewed women are unemployed. According to Participant 8, “housing is a challenge especially raising 4 kids, you have to drag them from place to place, then they put you out, you move to another”. Participant 10 offered a possible reason for the housing challenge, “Cause people are mad that they are not paying for their house anymore, because you live longer than they expected you to, where do you think the money go come from?”. Other issues going on in someone’s life may affect engagement in HIV care sometimes, but all interviewed participants are engaged in HIV treatment.

Research Question 2

The second research question was: How do HIV positive African American female describe/explain viral suppression? Two themes emerged related to this question. These themes are: (a) Theme 12: Importance of viral suppression; and (b) Theme 13: Improved clinical outcomes. The following section addresses each them in turn.

Table 8

Specific codebook and themes from question 2

Question	Theme	Description
Question 2	12.Importance of education of viral suppression	Knowledge of viral suppression at diagnosis Current understanding of viral suppression
	13.Improved Clinical Outcomes	Improved CD4 count Improved immune system Achieving viral suppression and improved CD4 count among newly diagnosed ages 35 -54 years from year 2000 to 2018 Clinical outcome evidenced by self-reports and medical records Clinical outcomes evidenced by triangulation data from DC Health

Theme 12: Importance of viral suppression. All the 10 participants acknowledge the importance of virally suppressed. Each person had achieved viral suppression at least one time during the course of her HIV journey. Eight (8) of the

participant’s self- reported as currently virally suppressed. The 2 participants not virally suppressed are at 540 and 119000 HIV copies, respectively. One (1) has been off medication for the summer and the other off medication for 3 months. The goal of HIV treatment is to achieve viral suppression. Achieving this status reduces inflammation and is associated with various positive clinical outcomes.

Subtheme 12a: Knowledge of viral suppression at diagnosis. In this study, what the women reported through the interviews as being taught at diagnosis especially with reference to the importance of viral suppression, was assessed. Some of the participants indicated that they did not receive any education on importance of viral suppression at time of diagnosis. The experiences of the women with particular reference education of viral suppression at diagnosis was unanimously negative. Seventy percent (70%) of the women stated they were never taught at diagnosis the importance of engaging, remaining and achieving viral suppression. Interviewed participants made clear statement below of not receiving vital information at time of diagnosis:

- “I did not learn about viral suppression and that HIV affects aging” (Participant 1)
- “No education on viral suppression at diagnosis. The place that first diagnosed did not discuss viral suppression… first diagnosed virus was in millions, dying” (Participant 2)
- “They did not teach me anything but refer me to teaching hospital clinic” (Participant 3)
- “At diagnosis, they did not say anything that stuck” (Participant 4)

- “No one communicated diagnosis in small clinic, here you go, HIV pamphlet and here you go with lots of people in the waiting room looking at your HIV pamphlet” (Participant 5)
- “The thing that messed me up was that I did not have a social worker, I did not have help, I did not know nothing” (Participant 9),
- “At that time, they were just trying to save our lives” (Participant 10)

However, 20% of the women acknowledged receiving some general information on HIV but they either were not in the right frame of mind to receive any education and/or were much more focused on making sure that their babies were not born with HIV. According to Participant 3, she was told “If you take this medicine, you will live longer, and baby won’t have it”. And Participant 7 stated, “Education at the time of diagnosis, not in a right frame of mind to understand teaching”. Only one Participant (6) acknowledged receipt of education about viral suppression at time of diagnosis by her medical provider, who also referred her to get involved in a research study. Overall, 70% of the participants were not provided information on the best goal of HIV treatment, taking medication to achieve viral suppression and reduce viral inflammation

Subtheme 12b: Current knowledge of viral suppression. After living with HIV for ten years or more, 100% of the participants exhibited knowledge of the meaning of viral suppression. They take joy in being virally suppressed. With reference to Table 9, 80% of the women are virally suppressed. Nonetheless, all the women have experienced viral suppression during some point in their journey.

For the two participants who indicated that they were not currently virally suppressed, when considering a jump in viral load, expressed confidence in their knowledge about what to do to get the viral count back in order. Participant 1’s viral load is 540 copies. She stated, “I was taking medication, but in summertime, the sun makes me to itch, affects my stomach… I had to do what is best for…stop taking medicine during summertime and resume after 3 months break”. Participant 5 has been off medication, non-adherent due to housing issues and moving, and she states, “was undetectable, I will get it right back”. All interview participants expressed knowledge of importance of achieving viral suppression and take pride in discussing the accomplishments. The increased knowledge was attributed to years of engagement in HIV care and attending support groups

Theme 13: Improved clinical outcomes.

The clinical outcomes for the participants were collected through self-reports. Some of the self-reports were actual laboratory documents from the laboratories and medical records. Some of the participants have access to patient portal in their clinics to look up CD4 count and Viral load values and read medical providers notes. Part of the improved health outcomes were also assessed through surveillance aggregated data obtained from DC Health

Subtheme 13a: Evidenced by self-reports and medical records. Table 9 shows the clinical outcomes of the interviewed participants. At diagnosis, viral load was at millions while 80% are currently virally suppressed. The immune system also shows a rebound immune reconstitution. At diagnosis, 100% 0f the women were diagnosed as

AIDS status with CD4 counts below 200, while current CD4 counts are above 350 cells per cubic millimeter for 80% of the participants. Participant 7 acknowledged, "been a roller coaster, having missed so many medications, been on salvage, this is my last option… built many resistances due to non-adherence".

Table 9

Clinical Outcomes of Participants

Participants	Current Age (years)	Age (years) at Diagnosis	CD4 Count at Diagnosis	CD4 Count Nov. 2019	Viral load at Diagnosis	Viral Load Nov. 2019
Cases\\PARTICIPANT 1	53	33	150	610	500000	540
Cases\\PARTICIPANT 2	43	22	150	584	1000000	20
Cases\\PARTICIPANT 3	44	30	132	1300	950000	20
Cases\\PARTICIPANT 4	48	36	150	763	500000	20
Cases\\PARTICIPANT 5	40	23	69	160	1000000	119000
Cases\\PARTICIPANT 6	55	45	3	485	1000000	20
Cases\\PARTICIPANT 7	39	23	5	219	1000000	160
Cases\\PARTICIPANT 8	55	28	150	375	1000000	20
Cases\\PARTICIPANT 9	43	25	2	824	1000000	20
Cases\\PARTICIPANT 10	60	34	215	1400	1000000	40

