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# Challenges of Aging With the HIV Virus and Comorbidities

Rommie Navylia Abele
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# Walden University

College of Health Sciences

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Rommie Navylia Abele

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Dr. Peter Anderson, Committee Chairperson, Public Health Faculty
Dr. Frederick Schulze, Committee Member, Public Health Faculty
Dr. Frazier Beatty, University Reviewer, Public Health Faculty

Chief Academic Officer
Eric Riedel, Ph.D.

Walden University
2017

Abstract

# Challenges of Aging With the HIV Virus and Comorbidities

by

Rommie Navylia Abele

MSPAS, University of Nebraska, 2009

BS, University of Maryland Eastern Shore, 2007

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Public Health

Walden University

December 2017

# Abstract

Since the introduction of antiretroviral therapy, the survival rate of infected HIV patients has been on the rise with a predicted increase by 2030. The longer a person lives with the virus, the more prone to HIV-associated chronic diseases he or she becomes, but it is not clear whether these diseases are solely from aging with the virus or from long-term use of antiretroviral therapy. Scientists demonstrated that the introduction of antiretroviral therapy led to an increased life expectancy yet early onset of comorbidities; however, they failed to address the challenges that people 50 years old or older face, as well as other factors affecting their quality of life. The purpose of this study, driven by both social constructivism as well as the advocacy worldview, was to explore the lived experiences of participants older than 50 living with HIV to gain an understanding of how long-term use of antiretroviral therapy relates to the onset of comorbidities, which would lead to a new understanding of the challenges they face. These findings could give healthcare providers insights on the population in question, their challenges, and how to better address their concerns. The methodology of the study was a phenomenological approach; data were collected through responses from 10 participants during recorded telephone interviews. The recorded data were transcribed before being analyzed using Nvivo software. The results indicated that these participants live in daily survivorship filled with constant struggle between a series of comorbidities that develop overtime. Additionally, their journey is not only coupled with unmet needs of today but also with uncertainties of tomorrow. The findings can improve the current social conditions of those who are older and suffering from HIV by providing information to healthcare professionals who can improve or maintain the health of this population.

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# Dedication

First and foremost, Honor and Glory be to my Almighty Father without whom I am nothing. It is “through You and with Your strength that I can accomplish all” Philippians 4:13.

To my mother, Jacqueline Kayila, the strongest and most dedicated woman I know to the success and happiness of her children. Thank you for all the sacrifices you have made for me over the years to ensure I received the best education possible. Thank you for instilling in me self-resilience and discipline. Thank you for believing in me and supporting me throughout this long and difficult journey. Thank you for encouraging me to always shoot for the stars and be the very best version of me possible. Above all, thank you mummy for your unconditional love and prayers.

To my grandfather, Fidele Ntsissi, the wisest and humblest man I know. You are the epitome of a great father, a great leader, a great inspiration. Thank you for all the sacrifices you have made for me throughout my life. Thank you for your constant presence and advice. Thank you Grandpa for your unconditional love and encouragements.

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To my spiritual family, “GIEL les Papillons,” thank you for your encouragements, your unconditional love, your Faithfulness that our Lord would make this project possible, and above all your prayers.

Table of Contents

# List of Tables

# Chapter 1: Introduction to the Study

In this study, I looked at challenges of aging with the HIV virus and comorbidities that arise. I explored the lived experiences of people over 50 years old as they age with HIV infection as well as challenges that they encounter from being on antiretroviral therapy (ART) for a long time. Since the introduction of ART as a treatment for HIV, life expectancy has been prolonged, reducing the mortality of the affected from 2.2 to 1.8 million (Negin, Mills, & Barnighausen, 2012). As of 2015, 50% of HIV individuals in the United States are 50 years old or older (Adekeye, Heiman, Onyeabor, & Hyacinth, 2012). However, prolonged life expectancy comes with challenges like comorbidities (Cahil & Valadez, 2013). The current literature does not address the challenges of HIV patients older than 50 living with diagnosed comorbidities (Cahill & Valadez, 2013). For this study, I interviewed HIV patients older than 50 with at least one comorbidity, who had been living with HIV for at least 20 years, and had been taking antiretroviral therapy which enabled me to seek understanding of their experiences. This information will improve their current social condition by improving the knowledge of healthcare professionals, thus promoting their overall health and quality of life.

In the following chapter, I will briefly outline information on the background of the study, the problem statement, the purpose, the research questions, and the theoretical framework. Additionally, I will address the nature of the study, the key definitions used, the assumptions, the scope and delimitations, the limitations, and the significance of the study. I will conclude with the overall summary of the chapter.

## Background

Advances in research have led to an increased life expectancy among people 50+ living with HIV. Because life expectancy for this population is expected to increase further, researchers should examine challenges such as new onset of chronic diseases surrounding normal aging and aging with both the virus and usage of ART (Deeks, Lewin, & Havlir, 2013; Samji et al., 2013). Rueda, Law, and Bourke (2014) and Negin, Mills et al. (2012) noted that prolonged use of ART has made this population group prone to chronic diseases, with 65% of them reporting an onset of up to two chronic diseases since testing positive. The literature does not currently address the impact of such comorbidities on the life of HIV patients older than 50.

The aging population has a higher incidence of complications from comorbidities that arise from living with HIV virus (National Institutes of Health [NIH], 2016). As such, adequate treatment as well as proper monitoring is crucial for this growing group (NIH, 2016). Guaraldi et al. (2011) and Deeks et al. (2013) have shown evidence that there is limited access to health services as well as weak retention in care for HIV individuals over 50 years old. Additionally, Cahil and Valadez (2013) reported a lack of a proper system that would serve this group facing multimorbidity issues. Research has not addressed the rationale behind this weak retention and whether HIV individuals older than 50 are aware of the negative impact of being on ART, aging with the virus, and comorbidities that may arise from the combination.

Brennen, Emlet, and Eady (2011) reported that this population is affected by social issues such as depression, stigma, and neglect, suggesting a lack of support from their respective communities; however, the literature does not provide an understanding of the experiences of those living and aging with HIV. Brennen et al. also outlined the lack of adequate policies to address issues of this aging group mainly due to the lack of basic knowledge and understanding of their needs and the challenges they face. Rueda et al. (2014) recommended that studies should be conducted that focus on exploring challenges of the aging population living with HIV and comorbidities. Through this study, I focused on gaining a better understanding of the lived experiences of people 50+ living and aging with HIV and comorbidities and the challenges that influence their lives as HIV-positive individuals.

## Problem Statement

HIV was once a death sentence but infected individuals' life expectancies have been increasing since the introduction of ART (Negin, Mills et al., 2012). However, this victory has been coupled with the onset of chronic diseases either from old age, aging with ART, or a combination of both (Rueda et al., 2014). Although the literature has failed to address the challenges that this population group faces as well as other factors affecting their quality of life, it has shown evidence of HIV being linked to early onset of chronic comorbidities (Cahil & Valadez, 2013). Because the percentage of people 50+ living and aging with HIV and the success of ART are expected to increase further by 2030, studies should address the issues they face (Adekeye et al., 2012).

## Purpose of the Study

The purpose of this qualitative phenomenological study was to explore the lived experiences of participants 50 years old or older living with HIV. This enabled me to gain an understanding of the challenges they face as they age with the virus and comorbidities. The findings will provide information that can improve the quality of life for this population.

## Research Questions

The study addresses the following research questions (RQs):

RQ1: What are the experiences of people 50+ living with HIV?

RQ2: How do people 50+ describe their experiences with HIV?

RQ3: How do HIV-positive patients older than 50 describe the challenge of living with HIV and diagnosed comorbidities?

These were questions and prompts that I presented to the participants of the study to answer my RQs:

1. Tell me about your experiences living with HIV.
2. Tell me about the effects HIV has had on your daily life and your relationships with family, friends, and coworkers.
3. Describe your awareness of sexual risks associated with HIV infection.
4. Tell me about your health care experiences since testing positive for HIV.
5. What is your knowledge of HIV resources and support programs in your community?

6. What is your experience with those HIV services?
7. Describe your experience with support from your family or lack of support.
8. Describe any experiences you might have had where friends, family, coworkers, or anyone else avoided you because of being HIV positive.
9. Describe your experience with your local HIV clinic.
10. Describe your relationship with HIV medical specialists?
11. Describe your knowledge on follow up care with HIV specialists when living with HIV.
12. Describe your experience of living with HIV and being on ART.
13. Describe your awareness of the impact of long-term use of ART.
14. What is your experience of living with HIV and being on multiple medications?
15. What is your experience of coping with side effects of multiple medications?
16. Describe whether you believe people in general have a decline in their health as they age.
17. Describe your knowledge of aging with the HIV virus.
18. Describe your knowledge of health complications that arise from getting older with HIV.
19. Describe your knowledge on follow up care with generalists when aging with HIV.

20. Describe your knowledge of side effects of multiple medications used to treat complications of old age.
21. What is your experience of coping with the combination of new comorbidities and HIV since diagnosis?
22. Describe your current quality of life.
23. Outline factors that could improve your current quality of life.

## Conceptual Framework

I used two frameworks for this study: social constructivism and advocacy worldview. Berger and Luekmann introduced the social constructivism in 1966. They outlined three main propositions in their framework: the foundation of knowledge in everyday life, society as an objective reality, and society as a subjective reality (Berger & Luckmann, 1966). I also used the advocacy worldview framework, which was introduced in 1997 by Heron and Reason. Heron and Reason (1997) outlined three propositions to their framework: the ontology subjective-objective, the extended epistemology, and axiology. I will provide more detail on these in the literature review.

The constructivist framework was appropriate because I focused on exploring the lived experiences of people 50+ living with HIV and their comorbidities. To recommend appropriate actions, a researcher needs an understanding of the phenomenon (Berger & Luckmann, 1966), which is best described by those experiencing the phenomenon for themselves. The advocacy worldview is also appropriate for the purpose of understanding the lived experiences of the participants by engaging them and using the gathered information to improve their social living conditions. The advocacy worldview allows a researcher to use knowledge gathered from experience to improve the quality of life of those involved in the phenomenon in question (Herron & Reason, 1997).

The phenomenology of the study was to assess the lived experiences of people 50+ living with HIV. I attempted to identify their experiences, understand them from their perspectives, and understand how these experiences affected them. People typically understand others' perceptions of things based upon their experiences (Berger & Luckmann, 1966), which is another reason why social constructivism was the approach I used.

Using a qualitative approach via open-ended interviews enabled me to understand lived experiences by providing detailed information on their experiences. Qualitative interviews are essential when seeking better understanding of participants' experiences, as they help participants in elaborating into as much depth as possible on their opinions and experiences of the topic at hand (Milena, Dainora, & Alin, 2008).

## Nature of the Study

Scientists choose a phenomenological approach when they seek to identify human experiences pertaining to a specific phenomenon described by the participants (Creswell, 2009), which made it the appropriate choice for this qualitative study. I obtained primary data via recorded telephone interviews. The included participants, recruited from an AIDS agency and the online HIV community, were 50 years old or older, were living with HIV for at least 20 years, were on ART, and had at least one comorbidity since testing positive for HIV. Only those that have a connection to the phenomenon in question were included in the study. I used Nvivo software to analyze the data because it is adequate to analyze large qualitative texts (Zamawe, 2015).

## Definitions

*Comorbidity:* A specific entity that develops during the clinical course of a patient with a specific disease being studied (Valderas, Starfield, Sibbald, Salisbury, & Roland, 2009).

*Multimorbidity:* Co-occurrence of multiple chronic diseases seen in a patient (Valderas et al., 2009).

## Assumptions

I assumed that participants would have appropriate knowledge of the topic based on their experiences. I also assumed that through these experiences I would gain a better understanding of participants' daily life and challenges. Another assumption was that there would be institutions that would allow others in similar situations to interact, which is why I included interview questions to determine whether my participants were enrolled at an HIV community center, interacting and sharing their challenges with others.

Based on the advocacy worldview framework, I assumed the information gathered through the interviews could enable me to outline the need of the population sample to improve their conditions. Another assumption from this framework is that community-based research is critical, as it shows the relationship between the person holding the knowledge (the aging population) and the knowledge itself (Heron & Reason, 1997). Although this assumption would be important for certain qualitative studies, I used an interview-based approach, assuming that the results from the interviews would enable me to understand participants' experiences and improve the social conditions in which they live.

I also assumed that the participants have lived with HIV for at least 20 years and would share their experiences and challenges. Another assumption was that using a recorded semistructured telephone interview would make the participants comfortable in sharing their lived experiences. Semistructured interviews are assumed adequate to obtain sufficient insight on the experiences and challenges of the population in question.

## Scope and Delimitations

I studied the experiences with HIV among individuals older than 50 because the current literature lacks publications on the challenges this population endures. In the study, I outlined the challenges they face, providing an understanding of their perspectives that could be used to improve the quality of life for HIV-positive individuals.

The inclusion criteria were participants 50 years old or older, living with HIV for at least 20 years, on ART and with at least one comorbidity, while the exclusion criteria excluded newly diagnosed HIV patients and those not fluent in English.

I used constructivism and advocacy/participatory frameworks in my study. The constructivism framework allows a researcher to gain an understanding of the phenomenon in question by relying on the participants' experiences of the situation being studied (Creswell, 2009). The advocacy framework outlines that information gathered from the participants will be used to improve specific social issues as well as their quality of life (Creswell, 2009). Using these frameworks was essential in seeking to understand the challenges HIV patients 50+ face when living with the virus.

Researchers use the post-positivism framework to identify and/or assess causes that influence a particular outcome (Creswell, 2009). Because this involves measurement and experiments, it is better suited for quantitative research, meaning I did not use it for this study. Researchers use the pragmatism framework to answer to the “what” and “how” of research (Creswell, 2009). Because this framework includes both a quantitative and qualitative aspect, it is best suited for a mixed method study, so it was not used in my study.

To ensure transferability, I provide step-by-step parameters of my methodology. Transferability, also known as external validity, is present when researchers present findings in enough detail that the study could be replicated (Shenton, 2004). A sufficient description of the phenomenon in question should be provided for the reader to grasp the context then adequately compare it to their own experience (Shenton, 2004).

## Limitations

Limitations can arise in both quantitative and qualitative studies and are defined as influences occurring during a study and which the scientist cannot control (Baltimore County Public School, 2017). Because limitations can affect the overall result of the study, they should be outlined if present (Baltimore County Public School, 2017). One limitation was the difficulty in generalizing results to a population that does not share the phenomenon in question (Shenton, 2004). Because of the small number of participants included in the research, the overall study results might not be generalizable to a larger population (Anderson, 2010). The experiences and challenges gathered from the interviewees may also not reflect that of the entire population, even with similar background, as the study will only involve a smaller sample of participants.

To avoid potential limitations regarding incentives for participants, I went through the process of pre-approval through the Institutional Review Board (IRB). An incentive should not be used for coercion but rather as a form of compensation for their agreed upon participation (Metropolitan State University, 2017). The incentive should be based on the subject time and expenses such as transportation (Metropolitan State University, 2017). To assess the credibility of the results, a researcher must look at both the reliability and validity of the study (Anderson, 2010). I used respondent validation, allowing participants to view the collected data, to assure the accuracy of results.

## Significance

The findings of this study could be useful in uncovering challenges HIV people 50+ face and subsequently their experiences living with HIV and comorbidities. This insight could improve healthcare providers' understanding of the needs of this group so they can address them appropriately. Gaining adequate understanding of this group's experiences and needs could be key in not only promoting better care, such as screenings for their comorbidities, but also contributing in the development of appropriate community programs as well as framing of proper policies tailored to improve their quality of life (Emlet, Frederiksen-Goldsen, & Kim, 2013). Sankar, Nevedal, Neufeld, Berry, and Luborsky (2011) have recommended that social issues and health limitations are present among HIV people 50+ and should be investigated further. These findings can be used to improve the current social conditions this group faces in hope of reducing their psychosocial burden and promoting and maintaining their health (Sankar et al., 2011).

## Summary

HIV has become a chronic disease since the introduction of the use of ART. Because of the comorbidities that develop over time, it is crucial for healthcare providers treating older individuals with HIV to gain a full understanding of the issues these individuals face. While I briefly provided information on the steps used in conducting this phenomenological study in this chapter, in the following chapter I will elaborate in the literature review of studies relevant to this topic.

# Chapter 2: Literature Review

The purpose of this phenomenological study was to understand the lived experiences of people 50 years old or older living with HIV to address their challenges and improve their quality of life. In this chapter, I will report on the strategies used during the literature search, the social constructivism and participatory frameworks I used in the study was, and a literature review of key variables.

