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Exploring Barriers to Care: Provider Efforts to Improve Retention in Urban-Rural Clusters

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Abstract

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MS, Walden University, 2016

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Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Human & Social Services- Public Health specialization

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Abstract

Over the years, the infection rates for HIV in the United States has changed partly due to lack of engagement and medication adherence which can lead to substantial declines in individual health. Factors that contribute to the individual's adherence can include transportation cost, childcare, and lack of finances to name a few. These barriers can often be decreased with the help of supportive service providers and improvement in the patient-provider relationship. Currently, there is limited research that explores how to reduce patient barriers to care, specifically in rural areas. This qualitative study examines how Illinois health care providers help HIV-positive women overcome barriers to adherence by using the Andersen's behavioral model. The purpose of this qualitative study was to explore the barriers and challenges healthcare practitioners consider when providing care to HIV-positive women. I performed a qualitative data collection via emailed surveys from practitioners using a snowball method. The participants had to work with women, or female identified, patients who resided within Cook County or the collar counties of Illinois and be linked to care. The data was analyzed by using NVivo revealed that barriers identified in 2013 had a significant reduction in some geographical areas. The results also revealed that for women heterosexual transmission account for the largest route of transmission however transgender and MSM still have the most unmet needs and lower adherence and retention rates. The findings from this research might contribute to the efforts of current and future researchers, to inform and develop awareness to the many people living with HIV/AIDS.

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Dedication

This dissertation is dedicated to the many people that may use this topic for future research. To the many people who work in the fields of human and social services that desire to contribute to the fixing of systems to improve services and care continuums. I would also like to dedicate this dissertation to my deceased grandmother, Isabelle Perkins, who taught me as a little girl to live out my dreams and keep helping those less fortunate since I had a passion for helping people. My best friend, Medgine, who was the perfect voice of reason during our struggles and concerns, my husband Charles, my aunt Linda, and my grandpa Louis, all deceased, and whom I lost during this dissertation journey. I remember the time that I had to take a break from school due to my overwhelming emotions related to their deaths. I know you all would have told me to keep going no matter what and that you were there in spirit. I would also like to dedicate this dissertation to all those living with HIV/AIDS and working through the obstacles faced with surviving each day. Last but not least, to those individuals who lost their lives during my research to an expected pandemic of COVID-19.

Acknowledgments

I would like first to acknowledge God, who has given me the strength and sanity to endure this journey. There were many nights of prayer for clarity and continued motivation, as well as those days that I wanted to give up. I would also like to thank my parents, who did not understand this lengthy process, yet supported my journey. To my besties, Kesha, Marilen, Medgine, and Shakeyla, who had to endure my frustrations, losses, and successes during this process, I love you all. Thank you all for your tireless support and encouragement during this process. To Monica, my sounding board, where would I be without you? To Jessica I would still be figuring it all out if it was not for your continued support and flexibility. I would also like to thank everyone else who stuck with me during this tedious process, as the only thing that was certain was the end. Lastly, I would like to thank Dr. Awanda Jones, Chicago State University, for encouraging me in undergrad to go all the way to the top. Dr. Jones said, “It is not many of us African American, yet alone females, with doctorates, so never let anyone tell you that you cannot obtain it.” My dedication to research is best summarized as,

> Thus, my whole life of acts– experiencing, thinking, valuing, etc. – remains, and indeed flows on; but what was before my eyes in that life as ‘the’ world having being and validity for me, has become a mere ‘phenomenon’ and this in respect to all determination proper to it. (Husserl, 1970, p. 77/8)

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Chapter 1: Introduction to the Study

Introduction

According to the Center for Disease Control and Prevention (CDC), less than half of the people living with HIV/AIDS are linked to and are retained in care (Holtzman et al., 2015). The National HIV/AIDS strategy had four critical goals, three of these goals will support improving retention and adherence in the United States HIV/AIDS care (The White House, 2015). Retention in HIV is defined as medical care that has been provided at least twice within a calendar year (Bumphus-Corbin, 2017). Adherence refers to the person following the suggested regimen of care as it related to one's HIV/AIDS status (Bumphus-Corbin, 2017). The National HIV/AIDS strategy goals were (a) reducing new infections, (b) improving health care access and outcomes, and (c) reducing health disparities; all of which will increase the survival rate and decrease HIV transmission (The White House, 2015). In the United States, women accounted for 19% of new HIV diagnoses totals in 2016, and 24% of the 18,160 AIDS diagnoses in 2016 (CDC, 2018a, p. 1). Like other chronic medical issues, HIV/AIDS requires additional social and psychological support to increase the individual's longevity of life (Gonzalez et al., 2004).

Individuals in rural areas are more likely to be diagnosed with late-stage HIV infection and avoid health care centers due to stigma (Nelson et al., 2018). Upon an individual being diagnosed as HIV-positive, there are several steps along the care continuum that must be completed in order to benefit from HIV care. These steps include HIV testing and diagnosis, linkage to and retention in HIV primary care, and delivery and adherence of antiretroviral therapy (Yehia et al., 2015). However, in rural areas of the United States, the recommended steps of care are not always followed. Individuals in rural areas often have fewer resources and access to services than people living in metropolitan or non-rural areas (Nelson et al., 2018). In addition to the lack of resources and access to services, other barriers interrupt the care continuum. The barriers that I explored in this study were access to transportation, childcare challenges, stigma, lack of family support, and lack of healthcare providers/facilities.

The HIV care continuum has been used since 2011 to measure the progress of HIV care in the United States (Nelson et al., 2018). Despite the HIV care continuum recommendations, there is still no documented standard HIV care model. Health inequities vary, in addition to comorbidities, thus allowing for significant differences in the care outcomes of people living with HIV/AIDS (PLWHA) in the United States (Nelson et al., 2018). In 2017, there were 223 rural health clinics in Illinois (CMS, 2017a). Federally qualified health centers (FQHCs) provided services at 413 sites within the State of Illinois and served over one million individuals (CMS, 2017a). Although these numbers appear large, there are still disadvantages, including employee to patient ratio, access to clinics, the specialty of services, and funding sources available. Without proper considerations of services provided, individuals who are seropositive are faced with increased barriers to care.

Background

Understanding how to utilize various approaches to communicate necessary information to PLWHA has become a critical component related to prevention and care.

The approaches can be a single universal approach or multiple integrated approaches. Airhihenbuwa and Obregon (2000) identified that past research on communication has typically focused on implementing strategies into theory rather than allowing for the experiences to shape and develop its framework. Many of the models and theories used in the past to engage PLWHA have been the health belief model (HBM), reasoned action, social cognitive, diffusion of innovation, and social marketing (Airhihenbuwa & Obregon, 2000).

Rural American healthcare options often look different compared to urban areas (Schafer et al., 2017). A number of researchers have provided different perspectives of health models—e.g., health promotion model (HPM), behavioral model of health (BMH)—used in HIV care and how appropriate and effective the level of care is to an individual's adherence (e.g., Airhihenbuwa & Obregon, 2000; Chu & Selwyn, 2011; Dailey et al., 2017; Ng & Caires, 2016; Petersen, Hutchings, Shrader, & Brake, 2011; Rodriguez & Dobalian, 2017; Sutton, Anthony, Vila, McLellan-Lemal, & Weidle, 2010). It is being able to determine what a client needs and identify that individual's entry point into care, which is most critical in a person who is living with HIV/AIDS medical journey (Petersen et al., 2011). Upon examining the barriers that impede or prevent retention rates in HIV care, Pellowski (2013), Rodriguez and Dobalian (2017), Sutton et al. (2010), and Trzynka and Erlen (2004) reported the perspective of being an HIV-positive woman in rural America by examining the Vermont model and the Wood model.

The Vermont model evaluated three significant barriers to improve access to care for individuals in rural areas. Researchers Grace et al. (2010) attempted to improve care by mimicking the care provided in urban centers for those in rural areas, which included reducing travel time by distributing clinics with trained HIV specialist widely across rural areas. The Vermont model, studied by Grace et al. (2010), also incorporated social workers to act as case managers, which increased psychosocial support and immediate resources. Lastly, the Vermont model addressed barriers related to lack of knowledge about services by having the implemented clinics serve as coordinators between patients, community services, and regional AIDS Service Organizations (Pellowski, 2013).

The Wood (2008) model, also called the health services clinic model (HSC), distributed comprehensive care to rural areas by including substance abuse treatment into HIV care (Pellowski, 2013). The Wood model identified and addressed 15 of the 27 barriers, including transportation, provider discrimination, lack of trained professionals, and many stigmas associated with late diagnosis of HIV and care (Pellowski, 2013). The Wood model provided improved care in rural areas by having a mobile van for home visits, provided free medications to patients, improved patient-provider relationships, and remained flexible in their scheduling (Pellowski, 2013). Although both of these models incorporated more comprehensive care in rural areas, they also shared weaknesses, such as addressing stigma and sociocultural factors (Pellowski, 2013).

The CDC (2020a, c), and Avert (2019) provided statistics on women and HIV in the United States. Many studies, including those conducted by Pellowski (2013), Shelton et al. (1993), Simoni, Frick, and Huang (2006), Smith, Fisher, Cunningham, and Amico (2012), and Trzynka and Erlen (2004) identified and discussed barriers that created challenges in HIV adherence. The main barriers presented frequently included transportation, access-to-care, and childcare. Chu and Selwyn (2011), Maulsby et al. (2016), and Weismann et al. (2014) discussed changes needed within healthcare organizations for women and HIV. These discussions were meaningful as women also have different needs than men when living with HIV/AIDS. The domestic and international expert's forum discussions helped to identify best practices in HIV/AIDS care at the May 2013 Global Engagement in Care Convening on improving comprehensive care and continuity access to improve comorbidity and mortality rates (Maulsby et al., 2016). When developing comprehensive services for women, they should include quality of life (QOL) issues. The issue of QOL studied by Vyavaharkar et al. (2012) found that the perception of an individual's QOL could impact rural women with HIV significantly, causing a barrier associated with internalized stigma and depression.

Gwadz et al. (2017) and Coleman et al. (2017) examined five intervention components using a multiphase optimization strategy (MOST) that would improve the strategies and services to reduce barriers to HIV care and antiretroviral therapy (ART) initiation. The MOST strategy consists of three phases: preparation, optimization, and evaluation (Gwadz et al., 2017). Gwadz et al. (2017) found that continued research is still needed to optimize and create effective and less cost-effective strategies to support PLWHA. If practitioners consider using multilevel approaches when creating a useful care model for PLWHA, retention may become less problematic, and individuals requiring care may be less reluctant to engage in care.

Problem Statement

HIV has been a global public health issue since 1981 (Avert, 2019). Since 1981 to 2018, there were 3,778,000 women who died from this disease (CDC, 2019c, p. 85, Table 10a). At the end of 2016, an estimated 258,000 women were living with HIV (CDC, 2019a, p. 2), of which, 89% had received a diagnosis, 66% had received HIV medical care, and 51% retained in care (CDC, 2020b, Slide 22).

According to the DPHI (2014, p. 3), Illinois HIV/AIDS epidemiology profile for rural areas of Illinois had approximately 36,064 people living with HIV/AIDS (PLWHA), and women accounted for 47,500 new infections in 2010 (p. 1)**.**

In 2018, an estimated 1,173,900 persons aged ≥13 years were living with HIV, including 161,800 (13.8%) person whose infection had not been diagnosed; the prevalence rate was 427.5 per 100,000 population (CDC, 2020a, p. 40, Table 7); and 85% of heterosexual women accounted for an HIV diagnosis (CDC, 2020a, p. 6). In 2018 alone, the estimated number of new HIV infections was 36,400 with a rate of 13.3, where the rate for males (22.1) was 5 times the rate for females (4.8) (CDC, 2020a, p. 5).

The onset of the HIV/AIDS pandemic has increased the need for specialized social services for everyone who has been impacted by HIV/AIDS in both urban and rural areas (NASW, 2015; Shelton et al., 1993). Social workers have the skills, opportunity, and commitment to engage clients in HIV/AIDS prevention, care, and treatment utilizing a comprehensive bio-psycho-social approach (NASW, 2015). The HIV care continuum requires understanding the gaps in services or policy that may be a barrier to connecting people to care and treatment they need. The HIV care continuum is implementing community-level interventions to develop best practices and policy guidance for HIV positive individuals (NASW, 2015). Sometimes these unmet needs require specialized services, which includes case management, food services, and improved geographical area resources.

The U.S. Department of Health and Human Services identified that social support is a reasonable accommodation for improving health outcomes for PLWHA (Anima-Korang, 2017). With the increase of HIV/AIDS, particularly in heterosexual women, many areas of individuals' health, family lives, and future quality of life have been affected by both beneficial and adverse outcomes (Vyavaharkar et al., 2012). Residing in rural communities while having a seropositive diagnosis often reduces the choices of available Ryan White providers (clinics/facilities that provide HIV services), which are considered safety nets for PLWHA (Weissman et al., 2014). In addition to the lack of facilities, the lack of sufficient medical providers who understand and have the specialty training related to caring for PLWHA delays individuals from getting tested for HIV, obtaining proper medical treatment, and reduces funding made available to these areas (Dailey et al., 2017).

Newly diagnosed HIV cases were compared to the United States HIV rates for women in rural versus urban communities, particularly in the deep South, declined from 19.2% in 2008 to 14.1% in 2014 (Reif, Safley, McAllaster, Wilson, & Whetten, 2017). Overall statistics were down 21% for women across all 50 states and the District of Columbia from 2010-2016 (CDC, 2019a, p. 1). The Illinois Department of Public Health described rural or non-metropolitan districts in Illinois as a population of "fewer than

60,000 people" (Illinois Department of Public Health [IDPH], 2016a, p. 1). The most significant number of those infected are consistently identified as being in the Southern rural areas and are African American, of lower socioeconomic status, and at risk of acquiring HIV through sexual contact (Reif et al., 2014). Supportive services are imperative as access to care in rural areas often presents a challenge or barrier to care (Anima-Korang, 2017). According to Simoni et al. (2006), social support is vital as there is a direct correlation between an individual's mental health, physical health, and patient-physician relationships.

Significant obstacles include systemic and individual barriers, such as homelessness, accessing transportation, finding childcare, stigma, lack of family support, lack of providers and facilities, patient refusal, concerns related to confidentiality, stress, missing work, and poverty (Abbott & Williams, 2015; Rodriguez & Dobalian, 2017). From 1981 until now, HIV has transitioned from an acute terminal illness to a chronic illness that can be controlled and managed with the proper help (Vyavaharkar et al., 2007). Early detection and continuation of HIV care are critical in achieving optimal viral suppression, which is necessary to reduce the transmission of the virus (National Rural Health Association [NRHA], 2014). The data currently suggest that rural women are at higher risk for nonadherence and poor retention, which increases the possibilities of comorbidities and mortality rates (Mignano, 2016).

Although the previous research regarding how living in a rural area impacts the continuum of care for people living with HIV/AIDS illuminates essential findings, the literature review produced no research on how medical personnel help reduce the barriers that interfere with treatment adherence through the use of traditional or alternative models. However, there was research supporting how practitioners and Ryan White providers differ in providing HIV care and are disproportionately located in urban areas (NRHA, 2014). Further investigation is warranted to examine and verify that no standard healthcare regimen is being used in urban-rural cluster areas to decrease the barriers that women experience when seeking medical care for HIV/AIDS. Very little has been published about the current models of care development (HIV/AIDS-dedicated treatment and traditional consultative models, which are a primary care physicians' referral to an off-site specialist), and effect on HIV treatment; however, there is still a need to improve retention and care efforts (Krebs et al., 2018). The HIV/AIDS dedicated treatment, and traditional consultative models are the primary care physicians' referral to an off-site specialist. Although a medical cure for HIV/AIDS has not been identified, long-term care and adherence to medication regimens are crucial to achieving viral suppression, which can extend the life expectancy of women with HIV.

Purpose

The purpose of this qualitative study was to explore the barriers and challenges healthcare practitioners consider when providing care to HIV-positive women. The specific barriers that I explored were patients' access, transportation issues, childcare issues, stigma, lack of family support, and lack of providers and facilities. Past studies examined the association between social support and HIV treatment adherence (Vyavaharkar et al., 2007). HIV care also varies and can have different engagement points ranging from the initial diagnosis to being fully engaged in care (Williams, Amico,

& Konkle-Parker, 2011). HIV/AIDS is a complex disease that requires comprehensive and flexible care to be most effective (Mosack et al., 2016). People living with HIV/AIDS are advised to take antiretroviral therapy medications consistently to maintain better health, which includes preventing treatment resistance, control of symptoms, and managing their viral load to reduce transmission opportunities (Cook, Schmiege, Starr, Carrington, & Bradley-Springer, 2017).

The exploration of empirical research articles regarding patient-provider relationships and interviews determined that healthcare practices being used seldom produce positive adherence rates within rural communities; however, these practices are more effective in urban areas. If healthcare providers can understand the importance of how the delivery of services affects HIV care, then hopefully, an increase of social support can be implemented to prevent adherence gaps in treatment.

Research Question

What do Illinois health care providers do to help HIV-positive women overcome barriers to adherence while continuing with recommended care continuums?