Subtheme 13b: Evidenced by triangulation data. Data for triangulation obtained from DC Health confirmed the clinical outcomes obtained from the participants. Table 3 shows the number of AA women diagnosed with HIV in Washington DC. The median viral load at diagnosis was 1205 in 2000. Of the women diagnosed in 2000, 73 were

between the ages of 25 and 34, 77 of them ages 35 to 44 years, 46 women between 45 and 54, and 5 were ages between 55 to 60 years. At the same time, CD4 counts at diagnosis was at AIDS defined status (156 viral copies) when CD4 count is below 200. Table 3 also shows an analysis of the AA women between ages 35 and 54 years and diagnosed in year 2000. The clinical outcomes of the same cohort in year 2010 and 2018 are also displayed in Table 3. The clinical outcomes show a reduction in viral load from a median load of 3,687 in the year 2000, 47 in 2010 and 46.5 in 2018. Also relevant is the median CD4 count in year 2000 which steadily increased to 586 in 2010 and 612 in 2018. This data supports the positive clinical outcomes the participants self-reported during the individual interviews in Table 9.

Research Question 3

The third research question was: How do HIV positive AA women explain/describe the high rate of HIV infection among African Americans women in the District of Columbia? Five themes emerged related to this question. These themes are: (a) Theme 14: Unprotected Sex and nonuse of condoms; (b) Theme 15: Gender Roles/Issues in HIV infection; (c) Theme 16: Nondisclosure of HIV Status; (d) Theme 17: The importance of high community viral load; and (e) Theme 18: Importance of community education and knowledge of HIV transmission. The following section addresses each them in turn.

Table 10

Specific codebook and themes from question 3

Question	Theme	Description
Question 3	14.Unprotected sex and multiple sex partners in closed area	Presence of multiple partners in closed area Search for love, acceptance and loneliness Denials of HIV at diagnosis Among the population
	15.Gender role/Issues in HIV infection	Incarceration and nonuse of condom Unable to disclosure HIV status to sex partner
	16. Non-Disclosure of HIV status	Reducing HIV infection among AA women
	17.The importance of high community viral load	
	18. Importance of community education and knowledge of HIV transmission	

Theme 14: Unprotected Sex and nonuse of condoms. According to the 10 participants, unprotected sex was mentioned as the main culprit of the high rate of HIV among AA women in the District. As described, at the end of the day, no matter what one is seeking, if condoms are used, transmission would definitely decrease. One hundred percent (100%) of the participants discussed having multiple sex partners in the same neighborhood. The following quotations describe the role of unprotected sex in the high rates of HIV:

- “You don’t think of anything until it is over and you wind up with STD. you are to blame, you did not put it (condom) on” (Participant 2)

- "Women are having unprotected sex" (Participant 6)
- "Women not knowing to protect themselves" (Participant 7)
- "Women are not protecting ourselves; we think men will protect us" (Participant 8)
- "The nonchalant protection of themselves, you don't just go sleep with any guy... We are not using protection, protection is there, there are female condoms that give protection for 8 hours, whole 8 hours to keep condom inside, why are you not using condom"? (Participant 9)

Other reasons adduced by the women are what participants called "ignorance", "loneliness" and "looking for love in the wrong places". All participants also called for people to learn their HIV status as a means to reducing the infection rate. "People not knowing their status and who they are dealing with" (Participant 3). In addition, Participant 6 stated, "knowing status is not enough but honesty in communication" and Participant 5 reinforced the same line of thought stating, "No one is communicating, lack of honesty… before you lay your legs open, know your status". The need among women to belong and have a sense of belonging was also raised. "People are just lonely, and people use sex as water, black woman thinks having a man means love, sex is not love…ignorant among black people and they keep themselves ignorant, there are too much stuff out there to cling to ignorance (Participant 4). Interviewed participants echoed in many ways the need to have sex with condom, get tested to learn one's status in order to prevent from acquiring HIV.

Theme 15: Gender Roles/Issues in HIV infection. The primary gender issue identified by participants was regarding men returning from incarceration and multiple sex partners in same neighborhood. All of the 10 participants discussed men as the central force for HIV transmission in their communities. Specifically reported that men returning from incarceration. “Men going to prison, coming back and infect women, I think because in South East… might go with cousin and cousin with another person, multiple partners in the close area… have multiple partners in same area” (Participant 1). According to Participant 3, ‘Man coming from incarceration and not telling truthful, … knowing you have something like that, coming home, just spreading, it’s crazy … but while having sex, having sex dealing with different sex partners”. The participants believe that men returning from prison have a secret life while in prison. Participant 5 stated, “It is not women, it’s the men, 99% of the time, it came from the men that has been with another men, came home and spread it… come back to love women, whole time had a boyfriend”. Participants in their individual interviews lay blame on men for the high rate of HIV infection among the heterosexual women in the black community.

Theme 16: Non-Disclosure of HIV Status. The 10 participants discussed non-disclosure issues as another factor contributing to the high rate of infection in the District of Columbia. The reason for non-disclosures sometimes hinges on previous experiences of breach of confidentiality from friends and family members. Once the trust was broken, the women shut down and swore to never disclose to others, including sexual partners for fear of how they may react and mistreat them. One participant was so afraid of her partner that she hid her medications for months. “Someone I knew who I told about status, co-worker told others, others did not want to work with me- the co-worker I told, told other coworkers" (Participant 3). Participant 5 stated, "confided in a sister then she became the enemy, one day, something did not go her way and now she is talking bad and disclosed to others". Although some participants would not allow their bad experience to prevent them from disclosing to close family members and significant others believing that it is the right thing to do. Disclosure brings peace of mind according to Participant 6 and Participant 8 would only disclose if God led her to do so. When HIV status is not disclosed, the sexual partner does not take precaution to prevent from getting infected leading to more HIV infections among the multiple sex partners.

Theme 17: The importance of high community viral load. The participants acknowledged having HIV virus in the blood in millions counts when diagnosed. With all the ten participants having virus in millions shows that the community viral load was very high and anyone having sex in such community have a higher chance of being infected with HIV. After diagnosis, 8 of the participants denied the diagnosis of HIV and went about living a 'normal lifestyle' in pretense while spreading the virus. All the10 participants described the treachery among many people who live in the community. They denounced the culture of secrecy and denials of HIV in the black community. Eight of the interviewed women mentioned a time when they were in denial about the diagnosis and went about acting as if everything was normal. And in that timeframe, they were having sex as usual without protection. Participant number 10 did drugs heavily for 4 years and had sex with everyone as she was selling sex in the street. It took another participant 10 to 15 years to acknowledge the diagnosis and get in care (Participant 2). At the time of denials, life was going on as usual with unprotected sex.

