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Experiences of Older Adults With HIV/AIDS Enrolled in Case Management Programs in Northwest Indiana

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Walden University
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Abstract

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MSW, Indiana University, 2010

BA, Purdue University, 2002

Project Submitted in Partial Fulfillment

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Abstract

In 2016, more than half of those infected with HIV/AIDS were age 50 years or older. Since the introduction of antiretroviral therapy, the survival rate of HIV patients has been on the rise with a predicted increase by 2030, but this has also contributed to early onset of comorbidities such as cardiovascular disease, osteoporosis, and kidney failure. The purpose of this generic qualitative study, driven by ecological systems theory, was to explore the experiences of older adults (age 50 and older) with HIV/AIDS who were enrolled in case management programs in Northwest Indiana. Data were collected from semi structured interviews with 13 participants. Data were analyzed using a content analysis approach. Findings showed that the participants' definition of case management programs aligned with their expectations, which were to receive support, education, and assistance in managing their health and locating financial assistance. Findings may be used to positively promote social change by identifying the areas of need for participants as they age.

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Dedication

On June 11, 1997 (high school graduation day), before I walked across the high school stage for the last time, my mother took a brief moment to write in my yearbook. Inscribed she wrote “To my lovely daughter, may you remain sweet and giving to all who are around you, and I hope to see a doctor in the family.” Through perseverance, this doctoral dissertation was completed not only because of the values instilled in me during my childhood and adolescence but also because of the dream my mother had for my life. I dedicate this dissertation to my mother because she taught me how to go after my dreams, whatever they may be. Although my mother did not live to see me graduate from college or go on to obtain my master’s degree, I hope that she is smiling in heaven, knowing that I fulfilled her dream for me.

Acknowledgments

First and foremost, I want to give all of the Honor and Glory to my Almighty Father without whom I am nothing. It is "Through You and with Your strength that I can accomplish all" (Philippians, 4:13). To my committee team, thank you for your willingness to take part in this important journey with me. Specifically, to my committee, Dr. Carolyn Ewing and Dr. SoNia L. Gilkey. To the Walden University Writing Center, thank you for your availability and quick response time. To the Walden staff and peers who have become wonderful friends throughout this journey, thank you for your support and guidance. To my spiritual family at New Revelation M.B. Church, thank you for your unconditional love, your encouragement and above all your prayers. Last, my gratitude and sincere thanks are extended to my family and friends. I appreciate your endless love, humor, and support in good times and bad. I love you to the moon and back. I look forward to the many fun times ahead.

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Section 1: Foundation of the Study and Literature Review

In this study, I explored the experiences of people age 50 and older living with HIV/AIDS enrolled in case management programs in Northwest, Indiana. As of 2019, the Centers for Disease Control and Prevention (CDC, 2019) reported that approximately 1.2 million people were living with HIV in the United States, and about 14% (1 in 7) were unaware that they had the virus. When antiretroviral therapy (ART) was introduced as a treatment for HIV, life expectancy was prolonged, reducing the mortality rates from 2.2 to 1.9 million (Negin et al., 2012). The advancements of antiretrovirals have contributed to individuals living longer lives, which has shifted HIV/AIDS to a chronic and mostly manageable condition (Cahill & Valdaz, 2013). However, many long-term effects go along with taking highly active ART (HAART). Individuals aging with HIV can often develop inflammation, cardiovascular issues, and kidney, liver, bone, and neurological diseases (Kearney et al., 2010). As the HIV+ adults age, their ability to metabolize antiretrovirals decreases, resulting in toxicity. Cahill and Valdaz (2013) showed that prolonged exposure to HAART may also increase the risk of heart attack or heart disease, putting people at a higher risk of death or contracting new illnesses.

Cognitive impairments can also present when HIV/AIDS patients have been on HAART too long. Recent research indicated that certain combinations of ARVs can cause bone loss or osteoporosis (Kearney et al., 2010). Additionally, older adults with HIV/AIDS become more susceptible to developing certain cancers, such as Kaposi sarcoma, aggressive B-cell non-Hodgkin lymphoma, and cervical cancers (Kearney et al., 2010). With each new diagnosis, the older HIV/AIDS patient develops further limitations to functioning, which affects their quality of life.

Between 1989 and 1992, the CDC (1993) recognized that the transmission of HIV could be prevented through HIV-prevention case management programs. HIV-prevention case management provides one-on-one client services for those who are HIV positive. The case management program offers education on the disease and prevention techniques that are designed to prevent unnecessary hospitalizations, increase medical adherence, reduce risky behaviors that result in the further spread of the virus, and assist in delaying the onset of symptomatic HIV disease, which improves the client's health status (CDC, 1993). The case manager's role is to link clients to medical providers, such as infectious disease physicians, primary care physicians, and dental care practitioners. Case managers also assist in enrolling clients in health insurance programs, public benefits, or medication assistance programs. Case managers also serve as a referral source to substance abuse and mental health treatments, food pantries, housing programs, and other support programs (Aliveness Project Northwest Indiana [APNWI], 2019).

This type of case management program also serves as a method to address psychosocial issues that affect this vulnerable population, and it has become a standard practice to provide comprehensive care for persons living with HIV and AIDS in the United States and has aided in improving their lives (Thurman et al., 2010). Studies have shown a link between case management services and higher adherence to medical regimens among this population (Thurman et al., 2010). Therefore, with improvements in medical treatment, medications, and utilization of case management programs, HIV-positive individuals can live well into their senior years (Emlet, 1997). By interviewing HIV patients age 50 and older enrolled in case management programs in Northwest Indiana, I hoped to understand their experiences aging with HIV and learn how case management programs play a role in managing their illness as they age.

In Section 1, I present the problem statement, purpose statement, research questions, nature of the project, significance of the study, theoretical framework, and values and ethics. Additionally, I provide key definitions. I conclude with a summary.

Problem Statement

According to the CDC (2019), approximately 1.1 million people were living with HIV in the United States, and about 14% (1 in 7) were unaware that they had the virus. As of 2018, more than half of those infected with HIV/AIDS were age 50 years or older (CDC, 2019). Across Indiana, there were 12,708 individuals diagnosed with HIV/AIDS (Indiana State Department of Health, 2019). In Northwest Indiana (Lake, LaPorte & Porter counties), 1,589 confirmed individuals were living with HIV/AIDS. Approximately 368 of the 1,589 HIV-positive residents were enrolled in the case management program in Northwest Indiana (APNWI, 2019). As of November 2019, 172 of those individuals enrolled were age 50 years or older (APNWI, 2019). Between 1989 and 1992, the CDC (1993) recognized that the transmission of HIV could be prevented through HIV-prevention case management programs. The diagnosis-specific case management program provides education on the disease, prevention techniques, and healthcare and psychosocial needs, which aids in delaying the onset of symptomatic HIV disease and prevents or reduces behaviors that result in the further spread of the virus while improving the client's health status (CDC,1993).

Historically, HIV/AIDS has been perceived as a young person disease (Hughes, 2011); therefore, case management programs and prevention interventions efforts were developed to target the younger population (Emlet, 1997). Thirty-plus years later, it is understood that HIV/AIDS patients have various needs and require different levels of assistance due to their circumstances. There are also significant differences in the psychosocial issues between a 25-year-old, a 50-year-old, and a 75-year-old living with HIV/AIDS (Cahill & Valdaz, 2013). As the needs of this population evolve, it is the social worker's responsibility to understand the varying needs of not only the aging population but also of those with chronic conditions such as HIV/AIDS (Cahill & Valdaz, 2013). Emlet & Poindexter (2004) reported that social workers lack knowledge about the services needed by older Americans.

The executive director of the APNWI, reported that in the 20-plus years of working in HIV services in Northwest Indiana and for the Indiana State Department of Health, staff had received no training to address the needs of those aging with HIV/AIDS (personal communication, November 5, 2019). Research in this area revealed a pattern of limited resources for HIV-positive individuals age 50 or older; as for Indiana or the Northwest Indiana region, no current research existed, which showed a need for additional research. Although studies showed how case management programs improve the lives of those impacted with this disease on a national level, HIV/AIDS case management programs in Indiana had case managers with limited knowledge and insufficient training on the needs of geriatric HIV/AIDS patients (Emlet & Poindexter, 2004). Therefore, I explored the clients' perceptions of what they think case management is and allowed them to describe their experience of case management based on their expectations, along with obtaining their perspective on what services would benefit them as they aged with this disease.

Purpose Statement

The purpose of this generic qualitative study was to explore the experiences of participants who are age 50 years and older living with HIV/AIDS and enrolled in case management programs in Indiana. Semi structured interviews were used to capture participants' perceptions of case management, expectations of program services, and age-related challenges. Findings may provide insights that lead to improved program services.

Research Questions

This study was guided by the following research questions:

RQ1: How do program participants, age 50 and older and diagnosed with HIV/AIDS, define case management?

RQ2: What expectations do program participants, age 50 and older, have of HIV/AIDS case management programs?

RQ3: How do the program participants, age 50 and older diagnosed with HIV/AIDS, describe their experiences in case management programs?

RQ4: Excluding current programs in place, which programs or interventions do the program participants, age 50 and older diagnosed with HIV/AIDS, desire as they age?

Nature of the Doctoral Project

The purpose of this generic qualitative study on aging with HIV/AIDS was to explore the experiences of older adults (age 50 years and older) enrolled in case management programs in Northwest Indiana. Although HIV case management programs have been proven an effective practice method, each patient enrolled in case management services may not have had the same experience as the next person. Royse et al. (2016) argued that human services professionals should consider whether the expertise and services consumers expect are available. Results from this study could benefit the social service agencies who provide services to older long-term HIV survivors.

Definitions

Antiretroviral medications: Drugs prescribed to control HIV, often made up of three different types of ARV agents from two different classes such as nucleoside reverse transcriptase, nonnucleoside reverse transcriptase inhibitors, and protease inhibitors (Nguyen & Holodniy, 2008).

Case management: A collaborative process of assessment, planning, evaluation, coordination of services, and advocacy for individuals and families (Eack et al., 2009).

Case manager or care coordinator (may be used interchangeably): A person (e.g., social worker or nurse) who assists in the planning, coordination, monitoring, and evaluation of services for a patient with emphasis on quality of care, continuity of services, and cost-effectiveness (Merriam-Webster, n.d.).

Comorbidity: A specific entity that develops during the clinical course of a patient with a specific disease being studied (Valderas et al., 2009).

Human immunodeficiency virus (HIV): The retrovirus generally agreed to cause AIDS; symptoms of HIV infection can include opportunistic infections, developmental regression, immune system dysfunction, and comorbid factors associated with pharmaceutical management (CDC, 2013).

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

Older adult: Individuals aged 50 years or older living with HIV disease. The definitional category is not only promoted by the CDC but is also used by most social science researchers, epidemiologists, and healthcare providers (CDC, 2013).

Significance of the Study

Since the 1980s, HIV/AIDS in the United States has been perceived as a young person disease, and life expectancy was between 1 and 2 years; as a result, case management programs and prevention interventions efforts were developed to target the younger population but did not consider the older adults aging with HIV/AIDS (Emlet, 1997). It was essential to evaluate the current HIV/AIDS case management program in Indiana to understand what the experience of people living with HIV age 50 years or older has been to determine whether the program was meeting not only the established goals of the Ryan White Care Act but also the growing needs of the consumer. Findings may improve understanding of the needs of the aging HIV/AIDS patients enrolled in case management services through their described experiences and expectations of case management programs. Additionally, the findings may reveal the challenges HIV patients age 50+ face and their experiences living with HIV and comorbidities.

The agency and the consumer could also benefit from this study in differing capacities. The agency care site may benefit from the findings on the areas in which they are doing well and areas that need some improvement based on participants' experiences and expectations of case management programs. Gathering feedback from patients is a part of engaging them in their care. Feedback from consumers provides an opportunity to highlight and address aspects of the care experience that need improvement (LaVela & Gallan, 2014). Feedback empowers agencies to make data-informed corrections to program services. When participants are allowed to provide feedback openly and honestly, they feel not only included but also validated when their voices are heard. Furthermore, when changes in program services have been made based on the participant perspectives, it creates a more significant buy-ins to the program services and increased adherence and improved overall health, which reduces the transmission of the disease (LaVela & Gallan, 2014).

Theoretical Framework

Through the lens of ecological systems theory, this study explored the experiences of HIV/AIDS patients age 50 and older enrolled in case management programs. Bronfenbrenner formed ecological systems theory in 1994. The ecological systems theory was initially used to explore the links between the developmental influences of children and the environment (Devyani et al., 2016). Bronfenbrenner (1992) reported that the natural environment is the primary source of influence in a developing person; moreover, human development is influenced by different environmental systems. Bronfenbrenner (1992 as cited in Hosek et al., 2008) identified five ecological systems: the microsystem (the immediate environment a person is in), the mesosystem (the relationship between two or more settings), the exosystem (the environment that a person is not directly involved in), macrosystem (consisting of larger structures), and chronosystem (the influence of environmental events and transitions over the life course) that impact an individual's development. The individual is at the center of the environmental systems ranging from the immediate setting, such as family, to more remote contexts, such as the broader culture (Devyani et al., 2016). Each tier can influence the patient's experience in case management. The current study focused on the patient's experience at the micro, meso, and macro levels.

The microsystem, the innermost environmental layer, refers to interactions in the person's immediate surroundings (Devyani et al., 2016). The microsystem is where the day-to-day practice occurs and most of the direct influence on the participant resides (Smith et al., 2019). Individuals enrolled in case management programs tend to be those who are likely to have lower income and education, be uninsured or underinsured, be on public insurance programs, have a history of mental health or addiction issues, and have limited support systems (Brennan-Ing et al., 2016). Because of the varying psychosocial problems, the participant's experience in case management programs can be influenced either positively or negatively (Devyani et al., 2016). Additionally, the severity of the patient's illness; the health care professional's knowledge and beliefs; and operating hours, location, and services can also directly influence the patient's experience (Adhikary et al., 2018).

The mesosystem (the relationship between two or more settings) is the second level of Bronfenbrenner's environmental layers. Although interactions within the microsystem impact the participant, links between contexts also influence the participant's experience (Devyani et al., 2016). For example, the communication or lack of communication between the HIV case management agency and medical providers or other service providers such as housing, mental health, and addiction programs can influence the experience of the participant enrolled in HIV/AIDS case management program services (Greenfield, 2012).

The macrosystem refers to the sociopolitical, economic, cultural context, and social institutions that shape the organization (Latkin et al., 2010). When legislative changes at the local or national level, along with inadequate or reduced Ryan White government funding, restrictions in case management and other supportive services and shifts in the controlling political party occur, it affects a patient's experience in case management programs in some way, shape, or form (Brennan-Ing et al., 2016). Additionally, events that happen at the macro level may impact the patient's experience at the micro and meso level because some events on the macro level may influence the individual through the availability of resources (Latkin et al., 2010). For example, an economic crisis at the macro level could leave individuals with fewer resources, such as employment, health insurance, housing, and food. Therefore, the interactions or experiences individuals have with others and within these various environments are essential to human development (Hosek et al., 2008). When used to evaluate HIV/AIDS case management programs, ecological systems theory supported the idea that the environment can influence a patient's experience.