Framework

By using Andersen's behavioral model (ABM, 1968, 1995) for a theoretical lens and identifying the behaviors and thinking associated with adherence (Holtzman et al., 2015), professionals may be able to adjust their regimen of care to better suit the compliance of people living with HIV/AIDS without creating a gap for an interruption in the care continuum (Ng & Caires, 2016). Although no single model or technique can improve the adherence of HIV patients, the development of a continuum of care plan that encompasses concepts from several health models can better support the individual’s treatment regimen (Ng & Caires, 2016).

The ABM was revised four times, with the last revision in 2001 (Anthony et al., 2007). The latest revision has four conceptual categories that are explored, including (a) traditional predisposing factors, (b) enabling factors, (c) need factors, and (d) vulnerable predisposing factors (Anthony et al., 2007). Human behavior operates within a framework that demonstrates how personal, behavioral, and environmental factors influence each other reciprocally (Schunk, 2012). The influences identify an individual’s motivation, social learning paradigms, self-efficacy, and mental functions. When attempting to understand the phenomena related to adherence to the HIV care continuums in urban-rural clusters, it appears that globally there are growing concerns regarding barriers related to care. However, these concerns cannot be generalized to all urban-rural clusters in the United States.

The ABM was selected to look at some of the motivating factors that patients identify with providers that promote adherence to their suggested treatment care continuum. ABM provides a theoretical framework for understanding how the patient and influential factors impact health attitudes and behaviors, decision-making, and outcomes (Holtzman et al., 2015). These external factors include attitudes, and learned behaviors regarding managing healthcare needs, lack of trust of doctors, personal beliefs related to healthcare diagnoses, or treatment needs. Through interactions and observations with other individuals, patients can also learn an individual’s thoughts about their diagnosis and consequences of decisions (Schunk, 2012).

In reviewing models related to HIV care, there are four standard practices suggested to improve HIV care in both urban and rural areas. These four practices are: (a) remote consultation services, (b) integration of HIV care into the existing programs and clinics population align with this study, (c) traditional consultative models, and (d) nurse practitioner-physician joint practices (Chu & Selwyn, 2011). Remote consultation services could provide 24-hour expert access via telephone for individuals in urban-rural areas and integration of HIV care into the population. Remote consultation can also allow for local care clinics and specific programs to help provide some HIV-specific care for individuals residing in communities that lack access by placing nurse practitioners within those clinics (Chu & Selwyn, 2011).

Nature of the Study

The purpose of this qualitative study was to explore the barriers and challenges for the patients that healthcare practitioners consider when providing care to HIV-positive women using an inductive approach. This research examined the professional perspectives and experiences of those working with PLWHA. The qualitative method best aligns with the study’s intent to consider the providers’ professional experiences while also considering the impact of how barriers interfere with care continuums to the participants they serve.

Initially, I was to conduct a meeting with healthcare practitioners who work directly with HIV-positive women by using a semistructured interview; however, due to COVID-19 pandemic, I had to email surveys in place of doing interviews. There was no researcher bias, and that all boundaries and intent with this research study were clear to each participant. I clearly stated that there was no financial gain as the researcher.

Initially, the study's setting was to occur at a large Midwest health department; however, it changed due to COVID-19 pandemic to another large Federally Qualified Health Center organization that encompassed both the Cook County area and two of the Collar Counties (Will and Lake) of Illinois, which are considered an urban-rural cluster count. However, there is one city (Waukegan) within the county that is considered urban. I emailed a personal friend to inquire about participating at which time she connected me to other individuals via email. Upon other respondents contacting me I emailed the respondents a consent form when I contacted them regarding their willingness to participate in the study. The participants' eligibility requirements were to provide direct services to clients that are a) female or female-identified, b) HIV-positive, c) residing in an urban-rural cluster area, and d) linked to care. I secured a minimum of six and six surveys were distributed in total. A total of nine people inquired about this study; however, six completed everything from start to finish. The request for participants continued until saturation was achieved. After collecting the surveys, the data analysis began. I determined if a particular care regimen or practice improved the healthcare of HIV-positive women in Cook County and surrounding Collar County (Lake and Will) areas. Through examining the healthcare practices used amongst the practitioners, I reported how providers could help improve adherence rates by addressing barriers that contribute to poor adherence and interruption in the care continuums.

The survey responses provided insight into the various stages and levels of care that a patient is receiving or provider administering. Many of the articles reviewed, identified that future research is crucial in selecting, attempting to dissect, and evaluates supportive interventions that careful assessment of personal and social contextual factors (Gjesfjeld, Greeno, & Kim, 2008). Therefore, upon developing the data content analysis, proper labeling and coding of the emerging themes and statements are critical. Proper data analysis occurred through reading, nonbiased thinking, and data collected from the surveys. I used NVivo to organize the data. NVivo can hide or restrict specific data that I would be attempting to retrieve and weigh the coding to determine if it is appropriate or how to use it accordingly (Gibbs, 2005). In addition to coding the surveys and using NVivo, I took notes on each survey and maintained those recordings for reflection purposes.

Definition of Terms

Adherence: is defined as the degree to which the individual's behavior parallels with the recommendations of their provider (Mignano, 2016).

Care continuum: is defined for this study as the steps involved in caring for an individual. This includes diagnosis, linkage, retention, and re-engagement (Mignano, 2016).

Community health worker (CHW): The CHW is defined by the American Public Health Association as a frontline public health worker who is a trusted member of and/or has an unusually close understanding of the community served (Arya et al., 2014).

Coronavirus disease 2019 (COVID-19): COVID-19 a highly contagious respiratory virus that originated in China and spread globally in 2019, and has been changing constantly across the globe. This virus has symptoms that range from mild to severe and can be deadly. This virus has been classified as a global pandemic (Mayo Clinic, 2020).

Disparities: describes how HIV may have a more significant impact between races, sexual orientation, geography, income, and sex or gender (CDC, 2019b).

Federally qualified health centers (FQHC): are community-based health care providers that receive funds from the Health Resources and Services Administration (HRSA) program to provide primary care services in underserved areas. They "must meet government requirements, including providing care on a sliding fee scale and operating under a governing board that includes patients as stakeholders" (HRSA, 2018, para. 1).

Retention: Retention in HIV care means that medical care has occurred at least two times in a calendar year and at least 2–6 months apart (Mignano, 2016).

Rural: The United States Census Bureau does not actually define rural; however, the Health Resource and Service Administration stated that "rural encompasses all population, housing, and territory not included within an urban area" (HRSA, 2020a, para. 2). "The Illinois Department of Public Heath's Center for Rural Health defines a county as rural if it is either outside of an urban area or part of an urban area with a population of fewer than 60,000 persons" (IDPH, 2016a, p. 1).

Ryan White: A 13-year-old boy with hemophilia diagnosed with AIDS in 1984 following a blood transfusion. Ryan gained national attention due to experienced discrimination because of his status and became the face of public education about HIV/AIDS. Congress passed a legislative act in is name in August 1990 called the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act (HRSA, 2020b). The Ryan White Part A Program is a federally funded program that funds and provides medical and supportive services for people living with HIV and AIDS. The program consists of two major components; the Planning Council and Grantee Administration. The Planning Council determines the services needed and the amount of funding dedicated to each service (HRSA, 2020b). The Grantee's Office is responsible for program administration. The Ryan White providers are facilities, such as a clinic, community agency, or other facility that provides HIV services to HIV-positive patients (HRSA, 2020b).

Urban clusters: is an area that has "at least 2,500 people but less than 50,000 people" (U.S. Census Bureau, 2020, para. 2).

Undetectable: Undetectable viral load means zero risk of HIV transmission between sexual partners. It shows that the HIV care regimen is working (CDC, 2019b).

Wraparound program: a way to "coordinate services (e.g., case management, support specialist, counseling, psychiatric, and health services in the community) for children with complex healthcare needs" (Rural Health Information Hub, 2020, para. 1).

Assumptions

I assumed that all participants were honest and forthcoming with their answers without breaking patient confidentiality for any patient they were providing services. I emailed all surveys to participants, and maintained confidentially of all results. I assumed that the providers were familiar with the barriers or challenges that impede patient adherence and would offer insight to find a resolution for care improvement. Lastly, the assumption is that this study can contribute to future research to help improve HIV care for rural and urban cluster areas and treatment adherence.

Scope and Delimitations

The study has scope and delimitations to medical professionals working directly with women living with HIV/AIDS, residing in Cook County, Illinois and/or surrounding Collar Counties of Lake and Will, at least 18 years old, and having been linked to HIV care. The preferred area of research was Area 5 of rural Southern Illinois; however, upon contacting the local health departments covering those areas, the number of women who were HIV-positive were low. Initially, the study's setting was to occur at a large Midwest health department; however, it changed due to the COVID-19 pandemic to another large Federally Qualified Health Center organization that encompassed both the Cook County area and two of the Collar counties (Will and Lake) of Illinois. A previous study completed in this area included information on PLWHA in general and how a healthy support system is crucial to adherence (Anima-Korang, 2017). However, this study is specific to women living with HIV/AIDS and how health care providers help HIV-positive women overcome barriers to adherence while following the recommendations of care. PLWHA have complex needs and could benefit from a multidisciplinary approach when developing a treatment plan supporting medical and social service needs (Rodriguez & Dobalian, 2017).

Initially, the study was to use purposive sampling but that changed due to the COVID-19 pandemic, to snowball sampling, which supported the inclusion eligibility. Due to the population's vulnerability and COVID-19 pandemic, this researcher decided to exclude patients and consider provider perspectives only. Due to the identified barriers and influences affecting care to individuals residing in rural communities, the providers' perspectives and common themes identifying factors that reveal when and why individuals' treatment continuums are interrupted is essential to learn how practitioners can reduce barriers for women living with HIV/AIDS. It has been determined in past research that medical and non-medical support staffs are critical to providing services to PLWHA (Rodriguez & Dobalian, 2017).

Limitations

Limitations included the small sample size of six participants. However, Boyd (2001) regarded two to 10 participants as sufficient to reach saturation.

Limitations of this research study could also include interpretation validity. Content validity assesses whether a test is representative of all aspects of the construct (Creswell, 2013). To produce valid results, the content of a test or survey must cover all relevant parts of the subject it aims to measure; however, if some aspects are missing from the measurement or if irrelevant aspects are included, the validity is threatened (Creswell, 2013). Respondents answered the survey questions, which contained open-ended questions based on the research question and existing barriers or challenges for HIV-positive women. Therefore, the research question guided this study to avoid compromising the content validity. Dudovskiy (2018) stated that a researcher needs to provide an explanation regarding the survey, purposes, values, and potential biases. I provided a clear explanation for the purpose of this study, the goals, potential biases, framework, and the survey, which included relevant questions that measured the providers' perceptions of barriers, support and coping, acceptance of their disease, and access to healthcare.

Before the COVID-19 pandemic appeared, it was my intention to use purposive sampling and face-to-face interviews. However, I had to redesign my research to use snowball sampling and emailed surveys, which required a rewrite of my proposal and IRB paperwork. These items now had to be reviewed and approved by Walden's IRB committee for a second time before data collection could begin. After receiving the IRB approval, data collection began using the emailed surveys. After receiving each respondent's completed survey, I assigned a unique number to that respondent, and began transcribing their completed survey into a Word document making sure to accurately transcribe the written words of each respondent. I double checked each Word document against the written words by each respondent several times to check for accuracy. I then sent the transcribed Word document to NVivo for data analysis.

Previous research limitations have identified significant service differences in public versus private clinics (Beane, Culyba, DeMayo, & Armstrong, 2014). This information is noted to show that care practices (e.g., private insurers have more care options than those with pubic insurance funding) can vary in addition to the lack of a standard care model for providing services.

Additional limitations include underexplored research about the barriers to treatment that inhibits relevant information related to retention in care interventions (Williams et al., 2011; Yehia et al., 2015). The literature mentions quantitative studies that describe demographic and clinical characteristics associated with retention in HIV care; however, there are no qualitative studies that examine why or how these barriers and facilitators contribute or inhibit retention in care. Therefore, developing care models where social and financial barriers are addressed, mental health and substance abuse treatment is integrated, and patient-friendly services are offered is important to keeping HIV-infected individuals engaged in care.

The last possible limitation considered was reactivity because when working with such a vulnerable population, the practitioners interviewed might respond in a manner other than how they treat patients.

Significance

HIV/AIDS retention and adherence rates are considered problematic for people living with HIV/AIDS in the United States (Smith et al., 2012). For this study, retention relates to the number of people who remain engaged in care and adherence to the suggested medication regimen. Poor retention in care becomes a social and public health concern on an individual and community level (Smith et al., 2012). Compliance with HIV treatment and the need for better social support services has been studied extensively (Tarquinio & Fischer, 2001). There are times when an individual’s behavior regarding proper self-care can interfere with the decisions that an individual makes regarding health care practices and needs (Tarquinio & Fischer, 2001). When a woman presents with multiple barriers that interfere with the ability to remain engaged in care (e.g., childcare, transportation, and the need for food), she prioritizes those things necessary to survival first, and then everything else will follow. There are learned behaviors, such as a lack of trust in medical professionals, that need consideration regarding seeking and managing health care. Looking at this topic from ABM indicates a need to provide more insight to address the problem of adherence and retention to care. Even with remarkable advances in HIV/AIDS treatment, there are significant gaps that demonstrate efficacy in the United States care continuum (Gwadz et al., 2017). By identifying the gaps in medical care and additional needs, this research can contribute to the reduction of barriers to care.

As it relates to Walden's mission of positive social change, the relevance of this research study is crucial to an epidemic that continues to impact people around the world. Building this particular research study from various angles included the reduction of particular barriers that interfere with treatment adherence, wraparound services for individuals who identify with HIV positive status, and educational information for practitioners to consider when providing services to this vulnerable population. There is currently no cure for HIV/AIDS (CDC, 2018); therefore, there is a need for additional research that is beneficial to the care and concern for people living with HIV/AIDS (PLWHA). More research could reveal newer barriers, such as addiction, as a critical component to the lack of adherence despite the identified barriers and retention of care for people who have substance abuse disorders is complicated and presents with various challenges.

Summary and Transition

This chapter provided a brief background to describe the problem of HIV in urban and rural cluster areas and what health care providers do to reduce the barriers that HIV-positive women experience while attempting to adhere to and follow the regimen of care. This chapter provided the methodology, target population and included relevant definitions for this study. Chapter 2 provides an in-depth look at the factors impeding retention to care and how ABM supports this study.

Chapter 2: Literature Review

Introduction

HIV is a global health concern for more than three decades (CDC, 2019a). At the end of 2017, an estimated 236,589 women were living with HIV (CDC, 2019b, p. 8), of which 90% had received a diagnosis, 68% had received HIV medical care, and 52% retained in care (CDC, 2019b, 2020a, b). Retention in care has been a concern for women living in urban-rural areas receiving HIV care (Ng & Caires, 2016). Social support is also a contributing factor in improving health outcomes (Anima-Korang, 2017). Pellowski (2013) identified 27 barriers that interfere with women residing in rural areas (Abbott & Williams, 2015; Rodriguez & Dobalian, 2017). Data also suggested that women in urban and rural areas are at higher risk for nonadherence and poor retention, contributing to increased comorbidities and mortality rates (Mignano, 2016). Gonzalez et al. (2004) found a positive association of social support, which proved necessary for the longevity of an individual’s life; also, treatment for HIV is essential to survival and QOL (Williams et al., 2011). One concern is that no one model is considered the best practical care continuum for those individuals living with HIV/AIDS (Nelson et al., 2018). Therefore, to create a higher adherence rate in women’s HIV care, an examination of the models is needed to determine the most effective care practice. Sankar, Luborsky, Schuman, and Roberts (2002) mentioned that previous studies identified that treatment and efficacy of treatment are crucial to adherence patterns.

The purpose of this qualitative case study was to explore the challenges and barriers that healthcare practitioners consider when providing care to HIV positive women. The specific barriers explored included the patients' access to transportation, ability to find childcare, stigma, lack of family support, and lack of providers and facilities. HIV/AIDS is a complex disease that requires comprehensive and flexible care to be most effective (Mosack et al., 2016). If practitioners can help reduce barriers allowing individuals to become more compliant and adherent to their care regimens, women in urban and rural areas may have fewer perceived barriers to overcome.

Statistics related to HIV include more information on HIV positive men. The literature review reached the saturation point for barriers impacting women living with HIV in urban-rural areas. Therefore, the literature review contains approximately six to seven articles related to HIV and the barriers men experience in rural areas, and how providers provide services to reduce the barriers for men in rural America.

Literature Search Strategy

The library databases utilized to search keywords of peer-reviewed articles were EBSCO, CINAHL Plus, Google Scholar, Science Direct, MEDLINE, and ProQuest. The CDC and the U.S. Census Bureau were used to gather the most current statistical information related to this research, particularly women living with HIV/AIDS. Also utilized were the Rural Health Information and Illinois Department of Health websites to support existing information.

Key terms included: *rural, rural Illinois, women, HIV positive women, HIV, HIV/AIDS, United States or USA, barriers, barriers to care, care continuum, continuum of care, retention, adherence, adherence to care, qualitative, HIV care models,* and *ABM.*

The literature review contains the seminal literature from Andersen (1995) and studies prior to 2014 to support the theoretical framework used to identify how the theory applies to this study. Additional literature provided further clarification for terms used, relevance, confirmation of the gap, preferred population, past and current perspective of the study's purpose. When using Google Scholar, these searches resulted in other studies that existed outside of educational databases. Many articles' links lead to government pages that track statistics and other information related to this subject matter, including substance use, nursing, prevention, but mainly relevant to nursing and public health fields. Also utilized was a published dissertation by another scholar, which provided information in the same geographical area as this study.