## Literature Search Strategy

To adequately conduct this literature review, I searched for peer-reviewed full text articles in the Walden Library database using CINAHL and MEDLINE as well as Google Scholar and ProQuest Central. The articles were searched from the years 2010-2015 using the following keywords: *elderly*, *HIV*, *comorbidities*, *challenges*, *psychosocial issues*, *depression*, *multi- morbidity*, *health services*, *health policies*, and *antiretroviral therapy*. After identifying five themes in my literature review—"increased life expectancy of people 50+ living with HIV," "onset of comorbidities from aging with the HIV virus," "limited access to tailored health services for people 50+ living with HIV," "unaddressed psychosocial issues among 50+ HIV patients," and "lack of policies and health care services for 50+ HIV patients"—I searched for articles that were relevant to each theme. For example, for "increased life expectancy of people 50+ living with HIV," I used the Walden library database and Google Scholar search engines, using the key terms *life expectancy*, *elderly*, and *HIV*. I narrowed down the search years between 2010 and 2015 to obtain more current literature. I only selected full peer-reviewed articles for each theme.

## Framework

One of the frameworks I used was social constructivism, introduced in 1966 by Berger and Luekmann. Through this framework, the scientist seeks to understand a person's reality and daily experience as well as how it affects their daily life (Berger & Luckmann, 1966). Berger and Luckmann (1966) stated that an individual's reality is socially constructed, meaning what happens to us in our everyday lives reflects the reality as seen and interpreted by others. Additionally, others understand our perceptions of things based upon our experiences (Berger & Luckmann, 1966).

Berger and Luckmann (1966) outlined three main propositions of their framework: the foundation of knowledge in everyday life, society as an objective reality, and society as a subjective reality. In the first proposition, knowledge is a reality acquired through everyday life from experience, familiarity, and interaction with others in society. In the second proposition, objective reality consists of the presence of institutions that provide a place where individuals can relate to each other when faced with specific situations. In the last proposition, they noted that humans, in participating in social institutions, participate in the objective reality created by the institutions included in the second proposition (Berger & Luckmann, 1966).

Using social constructivism, Hjelm, Bard, Berntorp, and Apelqvist (2007) conducted a study exploring the beliefs of Middle Eastern and Swedish native women regarding their health 3 months postpartum. Their main goal was to assess the participants' own perception of whether they perceived gestational diabetes (GDM) as a prediabetic condition (Hjelm et al., 2007), meaning a social constructivist framework was appropriate for their explorative study. Hjelm et al. found that overall, participants' own beliefs about health and illness significantly affected their awareness of risk and self-care practice postpartum. While Swedish women showed a strong desire to acquire more information following their high-risk awareness, Middle Eastern women actively sought guidance from clinicians following their increased risk awareness (Hjelm et al., 2007). Hjelm et al. stressed that the exploration of the participants' beliefs from their own respective lived experiences was a major strength in their study, which came from using the social constructivist framework.

Because my study similarly explored participants' perspectives, I chose a social constructivist approach. My intent was to understand the lived experiences of individuals 50+ living with HIV. Nobody can grasp a better understanding of the challenges people 50 years old or older face as they age with HIV than themselves. As Berger and Luckmann (1966) stated, such understanding would allow me to properly analyze the phenomenon in question. Understanding those experiences through their own reality could provide information specific enough to recommend appropriate actions that could better address their needs.

The second framework I used was the advocacy worldview framework, introduced in 1997 by Heron and Reason. Heron and Reason (1997) noted that the constructivism framework lacked true knowledge from experience, so they introduced the participatory/advocacy worldview. Heron and Reason (1997) described this framework as one in which a person's reality is seen as an interaction between the cosmos, the primordial reality, and the mind. In other words, his or her reality encompasses the interaction of several entities as a whole. Heron and Reason (1997) outlined three propositions to their framework: the ontology subjective-objective, the extended epistemology, and axiology.

The first proposition describes the true nature of reality as a person interacts with the world in which he or she lives and what could be done to improve the environment in which he or she lives (Heron & Reason, 1997). This framework enables community-based research to be conducted, as the research would assess people's understanding of the environments in which they live in and what could be done to improve them. The second proposition notes that through community-based research, there is a primordial relationship between the person who holds the knowledge and the knowledge itself so that, the one who holds the knowledge shares that knowledge in four independent ways: experiential (participatory interaction with others and the world), presentational (representation of a person's knowledge and experiences through stories), propositional (representation of an individual's knowledge through facts and theories), and practical (representation of a person's knowledge through action as seen in community-based research). The final proposition states what an individual considers as valuable being something close to them (Heron & Reason).

Hoelscher et al. (2012) conducted a community-based study using the advocacy worldview framework to assess the impact of two interventions on the prevalence of childhood obesity among minorities in central Texas. Throughout the 4-year program involving 97 schools, participants started reporting positive behaviors as well as improvements in their daily lives (Hoelscher et al., 2012). The authors noted that implementing a community-based school program could enable clinicians to reverse childhood obesity among these children (Hoelscher et al., 2012). This study attested to the importance of involving the community and its members into the program to gain adequate understanding that could outline a childhood obesity prevention plan in the areas in question. Because community involvement was significant to understanding and improving the health conditions of these children, Heron and Reason's advocacy worldview/participatory framework worked for this study. By conducting collaborative research "with" their participants rather than solely "on" their participants, Hoelscher et al. were able to acquire pertinent answers and apply them for the improvement of the environment in which these children live and their well-being.

This framework was also appropriate for my study because I wanted to understand the lived experiences of people 50+ living with HIV by engaging the participants and using the obtained information to improve their social living conditions. As Heron and Reason (1997) stated, the participatory/advocacy worldview uses knowledge gathered from experience to improve the quality of life of those involved in the phenomenon in question. Gathering the needed information pertaining to the true needs of baby boomers living with HIV could be applied to outlining policies and programs that could improve the quality of life of this population.

### Theme 1: Increased Life Expectancy of People Living with HIV.

The mortality rate of older HIV patients has decreased over the years, especially since the use of ART. HIV, once a death sentence, is now as manageable as any other chronic disease if the treatment is initiated and maintained; in fact, 50% of individuals 50 years old or older are living with the virus in the United States. (Adekeye et al., 2012). The introduction of antiretroviral therapy in the 1990s has increased life expectancy of people older than 50 living with HIV (Negin, Mills et al., 2012), which is encouraging as it shows the success of ART in treating HIV patients. Rueda et al. (2014) reported that the survival rate of HIV infected individuals is continuing to increase. Samji et al. (2013) and Deeks et al. (2013) noted that, especially with the advancement of HIV research, life expectancy is expected to increase even more over the next decade. However, as science continues to prolong the life expectancy of those with HIV, new challenges associated with normal aging and use of ART are expected to arise and should be addressed.

Although Rueda et al. (2014) and Samji et al. (2013) both showed an expected increase in survival rates among HIV patients older than 50, their methods differed; Rueda et al reviewed the current literature while Samji et al. conducted a 7-year study. Rueda et al.’s purpose was outlining results of studies focusing on psychosocial challenges of aging with HIV, but Samji et al.’s goal was estimating potential changes in life expectancy among American and Canadian HIV individuals 50+ taking ART. Rueda et al. searched through 13 national and international electronic databases but only limited such search to databases written in English; they reviewed articles that were of qualitative, quantitative, or mixed nature that pertained to participants 50 years old or older. By contrast, Samji et al. collected their data from a regional AIDS cohort database sponsored by NIH, obtaining estimates of life expectancy from mortality rates from the cohort design of HIV infected individuals in Northern America and Canada. Samji et al. focused on a population of 20-year-old Americans and Canadians, which they followed for 7 years while calculating what their life expectancy would most likely be at 70 years of age should they remain on ART. One issue with the study was that the sample size of 82,000 subjects was not an adequate representation of the population of both Canada and the United States (Samji et al., 2013). Another issue was that the authors did not outline what challenges or side effects if any, would these participants encounter over time, which supports the need for the current study.

As opposed to younger populations with HIV, older populations living with HIV are more prone to comorbidities (Rueda et al., 2014). Rueda et al. found that in the United States, 94% of HIV patients over 50 have at least three comorbidities such as hypertension, diabetes, coronary heart disease, or major depressive disorder. For older HIV patients, this multimorbidity was coupled with decreased physical functioning (Rueda et al., 2014). This decrease could affect their day-to-day activities, making them in need of social support. Although having at least one comorbidity was common, Rueda et al. reported that the presence of depression not only varied by location, it was 10 times lower among males. This could suggest that socioeconomic factors affect ease of access to HIV services and that men could have other means of coping with their condition. Lastly, gay and bisexual men had a lower incidence of depressive disorders as well as better quality of life than heterosexuals; which the authors attributed to the presence of supportive programs (Rueda et al., 2014). In other words, there is a lack of social support for the heterosexual HIV population that has resulted in a higher incidence of depression.

The use of ART has been shown to increase the projected life expectancy of those with HIV. Samji et al. (2013) reported that life expectancy of their participants increased over time from 36.1 years in 2000 to 51.4 years in 2007 with a standard error of 0.5. Using intravenous drugs, being of African American decent, and having a CD4 < 350 cells/mm$^3$ were significant risk factors to a lower life expectancy (Samji et al., 2013). This could suggest that minorities have poorer chances of survival than their counterparts due to lack of access to the health care system in general. Additionally, women were noted to have a higher life expectancy than males, which the authors attributed to women accessing health services more than their counterparts (Samji et al., 2013). They concluded that if diagnosed and placed on ART early on, an individual could be expected to live up to 70, significantly reducing the mortality rate. Overall, Rueda et al. (2014) and Samji et al. reported an increased life expectancy with use of ART, almost always a presence of depression, decreased physical function, and lack of social support.

Despite the positive implications of these studies, there needs to be additional research on the challenges of older individuals with HIV. This would allow researchers to gain further understanding of this population's experiences not only when aging with the virus but also factors that could influence their psychosocial well-being (Rueda et al., 2014). Qualitative studies focusing on the lived experiences of aging patients with HIV would not only increase understanding of this group but also contribute to policy planning (Rueda et al., 2014). Samji et al. (2013) also noted that several factors affecting life expectancy of HIV individuals over 50 ought to be further investigated to tailor appropriate health services, which was one of the intents of my study.

As the rate of HIV infection among people 50+ increases, so does the onset of chronic diseases. Negin, Martiniuk et al. (2012) showed that the incidence of HIV infected baby boomers is expected to nearly double, from 9% to 17% by the year 2040, while Deeks et al. (2013) estimated the number of infected HIV individuals 50+ to triple to 9 million by 2040. In other words, there is a need to follow the life span of this population to identify any potential complications that may arise to address them in a timely fashion. Vance, Mugavero, Willig, Raper, and Saag (2011) and Kim et al. (2012) showed that not only will the use of antiretroviral therapy continue to prolong the life of infected HIV individuals 50+, it will also lead to the onset of comorbidities. There have been few studies addressing the impact of these comorbidities on the lives of HIV patients over 50.

Despite a lack of studies on the impact of these comorbidities, researchers have looked at older individuals with HIV and potential comorbidities. Negin, Martiniuk et al. (2012) and Vance et al. (2011) assessed the prevalence of HIV among participants 50 years old or older as well as comorbidities arising from such prolonged life expectancy. Kim et al. (2012) also conducted a similar study, assessing a possible correlation between obesity and multimorbidity among HIV patients. Negin, Martiniuk et al. conducted a cross sectional study using a self-reported questionnaire with participants 50 years older with a cohort of participants aged 18-49 for comparison purposes; however, the challenges of those in a 18-49-year-old cohort may not be representative of challenges experienced by people 50+ living with HIV. Vance et al. (2011) also conducted a cross sectional study where they reviewed roughly 14,000 electronic medical records on HIV patients who attended an HIV clinic to better assess any patterns of comorbidities that would arise (Vance et al., 2011).

Negin, Martiniuk et al. (2012) showed an association between HIV and comorbidities in older populations, such as rates of hypertension, as opposed to the cohort of participants aged 18-49. However, they noted that despite numerous studies showing a correlation between living with HIV and multiple comorbidities, they could not find any other comorbidity besides arthritis and hypertension in their study (Negin, Martiniuk et al., 2012). Since the cohort group aged 18 to 49 is hardly composed of an older population, the above results cannot easily be generalized to the appropriate population of individuals over 50 diagnosed and treated for a longer period of time.

Vance et al. (2011) reported that the older the patients, the more likely they were to have been diagnosed with HIV a long time ago, and the more likely they were to have a longer list of medications for several comorbidities (Vance et al., 2011). The latter suggest that people 50+ living with HIV are not only at risk for side effects of ART, they could also be at risk for side effects of the medications treating their newly diagnosed chronic diseases. However, based on their study, it is not clear whether the onset of newly diagnosed comorbidities results from long-term use of ART, old age, or a combination of both. Like Negin, Martiniuk et al. (2012), Kim et al. (2012) showed a statistical significance in terms of multimorbidity among older HIV patients on ART (Kim et al., 2012). This means that this multimorbidity could be the next major challenge replacing the old challenge of being diagnosed with HIV decades ago.

In terms of limitations, Kim et al. (2012) stressed the inability to generalize the overall results because the data was obtained at one clinic rather than at several sites. By contrast, Negin, Martiniuk et al. (2012) reported their limitations to be associated with self-reporting of data. The overall response rate estimated at 76% was due to failure of more participants over 50 years to consent to the study (Negin, Martiniuk et al., 2012). This raises a concern for my research on HIV among people 50+, a sensitive topic for those living with the virus for various reasons including but not limited to stigma and lack of social support.

Negin, Martiniuk et al. (2012) showed the need to focus on HIV individuals over 50 taking ART to better assess their length on the medication, which could influence the incidence and prevalence of comorbidities possibly associated with both living with the virus and being on triple antiretroviral therapy (Negin, Martiniuk et al., 2012). Essentially, HIV patients should be monitored closely from the time of diagnosis to initiation of ART to assess how well they respond to the medication over time and address any side effects and/or complications that may arise. Negin, Martiniuk et al. also stressed the need for integration of care on multimorbidity among this age group. The authors could be implying that general healthcare providers and HIV specialists should work together to better serve this population. Essentially, healthcare associates should address the challenges of these patients to appropriately assess the side effects of their poly-pharmacy in order to, adjust their medications accordingly.

Vance et al. (2011) stressed the importance of nurses understanding the different comorbidities, i.e., hypertension, heart diseases that HIV patients over 50 face as they are living longer with the virus. To Vance et al., such understanding could be instrumental to ensure healthcare providers better treat their patients (Vance et al., 2011). Being knowledgeable about the various chronic diseases HIV patients face is as important as being knowledgeable about the side effects and interactions of the medications they are on, as well as how it affects their lives as a whole. As such, understanding the lived experiences of these participants could benefit clinicians as well as policy makers in making impactful changes. Lastly,Vance et al. stressed the great need for policies that would focus on funding the treatment of HIV patients over 50 living with various comorbidities, especially as the life expectancy is ascending (Vance et al., 2011). Kim et al. (2012) stressed the need for scientists to focus on guidelines pertaining to the impact of multimorbidity on the quality of life for HIV patients over 50 on ART, so that clinicians could make informed decisions that would benefit this population (Kim et al., 2012).

As opposed to Vance et al. (2011) and Kim et al. (2012), Negin, Martiniuk et al. (2012) did not find any evidence of depression among their participants. Nonetheless, all authors did find increased life expectancy and increased incidence of multi comorbidities when aging with HIV and using ART. However, the authors did not outline a possibility that the type of comorbidities that arose among certain patients might be dependent on specific risk factors such as years of HIV diagnosis, years on ART, or poly pharmacy as I explored in my study.

### Theme 2: Onset of Comorbidities

The introduction of ART has prolonged the longevity of people 50+ living with HIV; however, it has presented new challenges in forms of chronic diseases. Rueda et al. (2014) and Negin, Martiniuk et al. (2012) stressed that onset of comorbidities were higher in this older population on ART than among their counterpart not on ART (Rueda et al., 2014; Negin, Martiniuk et al., 2012). This, although unclear, may imply that being on ART is more of a culprit to early onset of chronic diseases than older age. Rueda et al. added that at least 94% of HIV infected individuals over 50 that are on ART presented with at least one comorbidity, with the majority presenting with at least three (Rueda et al., 2014). This percentage is devastating because it implies that not only is being on ART a risk factor to early onset of chronic diseases, it is now a major risk factor to both multimorbidity and the challenges that come with it. Although Negin et al. also showed an increased onset of comorbidities, they outlined that only 29.6% of people over 50 presented with two or more comorbidities (Negin, Martiniuk et al., 2012). Deeks et al. (2013) showed that in the United States, there is a 1.5 fold increased risk of people 50+ developing at least one comorbidity when on ART (Deeks et al., 2013). This outlines that older HIV patients, although on ART, are becoming sicker than anticipated decades ago. Each chronic disease they face has a different effect on their body and knowing how they are affected on a daily basis is crucial for healthcare providers to tackle each challenge as it arises.