Theme 18: Importance of community education and knowledge of HIV transmission. The 10 participants complained about great ignorance in the black community of health education and lack of knowledge about HIV transmission. The average black person on the street of the District of Columbia lack information of what happens in their body. The lack of knowledge of how HIV is contracted, and its mode of transmission. According to Participant 4, "ignorance among black people and they keep themselves ignorant, there are too much information out there to cling to ignorance." Participant 8 stated, "People said, don't touch, phobia, like you touch it, it is contaminated, fool, where is your literature, where is research at, they don't know nothing about it, they put you on an Island". The reference was made to young people who have indiscriminate sex encounters. According to participant 6, "Start at 8 years old, teaching more ladies to care about their bodies…Start educating and teaching in the homes and schools, you cannot get it any other way, eating behind someone, unprotected sex is the key factor…educating young people.. Kids having sex, not knowing what sex means, 8 to 9 years old having babies". In addition, ignorance of transmission is also seen among older women who believe they will not get pregnant but forget that there are other infections including HIV. The women advocated for different messages for young people whether positive or negative. In their community, the disease is still regarded as gay disease and heterosexual males are not interested in anything gay (Participant 1). The participants expressed concern at heterosexual males, whom they described as lacking health education, does not like to go to the doctor, as the major vehicle that propagates the spread of the HIV disease among black females. Participants in this study discussed the need to educate the black community and get the community to get engaged in health knowledge. In addition, participants discussed organizing community days, where people get tested and if they are negative, be engaged in the pre exposure prophylaxis (PrEP), take a pill once a day and if positive to get engaged in HIV treatment at once.

Summary

This chapter presented the results of the research. Ten AA women who took part in the research provided answers to the research questions. Data collections involved one-to-one interviews with the participants answering open-ended questions. In this chapter also is the results of the data collected from the participants. The three research questions and sub-questions were interrelated to gain a more thorough understanding of the lived HIV experiences of the women interviewed. The questions explored how the women describe their lived experience, how they have lived and are still living with the disease for 10 years or more.

The results to question 1 indicate the interrelationships between many factors and the meaning of the lived experience. The women shared among other things, the age of infection (reproductive age/pregnancy), family culture, era of denials of infection and noninvolvement in HIV care, positive strengths that contributes to resilience, spirituality, support groups and relationships.

The aim of subquestion 1a was to glean in more details what antiretroviral medication and treatment adherence looked like for the interviewed women. Results for subquestion 1a showed that all the women are experienced with antiretroviral medication and are in various stages of medication adherence. Some expressed difficulty with the medication such as swallowing issues and side effects but these difficulties did not stop them from diligently taking the medication to remain alive. In addition, the results indicate that the women did not experience challenges in getting access to care in the District of Columbia and became empowered in living with the disease.

Subquestion 1b was asked to learn more about the women's experience with stigma and some of the effects of living with the disease. In response, the women described stigma and discrimination as ignorance, fear of the unknown, lack of education, gossip and hearsay. Many of them have never experienced stigma directly but have knowledge of colleagues that have and decry its practice. Answers to this question also revealed struggles with self -stigma and other challenges that the women had to deal with daily.

The aim of research question 2 was to acquire specific information about what the women knew at the time of HIV infection on one of the goals of treatment and to learn more about the education they received at that crucial time of diagnosis. Answers to research question 2 revealed the unavailability of education to increase or acquire skills on what to do to achieve viral suppression. Many were diagnosed with a very low CD4 count and high viral load. In contrast, women demonstrated that they have since then gained much more extensive knowledge regarding viral suppression. They have positive clinical outcomes, low viral loads and high CD4 counts, substantiated with surveillance data from DC Health. Their clinical outcome data showed their rebound from AIDS status to being HIV positive per CDC staging of the disease.

The last question was intended to solicit the women’s perspectives on what factors are contributing to the high infection rate of AA women in the District of Columbia. The participants’ answers to research question 3 identified unprotected sex as the major cause of infection among these women in the District. Other factors mentioned were denials of HIV diagnosis, gender roles and issues related to high incarceration rates among men. The participants also discussed the impact of nonuse of condoms among men and women and non-disclosure of status to sexual partners.

In Chapter 5, I provided an interpretation of the findings, an exploration of implications, a discussion on limitations of the study, recommendations for policy, future research and conclusion. The potential impact of social change was also described. As part of Chapter 5, strong recommendations for practice were provided and discussed within the boundaries of the scope of the study.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

This qualitative study was conducted to increase the understanding of HIV infection and viral suppression from the perspectives of AA women living with HIV. The study used a phenomenological approach to uncover the lived experiences of HIV positive AA women and viral suppression, including how HIV positive AA women describe and explain both the actual stigma of the disease and the discrimination coming from family, friends and the community.

Another aspect of this research was the use of a feminist lens to understand black women's unequal position regarding HIV infection. Pursuant to understanding their lived experience, it is important to understand the increases in HIV infection among this particular group. There are findings that support gender as the basic framework that conditions women to an increased risk of HIV infection. This point of view means that issues of gender roles and socialization have to be explored further to understand HIV vulnerability among AA women. This study equally confirmed that geo-behavior is a link to vulnerability to HIV infection. Examining the lives of this group of women provided a new and better opportunity to learn how they experience this disease, what prevention methods might be most effective, and how their experiences link to achieving successful viral suppression which is a prelude to ending HIV infection.

Key Findings

HIV AA women who are living in DC have exhibited resiliency and empowerment in their lived experiences with HIV infection. HIV positive AA women are dependent on many factors unique to them and their community when surviving and living with this disease. All of the women were infected at reproductive age of 22 to 45 years. Participants in my study discussed their resilience and empowerment toward being infected in their prime of planning families, getting education, and raising children. They relied on self-efficacy, spirituality, support groups, and relationships as major strengths to address and handle their unique challenges. At the initial time of diagnosis, many were in denial, but this issue was conquered. Positive relationships with spouses or significant others played a critical role in supporting their survival. Most importantly, the participants expressed an increased understanding of viral suppression after many years of lack of education on its importance, especially at the time of diagnosis. Viral suppression as a goal of HIV treatment was well understood, as these women adhered to antiretroviral medication to achieve suppression of the virus. Access to HIV treatment and antiretroviral medication in DC was expressed as unfettered providing these AA women the platform to survive the adversity of their infection.