HIV Statistics on Men

According to the CDC (2019b; 2020a, b), the most recent data on men showed that 85% (30,521) of men accounted for the total new HIV infections amongst men, women, and children. The CDC (2019b) also reported that of the 81% (765,129) of men living (age 13 years or older) with an HIV infection (pp. 6, 8), 82% of those men identified as gay, bisexual, or men who have sex with men (MSM, p. 8). Many of the risk factors that contribute to HIV infection in men are (a) sexual contact, especially anal; (b) sexually transmitted infections (STIs); and (c) injection drug use and other substances (CDC, 2019b). New infections for men have consistently ranked highest in the United States deep Southern regions (Reif et al., 2017). In 2013, 40% of individuals diagnosed with HIV resided in the Deep South, which accounted for 28% of the U.S. population (Reif et al., 2017, p. 847). In 2008, the CDC reported an HIV prevalence rate of nine times (45.4) more for African American men versus the rate (5.2) for Non-Hispanic Caucasian men (CDC, 2020a, p. 6). However, meta-analyses have shown that there are no differences in the risk-behaviors for contracting HIV (Rosenberg, Millett, Sullivan, del Rio, & Curran, 2014).

The majority of the literature supports men and how HIV has affected their lives. Rosenberg et al. (2014) revealed that men experienced disparities at all the HIV care continuum stages, more notably in the retention stage. The literature, specifically for women studies, reported that most women living with HIV/AIDS contracted the virus from heterosexual contact or injection drug use (IDU) and other substances (CDC, 2020a, p. 7). IDU and other substances can become a coping strategy for PLWHA, and can create significant barriers to care (Grau et al., 2017). Women are least likely to use HIV primary care services and have a higher mortality rate than men despite their time on medications (Grau et al., 2017). Therefore, based on the literature, it is necessary to address all the concerns, barriers, and disparities along the HIV care continuum to accomplish significant reductions in HIV.

Lack of Access in Rural Areas

Rural Americans cope with several complex factors that create healthcare disparities not found in urban areas (Douthit, Kiv, Dwolatzky, & Biswas, 2015; Pellowski, 2013). The factors include varying climates, such as economic, social, educational, and political, that impede rural Americans from attaining healthier lives (Douthit et al., 2015). Disparities in access to health care in rural areas, compared to urban areas, include a higher incidence of chronic disease, poorer health outcomes, and less access to digital healthcare (Douthit et al., 2015). Rural residents may be at a disadvantage for accessing and engaging in care (Nelson et al., 2018). Weissman et al. (2015) conducted a study in the Southeastern United States and identified that PLWHA in rural areas were more likely to have an AIDS diagnosis within a year of receiving an HIV diagnosis than PLWHA in urban areas. Despite the improvement in healthcare for PLWHA, many people with HIV in the United States connect to care once they are in the advanced stage of the disease, creating ongoing concerns related to lack of consistent adherence or the discontinuation of the recommended therapy (Institute of Medicine [IOM], 2011).

The CDC (2018, 2020c) provided statistics that identified infection patterns and rates related to HIV care. Between 2011 and 2015, the CDC reported a 16% HIV decline among all women (2017a, p. 17). However, the percentage of new HIV diagnosis increased amongst MSM in the United States overall from 59.9% to 69.8% (Reif et al., 2017). This outcome proved to be both positive and negative due to the increased availability of life-saving medications and limited access to clinical services. According to Rodriguez and Dobalian (2017), HIV rates in some rural areas are twice as high as the general United States population and lack Ryan White clinical facilities for specialized care. Ryan White clinics provide additional support to HIV patients in need of primary HIV medical care, essential support services, and medications for low-income people (HRSA, 2020b). Weissman et al. (2014) and Vyavaharkar, Glover, Leonhirth, and Probst (2013, p. ii) identified that 95% of rural communities compared to 69% of urban communities lacked Ryan White clinic/facilities provider presence. Rural doctors are underpaid and lack the training available to their urban counterparts (Douthit et al., 2015). Questions and concerns were raised around doctors offering subpar services to patients due to the lack of support and career advancement opportunities (Douthit et al., 2015). Individuals with HIV/AIDS in the United States are often identified as minorities from an underprivileged, lower socioeconomic group, uneducated, and typically African American (Okoro & Odedina, 2016). Lower socioeconomic status can indirectly affect health and increase high-risk behaviors (Abbott & Williams, 2015).

Rural Versus Urban Care

Chu and Selwyn (2011) looked at the changes in the HIV epidemic and the need for new care models for treating HIV/AIDS care. The study documented the two basic care models used and included a clinic to treat PLWH and traditional models that referred clients to specialists in their areas (Chu & Selwyn, 2011). Alternative care models included 24-hour remote consultation, nurse practitioners-physicians' joint care, and the integration of HIV care into specific community-based clinics (Chu & Selwyn, 2011). In addition to care models, patient adherence needed to be clearly defined. Jimmy and Jose (2011) reported three types of medication adherence: primary nonadherence, non-persistence adherence, and non-conforming. However, no literature supported maintaining varying medical care retention.

The ABM allowed researchers to understand and improve access to care for PLWHA (Rodriguez & Dobalian, 2017). The purpose of using the ABM was to add to the literature on HIV in urban-rural areas and create new dimensions that could help impact care or suggest ways to address unmet health care needs (Rodriguez & Dobalian, 2017). Sixty-two semistructured interviews were conducted in rural Florida using the ABM. The authors based their study on a more extensive study that looked at ways to improve overall healthcare systems (Rodriguez & Dobalian, 2017). The health service clinic (HSC) researchers found that nurses play a significant role in helping PLWHA navigate through the health care system after being linked to care (Mignano, 2016; Pellowski, 2013). The health promotion model (HPM) is a nursing model created to address adherence behaviors and used as a building block in changing behaviors for patients seeking care (Ng & Caires, 2016). This model resulted in changed behaviors through education. However, no studies applied the HPM among PLWHA (Ng & Caires, 2016). Despite the outcomes of these studies, Yehia et al. (2015) suggested that a longitudinal study be completed over time to address retention and adherence adequately.

Nelson et al. (2018) revealed that in 2013, people diagnosed and linked promptly to care failed at retention in rural versus urban areas throughout the United States. This failure in retention is due to the inconsistent monitoring and data collection for HIV along the HIV care continuum (Nelson et al., 2018). The data from the Illinois Department of Public Health (IDPH) HIV/AIDS/STD surveillance found that “Illinois has 102 counties, and in 2013, 83 are classified as rural” (IDPH, 2016a, p. 1). Southern Illinois rural counties resulted in higher prevalence rates of HIV-infection. At the end of 2013, Illinois had (6%) n = 2,189 of people living with HIV/AIDS in rural areas (IDPH, 2016a). One of the more significant factors contributing to differences in care is that rural residents are less likely to be tested or seek medical care for HIV treatment (Nelson et al., 2018; Pellowski, 2013). However, when looking at policies on access and provisions to providing HIV care, the Institute of Medicine (2011) expressed concern about the accuracy of data collection for reporting purposes and how this lack of accuracy can affect funding allocation and resources in particular areas.

In rural counties, the majority of people diagnosed from 2009 - 2013 with HIV infection were (51%) non-Hispanic White (IDPH, 2016a, p. 2). Figures 1, 2, and 3 represent the State of Illinois and systemic and individual barriers in addition to the incidence rates per 100,000 population by county and county rural status for persons living with HIV. According to the figures, there are three major counties, considered as urban areas, with a higher incidence in the rate of infection. Although Illinois 2013 statistics reported high prevalence rates found in Johnson, Fayette, and Alexander counties, all located in the Southern region of Illinois, these counties have low rates of women to study (IDPH, 2014a, p. 3). For the purpose of this study, I examined Cook County (Chicago) and two of the Collar counties (Lake and Will) of Illinois (see Figure 2). These counties are also profoundly impacted by the current opioid epidemic, which can contribute to higher incident rates of HIV because of intravenous drug use and other high-risk behaviors.

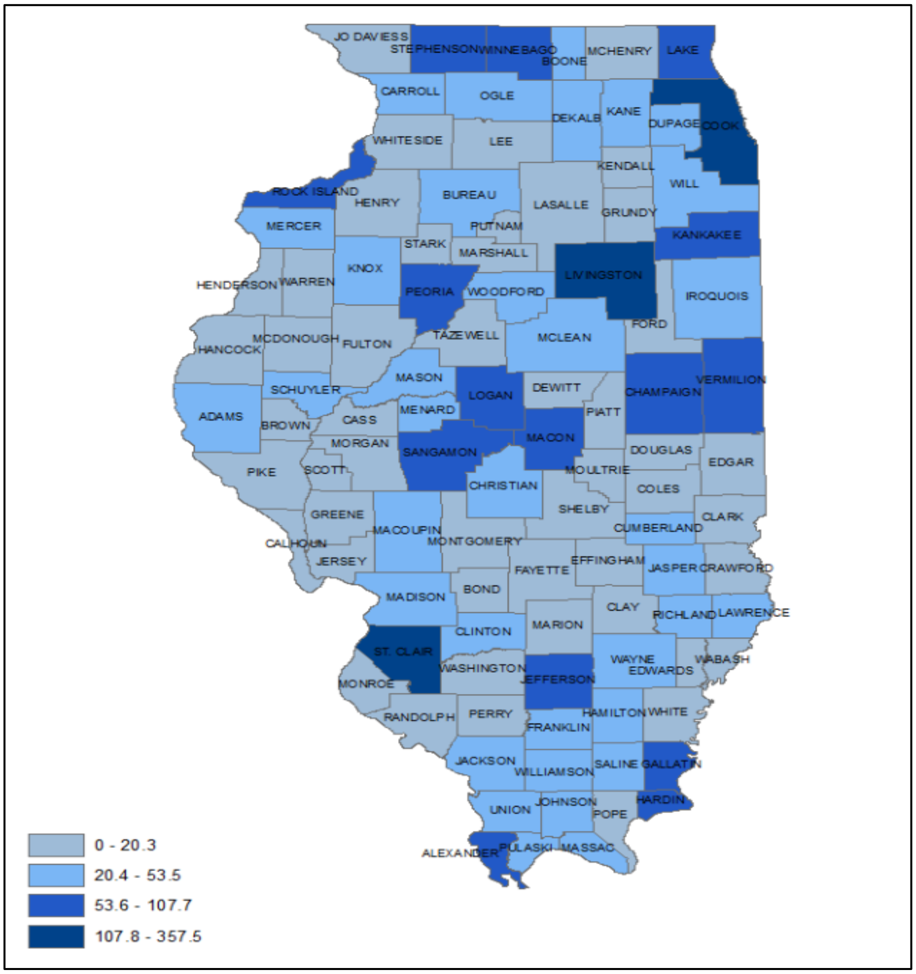

Figure 1. The rate of women living with HIV disease per 100,000 female population by County, Illinois, 2013. Adapted from "*2014 Illinois HIV/AIDS Epidemiology Profile*," by Illinois Department of Public Health, June 2014a, Fig. 9, p. 3.

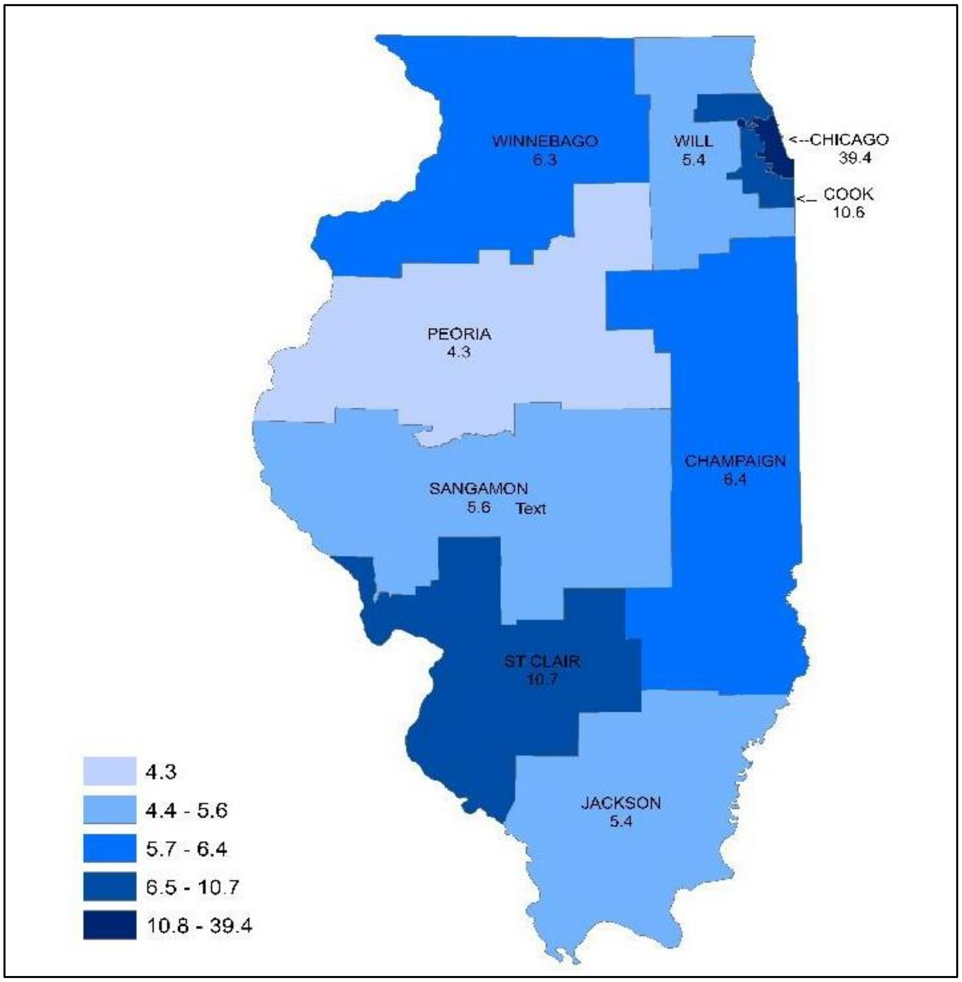

Figure 2. HIV disease diagnoses by region, Illinois, 2009-2013. Adapted from "*2014 Illinois HIV/AIDS Epidemiology Profile: Overview of HIV Disease*," Illinois Department of Public Health, January 2016c, Fig. 2, p. 1.

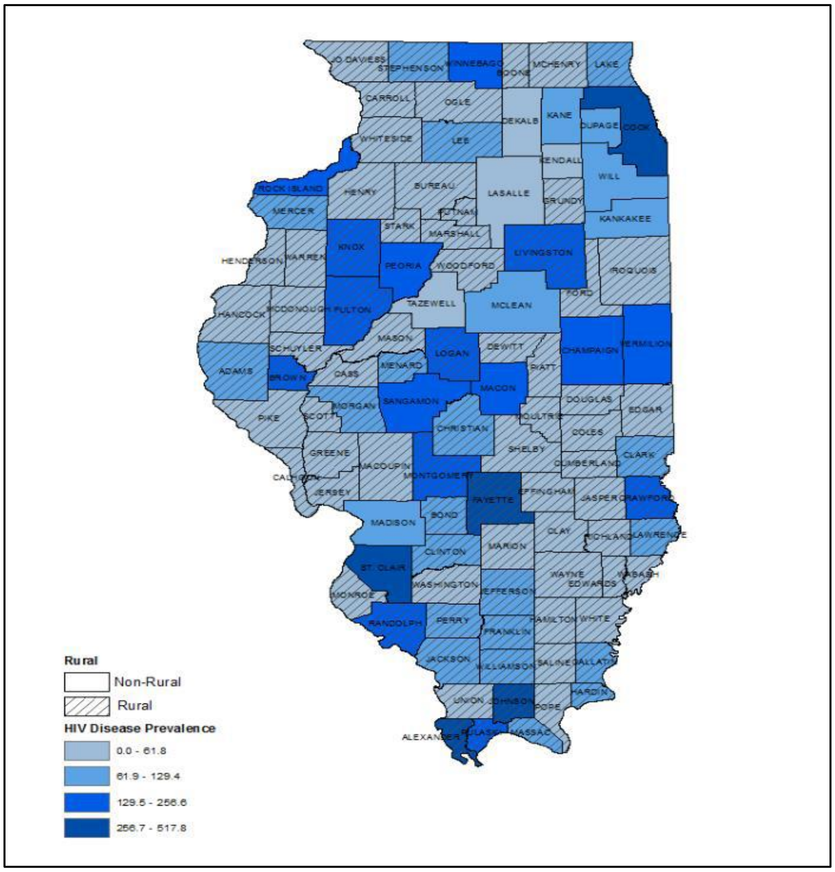

Figure 3. The rate of people living with HIV disease per 100,000 populations by county and rural status, Illinois, 2013. Adapted from "*HIV Rural Communities*," by Illinois Department of Public Health, January 2016, Fig. 6, p. 3.