Oursler et al. (2011) conducted a cross sectional study to assess a possible association between age and comorbidity with physical function between HIV patients and non-HIV patients. They enrolled HIV participants being followed for various chronic issues across eight VA centers and clinics (Oursler et al., 2011). On the other hand, Liu et al. (2014) conducted a study to assess depression and quality of life of young (18-49) and older (> 50) participants living with HIV in China for comparison purposes. Participants were selected from a health center where they had received proper HIV care and treatment (Liu et al., 2014).

As stated above, the older and the more prone to chronic diseases someone becomes, the more impact could be noted on a physical body level. Oursler et al. (2011) reported a significant decline of physical function among HIV patients older than 55 ($p < 0.001$) as opposed to their counterparts who were not infected. This could suggest that the diagnosis of HIV alone could prevent these patients from performing their activities of daily living. Ourlser et al. added that although having a history of cardiac disease was a predictor of poor physical function, the latter was worsened in a patient with a history of hypertension. A 50-year-old HIV patient with noted comorbidity showed a physical function level of a 68-year-old uninfected patient with no noted comorbidity (Oursler et al., 2011). In other words, old age and presence of comorbidities in HIV patients worsened their health condition as compared to the general population. Oursler et al. concluded that age associated comorbidities do affect physical function in HIV patients.

Similar to Oursler et al. (2011), Liu et al. (2014) reported that the older the HIV patient was, the lower the level of well-being, the higher the level of depression, and the poorer the quality of life; which they attributed to low physical health and ongoing psychological challenges. The above findings may imply that as this population ages with the virus and as other diseases and challenges arise, they become unable to physically care for themselves and experience a depressive state. This ultimately outlines the greater need for programs that would ease this transition and provide interventions for them to improve their quality of life. Additionally, Liu et al. reported that 74.2% of older HIV patients were depressed as opposed to 48.7% of younger HIV patients. This gap in percentage might suggest that older HIV patients encounter more challenges than their counterparts, which need to be identified and addressed. Social interactions were lower among older HIV patients as opposed to their counterparts; and as the level of depression progressively increased, the level of well-being and physical health further declined (Liu et al., 2014). The authors could be suggesting that the lack of social services and/or support from their family or their community plays a major role in high level of depressive state in older HIV patients.

The above authors also both reported an increased onset of comorbidities among aging HIV patients on ART, as well as higher level of depressive behaviors, and lower level of physical function. However, they failed to address whether such depressive mood is a result of aging with HIV, aging with the comorbidities that develops, or lack of family social support. In addition, they did not address whether the noted decreased in physicality is due to the side effects of poly pharmacy from multi comorbidities, side effects of ART, or simply aging.

As state above, living with HIV and being on treatment leads to multiple chronic diseases especially for the aging population. Multimorbidity, defined as the onset of two or more chronic diseases, is present in 65% of HIV infected patients on ART (Kim et al., 2012). Guaraldi et al. (2011) addressed that aging with HIV contributes to a 3 to 15 times higher comorbidities related mortality (Guaraldi et al., 2011). Similar to Guaraldi et al., Vance et al. (2011) added that aging with the virus coupled with use of ART would simply continue to increase the prevalence of comorbidities in that group (Vance et al., 2011). This suggests that both age and use of ART are associated with onset of chronic diseases in the HIV patient. Both Rueda et al. (2014) and Negin et al. (2010) also addressed this complex phenomenon of aging with HIV and the need for adequate services that would address the true needs of this group (Rueda et al., 2014; Negin et al., 2010).

Guaraldi et al. (2011) compared infected and non-infected HIV patients in terms of onset of comorbidities. They reported that specific age related chronic diseases were noted among HIV patients older than 50 (Guaraldi et al., 2011). This association between age and onset of comorbidities in the older HIV patient align with findings of Oursler et al. (2011). Guaraldi et al. further reported that individual prevalence of multi morbidity ($\geq$ 2 noninfectious comorbidities) were significantly higher among HIV patients as compared to control patients ($p < 0.01$). They also illustrated that prolonged ART exposure were statistically significant predictors of multi-morbidity; suggesting the need for these comorbidities to be screened early on for HIV patients to be treated appropriately (Guaraldi et al., 2014). In fact, 40-year-old HIV patients were noted to have risk factors similar to that of 55-year-old un-infected patients (Guaraldi et al., 2014). The above implies that early onset of chronic diseases among HIV patients may precipitate the ‘normal’ process of aging.

Vance et al. (2012) reported that as HIV patients’ viral load decreased, the prevalence of comorbidities increased, and so was the number of medications they were taking for treating their comorbidities. These comorbidities including but not limited to hypertension, diabetes, and coronary artery disease were the most commonly seen (Vance et al., 2012). The above findings might suggest that the authors’ population sample was mainly obese since it is a major risk factor for the comorbidities outlined. They also reported that HIV older patients had at least 2 comorbidities as compared to their counterparts (Vance et al., 2012). These findings were consistent with those of Negin, Martiniuk et al. (2012) and Guaraldi et al. (2011).

In their study, Burgess et al. (2015) showed that as opposed to non-infected patients, older HIV patients already have several comorbidities including major depression, and thus the choice of ART should be carefully considered since some ART medications are contraindicated in uncontrolled depressive disorders (Burgess et al, 2015). These findings align with those of Liu et al. (2014). This suggests that careful attention is needed when treating HIV patients in order to appropriately identify possible drug interactions, adjusting dosages, and/or switching the medications as needed. Additionally, Burgess et al. noted that in the United States, the onset of cardiovascular diseases was noted at a much younger age among HIV patients than non-infected ones. The latter was due to un-treated HIV infection in some and the adverse effect of prolonged ART use in others (Burgess et al., 2015). The authors are implying that, as with any comorbidity, side effects are noted from either not starting ART treatment in a timely fashion or from medication used to treat the condition in question. They concluded that because of the risk of drug related complications; early screening is necessary for appropriate choice of ART (Burgess et al., 2015).

The above authors reported a similar consensus of increased multi comorbidities among aging HIV patients, with depression and hypertension almost always present. However, they reported a strong predictor of even higher onset of comorbidities among male as opposed to female. There could be a possibility that females may be more prone to ensuring they seek appropriate HIV care whether or not they might lack social support. As such my research geared towards understanding the lived experiences of people over 50 and the challenges that may develop is of value.

## Theme 3: Limited Access to Health Services

With the onset of comorbidities, adequate routine healthcare access for people over 50 living with HIV is paramount. However, the literature shows a very scarce access to such services (Guaraldi et al., 2011). Not only is this suggesting a continued increased number of un-diagnosed chronic diseases among HIV patients, but it also suggest un-addressed factors preventing such access, and/or lack of services to meet the demands of this group. Patel et al. (2016) addressed this high incidence of HIV infected patients over 50 with multiple untreated comorbidities, which they attributed to the use of clinics not equipped with properly trained HIV personnel (Patel et al., 2016). Mugavero, Amico, Horn, and Thompson (2013) noted that although the introduction of ART has prolonged the life expectancy of people over 50 living with HIV, most patients still lacks adequate access to the HIV care (Mugavero et al., 2013). In addition, they outlined the need for public health lawmakers to create policies that would strengthen better monitoring of this population living with HIV as well as tailoring interventions that would encompass both the clinical and community-based aspect (Mugavero et al., 2013).

Patel et al. (2016) showed the relationship between onset of comorbidities and length of diagnosis with HIV (Patel et al., 2016). Such association suggests the utmost importance of early diagnosis of HIV as well as close monitoring of conditions that may arise from both the virus itself and its treatment. Patel et al. outlined that years living with the virus and use of ART were significant predictors of onset of comorbidities among this older population. In addition, they reported that at least 84% of HIV patients over 50 had more than one comorbidity while 61% reported more than two. Among these comorbidities, they outlined depression, hypertension, and hypercholesterolemia as the most commonly encountered. They also reported that limited or no access to health services was directly correlated to the increased onset of multimorbidity seen among this group. As such they recommended a need for researchers to focus on examining patients' access and experience to health care services (Patel et al., 2016).

Although Mugavero et al. (2013) reported that half of HIV individuals over 50 lack access to HIV care, Patel et al. (2016) reported that with more than half having at least two comorbidities, some lacked access while others failed to be retained for follow up (Mugavero et al., 2013; Patel et al., 2016). As stated above, there is a certain level of complexity involved when treating an older patient living with HIV, diagnosed with depression, and other multi comorbidities. However, the authors failed to outline such complexity as possible reason behind this lack of adequate health support. Also, there is the possibility that family social neglect plays a part in this population being too overwhelmed and thus unable to seek care and follow up. In addition, there is a possibility of this population perceiving that clinicians might not address their needs due to their inexperience in dealing with patients facing such complex multi diagnoses.

Moreover, there could be a possibility of this group simply not being aware of the presence of services that could address their needs.

Access to healthcare services remain of high importance for HIV patients not only for initial diagnosis but also for long-term care. Samji et al. (2013) outlined that despite ART associated prolonged longevity, there is still a sizable difference in mortality between patients who have adequate HIV care access and those who lack such access (Samji et al., 2013). Deeks et al. (2013) also outlined this weak delivery of care for HIV infected patients, stressing that access to appropriate care and retention in care is key (Deeks et al., 2013). Unfortunately, in the United States, only about a third of HIV patients have access to an adequate HIV system (Deeks et al., 2013). There is a major lack of a proper system and lack of healthcare providers to care for infected HIV individuals over 50 facing multimorbidity issues (Cahil & Valadez, 2013). As infected HIV people over 50 continue to age and continue to lack access to services addressing their needs, the challenges they face daily will simply worsen.

Based on their results noted above, Samji et al. (2013) recommended that researchers and lawmakers focus on policies that could improve health outcomes of people over 50 living with the virus (Samji et al., 2013). In addition, since their research showed that such life expectancy is subject to increase over the next decade, they stressed that further studies focus on improving the current quality of life of this population (Samji et al., 2013). To design appropriate services that would improve their current quality of life, scientists have to assess factors currently affecting their daily living. As such, Rabkin, Kruk, and El-Sadr (2012) similarly reported that early screening, psychosocial support, and HIV treatment facilities are needed for older HIV patients, already at risk for side effects of poly pharmacy (Rabkin, Kruk, & El-Sadr, 2012).

Although the authors reported increased mortality among HIV patients and increased lack of access to adequate HIV care, they failed to outline the possibility that HIV individuals over 50 lack awareness of the negative impact of being on ART, aging with the virus, and the comorbidities that arise; thus lack awareness of the importance of seeking and following up care. Additionally, they did not outline the possibility that the public heath sector might not yet fully be equipped to keep up with the demand of the growing population of individuals over 50 aging with HIV and multi comorbidities. Research geared towards addressing such lack of awareness and challenges is of necessity to properly outline a program that could address their needs. In conducting my study, questions pertaining to the aforementioned awareness or lack of awareness were investigated when interviewing the participants.

## Theme 4: Unaddressed Psychosocial Issues

The limited access to healthcare is not only leading to unaddressed comorbidities but also to psychosocial issues among HIV patients over 50. Kim et al. (2012) outlined a series of multi morbidities categorized under metabolic, behavioral, and substance use (Kim et al., 2012). Brennan et al. (2011) noted evidence of not only psychosocial issues such as depression and stigma but also neglect among people over 50 living with HIV (Brennan et al., 2011). This may suggest that they lack social support from their immediate communities. In addition, it could further suggest that they feel misunderstood by the healthcare system failing to address their needs. Sankar et al. (2011) also noted that while 25% of HIV patients over 50 showed signs of moderate depression due to overall poor physical health and lack of social support; 39% could be diagnosed with major depressive symptoms due to isolation and lack of social support (Sankar et al., 2011). This high percentage suggests that access to social services could reduce this level of depression.

In their study, Kim et al. (2012) assessed predictors of multimorbidity and identified hypertension, diabetes, chronic kidney disease, hyperlipidemia, and depression as major comorbidities (Kim et al., 2012). This finding of chronic kidney disease was interesting, as previous authors did not note that. In fact, most medications are filtered by the kidneys, which as we age decline in function. One would expect to see that process worsen in an older HIV patient with poly pharmacy. Kim et al. also outlined that obesity was correlated to higher increased incidence of multimorbidity (Kim et al., 2012)

Brennen et al. (2011) recommendations where centered on the need for future research to focus on the psychosocial need of elderly living with HIV. Additionally,, they outlined the lack of current research pertaining to the need of such population and the impact such research would have. Lastly, they stressed that more insight into the current social system is needed to better the overall lifestyles of the population in question (Brennen et al., 2011). Similar to Brennen et al., Sankar et al. (2011) recommended a need for healthcare providers to understand the need of this aging population living with

HIV, the social stigma they endure, and also for researchers to focus on the complexity of aging with HIV and the comorbidities that develop (Sankar et al., 2011).

Although Brennen et al. (2011), Sankar et al. (2011), and Kim et al. (2012) similarly reported depressive behaviors partly due to social stigma, isolation, or neglect to be common, they failed to outline the reasons behind the limited access to HIV care (Brennen et al., 2011; Sankar et al., 2011; Kim et al., 2012). On the other hand, Sankar et al. pointed out a higher level of low social support among minorities and reluctance of undiagnosed HIV individuals over 50 to learn about risks associated with HIV (Sankar et al., 2011). This could show that uninfected people over 50 simply lack awareness of the true risks associated with HIV, and since fearing social isolation from their respective families choose not to be tested. Additionally, those infected may simply not be aware of the possible negative impact of aging with the combination of HIV and depression. As such my research geared towards examining such impact could assist in improving their quality of life.

## Theme 5: Lack of Policies and Heath Care Services

Tailoring adequate policies are essential to improving the quality of life of people over 50 living with HIV. Brennen et al. (2011) shared that no policies have been outlined to address the issues of this aging population due to lack of basic knowledge surrounding their needs (Brennen et al., 2011). For public health lawmakers to outline a program that could meet the current needs of this population while being successful, a clear understanding of those needs has to be outlined. Patel et al. (2016) also noted that the needs of this group are not met due to a lack of knowledge of their experiences as it pertains to access to care (Patel et al., 2016). Cahil and Valadez (2013) reported that the lack of policies addressing this population's issues and needs is preventing improvement of their current quality of life (Cahil & Valadez, 2013). There is a pressing need for this group's issues to be researched and properly addressed (Deeks et al., 2013).

Patel et al. (2016) conducted a cross sectional study to measure participants' lifestyle, access to healthcare, diagnosed chronic diseases, as well as medications throughout their journey living with HIV. Based on their results, they showed an association between using healthcare services not equipped with qualified HIV personnel and increased comorbidities (Patel et al., 2016). Non HIV specialists may not be as familiar with side effects and cross interactions of specific HIV medication with medication used to treat chronic diseases. This could suggest that patients being initially treated and followed by HIV specialists are more likely to have a better prognosis than those being treated by generalists. These findings stress the importance of access to HIV healthcare services to meet the need of that growing HIV population (Patel et al., 2016). It was necessary through my research that I gained an adequate understanding in regard to not only whether or not my subjects have adequate access to HIV care services, but also whether or not they feel that their needs are met.

Brennen et al. (2011) similarly recommended that more healthcare centers be implemented and more HIV specialists be adequately trained. They found that the lack of policies geared towards older HIV patients was attributed to stigma. They also reported that appropriate emotional support should be provided to both the affected patients and their respective families (Brennen et al., 2011).

While Brennen et al. (2011), Patel et al. (2016), and Cahil et al. (2013) all came to a similar conclusion that there is a lack of policies addressing the “needs” and/or “issues” of the aging HIV patient, they similarly reported that this population faces challenges associated with aging with the HIV virus (Brennen et al, 2011; Patel et al., 2016; Cahil et al., 2013). However, they failed to outline what the challenges and issues are. They also failed to consider the possibility of absence of awareness of the negative impact of aging with HIV, from the patient and the clinician standpoint. People over 50, already stigmatized by their community and family members for being HIV positive, could possibly show reluctance in seeking proper HIV care for fear of being yet again stigmatized by clinicians. Or, due to their lack of social support, they could simply lack the physicality to transport themselves to the doctors.