Values and Ethics

Values and ethics have philosophical and practical significance for the profession of social work. The National Association of Social Workers (NASW, 2021) core values and ethical standards guide social workers' choices and actions across various roles, settings, and client populations. Values and ethics help to distinguish social work from other professions and provide a basis for accountability. Ethical decisions rely on a solid understanding of the codes that guide the profession, on practitioner self-awareness, and on the use of thoughtful, thorough frameworks for weighing choices when dilemmas or conflicts arise (Sobocan et al., 2019). Social workers must understand concepts such as self-determination, confidentiality, informed consent, competence, and conflicts of interest and how these standards may be challenged or upheld in practice and research (Sobocan et al., 2019).

Research is essential for the continued growth and improvement of the social work profession and the development and refinement of program services that benefit vulnerable populations such as those aging with HIV/AIDS (Council on Social Work Education, 2001). According to the NASW (2021), researchers help assess the needs and resources of the people served in their environment and evaluate programs and their effectiveness. Social work researchers have the responsibility to conduct research informed by the professions' values. The social worker has a duty to promote social justice and challenge discrimination and unjust policies and practices that the identified populations may face (Sobocan et al., 2019). In the current study, I explored the experiences of HIV/AIDS patients age 50 and older enrolled in case management programs while keeping the NASW core values such as service, social justice, importance of human relationships, integrity and dignity, and worth of a person in mind.

Service is the primary goal of all social workers. Service is the value from which all other social work values stem. Social workers often place others' needs above their interests and use their skills and knowledge (from education and experience) to help people (NASW, 2021). Service is vital in case management practice with older clients dealing with HIV because older people living with HIV often experience stigma and discrimination, which can lead to social isolation, loneliness, depression, minimized health-seeking behaviors, and concerns with older care situations (Brennan-Ing et al., 2016). Through the NASW core value of service, social worker case managers can utilize their knowledge, values, and skills to address the older patient's concerns (NASW, 2021).

Social workers also advocate on behalf of the oppressed and voiceless or those unable to advocate for themselves. I incorporated the NASW social justice core value by allowing participants to respond freely. Throughout the process, confidentiality enabled participants to feel included and validated when their voices were heard. Furthermore, when changes in program services have been made based on the participant perspectives, it creates a significant buy-in to the program services and increased adherence and improved overall health, which reduces the transmission of the disease (LaVela & Gallan, 2014).

Dignity and respect are something that every person has a right to have. To maintain public trust and confidence in human research, participants must be treated with respect (Pieper & Thomson, 2014). Because each person is different and comes with a separate set of cultural and social values, the researcher needs to be mindful of those differences by treating each person with dignity and respect throughout the research process. Social workers must also display integrity and behave in a trustworthy manner (NASW, 2021). Therefore, when highly sensitive information, such as an HIV/AIDS diagnosis, is present, the researcher must attempt to alleviate the possibility of intrusion into the participants' autonomy (Sanjari et al., 2014). The consenting process ensured each participant understood the study's purpose, benefits, and risks, and their right to withdraw from the study at any time.

When working with individuals in HIV/AIDS programs, it is essential to maintain human relationships. Each participant had differing experiences, some more tragic than others; therefore, social workers are responsible for exposing each participant's strengths and using them to teach the participants how to communicate effectively with others. In the current study, if a participant expressed some concerns that had not been addressed in the case management program, or if they experienced some discomfort or stress in the interview process, they would have been provided with a referral to ancillary services to assist them in processing their concerns (see Sanjari et al., 2014). No participants expressed concerns; therefore, no ancillary referrals were made.

As indicated in the NASW (2021) code of ethics preamble, "the social work profession's primary mission is to enhance human wellbeing" (NASW, 2021), which should be considered when conducting ethical research. However, the NASW core value of competence should also be regarded in social research. Competence in social work practice means the social worker will practice within their area of expertise, and when there are areas in which they are not knowledgeable, they will strive to increase that knowledge through research and continuing education (NASW, 2021). Social workers should routinely review the professional literature and keep current on the emerging knowledge relevant to the social work practice (NASW, 2021).

Sanjari et al. (2014) also reported that competence and expertise are achieved when research is conducted, and from that research, practitioners can choose reliable and evidence-based interventions. Evidence-based interventions also lead to outcomes that further develop the profession, leading to competence in the field. Competence is not stationary; it is a never-ending process that comes with being a social worker. Competence should not be limited to working professionals but should be expanded to all human beings. Regarding case management with older clients who are dealing with HIV/AIDS, social work competence in HIV case management is critical because failure to be knowledgeable in HIV services can delay medical treatment, adherence, and enrollment in ancillary services for this population, thereby affecting mortality, overall quality of life, and spread of the disease (Relf et al., 2011). Results of the current study may contribute to the field of social work by providing future social workers and those affected by HIV/AIDS with evidence of how those aging with HIV/AIDS are impacted at the micro, meso, and macro levels and how case management services can demonstrate accountability for the organization of patient care and build respectful relationships among care partners (Brennan-Ing et al., 2016).

Although the NASW code of ethics does not guarantee ethical behavior, it establishes parameters to ensure that clients are treated with respect and dignity. I sought to describe each participant's experience in HIV/AIDS case management programs and explore any policies or practices that may conflict with the programs' goals and objectives or the NASW code of ethics. Current findings may contribute to the competence of future social workers in the field of HIV/AIDS or those working with individuals aging with HIV/AIDS.

Review of the Professional and Academic Literature

To conduct this literature review, I searched for peer-reviewed full-text articles in the Walden Library databases, including Medline, ERIC, ProQuest, and SAGE Journals, and internet search engines such as Google Scholar and APA PsychNet. The following keywords for the primary search were used to initiate a search of aging with HIV/AIDS: *successful aging with HIV/AIDS*, *medical case management*, *HIV case management*, *Ryan White Care Act*, *patient experience*, *evolution of case management*, *older adults with HIV*, and *geriatrics*. Six themes were identified in my literature review: a brief history of HIV/AIDS, HIV infection in older patients, the evolution of HIV/AIDS case management, government funding of HIV case management programs, HIV case management programs in Indiana, and impact of case management on HIV client outcomes. Additional articles were located that were relevant to each theme. Key terms including *elderly response to antiretrovirals*, *comorbidities*, *psychosocial issues,* *challenges for older HIV patients*, and *HIV case management programs* were used to expand the literature search for potential articles relevant to the study.

History of HIV/AIDS and Its Impact on Older People

HIV weakens the immune system by destroying CD4 cells (T cells) that fight disease and infection (CDC, 2019). HIV is the virus that causes AIDS and is mainly transmitted from person to person through bodily fluids during sexual contact and IV drug use or from an infected mother to fetus in utero or through breastfeeding (CDC, 2019). Untreated, HIV reduces the number of CD4 cells (T cells) in the body, making the person more likely to get other infections or infection-related cancers. Over time, HIV can destroy so many CD4 or T cells that the body cannot fight off infections and disease. These opportunistic infections or cancers take advantage of a fragile immune system and signal that the person has AIDS, the last stage of HIV infection (CDC, 2019).

It has been widely believed that the evolution of HIV/AIDS began in Kinshasa, in the Democratic Republic of Congo, around 1920, when HIV crossed species from chimpanzees to humans (CDC, 2019). Sporadic cases of AIDS were documented prior to 1970, and data suggested that the epidemic started around the mid to late 1970s. It is unknown how many people were infected with the virus by the 1980s, and during that period, HIV was unknown, and the transmission was not accompanied by noticeable signs and symptoms (CDC, 2019). By 1980, what became known as HIV had spread to five continents (North America, South America, Europe, Africa, and Australia), infecting between 100,000 and 300,000 people (CDC, 2019).

In 1981, there were five cases of a rare lung infection called *Pneumocystis carinii* pneumonia, which was found in a small group of gay men in Los Angeles, California (Avert, 2019). There were also reports of several men who had an unusually aggressive cancer called Kaposi's sarcoma. By 1982, as scientists learned more about the disease, they understood that the cause of these immune deficiency diseases was sexually related (Avert, 2019). Currently, there is no cure or vaccine for HIV; however, the disease can be managed through ART, adequate nutrition, and proper medical care (Venter et al., 2009). Although there are antiretroviral treatment options available, like any other medication, they can influence each person differently, specifically older people, and the side effects can be more aggressive than they are with younger people causing bone density loss, kidney and cardiovascular issues to name a few (Venter et al., 2009).

Over 30 years ago, there was limited knowledge and treatment options available (Emlet, 1997); therefore, aging issues were not a priority at that time, and the research did not focus on individuals growing old with this disease. Recent literature showed that not much has changed as the funding and programs available continue to target the younger population while minimizing the need to understand how HIV/AIDS impacts the aging adult (Moremen, 2015). Aging with HIV is an urgent issue due to the increasing number of people over the age of 50 living with HIV/AIDS (Chambers et al., 2014). Older adults in HIV research are often defined as age 50 and older (Emlet et al., 2002). Older adults make up several distinct groups, such as the long-term survivor, newly diagnosed, individuals who are not aware of the diagnosis, and people who engage in risky behaviors that may put them at risk for HIV (Emlet et al., 2009). According to the CDC (2019), this population accounts for 17% of the 39,782 new HIV diagnoses in the United States. This group also represents 19% of all AIDS diagnoses, 29% of people living with AIDS, and 35% of AIDS-related deaths (CDC, 2019). As a result of the advanced treatment options available, the mortality rate of older HIV patients has decreased over the years (Simone & Applebaum, 2008). According to Adekeye et al. (2012), HIV is no longer considered an immediate death sentence. The life expectancy of HIV-infected people after receiving HAART is now extended, approaching that of the general population (Manfredi, 2002). With continued advances in medical care, there may be further increases in longevity (Adekeye et al., 2012).

Although the advances in modern medicine have increased longevity, HIV in older adults is still a concern due to the physical, mental, and psychological issues associated with aging and HIV (Chambers et al., 2014). Aging with HIV is reported to be linked to multiple chronic conditions such as diabetes, cardiovascular disease, osteoporosis, and chronic kidney disease despite numerous treatments such as nonnucleoside reverse transcriptase inhibitors, protease inhibitors or combination therapy, and also linked to concurrent viral infections, substance abuse, mental health issues, and polypharmacology (Chambers et al., 2014). HIV/AIDS has not spared any age group, specifically older people (Adekeye et al., 2012). Data from the CDC also indicated that older adults are more likely to be diagnosed at a later stage than younger patients (CDC, 2016; Chambers et al., 2014) due to the perception that older adults are not considered an at-risk group because it is assumed that this group is not sexually active (Moremen, 2015).

Despite common misperceptions, risky sexual behaviors exist in older people as well (Adekeye et al., 2012). HIV screening of older adults should not be overlooked. However, a diagnosis of HIV in older patients is often delayed because of the perception that HIV is an infection of the younger population or that sexual activity is uncommon in older adults, despite the evidence that showed a large number of people living beyond age 50 are sexually active (Kearney et al., 2010). Failure to screen older adults can lead to late diagnosis, contributing to poorer health prognosis, advanced immunodeficiency, increased risk of developing AIDS, and short-term mortality (Chambers et al., 2014).

Another reason why older adults are not being screened for HIV or other sexually transmitted infections (STIs) is that the older adult is not transparent about sexual activity (Greene et al., 2013). Almost a decade ago, Green et al. showed that in the United States, after age 50, only 38% of men and 22% of women report discussing sexual activity with their physician. Greene et al. also noted older adults often lack an understanding of HIV transmission, do not perceive self-risk, and are less likely than younger individuals to use condoms even when they have multiple sexual partners. Some high-risk behaviors, such as needle sharing, may be less frequent among older drug users, but sexual risk-taking, including sex in exchange for money or drugs, is not (Green et al., 2013). Likewise, according to the CDC (2016), women who are no longer worried about becoming pregnant are less likely to practice safe sex.

Older People’s Response to Antiretrovirals

According to Mpondo (2016), old age is associated with rapid progression of AIDS, but since 1996, when HAART became available and widely used, Nogueras et al.

(2006) reported that HIV infection transitioned from acute to subacute disease to a chronic and controllable condition. The use of antiretrovirals that assisted in managing HIV disease also contributed to the dramatic increase of people aging with HIV disease (CDC, 2016). Individuals successfully treated for HIV continue to have an overall improved long-term prognosis; however, there are long-term consequences of using these drugs in older HIV patients. Compared to HIV uninfected persons, long-term treated HIV-positive adults are at an excessive risk of a number of HIV-associated illnesses. These non-AIDS conditions are typically linked with advancing age, such as cardiovascular disease, kidney disease, liver disease, osteoporosis, cancer, and cognitive impairment (High et al., 2012). HIV also causes a loss of effective immune surveillance, contributing to cancers and other complications (High et al., 2012).

The use of ART on HIV-infected people is a likely factor in the premature development of specific age-associated diseases (High et al., 2012). Allavena et al. (2018) also suggested that the toxicities from these medications may play a role in specific organ systems and interact with medical conditions typically associated with advanced age. For example, Tenofovir, commonly used as a first-line regimen in some African countries, has been declared nephrotoxic; it can exacerbate renal insufficiency in older patients, primarily when used with other protease inhibitors (Mpondo, 2016). There are limited data on the toxicities of ART in the older population because most studies exclude older patients (Mpondo, 2016). Still, the data showed that toxicities with ART are more common in older people than younger people.

Onset of Comorbidities

With HAART, HIV has become a manageable chronic disease by decreasing opportunistic infections, but non-HIV-related complications have been on the rise with older patients (Mpondo, 2016). Multimorbidity increases as individuals age, and comorbidities such as cardiovascular disease, diabetes, osteoporosis, depression, and dementia are more common in this population (Allavena et al., 2018; Kearney et al., 2010). Both old age and HIV can also lead to a reduction in muscle mass. Patients taking multiple drugs are at an increased risk for falls due to drug-to-drug interactions, adverse drug effects, increased hospitalizations, and poor adherence (Mpondo, 2016).

Management of older adults with HIV and multiple comorbidities presents challenges to infectious diseases physicians and geriatricians alike. Older HIV-infected patients are also prone to having similar chronic diseases as their HIV-negative counterparts, as well as illnesses associated with co-infections. Age-related physiological changes may affect the pharmacokinetics and pharmacodynamics of antiretrovirals and comedications, thereby predisposing the older person to adverse drug reactions (Back & Marzolini, 2020). Additionally, when added to an antiretroviral regimen, medical treatments associated with these conditions increase the risk for polypharmacy (Simone & Applebaum, 2008). Polypharmacy also brings its own challenges for this population, such as pill burden, which causes harmful effects to treatment adherence, adverse drug reactions with overlapping side effects, physical decline, cognitive impairment, frequent falls, hospitalization, and mortality (Back & Marzolini, 2020).