My respondents explained the high rate of HIV infection among AA women as mainly attributed to unprotected sex. According to them, heterosexual men and nonuse of condoms propagated increased instances of HIV infection among AA women in the District. In addition, AA women are more vulnerable to HIV because of where they live, and their potential pool for sex and relationships in their neighborhood. This study added to the knowledge that HIV stigma negatively affects the patient’s engagement in HIV care. Although, the AA women in my study have devised positive means and better ways to actively connect to care and not allow stigma to affect engagement in HIV treatment.

However, stigma, they said, affects their disclosures and leads to people engaging in sexual practices without disclosing HIV status to their partners and not wearing condoms. The more condomless (unprotected) sex there is in a community that has a high viral load becomes a recipe for disaster via the incidence of increased HIV infection.

Interpretation of the Findings

The findings were interpreted in three major ways. New information obtained geared towards advancing new knowledge in HIV care, treatment and/or prevention. The second part of the interpretation discussed the confirmations of other literature from peer review articles. In the third aspect, findings were also interpreted from the theoretical framework of resilience and empowerment theories applied in the study.

Advancing New Knowledge

This study offers new knowledge and information relevant to answering all three of the research questions. The most important knowledge gained is this research is that my study participants were not provided education on viral suppression as a goal of HIV treatment and its subsequent benefits of reducing HIV inflammation at the time of diagnosis. However, these HIV positive AA women became very knowledgeable after living with the disease for 10 years or more and engaging in HIV treatment. The knowledge was acquired because of the women’s tenacity to learn and know all they could about the disease. However, they had to go search out this knowledge from both HIV clinics and churches. Viral suppression is a clinical outcome that is positively associated with an improved health outcome. Women in this study achieved viral suppression at least once in their course of the disease with an improved CD4 count from the time when their diagnosis of infection was confirmed. Providing information on the benefits of viral suppression may thus be beneficial to women to help them engage in HIV treatment as a precursor to achieving and maintaining viral suppression.

Another critical key finding of my study that advances the HIV/AIDS knowledge is that HIV positive AA women interviewed have unfettered access to HIV treatment in the District of Columbia. The women laid emphasis that Health Care Services operating in the District of Columbia who receive Ryan White Funds for HIV treatment do not discriminate against women who are HIV positive. Antiretroviral medications are available to all AA women who are un-insured or underinsured and have no other means of paying for their HIV treatment. All the AA women interviewed were referred to clinics that specialize in HIV care. After diagnosis. The women also have access to all Food and Drugs Administration (FDA) approved HIV medications to treat their infection.

One of the positive strengths that contributed to the women’s resiliency in this study group is involvement in a good relationship with a HIV positive or negative significant other or spouse. Positive relationships with spouses or significant others play a critical role in supporting survival. According to the women in this study, good relationship with men is a positive strength that can shield from experiencing stigma in the community.

Although 8 of the participants achieved viral suppression, defined as viral load below 200 by CDC (2018) and Cohen et al. (2016), they also described difficulties adhering to the prescribed medications. The quest for a cure for HIV is paramount in the minds of these longtime survivors. Many respondents described praying and hoping for a cure, while others were looking for another way of taking their HIV medications. Some new HIV medications under development may offer solutions to some of these needs, especially with long-acting, monthly or bimonthly injectable (Simoni et al. 2019). Women who have trouble taking daily medications or experiencing swallowing difficulties may benefit from these new drugs coming into the pipeline once they are approved.

Support for Findings of Other Studies

The resilience of these women after HIV infection was well elucidated in this study. The respondents in this research attributed their survival of the disease to numerous things, including developing positive strengths in the face of adversity. The decision to deal with HIV infection and engage in treatment was personal. It was attributed to various things depending on the person who was infected. There was a decision to survive and thrive, regardless of the circumstances. The interviewed AA women have great attachment to their children and for many of them, their children are the thread to which life is attached, confirming a study by Islam, Minichiello and Scott, (2018).

The women in my study stated spirituality was another pillar of resilience which helped them to build self-efficacy. There was lots of praying including praying over medication to work effectively in the body among the participants. When someone is a believer in a higher power and God, self-efficacy is built to conquer adversity. According to Nokes, et al. (2012), enhancing one’s self-efficacy was found to be a predictor of medication adherence. Multifaceted interventions approach that are used to reduce stigma, provide social support network, HIV education, provide support groups, as studied by Stewart, Hong and Powell (2018) may also provide relief and improve the continuum of care. The AA women in the study developed a connection to God (spirituality), engaged in support groups, and have a strong determination to live for their children's sake, thus supporting the study by Dalmida, et al., (2017) that found that religious attendance and social support are significant predictors of adherence to antiretroviral medications. The participants attachment to their support groups provided them with a safe place where they met and discuss challenges and proffer solutions.

Another key finding is the importance of medication adherence for HIV positive AA women in the District. They devised different means to ensure that they remain adherent to their medication. The 10 participants understood that continued adherence to medication results in viral suppression. My study showed that 8 of the respondents were adherent and virally suppression. These respondents also understood the importance of medication adherence and the role of consistent medication for healthy outcomes. When an HIV positive individual is on medication and adherent, viral suppression is achieved. Adherence to medication at least 95%of the time is clearly associated with improved health outcomes (CDC, 2013). Care providers are encouraged to assess periodically for medication adherence to identify the people at risk for non-adherence. Analysis of Medicaid data showed that 57% failed to restart ART after 18 months of stopping (Zhang, Shireman, Youn, Lee & Wilson, 2018) and adults are more adherent to medical visits and experience greater viral suppression than younger females (Waldrop-Valverde, Guo, Ownby, Rodriguez & Jones, 2013). The mean age (48 years) for this study, supported the findings that adults experience greater viral suppression than younger females. My qualitative sample supported findings in the literature of larger quantitative study (Castel et al. 2016) and gave a contextual understanding of how AA HIV positive women talk and understand these issues. The findings of this study support Castel et al. who stated that 83% of people who had ARV adherence in the past seven days were engaged in care compared to 69% of people who were out of care. Although in my study, 100% of the women were engaged and retained in care, two of them still had personal reasons not to adhere to their medications, which resulted in not being virally suppressed. According to Musinguzi (2018), interruption of HIV treatment often leads to increased immune activation, which then negatively affects health outcome.

This study added qualitative support to the fact that AA women in DC are at high risk of HIV infection because of where they live and who they are with. According to Brawner (2014), despite efforts to reduce risk, people who are located in areas where there are higher concentrations of HIV infected people still face a higher vulnerability of infection, which is referred to as geo-behavioral vulnerability to HIV.