As with living with any disease, there are several negative effects of living and aging with HIV. This could only be adequately understood from these patients’ perspective. As such, in order for clinicians and public health practitioners to properly address the needs of this population and for lawmakers to outline policies specifically tailored to this group, proper understanding of their lived experiences and challenges is paramount. The overall results of my study could provide clinicians with evidence that could help them to better address the needs of this population, while providing lawmakers with enough information to outline appropriate policies that could improve their quality of life.

## Conclusion

Overall the literature shows that people over 50 living with HIV face several challenges from onset of multimorbidity, to psychosocial issues, to lack of appropriate access to care addressing their needs (Guaraldi et al., 2011). With the number of individuals in that group continuingly ascending, there is a great need for a better understanding of their experiences so that tailored policies and health care systems focusing not only on access but also retention be developed (Mugavero et al., 2013). The following chapter will provide a detailed method of research of my study.

# Chapter 3: Methodology

The purpose of this phenomenological study was to understand the lived experiences of people older than 50 living with HIV to address their challenges and improve their quality of life. In this chapter I will report information on the research design and rationale, the role of the researcher, the step-by-step methodology, and the issues of trustworthiness or credibility. This chapter will conclude with an overall summary of the chosen methods for this study.

## Research Design and Rationale

I sought to answer the following questions: What are the experiences of people 50+ living with HIV? How do people 50+ describe their experiences with HIV? How do HIV-positive patients older than 50 describe the challenge of living with HIV and newly diagnosed comorbidities?

I used phenomenology to assess the lived experiences of people living with HIV. I attempted to identify participants' experiences, and understand these experiences and how they affected the participants, so I could outline ways that could improve their quality of life. To answer my research questions, I chose a qualitative research approach. Creswell (2009) identified five types of qualitative research: ethnography, grounded theory, case study, phenomenal, and narrative research. Researchers choose one of these types of research depending on the purpose of their study.

When choosing ethnography as a research design, the researcher studies an intact cultural group of participants within a natural setting over a specific extended length of time. During that study period, observational as well as interview data are collected. The main idea is to capture the lived realities of those participants within their natural setting (Creswell, 2009). This design was not suited for my study which purpose was to understand lived experiences based on a specific phenomenon rather than studying cultural groups. Grounded theory is used when researchers generalize an abstract theory of an action based on the view of the participants. During that study process, data is collected at various stages. Creswell (2009) outlined that to maximize similarities and differences among different groups within the study, researchers rely on constant comparison of data with sampling of different groups, which is unique to this theory. This design was not suited for my study as I was seeking to assess and describe characteristics of individuals sharing a similar phenomenon rather than looking at different groups. Case studies are often used when researchers explore a program, process, or simply individuals. In doing so, detailed information pertaining to the participants is collected over a specific period of time (Creswell, 2009). This design was not suited for my study because I was not seeking to observe a particular behavior nor understand a given phenomenon; instead, I was seeking to assess experiences of individuals pertaining to a specific phenomenon. Narrative research involves the researcher studying the lives of the participants while asking them to provide detailed stories about it. Eventually, the collected story line is retold into a narrative form by the researcher, specifically combining both the participants and researcher’s view (Creswell, 2009). This design was not suited for my study because I was not simply interested about details of participants’ lives; instead, I was interested about their living experiences pertaining to a specific phenomenon.

In a phenomenological approach, the researcher identifies human experiences pertaining to a specific phenomenon described by the participants (Creswell, 2009). The researcher aspires to understand the lived experiences of the involved participants over an extended period of time, which allows patterns to form. In this approach, researchers disregard their own experiences to focus on understanding the participants' experiences (Creswell, 2009). Husserl, the fountainhead of phenomenology of the 20th century, reported that individuals are usually certain about things that happen to them, which means all that happens outside of their immediate experience ought to be excluded (Groenewald, 2015). Based on Husserl's belief that reality must be treated as pure phenomenon, data collection should begin at the source to keep the data as accurate as possible (Groenewald, 2015). In other words, data should be collected from the individuals that experienced the phenomenon in question.

This study's phenomenon was the experience of people 50+ living with HIV and comorbidities. The intent of my research was to understand, from the participants' perspective, the experience of living with HIV as an individual older than 50. By obtaining detailed information of these experiences from participants, I aimed to draw conclusions that could be effective in improving their quality of life as well as that of individuals living with similar experiences. Because I studied participants' experiences as phenomena and collected data from their descriptions of these experiences, the phenomenological approach was appropriate for my research.

## Role of the Researcher

My role as a researcher in this study was to ask a series of open-ended questions through a recorded telephone interview to gain an understanding of participants' experiences. Throughout the interview, I engaged with my participants as they described their experiences, enabling me to see through their perspectives. Finally, as the main researcher, I was involved in all aspects of the study from defining the concept of the study to collecting, transcribing, and analyzing the results.

Having a known relationship with the participants could create potential bias. I did not have pre-established personal relationship with my participants and did not purposefully include participants in the study based on my relationship with them. I used a pre-outline inclusion and exclusion criteria to select my participants. Additional bias could appear when the researcher introduces an error by selecting particular data collection or outcomes (Pannucci & Wilkins, 2010). I addressed this by remaining objective and mindful of my interpretations of participants' experiences. Although it was important to establish a professional relationship with the participants, I was mindful of bias that could arise such as misinterpretations (Sanjari et al., 2014).

Just like bias, ethical issues may have occurred throughout the study. Because my research is centered on a sensitive topic which some are not even yet comfortable discussing with their family members, I used a coding system and did not provide the names of participants. In dealing with sensitive topics involving vulnerable individuals, Sanjari et al. (2014) recommended having an advocate present during the interview process; however, this was not necessary as my participants were fairly comfortable in sharing their experiences.

I recruited participants through a local HIV care clinic as well as through online HIV groups. I did not have an already built relationship with my participants and did not conduct the study in my own professional environment, which avoided any potential conflict of interest. In recruiting participants from an HIV agency and an online HIV community, I offered participants an incentive in the form of a gift card, which the IRB approved.

## Methodology

### Participant Selection Logic

Participants for this study were individuals 50 years old or older living with HIV for at least 20 years and those with at least one comorbidity since their diagnosis. I used purposeful sampling in recruiting participants from a local HIV clinic where they normally received treatment. Purposeful sampling is a type of sampling in which participants are intentionally selected for the study to outline specific predefined characteristic they have which, are essential in understanding the phenomenon being studied (Luborsky & Rubinstein, 1995). Participants were only be selected if they had a connection to the phenomenon. Since my phenomenon was the experience of people 50+ living with HIV and comorbidities, I selected those 50+ living with HIV, so they can provide adequate insight on their experience of living with the virus as well as complications that may developed from it. Participants were included in the study regardless of their race, gender, social economic status, and sexual orientation. The most important inclusion factors were being 50 years old or older, living with HIV for at least 20 years, being on ART, and having at least one comorbidity. Newly diagnosed HIV patients were excluded from the study.

Determining sample size is another important factor in research, and researchers need to be careful not to have too small or too large of a sample (O'Reilly & Parker, 2012). A larger sample could lead to sampling errors, which could affect the results (Marshall, 1996). The choice of sample size depends on the parameters of the phenomenon being studied (Marshall, 1996). In qualitative research, the sample size tends to be smaller than it would be for quantitative study since the scientist is more concerned with the meaning as supposed to the quantity (Manson, 2010). With a phenomenology design, using a small number of participants is beneficial, as it prevents a large sample that produces repetitive data (Manson, 2010). I planned to study up to 25 participants to ensure saturation is met. Data saturation is reached once additional interviews no longer yield new information and when further coding is no longer feasible (Bonde, 2013; Fusch & Ness, 2016; Sargeant, 2012). To adequately assess that saturation is reached, Sargeant (2012) recommended documenting new themes as they emerge throughout the interview. Failure to adequately attain saturation can negatively affect the validity of the study (Fusch & Ness, 2016).

There are several types of saturation used in qualitative research: theoretical, data, and thematic saturation (O'Reilly & Parker, 2012). With thematic or data saturation, the scientist should continuously collect information until no new information emerges. Theoretical saturation occurs when the scientist notes that all the involved categories are accounted for, but that variability may also exist between the outlined categories (O'Reilly & Parker, 2012). In my study, I used data saturation (through data analysis) and thematic saturation (through theme analysis). I recorded new data throughout the interview and placed them into thematic patterns. Once no new thematic patterns emerged, I determined saturation was met and obtained my sample size.

Participants who fit the inclusion criteria, who were receiving treatments at the agency and those in the online community, were provided with documentation offering them the opportunity to participate in the study; if retained for the study, they were contacted via their self provided telephone number to schedule their interview. The interviews occurred wherever each participant felt comfortable, as they were conducted via telephone. The first participants fitting the profile and yielding to saturation were retained for the study.

## Instrumentation

Prior to data collection, I obtained IRB approval (03-07-17-0379944). Each participant was required to turn in his or her signed consent and give verbally explain their understanding of the signed consent. They were reminded of their right to voluntary refuse to participate or choose to exit at any given time. Once these were completed, I conducted telephone interviews with the participants, going over a predetermined open-ended questionnaire, focusing on the participants’ experiences of living with HIV including the adverse effects. Throughout the interview, I remained engaged with participants by not taking notes and instead recording each session using a digital recorder. Once all interviews were complete, a professional transcriptionist completed the transcription. I ensured that the transcriptionist turned in a signed confidentiality agreement attesting to the privacy of the participants and data.

Because I used a phenomenological approach, conducting telephone interviews helped me gain insight into the experiences of my participants. “Humans” are an important “instrument” when conducting qualitative research, as they can directly interact with the phenomenon in question within their own environment (Sanjari et al., 2014). Researchers should look for biases that are likely to occur from working in these natural settings (Sanjari et al., 2014). Kuzmanić (2009) stated that a researcher should assess the validity of the data throughout the qualitative interviewing process through proper data collection, analysis, interpretation, and transcription. The instrument I used to collect data was in-depth semistructured interviews, which is common in qualitative research. In-depth interviews are essential in getting participants to elaborate their opinions and experiences on the topic at hand (Zaharia, Grundey, & Stancu, 2008), meaning an in-depth interview worked as an instrument to answer my research questions regarding participants’ perspectives. Another benefit of using in-depth interviews as opposed to focus groups is that participants are typically more relaxed and willing to elaborate on sensitive topics (Zaharia, Grundey, & Stancu, 2008).

Some researchers are inclined to observational qualitative research, with a focus on outlining their comments as opposed to sharing those of the subjects; however, researchers can use interviews to outline the subjects' narratives and their shared experiences while masking their opinions of the phenomenon at hand (Edwards & Holland, 2013). Phenomenologists choose interviews because of their interest in the meaning of a specific phenomenon as it is understood and lived by the participants (Englander, 2012). To attain this knowledge, an interview should contain questions aimed at uncovering and understanding details on the phenomenon in question, such as questions that would make it easier for participants to describe, in as much detail as possible, anything related to their experience of the phenomenon in question (Agee, 2009; Englander, 2012). Framing research questions is the essential part of data collection in qualitative interview, meaning they should be specific to gather sufficient data from the interview (Turner, 2010). Open-ended questions should be used to avoid guiding the participants' answers (Turner, 2010).

Follow-up questions should pertain to specific details surrounding the phenomenon based on answers provided in the initial questions (Englander, 2012). When formulating follow-up questions, scientists should ensure they obtain the needed information as well as keep participants engaged in the topic at hand (Turner, 2010). Based on these guidelines for conducting interviews and writing questions, I formulated simple and clear follow-up questions to incite participants to share information on their experiences of aging and living with HIV as well as the comorbidities that arise from it. These questions were as follows:

1. Tell me about your experiences living with HIV.
2. Tell me about the effects HIV has had on your daily life and your relationship with family, friends, and coworkers.
3. Describe your awareness of sexual risks associated with HIV infection.
4. Tell me about your health care experiences since testing positive for HIV.
5. What is your knowledge of HIV resources and support programs in your community?
6. What is your experience with those HIV services?
7. Describe your experience with support from your family or lack of support.
8. Describe any experiences you might have where friends, family, coworkers, or anyone else avoided you because of being HIV positive.
9. Describe your experience with your local HIV clinic.
10. Describe your relationship with HIV medical specialists.
11. Describe your knowledge on follow up of care with HIV specialists when living with HIV.
12. Describe your experience of living with HIV and being on ART.
13. Describe your awareness of the impact of long-term use of ART.

14. What is your experience of living with HIV and being on multiple medications?
15. What is your experience of coping with side effects of multiple medications?
16. Describe whether you believe people have a decline in their health as they age.
17. Describe your knowledge of aging with the HIV virus.
18. Describe your knowledge of health complications that arise from getting older with HIV.
19. Describe your knowledge on follow up of care with generalists when aging with HIV.
20. Describe your knowledge of side effects of multiple medications used to treat complications of old age.
21. What is your experience of coping with the combination of new comorbidities and HIV since diagnosis?
22. Describe your current quality of life.
23. Outline factors that could improve your current quality of life.

## Recruitment, Participation, and Data Collection

I collected data from my participants through individual recorded telephone interviews. Data were collected from subjects recruited from an HIV agency and an online HIV community. As this is a sensitive topic, I did not have a time limit for the interview. I used a digital recorder throughout each session. Even though my target sample of up to 10 participants seemed attainable, I recruited more in case some decided to drop out. After completion of each interview, participants were thanked for their time, participation, and genuine honesty. Their $5 gift card was provided along with additional information pertaining to a phone line where they could reach me directly should they have further questions regarding the study. Information pertaining to their follow-up interviews, scheduled at a later date, was provided as well. An additional $5 gift card was provided after the follow-up interview. The follow-up interview was critical to present participants with the core themes to attest for the accuracy and appropriate representation of their own experiences while giving them an opportunity to comment on them (see Creswell, 2009). Participants who dropped out of the study during the initial interview phase or the follow-up interview could keep their incentive.

## Data Analysis Plan

To properly analyze the collected data, Creswell (2009) recommends following specific steps as follow, which were helpful in my study.

1. I analyzed each interview conducted that day, writing notes post interview, ensuring I had a specific pre-narrative for my final report. Once the transcriptions were in my hand, I read them before adding notes based on the transcribed interviews.

2. I read through the collected data to get a better understanding of the whole picture, capturing the main common points.

3. Once I completed the above, I put the data into Nvivo software to organize the written notes by categories based on their communality from major, to minor, to unique.

This is called coding and it helped me better understand what each category meant as whole.

4. I later made up specific codes to represent each outlined category while assigning it to each segment of the transcribed data.

5. I then assigned to each group topic, a word that properly described it before turning that group into category, checking once more for communality.

6. Once satisfied with the category name, I alphabetized each code.

7. I organized the collected data based on the assigned category under the now alphabetized code, before beginning the preliminary analysis.

8. Once satisfied, I grouped the various categories under a broader group called "themes" to encompass the main idea at hand.

For proper data analysis, adequate software should be used; I opted for Nvivo software because it has proven adequate for scientists in both evaluating and interpreting qualitative texts (Zamawe, 2015). This software was be extremely useful, especially considering that my gathered data was from 10 in depth interviews. Had I encountered any discrepant cases, I would have included that in my analysis and presented that evidence. This serves to maintain my credibility thus validating my study (Creswell, 2009).

## Issues of Trustworthiness

In order to assess credibility, also known as internal validity, scientists seek to outline a true picture of the studied phenomenon**;** this is an important factor as it shows how compatible the results are with actual reality (Shenton, 2004). Used to establish credibility, triangulation involves using other methods to gain information on participants. In my study, I used interviews as my triangulation method because it enabled me to obtain information regarding my participants' experiences from their own perspective.

To ensure genuine participation and shared experiences, each prospective participant was reminded that they have the right to decline participating in the study or withdraw at any given point without explanation. I also ensured to make them feel as comfortable as possible so they could openly share as much as they felt comfortable sharing; which helped maintain the credibility of the collected data. Peer review is always important in scholarly work. I welcomed any scrutiny and advice from my committee and peers throughout this process. In fact, their non-bias outlook on my project brought up fresh ideas that I used to improve my methods and also to avoid jeopardizing the credibility of my entire study.

In addition, I ensured to clearly explain the phenomenon under study so that the reader may attest to whether or not the overall results correlate with the underlined studied phenomenon (Shenton, 2004). Creswell (2009) recommended using member checking to assess the accuracy of the findings. During the follow-up interviews, I assessed for accuracy of their reported data to ensure I had an accurate representation of their interview.

Transferability, also known as external validity, is noted when scientists provide the reader with enough supporting information on the area of research so that they can decide whether the overall findings are credible enough to be applied or replicated (Shenton, 2004). In my study, I gathered sufficient data in sufficient depth so that readers could get a better understanding of the experiences of people over 50 living with HIV and comorbidities; hoping that such knowledge would guide them in making improvements in their clinical settings. In addition, I ensured to also provide all parameters pertaining to how the study was conducted so they could replicate the study.