Each patient who takes ART for treatment of HIV/AIDS will respond differently. Some may acquire various comorbidities, and others may not be affected at all. Allavena et al. (2018) conducted a cross-sectional study to compare a French Dat' AIDS cohort, the population age 75 and older (16,436 subjects), to an older group age 50 to 74 years (572 subjects) to assess the extent to which the 75 and older population aged differed from the 50–74 population in terms of demographic and immuno-virologic characteristic, ART history, current ART, and comorbidities. Results showed that the comorbidities were significantly more frequent in the 75 and older group, except for dyslipidemia (abnormal amount of lipids). The most frequent comorbidities in the 75 and older group were dyslipidemia (60.8%), hypertension (43.5%), chronic renal disease (29.4%), and cardiovascular disease (23.4%). In the 75 and older group, 32.2% of the subjects had no more than one comorbidity, 49.5% had 2 or 3 comorbidities, and 18.4% had four comorbidities or more, compared to 60.1%, 34.7%, and 5.3%, respectively in the 50–74 group. Overall, comorbidities are increasing with age and may be induced or worsened by ART (Allavena et al., 2018).

Psychosocial Issues

As more is learned about how HIV/AIDS affects individuals from the biological standpoint, less is known about how aging with HIV/AIDS influences those from the psychosocial perspective (Emlet, 1997). Although HIV/AIDS has become a manageable disease as of 2020, people living with HIV/AIDS (PLWHA) continue to have many challenges, such as increased social isolation, discrimination, disclosure, and stigma, which impacts their self-image and mental health and can prevent them from adhering to treatment recommendations (HIV.gov, 2021). Emlet and Pointer (2011) disclosed that older adults who receive less social support and experience barriers to services and stigma are at higher risk of experiencing psychological symptoms. Moreover, older adults with HIV/AIDS must also confront problems in service availability and encounter staff who are not knowledgeable in the emotional and psychological issues that influence this group (Zelenetz & Epstein, 1998). Disclosing HIV status to family and friends produces a fear of rejection or a feeling of shame that increases the chance of depression (Emlet, 1997). Older adults showing difficulty with expressing interpersonal emotions have been reported to have trouble accessing services such as support groups, case management, or counseling services (Emlet, 1997).

PLWHA continue to have many challenges that can prevent them from adhering to treatment recommendations. Stigma, cultural implications, race, age, sex, sexual orientation, health care illiteracy, discrimination, lack of nutritional foods, and socioeconomic factors are some of the issues that impact this group of individuals. Likewise, HIV disease disproportionally affects people who are in poverty and can lead people into poverty due to the high costs of medications, medical treatment, and inability to work that is often accompanied by loss of employer-related health insurance (Thurman et al., 2010). Additionally, older people with multimorbidity are at risk of receiving fragmented care because of complex health systems. Emlet and Poindexter (2004) reported that interventions such as case management programs have been effective in addressing some of the challenges faced by this population and have become the standard practice in assisting PLWHA.

Origin of Case Management

Case management is not a new concept or a new patient care function. However, case management has gained increased popularity over the past twenty-plus years (Tahan, 1998). Depending on the client population and context, the definition of case management may vary. Case management also referred to as care coordination, is considered a complex, integrated health and social care intervention that is mainly used for patients or patient populations that require intensive levels of care (people in the terminal phase of life, elderly, frequent hospitalizations, high-risk socioeconomic factors, and the mentally ill) (Lukersmith, Millington & Salvador-Carulla, 2016). Case management is a collaborative process of assessment, planning, evaluation, coordination of services, and advocacy for individuals and families (Eack et al., 2009). The overall purpose of case management is to improve satisfaction, quality of life and to reduce costs associated with frequent users of services (Eack et al., 2009). Case managers are responsible for promoting increased quality of care, resulting in improved life through coordination of resources, integrating different professional contributions, and ensuring continuity of care through all stages of treatment (Fabbri, De Maria, & Bertolaccini, 2017).

The roots of case management went back to the early 1800s and were first used in settlement houses for immigrants and the poor (Tahan, 1998). In 1900, the visiting nurse service, called home health care services today, was established to provide comprehensive care to patients in the community setting (Tahan, 1998). Care coordination, another model of case management formed in 1901 and was a preferred approach used by social workers. The care coordination approach focused on linking individuals and families with available resources (Tahan, 1998). Case management also branched out into mental health during the 1950s after World War II, when the disabled, mentally ill, and emotionally disturbed veterans and their families needed extensive assistance (Tahan, 1998). During the 1960s, the government created a policy to move mental health patients out of state-run “insane asylums” into federally funded community mental health systems as a way to improve treatment while cutting government funding. Case management was a response to the deinstitutionalization of the severely mentally ill population. Deinstitutionalization had a significant impact on the mental health system, including the client, the agency, and the counselor (Lukersmith, Millington & Salvador-Carulla, 2016). When clients with serious mental illness presented challenges with learning to live in the community, mental health agencies responded to these specific needs, using case management programs, thus requiring a shift in how services were delivered and how mental health counselors need to be trained (Lukersmith, Millington & Salvador-Carulla, 2016). Around the 1970s and ‘80s, there was a noticeable increase in the cost of health care and decentralization of health services which influenced the role of case managers (Lukersmith, Millington & Salvador-Carulla, 2016). Therefore, by 1970, Medicaid and Medicare programs were established, and case management became an essential focus of demonstration projects funded by the Medicaid and Medicare waiver programs (Tahan, 1998). By 1980 the prospective payment system was established, which introduced case management models into existing patient care delivery.

By the 1990s, managed care organizations began increasing their use of case management in all care settings to assist in controlling patient care costs (Tahan, 1998). Therefore, case management was implemented in countless settings such as acute, post-acute hospitals, rehabilitation centers, long-term care facilities, and community-based settings (Lukersmith, Millington & Salvador-Carulla, 2016).

Specialized or diagnosis-specific case management programs also began to form around this time frame. There are various types of specialized case management programs such as mental health, addiction, developmental disabilities, oncology, renal, home health care, housing, HIV/AIDS, etc.; however, each program can include the older adult but is does not focus on their specific needs (You et al.,2012). As people grow older, their health needs are likely to become more complex and chronic. The quality of life in chronic illnesses can vary with age, especially with older adults (Hyduk, 2002). Chronic conditions can affect their mobility, functional status, emotional balance, and self-esteem declines because of their dependence on others (Somrongthong et al., 2016). Case management can help older adults access services and resources to improve their quality of life and age safely in place (Wacker & Roberto, 2008). This form of specialized case management is a key component in social work and is often the treatment of choice when working with the elderly (Morrow-Howell et al., 1992).

Specialized case management programs can identify psychosocial issues using comprehensive assessments and can help address the older adult’s concerns through care plan development, service implementation, patient-centered interventions, monitoring, and reassessment (Wacker & Roberto, 2008). Patient-centered interventions can include psychotherapy, psychoeducation, and teaching independent living skills (Morrow-Howell et al., 1992). For those older adults and their families that are struggling with the patient's physical limitations and cognitive impairments, psychosocial interventions such as problem-solving and supportive therapy can be utilized (Morrow-Howell et al., 1992).

There is no standard definition for case management with older adults, and the role of the case manager will vary depending on the patient's needs; however, the overall goal for older adult case management is to assist the service provider in containing cost by managing the patient's care (Hyduk, 2002). Yu, Gallant, & Cassidy (2020) note that case management is not only a practical approach to reduce health care expenditures, but it also improves patient outcomes (Yu et al., 2020). Older adults with chronic illnesses or disabling conditions that need more medical care, psychological and physical support than the average individual would benefit from case managers (Yu et al., 2020).

There is limited research available on how case management may improve the health and wellbeing of older adults (Hasche & Lavery, 2015). The research is limited to describing the roles, the psychosocial needs, and achieved outcomes rather than its use and application in various settings and its impact on the aging adult (Hasche & Lavery, 2015). In an effort to demonstrate the impact case management has on older adults, You et al. (2012) conducted a systematic review to evaluate the effects of case management in community aged care on the patient and the caregiver outcomes. Ten randomized control trials (RCTs) and five comparative observational studies were identified in the systematic review. The researchers summarized the effects of case management interventions in community-aged care based on whether the majority of the studies reported significant positive outcomes for this population. Client outcomes included mortality, physical or cognitive functioning, medical conditions, behavioral health issues, unmet service needs, and psychological health or wellbeing, and satisfaction with care. When examining mortality/survival days, there was a significant effect of case management in the community aged care intervention on reducing patient mortality. However, there were inconsistent results for case management effect on physical and cognitive functioning.

You et al. (2012) noted that the case management intervention had more of an effect in the long term rather than the short term. Reviews of medical conditions indicated that patients reported less pain while enrolled in the intervention, whereas others reported no significant difference. In the category of psychiatric or behavioral problems, they did not find a significant intervention-control group difference (You et al., 2012). In improving unmet service needs for the community aged, the research showed that case management interventions had a significant effect on enhancing clients' unmet needs (You et al., 2012). Psychological health and wellbeing also had more evidence for good outcomes of case management interventions for older patients (You et al., 2012). The researchers concluded that a large proportion of older adults would continue to use case managers to assist them in advocating for their needs. The overall review provided consistent evidence that case management interventions improved older adult patients' psychological health or wellbeing and displayed significant improvements in unmet service needs (You et al., 2012). In contrast, there were inconsistent or mixed results in how case management affects the physical or cognitive functioning in older adults. (You et al., 2012). The limitations of the study were that the researchers did not review studies that compared different types of case management, and they did not search studies that were published in non-English journals. Further research was recommended to investigate what specific components of case management are crucial to improving client/patient outcomes.

HIV/AIDS Case Management

During the time when case management was being utilized in numerous acute and post-acute settings, HIV/AIDS was on the rise. Case management had been proven to be effective in other healthcare settings and helped to improve quality of life while reducing health care costs for patients that were mentally ill or had multiple comorbidities (Tahan, 1998). Therefore, the CDC recognized that the transmission of HIV could be prevented through the use of case management programs and adopted the case management intervention into HIV/AIDS care between 1989-1992 (CDC, 2016). HIV-prevention case management was explicitly designed to assist HIV-infected persons in receiving services that will prevent or reduce behaviors that result in further spread of the virus, delay the onset of symptomatic HIV disease, and improve the client's health status (CDC, 2016). This type of diagnosis-specific case management program was used to help address various psychosocial issues that impact this vulnerable population and has become a standard practice to provide comprehensive care for persons living with HIV/AIDS (PLWHA) in the United States and have aided in improving their lives (Thurman et al., 2010). The goals of this intervention are to aid in retention in care, maintain compliance with medical and service specifications, and reduce risky behaviors that further spread the disease (HRSA, 2019). These activities are to be conducted by qualified case managers who assess the client's physical, psychosocial, environmental, and financial needs as well as facilitate the client's access to, maintenance of, and adherence to primary health care, support services, HIV prevention, and risk reduction services (Fabbri et al., 2017). A case manager is assigned to help those living with HIV/AIDS access and prioritize needs such as health care, housing, finance, and social support. The overall objective of case management is to promote and support individual independence and self-sufficiency. Case managers are responsible for evaluating the needs of individuals and families, the effectiveness of care plans, arranging doctors' appointments, and providing education on various medical conditions such as mental health, diabetes, heart disease, and cancer that impact the patient and their families (Fabbri et al., 2017). Case managers also act as a liaison between patients and their insurance companies to ensure they receive exceptional health care at a fair price (Fabbri et al., 2017).

Government Funding of HIV Case Management Programs

Funding for HIV case management services is spread across multiple federal departments, including the Health and Human Services (HHS), Housing and Urban Development (HUD), Justice Department, Veteran Affairs (VA), and Defense (HIV.gov, 2021). The HHS also utilizes funding from the Centers for Medicare & Medicaid Services (CMS), Health Resources and Services Administration (HRSA), Centers for Disease Control and Prevention (CDC), Substance Abuse and Mental Health Services Administration (SAMHSA), the Indian Health Service (IHS), the Food and Drug Administration (FDA), the Office of HIV/AIDS and Infectious Disease Policy (OHAIDP), the Office of Minority Health, and others (HIV.gov, 2021).However, the

HIV case management programs are most known today because of a young man named Ryan White. Ryan was from Kokomo, Indiana, and was diagnosed with AIDS at age 13. During this time, there was little information about the disease and limited treatment options available; therefore, Ryan faced stigma from the community and discrimination by health care providers and in the education system because of the community's lack of knowledge on the disease. Ryan's mother had to fight for him to be able to attend school and against discrimination, which brought public attention to HIV/AIDS (HRSA, 2019b). It was because of Ryan White and his mother that the Ryan White Care act exists.

The Ryan White Care Act Program is federal legislation that addresses the unmet health needs of persons living with HIV disease (PLWH) by funding primary health care and support services such as case management programs to enhance access to and retention in care (HRSA, 2019b). The Ryan White Care Act was first enacted by Congress in 1990; then, it was amended and reauthorized in 1996, 2000, 2006, and 2009 (HRSA, 2019). Ryan White HIV/AIDS program has several parts. Part A funds medical and support services to eligible metropolitan areas. Part B administers funds to states and territories to improve the quality, availability, and organization of HIV health care and support services (case management programs) (HRSA, 2019b). Part C administers funds to local community-based organizations to provide comprehensive primary health care and support services in an outpatient setting (HRSA, 2019b). Part D administers funds for local, community-based organizations to provide outpatient, ambulatory, family-centered primary and specialty medical care for women, infants, children, and youth living with HIV (HRSA, 2019b). Last, Part F funds the training of clinicians, technical assistance, and the development of innovative models of care to improve health outcomes, thus reducing the transmission of the disease (HRSA, 2019b). Some programs include Dental, Minority AIDS Initiative, AIDS Education and Training Centers Program, and the Special Projects of National Significance Program (HRSA, 2019b).

Impact of Case Management on HIV Client Outcomes

The number of individuals aged 50 and older that are living with HIV/AIDS has increased consistently during the 21st Century (Emlet et al., 2009). Despite the growing interest in aging with HIV, most of the research focuses on the pathological consequences of aging with HIV rather than understanding the benefits that case management has on mortality of those infected with HIV/AIDS (Vance et al., 2008). Studies that explore service utilization among HIV/AIDS patients tend to ignore age as a variable. According to Emlet et al., (2009), health care systems that are influenced by public policy tend to separate issues that are connected, such as aging with HIV. This population could potentially access assistance through aging networks (ADRC) or through Ryan White prevention case management programs; however, older adults with HIV/AIDS do not access formal support programs that non-HIV+ older adults typically access (Emlet et al.,2009).

The gaps in linkage and engagement in HIV medical services continue to drive HIV transmission (Lopez et al., 2018). Case management provides a range of patient-centered services that link patients with health care systems, substance abuse and mental health counseling, housing, and transportation assistance. The intent of case management was to collaborate at the micro, mezzo, and macro levels to identify and eliminate barriers to HIV care and provide access to treatment (Lopez et al., 2018). Despite the research that supports case management as an appropriate intervention to improve HIV management, there is a minimal understanding of the impact case management has on those engaged in the program and its potential influence overtime on HIV clinical outcomes (Lopez et al., 2018).