Although everyone in this study had unfettered access to antiretroviral medications (ARV), 8 out of the ten participants were virally suppressed. This study finding supports the study by Robertson et al (2017) and their comparative analysis of two groups who received care coordination and followed for 24 months. There was no difference noted in their access to medication, but a difference was attributed to adherence. The two non-virally suppressed women in this study reported non-adherence to ARV and taking medication holidays. However, this small qualitative sample of 10 women provides a snapshot of high viral suppression rate. The national average of viral suppression is 49% (CDC, 2017).

The HIV Care Continuum

The care continuum in this study supports the Ryan White care continuum for women living in the District with 80% viral suppression in 2018. However, there is still a gap in viral suppression to meet the goal in the Mayor's ending the HIV epidemic plan (Bowser, 2017). A description of HIV care continuum in this small qualitative sample of 10 AA women when laid beside large quantitative studies of HIV care continuum is noteworthy. There is a support for DC Ryan White HIV Care Continuum in 2018, the DC HIV general population and the national HIV Care Continuum, as portrayed in the table below:

Table 11

Comparison of HIV Continuum of Care

Indicators	The Current Study (Olejemeh, 2020 unpublished)	DC Ryan White Data (2018)	DC, General Population (2018)	USA (2014)
% Diagnosed	100%	100%	100%	85%
% Receiving Care	100%	73%	98%	62%
% Retained in care	100%	95%	79%	48%
% Virally Suppressed	80%	80%	66%	49%

The viral suppression snapshot of this qualitative study supports the viral suppression of the Ryan White Program in DC at 80%. However, there is still a gap of 10% that needs to be targeted to achieve 90% viral suppression goal by year 2020 as articulated by the DC 90-90-90-50 goal plan to ending the HIV epidemic in the District (Bowser, 2017).

High Community Viral Load

Study respondents reported being diagnosed during pregnancy (8), and 2 were very sick when diagnosed. The viral load at diagnosis ranged from 500,000 to millions. Depicting that the viral load for my respondents at diagnoses were very high. One of the hallmarks of high infectivity of HIV is a high community viral load (Castel et al, 2012; Das et al. 2010; Das, 2012). According to Brawner (2014), community viral load is a population marker for the infectivity of people living in a specific geosocial area, and Castel (2012) was able to demonstrate that a reduced community viral load is associated with the reduced incidence of HIV. This current study supports such knowledge.

Increases in HIV Infection Among AA Women

My respondents reported HIV acquisition primarily through having heterosexual unprotected sex with men supporting the study by Drayton & Grant, 2017 and CDC (2018) report. The lack of knowledge of HIV transmission among African American did not translate into making less risky choices, as discussed by Klein, Sterk and Elifson (2016). The same way, knowledge of HIV transmission did not translate into reduction in the acquisition of the disease, as my study supported Perkins, Stennis, Spriggs, Kwegyir-Afful and Prather (2014). Many of the participants reported unprotected sex with men who did not know their own HIV status or refused to disclose their status. In a study by Lindong, Edwards, Dennis and Fajobi (2017), AA youths did not perceive themselves as having highly risky behavior and knowledge of HIV did not deter these young girls from high risk behavior even in detention facilities (Baillargeon et al, 2017; Raidford, Seth, Fasula, & DiClemente, 2017). Increased effort to create more awareness and deliver HIV education in these communities are necessary and indeed critical to reducing HIV infection. The study participants reported that lack of knowledge for how HIV is transmitted among the AA population is attributed to ignorance, seeking love and acceptance. Any program that targets AA women living in DC may be able to make progress in reducing the rate of infection by including these topics.

Gender Is Associated with Increased HIV Infection Risk

Of the 10 women interviewed for this study, 4 live with their husband or significant other. Some respondents have children and the father of the children are not part of their daily living or care. Brawner (2014) proposed a gender responsive model as an initial step to more dialogue and examination of HIV/AIDS as a social issue. Issues of gender roles and socialization may also have to be explored to understand the nature of HIV vulnerability among African American women. Nine (9) of the women interviewed were infected by heterosexual contact with men whom they were in relationship with, and one was raped. All of the participants reported men as the central force for HIV transmission in the AA community especially men returning from incarceration. This finding supports Bradley, Geter, Lima, Sutton, and Hubbard McCree (2018) that there is disparity in AA HIV infection due to high rate of incarceration among black men. The study by Rice, et al. (2018) was also supported as they mentioned that gender was one of the multiple interrelated social determinants that continues to perpetuate HIV stigma. In this study, gender was indeed associated with an increased risk of HIV infection.

Findings in the Context of the Theoretical and/or Conceptual Framework

For this study, I applied truly relevant theories of resiliency and empowerment. These theories supplied the framework that guided the development of the semi-structured interview questions that were used. The focus was on strength, either innate or built from family interactions, overcoming adversity, staying on medication, and achieving positive health outcomes. Based on these findings, resiliency and empowerment played critical roles in women's ability to survive the disease. Resiliency is appropriate, as it is built alongside the continuum of care from diagnosis, engagement in care, and taking medication to viral suppression and especially the resilience constructs of self –efficacy, motivation, and protective factors. According to Dr Catherine Panter—Bricks, resiliency is not a one-time achievement, but must be sustained over time along with the continuum of care (Southwick, et al, 2014). Using the empowerment theory, women turned inwards and identified the source of their disenfranchisement and took charge to ensure better life outcomes (Turner & Maschi, 2015). Some became involved in support groups, focused on raising children, got more education, and ultimately made the decision to live. These decisions helped them overcome the trauma and adversity of HIV infection, leading to their surviving HIV for 10 years or more and achieving positive health outcomes. The construct of nurture and nature in this study showed how home discipline and family culture may positively affect one's adaptive ability. This resilience guided study also allowed the researcher to emphasize successful adaptation for overcoming negative challenges. These two theories were indeed a best fit for this study.

Methodology: A Phenomenological Approach

A phenomenological approach was applied in the data analysis using the hermeneutic loop. Each participant's understanding and meaning of their experience brought meaning to the whole. Participants also showed uniqueness in their experiences. They discussed the meaning of their infection, as each tried to look for meaning and action. A cyclical loop, at the first stage, indicated that some were in denial and without any treatment spanning 2 years all the way up to 15 years. After which, their engagement in HIV treatment became a part of life. As they continued to gather information and knowledge of the disease, they had to deal with challenges, such as taking daily medication, attending medical visits, and having laboratory visits. More reflection on what the disease meant triggered more challenges, a personal reflection to survive, and greater understanding of the need to remain in care and be virally suppressed. Eighty percent (80%) of the participants are virally suppressed while one hundred percent (100%) currently retained in HIV treatment.