Dependability, also known as reliability, outlines that most researchers use an approach similar to that of another so it can be replicated (Creswell, 2009). As stated above, I provided the reader with the detailed methodology used in my study, so that it is easily replicable in a similar context, using the same methods, and the same type of participants. These details should enable another researcher to obtain results similar to mine. Even though Shenton (2004) stressed that in phenomenology or qualitative research, aspiring to obtain similar results could be a challenge; researchers should at least be given the entire methodology so they could attempt to replicate the study. In addition, I kept a trail of all documentation used during the process so that it could be easily traced back if needed. Shenton describes this process as “audit trail”. To be specific, I kept a record of everything I did, whether it seemed important or not, from notes I wrote in my journal pertaining to the study, to interviews, and transcription. That way, other scientists could easily audit, retrace, and replicate if needed.

Confirmability is achieved when scientists successfully take steps to show the reader that the presented overall results in fact derive from the collected data and not from their own predispositions or interpretations (Shenton, 2004). As such, I remained as objective as possible to ensure that I presented information from the participants without adding my personal interpretation; I also provided direct quotes from participants. This also allowed me to avoid any researcher bias.

## Ethical Procedures

Prior to reaching out to prospective participants and collecting any data, I needed to go through a mandatory approval process for the protection of the participants. To be specific, I filled out and submitted my application to the Institutional Review Board (IRB), and only once approved did I proceed with data collection. To ensure IRB had a better understanding of my anticipated study, I attached my proposal to my application so they could make an informed decision.

IRB ensures that all upcoming scientists, at their respective universities, comply with ethical standards and regulations outlined by the federal government. As such, Walden's IRB must approve all submitted proposals before any data is collected (Walden University, 2015). Once approval was obtained, I obtained consents from each participant and ensured that their physical and emotional being was well maintained. In fact, according to IRBs' guidelines, participants' human rights should be respected and they should not be placed in any physical or emotional risk for the sole gain of the researcher (Walden University, 2015). In regard to their privacy, coded names were used in lieu of their name so that all terms of confidentiality in accordance with the consent were fully respected.

Ethical issues may arise; however, researcher should anticipate them and be ready to correct them ahead of time because, maintaining the integrity of the research and thus the validity of the results is important. Throughout the study, I always kept my participants' interest first in mind and avoided engaging in any misconduct that would have poorly reflected on my committee team, my university, and me. Additional ethical issues that may arise with use of incentives when recruiting participants could be seen as bribery. To avoid that, I made sure to obtain IRB approval before offering participants a gift card thanking them for their time and participation. In addition, although I thought that recruitment via the AIDS agency and the online HIV community was adequate, I needed to obtain IRB approval before proceeding with that choice.

Participants were reminded that they could choose not to be included in the study and also exit it at any given time shall they wish to do so. For that reason and to maintain my sample size, I attempted to recruit up to 15 participants to account for those that could exit early but still ended up with my sample size of 10. In addition to recruiting via the AIDS agency, I also posted my advertisement for research at various online HIV groups. During each interview, I had a back up recorder in case I encounter some mechanical failure with one. Once the interview was completed, I transferred the information to a personal drop box on my personal computer, which can only be accessed via a password only known by myself. I backed up my computer each night with a personal external hard drive that I keep in a locked cabinet at my residence. All data pertaining to the study were only shared between the transcriber (who signed a confidentiality agreement), my chair, and me.

## Summary

Using a phenomenological approach in conducting this qualitative study was essential to better understanding the phenomenon of people over 50 living with HIV and comorbidities, as well as the complications that arise from that. As the primary researcher in the study, I followed proper ethical guidelines to maintain patients' privacy, emotional, and physical well-being at all times. The data collected through telephone-recorded interviews of a small population sample were later transcribed before analysis using Nvivo software. The overall findings enabled me to get a better understanding of their lives as HIV patients, which could help in improving their quality of life.

# Chapter 4: Results

The purpose of this qualitative phenomenological study was to explore the lived experiences of participants 50+ living with HIV to gain an understanding of the challenges they face as they age with the virus and comorbidities that develop. The following RQs guided my study:

RQ1: What are the experiences of people 50+ living with HIV?

RQ2: How do people 50+ describe their experiences with HIV?

RQ3: How do HIV-positive patients older than 50 describe the challenge of living with HIV and diagnosed comorbidities?

In the following chapter, I will outline a description on the settings, participants' demographics, data collection, data analysis, evidence of trustworthiness, and study results. I will conclude with an overall summary of the chapter.

## Setting

I conducted this study via recorded telephone interviews. All participants had provided consent to the above in accordance with IRB policies and all agreed to participating and being recorded. Scheduling each interview required flexibility; as a result, some interviews were conducted on the weekends. There were no personal or organizational conditions that appeared to influence the participants that could affect the interpretation of the study results.

## Demographics

The demographics and characteristics of my 10 participants, presented in Table 1, include their age, sex, sexual orientation, number of years living with the virus, and number of comorbidities present. All participants met the inclusion criteria of being over 50 years of age, living with the virus for at least 20 years, living with at least one comorbidity, and being on ART. Eighty percent of the participants were homosexual, 10% were bisexual, and 10% were heterosexual.

Table 1

*Characteristics of Participants*

| Participants (P) | Sex | Age | Sexual orientation | Years since diagnosis | Number of comorbidities |
|---|---|---|---|---|---|
| P1 | Female | 62 | Heterosexual | 29 | 6 |
| P2 | Male | 60 | Homosexual | 30 | 7 |
| P3 | Male | 52 | Homosexual | 21 | 3 |
| P4 | Male | 59 | Homosexual | 30 | 7 |
| P5 | Female | 65 | Bisexual | 28 | 4 |
| P6 | Male | 63 | Homosexual | 27 | 3 |
| P7 | Male | 64 | Homosexual | 32 | 7 |
| P8 | Male | 51 | Homosexual | 30 | 5 |
| P9 | Male | 74 | Heterosexual | 21 | 1 |
| P10 | Male | 55 | Homosexual | 25 | 9 |

## Data Collection

I recruited 10 participants with whom I conducted and recorded telephone interviews. Once I obtained IRB approval from the university, I began the recruiting process in early March 2017. I mailed a priority sealed and marked “confidential” envelope to the head of the AIDS resource agency at which participants received treatments. The agency, via their CEO, had approved and agreed to advertise the research; I had no part in the recruitment of participants at the facility, hence no access to their respective medical records. The mailed envelope contained all necessary documents pertaining to the study: 15 approved IRB consent forms, prelabeled and prestamped envelopes with my return address for them to return their signed consents form if they wished to participate in the study. Within a few weeks, I received two consents back from participants, which I reviewed carefully to ensure they met the inclusion criteria before calling them to schedule their initial telephone interview. The initial interview was roughly 1 hour and 15 minutes. At the end of the interview, participants were reminded that, as stated in the consent, they would be contacted in a few days to schedule the follow-up interview to attest for accuracy of the collected data. Additionally, the follow-up interview covered additional questions based on their responses in the initial interview to obtain clarifications in certain areas and/or additional details. The follow-up interview were roughly 30 minutes.

The data collection process started on 4/24/17. Each participant was called on the day scheduled for the interview. While some were present and ready to proceed, some asked if they could reschedule, which I was able to accommodate. Each time I called a participant, I re-introduced myself to them, ensuring they knew whom they were talking to, before proceeding to confirming once more that they had consented to the study and that this would be recorded. They confirmed that they had consented on their own free will and were ready to proceed. I recorded each interview session with an audio recorder and later transmitted the audio file for transcription to a transcription company bound to a confidentiality agreement. Upon obtaining the full transcript within 24 hours, I reviewed it and contacted the participants for a follow-up interview based on their previous responses for accuracy of the data and to obtain clarifications and/or additional details in certain areas. The last interview was conducted on 8/27/17.

While awaiting eight prospective participants, after additional investigation I found that most of my population sample is active in the online community where they find support from others fighting the same disease. After IRB approval for a change in procedure in early July 2017, I posted an advertisement for my research on various Facebook groups for long-term HIV survivors. The advertisement posted contained my e-mail address for prospective participants to e-mail me with additional questions or to request the full consent that would enable them to make a better-informed decision. Twelve prospects initially submitted an e-mail requesting the consent form for review and eight e-mailed back their consent for possible inclusion. After one e-mail to the remaining prospects without a response back, I did not pursue them as participants. I reviewed the eight prospective participants' forms to ensure they met the inclusion criteria; I later contacted them back to set up the initial interview. This lasted on average 1 hour to 1 hour and 15 minutes. They were also reminded at the end of the interview that they would be contacted in a few days to schedule their follow-up interview, which lasted roughly 30 minutes.

I did not encounter any unusual circumstances. However, during interviews there were instances where participants, while answering one question would unknowingly answer a question I was going to ask at some point later in the interview. I remained flexible and did not repeat a question already answered in this manner. Additionally, I did not redirect tangential responses, because I found what the participants were sharing was valuable.

## Data Analysis

I used the same notebook throughout the interview process as a research log, writing down names and acronyms of the participants as well as interview dates. On the day of each interview, I wrote down the date, the start time, and overall length of the interview. At the end of each interview, I listened once more to the recorded audio then wrote down key elements and initial thoughts in the margin of the page addressed to the participant in question. Upon receiving back each transcribed document, I read it multiple times, noting similarities in experiences among participants as well as any other shared experiences not necessarily related to the research questions. When I encountered the need for added details or clarifications on a specific thought shared by the participants, I wrote them down and generated questions to be asked in the follow-up interview.

After reading each transcript and adding key words and/or phrases pertaining to each interview in the margin of my notebook, I formatted the transcribed interviews in

Nvivo style before importing the data into Nvivo software. I ran a query in Nvivo to confirm major experiences shared by the participants. Following that, I began the process of coding. Coding is a process used by researchers to purposefully section out specific segments of the interview transcript whether it be small segments of a sentence, a whole sentence, or a full paragraph when deemed to be relevant enough to answer the interview questions, but more importantly the research questions (Wong, 2008). While coding, I gradually and carefully organized each coded section under a specific category based on similarities. I read each coded category to ensure the containing segments were addressing the same idea and the responses were similar. The names that I chose for each category derived from the overall description of the participants' shared ideas or language. Once I completed naming all the various categories, I grouped them under a broader group called themes to encompass the main idea at hand.

Three main themes emerged from my analysis: 'from fear of the unknown to ownership,' 'from ownership to survival,' and 'the constant struggle of surviving with HIV.'

### Theme 1: From Fear of the Unknown to Ownership

The first theme encompasses three categories and emerged from interview questions one, two, and four. This theme describes that participants went from a state of fear to a state of ownership.

**Category 1: Fear, anger, and rejection.** In this category, participants described the early stages with words such as "fear," "angry," "scared," "shock," "mind numbing," "surprised," "at a loss," and "denial." The majority of participants reported experiencing fear at the onset of the diagnosis because little was known about the disease process and its treatment. For instance, P1 stated "in the beginning it was very alarming because there was so much fear and ignorance and no knowledge about it." P3 also stated, "the first one with the initial stage when I was diagnosed, it was—I was scared. I was shocked." P2 added, "I've been positive since the onset of the disease and at the time nobody was aware of HIV, you know, back then it was called HTLB3. Then they finally identified the virus and a couple years after that, they introduced AZT as the only drug." P3 shared that he experienced tremendous fear surrounding his fate stating,

> I was scared. Didn't know what to expect. Gave myself about five years to live, basically. A few of my friends around me died between two and five years, so it was a terrible time like watching a dragon move through my friends. And so, in 1996 I thought five years. That's it.

While some, like P5 experienced anger "at first, I was extraordinarily angry, then I got it," others experienced stages of denial as seen with P4:

> I was using methamphetamine to self-medicate, and go in too crazy, and just self-destruct. I hadn't really reached the point where I was ready to fight and do everything I could to baffle the virus. The fear was causing me to want to self-medicate, and then dealing with the depression. So, I stopped counting suicide psych ward visits after 17 times.

**Category 2: Fear of rejection before acceptance.** In this category, most participants reported waiting as long as possible before sharing their diagnosis with family members and/or friends for various reasons. P3 stated,

> I was scared to disclose my status to my colleagues, even my family, and eventually it became quite nice when I could do my part by telling. So, I went from actual fear to acceptance. But first my family was devastated and also scared.

Others feared stigma or adding stress to their relationships. To that effect P7 reported,

> I just didn't want to discuss it with anybody, and because of the judgmental, that people would think worse of you because of it, or just the psychological thing that after they find out, it could be traumatic or destroy something.

P8 stated, "I did not disclose my HIV status to the rest of my family until I was hospitalized with PCP. Partly out of apprehension and anticipation of the stigma and the strain it would put on those relationships."

Some participants chose to openly share their diagnosis with friends yet ended up losing them. P8 stated, "I lost some friends in the 90s because I was open about my status." P3 reported, "I feel like it's messed up. I had a partner at the time and he sort of pushed me aside when I was diagnosed." Other participants shared that they were already living with an almost nonexistent relationship with family members because of their sexual orientation. For example, P4 reported, "my brothers are both homophobic. Support from my family hasn't really been there." P2 shared the same point:

> my biological family found out I was gay, oh gosh 1977 when I was kicked out of the Navy for being gay. And I didn't speak to them for about 30-35 years or so. And then once my father found out that I had HIV he started feeling guilty and so we started having some communication, but we never restored a normal healthy family relationship. My sister and brother still want nothing to do with me at this time.

Despite the fear, a couple of participants were eager to share with their friends and/or loved ones for support did get that support. P9 stated, "I knew it was something I'd have to live with, and I dealt with it pretty well just that way, by telling one or two others that were already infected people and just telling them helped." P10 added, "My family's been pretty amazing I would have to say" and P6 stated,

> I was just uncomfortable with it, of course. I told my family. That went very well. It was hardest for my brother, of course, because he is having a hard time with just my being gay and then you throw this on top of it. I must say he has come a long way.

**Category 3: Ownership and self-advocacy.** In this category, participants moved from a state of ownership to one of self-advocacy. P3 reported, "when I realized that it wasn't going to happen, I wasn't going to die, I started living again. And since then I have made the most of it. And now I'm planning to retire. I'm not planning for death." P2 noted, "HIV in my experience, this is a disease that every single patient needs to be their own best advocate." Some participants started self-advocating. P10, for example, said,

> Early on I didn’t have a good relationship with my healthcare providers because I wouldn’t take the AZT so the doctor didn’t think I was cooperating with them. But I had side effects. I had neuropathy within two to three weeks of taking the pill. It was pretty intense and I just decided not to take it.

Similarly, P6 reported, “I wanted to go as long as possible without going on medication, because the only drug, AZT had a lot of side effects.” P5 also rejected AZT because as she stated,

> I knew that AZT was killing people. That people who took AZT were dying. I mistrusted the meds. I knew I didn’t want to get on AZT. I knew I had to find support. I had to find a doctor who would trust me.

Participants continued to self-advocate for their overall health. For instance, while seeking physicians to embark on this journey with her, P5 shared, “I was going to interview doctors, I made up a list of questions. I found one, I liked him.”

Participants also shared their struggle to get on the medication or tolerating it. P3 stated, “at first, the medication was incredibly expensive, I couldn’t afford that, and my grandmother paid for my medication for five years until our Medical Aid picked it up; because in 1996, it wasn’t covered by any Medical Aid.” P8 stated,

> I didn’t have insurance at the time and I was probably in the hospital more than out, with a list of—a lot. I was increasingly ill over the next several years. It was extremely difficult, then I was basically granted emergency Medicaid because of the—who knows how many thousands of dollars of hospital bills.

Those who were insured had to sometimes battle with their insurer for treatment. P2 shared, “It took two years for the VA to authorize my surgery. And so, because it took two years my left leg is paralyzed because of it.” Along the same line, P8 shared,

> it has gotten more difficult to get sculptural treatment as of a couple of years ago. At one point, you could get the facial filler material through the program on a sliding scale based on income. Now, the reimbursement rate is so low that there are no doctors who will accept Medicare for that. So, it’s effectively not available. Also, if you have any insurance, they won’t give you the material. You have to try to battle it out with your insurance company.

Some participants like P10 shared their struggle with tolerating treatment: “At first it wasn’t too bad. Then, I couldn’t handle any of the HIV meds, so between 2004 and 2008 I was hospitalized probably about 25 times, so the last 12 years have been pretty miserable.”

Participants noted that obtaining good coverage depends on the insurance. To that effect P2 stated,

> Because I am a veteran of the United States Navy, by and large my healthcare has been pretty good, I have access to great specialists at the VA. Now, I am aware of friends that have had issues with getting consults to specialty physicians because of their being on Medicare or Medicaid or you know whatever.