Systemic and Individual Barriers

Barriers to care vary per individual, community, or geographical area's needs. The medical staff identifies many of these barriers when they interact with the patient. Identified barriers, such as accessing transportation, stigma, lack of providers and facilities, and concerns related to confidentiality, interfere with patient adherence to HIV care (Rodriguez & Dobalian, 2017). Studies of Heckman et al. (2004) and Pellowski

(2013) found that PLWHA in rural areas would often travel to urban areas for specialized HIV care. One primary reason is that health care providers are usually from the same area and viewed as friends or neighbors (Douthit et al., 2015). Pellowski (2013) also identified provider discrimination, which increases adverse outcomes for engaging patients into care.

HIV/AIDS has the stigma related to the of fear of the illness, contagion, and death surrounding PLWHA's ability to access services (Brown, Macintyre, & Trujillo, 2003). Kalichman, Katner, Banas, and Kalichman (2017) identified that individuals experience three types of HIV/AIDS-related stigma when living with this disease. These stigmas include internalized, anticipated, and enacted stigma (Kalichman et al., 2017). Rural communities demonstrated higher results of internalized stigma due to population density and being outside of the urban areas (Kalichman et al., 2017). Grau et al. (2017) identified that incorporating HIV services into non-HIV clinics could reduce provider discrimination and stigma. One suggestion included changing the organization's name to avoid identifying the clinic as an infectious disease clinic or an HIV care clinic (Grau et al., 2017). These researchers also suggested improving the HIV care continuum, and all health systems are encouraged to remain flexible and responsive to PLWHA needs and preferences while maintaining patient confidentiality and reducing stigma.

Systemic policy-related barriers include public financing strategies related to HIV care. Traditionally HIV care and prevention are funded by the CDC, Ryan White Care Act, Housing Opportunities for Persons with AIDS (HOPWA), and Substance Abuse and Mental Health Services Administration (SAMHSA) (Reif et al., 2017). According to the

Institute of Medicine (IOM), the current federal-state partnership for HIV care is unresponsive to considering the severity of this HIV/AIDS epidemic (IOM, 2011). Public insurance programs determine the proportion of coverage for HIV care; however, resources and priorities vary across the states, which creates an ineffective system for managing services for people living with HIV/AIDS (IOM, 2011). However, increasing funding does not always improve or increase access to care. One of the main reasons is that there is a rigorous criterion that limits those able to access these benefits (Pellowski, 2013). Currently, Ryan White is the only federal grant program designed to help support PLWHA and is typically the last resort of funding for lower-income individuals. The Ryan White program serves as a wraparound program to pay for medications and services that other funding sources do not usually cover (IOM, 2011). The Deep South ($3316.50) and the Midwest ($3207.90) receive the least amount of money from the federal resources compared to other regions ($3540.80) within the United States (Reif et al., 2017). Pellowski (2013) reported that budgetary concerns are an issue across the United States, where 15% of PLWHA identified that the lack of insurance has always been a barrier, in addition to the 37% of people needing help with medication payments.

Provider Discrimination

When looking at provider discrimination research, both men and women have expressed concerns about the quality of service. Women seeking care for HIV services tend to expect that the providers will show compassion, express empathy, comfort, and be honest (Yehia et al., 2015). Whereas the men are looking at being respected, experience less judgment and honesty (Yehia et al., 2015). Participants identified that this discrimination gives the illusion that a patient may be doctor shopping (Arnold et al., 2017). However, this is not the reality at all; it appears related more to the perceptions of the patient-provider relationship. Pellowski (2013) identified that 6% of PLWHA in rural areas and 11% of PLWHA in another study were turned away by providers. Care discrimination creates barriers to care since some individuals are refused care, while others are treated so poorly that they do not return to care, and individuals who seek care are not always open and honest due to perceptions of negative judgments (Pellowski, 2013).

Conceptual or Theoretical Framework

For this study, Anderson's behavioral model (ABM) was the best fit theoretical framework. This model was developed in 1968 and most applicable for this study since the ABM was designed to understand why families use health services, define and measure equitable access to healthcare, and assist in developing policies to promote access (Andersen, 1995). There were other revisions made to the model; however, this study will use the fourth model revision. Other previous revisions considered environmental and psychosocial factors (Andersen, 1995). When looking at health care models related to providing HIV care, the researcher considered the health belief model (HBM) and the transtheoretical model. However, the ABM considered the actual patient and the predisposing factors of health behaviors that were effective for building retention and treatment interventions (Anthony et al., 2007). No one particular model has been used to provide comprehensive care on the HIV care continuum. However, CDC (2001) identified that linkage to care is a priority to improve adherence in HIV care (Coleman et al., 2017).

The ABM 2001 model includes 4-key factors that attribute to the individual's ability to remain in care, including (1) traditional predisposing factors which include basic demographics including sex, gender, and race; (2) enabling factors, which include insurance and clinic access; (3) need factors, which includes illness, HIV symptoms, or disability; and (4) vulnerable predisposing factors, such as behaviors, beliefs/attitudes, and psychosocial factors (Anthony et al., 2007). Anthony et al. (2007) mentioned that by identifying the factors early that can create challenges or barriers, then HIV clinical care could begin to close the gap between HIV-testing and treatment.

The Antiretroviral Treatment Access Study (ARTAS), performed by Anthony et al. (2007), was a randomized control trial examining whether case management was better than passive referral in long-lasting linkage to care for newly diagnosed individuals. The ARTAS case management was modeled on a strengths-based approach, rooted in theories of empowerment and Bandura's (1986) self-efficacy concepts. The trial found a significant variation between several 4-key factors, grouped between traditional predisposing factors, enabling factors, and vulnerable predisposing factors. Pellowski (2013) identified that rural individuals are more likely to seek HIV treatment or therapies later than urban areas despite having twice as many barriers to care as their urban counterparts.

Previous studies, including Pellowski (2013), Rodriguez and Dobalian (2017), Shelton et al. (1993), Simoni et al. (2006), Smith et al. (2012), Sutton et al. (2010), and

Trzynka and Erlen (2004), and Yehia et al. (2015) described the barriers and necessities to engaging an individual who is living with HIV into care. As mentioned previously, many of the studies revealed that the various factors impede or create obstacles for those wanting to remain compliant to care regimens. Below is an example of Andersen's behavioral model (see Figure 4), which demonstrates how demographics, education, risk perceptions, and the perceived need for care impact women's ability to see or utilize available health care services. This framework supports this study since the practitioners would provide insight into why or what barriers women reported while engaging in care. This insight would provide information for future studies to utilize the outcomes, and reduce the barriers that HIV-positive women experience in rural areas.

Figure 5 below by Gelberg et al. (2000), demonstrates the behavioral model for vulnerable populations, which focuses on understanding health services used by homeless adults and on the value of the model in understanding improvement in the health status of these persons.

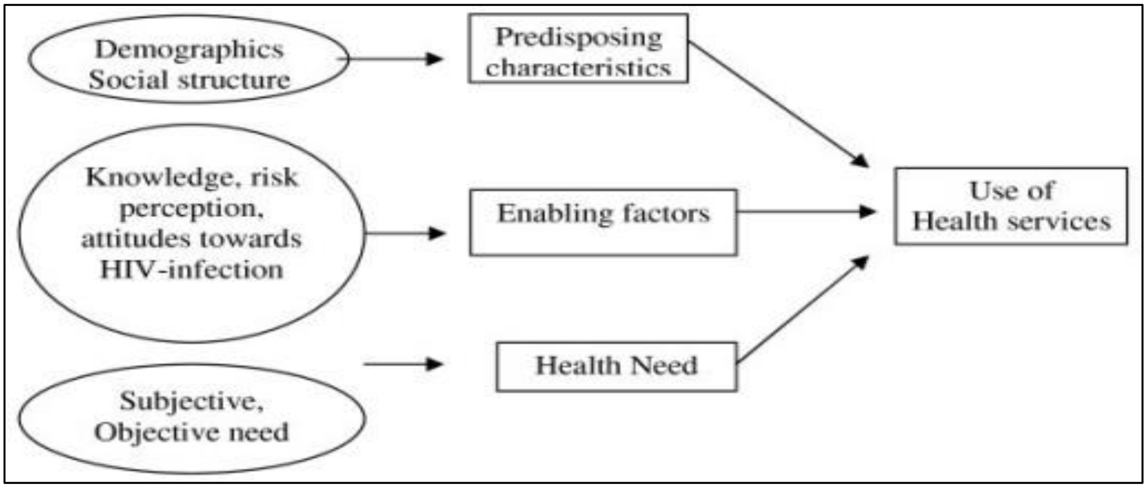

Figure 4. Modified health service use behavioral model. Adapted from "Revisiting the Behavioral Model and Access to Medical Care: Does it Matter?" by R. M. Andersen, 1995, *Journal of Health and Social Behavior*, *36*(1), Figure 1, p. 2.

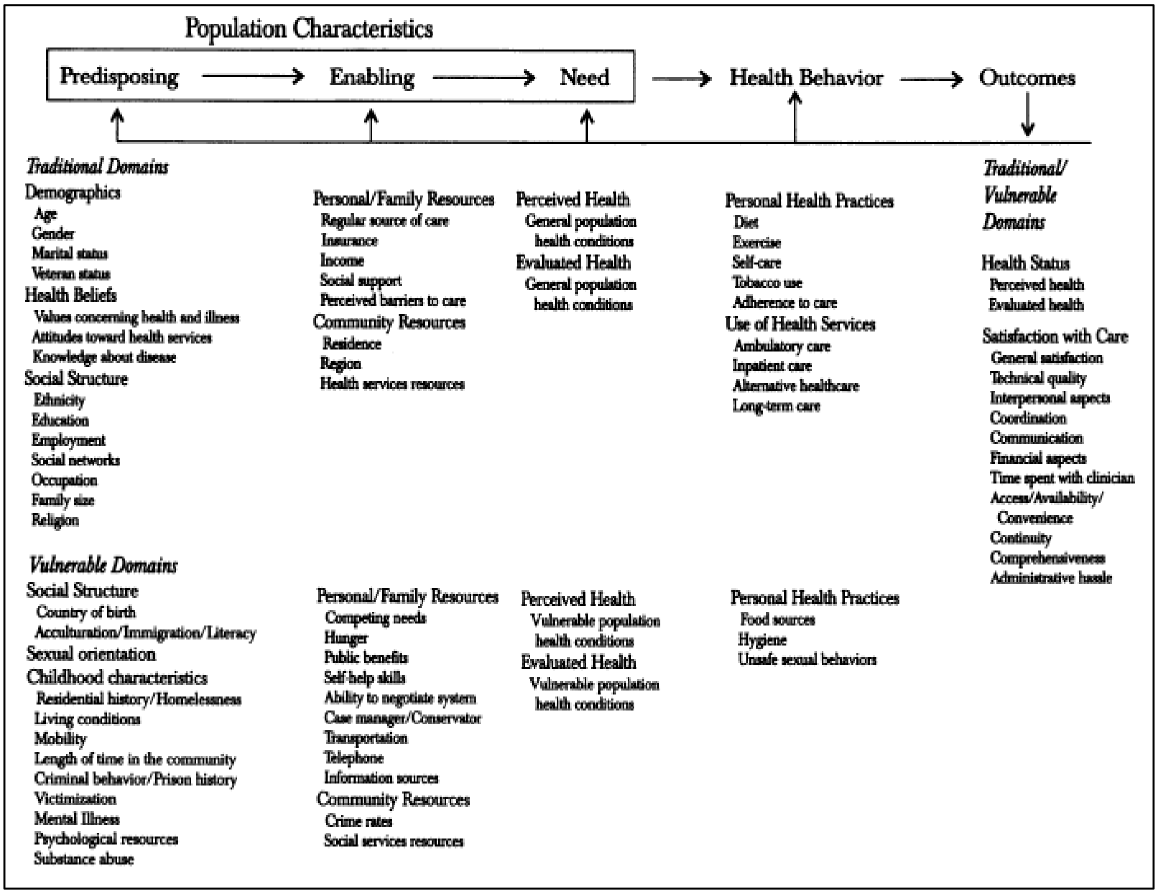

Figure 5. The behavioral model for vulnerable populations. Adapted from "The Behavioral Model for Vulnerable Populations: Application to Medical Care Use and Outcomes for Homeless People," by L. Gelberg, R. M. Andersen, and B. D. Leake, 2000, *Health Services Research*, *34*(6), p. 1728.

Summary and Conclusions

A significant theme presents in the literature related to rural areas, which lacks research studies across the United States regarding what is needed to adequately improve adherence within the HIV care continuum. Different themes are recurrent and focus on the systematic barriers and disparities identified throughout other studies (Abbott & Williams, 2015; Pellowski, 2013; Rodriguez & Dobalian, 2017). As previously mentioned, these barriers include transportation, specialty care, access, and insurance concerns (Pellowski, 2013). The disparities shown are mainly in impoverished communities, Southern African American communities, and African American MSM communities (Rosenberg et al., 2014). This study seeks to fill the gap for rural providers who lack specialty training to assist in decreasing barriers for HIV positive women in high disparity rural areas and increasing adherence to care regimens. This study adds to the knowledge base about women who are impacted by HIV disease. Limited research exists for women living with HIV in rural America, and due to the increase in infection rates, these are the individuals who need to be studied.

Chapter 3: Research Methodology

Introduction

The purpose of this qualitative study was to explore the barriers and challenges that healthcare practitioners consider when providing care to HIV-positive women. The study provides the statistics of men and how HIV statistics primarily center on this population. The statistics that primarily reflect men support the need for continued research on the HIV positive women population. This research study allowed for an opportunity to improve the health care delivery for PLWHA because the medical care an individual receives is most certainly a function of the family's demographic, social, and economic characteristics as a unit. This research suggests that people's use of health services is a function of their predisposition to use services, factors which enable or impede use, and their need for care. This chapter presents a description of the research and rationale to reflect the appropriateness of the study. It also contains an overview of the researcher's role, methodology, recruitment procedures, issues of trustworthiness, and ethical concerns. The chapter concludes with a summary of the main points and research methods.

Research Design and Rationale

This study's primary research question was: What do Illinois health care providers do to help HIV-positive women overcome barriers to adherence while continuing with recommended care continuums? I employed a qualitative study using a survey with open-ended questions. I used a qualitative research study because of the need to present a detailed view of how healthcare providers can improve health care systems for HIV-positive individuals. Another rationale for choosing this particular design and approach is because much of the literature supports the patient's accounts of the feelings and experiences but not the providers' efforts and experiences. According to Hycner (1999, p. 156) "the phenomenon dictates the method (not vice-versa) including even the type of participants." Creswell and Poth (2017) noted that qualitative research enables us to make sense of reality, describe and explain the social world, and develop explanatory models and theories. The researchers stated that it is the primary means by which the theoretical foundations of social sciences may be constructed or re-examined. The surveys were emailed to the individuals who provided service to PLWHA; therefore, a qualitative research design was the best approach for the purpose.

Role of the Researcher

According to Patton (2015), the researcher's primary role is to maintain integrity, remain unbiased, and maintain professional boundaries. Since the researcher is the central instrument in all phases of the research process, from framing the question, to sampling, to observing participants and gathering data, to analyzing and interpreting data, and to preparing the research report; therefore, the researcher must be knowledgeable in qualitative methodologies (Moustakas, 1994; Patton, 2015). There were no personal relationships, professional relationships, or financial gain when conducting this study. Ethical concerns that could arise are that the participating providers could potentially discuss barriers or retention concerns of a client they provided HIV case-management care by my current employer. The researcher maintained patient confidentiality at all times.

Mouton and Marais (1990, p. 12) stated that individual researchers “hold explicit beliefs” and cannot be detached from their own presuppositions and should not pretend otherwise (Hammersley, 2000). Throughout this research, I ensured that there was no researcher bias and that all boundaries and intent with the research were clear and explained to each participant, which included mentioning that there was no financial gain on behalf of the researcher.

Methodology

The methodology section contains participant population, instrumentation, data collection, data analysis, trustworthiness, and ethical considerations.

Participant Selection Logic

Initially, I chose purposive sampling, considered by Welman and Kruger (1999) as the most important kind of non-probability sampling, to identify the primary participants. Purposive sampling is a sampling technique where the researcher relies on their judgment when choosing members of population to participate in the study (Creswell & Poth, 2017; Patton, 2015). However, due to the COVID-19 pandemic, I had to use snowball sampling, which is a convenience sampling method. In snowball sampling, the existing study subjects recruit future subjects among their acquaintances and sampling continues until data saturation (Burns & Grove, 1993). This study included healthcare practitioners who worked directly with HIV-positive women to obtain their perspectives as providers regarding retention and adherence concerns. The inclusion criterion for eligibility to participate in this study, is that the participants must be a practitioner that provide direct services to clients that are (a) female or female identified,

(b) HIV-positive, (c) reside in an urban-rural area, and (d) linked to care. The exclusion criteria included clients that were male. The automatic exclusion from this study will occur if any of the inclusion criteria does not apply.

Initially, I wanted to recruit participants from a Midwest community service agency serving persons with HIV/AIDS in and around the Collar County area in Lake County in urban-rural Illinois. However, the study's setting changed due to the COVID-19 pandemic to another large Federally Qualified Health Center organization that encompassed both the Cook County area and two of the Collar Counties (Lake and Will) of Illinois. I utilized the phone for one participant to gather their email address. The other five participants, I contacted via email only through the use of snowball sampling. At this time, I emailed a consent form and upon the receipt of the consent I emailed the survey, and provided a three week time frame for return of the completed survey.