Each participant expressed an understanding of their whole experience, and many used spiritual and religious arguments to cement their positive experiences. This methodology was very effective in the current study, allowing for personal uniqueness of a lived experienced to be described by these women. Each person's uniqueness and understanding of their adversity was exclusive for them and not related to others' experiences. Using this method made all the women, experts in their experiences, and able to discuss those experiences profusely and profoundly.

Limitations of the Study

One notable limitation was the use self-reported information. The participants may have tried to impress the interviewer by stating details that may not have necessarily been accurate. It is also possible that someone may have said certain things just to impress or create an atmosphere of strength when they were actually struggling. There is no way to really verify such distinctions. However, the two variables, viral load and CD4 count for health outcomes were verified through data triangulation and produced similar results as reported by the participants.

Another limitation may be what Creswell (2014) called the power relationship between researcher and participants. Although the researcher did not work with, know, or relate to the participants, purposeful and snowball recruitment may have influenced the participants. Some may have discussed the HIV knowledge of the researcher with their peers which then could have influenced their responses to questions. Two participants came from the same organization, seven from another, while one came from a still different organization. These participants also attend various support groups and may have discussed the study and the researcher in them. Interested participants were still calling to be part of the study after the study was completed because they heard about the study from others and exchanged information about the study among the group.

Being a qualitative study, these findings may not be generalizable outside of the study sample and the District of Columbia. The sample was not conducted using a random sampling design, thus creating a limitation wherein the sample may not have been the best possible representation of HIV positive AA women. In addition, many of the participants reside in Wards, 1, 5, 7 and 8 and thus may not geographically represent all the nine (9) wards in the District of Columbia.

Recommendations

The importance of viral suppression to the treatment of HIV and its health outcome is synonymous to surviving the disease. Even when infected women are not ready to receive education about the importance of viral suppression, providers should not abandon the idea and its goal and need rather to continue to provide the information at every encounter with their patients. Spirituality, involvement with support groups, self-efficacy, relationships with significant others should also be assessed by healthcare providers and incorporated into each patient’s treatment plan. According to Dalmida, et al. (2017), the factors that affect treatment adherence should be considered in the treatment plan by the care team that includes mental health providers, social workers and pastoral counselors. These inclusions should reinforce the factors that will help AA women the most to remain in and continue their HIV care.

The lived experiences of HIV positive AA women researched through this qualitative study provides information that is very critical to the ongoing reduction of HIV infection among the black population. Policy makers and DC Health should incorporate all the factors identified by these women as strengths that led to their surviving this adversity and develop these factors into a comprehensive assessment tool to use to develop better interventions for HIV positive women. Further still, develop key social marketing strategies for community education and engagement that addresses unprotected sex, stigmas, disclosure of HIV status to sexual partners and multiple sex partners. Social marketing techniques could be used to create greater awareness of these issues in the community while at the same time equipping clinics with more clinical providers to serve more patients/clients who will hopefully return to engage in HIV care.

Most importantly, this study supports that gender is a factor that affects the increased rate of infection among AA women. Both community education and engagement targeting especially AA men reentering society after incarceration, organizing town hall meetings on the issue of HIV awareness, testing and linkages to HIV treatment can indeed be beneficial in reducing HIV infection in AA community and in DC.

Future Research

In the past 10 years or more, AA women entered HIV care late in the progression of their disease with a very low CD4 count and high viral loads. Thus, future research may want to investigate whether this trend has changed, especially by looking at AA women who have been diagnosed in the last one or two years. Another future research topic might be to conduct the same type of research among White females and Hispanic females in order to compare the three populations and more adequately discuss health disparities among the general HIV positive female population in the District of Columbia.

Implications for Positive Social Change

The findings of this study have the potential for positive social change for black AA women living in the district. Most important is the social change in the advancement of HIV treatment and prevention in the era of the Mayor Bowser 90 -90 – 90 - 50 initiative plan in the District (Bowser, 2017). This study calls for a more concerted effort to target AA women for achieving 90% viral suppression by 2020. At the moment, this study finding shows the level of viral suppression at 80% and thus 10% away from reaching the DC goal. The end of HIV/AIDS is indeed contingent upon diagnosing all infected persons and providing full access to ARV to ensure successful viral suppression for all persons with HIV disease.

This study contributes new knowledge on the lack of education for viral suppression among HIV positive AA women at diagnosis. HIV positive AA women do not receive education on one of the hallmark outcomes of HIV treatment, namely, viral suppression. Interventions can be developed with well-crafted education on viral suppression that is provided to all AA women who test positive for HIV. The knowledge gained will be critical to engaging in treatment to achieve greater viral suppression. Developing and implementing such education in all Ryan White clinics in the District will also contribute needed information on the importance of medication adherence to achieve viral suppression as well as the importance of viral suppression. According to the research, when viral suppression is achieved, inflammation is drastically reduced thereby leading to better health outcomes sooner and for longer periods (Eshleman et al. 2017; Cohen, McCarley & Gamble, 2011; Crepaz et al, 2016).

In addition, the findings of this study will impact how to address health disparities. This study identified spirituality, support groups, and positive relationship with men as some of the strengths that helped these AA women to engage and continue to remain in care after many years of living with the disease. This knowledge could lead to policy changes to include all these factors and combine them into a more comprehensive assessment tool in every clinic that is serving AA women in the District.

The knowledge gained in this study will be beneficial for addressing the high rate of infection among AA women. DC Health/HAHSTA can thus develop community education that will address unprotected sex, stigma, disclosure of HIV status to sexual partners and multiple sex partners. Social marketing techniques could be used to create awareness of these issues in the community while also equipping clinics with more clinical providers to serve more people who will choose to return to engage in the important HIV treatment.

Conclusions

In summary, the strongest predictor for surviving HIV among AA women in the District of Columbia is having unfettered access to HIV treatment, a level of spirituality, the availability of antiretroviral medication, engagement in support groups, and viral suppression. To achieve viral suppression, one must adhere to antiretroviral medication. Discussion on the importance of viral suppression at the time of diagnosis and during the course of treatment is very important. This study provided increased knowledge to target prevention of HIV transmission and highlight the importance of heterosexual transmission for HIV in DC. Viral suppression predicts positive health outcomes and improved immune system. Therefore, any experience of achieving viral suppression will hopefully translate into decreasing HIV transmission and the community's viral load. This study also adds to the wealth of knowledge of stigma on disclosures of HIV status to sexual partners and the non-use of condoms during sexual intercourse. Targeted HIV education for DC's black community should continue to include information on transmission, biology, treatment and care to provide greater support for all women who live with HIV.