Regarding the impact of case management on client outcomes with HIV/AIDS patients, Brennan-Ing et al. (2016) reported that of the 1.2 million people in the U.S that are infected with HIV, only 40% are engaged in care, 37% are prescribed antiretroviral therapy (ARV), and 30% have achieved the targeted clinical outcome of viral suppression. Of that 1.2 million, approximately 840,000 people are not receiving adequate HIV care, which shows in their lack of viral suppression (Brennan-Ing et al., 2016). Services available to HIV+ clients in need of care are not easily accessible in many communities (Pellowski et al., 2013). Pellowski et al. (2013) also suggest that clients who may seek services are more likely to have lower incomes and education, be uninsured or publicly insured, have a history of addiction, and be a minority. Additionally, the inability to achieve viral suppression can be attributed to a multitude of factors such as mental health, unstable housing, incarceration, poor health literacy, financial issues, and lack of proper nutrition (Brennan-Ing et al., 2016). Furthermore, Thurman et al. (2010) report that case management programs have been effective in addressing some of the challenges faced by this population and have become a standard practice to provide comprehensive care for persons living with HIV/AIDS (PLHA) in the United States

Brennan-Ing et al. (2016) conducted a study to understand the impact of target case management (TCM) on people dealing with multiple comorbid conditions such as HIV. The effect of TCM on clients was examined over a one-year time and compared TCM clients and non-TCM clients. The study focused on changes in clinical, cost, as well as medical and pharmacy utilization data between both groups. CD4 counts were also compared between TCM clients and non-TCM clients. Results showed that the increases in medication costs over time were associated with increased care engagement. Findings have also shown that TCM programs were able to achieve their goals of improving care engagement and treatment adherence prescribed antiretroviral therapy (ARV), with 30% achieving the targeted clinical outcome of viral suppression (Brennan-Ing et al., 2016). The study also proved that successful case management models demonstrate accountability for the organization of patient care, build respectful relationships among care partners with good communication, and supports patients regardless of where they access health care. The overall findings support the hypothesis that TCM improves clients' engagement with care and treatment adherence as evidenced by significant increases in service utilization, medication costs, and total costs (Brennan-Ing et al., 2016). However, upon reviewing the literature, it was found that there is limited information available to understand how case management programs aid in addressing the needs of older adults with HIV/AIDS.

Historically, there have been policies and program funding that have been allocated to specialized case management programs such as HIV/AIDS prevention programs, but the effect has gone unmeasured (Lopez et al., 2018). In Northwest Indiana specifically, information regarding the specific challenges and needs of this population or the impact of case management on patient outcomes could not be found; however, Lopez et al. (2018) conducted a study in the Midwest to analyze the patterns of change regarding CD4 T-cell count and viral loads among those that engage in medical case management services (MCM) versus those that do not. The study was conducted at Washington University Infectious disease clinic (WU ID) with participants aged 18 and older during 2009 and 2015. Data collected from participant medical records included age, sex, race, level of education, income, employment, housing status, years living with HIV, and receiving care at WU ID along with CD4 and Viral load counts. Services at the WU ID clinic included mental health referrals, health insurance attainment, transportation, emergency housing/food assistance, treatment adherence counseling, and linkage to HIV care and treatment (Lopez et al., 2018). In this longitudinal study, 2773 patients were observed during 2009 and 2015. There were 975 participants that received medical case management services compared to 1798 who did not receive medical case management. The participants who received case management were more likely to be between the ages of 25-44, male, African American, unemployed with only a high school diploma. The patients engaged in MCM started the study with a lower CD4 count and higher viral loads. The average patient began with a CD4 of 385 and increased over time(Lopez et al., 2018). The baseline unconditional mean model assessed the mean CD4 T-cell count as 492.18 in 2009 for all patients. The baseline unconditional linear growth model studied patient changes over time. The positive, significant linear effect revealed CD4 T-cell counts increased over the years; however, the negative, significant quadratic effect showed the rate of CD4 T-cell count growth would decline over time (Lopez et al., 2018). Those engaged in MCM indicated a linear, increased change in CD4 T-cell counts over the years in comparison to non-MCM patients (Lopez et al., 2018). The study's goal was to measure the impact of MCM on HIV clinical outcomes; results showed an improvement in HIV clinical outcomes that occurred faster with those engaged in MCM versus those that did not engage in MCM (Lopez et al., 2018). Overall, the outcomes showed that there were improved health outcomes for those PLWHA and a reduction in the transmission of the disease (Lopez et al., 2018).

Hyduk (2002) reported that the goal for older adult case management is to assist the service provider in containing cost by managing the patient's care. Boyd and Fisher (1996) conducted a comparison study between case-managed and non-case-managed chronically ill older adults to determine if community-based case management for chronically ill older adults was cost-effective. The study consisted of twenty-seven individuals in a control group and twenty-seven in an experimental group. The experimental group received the in-home case management services in which the professional nurse followed each participant in their home setting over a year to address patient concerns and monitor conditions. Results show that there was a difference between the control group and the experimental group in the number of hospital admissions and length of stay. The study concludes that community-based case management for chronically ill older adults can positively influence the health and well-being of the patient and reimbursement for institutions (Boyd & Fisher, 1996).

There is limited research available that examines the effects of case management and the elderly; however, there is growing evidence that shows how case management may improve the quality of life for older adults by removing stress, increasing coping ability, and improving mood (Hasche, & Lavery, 2015). In comparison, there is some evidence that shows the benefits or outcomes of case management; Sargent et al. (2007) report that case management programs for the elderly tend to focus on the coordination of care and prevention of various illnesses rather than the psychosocial support that is needed. A small number of studies include psychosocial support as a key component in case management with the elderly. Sargent et al. (2007) conducted a study to explore the patient and caregivers' perspectives on case management to obtain an understanding of how the case management intervention model was being delivered to patients. In-depth interviews were used with a sample of 72 patients and 52 caregivers. Five themes were identified, including clinical care, coordination of care, education, advocacy, and psychosocial support. Results showed that clinical care and psychosocial supports were viewed equally important; however, the patient's and their caregiver's perceptions regarding case management were in direct contrast to the descriptions provided by the Department of Health. The findings suggest that policymakers should seek input from their stakeholders on what issues affect them (Sargent et al., 2007).

In reviewing the literature, it was recognized that older adults with HIV/AIDS are confronted with many challenges that reduce their quality of life, such as finances, housing, food insecurity, depression, PTSD, sexual identity, the stigma of ageism, and diagnosis related stigma, along with the burden of age-related comorbidities such as arthritis, hypertension or diabetes (Heckman et al., 2000). Additionally, older adults with HIV/AIDS may have also lost multiple partners or friends, resulting in limited social support; therefore, they may experience grief or feelings of “survivor guilt” (Emlet et al.,2002).

According to Gutheil and Chichin (1991), frail older adults and older adults with HIV/AIDS may require some of the same resources and social supports; however, rather than join forces, they may have to compete for scarce resources. Older adults can be caught between aging and HIV services, where their HIV issues may not be addressed by aging programs (Emlet et al., 2002). As previously discussed, Thurman et al. (2010) report that case management programs have been an effective intervention for addressing some of the challenges faced by this population. HIV case management can provide older adults with assistance in locating and obtaining attendant care, homemaker services, skilled nursing, nutritional counseling, psychosocial counseling, transportation, and food and housing subsidies (Emlet & Farkas, 2001). Case management programs can also assist in improving the coordination of health and social care with the use of case managers who can help with addressing the needs of this population.

Thurman et al. (2013) report that when individuals are enrolled in case management programs, it can contribute to addressing psychosocial issues such as social isolation, discrimination, disclosure, and stigmas that affect their self-image and overall mental health. Psychosocial stressors can cause barriers to services and medical adherence (Emlet & Pointer, 2011); therefore, participation in case management programs can assist in an increase medication adherence, and improve quality of life, while reducing the transmission of HIV/AIDS in the United States (Thurman et al., 2010). Thurman et al. (2010) also reports that there is a link between case management services and higher adherence to medical regimens among this population when used. The readiness of social work, case management, and counseling services is essential in helping older adults with HIV/AIDS face the multiple psychosocial issues that come along with living with this disease (Zelenetz & Epstein, 1998).

Emlet and Farkas (2001) report that services for this population can be provided by older adult case managers and AIDS organizations; however, they have been slow to respond to older people with HIV leaving them stuck between systems. Older adults with HIV/AIDS can access services through either Ryan White programs or the Aging and Disability Resources Centers (ADRC); however, each system operates independently (Emlet et al., 2009). In Northwest Indiana, HIV Prevention case management programs and the Aging and Disability Resources Centers (ADRC) also operate independently from each other; as a result, there is limited funding available to address the needs of those aging with HIV (T. Morris, personal communication, November 5, 2019). Since the AIDS epidemic is a global health concern, it is imperative that the aging network organizations and AIDS services organizations address the unique needs of HIV/AIDS patients (2009). Much could be gained by integrating both programs. Emlet et al. (2002) report that each older adult faces a different challenge regarding HIV/AIDS compared to younger adults; therefore, it is essential that practitioners incorporate the important elements of a geriatric assessment with the aspects of HIV assessment. The integration will result in a more in-depth understanding of the needs of HIV+ older adults. As

HIV/AIDS affects older adults in direct and indirect ways (Gutheil & Chichin, 1991), combining both programs can aid in delivering person-centered programs to address the long-term care needs of older adults with HIV/AIDS.

Summary

Since the late 1980s and continuing today, case management has been engrained into the structure of health care delivery for people living with HIV. Case managers are called upon to help people address issues of injustice and inequality along with their basic needs such as food, housing, and safety. However, Zelenetz and Epstein (1998) report service availability and the patient's encounter with staff that is not knowledgeable on the emotional and psychological issues that influence them to create additional issues and may prevent them from seeking assistance. Kiplagat et al. (2019) conducted a study to explore the challenges faced by older adults living with HIV in western Kenya; the study corroborates Zelenetz and Epstein's statements. Kiplagat et al., (2019) study also found that the challenges faced by older adults included difficulty managing comorbidities, inadequate facilities, inadequate social support, stigma, and poor patient-provider communication. Challenges such as these prevent older adults from seeking services and consistently adhering to treatment recommendations (Kiplagat et al., 2019). Kiplagat et al. (2019) further support the idea that additional research and attention are needed to ensure consistent engagement in HIV care for older adults to improve their access to and experience HIV care, which is vital to managing their other chronic conditions illnesses. Additionally, employing staff that matches the needs of older adults is necessary.

As a social worker, I wanted to understand HIV/AIDS and the biological and psychosocial effects of the disease. In reviewing the literature, it was found that there is limited information available to know how case management programs aid in addressing the needs of older adults with HIV/AIDS. In Northwest Indiana, specifically, there are case management programs available for the elderly and for HIV/AIDS patients; however, the two programs operate independently from each other. Additionally, there was inadequate information available identifying the specific challenges and needs of this population.

In conclusion, the literature reviewed provided some understanding on how HIV impacts the older population from the biopsychosocial standpoint, the various types of case management programs, the role of the case manager, and the available funding to support HIV/AIDS patients. Still, additional research is needed to understand the experiences of older adults enrolled in case management interventions and how it impacts them at the micro, meso and macro levels from the perspective of the participants (Hjelm et al., 2015). Knowledge obtained from such research could help to better understand and further advance the progress and design of case management programs aimed at older adults (Hjelm et al., 2015). Therefore, this study examined the case management experiences of older adults living with HIV/AIDS and enrolled in case management programs to increase knowledge on the various psychosocial issues that influence this specific group in Northwest Indiana.

Section 2: Research Design and Data Collection

Across the state of Indiana, there are 10,997 individuals diagnosed with HIV/AIDS (Indiana State Department of Health, 2019). In Northwest Indiana (Lake, Laporte, and Porter counties), there are 1,589 confirmed individuals living with HIV/AIDS, and 368 of these are enrolled in case management programs. Additionally, 172 individuals enrolled are age 50 or older (APNWI, 2019). Emlet and Poindexter (2004) reported that social workers tend to be unknowledgeable of the services that are needed by older Americans. Additionally, gerontology social workers have limited knowledge and insufficient training on the needs of older adults with HIV/AIDS. Although case management has been proven to be an effective method of practice, each patient who is enrolled in case management services may not have the same experience as the next person. The purpose of the current generic qualitative study was to examine the experiences of patients aged 50 years and older with HIV/AIDS enrolled in case management programs in Northwest Indiana. In this chapter, I discuss the research design and rationale, methodology, and ethical procedures. This chapter concludes with a summary of the chosen methods for this study.

Research Design and Rationale

In this generic qualitative study on aging with HIV/AIDS, I interviewed 13participants to obtain answers to the following research questions:

RQ1: How do program participants, age 50 and older and diagnosed with HIV/AIDS, define case management?

RQ2: What expectations do program participants, age 50 and older, have of HIV/AIDS case management programs?

RQ3: How do the program participants, age 50 and older diagnosed with HIV/AIDS, describe their experiences in case management programs?

RQ4: Excluding current programs in place, which programs or interventions do the program participants, age 50 and older diagnosed with HIV/AIDS, desire as they age?

A generic qualitative approach was used. This approach was a good fit to answer the research questions because it is used to obtain an understanding of the meaning that people attribute to their experience (Madill & Gough, 2008; Yoshikawa et al., 2008). Creswell (2009) identified five types of qualitative research: ethnography, grounded theory, case study, phenomenology, and narrative research. Based on the purpose of the study, a researcher can choose one of these options. However, according to Percy et al. (2015), some topics are inappropriate for qualitative research or cannot be tailored to the traditional qualitative designs, such as ethnography, case studies, grounded theory, or phenomenology. Exploring patient experiences in case management programs called for a qualitative inquiry; however, the more common approaches were not suitable for the current study. Percy et al. reported in situations where the common approaches such as ethnography, case study, or grounded theory are not appropriate, the researcher should consider using a generic inquiry. Additionally, Merriam (2009) described a generic qualitative study as having been derived philosophically from constructionism, phenomenology, and symbolic interaction. Researchers who are interested in understanding how people interpret their experiences and what meaning they attribute to their experiences (Merriam, 2009) use a generic qualitative approach. Therefore, I used a generic qualitative approach to understand the experiences of geriatric patients with HIV/AIDS enrolled in case management programs in Northwest Indiana.

Methodology

Prospective Data

I conducted in-depth semi structured interviews with open-ended questions (see Appendix), which is common in qualitative research, to obtain the information needed to answer the research questions. Interviews with open-ended questions allow the participants to explain their responses through personal experiences or perceptions (Mathers et al., 1998). According to Mathers et al. (1998), semi structured interviews provide opportunities for both the interviewer and the interviewee to discuss the topics in more detail. Additionally, if the interviewee is having trouble articulating their thoughts, there is freedom or flexibility to use probing questions to allow the interviewee to elaborate on their response (Mathers et al., 1998). Another benefit of using the in-depth interview as opposed to focus groups is that participants are more relaxed and willing to discuss sensitive topics in more detail (Jamshed, 2014).