Initially, I intended to secure a minimum of nine participants using purposive sampling; however, because of the COVID-19 pandemic, I used snowball sampling, which resulted in six respondents that agreed to be participants and completed the survey. Boyd (2001) regards two to 10 participants as sufficient to reach saturation. The surveys were distributed to participants that met the inclusion criteria.

Instrumentation

This qualitative research used a survey with open-ended questions, allowing participants to write down their perceptions, attitudes, behavior, and interactions to gain an in-depth understanding of the phenomenon. I developed the survey, which was partly adapted from research studies obtained while doing the literature review and through my work experiences. The survey was not pilot tested but was reviewed by my advisor for this capstone project. No changes were made after the advisor reviewed the questions.

The survey contains four demographic questions with one probing question, four questions for the section on Identifying Barriers, two questions for the Support/Coping section with three probing questions, three questions for the Disease Acceptance section, four questions for the Residential Area Access, and two additional questions for participants to answer. The final statement on the survey asks, are there any further questions that you may have or statements that you would like to share at this time?

Participants had three weeks to complete the survey and email the completed survey back to the researcher. Six completed surveys were received from practicing practitioners who see HIV-positive women for a 100% return rate.

Data Collection

The theoretical framework lens supports this study, which is Andersen's behavioral model developed in 1968 by Ronald M. Anderson. When considering this framework, I developed the surveys utilizing open-ended questions for the participants based on the purpose of the ABM and studies found during the literature review. ABM has been used throughout various healthcare facilities as a way to assess the perceived needs and actual needs for health care services. These entities include HIV care, Hypertension, Mental health, and vulnerable populations (e.g., homelessness). A goal in using the ABM model was to assess the provider's point of view on the concerns or issues related to the lack of patient adherence in treatment. The providers provided their perceptions on various points where adherence and retention become a problem for the patients and identified how they work to reduce the barriers or obstacles experienced. It was essential to capture the providers' point of view related to the outcomes and experiences of their patients to determine the barriers to care.

I emailed the survey to respondents to collect the providers' perceptions, which allowed for an in-depth understanding of the phenomenon. I began emailing the surveys on June 2, 2020 to collect data from a minimum of six respondents that agreed to participate. The emailed surveys contained a closing date of July 1, 2020 to return the completed survey. I informed the participants in advance that I may contact them via email for any clarification or additional information if follow-up was necessary about any of the participants' responses. To avoid compromising the interpretation validity, I used open-ended questions for this study, which allowed participants to answer the questions in their own words. I entered the survey data into a Word document, so it could be transcribed by NVivo. I notified the participants that they could maintain an emailed copy of their survey's responses and the outcome of this study's results.

Data storage included transcribed Word documents of each participant's completed survey, field notes, and filing of all hard copy documentation. The interview transcriptions and field notes are stored electronically on a hard drive and a memory stick, which are password protected. The computer and memory stick are stored in a locked room in the researcher's office. The hard copies of the survey are stored in a locked file box in the researcher's storage facility along with all of the literature research articles used. The According to the IRB Guidelines and federal regulations, all data are to be destroyed after three years of publication of this capstone research. The emailed survey copies, Word, and Excel files will be shredded rendering all documentation unusable.

Assurance of Volunteerism - Right to Withdraw - Privacy

I ensured that the participants understood that their participation was completely voluntary and provided a detail explanation about the confidentiality of the study by using a consent to participate form. I reminded participants that their participation in the study was voluntary and they could dropout at any time as there was no risk associated with continued or discontinued participation. I also informed the participants that their participation in the study would have no effect on future or current relations with Walden University.

Data Analysis Plan

Kensit (2000) cautioned that the researcher must allow the data to emerge while doing qualitative research, which means capturing “rich descriptions of phenomena and their settings” (p. 104). The survey data captured the practicing providers’ perceptions when answering the open-ended questions surrounding HIV in Cook County and Collar Counties of Lake and Will County in northern Illinois. I transcribed the providers’ perceptions into Microsoft Word using the particpants’ exact written words without any distortion and assumptions by the researcher. Qualitative research methodology allowed the researcher to understand the providers’ views, perceptions, attitudes, behavior, and interactions to gain an in-depth understanding of the phenomenon (Pathak, Jena, & Kalra, 2013). Each participant’s survey was coded based on their county, a unique number, and a participant number, for example: CC60640N1. The CC stands for the county, 60640 is a unique number assigned to each participant, and finally the participant number of N1 to N6. After transcribing the interview data, thematic analysis allowed the data to be coded to obtain the recurring themes and sub categories and then to determine the major themes.

"Memoing" (Miles & Huberman, 1984, p. 69) or taking field notes was another important data source in qualitative research that I used in this study. It is the researcher's field notes recording what the researcher hears, sees, experiences, thinks, and details about the setting or the participants' reactions in the course of collecting and reflecting on the process (Miles & Huberman, 1984). Unfortunately, the face-to-face interviews did not take place due to the COVID 19 pandemic. Instead, I emailed a survey for participants to complete in their own words. As I read each of the surveys, I took notes related to themes or specific comments to compare to other transcripts. However, it is important that the researcher maintain a balance between descriptive notes and reflective notes, such as hunches, impressions, feelings, and so on. Miles and Huberman (1984) emphasized that memos (or field notes) must be dated, so that the researcher can later correlate them with the data. Field notes are a secondary data storage method in qualitative research and are crucial in qualitative research to retain data gathered (Lofland & Lofland, 1999).

Transcription

I did not need to transcribe the surveys as the respondents typed the responses onto the emailed document and returned the written survey to this researcher. I used the NVivo transcription to analyze the information, which prevented any discrepancies since I have a learning disability of dyslexia. I double-checked all transcribed surveys to provide a second look for accuracy of the transcribed data. The review also included reading and comparing each survey again to identify and note any changes or discrepancies.

Coding

Careful analysis helped identify, label, and code the emerging themes and statements obtained through active reading, nonbiased thinking, and data collected from the surveys. After coding the interviews, I began to group the categories into cluster units to identify and label themes. Clusters of themes formed when grouping units that have the same meaning together (Creswell, 1998; Moustakas, 1994) and identifying significant topics, called units of significance. Groenewald (2004) identified that by grouping units of meaning together develops clusters and identifies units of significance. I would be coding the data provided by the participants personally to identify reoccurring themes and patterns of the information obtained.

Software for Analysis

I used NVivo, a qualitative data analysis computer software package by QSR International, since I found that the strengths of this software could organize, analyze, and find insights in the qualitative data where deep levels of analysis are required to make sense of the data. Gibbs (2005) stated that NVivo allows the opportunity to hide or restrict specific data, that could be retrieved later, and to weigh the coding to determine if it is appropriate or how to use it. NVivo assists in backing up the findings with evidence. Groenewald (2004) identified that NVivo and other computer software programs do not help with qualitative phenomenology. Therefore, in addition to coding the surveys and using NVivo, I took field notes on each interview and maintained those recordings for reflection purposes.

Issues of Trustworthiness

A summary of each written response, including the themes generated from the data, was emailed to each participant for a validity check to detemine if the essence of the interview had been correctly captured. Gibbs (2005) stated validity check, also known as member checking allows participants to clarify what their intentions were, correct errors, and provide additional information if necessary. I used triangulation by using field notes and constant comparison of data when establishing themes in the interview data to strive for true information.

Creswell (2013) noted that credibility in research is an assessment of whether or not the research findings represent a credible conceptual interpretation of the data drawn from the participants' original data. To ensure credibility of the data, the participants provided their written perceptions and experiences to the questions on the survey in their most comfortable environment without any distractions. The purpose of this research allowed for selection of participants for this study, who had experiences related to the phenomenon being researched. Participant selection was through snowball sampling for this research study. I had no further contact with the participants than that of the survey and follow up if necessary, for a validity check. The survey process occurred in an environment and location that was distraction-free and private for the participants. The information provided from the survey did not include disclosure of a patient's name, medical record number, or date of birth; however, the participant may disclose specific instances of a barrier or challenge that a patient experienced. The study was ethical and grounded in norms. Each survey transcript was reviewed for accuracy by comparing to the written response, and the written notes based on keywords and themes. All participants' surveys and information collected were kept confidential and organized on an individualized basis. All documents, recordings, notes, and other information were maintained in a locked filing cabinet at my office.

Ethical Considerations

The Walden Institutional Review Board (IRB) committee approved all ethical procedures and considerations, and benevolence, in addition, consideration of any fiduciary responsibility to avoid all harm to participants. All approvals necessary occurred before any research was conducted. All participants signed an informed consent granting permission to participate in this study before being interviewed. Permission from the IRB committee was not requested for consent to interact and observe any HIV-positive women, a vulnerable population, as COVID-19 prevented reporting to the clinical settings and communicating with any staff or client in any capacity. The individual providers participating understood the procedures of the research, including the risk and benefits. Their participation was voluntary, and the confidentiality of each provider and patient discussed was protected. The participants received a $10.00 coffee card upon return of the completed survey.

Summary

This chapter described the purpose, the rationale, and the research design for this study. The ABM is a known tool that served the purpose to understand the satisfaction with providers and the needs of their patients, and to understand how providers are reducing barriers to adherence and retention. I devised a plan to help understand the steps taken to complete this research study. Data collection followed after receiving approval of Walden’s IRB process. I followed all ethical guidelines and considerations while conducting this research. The next chapter discusses the results of this study.

Chapter 4: Results

Walden University IRB granted research approval in March, 2020, to conduct this qualitative study to explore the barriers and challenges healthcare practitioners considered when providing care to HIV-positive women (Approval number 03-02-20-0291480). For this qualitative study, the specific barriers that I sought to explore were patients' access, transportation issues, childcare issues, stigma, lack of family support, and lack of providers and facilities. The research question guiding this study was: "What do Illinois health care providers do to help HIV-positive women overcome barriers to adherence while continuing with the recommended care continuum?" The purpose of this chapter is to document and report the study's findings from individuals recruited from the Cook County and Collar counties (Will and Lake) of Illinois. In addition to providing an in-depth review of the collected data, participants, results, and trustworthiness of the data, I identified how Andersen's behavioral model aligned with the study's intent.

Setting

The study was primarily based in Illinois and had a change of placement and data collection due to COVID-19 closures and social distancing laws. Illinois is a very diverse state, in which Cook County has 5.15 million individuals and the Collar Counties (five communal areas) has 3.2 million people (Census, 2019). In 2018, there were 35,841 people living with HIV in Illinois, and 1,361 were newly diagnosed in 2019 (CDC, 2020).

Initially, the study’s setting was to occur at a large Midwest health department; however, it changed to another larger Federally Qualified Health Center organization that encompassed both the Cook County area and two of the Collar Counties, Will and Lake, of Illinois. The Walden IRB approved the second submission related to these changes. Another change that occurred because of the COVID-19 pandemic was that the study was originally supposed to use purposive sampling and nine face-to-face interviews, but that changed to surveys being emailed to the study participants. My intention to use purposive sampling also changed to snowball sampling. The snowball sampling was quite different from what I expected; however, I secured six participants for the revised study.

The participants answered the survey from their homes or offices at their leisure before the study’s closing date of July 1, 2020. The survey allowed the providers to give their accounts and experiences about providing services to women living with HIV. Due to the study’s inclusion criteria not specifying that an individual had to be born female, the survey data includes information about transgender male to female (MTF) individuals.

In receiving an email regarding individuals being interested in my study, I sent a follow-up email thanking the respondents for showing interest in my research, and I also attached the consent form to the reply. The following email contained the survey. I maintained a printed copy of the email communication for each respondent coded under a unique identifier (CC60607N3, LC60073N4, CC60607N2, CC60640N1, CC/WC6063760478N5, and CC60617N6). To maintain confidentiality, I kept the printed copy in a locked and secured cabinet in my office.

The study consisted of six individuals; four were from the Cook County area, one worked in Cook and Will County, and one from Lake County. All participants consented and agreed to communicate via email. There were no follow up emails for clarification needed. The minimal conditions and disturbances included the ongoing COVID-19 issues, and work changes that caused restricted data collection and timeliness of results.

Research Participants

The qualitative research study participants were recruited using snowball sampling from the Cook County and Collar Counties (Lake and Will) area of Illinois's Midwest area. Initially, the study's setting was to occur at a large Midwest health department; however, it changed due to COVID-19 pandemic to another larger Federally Qualified Health Center organization that encompassed both the Cook County area and two of the Collar counties (Lake and Will) of Illinois. Participants came from various agency sites located in the Midwest after receiving an email shared via other practitioners and colleagues.

Participants' Demographics

The population for this study consisted of six professionals who provided direct care to women living with HIV in Illinois. The participants included direct case managers, practitioners, or medical doctors who specialized in infectious diseases. All the participants spoke English and provided services to women who were at least 18 years or older. Table 1 displays the coding and demographics for each participant, including the time providing care to the community, and the familiarity of working with people living with HIV/AIDS.

Table 1

Demographics of Study Participants

Participants' Number	Gender	Specialty/Population Served	Familiarity With HIV/AIDS	Time in the Field
CC60640N1	F	Nurse Practitioner/ Family medicine for Infectious Diseases- Works with homeless and refugees	Very familiar – Currently serves a patient panel of over 130	27 years
CC60607N2	F	Nurse Practitioner- Medically underserved and homeless	Very familiar – Pathophysiology, epidemiology, and treatment options	19 years as Registered Nurse 7 years Nurse Practitioner
CC60607N3	F	Primary Care Provider- Homeless, underserved, and transgender	Familiar - History of the disease and treatment options	2 years
LC60073N4	F	Case Manager- PLWHA and underserved	Very Family – Care continuum, engagement needs, testing	14 years
CC60637/WC60478N5	M	Medical Director & Professor of Medicine- Black MSM and transwomen	Very familiar- All levels of services	27 years
CC60617N6	F	Medical Doctor- Infectious disease for women and children	Very Familiar – All levels of care, needs, and services	20 years

Two of the participants were medical doctors and professors for a prestigious area Medical School and had spent several years working with people living with HIV/AIDS, averaged 18 years or older. The other participants included two nurse practitioners, one case manager, and a primary care provider. The data shows there were five females and one male participant. One female had two years of experience, two had 27 years experience, whereas the other three had 14 years or greater field experience.

Data Collection

During the first step of the data collection process, I made myself available for additional questions related to the interest in my study by providing my phone number and Walden and personal email address. The email offered a brief synopsis of my study's intention, and I thanked the respondents for choosing to participate in this research project. I reminded them that the survey was completely voluntary and that they could withdraw at any time without question or penalty. I provided the consent form and requested that if they could not scan or email me the signed copy that they simply could respond "I consent" to the email to receive the last stage of the research, which was the survey. Approximately 3–4 days after sending the survey, I inquired and asked if there were any questions or concerns via email. I did not receive any responses regarding questions related to the study.

The data collection utilized the interview protocol (see Appendix A), which was amended to be an electronic survey due to the COVID-19 pandemic. The survey included 23 open-ended questions under six categories based on this study's research question. Each participant received the same survey. I ensured each participant that their anonymity would be maintained. Each participant was advised that the survey would take approximately 20 minutes at a minimum to complete. The participants completed the survey and returned it via email, at which time, a $10 Dunkin Donuts card was sent electronically to the study participant who completed the survey. None of the participants withdrew from the study or experienced emotional distress. Each survey participant followed the same procedures with no significant deviations from the topic, and there were no significant delays. Through snowball sampling, I asked the study participants at the conclusion of their survey, to share with other providers, who met the inclusion criteria, and might want to participate in this research.

I intended to use a service provider to transcribe the interview data; however, due to the study's changes due to COVID-19, I was able to use the participant's returned survey responses as is and simply import it into NVivo. This study's data collection process did not deviate from the data collection method described in Chapter 3. I used open-ended survey questions that implore raw data from the viewpoint of the providers.

Data Analysis

Following Creswell's (2013) three stages of data analysis, I began with obtaining rich in-depth responses (transcription), developing a list of the reactions and grouping them into themes and categories (reduction) using open coding, and presenting the data using figures, tables, and discussion. NVivo provided in-depth coding of the data. Key code words were considered using inductive coding and compared to the research problem and question. Next, the codes were sorted and organized into broader themes using textural descriptions (see Moustakas, 1994). I read all the survey responses a minimum of three times, on different occasions, to mentally formulate some pieces that were not presented during the coding analysis. I made notes on each printed survey to pinpoint specific words and documented my thoughts about the comment. Taking notes and re-reading several times provided me with some starter keywords based on the participants' perceptions.

The themes that emerged described the experiences and perceptions of the participants who work directly with PLWHA. Participants could retain a copy of their survey responses since the communication transpired via email. The data were already transcribed in the participants' actual words, further reducing errors with transcribing. Themes developed by identifying noteworthy statements and grouped into key code words to create richer data. As I looked at the data, I attempted to couple feelings of positive and negative experiences from the providers' experiences. I imported all transcribed surveys into the NVivo software. Table 2 illustrates the themes and subthemes that emerged during the coding process. These themes helped answer the research question: "What do Illinois health care providers do to help HIV-positive women overcome barriers to adherence while continuing with recommended care continuum?"