P7 added, “I am getting all of my healthcare and great coverage from the Veterans Administration.”

## Theme 2: From Ownership to Survival

The second theme encompasses three categories and emerged from interview questions five to ten. In this theme, participants described moving from a state of ownership to a state of survival.

**Category 1: Knowledge and utilization of resources for survival.** In this category, participants stated that from the moment they accepted the diagnosis, they started learning about the virus and P6 stated, "it was learning a lot about medications and pharmaceutical terminology, and things that you never thought you would become so aware of and so overwhelmed with." Several mentioned that upon their diagnosis they were immediately linked to a local HIV clinic or provided information on various resources. P4 stated, "I just immediately got plugged into the AIDS service organization here. They hooked me up with everything." P6 stated, "When I moved, I did my homework. I did my research. I found out where to go and what to expect" and P9 stated, "You'd have to ask a few questions, and a doctor or the county would direct you right to it." Nonetheless, the majority of participants reported that the presence of these resources has been beneficial for them to not only acquire knowledge about the disease process and how to live as healthy as possible with it, but also to have social support. P10 reported, "They do a lot of tea time, they'll have workshops on living well with HIV, how to make out your will, how to live on a budget, healthier exercise, healthy eating. So that's really good." P1 stated,

> I have gone to HIV 101 classes; I have attended HIV University through WORLD the Women's Organize agency. We have luncheon learns and dinners that are sponsored by the drug companies. We have a weekly social support group and activities.

Some like P9 added, "The group therapy once a month helps."

While on their learning journey to survival, some participants reported that they began learning to be an example for others also facing the virus and going through stages they had already gone through. P1 stated, "I trained to be an HIV tester and counselor. I have done public speaking, I attend support groups, and I do peer navigation for newly diagnosed people." P5 shared,

> I found a group of women here. We formed a support organization for women that still exists. The original group of us women really helped me get through those early years. I wound up doing AIDS work myself. I was an AIDS case manager for 18 years.

P8 stated,

> I specifically work with a lot of the newly diagnosed people to insure they are immediately linked to care. And I generally mentor them for – anywhere for six months to a year to try to ensure that they remain in care for that first year. I do often see a direct impact, and being an example of just saying I'm here 30 years later, and I wasn't supposed to live five years.

P4 also stated,

> I would go to the support groups. What I got a kick out of was going and talking with newcomers that were scared to death. I loved talking to them and letting them see, here is a long-term survivor. You can survive. It is not a death sentence anymore. You don't worry. Basically, just sort of be with them and support them.

Lastly, P2 noted, “While I was working I became an HIV/Aids certified RN.”

**Category 2: Societal support, another key to survival.** In this category, participants outlined the importance of societal support to their survival whether it is from immediate family or partners, society via support programs, or friends. Some participants reported the benefit of utilizing the available resources to avoid more solitude and depression. P6 stated, “And yeah, the activities – the more the better. It’s kind of cool that they're pretty active like this. I need to do this because I get depressed so easily. I gotta keep busy.” Others like P1 added,

> I wish there were more social things you know. Sometimes it gets old talking about HIV all the time. I attend a support group even though sometimes they repeat the same presentations over and over. I go for the emotional support and the socialization.

More than half of the participants reported having familial support either from immediate family or from their partner. For example P1 stated, “now we have an awesome relationship, it is very rarely talked about.” P8 noted,

> All were very much supportive, they all came to visit me in the hospital numerous times, because I was in the hospital numerous times. They provided some financial support, although none of them was in the – a great position to do that.

P10 shared, “When I do get sick, one of my siblings will come out and help me, or a cousin will come out and help me. And that’s happened more often than I care to.” P5 stated, “My main support is through my partner; which is not the best scenario. If anything happened to him, I would probably be devastated;” and P2 stated, “My sister and brother still want nothing to do with me at this time. So my husband is my family, and I’m his.”

Some also shared this lack of familial support. P10 stated, “I’m not close with my family. My friends, you know, we really had to stick together. And most of them are dead now. It’s hard to make new friends.” P2 similarly stated,

> I’ve gotten to the point where I’m so independent without them that as this point in my life they don’t have any effect on me. Now, when I was very sick you know it would have been very nice to have some familial support particularly after the time I left my ex because I had marginal income, but I didn’t have that family of support to fall back on. So, I just had to make do with the best I could.

Others shared issues that arose in their workplace over the years because of their status. P1 stated,

> I had been a waitress prior to having HIV and I was told when I got out of prison on parole that because I had this virus I would never be able to serve food again

> which turned out to be false. But because I believed the parole board I gave up over ten years in the culinary union. I gave up a pension and was forced to work other places.

And P10 stated,

> I was fired from a job for being positive. Unfortunately I told a coworker about it, and that day I was fired. They told me I was fired for stealing, and I don't steal. So I believe that's why I was fired.

**Category 3: Effective patient-clinician partnership.** This category outlines the importance of a good relationship between the participant and his/her HIV clinician. For the most part, participants reported having a good partnership with their clinician. They all described the latter as more often than not a regular general practitioner, and in some instances a general infectious disease specialist in lieu of a specialized HIV specialist. P2 stated,

> I go to the infectious disease clinic. In the VA system they have no HIV specialists and they don't treat a tremendous number of HIV positive patients. So, sometimes I end up being the teacher to providers, even occasionally to the infectious disease docs that I've had over the years.

Others also reported seeing generalists who seek beyond their scope of practice for their patients. P4 stated, "He is not a specialist, he is a regular family physician but in his own right because of the attention he pays and the talks he does on HIV and AIDS, he is specialized. And he listens to me." Others reported seeing a general ID specific physician. P8 stated, “I go to a life based clinic at the medical university, which is an ID specific clinic” and P1 added, “I go to the Wellness Center, which is the primary HIV care.” Despite the type of physicians that they see, they all reported having sort of a partnership with their doctor, which helped in their journey to survival. P5 stated, “I had to find a doctor who would trust me. I found a doctor that would listen to me. That I trusted and would watch my T-cells with me;” and P8 stated, “my relationship with my doctor is great. He and I actually hit on some of the things committees offer, so we genuinely have a great partnership.”

## Theme 3: The Constant Struggle of Surviving with HIV

This theme emerged from interview questions twelve to twenty. In this theme, participants shared their constant struggle of living with the virus as well as living with the side effects and comorbidities that developed overtime.

**Category 1: Daily survivorship.** In this category, participants shared their daily survivorship. They reported that although some days might be decent, most are not. P7 stated, “I’ll go a week where I just completely forget, on top of the world. And the next week, suddenly I can’t get out of bed, and then it causes me to get depressed.” P2 added, “It’s just that some days you have really good days and some days you have days that are – you feel like you have been run over by a Mack truck.” Participants shared the frustration and struggle with their newly day-to-day routine. In fact, P6 stated,

> The medication is almost a part time job for me. I am on so many medications right now. I take them four times a day. I have to remember to take them and then

> I'm taking, of course, other medications for my back and my depression and for my heart. And so, it's pretty intense, and it is easy to miss when you take this many.

P8 stated,

> I take five pills twice a day just for anti-virals. So, you know I'd say my biggest problem at this point is pill fatigue. I don't allow myself to give into it but I go through periods when I resent every pill I do have to take.

The majority of participants shared that they have come a long way from having to take several pills a day or a bigger dosage to smaller amounts. In fact, P7 stated,

> I was on sometimes upwards of 25, 30 pills a day, and had to take them in the morning and the afternoon, and your whole existence revolved around when you needed to take your medication, when you needed to eat something, or these are on an empty stomach, and whether you need to do all these things.

P8 stated, "It is fewer pills – I mean I still take five pills twice a day just for antivirals but that is a far cry from 30 pills a day, that was just antivirals at one point." P1 stated, "Today I take one pill once a day for HIV where as little as ten years ago I was taking forty to sixty pills a day." P2 pointed that the dosage was way too high: "I was taking 2400 mg of AZT a day. The dose of AZT now is about 200 mg a day. But that was the only drug they had to give us and it just made me sick." However, some shared the frustration of still taking a lot of them today. P10 stated,

> I take about 36 pills a day. So I really have to keep on top of the pills. It just really sucks. I have friends that have been on therapies for 10 years and I'm lucky if I can get a year or two.

Participants reported a series of noted side effects, which add to their daily struggle. These side effects are either from the medication used to treat the virus and/or for having lived with the virus for such a long period of time. For instance P1 reported, "insomnia, chronic diarrhea, and the gastrointestinal." P2 stated, "extremely vivid dreams and chronic diarrhea." He added, "I don't attribute the diarrhea to the medication, I attribute it directly to the HIV itself." P6 reported, "It was a combination of the diarrhea and the nauseousness and perhaps it gave me a little bit of an uneasiness." Other recurring side effects mentioned by most participants were "osteopenia, osteoporosis, pericarditis, back and bone pain, extreme fatigue, mental issues, dyspareunia, decreased libido, chronic kidney disease, lipo dystrophy, lipo atrophy, peripheral neuropathy, memory loss, memory loss, poor concentration."

**Category 2: Aging before your time.** In this category, participants reported noticing that they are aging before their time. This could be due either from the disease process itself, from being on the earlier ART drugs, and/or simply from the side effects of the current drugs. Most participants reported extreme fatigue, which they are experiencing more often and which prevents them from being as active as they once were. For instance, P6 stated,

> So you got two things going after your body, side effects, as well as the HIV virus. You lose a lot of your energy and a lot of your stamina, endurance. I am slowed down because of my back, and that pisses me off.

P3 added, “I am more fatigued now. I get tired more easily. I used to go jogging on the beach with the dog. I can’t do that anymore, that’s my main frustration.” P8 stated,

> The fatigue is probably in a lot of ways my biggest challenge at this point especially returning to work full time. I do not have the stamina that I would expect to have as a 61-year-old man. Sometimes at my lunch hour I close the office door and take a nap for an hour, and then there have been a few days when I simply called in because I just could not make it through a day in the office.

P10 also stated,

> There’s a lot of fatigue, so there’s a lot of worry about the side effects with the bone density, the liver. Every pill I take has a side effect, so we can’t really tell what is really causing all the fatigue.

Others also experienced neuropathy, which made it difficult for them to get around. In fact, P3 stated, “I try not to talk about it all the time, the side effects, especially the neuropathy. I get frustrated with myself. It’s fairly uncomfortable to walk around – I try and maybe hide it.” P10 added, “I have neuropathy from the waist down, so it’s hard to get around.”

Some participants pointed out memory loss as an issue too early to happen at this stage in their life. In fact, P8 stated,

> I am having issues with memory and concentration. I just feel like I'm inappropriate to my age. I will often struggle for a word that seems to me that's something that people significantly older than me do as often as I do.

Similarly, P10 reported, “I am now experiencing memory loss.”

Other participants stressed going on disability not by choice but again as a result of either the virus itself and/or the side effects from the medications. To that effect, P2 stated,

> Because of HIV I have lost the ability to work not once, but twice, the first time being in ’99 and the second time being in 2013. And the first time was a direct causation from the HIV. The second time was from the side effects of at least one of the medications, we don’t know which medication.

P6 stated,

> I was forced into retirement through disability. And I wasn't prepared for retirement at all. I wasn't ready to retire, but I was unable to work through disabilities. HIV does affect your entire body and it makes it weaker.

P10 added,

> Between 2004 and 2008 I was hospitalized probably about 25 times. So, I have had pericarditis as a result of one of the meds. I had to go on disability, which I wasn’t too happy about. And then I asked my doctor when I was gonna go off disability, and he told me never.

**Category 3: Existing despite the odds**. In this category, most participants described their current quality of life as not really "living" more like "existing", fighting one battle after the next. In fact, P7 stated, "I am existing. It's very difficult to find joy in things. You try to distract yourself with projects and volunteerism and things like that." P8 shared, "I went on disability in '94 and I basically lived poverty from the time I went on disability."

Participants also shared aspects affecting their lives. In fact, the decrease or lack of libido among several has impacted them. P7 stated,

> My sex drive has been affected. I definitely have nothing for ten years. I feel like less of a person. It is like that was part of my joy. It is like breathing and eating. Now, I have no sex drive. I try and take pills. I try and take steroids. I try whatever to try and get my libido. It has just ruined that for us.

P8 added,

> Basically I have no sex life at this point, I have very low libido for like 5 years, which seems to me to not be appropriate for someone my age. I am very self-conscious about my appearance, especially without any clothes on. And my libido, it's not because my testosterone is low, because I have had that monitored. Who knows how much that might be due to HIV itself, to the stew of chemicals I take every day, I don't know but it's inappropriate for my age.

This has also affected women. In fact, one reported her struggle with dyspareunia. P5 stated,

> I can't have normal sex now, because I have too much pain. It's painful to have a penis in my opinion. I don't think that other menopausal women who don't have HIV have that necessarily, I don't know.

The majority of participants similarly reported struggle with change in appearance, which affects their self-esteem. In fact, P7 stated,

> Fat distribution – one of the side effects is that you have light atrophy where the muscle patch in your face disappear, and so suddenly you're walking around looking like a human skeleton. You look in the mirror and – and I don’t think anyone’s really fond of looking in the mirror at all, just even to comb your hair, brush your teeth. It’s like a passing glance because it just makes you too depressed to see the physicality’s that’s happened.

P6 added,

> The loss of muscle – I probably got to see that about five years in when I started the medication, and I also have the flaps on my face from the muscle loss. My arms and legs are quite thin for a big guy, and my legs, my veins are very pronounced. This all started about five years in. So you’re looking at about 1995.

P3 also stated, “redistribution of body mass. I found my stomach is quite a bit bigger. I’ve lost mass on my legs, my arms and my bum.”

P8 added, “My body shape changes, the fact that my ass, quite frankly, is deflated. It looks like a 70-year-old because of the atrophy. And that affects my skin also.”

Several participants shared another aspect affecting their appearance and thus self-esteem: lack of dental coverage. In fact, P8 stated,

> Medicare still does not offer preventive dental coverage, except for emergency extractions, and even that's very limited. So at this point, after years of just not having access to anything, I had a bunch of teeth that rotted out and have now had to be extracted.

And P7 stated,

> In treating people with HIV, we have to find a way to help people keep their teeth, and to keep their smile, and to not show the signs on your face. Because it's like if I'm walking down the street, most people don't think that's a gay guy. But, because of were the teeth were, and my face- the lipo atrophy, I look sick. People would go, "He must be…," Do you know what I mean? But, there should be some level of preventative dentistry. Because you can't go through life--you're just already defeated before you even step out the door if you don't have a smile, if you don't have the teeth.

## Evidence of Trustworthiness

To ensure credibility of the study and thus genuine participation and shared experiences, I reminded each prospective participant that, as stated in the consent, they had the right to decline participating or withdraw at any given time without any explanation. At the beginning of the interview and throughout the process of the study, I ensured to develop a respectful relationship with the participants as well as ensured they were as comfortable as possible. This enabled them to openly share in depth information regarding their experience with the phenomenon at hand. Throughout the interview process, member checks were performed. Specifically, at the end of the initial interview and after review, a follow-up interview was conducted to obtain clarification where needed as well as perform member checks to assess the accuracy of the collected data.

To ensure transferability in my study, I reported information on the phenomenon at hand as well the overall descriptive details on the research findings. This will enable other scientists to ensure transferability in their own research and thus decide whether those findings are credible enough (Shenton, 2004). Additionally, I provided details pertaining to the participants' demographic characteristics and specific parameters pertaining to how the study was conducted, so it could be easily replicated if needed.

Dependability in this study was maintained by providing the reader with a detailed methodology used in my study, ensuring that a similar study done in the same context, using a similar method, and with the similar type of participants would be easily replicable by other scientists (Shenton, 2004). Additionally, I ensured to keep a trail of all documentation pertaining to the research (Creswell, 2009). Specifically, I kept all audio and transcribed transcripts, as well as journal notes so that other scientists could easily retrace and replicate if needed. Confirmability in this study was maintained by showing the reader that presented results derived in fact from collected data and not from my own interpretations (Shenton, 2004). As such, I provided direct quotes from the participants throughout without adding my personal interpretation.

## Results

Throughout my research, I sought to answer three main research questions labeled RQ1, RQ2, and RQ3. Based on the conducted analysis, three themes were substantiated from various interview questions to answer the above research questions. Theme 1, 2, and 3 respectively answered RQ1, RQ2, and RQ3.

RQ1: What are the experiences of people 50+ living with HIV?