Participant Selection and Recruitment

Participants for this study were residents of Indiana age 50 years or older with HIV/AIDS and enrolled in case management programs. Prospective participants were recruited from the local AIDS service organizations. A letter was distributed to all HIV/AIDS case management agencies in Northwest Indiana, notifying them of the study and asking for their participation in the recruitment of participants. Flyers were created to explain the program study along with contact information to register for the study. Additional recruitment flyers were posted as an advertisement on various social media outlets such as Facebook, Instagram, and LinkedIn. Interviews were scheduled with each participant at different times and days to draw a wide range of case management clients. Participation was voluntary.

Sampling

Purposive sampling was used to recruit a participant sample of individuals 50 years or older living with HIV/AIDS in Northwest Indiana and enrolled in case management. Purposive sampling is widely used in qualitative research for the identification and selection of information-rich cases (Palinkas et al., 2016). Researchers who use purposive sampling identify subjects based on the study's purpose with the expectation that the individuals have firsthand experience of the identified phenomenon (Palinkas et al., 2016), which will provide unique and rich information of value to the study (Lee-Jen Wu et al., 2014). As a result, the participants of the accessible population are not interchangeable, and the sample size is determined by data saturation, not by statistical power analysis (Lee-Jen Wu et al., 2014). Participants were included in the current study regardless of race, gender, sexuality, socioeconomic status, or religious beliefs. The most important inclusion factors were age 50 years or older, HIV/AIDS status, and enrollment in case management programs.

Determining sample size is another critical factor in research, and researchers need to be careful not to have too small or too large of a sample (O'Rielly & Parker, 2013. Sandelowski (1995) recommended that qualitative sample sizes be "large enough to allow the unfolding of a new and richly textured understanding of the phenomenon under study," but small enough so that there is a "deep, case-oriented analysis" (p. 183). However, according to Marshall (1996), a large sample size could lead to sampling errors, which could affect results. In qualitative research, the sample size is typically smaller than it would be for a quantitative study because the researcher is more concerned with the meaning as opposed to the quantity (Manson, 2010). Marshall also noted that appropriate sample size is one that answers the research question(s).

Mason (2010) found that there are times when one participant will suffice, and 35 or more participants are required in other situations. In addition, *saturation*, or continuing with the interview process until the information becomes repetitive, is sometimes recommended. However, there are uncertainties about whether saturation is possible due to the variability of answers possible in interview research (Curry et al., 2009). Cooper and Endacott (2007) reported that sampling should continue to the point of saturation. Therefore, the researcher should continue to recruit participants until no new data emerges. Cooper and Endacott also reported that recruitment of five to eight participants is usually sufficient for a homogenous sample, but 12–20 is adequate for a heterogeneous sample, such as the current study that explored the experiences of HIV/AIDS patients age 50 and older.

Additionally, researchers conducting a generic qualitative study aim to have enough participants to gain rich information about the phenomenon rather than to generalize to other populations. All of these considerations can create confusion as to the appropriate sample size. However, because qualitative research's primary goal is to have an information-rich sample (Percy et al., 2015), there was an anticipated minimum of 12–15 participants in the current study. Saturation was reached at 13 participants.

Instrumentation

The approach that was used to collect data for this study was semi structured interviews, which is common in qualitative research. To understand the experiences of those aging with HIV/AIDS, I developed an interview guide that contained questions that made it easy for participants to describe in detail anything related to their experience in case management. Framing interview questions is also another essential part of data collection in a qualitative study, meaning questions should be specific to gather sufficient data from the interviewee (Turner, 2022). Additionally, using open-ended questions will help to avoid guiding the participants' answers (Turner, 2010). Based on these guidelines for conducting interviews and writing questions, I formulated simple questions that would allow the participants to share their experiences of case management as they age with HIV/AIDS (see Appendix).

Data Collection

Data were collected from the participants through semi structured interviews, which were conducted over the phone, Zoom, or in person. Because HIV/AIDS is a sensitive topic, there was no time limit for the interview. According to Cooper and Endacott (2007), interviews in qualitative research are typically recorded. Therefore, I used a digital MP3 recorder to record each interview and kept a backup recorder in case technology challenges presented themselves. The process of data collection for this study involved the use of an in-depth semi structured interviews with open-ended questions. I opened the conversation with a general question: Based on your experience, how would you define case management? Based on the responses of the participants, I proceeded to ask participants additional questions that were deemed necessary for the study, allowing them to respond freely without any pressure or undue influence.

Data Analysis

Once the data were collected, the interviews were transcribed using a health insurance portability act (HIPPA) compliant transcription program such as NVivo. NVivo software is often used in qualitative data management and has features such as character-based coding, rich text capabilities, and multimedia functions that are crucial for qualitative data management (Zamawe, 2015). Additionally, the software is not methodology specific. Therefore, it works well with a wide range of qualitative research designs and can assist with improving accuracy in qualitative studies (Zamawe, 2015). The process of transcribing also allows the researcher to become more acquainted with the data (Reissman, 2006). Recorded interviews were transcribed from the recording device verbatim using the NVivo software, then converted into a Word document and converted to a password-protected PDF file stored on a password-protected computer, and then backed up on an external hard drive that will be stored in a Sentry brand safe.

After the data were transcribed, the analysis process began with using a content analysis approach. According to Kleinheksel et al. (2020), qualitative content analysis is a research method used to analyze and interpret textual data such as written documents, interview transcripts, or other forms of communication. Content analysis is a well-established data analysis method that has evolved in its treatment of textual data. Content analysis was introduced as a strictly quantitative method of recording counts to measure the observed frequency of preidentified targets in consumer research. However, as the naturalistic qualitative paradigm became more prevalent in social science research and researchers became interested in the way people behave in natural settings, the process of content analysis was adapted into a textual approach. Krippendorff (2018) reported that content analysis has the potential to be a useful method because it can help researchers develop a deeper understanding of a phenomenon by providing structure to a large amount of textual data through a systematic process of interpretation.

Krippendorff (2018) described two general types of content analysis: conceptual analysis and relational analysis. Conceptual analysis determines the existence and frequency of concepts in a text. Relational analysis develops conceptual analysis further by examining the relationships among concepts in a text. Each type of analysis may lead to different results, conclusions, interpretations, and meanings. In conceptual analysis, a concept is chosen for examination, and the analysis involves quantifying and counting its presence. The main goal is to examine the occurrence of selected terms in the data. Relational analysis begins like conceptual analysis, where a concept is chosen for examination. However, the analysis involves exploring the relationships between concepts.

In my qualitative study of the experiences of participants age 50 and older aging with HIV/AIDS and enrolled in case management programs in Northwest Indiana, I employed conceptual content analysis as a methodological approach. This analytical process enabled me to explore and interpret the complex narratives and experiences of individuals living with HIV in the context of aging. The content analysis method allowed me to systematically analyze the rich qualitative data collected through semi structured interviews and uncover underlying themes, patterns, and categories that emerged from the participants' accounts. By using this method, I gained a deep understanding of how aging influences the experiences, challenges, and coping strategies of individuals living with HIV, while also understanding the social, psychological, and health care implications. Content analysis contributed to the rigor and comprehensiveness of my qualitative research, providing valuable insights into the experience of aging with HIV and informing future interventions and support systems for this population.

Krippendorff (2018) reported that when conducting a content analysis, researchers should first identify the research question and choose a sample or samples for analysis. Next, the text must be coded into manageable content categories. This is a process of selective reduction. By reducing the text to categories, the researcher can focus on and code for specific words or patterns that inform the research question. General steps for conducting a conceptual content analysis include the following:

1. Decide the level of analysis: word, word sense, phrase, sentence, themes.
2. Decide how many concepts to code for: develop a predefined or interactive set of categories or concepts. Decide either (a) to allow flexibility to add categories through the coding process or (b) to stick with the predefined set of categories. Option A allows for the introduction and analysis of new and important material that could have significant implications to the research

question. Option B allows the researcher to stay focused and examine the data for specific concepts.

3. Decide whether to code for existence or frequency of a concept. The decision changes the coding process. When coding for the existence of a concept, the researcher would count a concept only once if it appeared at least once in the data and no matter how many times it appeared. When coding for the frequency of a concept, the researcher would count the number of times a concept appears in a text.
4. Decide on how you will distinguish among concepts: Should text be coded exactly as they appear or coded as the same when they appear in different forms? What level of implication is to be allowed? Words that imply the concept or words that explicitly state the concept.
5. Develop rules for coding your texts. After steps 1-4 are complete, a researcher can begin developing rules for translation of text into codes. This will keep the coding process organized and consistent. The researcher can code for exactly what he/she wants to code. Validity of the coding process is ensured when the researcher is consistent and coherent in their codes, meaning that they follow their translation rules. In content analysis, obeying the translation rules is equivalent to validity.
6. Decide what to do with irrelevant information: should this be ignored (e.g., common English words like “the” and “and”), or used to reexamine the coding scheme in the case that it would add to the outcome of coding?

7. Code the text: This can be done by hand or by using software. By using software, researchers can input categories and have coding done automatically, quickly, and efficiently, by the software program. When coding is done by hand, a researcher can recognize errors far more easily (e.g., typos, misspelling). If using computer coding, text could be cleaned of errors to include all available data. This decision of hand vs. computer coding is most relevant for implicit information where category preparation is essential for accurate coding.
8. Analyze your results: Draw conclusions and generalizations where possible. Determine what to do with irrelevant, unwanted, or unused text: reexamine, ignore, or reassess the coding scheme. Interpret results carefully as conceptual content analysis can only quantify the information. Typically, general trends and patterns can be identified.

Issues of Trustworthiness

In addition to having an adequate sample size, the study's quality is also tied to its credibility, trustworthiness, transferability, and dependability. Credibility, also known as internal validity, refers to how plausible the study and the results are. Researchers seek to outline the accurate picture of the studied phenomenon, which is a key factor in showing how compatible results are with actual reality (Shenton, 2004). According to Shenton (2004), researchers can use triangulation to prove credible research findings. Triangulation involves using other methods to gain information on participants. In this study, interviews will be used as my triangulation method to enable me to obtain information regarding my participants' experiences from their own perspectives. To ensure genuine participation and shared experiences, each participant was reminded that they have a right to decline participation in the study or withdraw at any point without explanation. Also, creating an environment where they feel comfortable sharing will help maintain the credibility of the data collected (Shenton, 2004).

Transferability, or how well the study can be applied to other times, situations, and people, cannot be demonstrated through the research because qualitative work findings are specific to a small number of individuals (Shenton, 2004). Furthermore, it is not the researcher's responsibility to show transferability, but rather, the researcher is responsible for providing detailed enough descriptions so others can make a judgment as to transferability (Shenton, 2004). That is, "since the researcher knows only the 'sending context,' he or she cannot make transferability inferences" (Shenton, 2004, p. 70). With this in mind, the present study included sufficient descriptions of the research context and assumptions so readers will have a proper understanding of it to determine whether the investigation might apply to other situations.

Dependability, or how well the study is described so that others may replicate it, was demonstrated by explaining how participants were recruited, contacted, and through the interview questions. This study provided the reader with a detailed methodology so that it is easily replicable in a similar context, using the same methods and the same type of participants. Shenton (2004) reports that aiming to obtain similar results can be a challenge in qualitative research. However, the researcher should at least be provided with the entire methodology to attempt to replicate it. I used an "audit trail" process as suggested by Shenton (2004) to document this process so that it can be easily traced back if needed. Information pertaining to the study, interviews, and transcriptions went into this “audit trail” or journal.

According to Shenton (2004), confirmability is achieved when researchers take the necessary steps to show the reader that the presented results, in fact, resulted from the data collected and not from the researchers’ own predispositions or interpretations. As the researcher, I remained as objective as possible to ensure that the information presented came from the participants’ perspective and is without my own personal interpretation. Providing direct quotes from the participants allowed me to avoid any researcher bias.

Ethical Procedures

Prior to recruiting participants and collecting data, this writer followed the mandatory approval process for the protection of the participants. Walden University’s IRB ensures that all scientists, including student researchers, comply with ethical standards and regulations outlined by the federal government (Walden, 2015). Therefore, an application to the Institutional Review Board (IRB) with details regarding the anticipated study was submitted for review. On April 4, 2022, Walden IRB approved the application for the study and provided the approval number 04-04-22-0748218. The following week, participant recruitment flyers were posted at participating agency and social media sites as described in IRB application. Once participants agreed to volunteer, they were reminded of the purpose of the study and made aware that the interview will be recorded and transcribed, however in accordance with HIPPA, their legal names or any identifying information will be omitted from the transcripts. Prior to each interview, informed consent was obtained from the participant to ensure that they are aware that their physical and emotional wellbeing will be maintained. Participants were affirmed that I will describe each of their experiences, feelings, and attitudes accurately. Participants were also informed that their participation is voluntary, and they can decide to withdraw participation at any time.

Since ethical issues may arise at any time, the researcher should anticipate them and prepare ahead of time as maintaining the integrity of the research study is crucial. Ethical issues such as observer effects, which include contamination or bias by the researcher or the research instruments, may affect the study. To avoid observer effects and maintain privacy, the researcher did not use the participants' real names in any of the interviews or in the research findings. Code names such as participant 1 or P1 will be given to each participant to maintain confidentiality in accordance with the consent form (Walden, 2017). Additionally, each interview was conducted individually to maintain confidentiality and will be digitally recorded in MP3 format. A backup recorder was made available in case of any technical issues. Upon completion of the interview, the information was transferred onto my personal computer, which is password and fingerprint protected and only known to me. I backed up my laptop each night with an external hard drive that is kept in a Sentry brand-locked safe stored at my residence. The interviews were transcribed using NVivo, a HIPPA compliant transcription program. Data will be retained for no less than five years upon completion of the DSW Doctoral Research Project, which is in accordance with Walden University policy (Walden, 2017).

Research participants often sacrifice a considerable amount of time and effort and may endure some inconvenience, discomfort, the pain of psychosocial risks. Thus, they should be given a token of appreciation for their contribution to the study (Resnik, 2015).Therefore, upon completion of the interview, participants were thanked for their efforts, debriefed on the nature of the study, and were offered a $25 incentive payment as a token of appreciation for their time and effort.

Summary

In summary, using a generic qualitative approach in this study was essential in better understanding the experiences of HIV/AIDS patients aged 50 and older enrolled in case management services and the complications or challenges they face daily. As the primary researcher in the study, I followed proper ethical guidelines to maintain each participant's privacy, emotional and physical wellbeing. To facilitate efficient data management and analysis, I employed NVivo software for transcription and coding, along with a spreadsheet for graph creation. The findings will be presented in the next section.

Section 3: Presentation of the Findings

This chapter presents the results of the generic qualitative study that explored the experiences of participants age 50 years and older living with HIV/AIDS and enrolled in case management programs in Indiana. The following research questions guided my study:

RQ1: How do program participants, age 50 and older and diagnosed with HIV/AIDS, define case management?

RQ2: What expectations do program participants, age 50 and older, have of HIV/AIDS case management programs?

RQ3: How do the program participants, age 50 and older diagnosed with HIV/AIDS, describe their experiences in case management programs?