Table 2

Themes and Subthemes

	Themes	Subthemes		
Row 1	Access	Chicagoland Area Access	Language barriers	Travel Times
Row 2	Adherence Meaning	Treatment Interventions Adaptation	Communication	Inclusive Services
Row 3	Healthcare Model	Patient-Centered or Differentiated Care	Trauma-Informed	HIV-Care Continuum
Row 4	Risk	Denial/High-Risk	Mental Health	Substance Abuse
Row 5	Patient Support	Integrated Teams Available	Doctor on Call	Family/Friends/ Communal Impact
Row 6	Staff Support and Training	Agency Barrier Reduction	Trainings and Continued Education	Internal and Systematic Changes
Row 7	Treatment Diagnosis to Care	Positive	New Diagnosis	Additional Needs

General Interpretation of Themes from Surveys

In reviewing the data, the transcript data revealed that many providers shared the same concerns and beliefs related to the importance of client care and patients following the care continuum when engaging in services. A few practitioners responded to some questions with more in-depth data, while other practitioners responded with similar responses like most of the already published literature. According to the responses, practitioners shared similar concerns about improving care for people living with

HIV/AIDS. There were improvements with medication regimens (once a day pill) and the AIDS Drug Assistance Programs (ADAP); however, there are still ongoing systemic structural and sociopolitical barriers, such as transportation, insurance, financial, and childcare concerns.

Interpretation of Results

I reviewed and interpreted the results related to the research question explored in this study. I provided a general interpretation of each participant's experiences and direct quotes from each participant's survey as it pertained to people living with HIV/AIDS.

Theme 1: Access

The participants identified that access was still an issue for those individuals living outside of specific Chicago areas and certain counties. As participant CC60640N1 noted, "This county is very good, Northside of Chicago has more resources than south side, likely."

Whereas, participant CC/WC6063760478N5 thought access was still a big issue and remarked that, "In Chicago, it is good; in the South and non-Medicaid spaces, it's bad."

While some participants identified that challenges can present related to access for PLWHA, most felt that the Chicagoland area had a reasonable number of resources for PLWHA.

Participant CC60607N2 had a more positive response, in that they felt like "…the Chicago land area, and Cook County, specifically, has an abundance of resources for HIV specific services."

As did participant LC60072N4, who also had a positive response, “In this area, there are approximately five major clinics that can provide specific HIV/AIDS services through Illinois’s 3 northern Collar Counties.”

While participant CC60617N6 remarked that, “Most people that I serve live on the south side and south suburbs. Access is available, but it depends on where the patient wants to receive services.”

Most providers did not believe that their clients traveled more than 15 miles or 10 minutes to get to their offices, such as participant CC60640N1 who remarked, “Most do not have cars, so are within city limits.”

And participant CC60607N2 commented that, “Typically, our patients were very local or traveled just within the Chicagoland area.”

While two other providers believed that their clients did not live in the city and had to travel for services, such as participant CC/WC6063760478N5, who said, “1–10 miles” and Participant CC60617N6 believed their clients traveled “5–15 miles.”

However, participant LC60072N4 stated, “At my location, some clients travel up to 30 minutes one way or longer if taking public transportation” … “they can use their insurance for rides” … “public transportation in the suburbs is distanced [sic out] than within city limits.”

And participant CC60607N3 stated that, “Most of my patients live in the same building as the clinic [identified two businesses]. Some [clients] may travel from outside of Chicago or across town,” indicating that it might take some clients longer to get to their appointments because they might have to travel 30 to 45 minutes longer since they live across town or outside the city limits.

When participants were asked about areas that needed improvement, Participant CC60640N1 commented that the "Easier process with Medicaid, the single formulary this year is better; however, I would like insurance to cover every single-tablet regimen (medication accessibility)." And participant CC60607N3 had basically the same response of "Affordable medications, reduced wait time."

Whereas, participant CC60607N2 thought the company was doing a pretty good job when they commented, "Honestly, I don't see much room for improvement, [business name] did a wonderful job using their connections in the community for recovery homes, shelters, etc., to help link people to care."

However, participant CC/WC6063760478N5 reported that "radical societal change in resources" is needed to improve access.

Participant CC60617N6 felt differently than the other providers, in that they felt that "If more people specialized in HIV, more doctors and practitioners could exist within standing clinics. Systemic stuff, you know."

And participant LC60072N4 felt that education and training needed improvement "Specific ID [infectious disease] training and care that could help improve the quality of care being provided to PLWHA."

Theme 2: Adherence Meaning

According to Smith et al. (2012), treatment adherence is critical to clients' chances of staying healthy and long-term survival rates. According to the National

Institute of Health (NIH), medication adherence is defined as the degree to which a person's behavior aligns with the recommendations of a healthcare provider (Machtinger & Bangsberg, 2006, para. 1, "Rates of Antiviral Adherence"). This recommendation can be from starting medications to maintaining medical appointments. Upon reviewing each survey, each of the participants identified treatment adherence from their perspectives. The providers collectively shared some of the thoughts as it pertained to maintaining adherence.

Participant CC60640N1 identified that adherence means that "patients are able to access care and keep in contact … as best they can with their team and healthcare professional."

Whereas, participant LC60072N4 identified that "treatment adherence means how [the providers] inclusively provide services."

In addition, participant CC60607N2 reported that adherence to "treatment interventions that are adopted and carried out by the patient at the recommendation of the provider."

Participant CC60607N3 also mentioned the importance of "ordering refills before medications run out … keeping track of symptoms and possible drug reactions and presenting for follow-up appointments as scheduled."

Furthermore, participant CC/WC6063760478N5 stated that "[the] clients [need to] understand that adherence means taking medication … that prolong life … while understanding the importance of the plan and how to be successful [in remaining compliant]."

Theme 3: Healthcare Model

Traditionally HIV/AIDS care begins with placing clients on a medication regimen immediately or as soon as possible from their initial diagnosis to reduce transmission (CDC, 2020e). Historically there was a "one-size-fits-all" model that was not succeeding in providing bearable access to HIV/AIDS medication and support (Grimsrud et al., 2016, p. 21484). In order to treat more patients and improve patient outcomes, service deliverables must be enhanced to support clients (Barker, Dutta, & Klein, 2017). The care continuum was reviewed to track the percentage of people at each separate step of care, which helped develop initiatives to increase the rate of diagnosis and improve linkage (CDC, 2020c). Upon review of each survey, the participants revealed the model or care plan that is used at their agency.

Participant CC60640N1 did not identify a specific model; however, identified that "testing on demand … rapid, oral, or blood [testing options]." Linkage to care coordinators to help support the client "no matter the results of the tests," … this way they can obtain "PrEP or HAART the same day."

PrEP means pre-exposure prophylaxis, which is the medicine people at-risk for HIV take to prevent getting HIV from sex or injection drug use. When taken as prescribed, PrEP is highly effective for preventing HIV. Whereas, "HAART is a customized combination of different classes of medications that a physician prescribes based on such factors as the patient's viral load" (how much virus is in the blood), "the particular strain of the virus, the CD4+ cell count, and other considerations (e.g., disease symptoms)" (NIDA, 2012, p. 1). Because "HAART cannot rid the body of HIV, it must be taken every day for life. HAART can control viral load, delaying or preventing the onset of symptoms or progression to AIDS, thereby prolonging survival in people infected with HIV" (NIDA, 2012, p. 1).

Whereas participant CC60607N2 reported using the "patient center model, trauma-informed care, and harm reduction models" for providing care. Having "a lot of resources under one roof" is helpful. Participant CC60617N6 agreed that "all inclusive [service] teams … reduce barriers for clients … [by having] a one-stop-shop."

However, participant CC/WC6063760478N5 reported the importance of "shared decision-making," which supports participant CC60607N3's thoughts related to the agency using "patient-centered and trauma-informed" care.

Participant LC60072N4 identified the use of "client-centered and trauma-informed care," in conjunction with participant CC60607N2, participant LC60072N4 reported it is important "to look at the whole person … [including] mental, physical, social, and emotional well-being."

In general, no participant identified a standard healthcare model being used during this study.

Theme 4: Risk

People living with HIV/AIDS are more likely to have other health issues. Some of the problems can be related directly to HIV or linked to other chronic and terminal issues (Remien et al., 2019). The risk for people living with HIV/AIDS can present in many different ways, including acceptance of the disease, behavioral health issues (BH), mental health (MH), and substance use disorders (SUD) (Remien et al., 2019). These risks can either help improve or interfere with an individual’s ability to adhere to the recommended care regimen (CDC, 2020c). Statistics show that men who have sex with men (MSM) had the highest rates of viral suppression (46%), whereas substance users had the lowest rates of viral suppression (35%) (CDC, 2020). Upon looking at how the participants characterized their clients risk behaviors after receiving their diagnosis, the participants identified that the behaviors are different for each person.

Participant CC60640N1 reported that “it [behaviors] varies - most don’t change … maybe they use condoms more.” Participant CC60607N3 also believe that “[the behaviors] remain the same or slightly reduced.”

However, CC60640N1 also identified that “some people don’t accept their diagnosis ... most people follow up early [after diagnosis], but for others, its challenging.”

Participant CC60617N6 reported that “it [behaviors] varies” … “some [clients] are concerned about their health and how they take their medications.” However, participant CC60617N6 also reported that some clients “continue to have sexually romantic relationships without discussing their status, increase[d] SUD, or disengage from care until they come to terms with their diagnosis or disease.”

Participant LC60072N4 identified “some clients reduce risky behaviors; some struggle with acceptance; while some go through a serious depression and require therapy.”

While participant CC/WC6063760478N5 reported “I don’t consider behaviors as risk behaviors.”

Therefore, when inquiring about how the communities [that they work in] have been impacted by the prevalence rate of HIV/AIDS, the participants responded accordingly.

Participant CC60640N1 identified “the risk is more SUD and MSM, then SUD or MSM alone … most newly diagnosed are males but we have a large number of cis female HIV positive participants.”

Participant LC60072N4 agreed that “the community is impacted by HIV/AIDS through MSM, SUD, and intravenous drug use (IVDU) … we have a heterosexual population that contacted the virus via sex and drugs.”

Despite the number of people who may not know their status, participant CC60607N2 reported that “the Chicagoland area does a good job of tracking possible outbreaks in certain areas … public health identifies higher-risk populations … for additional help and education.”

Participant CC60617N6 reported that “this community is impacted by a moderate rate of HIV/AIDS that is related to MSM and drug usage … young people are the least likely to know they are infected.”

Whereas, participant CC60607N3 identified that a downside to her agency area is that “the data for this community is unavailable … [HIV] impacts Black and Brown people more than White people.”

And CC/WC6063760478N5 reported “50% will get HIV in their lifetime, in this community; however, there are many other social and structural things to worry about, and HIV/AIDS is not at the top of the list … COVID-19, violence, trauma, and overdose [are].”

In considering all things mentioned, the participants responded to their client’s overall healthcare needs and behaviors from diagnosis to linkage to care.

Participant CC60607N2 stated,

> Again, it varies. Some patients get scooped up into the system and take all the resources they can handle and really change their lives, accept their diagnosis, and reduce their risks by taking their meds … maintain good relationships with their PCPs and specialist to take care of their mental health.

Whereas, CC606007N3 reported that it is common to see “Hypertension (HTN) and Diabetes Mellitus Type II (DMII).”

According to participant CC60607N2 the downside to those who accept their status compared to those who do not, is that “[sometimes] it is too much for patients to handle right away; they have other issues (substance use/MH) and choose to ignore it.”

Yet, participant LC60072N4 reported that “If an individual struggles with acceptance, the health care practices are often interrupted and sometimes discontinued … all things considered the compliance [at my agency] is normal.”

Whereas, participant CC/WC6063760478N5 reported that “young men are not use to regular care, [they] just going in when things are bad … but women are different.”

And participant CC60617N6 mentioned that “stigma and risk of family disowning the individual are still very prevalent, so many of my patients are still hiding their diagnosis from their friends and family.”

Theme 5: Patient Support

Research shows that if PLWHA have a good care team to assist them through the care continuum, they are more likely to achieve viral suppression (Grimsrud et al., 2016). Practitioners need to know the complications that present and the best regimen of care when providing services for PLWHA, as well as techniques to educate and motivate patients to continue treatment (NRHA, 2014). During the COVID-19 pandemic, telehealth became increasingly popular across all medical fields, as patients could not go to doctors' appointments unless the medical issues were severe (CDC, 2020e).

When looking at patient support the participants were asked to describe the support that patients identified after diagnoses.

Participant CC60640N1 reported that "many clients come alone to receive results" … "[at times clients are] tearful, [express] sadness, worry/fear, PTSD activation, and shame."

Participant CC60607N3 identified that the support patients received was "compassionate and hard work to get the participants what they needed."

Furthermore, participant CC60617N6 reported,

> I believe my cisgender female patient's sense that something may be going on with them, but not suspect HIV. My SUD users are more likely to think that they have something [a sexually transmitted disease (STI)] but never expecting HIV, … [therefore, causing some of them] to be shocked, regret getting tested, [and] some acknowledge that life, as they know, has changed.

However, participant LC60072N4 mentioned,

> Some have the support of friends but fear telling their families, especially if they live a ‘high-risk’ lifestyle or use substances … [The patients have expressed that] some have thoughts that life would be better without them being present in the moment, but then it passes ... [There is also] falling to the floor and extreme sobbing.

Participant CC/WC6063760478N5 also mentioned the support that the clients have may be questionable due to “stigma, and having support from friends and family; [and] whether to disclose,” which might be related to “issues with romantic partners.”

Upon reviewing the responses that described the support that patients are given after recognizing these experiences, I asked how the providers made themselves available during these times, and how often does care coordination occur for PLWHA.

Participant CC60640N1 reported, “We have [office] hours, as mentioned previously, also an on-call provider every day” … “We have bi-weekly case discussions with our medical case management [teams], and most people cases are discussed at least monthly, if not more often.”

Also, participant CC0607N2 identified, “There was an on-call provider all the time.” … “We always have monthly meetings for providers, and I know there were special meetings for the HIV teams where they would meet to evaluate and revisit workflows and systemic processes.”

Additionally, participant LC60072N4 reported that “All emergency services can be handled at an ER; otherwise, as case managers, our clients have our phone numbers and can call us if needed.” As for the team meetings LC600724N4 remarked, “Our team meets weekly on high priority cases and bi-weekly to staff other client's cases" … "this helps provide comfort and reduce the uncertainty of what direction to take [with the patients]."

Participant CC60617N6 mentioned, "We have an on-call staff to assist with patient's needs" and "regular team meetings to stay current, as patients can call after hours, and we want to discuss the needs and changes versus just reading in the notes."

Whereas, many responses were supportive, there were a couple of participants who saw a need for improvement. Participant CC/WC6063760478N5 identified that the "younger patients have my phone number; older ones call the on-call provider" … also team meetings "need to be more systematically done as opposed to ad hoc."

Participant CC60607N3 also reported that they have "call services" and that the meetings occur "more often, initially, then as needed [as time goes on]."

Theme 6: Staff Support

When looking at the relationship between practitioners and patients' needs, what was determined is that the relationship between HIV specialist and non-specialist needs to overlap to provide better preventative services for PLWHA. In 2014, HRSA expanded the list of performance measures related to providing HIV/AIDS care (Landovitz, Desmond, Gildner, & Leibowitz, 2016). These expanded measures included viral load monitoring, influenza vaccination, hepatitis B vaccination, and the standard core HIV care measures (Landovitz et al., 2016). Annual fasting lipids testing panel, cervical cancer, chlamydia, gonorrhea, syphilis, hepatitis C, and tuberculosis (TB) were also another series of recommended screeners for PLWHA (Landovitz et al., 2016). These measures were explicitly identified due to the screening rates being lower for PLWHA versus the general population. It is well-known that providers who treat a larger number of PLWHA deliver higher quality HIV treatment. When reviewing the survey, questions were asked to see how these organizations help correct or recommend various support levels to their patients and caseloads.

Participant LC60072N4 identified that it is important to,

> Help the clients understand the available services through their healthcare insurance. We also attempt to schedule, if possible, all necessary things in one visit, … as this prevents the client from returning to the doctor a few times a week, initially.

Participant CC60617N6 reported, “We give food referrals to outside agencies, we ensure case management, set up transportation via medic car or bus cards, and we also teach the clients how to set up refills delivered to their homes to prevent interruptions.”

Yet participant CC60640N1 reported more general responses, such as, “We have expanded and open access, longer hours, and Saturdays (pre-COVID-19). Case managers have cell phones for patients to call them.” While participant CC/WC663760478N5 mentioned, “We provide resources and support, including food and transportation.”

Whereas, participant CC60607N2 noted that,

> This clinic was the first clinic that I worked at, and so I don’t have a huge frame of reference for other agencies ways of handling HIV care … I thought this clinic did a tremendous job of getting patients connected to medical, mental health, dental, care coordination, and administration seemed to work hard to identify

> barriers to care through HIV care team providers champions, as well as HIV case managers being able to provide feedback and practice harm reduction to reduce barriers.

However, CC60607N3 who has the least amount of time working in the field with this population reported, “I don’t know … at this time I’m not sure how to answer this question.”