Theme 1: From fear of the unknown to ownership

Participants shared that their 20 to 30 years of experience from the time they received their diagnosis until today has been met with ups and downs. All of them went from a state of fear, anger, or denial of the then, unknown virus to the medical body, to a state of acceptance and thus ownership. P3 had stated, "with the initial stage when I was diagnosed, it was – I was scared." As such, in their own way, they embarked in a quest of knowledge to be better self-advocates and ultimately live a life as healthy and as long as possible with the treatments available to them at the time. However, the journey would not be without challenges. In fact, just as they had overcome fear of the virus and death that comes with it, they had to overcome fear of possibly being rejected by their loved ones and/or friends whom they would need for support and strength. To that effect, P7 reported,

> I just didn't want to discuss it with anybody, and because of the judgmental, that people would think worse of you because of it, or just the psychological thing that after they find out, it could be traumatic or destroy something.

Additionally, they had to overcome the challenge of attempting to acquire the pricey HIV medication when uninsured or unemployed as well as tolerating and surviving the effects of the only medication available for those that were able to acquire them. P8 shared, “I didn’t have insurance at the time and I was probably in the hospital more than out, then I was basically granted emergency Medicaid.” P10 on the other hand shared, “I stopped taking the AZT because I had neuropathy within two to three weeks of taking the pill.”

RQ2: How do people 50+ describe their experiences with HIV?

Theme 2: From ownership to survival

Once they passed the fear and denial stage, all participants had the desire to tackle the virus head on, one challenge at the time to survive as long as possible. As such, they dove deeper into self-educating on the virus, this time using various available HIV resources and programs.

P1 shared, “I have gone to HIV 101 classes and attended HIV University.” In the midst of all their numerous and frequent stays in the hospital, several participants pointed out the importance of having some kind of societal support whether from immediate family or partners, friends, or via social groups. P2 shared,

> When I was very sick it would have been very nice to have some familial support particularly after the time I left my ex because I had marginal income, but I didn’t have that family of support to fall back on. So, I just had to make due with the best I could.

Additionally, they shared tremendous stigma and injustice in the workplace in those times. For example, P10 stated, “I was fired from a job for being positive.”

Lastly, maintaining a healthy partnership with one’s clinician was also addressed as important. Participants shared that regardless of the fact that their clinicians are mostly non-HIV specialized physicians, they are specialists in their own right and more importantly, they listen to them and are open to learning from them. In fact, P2 shared, “sometimes I end up being the teacher if you will, to providers” and P5 added, “I had to find a doctor who would trust me. I found a doctor that would listen to me.”

RQ3: How do HIV-positive patients older than 50 describe the challenge of living with HIV and diagnosed comorbidities?

Theme 3: The constant struggle of surviving with HIV

Participants shared that their journey has not been without any challenges; in fact, it has been filled with side effects. The latter emerged from various HIV medications as well as from the long-term inflammatory process of HIV within their body. For example, P10 shared, “There’s a lot of fatigue. Every pill I take has a side effect, so we can’t really tell what is really causing all the fatigue.” They also shared constant struggle of keeping up with daily intake of their numerous pills to resenting them at times. P8 stated, “I take five pills twice a day just for anti-virals. So, you know I’d say my biggest problem at this point is pill fatigue, but sometimes I resent every pill I take.” Additionally, they shared that as years went on, some side effects became chronic affecting their daily lives. To that effect, P2 shared,

> Because of HIV I have lost the ability to work not once, but twice. And the first time was a direct causation from the HIV. The second time was from the side effects of at least one of the medications, we don't know which medication.

Other side effects affected not only their physicality but also their self-esteem, aging them before their time. P7 stated, "Fat distribution – one of the side effects is that you have light atrophy where the muscle patch in your face disappear, and so suddenly you're walking around looking like a human skeleton." However, the combination of multiple side effects coupled with numerous hospital stays forced the majority of participants into disability several times. Overall, they have come a long way; they are indeed survivors as P4 reported, "Frankly, I feel as though I have walked through the valley of the shadow of death. I done come out the other end. You know what I mean?"

## Summary

The purpose of this phenomenological qualitative study was to assess the experiences of people 50+ and older living with HIV. Ten participants took part in the study, undergoing open-ended recorded interviews following a pre-made questionnaire. Once transcribed, the data was analyzed using Nvivo 11 software where the coding process enabled categories and later themes to emerge. The following themes emerged from the analysis: 'from fear of the unknown to ownership,' 'from ownership to survival,' and 'the constant struggle of surviving with HIV.'

These three themes enabled me to answer the three research questions that drove my study. Overall, most participants reported their experiences of living with the virus as horrible in the earlier stages due to all the fear surrounding the lack of knowledge, the experience with the earlier drug, as well as the fear of immediate death as they witnessed several of their friends quickly succumb to the infection. They described their lived experiences as a daily survivorship between self-education, self-advocacy, and various challenges that develop overtime. Finally, they described their challenges of living with HIV and the comorbidities that develop as a constant struggle. In fact, besides having to stay on top of their medication, they also have to adjust day by day to the series of side effects that develop. Moreover, some had to adjust to being forced into disability before their time because of their non-properly responding body, a body supposedly young enough to carry them yet too weakened by the virus and/or the medication treating it. The lives of these survivors today are described as merely existing; existing in a world where they have lost their appearance overtime, their self-esteem, and now slowly losing their memory yet, still fighting for better days ahead.

In the next chapter, I will concisely summarize the findings before sharing the interpretations of the results, discussing the limitations of the study, recommendations for future research, implications for social change, as well as an overall conclusion of the study.

# Chapter 5: Discussion, Conclusions, and Recommendations

The purpose of this qualitative phenomenological study was to explore the lived experiences of participants 50 years old or older living with HIV and comorbidities to gain an understanding of the challenges they face, providing information that can improve their quality of life. After review and analysis of the collected data, three themes emerged: ‘from fear of the unknown to ownership,’ ‘from ownership to survival,’ and ‘the constant struggle of surviving with HIV.’ These themes were used to respectively answer the three research questions that drove my study. Overall, most participants described their 20 to 30-year experience as fearful in the early onset of the diagnosis followed by a period of acceptance, self-education, and self-advocacy to overcome the challenges that came to light overtime. Despite the constant struggles they face, participants described their journey as that of daily survivorship. To that effect, P3 stated, “I’m surprised every day. Every morning my first prayer is thank you God for another day. Every day. So, it’s just wonderful.” In the following chapter, I will address the key findings of the study, the interpretation of those findings, the limitations of the study, recommendations, implications for social change, as well as an overall conclusion.

## Interpretation of the Findings

### What are the Experiences of People Living with the Virus?

Participants shared their experiences of living with the virus as one filled with ups and downs and with higher incidence of side effects in form of comorbidities. These experiences confirm findings of Rueda et al. (2014) that the older population living with

HIV is prone to comorbidities. Additionally, some participants shared their frustration in attempting to acquire ART after their initial anger or denial phase as well as the battle between their body and the medication; however, they had a strong will to follow through with the treatment to live as long and as healthy as possible. To that effect, depending on participants' respective years of diagnosis, they reported surviving 20 to 30 years with a virus they were originally speculated to succumb to in at most 5 years if that. This confirms the findings of Samji et al. (2013) that if diagnosed and placed on ART early on, HIV patients are expected to live up to 70 years old.

## How do People 50+ Describe their Experiences with HIV?

Participants described their experiences as multifaceted from diving into self-educating, to struggling with fear of rejection from societal support, to isolation, and to developing somewhat of a partnership with their respective clinicians. In accepting their diagnosis, some participants decided to share that diagnosis with their societal "support" despite fearing rejection. This societal support varied from immediate family or partner, to friends/co-workers, to society via support groups. Unfortunately, some reported experiencing episodes of depression as well as stigma early after being diagnosed. This confirms the findings of Brennan et al. (2011) that this population may be affected by depression. Some of my participants reported experiencing solitude which led to depression due to moving into a newer community in which they were no longer surrounded by their peers. They lacked the support they needed from individuals sharing a similar sexual life choice and/or fighting the same virus. For instance, P6 shared, "I am lonely, you know, one thing that would really have to change would be to have more gay people around or to make it easier to meet people, because I think that diminishes the quality of life." This confirms the findings of Sankar et al. (2011) that while 25% of baby boomer HIV patients were moderately depressed due to overall poor physical health and lack of social support; 39% could be diagnosed with major depressive symptoms due to isolation (Sankar et al., 2011).

Additionally, some participants emphasized that they tend to be more isolated as they age for various reasons, confirming the findings of Liu et al. (2014) that social interactions among older HIV patients were lower than their counterparts. Some reported isolation as a self-choice because most to all of their friends succumbed to HIV infection. To that effect, P8 stated, "in many ways my original circle of friends as an adult are probably three-quarters gone." Others are simply choosing solitude rather than experiencing rejection for being positive and not initially disclosing it or for simply being positive. To that effect P4 stated,

> it is isolating. HIV tends to isolate people. Not always, but it can. You just want to be with yourself. Because like if you meet somebody nice, you didn't tell them you were HIV positive from the get go, there is going to be a problem. But there is a problem. The problem is if you tell somebody you're HIV, they don't want anything to do with you. You are damned if you do. You're damned if you don't. Then, why bother? Why bother?

Despite feeling isolated, most participants reported a good relationship as partnership with their HIV clinician; however, these clinicians were mostly regular clinicians or infectious disease clinicians as opposed to specialized HIV clinicians. As P2 stated,

> the doctors and it even sometimes applies to infectious disease docs, they don’t treat a tremendous number of HIV positive patients. So, they may not have a tremendous understanding of the processes by which the body reacts to your long-term HIV infection

To that effect, P10 added,

> there’s a lot of worry about the side effects. Every pill I take has a side effect. I have to be very careful. I can’t take calcium with one of the HIV meds. I can’t take steroids with one of the HIV meds. I don’t think the hospital doctors knew enough, because they put me on steroids, and they weren’t supposed to put me on steroids. So, I’m suffering severe side effects the last two months with that. And I also have to educate some of the doctors in the ERs or in the hospital and say no to certain medications.

This confirms the findings of Patel et al. (2016) that non-HIV specialists may not be as familiar with side effects and cross interactions of specific HIV medication with medication used to treat chronic diseases or side effects. This suggests that patients being initially treated and followed by HIV specialists are more likely to have a better prognosis than those being treated by generalists. Nonetheless, HIV healthcare services are important to meet the need of the growing HIV population (Patel et al., 2016). Patel et al. also addressed a high incidence of HIV-infected patients with multiple untreated comorbidities, which they attributed to the use of clinics not equipped with properly trained HIV personnel. To that effect P2 stated, “the doctors don’t treat a tremendous number of HIV positive patients. So, sometimes I end up being the teacher if you will, to providers.”

Moreover, Cahil and Valadez (2013) shared that there is a major lack of proper system to care for infected HIV patients 50 years old or older . Some participants reported lack of proper care such as with the side effects they develop or the battle with their respective insurers for various medications and/or procedures. To that effect, P8 stated,

> even having Medicare D and Medicaid in addition to that, having to appeal so many things that my Medicare D carrier has said, well, you can’t have that is a struggle. And having to go through an appeal process repeatedly to actually get medication that was appropriate to me is difficult. I was having muscle cramps. I still have a problem with that. And all of the medications that they kept insisting, no, take this instead, were directly counter indicated with my other medications. So that’s just a constant battle to keep the proper prescriptions flowing to the extent possible.

Some findings contradicted research I found in the literature review. Mugavero et al. (2013) and Patel et al. (2016) suggested that half of baby boomers lack access to HIV care while others fail to be retained for follow up. However, all participants reported having access to basic HIV care as well as good follow up and retention, despite the fact that their respective insurance carriers caused difficulty in seeing specialists to treat their comorbidities.

### How do People 50+ Describe the Challenges of Comorbidities?

Participants described their experience of living with the virus and comorbidities as a constant struggle, making it difficult for them to get around and enjoy a normal life. This confirms the findings of Rueda et al. (2014) that for older HIV patients, the multimorbidity was coupled with decreased physical functioning. My analysis showed that the longer participants had lived with the virus and the longer they had been on at least one ART, the more they experienced a major impact on their physical body such as fatigue or lack of stamina, making it challenging for them to get around. Oursler et al. (2011) confirmed this in reporting a significant decline of physical function among HIV patients older than 55 years ($p < 0.001$) as opposed to their counterparts who were not infected. On the same note, Patel et al. (2016) showed that years living with the virus and use of ART were significant predictors of onset of comorbidities among older HIV patients.

Participants reported that being on ART did prolong their life, however, it also increased their onset and incidence of comorbidities over the years. This is in line with findings of Vince et al. (2011) and Kim et al. (2012) that the longer this population lives with HIV, the longer their list of medications to treat their comorbidities. My analysis showed that early onset of comorbidities is not so much due to old age but more so to long-term usage of ART and living for a long time with the inflammatory process of HIV. Rueda et al. (2014) and Negin, Martiniuk et al. (2012) noted a higher onset of comorbidities and its number among this aging population on ART as opposed to those not on ART. Rueda et al added that at least 94% of HIV-infected older patients on ART presented with at least one comorbidity, with the majority presenting with at least three; which is consistent with findings among my participants. Negin, Martiniuk et al. and Deeks et al. (2013) also reported a similar increase. In other words, being on ART for an extended period of time is a major risk factor for early onset of chronic diseases as well as both multimorbidity and the challenges that come with it.

Some of my findings contradicted the research in my literature review. Liu et al. (2014) reported that the older the HIV patient was, the lower the level of well-being, the higher the level of depression, and the poorer the quality of life; which they attributed to low physical health and ongoing psychological challenges (Liu et al., 2014). However, I found that although some participants reported experiencing the above at one point or another, it was more so due to the number of years living with the virus, hence the effect of both longer-term inflammatory process of the virus and usage of ART on their body as opposed to their being or getting older.

**Social Constructivism**. Using this framework by Berger and Luekmann (1966) enabled me to understand the phenomenon at hand, notably, the lived experiences and daily challenges of people 50+ living with HIV from their own perspectives as they age with the virus. Common challenges were among participants were the lack of sufficient specialized HIV providers despite getting good care from the self-proclaimed HIV clinicians. P2 stated,

> I go to the infectious disease clinic. In the VA system they have no HIV specialists and they don’t treat a tremendous number of HIV positive patients. So, they may not have a tremendous understanding of the processes by which the body reacts to your long-term HIV infection. So, sometimes I end up being the teacher to providers, even occasionally to the infectious disease docs that I’ve had over the years. Because I’ve got specialized education that they haven’t had, you know they were educated as generalized infectious disease docs, not HIV docs

P4 stated,

> My doctor is really good. He trains doctors. Then, he has new doctors come in, they talk to me and I train them along with some of his other patients. Also, I have gone through so many HIV case managers. Some of them are wonderful. Some of them are idiots. Some of them don’t know what they're doing. Some of them shouldn’t be doing it.

Additionally, other participants shared the shortage of gynecologists treating or specialized in HIV women care; hence, they face a in finding someone qualified enough to address their concerns of aging with HIV while going through menopause. To that regard, P5 stated, “None of the gynecologists know anything about women necessarily. That’s the thing the women talk about in some of our groups. We don’t know what is affecting us. Is it just menopause? Or, is it HIV that is affecting us?” The above clearly shows that despite their efforts at providing care for this population, providers still lack the necessary knowledge. It is important for providers to be knowledgeable on poly-pharmacy and various interactions among such medications and the process by which the body reacts to long-term infection. This stresses the need for specialized HIV clinicians that could address the current and pressing concerns of this population.

Another aspect participants pointed out was in regard to isolation. Some mentioned the need for more activities: “it is isolating. HIV, it tends to isolate people. Not always, but it can. You just want to be with yourself” (P4). P1 added,

> we tend to isolate more as we age . . . I wish there were more social things like, you know, a lot of people, because they’re living on such a fixed income, can’t afford to go to like a show or even a movie. If they could take us to a movie or something, it would be nice.

Finally, P10 stated, “It’s just easier to be by myself. I guess I have fallen into a routine the last few years of you know I have my dog and that’s all I need. You know I really, I guess it’s not easy making new friends.”

**Advocacy Worldview**. Using this framework by Heron and Reason (1997) enabled me to understand and improve the health conditions of my participants. To do so, I listened to their shared experiences and more importantly their current needs, which could be used to contributing to policy changes and designing of appropriate programs. Brennen et al. (2011), Patel et al. (2016), and Cahil et al. (2013) reported the lack of policies addressing the needs and/or issues of the aging HIV patient due to lack of knowledge surrounding their needs, stressing that such knowledge could improve their current quality of life. Participants raised some concerns and needs of today such as current needs for specialized HIV clinicians better equipped to grasp how their bodies react to the series of medication overtime or how their body ages on ART while tackling menopause for instance. They also shared needs for more activities to reduce the isolation that they face.