A compelling argument can be made to support that AA women's lived experiences from this qualitative study in the District of Columbia can be generalized to other women in the District. These study findings illustrated somewhat themes related to living with HIV including resiliency, self-efficacy, support, spirituality, adherence, viral suppression, stigma and community education. The accessibility of treatment, medication, and support groups around the city offers a positive platform that can support engagement in care. Developing interventions using this new knowledge might be critical to reducing HIV infection overall.

As the District of Columbia plans to end the HIV epidemic (Bowser, 2017), taking greater care to develop District wide interventions to address the difficulties identified in this study is critical. As the nation and the world plans to end the HIV epidemics (HIV.gov, 2019b; United Nations on AIDS, 2014), the lived experiences of HIV positive AA women should be incorporated. Prevention interventions can be informed by the findings of this study and thus help prevent new infections among this group and enhance their level of engagement in ongoing focused and effective HIV treatment.

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Appendix A: Specific Codes and Themes that Emerged from Data and Quotations from Participants

Themes	Codes	Some Quotations from participants
1.Diagnosis at reproductive age 2.Adaptative ability to lived experience 3.Era of denials and not involved in care 4.Positive strength that contributes to resilience	Reproductive age Family culture Denials at diagnosis Resilience Spirituality Support groups Pregnancy Self-Efficacy Relationship	• Everyday say a prayer, God let this medicine work, God is good • God kept me going, he is my healer, keep positive attitude, keep my eyes on the prize, I will be fine • By the grace of God, the meds are working in your favor because the meds do not always work in people favor • When I got pregnant with my 3rd child, I went back to church where I started from… when I got myself together in the church that helped me to really digest and grasp • The Lord has seen me all of that • Diagnosed when pregnant with first child • Went to doctor for pregnancy care in 2007 • Diagnosed when pregnant at 23 years with 4th child • A safe place to vent, cry, disseminate information, give each other encouragement • HIV is past in my mind, that is why I do support group • Did drugs heavily for 4 years • There was nothing to live for, no history, gonna die anyway • If the medicine don't work, it is out of my control. The only thing I have control is taking it • I was undetectable, I will get it right back (table continues) • Not powerless, got knowledge and information

	• I immediately went into denial, did not believe it, I had no feeling • I was in denial at time of diagnosis and wanted to kill everybody • It took me 10-15 years to get into care • I have the knowledge that using medication, will survive and that kept me going • But there were times, I was tired about going to the doctors, the only thing that made me afraid is that I might catch cold and die • I don’t want to get sick and die • God is good, I found a man that loves me, he encourages me to take my medication, he encourages me to keep positive attitude, there is life after HIV, really is’ • Support group save my life • Housing and support group for women • Self-esteem groups • Participate in groups • I got involved with many support groups and is better

Appendix B: Responses to Question 1a

Responses to question 1a

Themes	Codes	Some Quotations from participants
5.Unfettered access to good HIV care treatment 6.Importance of daily medication adherence 7. Intense expectation for cure for HIV 8.Conscientization-personal transformation to engage in HIV care	Access to good care Empowerment Uniqueness in medication adherence Medication adherence lifeline Need for cure Need to survive	• DC is a good place for HIV treatment • No matter what you have, you will never be turned away in DC • I did not have problems finding clinic • Biktarvy once a day, that’s all • I found peace in the midst of my chaos • I advocate for myself, asks for medicine ahead of time just in case they are needed • You have to take medicine, keep all your doctor’s appointments, if not you deteriorate really fast • I take it in the afternoon, I don’t miss it because I take other heart medicines • It’s about taking medicine • Forgetting to take the medicine is like leaving your children at the subway station and leave them, if any of them die, you will die • One day, there will be a cure • Even though it did not have a cure, I could still live a long healthy life with medications and things of that nature • I think they can make a pill for that… and I am going to be part of it... I am a superstar, very special superstar • Do you think they already have a cure, they need a cure? • I am satisfied with care but I wanna to be cured, can they cure us?

Appendix C: Responses to Question 1b

Responses to Question 1b

Themes	Codes	Some Quotations from participants
9.Negative effects of HIV stigma on disclosures 10. Self-stigma/Blame as part of barrier to engagement in care 11.Challenges in the ‘lived’ HIV journey	Stigma Self-stigma/blame Difficult life journey Disclosure silence	• It took me a longtime to forgive myself, the shame of it…It is bad enough that outside world to shame you, it is worst -personal shame • When you tell anyone that you have HIV, the first question they ask is how did you contract it? nobody asks how you contract diabetes or other diseases • I only self- disclose since my friend used it against me • I live on daily basis with stigma, I am very careful in disclosing • Taking a chance, meeting someone and when do you tell? • Confided in a sister then she became the enemy, one day, something did not go her way and now she is talking bad and disclosed to others...It did not affect me, it does not stop a man from trying to take my draws • It has been a life altering thing that I face day to day • This is disease that cripples you not just physically but mentally • It was really hard, life changing • I tried to kill myself, I did, thank God it did not work, thank God, it did not work

Appendix D: Responses to Question 2

Themes	Codes	Some Quotations from participants
12.Importance of education of viral suppression 13.Improved Clinical Outcomes	Knowledge at diagnosis Education of viral suppression Knowledge of Viral load Knowledge of CD4 count Self-reports and medical records	• I did not learn about viral suppression • The first that first diagnosed did not discuss viral suppression • They did not teach me anything but refer me to teaching hospital clinic • At diagnosis, they did not say anything that stuck • They did not teach me nothing • No one communicated diagnosis in small clinic, here you go, HIV pamphlet and here you go with lots of people in the waiting room looking at your HIV pamphlet • She really helped me to come to grip to understand that what I have, even though it did not have a cure, I could still live a long healthy life with medication and things of that nature • Education at the time of diagnosis, not in a right frame of mind to understand teaching • They started me on medication and the medicine started working gradually from 2 cells up to 5…CD4 829, undetectable • I achieved viral suppression long time ago