RQ4: Excluding current programs in place, which programs or interventions do the program participants, age 50 and older diagnosed with HIV/AIDS, desire as they age?

In Section 3, I describe the setting, participant demographics, data collection, data analysis, evidence of trustworthiness, and study results. I conclude with a summary.

Setting

I conducted this study with participants either in person (at a designated care site), via telephone, or via the Zoom platform. The participants were given the opportunity to select which venue was most comfortable for them. Each interview was audio recorded. All participants provided consent to the interview in accordance with the IRB policies, and all agreed to participate and be recorded. Scheduling each interview required flexibility; as a result, some interviews were conducted in the evening and on weekends.

There were no personal or organizational conditions that appeared to influence the participants that could have affected the study results.

Demographics

The demographics and characteristics of my 13 participants are presented in Table 1, including their age, sex, and year of HIV diagnosis. All participants met the inclusion criteria of being 50 years of age or older, living with HIV/AIDS, and a resident of Northwest Indiana.

Table 1

Characteristics of Participants

Participant	Age	Sex	Diagnosis year
P1	50	Female	2000
P2	60	Female	2000
P3	64	Female	1989
P4	54	Female	1995
P5	65	Male	1986
P6	55	Male	2000
P7	65	Male	1994
P8	52	Female	2010
P9	67	Male	1990
P10	56	Male	2009
P11	63	Male	1996
P12	62	Male	1990
P13	66	Female	2019

Data Collection

Participants were recruited once I obtained IRB approval from Walden University. I began the recruiting process in April 2022. I posted the recruitment flyer on Linked In and Facebook. The partner agency's executive director was emailed the recruitment flyer with my contact information. The partner agency agreed to post the recruitment flyer throughout the care site. Within a few weeks, I began to receive interest from participants via email. I recruited 13 participants with whom I conducted and recorded interviews. Each participant met the inclusion criteria, and the interview was scheduled according to the participant's availability. The data collection process began on April 21, 2022. Prior to beginning the interview, I sent the participant the consent form via DocuSign for review and signature. The consents forms were returned within a day. Once the signed document was received, I scheduled the interview with the participant.

Each participant was called on the day scheduled for the interview. Each time I called a participant, I reintroduced myself to them, ensuring they knew whom they were speaking with, before proceeding to confirm once more that they had consented to the study and that the interview would be recorded. I also reiterated the purpose of the study with the reminder that participation was voluntary. If they felt uncomfortable, they could choose to exit the interview at any time. Participants confirmed that they consented of their own free will and were ready to proceed. Prior to starting the interview, I collected demographic information from each participant and included birth month and year, the year diagnosed with HIV by a physician, and each participant's self-identified gender. I recorded each interview session on the Zoom platform, and each participant was informed to turn off their camera. I also had an audio recorder as a backup. Each interview was 30 minutes to 1 hour depending on the participant. Additional prompts were employed to address the research questions and to provide clarity, if needed.

I did not encounter any unusual circumstances. However, during interviews there were instances when participants, while answering one question, would unknowingly answer another question I was going to ask at some point later in the interview. I remained flexible and did not repeat a question already answered in this manner. Additionally, I did not redirect tangential responses because I found that what the participants were sharing was valuable information. At the end of the interview, participants were thanked for their participation and were given a $25 visa gift card as a token of appreciation of their time.

Data Analysis Techniques

Immediately after each interview, the digital recording file was uploaded into NVivo software to facilitate efficient data management and analysis. NVivo is a HIPPA-compliant software that is bound to a confidentiality agreement. First, I used NVivo’s transcription features for transcribing the audio recordings of the interviews. NVivo’s powerful features and intuitive interface allowed me to convert the spoken data into written form systematically. The software’s ability to handle large volumes of text efficiently proved invaluable in managing the extensive data collected during my study.

Upon obtaining the full transcript within 24 hours, I downloaded the data from NVivo and stored them on an external hard drive for backup purposes and in a Sentry safe. Following the transcription of the interviews, the coding process began. I employed NVivo’s software for coding. Through NVivo’s coding capabilities, I assigned labels and categories to different sections of the text, enabling me to identify patterns, themes, and connections within the data. The software’s robust framework for coding facilitated a comprehensive and structured analysis, enhancing the reliability and validity of my findings.

Data from the semi structured interviews were organized and analyzed using what was described by Burnard (1991) as thematic analysis and also commonly referred to as content analysis. I began the coding process by familiarizing myself with the data. I thoroughly read and reread the interview transcripts to gain a comprehensive understanding of the participants' narratives. This step allowed for immersion in the data and identification of initial impressions and themes. Next, initial codes were generated based on frequency of recurring ideas, concepts, and emotions expressed by the participants. Once the initial coding was established, I systematically applied the codes to the interview transcripts in NVivo. Codes were subsequently recategorized as necessary to incorporate additional research material until a final list of key points and themes was determined. The presentation of results was organized by these themes, with relevant quotes from interviewees to illustrate the points being made.

Each relevant segment of the data was assigned one or more codes to reflect its content and meaning. As the coding progressed, a coding framework was developed to organize and structure the codes. The framework consisted of major categories representing overarching themes, with subcategories representing more specific aspects within each theme. This allowed for a hierarchical organization of the data and facilitated a deeper analysis of the relationships between different codes. Through this form of analysis, I moved back and forth from the details of individual interviews to an overview of the study findings and back to the details until final results generated were consistent with the interview material as a whole. After I used the NVivo software for transcribing and coding to visualize and present the analyzed data, I opted to use a Microsoft Excel spreadsheet. I extracted the relevant coded themes from NVivo and imported them into the spreadsheet for further analysis. The spreadsheet provided me with the flexibility and customizable options required to manipulate and transform the data for graph creation. With the diverse graphing options available in Excel, ranging from bar charts to line graphs and pie charts, I was able to visually represent the analyzed data effectively. The graphs served as visual aids to convey patterns, trends, and relationships identified during my analysis. By combining the strengths of NVivo's transcription and coding capabilities with the flexibility of Microsoft's Excel spreadsheet software for graph creation, I was able to display meaningful insights from the collected data.

Common experiences, expectations, and challenges in case management related to aging with HIV, such as the impact of social support on quality of life or need for additional education and community resources, emerged as prominent themes. The interpretation of the coded data revealed valuable insights into the experiences of individuals aging with HIV. The findings highlighted the multidimensional nature of the challenges faced by this population and the strategies they employed to navigate the complexities of their lives. The content analysis approach provided a systematic and rigorous method for analyzing qualitative data in this study on aging with HIV. The process of coding and organizing the data allowed for a thorough exploration of the participants' experiences, resulting in meaningful insights that may inform future research, policy development, and interventions aimed at supporting individuals living with HIV as they age.

Evidence of Trustworthiness

To ensure credibility of the study and genuine participation and shared experiences, I reminded each participant that, as stated in the consent form, they had the right to decline participating or withdraw at any time without any explanation. At the beginning of the interview and throughout the process of the study, I developed a respectful relationship with each participant and ensured that they were as comfortable as possible. This enabled them to openly share in-depth information regarding their experience with the phenomenon. Throughout the interview process, member checks were performed, especially at the end of the interview to obtain clarification where needed and to assess the accuracy of the collected data. To ensure transferability in my study, I reported information on the phenomenon and the overall descriptive details of the research findings. This may enable other scientists to ensure transferability in their research and decide whether my findings are credible (see Shenton, 2004). Additionally, I provided details pertaining to the participants' demographic characteristics and parameters pertaining to how the study was conducted so it could be easily replicated.

Dependability in this study was maintained by providing the reader with a detailed description of the methodology used in my study, ensuring that a similar study could be done in the same context using a similar method with similar participants (see Shenton, 2004). Additionally, I kept a trail of all documentation pertaining to the research (see Creswell, 2009). Specifically, I kept all audio and transcribed files, as well as journal notes, so that other scientists could retrace and replicate the study, if needed.
Confirmability in this study was maintained by showing the reader that presented results

were derived from collected data and not from my biased interpretations (see Shenton, 2004). I provided direct quotes from the participants throughout without adding my personal interpretation.

Findings

The data collected from the interviews with adults 50 years old or older enrolled in case management were used to answer the four research questions. In this subsection, I present the emergent themes and include examples of supporting and incongruent statements. The participants' responses are direct quotes regarding their personal experiences in case management. Also, to protect the confidentiality of the participants, all of the names associated with direct quotes are pseudonyms.

Themes

Each interview was analyzed to answer each of the four research questions. During the interview, I asked several open-ended questions and probing questions to ensure clarity and obtain more details. Based on the conducted analysis, there were four prominent themes that were present throughout the data set, which included assistance, education, support, and availability. These themes answered RQ1, RQ2, RQ3, and RQ4, respectively. The first theme that emerged from the analysis was assistance. Many participants reported that their case managers were instrumental in connecting them with resources such as housing, transportation, and medical care. Participants felt that the support they received from their case manager helped them to better manage their HIV and overall health. The second theme was education. Participants reported that they expect regular and clear communication with their case manager. This includes providing information about services and resources available, as well as updates on their progress and any new treatment options available to them.

The third theme was support, which can come in many forms. Participants often described case management as a supportive service that helps them access resources and services. Case managers are seen as a source of emotional and practical support, offering guidance and assistance in times of need. Overall, participants reported that they expect case managers to provide a supportive and empowering environment that helps them achieve their goals and improve their overall well-being. The fourth theme was availability. The participants viewed their case manager s as primary point of contact and a source of support to them for a variety of services. The participants reported that they have a limited support system; therefore, they rely on their case managers for guidance, and it is important to them to have their case managers accessible and responsive to their needs. In the next four sections, the themes for each research question are defined and presented along with the participants' statements that emerged.

Research Question 1

The first research question was the following: How do program participants, age 50 and older and diagnosed with HIV/AIDS, define case management? Three themes emerged from participants' responses regarding how they define case management. Of the 13 participants interviewed, 31.25% defined case management as a support system, 43.75% defined case management as a program that provides assistance, and the remaining 25% defined case management as a program that provides education on how to manage their diagnosis.

Assistance

The most commonly identified definition of case management was assistance. Most (43.75%) participants viewed case management as a program that provides assistance to individuals diagnosed with HIV/AIDS. Assistance was clarified as financial, housing, health care, insurance, connection to providers, or assistance with legal issues. P3 commented “I have been enrolled in case management since 1997, and I think case management is the opportunity to have someone help assist you in your care with your diagnosis.”

Support System

Social support is one of the most important functions in social relationships. Several participants (31.25%) defined case management as a support system for them. Several participants had been diagnosed with HIV over 20 years, and they reported that they had lost a lot of friends to the disease, or they had lost friends and family members because of their diagnosis. P13 commented,

> I would say some case managers give the support needed to patients concerning the diagnosis. I felt so much better after speaking with individuals about it and then connected me to the correct people to talk to. I was very depressed over it for a long amount of time. Well, just hearing about my diagnosis just stressed me out and depressed me. So, when the case management got involved, they gave me a sense of relief and where I could be myself again because I put myself down from there and they brought that positive attitude back into my life from the negative

> that I was going towards. So, it helped me tremendously and I don't know what I've done if I hadn't had this kind of support system.

Education

Most participants defined case management (25%) as a program that should provide education on their diagnosis, how to manage their condition and keep them up to date on any changes from CDC, or local health departments. One participant, P10 (56-year-old male diagnosed since 2009) commented, "I would say case management is keeping you updated and informed on different procedures and different benefits from the State and federal government level, as far as your health and well-being."

Table 2

Themes: RQ1 Definition of Case Management

Theme	Number of participants	Percentage of participants
Provide assistance	7	43.75%
Support system	5	31.25%
Provide education	4	25.00%

Note. Participants (*N* = 13) could provide more than one response.

Research Question 2

Participant responses to RQ2: What expectations do program participants, age 50 and older, have of HIV/AIDS case management programs? Participants were asked to describe their expectations of case management programs and four themes emerged from participant responses regarding what they expect from case management. Of the total participants interviewed (n=13), 31.25% of the participants report they expect the case managers to be available, 26.32% to provide education, 26.32% to be knowledgeable and 15.79% to serve as a support system.

Available

Many of the participants report that they expect the case managers who work in the program, to available to them (31.25%). It was important for the participants to be able to have access to their assigned staff member to review questions or concerns. One participant, P9 (67-year-old male diagnosed since 1990) commented, “There are so many issues that pop up in my life, I expect the case manager to respond timely and make themselves available to assist me in working through my issues.”

Provide Education

Of the total amount of participants in the study 26.32% of the them expect the case management program and their case managers to provide education to them regarding their diagnosis, available medications/treatments and how to manage them. One participant, P5 (65-year-old male diagnosed since 1986) commented,

> There are so many core issues going on in my life. I expect the case manager would be able to keep me aware of any new treatments that may be occurring or even things that might be of benefit medically, but things to watch out for with these conditions.

Knowledgeable

A case manager’s role is to help identify appropriate providers and facilities through the continuum of services, while ensuring that available resources are being used in a timely and cost-effective manner. Most of the participants (26.32%) report they expect their case managers to be knowledgeable about the diagnosis and the available treatment options, and community resources that are available. One participant, P4 (54-

year-old female diagnosed since 1995) commented, “I try to do things on my own, but if I can’t, then I call my caseworker, I expect them to be able to educate me on better resources.” Participant, P5 (65-year-old male diagnosed since 1986) also commented,

> As I grow older, I expect the case manager to be knowledgeable on , what I need to do as I grow older regarding housing or community resources. I like to be able to know that I can go on the case manager to assist me in finding other sources that might be more amenable to helping me.

Support System

Of the total amount of participants in the study 15.79% of the participants report that they expect their case managers to be supportive and consider their role to be one of a support system. One participant, P8 (52-year-old female diagnosed since 2010) commented,

> I expect the case manager to be very supportive people, especially when they’re dealing with people from different age brackets. Expect them to know and provide the right support in terms of its mental health and also in terms of engaging advocate also against the drug abuse, because that’s also a to cover.

Table 3

Themes: RQ2 Participant Expectations of Case Management

Theme	Number of participants	Percentage of participants
Available	6	31.58%
Knowledgeable	5	26.32%
Supportive	3	15.79%
Provide education on diagnosis	5	26.32%

Note. Participants ($N = 13$) could provide more than one response.

Research Question 3

Participant responses to RQ3: How do the program participants aged 50 and older diagnosed with HIV/AIDS describe their experience in case management programs. A single theme occurred. From their responses, the majority of the participants reported having a positive experience in the case management program. For example, one participant, P13 (66-year-old female diagnosed since 2019) commented,

> Overall, I went from being diagnosed to being connected with the right person. After being diagnosed, I had to learn how to cope and live with the diagnosis. And without this case management program in my life, I don't think I would have come out as successfully as I had. Now, because of this, I don't think negatively about the diagnosis anymore. I'm not depressed over it anymore. I'm going on with my everyday life. I try to stay healthy if I can. I try to eat the right things and I try to be positive in each and every way of my life. It's because of the people working with the case management program, the care and the programs that I was put into. So, I think my experience is excellent.