Participants also shared their needs for policies that would enable them to obtain adequate medical coverage to treat the side effects of being on ART for so long and aging with the disease. For instance, they stressed the need for basic dental coverage, which affects their appearance and self-esteem. Some participants mentioned that such preventive coverage is not available:

> Medicare still does not offer preventive dental coverage, except for emergency extractions, and even that's very limited. So, at this point, after years of just not having access to anything, I had a bunch of teeth that rotted out and have now had to be extracted. (P8)

P7 stated,

> In treating people with HIV, we have to find a way to help people keep their teeth, and to keep their smile, and to not show the signs on your face. Because it's like if I'm walking down the street, most people don't think that's a gay guy. But, because of were the teeth were, and my face- the lipo-atrophy, I look sick. People would go, 'He must be…,' Do you know what I mean? But, there should be some

> level of preventative dentistry. Because you can't go through life—you're just already defeated before you even step out the door if you don't have a smile, if you don't have the teeth.

Additionally, participants stressed the need for access or coverage to sculptra treatments for lipo-dystrophy and lipo-atrophy. Participants like P8 shared,

> it has gotten more difficult to get sculptural treatment as of a couple of years ago. At one point, you could get the facial filler material through the program on a sliding scale based on income. Now, the reimbursement rate is so low that there are no doctors who will accept Medicare for that. So, it's effectively not available. Also, if you have any insurance, they won't give you the material. You have to try to battle it out with your insurance company.

## Limitations of the Study

In my study, I included participants who were 50 years old or older, had lived with HIV for at least 20 years, were on at least one ART, and had at least one comorbidity to explore their experiences of living with HIV and the challenges that develop overtime. Since I used a phenomenological approach, one limitation is that my findings cannot be generalized to a population group that does not share the phenomenon in question (Shenton, 2004). Additionally, I used 10 participants in my study and because of this adequate yet small sample size, the overall study results might not be generalizable to a larger population even sharing the same phenomenon in question (Anderson, 2010). In fact, the experiences and challenges gathered from the participants throughout the interview might not reflect that of the entire population living with the phenomenon even with similar backgrounds. The last limitation noted was the fact that only 20% of my participants were female, hence minority, as opposed to their male counterpart.

## Recommendations

As stated in previous paragraphs, I used a phenomenological approach to explore the lived experiences of 20-30 year-old HIV survivors. Hence, the findings cannot be generalized to a larger population. Nonetheless, based on my findings, additional studies, noted below, could be conducted to uncover additional knowledge that could benefit this population.

- A mixed study exploring the experiences of menopausal women aging with HIV and the challenges that develop, as well as the relationship between aging with the virus and early onset of menopause.
- A qualitative study exploring the experiences of steroid use among long-term HIV patients on ART treatment.
- A comparative study on the effect of steroid use on short-term HIV patient on ART treatment versus long-term HIV patients on ART treatment.
- A comparative study assessing the relationship between long-term HIV infection and decreased sexual drive between male and female.
- A qualitative study exploring the effects of long-term HIV infection on sexual drive on loving relationships.

- A quantitative study assessing the relationship between aging with HIV and early onset of isolation.
- A quantitative study assessing the correlation between aging with HIV while on ART and early onset of disability.
- A quantitative study assessing the correlation between HIV long-term survivors and early onset PTSD.
- A quantitative study assessing the incidence of early onset of memory loss among HIV long-term survivors.
- A mixed longitudinal study exploring the experiences of ART use among long-term HIV survivors; and comparison/contrast of the side effects of similar ART dosages between males and females.
- A comparative study assessing differences in long-term prognosis between long-term HIV patients followed by HIV specialized clinicians versus non-specialized clinicians.

## Implications

I recommend that positive social change in the lives of people 50 years and older living with HIV start with mutual trust and respect between this population and their health care associates, notably HIV clinicians, HIV nurses, and HIV case workers. Researchers who are the voice of these participants in providing their gathered information and stakeholders who could use the collected data to outline and implement specific policies could also contribute to effective social change. Through my study, I was able to uncover and get a better understanding of the challenges $HIV^+$ participants face, as well as their daily experiences of living with HIV and comorbidities that develop. Using the reported data, other scientists could frame additional research questions for further studies, to expand even more the current body of knowledge in order to improve the quality of life of this population. Additionally, the healthcare associates, first in line in hearing the challenges and needs of the patients, should work closely with stakeholders and insurers to develop policies that would improve for instance their appearance and thus self-esteem, by ensuring they at least obtain basic preventive dental coverage under their insurance, which would enable them to access services not solely limited to emergency extractions. Moreover, healthcare associates and stakeholders should work with manufacturers and insurance companies in developing a sliding scale that could enable them to afford sculptra treatment, both procedure and injection material, based on their income.

Moreover, community programs ought to develop appropriate social activities to keep this population as occupied and active as possible as they tend to isolate more as they age as this could possibly lead to depression. To that effect, P1 stated,

> I think a lot of people that are considered long-term survivors like twenty-plus years maybe or even ten plus years feel that they are being put on the back burner, they start isolating themselves. I mean I attend a support group even though sometimes they repeat the same presentations over and over I go for the emotional support and the socialization.

Healthcare associates should then work with HIV programs and stakeholders in developing more activities for this aging HIV population already living on a fixed income, to get them out of solitude and thus depression. Similar to the Meals on wheels system used for our elderly population, HIV programs could develop and implement a sort of *Friends on Wheels* program for those who are too weak to leave their house. The latter could be beneficial for them just to have on a weekly basis someone to talk to, play a game of checkers, or even take a walk to the park with when they physically feel somewhat better.

However, for those like P4 who stated,

> the older I get, the more I tend to dislike human beings. I tend to want to isolate and not be around people. That's something I really struggle, because people can be jerks. I socialize on social media. I need to socialize more to have a better balance.

Or P10 who noted, “I guess I spend a lot of time in bed. The exhaustion is a key piece, so that causes a lot of isolation,” developing a sort of *Friends on Line* program might be a better way for them to socialize. Depending on the preference of the participant, this could vary from a simple weekly telephone call, to an internet video call, to an internet chat conversation for those still reluctant to the face-to-face aspect or still working towards it. I think it could be more impactful to once in a while have a team of volunteers, for either program, that are themselves HIV survivors or even newly diagnosed. That way, because they have been through or are going through similar challenges, the recipient might be more receptive to opening up to someone that may have a better understanding of what they are currently experiencing. Additionally, if the volunteer is newly diagnosed, the recipient might even find meaning in sharing his/her experience thus impacting someone else while forgetting his/her own struggle for a moment. On the other hand, other participants might simply prefer a *Friend on Wheels* or a *Friend on Line* that is not living with the virus because as P1 stated, “sometimes it gets old talking about HIV all the time.”

The information gathered from participants will be shared with stakeholders, HIV programs, and clinicians so they can better address those needs to promote better care for this population. Negin, Mills et al. (2012) showed that the incidence of HIV infected baby boomers is expected to nearly double, from 9% to 17% by the year 2040 (Negin, Mills et al., 2012). Deeks et al. (2013) similarly outlined the above, estimating that the number of infected HIV long-term survivors would triple to 9 million by 2040 (Deeks et al., 2013). As such, there is a crucial need to closely follow the health span of this population to identify any potential complications that may arise to address them in a timely fashion. To better assist this population as they continue to age with the virus, necessary steps ought to be taken for healthcare associates to grasp a better understanding of their daily challenges and needs, and thus reduce that burden. It is essential that the front line, notably the healthcare associates develop trust and partnership with the patient so they could easily open up to them and share their true challenges and/or needs upon onset. Also, it would be essential for the team of healthcare associates to meet periodically and brainstorm on how to better serve that population as well as how to better advocate for them via stakeholders.

Additionally, despite them aging with HIV, which seem to take precedence over their overall health, the team of healthcare associates ought to stress the utmost importance of yearly physical exams with their regular physician, thus encouraging that follow through so that for instance women do not skip out on their mammogram and men on their prostate exams. To that effect, P1 shared, “I very rarely—I mean, I should go for a PAP smear every couple of years, just you know, and I haven’t in a while. I recently just had my mammogram, which I hadn’t done in four years.”

In regards to being cared for by non-specialized HIV clinicians, P2 stated,

> there’s not enough of us and docs generally speaking don’t have enough time to investigate—I mean you think about all of the patients that they have and they’re not HIV docs—even the infectious disease docs for that matter are not specialized or solely treating HIV, so even they don’t have enough time to read the research—often it’s reliant upon a pharmacist or somebody else in the peripheral healthcare to make suggestions, rather than the providers themselves.

P5 added, “there is no gynecologist who sees an abundance of women with a HIV. There is no specialty gynecologists for women. None of the gynecologists know anything about women, menopause, and HIV necessarily.” Lastly, P10 stated, “I have to educate some of the doctors in the ERs or in the hospital.” Based of the above it is clear that participants are crying out for specialized HIV providers. As such, the team of healthcare associates should work with HIV programs and stakeholders in framing policies and providing funding so that, clinicians interested in caring for HIV patients, may acquire additional specialized HIV education, attend infectious disease Continued Medical Education (CME) conferences on current HIV topics; but also, take the time to follow the research and seek understanding of the side effects and interactions between various ART used to treat them.

Being that HIV clearly affects both males and females, pharmacists, emergency room clinicians or at least infectious disease clinicians seeing HIV patients in the emergency room settings, and gynecologists ought to also get current specialized HIV education if interested in treating that population. Moreover, guidelines could be developed to prevent clinicians not treating a designated amount of HIV patients on a yearly basis to take them on as patients. Specific guidelines should be developed by the team, stakeholders, and insurance companies to allow HIV patients to choose a specialized HIV clinician if the ones in their insurance network are not HIV specialized, and as such not equipped to treat them appropriately. Lastly, stakeholders and HIV programs should work with drug companies to offer periodic teachings on side effects and interactions of their approved HIV drugs not only to clinicians but also to insurance companies. The latter could be key in preventing the constant battle between insurers and patients attempting to avoid being forced to solely acquire a medication they know counteract severely with their current HIV regimen simply because it might be cheaper for the insurer.

In regard to follow up appointments for their HIV care, the team should work with HIV programs to implement a reminder phone call or text message especially for this aging group. In fact, some participants did report noticing memory loss as they are progressively aging with the virus. Although they understand how crucial their HIV follow up appointments are and are strongly against missing them, one cannot control the forgetful mind. For instance, P1 stated, “I mean occasionally because of my memory loss I forget, I always ask them to give me a reminder call, but for the most part I am pretty on it.”  And P8 added, “I am having issues with memory and concentration. I just feel like I’m inappropriate to my age.” Memory loss is clearly becoming an issue for long-term survivors; as such, reminder calls or texts could be essential in ensuring they do not miss these crucial appointments.

Overall and as stated above, these long-term survivors shared the impact of HIV on their daily lives, their feeling of being somewhat forgotten by this society, their need for activities that would create opportunities for them to socialize more, and their need for access to care to improve their physical appearance. Additionally, they shared their struggle to survive in this increasingly expensive society on low income, as P7 stated,

> Physically I can’t work more, and the other situation is that if I make one more dollar then I lose all my Medicare, I lose all my medication, and I can’t live like that. So, in that respect the biggest side effect is that we’re prisoners of our benefits and prisoners of what we need to survive.

Finally, they shared their fear of tomorrow in this same society still lacking accommodations for those on the verge of losing their independence or those without enough savings to retire. For example, P6 stated,

> I suppose that the challenge that’s playing on my mind quite a bit right now would be the vision and the thought process of losing my driver’s license, and that will just be horrifying. Not to be too dramatic, but that loss of independence at this age – I’m only 63.

And P8 stated,

> the impact of HIV and having been out of work for so long and been on disability and living barely above the poverty line is that at this point, while most of my friends have - own property and talk about retirement plans and 401Ks and things like that, I have no savings, no property, no retirement plan other than eventually I will go back on Social Security, either by disability or by actually retiring. But with no assets and no pension, no retirement savings, I’m hoping to be able to at least save something now that I am returning to work at 51. We’ll see how long I can continue working, but it’s a rather scary proposition.

Specifically, if implemented, the recommendations of my study could directly impact long term HIV survivors struggling in a world where they have outlived most of their friends and are somewhat rejected by a community of their own. For instance, if proper access to care and procedures is made available to them, this could allow them to continue living in lieu of simply existing, reclaiming their self-esteem while giving them a better incentive to step out of their secluded shell with confidence. Additionally, if suggested programs are put in place, this could enable them to create new bonds, socialize more, and eventually embrace the outside world thus reducing any possibility of falling into depression. Also, with the majority of people “forced” into disability because of the effects of the virus, or for those still struggling to maintain employment and thus adequate housing, framing proper guidelines that would ensure they obtain some sort of housing and nutrition assistance, could positively impact their lives. In fact, as P8 stated “when you're not sure where you next meal is coming from, your doctor’s appointment two weeks from now might not be your first priority”.

Finally, the study could also have a positive impact on the next generation of newly diagnosed individuals. P8 stated,

> With the younger newly diagnosed folks, 18 to 25 or even 18 to 30, they generally have no experience of having to take medication on a regular basis. No experience of having to engage in healthcare on a regular basis. Plus, they have no memory of how devastating HIV was. They never went to funerals two and three times a week the way that folks my age or just a little bit older than me did. They never watched friends die around them. So, getting them to understand the seriousness of the diagnosis and getting them to - having to grasp, mentally, at the age of 21 that you’re gonna have to take medication for the whole rest of your life and you really can’t miss any dosages, is a pretty difficult thing to struggle with. And they frequently don’t have any kind of insurance coverage. It they do, it’s often under

> their parent’s insurance whom they don’t want to be receiving statements or bills from the insurance company for HIV medication.

Although this generation no longer has to face HIV as a death sentence, not only do they have to grasp the seriousness of their diagnosis, they are currently living in a society where there is of yet no available facilities to care for those aging with the virus and not enough specialized providers to address their HIV associated chronic conditions to cite a few. Despite the plethora of shared experiences from long-term survivors, as stakeholders work on better aging days for those living with the virus, this newer generation could benefit from mentorship from these long-term survivors, as well as guidance towards a brighter future. As P4 stated, “You go towards it. You embrace it. You deal with it. You don't walk away from it. You have to run towards it, and deal with it in a proactive way versus just sitting back.” Lastly, key information obtained through these long-term survivors could be used to shape guidelines that could improve the current and future lives of newly diagnosed patients.

## Conclusion

This study was conducted to assess the living experiences of HIV-positive participants 50 years and older living and aging with the virus. To gather data, I conducted recorded telephones interviews with ten participants, which I later transcribed, prior to analyzing the data using Nvivo 11 software. The latter analysis led to three themes, which enabled me to grasp a more detailed understanding of the daily life experiences of these participants as well as their true needs. For the most part, participants described that upon freshly being diagnosed, they went from fear, to anger or denial, to a state of acceptance. Additionally, the majority described a series of challenges to constant survivorship as they continued on their journey. The latter journey has been met with daily struggles and unmet needs. In fact, most participants not only outlined their needs of today, more importantly they also shared their uncertainties of tomorrow. To that effect, some participants, in the wake of their body weakening overtime from the long-term effect of both the virus and ART, shared their fear of losing their independence before their time whether it be through disability as a direct result of HIV for instance or as P5 stated, through "aging and surviving with the virus in a society on low income." On another note, some participants shared their fear of aging out with the virus in a society that does not yet have available assisted living facilities for their population group. For instance, P8 stated,

> looking forward I'm scared because you know I'm apprehensive about the availability of care, the availability of living arrangements and you know eventually, an assisted living facility or I suppose a nursing home. There are as yet no accommodations, there's nothing that has been yet developed to address the needs of people living with HIV in those environments.

It is imperative that additional research be conducted to ensure that this population does not age and face these challenges alone, as they felt when their journey began. On the contrary, the medical and scientific body in collaboration with stakeholders ought to work together to address their needs outlined in this study and to uncover additional ones they might have, to ensure that the challenges they once faced when HIV was a death sentence do not resurface, and that they do not become prisoners of the now chronic disease. As much as they can advocate for themselves, we can also be their voice, we have to work together in ensuring their time spent on Earth is memorable and enjoyable in the outdoors rather than in solitude, behind closed doors, in fear of today and worry of tomorrow. As these survivors are fighting and holding out hope, we must continue to fight with them and for them, we must continue the quest for a cure. Because as P8 stated, "an HIV cure would be nice to improve my quality of life" and P2 added, "if somebody had a magic wand and could take HIV away from me, yeah, I mean that would be great."

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