Upon reviewing the responses related to how the agency helps to correct or process the situations after clients receive their diagnosis, participant CC60640N1 expressed, “We have integrated teams with counselors and case managers to help with severe reactions and secure patient safety [Immediate response and Delayed responses].”

Participant LC60072N4 reported, “We have onsite staff that can assist with the immediate trauma effects or information that the client can’t handle.”

Whereas, CC60617N6 identified,

> We invite them to bring someone who they trust to the appointments to help ease their concerns and increase understandings. We also suggest therapy, … and lastly educate until they are clear on what is going on in their bodies.

Participant CC/WC6063760478N5 shared a similar response reporting that “[We provide] counseling, inviting family and friends to come to an appointment, [and] referrals to therapy.”

However, participant CC60607N2 reported, “I have never been exposed to a negative type of situation during diagnosis. Our participants were provided with a ton of support.”

As for reviewing the types of trainings that each participant receives to help prevent re-traumatization, reduce internal stigma and stereotyping of clients, participant CC60640N1 reported, “Trauma-informed care training … actually tons of training annually, and some annual refreshers.” Participant CC/WC6063760478N5 reported that they are required to have “monthly training, both internally and with external consultants.”

Participant CC60607N2 identified that, “We always receive crisis management training, trauma-informed care education, and harm reduction training, which helped with these types of situations.” Participant CC60617N6 mentioned that, “We attend monthly training, including trauma-informed care, crisis intervention, and recognizing suicidal or homicidal ideations.”

Lastly, participant LC60072N4 expressed,

> We operate from a trauma-informed care approach, despite having this basic training … For more difficult cases, I seek supervision and debrief with my team … Training and continued education are crucial to this disease’s ever-changing conditions. HIV/AIDS does not have a look, a type, or a time, and everyone is susceptible if they do not practice prevention.

Theme 7: Treatment Diagnosis to Care

Revealing a status to a patient or participant can look different for various reasons. Some individuals could receive a positive diagnosis and become immediately accepting of the diagnosis, and others may have negative responses. During this initial interaction of informing an individual of their status, understanding the patient’s needs is essential to help ease the process. The participants were asked to provide a visual of a client's care process and to describe any additional services necessary for the client in conjunction with a positive diagnosis.

Participant CC60640N1 identified that,

> Patients are given labs and, hopefully, meds at the time of a positive test. They are connected with a case manager and healthcare provider, … referrals to SUD and behavioral health are offered. [The patients are also provided] a case manager, LCSW therapist, [and] psychiatrist if needed.

Whereas, participant CC60607N2 responded that,

> Patients typically present in 2 ways: they already have an HIV diagnosis and are seeking care or are coming into the clinic for testing and test positive. The medical provider does the ordering of the testing, and typically for a new diagnosis, we will use the help of care coordinators to help discuss new diagnoses, educate patients on their new treatment plans, and will start to guide them into care … typically help get them connected with social work as well, depending on their socioeconomic and mental health needs. [Additional services are available where needed, which include] mental health providers are standing by to help with crisis intervention or rapid stabilization.

Participant CC60607N3 detailed that, patients

> Present to the clinic for baseline labs that include an STI panel … for follow-up and additional labs … appointments with a provider, possibly with benefits, counseling, social work … follow up labs every three months to check for viral

> load until undetectable, then every six months or as needed. [Participant CC60607N3 also reported that] social work, case management, housing, benefits, literacy [is available] on ‘as needed’ (PRN) basis.

Participant CC60617N6 also reported,

> Clients report to the clinic to get tested, which includes a series of labs; they meet with the doctor and get placed with a team to help coordinate care … as the client continues the recommended medication regimen, the visits are lessened. [The agency also supported patients by having available] counseling, childcare, food services, transportation, additional insurance, medication support.

Whereas, participant LC60072N4 reported,

> Client’s report to the clinic from my standpoint post-diagnosis and is linked to a team of individuals that put together a comprehensive plan with the client to help reach an undetectable status, as soon as possible … From the case management stance, we conduct an assessment that looks into clients’ needs. [This participant also reported that] Case managers are critical to the clients being functional outside of the doctor’s office … [including connections to] counseling, case management, medication adherence conversation, [and] benefits specialist.

Participant CC/WC6063760478N5 identified that “[patients are] diagnosed … starting treatment; more visits and meetings in the beginning; but beyond the 1st year, if all is going well, can move to 2x/year visits.” Additional services suggested were “all sorts of social services, housing, ID card, employment, food, transportation, gender-affirming care.”

When asked to describe the problems that have interfered with HIV treatment adherence, the participants provided a variety of concerns. Participant CC60640N1 stated, “There are individual and structural barriers that contribute … behavioral health issues, SUD, lack of insurance, or ADAP … Structural barriers to care include hours of operation, shelter policies, language issues, trust, and trauma.”

Participant LC60072N4 reported, “This particular community is impacted by HIV/AIDS through MSM, SUD, and IVDU. We have a heterosexual population that contracted the virus via sex and or drug use with unknown individuals.”

Whereas, participant CC60617N6 identified that,

> This community has been impacted as the resources are not always plentiful, but they are present … Black and Brown people dying daily. There is the saturation of drug-infested communities where individuals are dealing with homelessness and chronic health issues, such as diabetes and hypertension.

Participant CC60607N2 identified,

> Although I do not provide direct HIV care to patients, I do take care of their primary care needs and have seen a lot of barriers to HIV care. The homeless suffer incongruently more with barriers to care than those who have housing … Patients have their priorities, like where they are going to sleep or eat today and sometimes with prescription assistance program and Ryan White funding.

However, some participants had responses that differed or were generalized from the others including participant CC60607N3, who reported that “this is the data that is available … it impacts Black and Brown people more than White people.” And participant CC/WC6063760478N5 identified “structural and social factors … [and] racism.”

The last question sought to identify how and why comprehensive care for PLWHA was implemented at their agency’s location. Participants responded with various ideas and one expressed uncertainty. Participant CC60640N1 reported “It is comprehensive … work, lots of paperwork and supportive, patient-centered [practices].”

Participant CC60607N2 noted that “at my agency, the extremely comprehensive care system of care for HIV/AIDS patients was already established, … so I can’t speak to the implantation process.”

Whereas, participant CC60607N3 mentioned that through “team-based care” and participant LC60072N4 reported that,

> It [implantation of care] is necessary. A client needs to know all the resources available to them to reduce stress and frustration, which negatively impacts their health … [lastly] ensuring that case managers are available because we are the heart of the individual’s care.

However, participant CC60617N6 identified that “having as many services in the same facility as possible or nearby for commuting people … finding ways to continue to reduce stigmas, so more help can become available outwardly, and more people can get tested.”

Thematic Summary

Each of the seven themes evolved from the participants’ responses. Those themes were access, adherence, meaning, healthcare model, risk, patient support, staff support and training, treatment, and diagnosis to care engagement. The participants described their experiences with providing care to women living with HIV/AIDS through developed semistructured open-ended survey questions. Each participant was allowed to answer the questions to the best of their understanding. There was only one time when inquiring about using a healthcare model where clarification without leading was necessary. The survey setup allowed the participants to see the questions reduced to the following categories of exploring known barriers, support and coping, disease acceptance, and area access. As the informed consent mentioned, the survey was entirely voluntary, and an individual could withdraw without penalty. Their experiences were all positive and hopeful for future changes in the delivery of services. The participants appeared happy about the services provided, as evidenced by their ongoing care and dedication to the field. One participant identified being in the field for two years whose responses seemed ambiguous and lacked experience in comparison to the other participants.

In theme one, participants expressed how working with women and trans women in the Chicagoland area varied from community to community and person and person in terms of access. Still, all localities and providers had the same end goal: to provide the best service to help reach an undetectable status.

There was an unspoken assertion expressed in theme two, that engagement in care and compliance to the recommended regimen of care allowed for the best chances at a prolonged life. The theme presented revealed that to provide the best care, a care team is critical to the engagement and retention of an individual. For all participants, access, resources, and medication adherence were an essential theme in answering the research question. Many participants stated keywords like additional medication or insurance, financial support, therapy and counseling, and improvement in socioeconomic and structural barriers in theme five. Other mentionable strategies included the importance of engaging in care early and finding the right support and medication regimen. I attempted to explore positive and negative feelings and emotions in the responses, but there were only positive and hopeful responses, as mentioned.

In terms of looking at the outside things that interfere with treatment adherence, the participants stated substance use, mental and behavioral health, and homelessness was more of considerable concern. This theme was developed under theme seven, which the sub-themes focused on additional needs for the patients from the initial diagnosis to care. In previous research articles, recurrent themes focused on systemic barriers or stigma (Abbott & Williams, 2015; Rodriguez & Dobalian, 2017), and made mention of things like childcare and transportation but did not go deep into conversations regarding how often these issues present. In examining the current participants' responses, the same themes of systemic barriers and a strong care team emerged. Overall, the participants' experiences revealed that having a good care team, in addition to, years of HIV/AIDS specialty service, provided the best opportunity to improve care and reduce barriers for PLWHA.

Evidence of Trustworthiness

This section discusses the study's credibility, dependability, and confirmability.

Credibility

Credibility in qualitative research is a way to look at the truth and value in the responses of the researcher’s findings (Korstjens & Moser, 2018). Through prolonged engagement and persistent observation, this researcher ensured that the data was raw and rich in context. Prolonged engagement is a long-lasting engagement in the field where you can become familiar with the setting and context to test for misinformation and get to know the data (Korstjens & Moser, 2018). I was able to set aside biases and personal experiences related to public health and HIV/AIDS. Persistent observation allowed me to identify the most relevant elements of the study by checking the information multiple times on different occasions.

Dependability

Dependability refers to the transparency and consistency of data analysis (Korstjens & Moser, 2018). Dependability also included the study’s interpretations and recommendations supported in the data received from the participants (see Korstjens & Moser, 2018). Since I emailed the survey, the participants had copies of their transcripts upon completion. I made an audit trail by compiling and reviewing the surveys and highlighted the responses as the participants emailed the survey results to the researcher.

Confirmability

Confirmability refers to the authenticity of each participant’s responses without influence by the researcher or deviation from previously published data (Korstjens & Moser, 2018). Confirmability was addressed by having all the participants respond to the same survey and several reviews of their typed responses after submission. I also removed any of my personal biases to prevent skewed data and or my interpretation of the data analysis.

Results

In this section, I present the findings from six participants using direct statements from their survey responses. Each participant worked directly with PLWHA in some capacity along the recommended HIV care continuum. Each participant volunteered to participate in the study by completing the survey. There was little to minimal risk to complete the survey. Each participant spoke about their efforts to acknowledge the needs, reduce barriers, and change their practices when working with PLWHA.

Of all the information received, there is still an increased need for access to education and care in specific communities, including the south side of Chicago and urban-rural clusters in Illinois Collar counties. There is also limited information available in the urban-rural cluster areas with no public records of PLWHA. This limited information prevents researchers from understanding the needs for PLWHA in areas thar are not being monitored. This does not mean that areas are lacking clinics but can more so speak to those individuals who may be unaware of their statuses. In searching for various agencies to conduct this research, many agencies identified that men were the primary patients. There was always a mention of women, followed by, but not enough women to conduct research here at this agency.

As for the practitioners and medical doctors, they contained a vast amount of experience and knowledge of working with PLWHA. However, with COVID-19 at the forefront of the community's it appears that providers may or may not have responded in-depth. For example, one of the participants in the Cook County area identified having worked in the field for approximately two years; her responses appeared to be vague and lacked substance. As for the remaining practitioners, the common theme was that both men and women still live with this chronic illness and all these patients experience the same barriers and needs during their care, especially in more impoverished neighborhoods.

Summary

In summary, my findings address the central research question. This study aimed to explore the barriers and challenges healthcare practitioners consider when providing care to HIV-positive women. The results illuminated that access, and structural and socioeconomical issues contributed to most barriers related to providing HIV/AIDS care. In reviewing the surveys, many of these similar themes and key words showed consistency in the needs associated with providing care. Overall, each participant provided and described their experiences in their words and to the best of their understanding. In looking at how this study related to Andersen’s behavioral model, ABM supports the need for longitudinal studies directly related to the client’s experiences versus the practitioners, the longitudinal studies can support and illustrate more thoughts associated with accessing care.

Chapter 5 will discuss the interpretations of the findings as they relate to the theoretical framework and literature outlined in Chapter 2. The chapter will present the study’s limitations, recommendations for future research, implications for social change, and conclusion.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this qualitative study was to explore the barriers and challenges healthcare practitioners consider when providing care to HIV-positive women. The participants' consisted of medical doctors and professors specializing in HIV/AIDS care, nurse practitioners specializing in HIV care, nurse practitioners specializing in internal medicine with HIV/AIDS experience, and case managers who work directly with PLWHA. In conducting this qualitative study, it was important to also consider the challenges and experiences from the practitioners' point of view. I used snowball sampling to recruit and survey six individuals who provided direct care and services to PLWHA.

Initially, I wanted to recruit participants from a Midwest community service agency serving persons with HIV/AIDS in and around the Collar County area in Lake County in urban-rural Illinois. However, the study's setting changed due to the COVID-19 pandemic to another large Federally Qualified Health Center organization that encompassed both the Cook County area and two of the Collar Counties (Lake and Will) of Illinois. These changes delayed my research efforts an entire term as I secured another organization. At that time, I was able to share my flyer with one person who asked other providers to participate in this study. Upon receiving emails from other providers of their interest to participate in this study, I determined their eligibility, and emailed the consent form to each of the providers. I administered the survey via an encrypted email. The survey consisted of 23 questions, including probing questions, to obtain richer, in-depth data. Each participant took approximately one to two days to return the consent form and four additional days to return the survey. Upon completion of the survey, each participant received a thank you email containing by a $10 coffee card. In the final email, I also implied that a future follow-up email might be necessary to obtain clarification for any survey response. In total, I had 10 people that showed interest in the study. Out of 10, six people returned the consent, including one medical doctor who acknowledged that she served more men than women and, therefore, could not proceed with the study. Of the six participants that completed the survey, there was one nurse practitioner who did not respond to one question, but indicated that she did not know how to respond.

In this study, emailing the survey provided for written transcribed responses, which reduced any transcription errors. I read each survey thoroughly and clustered the common observations into themes. In acknowledging the common themes, I did not want to take my known knowledge about PLWHA and miss the opportunity to explore additional identified information from the participants’ point of view.

During the reviews, I was able to identify and report how practitioners in Illinois helped to reduce or eliminate barriers for women living in urban-rural clusters. All participants identified their professional role and years working with PLWHA. All participants identified the same common interest of helping people who were diagnosed with HIV/AIDS to obtain access to medication needed to extend their life. The participants shared a common professional background, familiarity, and specialization with working with HIV/AIDS, and working with homeless or underserved individuals.

Participants responses revealed similarities related to the common themes of access, adherence, health care model, risk, support, trainings and support, and diagnosis to treatment. Participants noted that many patients travel within 10 to 15-mile radius within the Cook County area and spend up to 30 minutes in the Collar counties one-way. The common thoughts of adherence were for patients to effectively communicate, take their medication regimen as recommended by the practitioner, understand their additional needs, and how to obtain resources. In general, there is no standard healthcare model that exists in providing care to PLWHA; however, with a team of providers involved in the care planning, a prolonged life is possible.

Interpretation of the Findings

The CDC (2018a) identified that HIV/AIDS has been a global health concern for more than three decades. Overall, results from the participants' replies validated several findings from the literature. The results of my literature searches also showed how some research in the older literature may no longer be an issue that can be generalized. For example, the number of barriers identified from 2013 that impacted some patients adherence versus today's barriers and adherence concerns.

Previous data related to HIV/AIDS suggested that women in urban-rural areas are at higher risk for nonadherence and poor retention, which contributes to increased comorbidities and mortality rates (Mignano, 2016). Some of these risk reasons considered included stigma and confidentially concerns. These considerations related to the generalization of those that are higher risk can be considered inconclusive because those living with HIV/AIDS still have concerns related to stigma. However, the desire to live a longer life has increased adherence and retention for both women and men. The surveyed practitioners also identified that risk factors are still higher in men than women. The CDC (2020d) also reported that these higher risk factors include transwomen. These risks are backed by a study completed by the CDC and include increased and unmanaged mental health issues, substance use disorder, and continued denial of HIV status, in both men and women (CDC, 2020d).

As mentioned in Chapter 1, there is little to no information published on the care or best practices related to caring for PLWHA (Krebs et al., 2018). Each participant spoke about positive interactions with each of their patients in connecting them to care. The participants in this study did not identify any particular care model used; however, the main approach appears to be person-centered and trauma-informed practices.

Previous literature revealed concerns that no documented model is the best practical care continuum for those individuals living with HIV/AIDS (Nelson et al., 2018). In considering the theoretical framework of this study, Andersen's behavioral model (ABM), which was developed in 1968, the fourth revision was developed to understand the needs of individuals. ABM was developed to provide a theoretical framework for understanding how patients and environmental factors impact health behaviors and outcomes (Anthony et al., 2007). The use of the ABM also looks at the why's of an individual accessing health care services and how their needs and service usage could assist in policy development and promoting access (Andersen, 1995).