Another participant P12 (62-year male diagnosed in 1990) reports,

> I would say my experience has been very good. I'm very happy. I have received excellent service. Everyone has always been very nice to me and patient with me. And since I do live so far away, I am accommodated, the staff come to my home and help me resolve whatever concerns I may have and help me manage my health and navigate the healthcare system.

Table 4

Themes: RQ3 Participant Experience in Case Management

Theme	Number of participants	Percentage of participants
Excellent	2	15.38%
Very good	5	38.46%
Good	6	46.15%
Poor	0	0%

Note. Participants (*N* = 13) could provide more than one response.

Research Question 4

Participant responses to RQ4: Excluding current programs in place, which programs or interventions do the program participants aged 50 and older diagnosed with HIV/AIDS desire as they age. Four themes were identified among the thirteen participants. Of the thirteen participants 43.38% report they would like to see more support group programs, 30.43% would like to see financial assistance programs, 13.04% report people could benefit from mental health counselors and 13.04% health and fitness programs.

Support Groups

Support groups are used to develop and sustain positive strategies for living with the virus and strengthen their knowledge about HIV/AIDS as well as other diagnosis that impact this population. Professional and peer led support groups for mental health, addiction, women, MSM, etc. were desired programs requested by the participants interviewed. P4 (54-year-old female diagnosed since1995) reported “Stress is a big part of my life. I believe you must have a support team, and support groups will help people process and cope with what they are going through.” P5 (65-year-old male diagnosed since 1986) also noted, “I think one of the things that definitely would help would be a support group for elders, and women.”

Financial Assistance

Several participants report since being diagnosed, they had to leave their jobs and apply for Social Security Disability, therefore they are on a fixed budget. The current case management program offers assistance with various social determinants of health (SDOH), however the assistance is not ongoing and are directed towards housing, food or transportation. Some participants report that sometimes, the assistance needed does not fit into those categories. However, the majority of the participants indicate that safe and affordable housing is crucial to helping them manage their diagnosis, additionally they struggle with food, transportation costs and paying for insurance premiums or medication copays. One participant P1 (50-year-old female diagnosed since 2000) reports, “I think the needs are not only with support groups, or mental health, but also with financial support. I think it is important to have support from other systems like churches, community-based organizations, like being involved in support groups.”

Mental Health Counseling

Several participants (13.04%) described their experiences living with HIV/AIDS and report that at times they have felt depressed and alone. Many participants report that in the earlier days of the epidemic, they lost friends due to limited treatment options, they lost relationships with family and friends due to the diagnosis or their sexuality. It was during those moments that they felt they could have used someone to talk to. Participant P9 (67-yearold male diagnosed since 1990) reports, “I think it is important to have a behavioral health counselor on site that you can access, a lot of people are struggling with mental health and often times do not have anyone to talk to.” Participant P12 (62-year male diagnosed in 1990) also reports that she struggled with depression after being diagnosed and suggested that the case management programs have mental health counselors onsite to help people cope with and manage their diagnosis.

Health and Fitness Education

Regular physical activity and exercise are a part of a healthy lifestyle for everyone, including those with HIV. Several participants mentioned that having health & fitness and nutritional classes would be beneficial to have at the current care site. P11 (63-year-old male diagnosed since 1996) reports,

> I understand the importance of mental health support groups, but I also I think it would be beneficial to have exercise programs or programs that provide nutritional education so I can learn how to eat better and build up my strength.

Table 5

Themes: RQ4 Desired Case Management Programs

Theme	Number of participants	Percentage of participants
Support groups	10	43.38%
Financial assistance	7	30.43%
Mental health counseling	3	13.04%
Health and fitness education	3	13.04%

Note. Participants (*N* = 13) could provide more than one response.

Summary

The purpose of this study was to understand the experiences of participants who are age 50 years and older, living with HIV/AIDS, and enrolled in case management programs in Indiana. In chapter 3, I provided a review of the data collection, management, and analysis process. Purposive sampling was used to acquire a participant sample. An informed consent form was reviewed with each participant and signed via DocuSign prior to completing the interview. The responses from the interviews were used to understand how each participant defined case management, learn what they expect from the case management program and the staff, explore their overall experience, and gather which programs they would desire to be included in the case management program as they age. In response to RQ1, participants defined case management as a program that provided assistance, support system, and educated them on their condition, new treatment options and programs available to them. Answers to RQ2 revealed most participants expected the case managers assigned to them to be knowledgeable about the disease process and community resources, be available when needed and provide education and support.

Answers to RQ3 indicated that all participants have had a positive experience in the case management program. Responses from RQ4 showed that participants are looking for the case management programs to provide support groups, mental health counseling onsite, financial assistance and to provide programs for health & fitness, and nutritional education. All interviews were digitally recorded, which ensured the dependability and accuracy of the transcripts. In section 4, I will provide an interpretation of the findings, limitations, recommendations, social change and my experience will be provided.

Section 4: Application to Professional Practice and Implications for Social Change

This generic qualitative study was conducted to explore the experiences of participants aged 50 years and older living with HIV/AIDS and enrolled in case management programs in Northwest Indiana. I wanted to learn how the participants defined case management, what their expectations of the program were, how they described their experience, and what programs or services they believe they need as they age. To understand the lived experiences of individuals aging with HIV/AIDS, it was important to understand from their perspective what programs or services they think they need as they age. I employed a generic qualitative approach to explore the experiences of older adults enrolled in case management programs in Northwest Indiana. This approach was a good fit to answer the research questions because it is used to obtain an understanding of the meaning that people attribute to their experience (Madill & Gough, 2008; Yoshikawa et al., 2008). The findings that emerged from the data analysis related to the original research questions and confirmed the link between use of case management programs and improvement of the quality of life among this population (see Thurman et al., 2010).

Key Findings

One of the primary findings was how participants defined case management programs and their expectations of the program. Participants defined case management as a program that provides assistance in locating services to address their social determinates of health (SDOH), provides education on their diagnosis and how to manage the condition, and serves as a support system. Participants reported that their expectations from the program and the staff were to provide support, be available when needed, and offer education on the changes in treatment options or program services available to them.

Another key finding was revealed as participants reflected on how they became aware of the available program, how they were connected to case managers, and how they were assisted in accessing medical and psychosocial services. At the initial time of diagnosis, many participants revealed they were in the grieving process; also, they were in denial. Participants also reported they felt hopeless and alone, but this issue was addressed after their assigned case managers began to educate them on their diagnosis, assess their needs, and connect them to the appropriate providers. Participants reported that once they learned more about the diagnosis and the treatment options available, they began to find hope again, but that did not change the feeling of being alone and isolated.

During the initial days of the epidemic, people were not as knowledgeable about the condition, and stigma and discrimination became a part of the participants' lived experience. Many participants were rejected by friends or family, and they lost important people due to death as a result of AIDS, which put them in a depressed state. According to the participants, a good support system is a positive force that can shield them from experiencing stigma in the community. Participants also noted that positive relationships with family, friends, spouses, or significant others were important, but in the earlier days of the epidemic when people were scared and did not know how to respond, it was the case manager who played a critical role in supporting their survival. This final chapter is presented in five parts: interpretation of the findings in relation to the literature review and the conceptual framework, limitations of the study, application to professional ethics in social work practice, recommendations for social work practice, and implications for positive social change.

Interpretation of the Findings

The findings are interpreted in three ways starting with new information obtained to advancing program services for HIV/AIDS participants age 50 and older. The second part of the interpretation addresses the confirmation of other peer-reviewed articles. In the third part, findings are interpreted in the context of Bronfenbrenner's ecological systems theory.

Advancing New Knowledge

This study offered new knowledge relevant to answering all four research questions. The most important knowledge gained in this research was that the participants self-reported a positive experience in the case management program, which has led to their increased knowledge about the disease process and how to manage their condition. Participants reported that the case management program and staff had provided them with education on the disease, treatment options, navigating the health care system, locating providers, coping techniques, and access to financial resources to address SDOH, and staff provided support when participants had no one else to turn to. As a result of this assistance, the participants disclosed success in achieving viral suppression and a decrease in mental health symptoms. Through the education on community resources, some participants were able to achieve financial stability and purchase their first home. Participants reported that the education on financial assistance received in the case management programs helped them to focus on managing their health and improving their quality of life.

Another critical finding was revealed regarding the future for participants as they age. The participants reported that they will require additional support separate from the issues that were faced with the diagnosis. Participants described how they are noticing that they are aging before their time. According to several participants, their physicians informed them that this could be due either to the disease process itself, from being on the earlier ART drugs, or to the side effects of the current drugs. Most participants reported extreme fatigue, which they were experiencing more often, and which prevented them from being as active as they once were. As a result, participants indicated they need continued education on how to manage the condition as they age and will need assistance with finances due to the rising cost of living, with no increase in their social security benefits, or due to the disabling condition and inability to work. Providing resources to address their housing, transportation, food insecurity will allow them to focus on their health instead of worrying about where they are going to sleep or how they will get their next meal. Additionally, the participants reported that managing multiple comorbidities contributes to their depression and anxiety. They reported that onsite mental health providers, peer-led support groups, and education on health and nutrition are necessary in managing their condition as they age.

Support for Findings of Other Studies

This study’s demonstration of the positive experiences of older adults with HIV/AIDS enrolled in case management in Northwest, Indiana offered qualitative support to the research on how case management interventions are effective in managing the challenges faced by those affected by the disease. PLWHA have many challenges that prevent them from adhering to treatment recommendations. Stigma, cultural implications, race, age, sex, sexual orientation, health care illiteracy, discrimination, lack of nutritional foods, and socioeconomic factors are a few of the issues that impact this group of individuals. Through the use of comprehensive assessments, social workers can help identify and address older adults' concerns (Wacker & Roberto, 2011). Current participants described their experiences as a newly diagnosed patient, how they were introduced to the program, how they were educated on their condition and the impact of stigma, and how they learned to advocate for themselves. Case managers were able to assess the participants' needs, link them to available community resources, and refer them to service providers, which has led to improved quality of life and self-reported viral load suppression. This study confirms Emlet and Poindexter's (2004) finding that interventions such as case management programs are effective in addressing some of the challenges faced by this population.

As people are living longer with the disease, their health needs are likely to become more complex and chronic. The quality of life in chronic illnesses can vary with age, especially with older adults with HIV (Hyduk, 2002). Chronic conditions can affect people's mobility, functional status, emotional balance, and self-esteem because of their dependence on others (Somrongthong et al., 2016). Current participants reported that they feel like they are aging faster than those without the disease. Participants reported feeling extreme fatigue, vision changes, bone density issues, memory loss, and lack of clarity on what is to come and how to manage their conditions. This is consistent with the research by Yu et al. (2021) who noted that older adults with chronic illnesses or disabling conditions such as HIV/AIDS need more medical care and psychological and physical support than the average individual, and they would benefit from case managers.

Wacker and Roberto (2008) also supported case management interventions and suggested the program can help older adults access services and resources to improve their quality of life and help them age safely in place. Current findings support Yu et al.'s (2021) study, which provided evidence that case management interventions improved older patients' psychological health and well-being, and patients displayed significant improvements in unmet service needs. My examination of older HIV/AIDS participants' experiences in case management have extended the knowledge in the discipline by showing how the current programs and services have directly impacted the participants' overall health and improved their quality of life, as well as revealing what programs are needed to assist them as they age.

Findings in the Context of the Theoretical Framework

I applied Bronfenbrenner's ecological systems theory, which guided the development of the open-ended interview questions. The focus was on the participants' experience in case management and the how their experience was impacted at the micro, meso, and macro levels. Based on the findings, social support, education, and assistance in navigating the health care system impacted the participants' experience in the case management program. Additionally, the person who introduced the participant to the case management program provided a positive perspective on the program, which contributed to how the participant perceived the program and whether they would participate.

Brennan-Ing et al. (2016) reported that individuals enrolled in case management programs tend to be those who are likely to have lower income and education, be uninsured or underinsured, be on public insurance programs, have a history of mental health or addiction issues, and have limited support systems. Because of those varying psychosocial problems, the participant’s experience in case management programs can be influenced either positively or negatively (Devyani et al., 2016). Because current participants lacked a strong support system, knowledge of the disease process, and available resources, when their case managers connected them with community resources and provided support, they viewed the experience as positive.

The mesosystem (the relationship between two or more settings) is the second level of Bronfenbrenner’s environmental layers. Although interactions within the microsystem directly impact the participant, links between contexts also influence the participant experience (Devyani et al., 2016). According to current participants, the case management staff were supportive and helped to link them with health care providers who were knowledgeable about their condition and provided referrals to outside community agencies that assisted with SDOH, such as finances, housing, food, transportation, and counseling. Current participants were very pleased with the communication and outcomes of the referrals, which provided a positive experience.

The case management programs are funded through the Ryan White Cares Act, which is at the macro level system. If legislative changes at the local or national level, inadequate or reduced Ryan White government funding, restrictions in case management and other supportive services, and shifts in the controlling political party occur, it will directly affect a patient's experience in case management programs in some way, shape, or form (Brennan-Ing et al., 2016). The programs that were available at the beginning of the epidemic in Northwest Indiana were not fluid; however, over the years additional funding has been awarded, thereby improving the case management programs to address SDOH for the participants. As a result of the increase in program funding, current participants have not been impacted negatively, resulting in a positive experience. Bronfenbrenner's ecological systems theory supports the idea that the environment can influence the participant's experience.

Limitations of the Study

Although this study provided important information regarding the participants' experience in case management programs, the study is not exempt from limitations. The study's limitations included lack of scholarly articles or peer-reviewed journals on HIV/AIDS case management programs, HIV case management in Northwest Indiana, or aging with HIV/AIDs. Also, the small sample may not be representative of the larger population.

Since the 1980s, HIV/AIDS in the United States has been perceived as a young person disease, and life expectancy was between 1 and 2 years; as a result, case management programs, prevention intervention efforts, and research were established to target the younger population but did not consider older adults aging with HIV/AIDS (Emlet, 1997). As new treatment options have been developed to prevent the disease and lesson the symptoms, there has been little research to understand how HIV/AIDS impacts the older adult and how case management programs contribute to improving this population's quality of life (Hasche & Lavery, 2015). A review of the literature on HIV/AIDS has shown progress over the years; however, qualitative studies had not focused on topics such as aging with HIV or how case management benefits this population.

The second limitation of this study was the sample size. Sandelowski (1995) noted that qualitative sample sizes should be "large enough to allow the unfolding of a new and richly textured understanding of the phenomenon under study" but small enough so that there is a "deep, case-oriented analysis" (p. 183). Cooper and Endacott (2007) also reported that sampling should continue to the point of saturation. Therefore, the researcher should continue to recruit participants until no new data emerge. In Northwest Indiana, there were 172 individuals aged 50 and older who were enrolled in case management programs at the time of the study. HIV-positive individuals not enrolled in case management were not included in the study. I used a partner agency to recruit participants; however, there were participants from other AIDS service organizations in Northwest Indiana who also participated in the study. Recruiting participants from multiple agencies in Northwest Indiana offered a more representative picture of clients' experiences than studies of case management that focused on a single agency, as occurs often in HIV case management research. Data saturation in the current study became apparent when the stories, themes, issues, and topics surfaced were the same. However, the study's sample size represented only 7.5% of the population of older adults with

HIV/AIDS enrolled in case management in Northwest Indiana; therefore, it is not possible to generalize findings to the larger population in Northwest Indiana.