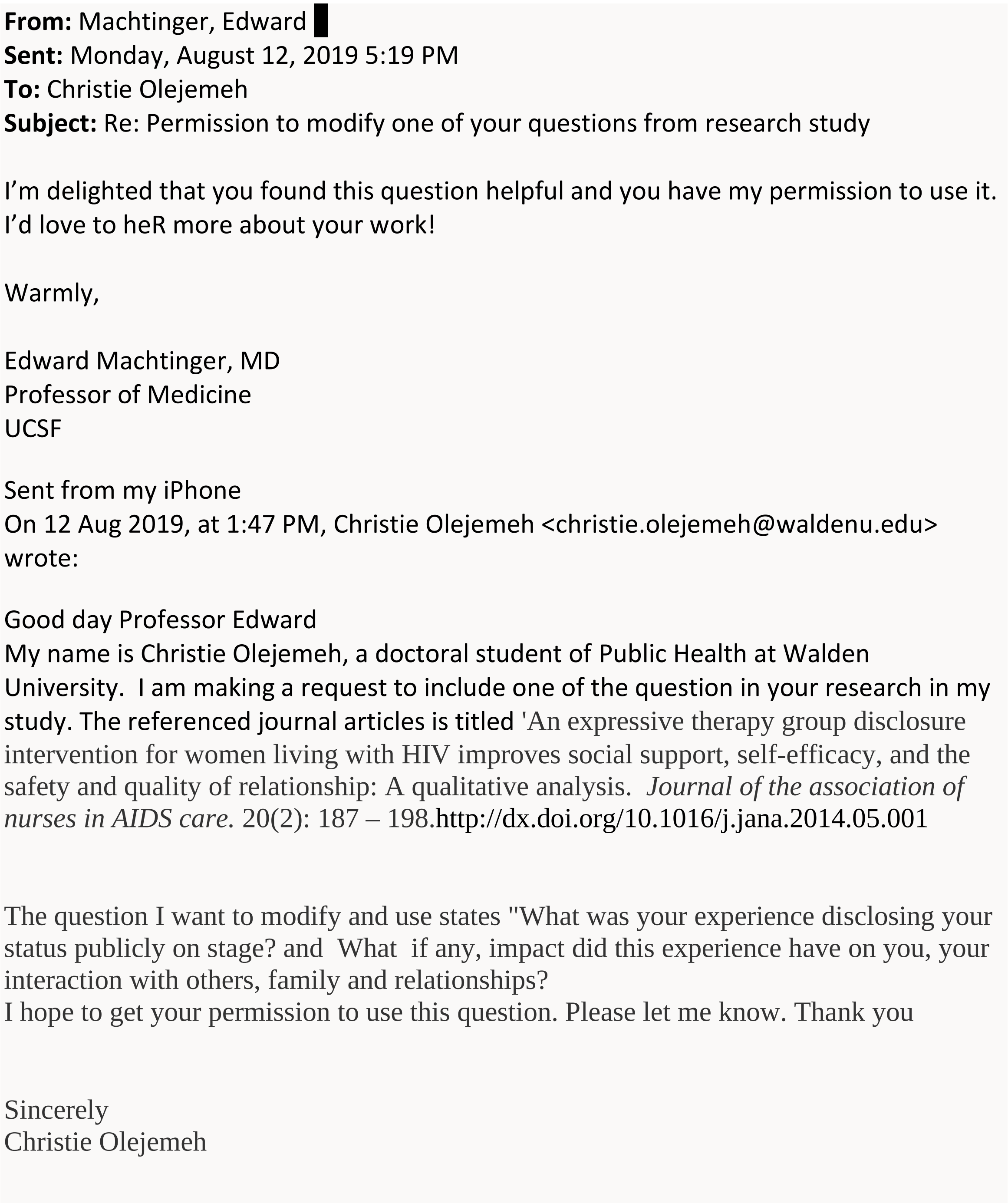
Appendix E: Responses to Question 3

Responses to question 3

Themes	Codes	Some Quotations from Participants
14.Unprotected sex and multiple sex partners in the same neighborhood 15.Gender role/Issues in HIV infection 16. Non-Disclosures of HIV status 17.The importance of high community viral load 18. Importance of community education and knowledge of HIV transmission	Unprotected sex Multiple sex partners Men coming home Nonuse of condoms Education Engagement	• Multiple partners in close areas • Lots of females do not like condom • They don't care about their body • You don't think of anything until it is over and you wind up with STD • People not knowing their status and who they are dealing with • Having sex, having sex dealing with different sex partners • Black woman thinks having a man means love, sex is not love • Men return from prison • Man coming from incarceration and not telling the truth • It is not women, it's the men, 99% of the time, it came from the men that has been with another men, came home and spread it • Education is a key • They should have different messages for young people positive and negative • Black men in their manhood cannot put themselves in anything gay • Health education for everyone, health education should tell you everything • It is the biggest thing if we have health education included in groups • Start at 8 years old, teaching more ladies to care about their bodies…Start educating and teaching in the homes and schools, you cannot get it any other way, eating behind someone, unprotected sex is the key factor…Educating young people.. kids having sex, not knowing what sex means, 8-9 years old having babies • Education, education got to matter

	• They need hotlines for HIV for people to talk and get help • On community days, get tested and you don’t have it, take this pill • We need to reach young people walk to community and talk to people, some of the other places young people go to, in the schools, like they have televisions running different things

Appendix F: Permission to Alter Survey Question



From: Machtinger, Edward [redacted]
Sent: Monday, August 12, 2019 5:19 PM
To: Christie Olejemeh
Subject: Re: Permission to modify one of your questions from research study

I'm delighted that you found this question helpful and you have my permission to use it. I'd love to heR more about your work!

Warmly,

Edward Machtinger, MD
Professor of Medicine
UCSF

Sent from my iPhone
On 12 Aug 2019, at 1:47 PM, Christie Olejemeh <christie.olejemeh@waldenu.edu> wrote:

Good day Professor Edward
My name is Christie Olejemeh, a doctoral student of Public Health at Walden University. I am making a request to include one of the question in your research in my study. The referenced journal articles is titled 'An expressive therapy group disclosure intervention for women living with HIV improves social support, self-efficacy, and the safety and quality of relationship: A qualitative analysis. *Journal of the association of nurses in AIDS care.* 20(2): 187 – 198.http://dx.doi.org/10.1016/j.jana.2014.05.001

The question I want to modify and use states ''What was your experience disclosing your status publicly on stage? and What if any, impact did this experience have on you, your interaction with others, family and relationships?
I hope to get your permission to use this question. Please let me know. Thank you

Sincerely
Christie Olejemeh