Pellowski (2013) spoke of many barriers to care, citing at least 27 known barriers that PLWHA—particularly women—experienced. In my survey, participants were asked about ways that they help to reduce known barriers for patients and the participant's responded that they help by providing transportation and providing meals. According to ABM for vulnerable populations, which contains factors that would affect the vulnerable populations access to health services, the barriers of transportation, accessing food, and adherence to care are categorized under the predisposing domain, the need domain, and the personal health practices domain (Gelberg et al., 2000, p. 1277).

As mentioned in my study, I included some information on men due to the literature primarily supporting studies that involve men. The discussion of transgender men, particularly those of color, are the least often to remain in care due to the HIV-related health disparities that persist, including stigma and heightened risk associated with sexual orientation (Schafer et al., 2017), which is classified under vulnerable predisposing factors (Gelberg et al., 2000). The ABM has three traditional conceptual categories including traditional predisposing factors, enabling factors, and needs factors (Gelberg et al., 2000). The ABM also has subcategories that include traditional/vulnerable domains (e.g., health status and satisfaction with care) and vulnerable predisposing factors that could impact health behaviors and outcomes, such as, social structure, personal/family resources, and perceived health (Gelberg et al., 2000).

Schaefer et al. (2017) conducted research related to what is known about HIV and what direction the healthcare field should be headed in. In this research, Shafer et al. (2017) identified that the HIV continuum of care has become the standard framework for understanding how HIV/AIDS has impacted the world globally and in developing interventions. The HIV continuum of care framework contains barriers and possible solutions that nonurban, rural areas face (Schaefer et al., 2017). The barriers that contribute to HIV epidemic include lack of access to primary care, lack of prevention and harm reduction services, limited affordable transportation, and lack of culturally congruent services (Schaefer et al., 2017). In addition, Schaefer et al. stated that the evolving opioid abuse epidemic poses a threat for increased HIV transmission.

The participants’ responses reflected concern for the HIV patients’ best interest, which was their care. Schafer et al. (2017) confirmed this finding in their study, but stated that despite the tremendous advances in the field of HIV across the continuum of care, much work remains to be done in the rural HIV epidemic. The participants’ priority was to ensure access to services and availability of resources for HIV positive women in rural areas to assist in reducing barriers. Anima-Korang (2017) and Schafer et al. (2017) confirmed these findings while noting the need for greater attention to the differences between urban and rural resource availability and the continuum of care. Each participant also mentioned systemic and social barriers that required a review from the state and local level. Randolph et al. (2020) confirmed systemic and structural racism are key factors affecting participation in HIV prevention and treatment services, especially for Black women. Randolph et al. also found that Black women have nearly 20 times the risk of White women in being infected with HIV, and lifetime HIV risk is greatest for people living in the southern United States. While Pellowski et al. (2013) found that a lack of socioeconomic resources is linked to the practice of riskier health behaviors, which can lead to the contraction of HIV. Yet Kalichman et al. (2017) found that living in poverty and a lack of food can result in transactional sex and power differences in sexual relationships, which can place an individual at risk of HIV infection. Even though HIV is predominately located in major urban areas, trends over the years suggest an increasing impact of HIV with women, minorities, older adults, rural residents, and those living in the South (National Rural Health Association, 2014; Petralia, 2016; Randolph et al., 2020; Reif et al., 2014).

In spite of each participants' efforts, their largest concern appears to be that urban-rural clusters are understudied. For example, in 2015, Lake County had 76% of men living with HIV/AIDS (*n* = 295 new HIV cases) versus 24% women; however, MSM mode of transmission was 50% and primarily impacting 35% Black males (AIDS Foundation of Chicago [AFC], 2017, p. 1, "10th District"), but there is no research undertaken pertaining to this population area. In 2015, Wills County had 75% of men living with HIV/AIDS (*n* = 253 new HIV cases), and 25% women; where MSM mode of transmission was 48% and impacting 43% Black males (AFC, 2017, p. 1, "11th District"), where to date, no research has been completed on this population area.

Regardless of urban-rural clusters being understudied, the reported numbers validated several findings from the literature. The literature related to HIV being understudied in urban-rural clusters continues to speak about the need for health departments playing a critical role in the HIV care coordination and prevention (Lightner, Shank, McBain, & Prochnow, 2020). There is also an increased need for trainings and stronger social networks for the care managers to assist in helping PLWHA. Due to the stigma and lack of testing sites identified throughout many rural areas, late-stage diagnosis is a big concern (Petrucci, Custer, & Nemec, 2019). Rural MSM are more likely to have migrated from an urban area back to a rural area with an AIDS diagnosis (Petrucci et al., 2019).

Another concern is that rural populations typically have community sociocultural expectations that could limit and prevent the need for testing, such as monogamous relationships and married individuals not desiring testing (Petrucci et al., 2019). Testing and communication barriers exist because if an individual were to test positive, it would shame the person or the family which would imply immoral behavior according to the community standards (Petrucci et al., 2019). The CDC (2019d) recommends testing everyone 13–64 years at least once as part of routine care, yet only 8% of providers screen for HIV, regardless of risk (Petrucci et al., 2019). Lastly, empowerment within communities is necessary to reduce stigma and support testing since women are typically overlooked and considered low priority on a local, state, and nation level (Petrucci et al., 2019).

Limitations of the Study

The focus of this research was to identify what do Illinois health care providers do to help HIV-positive women overcome barriers to adherence while continuing with recommended care continuums. This qualitative research study was to produce rich data to be used to show the efforts in the reduction of barriers. However, the data in this study had several limitations. The limitations of the study included understudied areas and limited research in Collar Counties (Lake and Will) and Cook County of Illinois’s Midwest area. Other limitations of the study included many agencies had minimal medical doctors and more nurse practitioners and case managers providing services for PLWHA. There appeared to be more Federally qualified health centers (FQHC) providing services for PLWHA than hospitals. Most of this study's results were derived from Cook County and two surrounding Collar Counties, whereas research in urban communities is rich and plentiful. However, rural areas are still understudied and have increased concerns and issues related to testing, treatment, adherence, and retention as this study indicated.

Another limitation might be the geographical location and inclusion criteria. I recruited practitioners who worked with women who were living with HIV in urban-rural clusters, in which specialty care providers are limited. I also chose to use the Chicagoland area and surrounding Collar Counties of Illinois; therefore, the findings of this study do not apply to the thoughts or experiences of all practitioners' in the United States or the State of Illinois.

Having an inclusion criterion that addressed women linked to HIV care was another limitation. When addressing how practitioners reduced barriers to care for HIV positive women already linked to care, it appeared that this study could have provided more information from those patients not engaged in care or a larger sample of practitioners. The gaps in previous research identified many of the barriers that patients experience; however, it did not identify how practitioners' help or deal with the barriers. There were additional providers who inquired about this study; however, they did not meet the data collection closing date.

Another limitation might be the development of my interview/survey tool. I originally planned to conduct face-to-face interviews, which changed to emailed surveys due to the COVID-19 pandemic. This change of process did not allow for the necessary probing to obtain richer data responses. Patton (2015) mentioned that there is a certain level of skill that a researcher needs in order to get in-depth responses when conducting qualitative interviews. I developed questions that aligned with the research question and that could produce a conversational or in-depth response. The study interview/survey tool received approval from IRB committee.

An added limitation to consider was the COVID-19 pandemic. COVID-19 created issues and changed priorities for individuals and agencies. COVID-19 is still active and continuing to alter the "normal" activities that individuals are use to doing daily. COVID-19 changed my desired agency and the way in which data was collected. Despite the interview/survey tool requiring moderate thought and little difficulties in responding to the questions, one participant struggled to answer a couple of questions. There were probing questions and clarifications used as a follow-up. This researcher did not interject any personal emotions or thoughts that would lead the responses in a different matter other than what was understood.

The last limitation to consider is the technical issues that were experienced, including limited access to scan and return the consent forms. In addition, there was the inability to observe the body language and facial expressions that would have been captured if face-to-face interviews were conducted. This researcher was able to utilize the paper trail of emails, and the written "I consent" attached to the emails to suffice for a stamped date, time, and consent for participation. I must note that two of the six participants to consent provided scanned signatures and consent forms.

Recommendations for Future Research

Early research denied and delayed the government from considering the issues that women faced, including the risk of HIV or those living with HIV (Corea, 1992). The NIH rejected women-centered grants that related to understanding cofactors of HIV in low-income ethnic minority women (Corea, 1992). However, women became a part of the research community in the 1990s after the CDC in 1993 reported that AIDS was the leading cause of death for African American women 25 to 44 years old.

The first AIDS case was reported in Illinois in 1980 (IDPH, 2016). Since the beginning of the epidemic in Illinois, HIV infection rates have been higher in males than females (IDPH, 2016). However, in 2000, women’s HIV infection rates increased (IDPH, 2016), predominantly impacting African American and Hispanic populations. This study focused on exploring how practitioners in Illinois reduce barriers for women living HIV/AIDS.

Future research could focus on the women that are living in rural settings and if the care differs from those in urban settings? The current research identified that there are less clinics and less practitioners with HIV specialization in rural areas. This was a small goal of mine in this research but there were not enough participants to determine this area of concern. Also, future research might look at encompassing all services into one clinic (e.g., labs, therapist appointments, provider appointments, and case management) might help increase appointment compliance.

Additional future research might attempt to understand if addressing medication beliefs amongst patients, who mistrust the medical care providers, might help improve medication adherence and healthcare outcomes. In addition, future researchers could examine if tele-health might help improve access, patient retention, and adherence while reducing stigma. Tele-health might be an important consideration based on the global pandemic of COVD-19, which the world has been experiencing. Tele-health offices in each rural clinic site might assist in reducing stigma, transportation issues, and increased confidentiality concerns since the appointment would appear to be a standard medical appointment.

Follow-up research might benefit from longitudinal studies to examine the different interruption areas, if any, to produce richer data experiences because patients, particularly rural, are prone to dropping out of care at various points of the HIV care continuum. Furthermore, developing a multilevel care model may be helpful in providing a standard for HIV/AIDS care. The barriers of engagement for HIV care across each stage of the care continuum needs further investigating because the sub-populations are not completely understood (Mignano, 2016). In addition, there is a need to understand how insurance providers can ensure that every patient living with HIV/AIDS receives coverage, whether private or public, and receives quality care.

Future research might also consider the migration process for those living with HIV. Past research indicates that people who are diagnosed in urban communities migrate to rural areas (sometimes returning home), which limits access and increases mortality rates due to comorbidities. Previous research also shows that people who may or may not be diagnosed in rural communities, often migrate to urban areas for increased access. Research is needed to determine whether HIV/AIDS stigmas are a precursor to or the result of residing in areas of lower or higher population density.

To conclude, one might consider conducting a study to determine and understand the challenges that individuals with mental health issues and substance abuse concerns are facing. Research suggests that individuals who are not stable on medication are more likely to disengage in care. The practitioners that participated in this research identified substance abuse disorders and mental health as barriers to remaining engaged in care. This study's findings should provide information for future researchers, practitioners, case managers, and individuals advocating and working with PLWHA. Although some participants, provided extensive information that allowed a small look into a much larger issue, there is still much more to learn and understand.

Implications for Social Change

The relevance of this research study, as it relates to social change, is that HIV disease continues to impact many individuals around the world. As a future researcher and a dedicated advocate for change in the field of HIV/AIDS, I proposed a research study that explored barrier reduction, which allowed for individuals to develop consistent healthcare and adherence in accordance with the HIV care continuum. The findings from this research might contribute to the efforts of current and future researchers, to inform and develop awareness to this population.

This study's findings may inform the public, governmental, and healthcare professionals of the barriers that still exist for PLWHA. These findings might also help to look at the systemic barriers that regulate and manage the healthcare systems, which create barriers and obstacles for individuals. The research can be constructed from various angles including talking to the practitioners, the patients, and the governmental advocates for HIV/AIDS. Determining how to prevent and improve barriers that interfere with treatment adherence, wrap-around services for individuals who identify with a HIV-positive status, and continued educational information for practitioners to consider when providing services to this vulnerable population is imperative to extending life.

As a person who is passionate about finding a cure for HIV/AIDS, I will continue to immerse myself in ways that would be more beneficial to the care and concern for people living with HIV/AIDS (PLWHA). The results from this study might provide a platform that can look further into providing and engaging women in care. Furthermore, these findings may help policy makers, healthcare administrators, and professionals to consider the services that are conveniently available to clients and how to improve care.

Conclusions

The purpose of this qualitative study was to explore how Illinois health care providers help HIV-positive women reduce barriers while continuing with the recommended care continuum. I used a snowballing sampling to recruit the six practitioners that provide care and support to PLWHA. I had some initial challenges obtaining surveys, but more participants completed the survey days before the closing deadline. The survey included semistructured questions that required approximately 20 minutes of the respondents’ time. Saturation was reached in surveying the six participants; however, I would of liked to have more participants from the Collar Counties. This research study sample included six participants, which identified as individuals who provided direct services to PLWHA.

This study was approved by Walden University IRB for data collection on March 2, 2020. Data collection commenced from June until July 2020. This study was guided by the framework of Andersen's behavioral model. The data that was provided by the participants was limited but consistent with current research. Based on the literature reviewed, it appeared that the 27 barriers presented as concerns and problematic throughout past research are still present; however, it appears that some of the barriers have been reduced. This study allowed for the participants to contribute their experiences with working with women who are HIV positive, and their struggles within an urban-rural cluster.

Summary

In this chapter, I presented content for the findings of my current research, as well as the interpretations of the findings as they related to the theoretical framework and literature outlined in Chapter 2. This chapter included a review of the limitations of the study, recommendations for future research, implications for social change, and conclusions.

Furthermore, this study found evidence that supports the fact that it takes a comprehensive team of professionals working with a patient to provide the best care to reduce health care disparities. An individual's health is affected by a complex system of social, economic, biological, and psychological factors (Parker, 2018). A comprehensive health team should be available to support many of the areas that HIV-positive individuals struggle with, including obtaining resources, case management, therapy, and transportation.

As researchers continue to work with this delicate population of individuals living with HIV/AIDS, I can only hope that researchers find a cure; however, in the interim, efforts are needed to ensure that all people living with HIV/AIDS have access to care, medications, and support while managing their chronic condition.

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Appendix A: Questionnaire

Introduction Statement

Hello, my name is Kenyata Fletcher and thank you for taking the time to participate in this dissertation capstone. This study seeks to explore the efforts of health care providers efforts in reducing or eliminating barriers to treatment for HIV-positive women. This questionnaire should take no more than 20 minutes of your time and has been divided into five categories. Please remember that this questionnaire is completely voluntary, and you may discontinue and withdraw your involvement at any time. Also, there is no monetary gain for me as a researcher. However, there is a $10 coffee gift card incentive for you as a participant upon return of this questionnaire.

(This study will continue if consent is given and inclusion criteria is met, otherwise, exclusion will be considered.)

Research Question

How do HIV/AIDS health care providers in Illinois help HIV-positive women in urban-rural clusters overcome barriers to adherence while continuing with recommended care continuums?

Do you have any questions?

Participants will be provided a county code (specific to their county) and unique identifier to protect their identity for example (Jackson county employee, site location (zip code), and interview number (N#) = J64289N5)

Demographic Questions

Please identify the following:

1. Describe your current job title, area or specialty of care, and primary population you serve?
2. Please describe your familiarity with HIV/AIDS disease?
3. How long have you been working in the field?
4. What is your gender?

Opening probing question: What does treatment adherence mean to you?

Identifying Barriers Questions

1. How would you describe the problems that have interfered with HIV-treatment adherence?
2. Can you give me a brief visual of a client's care process from initial diagnosis to the present time? *(including interrupted periods of care and reasons identified upon return*)

3. How would you describe the efforts that your agency is involved in to prevent or reduce these barriers?
4. How far would you say most clients travel for care?

Support/Coping

1. How would you describe the support that patients identify after diagnosis?
    a. *What type of situations has been identified?* ***(Probing)***
    b. *Describe how these situations are corrected or processed?* ***(Probing)***
    c. *Describe the additional services provided or suggested in conjunction with a positive diagnosis?* ***(Probing)***
2. Describe the support or training that the staff received to prevent re-traumatization, internal stigma, and stereotyping of clients?

Disease Acceptance

1. Can you identify from your perspective, how you would characterize the client's risk behaviors since receiving their diagnosis?
2. Tell me more about how the community has been impacted by the prevalence rates of HIV/AIDS in this county?
3. How would you describe the client's health care, risk/behaviors, and patterns upon diagnosis and linkage to care?

Residential Area Access

1. How would you best describe the availability of HIV specific services and care in this county?
2. Can you describe any areas or need for improvement regarding access to care?
3. Can you describe the model or care plan that is used by your agency?
4. Can you tell me how your agency deals with patients concerns or needs after hours?

Additional questions

1. How would you describe the implementation of the comprehensive care process for persons living with HIV/AIDS (PLWHA)?
2. How often is the coordination of care revisited for updates and improvement of services for PLWHA?

Are there any further questions that you may have or statements that you would like to share at this time?

Closing Statement

Thank you again for taking time to help me in my research efforts related to this important topic. I hope that I can learn and provide some valuable data related to this subject for future use. This information can be made available to you upon request, and if you have any questions or concerns, please feel free to reach out to me via phone or email. You may also contact Dr. Leilani Gjellstad at Walden University as mentioned in the consent.