Application to Professional Ethics in Social Work Practice

Social work researchers have the responsibility to conduct research informed by the professions' values. The social worker has a duty to promote social justice, challenge discrimination and unjust policies and practices that the identified populations may face (Sobocan et al., 2019). This research study examined the experiences of HIV/AIDS patients aged 50 and older enrolled in case management programs while keeping the NASW core values such as service, social justice, importance of human relationships, integrity, and dignity, and worth of a person at the forefront. The NASW principles that were relevant to this study were service, social justice, dignity and worth of a person, importance of human relationships and competence.

Participants in this study reported they expect their case managers to be available to them which aligns with the NASW code of ethics value of service. Service is the primary goal of all social workers. Service is the value from which all other social work values stem. Social workers often place others' needs above their interests and use their skills and knowledge (from education and experience) to help people (NASW, 2021). Service is vital in case management practice with older clients dealing with HIV because older people living with HIV often experience stigma and discrimination, which can lead to social isolation, loneliness, depression, minimize health-seeking behaviors, and create concerns with eldercare situations (Brennan-Ing et al.,2016). Through the NASW core value of service, social worker case managers can utilize their knowledge, values, and skills to help address the older adult patient's concerns (NASW, 2021). In this study, the participants believed that their interest were considered, and the case managers not only available for them, but provided them with knowledge (from their education and experience) to help them address their barriers to medical adherence and improve their quality of life.

Social workers also advocate on behalf of the oppressed and voiceless or those unable to advocate for themselves. This study incorporated the NASW social justice core value by allowing participants to respond anonymously. Throughout the study, anonymity enabled them to feel included and validated when provided the opportunity to share their opinions on their experience in case management. Future social workers shall also take into consideration the stigma and discrimination that this vulnerable population endures and aid in empowering them to advocate on their own behalf as well as advocating for them when they are unable to do so.

Dignity and respect are something that every person has a right to have. To maintain public trust and confidence in human research, participants must be treated with respect (Pieper & Thomson, 2014). As each person is different and comes with a separate set of cultural and social values, the researcher needs to be mindful of those differences by treating each person with dignity and respect throughout the research process. Social workers must also display integrity and behave in a trustworthy manner (NASW, 2021). Therefore, when highly sensitive information, such as an HIV/AIDS diagnosis, is present, the researcher must attempt to alleviate the possibility of intrusion into the participants' autonomy (Sanjari et al., 2014). Therefore, in this research study, the consenting process used ensured each participant understood the study’s purpose, benefits and risks, and their right to withdraw from the study at any time and were reminded that their information will be kept confidential. In this study, safeguards were used to ensure the participants confidentiality, such as using code names, provided a private location to conduct the interview. Future social workers shall also ensure that, when working with people, they treat each person with dignity and respect, and ensure that their confidentiality is maintained to behave in a trustworthy manner.

Additionally, when working with individuals in HIV/AIDS programs, it is essential to maintain human relationships. Each participant has had differing experiences, some more tragic than the other (Sanjari et al., 2014). In the current study, each participant reflected on the time when they were first diagnosed and described what that felt like and how they felt alone and hopeless. Reliving the past can be traumatizing for individuals, especially if they have not fully come to terms with the diagnosis. In the current study, participants were offered the option to be referred to ancillary services if they expressed some concerns that had not been addressed in the case management program, or if they experienced some discomfort or stress during the interview process. Future researchers should be aware of the potential impact that resharing a story can have on a participant and put appropriate safeguards in place.

The participants in the current study provided information for future case managers/social workers regarding what they consider to be important to them when receiving services in a case management program. As it relates to the NASW code of ethics, the participants reported that it is important to them that their case manager is competent in the subject matter before providing them with education on managing diagnosis. Competence in social work practice means the social worker will practice within their area of expertise, and when there are areas in which they are not knowledgeable, they will strive to increase that knowledge through research and continuing education (NASW, 2021). Social work competence in HIV case management is critical because failure to be knowledgeable in HIV services can delay medical treatment, adherence, and enrollment in ancillary services for this population, thereby affecting mortality, overall quality of life, and spread of the disease (Relf et al., 2011). As the social work researcher, I reviewed the most current professional literature to remain current on the emerging knowledge relevant to this population and social work practice (see NASW, 2021). Future social workers should ensure that they have the proper training before working with vulnerable populations such as those aging with HIV/AIDS.

Recommendations for Social Work Practice

In the upcoming years, the rate of new HIV diagnoses is projected to increase among older adults (CDC, 2016). The expected increase in new infections of those entering the age category of 50 and older suggests the need for ongoing investigations of those aging with HIV. The Council on Social Work Education (2001) reported that research is essential for the continued growth and improvement of the social work profession and the development and refinement of program services that benefit vulnerable populations such as those aging with HIV/AIDS.

The current study increased my understanding of the experiences of older adults aging with HIV/AIDS enrolled in case management programs as I learned from their perspective regarding what programs will benefit them as they age. Evaluating the patient experience is a key step in moving toward patient-centered care. By looking at various aspects of patient experience, one can assess the extent to which patients are receiving care that is respectful of and responsive to individual patient preferences, needs, and values. Gathering feedback from patients is also a part of engaging them in their care. Feedback from consumers provides an opportunity to highlight and address aspects of the care experience that need improvement (LaVela & Gallan, 2014). Further investigations on case management's impact on medical adherence and viral suppression for those ageing with HIV is warranted. Future research could examine how case management is integrated into HIV care.

I used a generic qualitative approach to explore the lived experiences individuals aged 50 and older living with HIV/AIDS and enrolled in case management programs. Hence, the findings cannot be generalized to a larger population. Nonetheless, based on my findings, additional studies, noted below, could be conducted to uncover additional knowledge that could benefit this population.

- Although HIV/AIDS and aging often are not perceived as being interrelated, the increase in the number of older adults infected with HIV/AIDS indicates that older adults are being overlooked in terms of HIV prevention and treatment (Linsk et al., 2003), therefore additional research to explore health care providers' awareness of how to screen and provide treatment for HIV/AIDS in the elderly population is needed.

- In Gonzalez et al., (2004) study, the researchers reported there is a link between social support and increased mediation adherence among participants between 18-65 years of age. The researchers hypothesized that social support would relate to adherence through its relationship with lower depression and greater PSOM (positive state of mind). Perceived quality of social support was significantly associated with medication adherence even after we controlled for age and alcohol consumption. According to Gonzalez et al., (2004) other research has reported relationships between similar positive aspects of quality of life and medication adherence among HIV patients, but they are unaware of research showing a relationship between PSOM, or other similar positive psychological state variables, and medication adherence in any illness group. Therefore, future studies should explore the role of social support in managing HIV/AIDS. This will help practitioners provide and implement evidence-based strategies for practice.
- Emlet (2007 reports that older adults are increasingly impacted by HIV, whether newly infected or long-term survivors, however little is known about how HIV related stigma in older adults because many studies do not include older subjects or ignore age as a variable, therefore additional research is needed and must ensure that older people are included as an identifiable group at every stage of the HIV research process.
- Emlet & Poindexter (2004) report that social workers lack knowledge about the services needed by older Americans. Therefore, the development of

> gerontology and social work curricula at colleges and universities that train aging specialists and service providers in the particular needs of the over-50 HIV-positive population would be beneficial for this population.

The findings from the recommendations for future research, listed above, will impact my own social work practice by provided me with additional knowledge on how case management interventions improve viral load suppression, knowledge on how to mental health is exhibited with older adults. Last, additional funding provided to targeted group will allow for the removal of barriers that prevent medical adherence which will also aid in preventing the spread of the disease.

Implications for Social Change

The findings from this study have shown potential for positive social change in the lives of those 50 years and older living with HIV/AIDS by showing the increasing need for education and awareness, improving access to healthcare and support services, which enhances their quality of life. Through this study I have learned that each individual who is aging with HIV/AIDS has varying expectations of case management services and unique needs as they age. HIV/AIDS is often associated with younger populations, and the unique challenges faced by older adults living with HIV/AIDS are often overlooked (Hughes, 2011). After listening to the participants in this study describe their experiences and unique needs as they age, I recommend that case managers, medical providers and mental health professionals understand that, developing a mutual trust and respect for one another will help to build rapport, which will assist in identifying the participant's concerns, barriers to medical adherence, and how stigma and discrimination impact their care. Also, through creating and implementing case management programs that specifically target older adults, awareness can be raised about the prevalence and unique needs of this population. This can help to reduce stigma and discrimination associated with HIV/AIDS in older age groups. Stigma and discrimination still continue regardless of age, therefore older adults living with HIV/AIDS may continue to face barriers in accessing appropriate healthcare and support services. Case management programs can help address these barriers by providing a coordinated and comprehensive approach to care (LaVela, & Gallan, 2014). This can include facilitating access to medical treatment, medications, mental health services, social support networks, and other resources tailored to the specific needs of older adults (Cahill & Valdaz, 2013). Additionally, case management programs for older adults can improve their overall quality of life. By addressing the physical, emotional, and social aspects of their lives, these programs can help older adults manage their health, cope with the challenges of living with HIV/AIDS and maintain their independence and well-being. This can lead to increased life satisfaction and better overall health outcomes (Cahill & Valdaz, 2013).

Through this study, I was able to uncover and get a better understanding of the unique challenges HIV+ participants have faced throughout this epidemic, understand their daily experiences of living with HIV while utilizing the case management services as well as learn what program interventions need improvement or need to be implemented to address their unique needs. As suggested by the majority of the participants, administrators over the case management programs ought to develop appropriate activities (educational and social) to keep this population active as well as up to date on current treatment recommendations. Roger et al., (2011) supports the participants ideology and indicates that social networks have proven to be very important both for older adults and for people living with HIV. Roger et al., (2011) further explains that, to an older adult who has been diagnosed with HIV/AIDS, social networks and social supports are key aides for improving their quality of life while coping with the disease and likely contribute to successful aging with HIV/AIDS. Furthermore, participants recommended bringing back programs such as support groups to educate them on how to manage diagnosis or provide coping tools, seminars to provide knowledge on how to eat properly and learn what exercises are appropriate for their age group. Developing a peer mentor program was also suggested to provide support to the older adult that is newly diagnosed as well as the long-term survivors.

Financial assistance was also requested as the majority of this population are “forced” into disability because of the effects of the virus, or for those still struggling to maintain employment and thus adequate housing. According to Durvasula (2014) ongoing stressors such as finances, employment related stress, and interpersonal relationships, as well as HIV-specific stressors such as fear of disclosure, stigma about HIV, body image issues, fear of infecting others or finding a partner, and end of life issues can be addressed through support programs. Therefore, if the suggested programs are put in place, this could enable them to create new bonds, socialize more, increase knowledge on how to manage condition and eventually embrace the outside world thus reducing any possibility of falling into depression (Durvasula, 2014).

Because HIV/AIDS research in older adults is scarce, little is known about how to provide services to older adults living with HIV/AIDS (Hasche & Lavery, 2015). Subsequently, few services are available for these individuals. Most HIV/AIDS education is tailored to a younger population, and much of the materials provided are not age-appropriate for older adults (Emlet, 1997). Because physicians and other health care providers play an essential role in HIV/AIDS prevention, they should pay special attention to the growing older population contracting this disease (Durvasula, 2014).

Furthermore, to better assist this population as they continue to age with the virus, necessary steps ought to be taken for healthcare providers and case managers to grasp a better understanding of their daily challenges and needs, and thus reduce that burden. It is essential that the case manager develops trust and partnership with the patient so they could easily open up to them and share their true challenges and/or needs upon onset. As stated by Wacker & Roberto (2008) it would be essential for the case management team to collaborate with the healthcare providers, stakeholders, and funders to develop policies that would improve program services and address health disparities to better serve the participants.

Furthermore, researchers who are the voice of these participants, and stakeholders can use the collected data to outline and implement specific policies that can contribute to effective social change. Additionally, using the reported data, other social scientists could frame additional research questions for further studies, to expand even more the current body of knowledge in order to improve the quality of life of this population and positive experience in the case management program. Last, If the recommendations of my study are implemented, they could directly impact older adults aging with HIV who are struggling in a world where they have outlived most of their friends and are somewhat rejected by a community of their own.

Summary

This study was conducted to explore the experiences of participants who are age 50 years and older, living with HIV/AIDS, and enrolled in case management programs in Indiana. To gather data, I conducted semi-structured interviews which were recorded either over the phone or on zoom with thirteen participants. The information was used to understand how the participant defines case management, their expectations of program services, and age-related challenges which was later transcribed and analyzed with the Nvivo software. The analysis revealed four themes, which enabled me to grasp an understanding of the experiences of the participants enrolled in case management programs. In response to RQ1, participants defined case management as a program that provided assistance, education support system, and educated them on their condition, new treatment options and programs available to them. Similarly, answers to RQ2 revealed most participants expected the case managers assigned to them to be knowledgeable about the disease process and community resources, be available when needed and provide education and support.

For the most part, in response to RQ3, participants described their overall experience as a positive one. While reviewing the participants experience in case management programs, the participants not only expressed their needs of today, but more importantly they also shared their uncertainties of tomorrow. To that effect, some participants, in the wake of their body weakening overtime from the long-term effect of both the virus and ART, shared their fear of losing their independence before their time whether it be through disability as a direct result of HIV. Therefore, in response to RQ4, participants report they are looking for the case management programs to bring back programs such as support groups to educate them on how to manage their diagnosis and provide coping tools. Participants suggested the creation of health seminars to provide knowledge on the proper diet and learn what exercises are appropriate for them as they age. Additionally, the development of a peer mentor program was also suggested to provide support to the older adult that is newly diagnosed as well as the long-term survivors.

In conclusion, while HIV/AIDS has become a manageable disease as of 2020, persons living with HIV/AIDS continue to have many challenges, such as increased social isolation, discrimination, disclosure, and stigma, which impacts their self-image and mental health and can prevent them from successfully adhering to treatment recommendations (HIV.gov, 2021), therefore it is imperative that additional research be conducted, with a larger sample, on this population to understand how case management programs directly impact participants medical adherence, viral suppression and improve their quality of life.

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Appendix: Interview Questions

1. When were you first diagnosed with HIV?
2. Since your diagnosis, how long have you been enrolled in case management programs ?
3. How would you define case management?
4. What is your experience with case management services in the program of which you are currently involved? If you have received HIV case management services in a previous program, describe your experience with that/those program(s).
5. What are your expectations of the case management program?
6. How has the case management program helped you to manage living with HIV and being on ART?
7. How has the case management program helped you to understand aging with the HIV/AIDS?
8. How has the case management program helped you to understand health complications that arise from getting older with HIV?
9. How has the case management program helped you to improve your current quality of life?
10. What programs or services other than the case management program of which you are currently enrolled in do you think are needed that will help you to better manage your illness as you age with HIV?