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The Lived Experience of African American Young Adult Men with HIV and Self-care Collaborative Management

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Abstract

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by

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MSN, Wayne State University, 1978

BSN, Wayne State University, 1973

Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
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Abstract

African American young adult (AAYA) men living with HIV often lack interventions that address the influence that HIV has on their quality of life, especially their relationships. Self-care collaborative management (SCCM) concerns related to disclosure and stigmatization complicate social, psychological, and SCCM behaviors. Intervention programs addressing these concerns should be based on relevant, accurate information, but this information is lacking for AAYAs. The purpose of this research was to explore and describe the lived experiences of male AAYAs with HIV and their use of SCCM. The study method was qualitative; Husserl's transcendental phenomenology was the design. The individual family self-management theory was used to contextualize the lived experiences of male AAYAs with HIV, the perceived support from families, and use of SCCM in daily life. Data were collected from six male AAYA who were interviewed by phone. Thematic analysis of data yielded six major themes related to SCCM: support systems, self-care, physical health, mental health, economics, and guilt. All participants shared the challenges they face in their SCCM. Three spoke of the support provided by their family members and significant others, while three talked of only receiving support from their peers. All six participants reported taking charge of SCCM needs, with some more successful than others. The findings highlight opportunities for health care providers to promote positive social change by developing holistic approaches to improving health outcomes in male AAYAs and supporting individuals' efforts to support themselves.

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Dedication

I hereby dedicate this dissertation to my loving husband, Dean Moore, MS, LPC who has offered steadfast support and devotion throughout this arduous journey. Also, to my five children, Dean II, Devon, Deshon, Toya, and Diamond Moore Shelby, all of whom are medical doctors. My family has been my source of unconditional love and encouragement from the very beginning, and their support has never wavered. I also express appreciation to those who make up my support network--to my Mother Evangelist, Della Jordan RN BSN, who would not let me give up, and my auntie, Mrs. Marilyn Smith, who prayed for me relentlessly throughout my entire dissertation journey. I am here because of all of you.

This dissertation is in memory of my beloved mother, Evangelist Missionary Della Jordan, BSN, RN.

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Chapter 1: Introduction to the Study

Past sexual experience, multiple sexual partners, and current sexual activity remains higher among male African American young adults (AAYAs) than any other group of young adults (Mellins et al., 2005; Wand & Ramiee, 2012). These trends contribute to the prevalence of human immunodeficiency virus (HIV) among this cohort (Mellins et al., 2005; Wand & Ramiee, 2012). The Centers for Disease Control and Prevention (CDC) reported that in 2016, AAYA men had a 43.9% higher rate of HIV infection than any other ethnic group (CDC, 2019).

AAYAs are often marginalized, which means that they may be treated as insignificant human beings who have no power within their community (Todman, 2012). Marginalization can result from racism and discrimination, social exclusion and oppression by the criminal justice system, unequal housing opportunities, and segregation within the educational system (Todman, 2012). The results of marginalization are the prevention of an active voice, identity, inclusive participation, and ongoing stigmatization of male AAYAs with HIV (Oeur, 2016). Scholars do not know how male AAYAs feel and think about being marginalized or how they find dignity, respect, and self-worth for themselves (Alvarez, 2017). The way male AAYAs think about belonging to a community of marginalization is also unknown (Oeur, 2016). Marginalization effects on male AAYAs show that these individuals seek self-efficacy and affirmation from their contextual environment for their contributions and accomplishments to their community (Alvarez, 2017). Oeur (2016) asserted that these young adults relentlessly pursue respect, esteem, dignity, self-worth, and masculine status. The current culture in the United States may impede AAYAs from thriving in society, keeping them oppressed and disadvantaged and maintaining their marginalized status (Todman, 2012).

Self-care collaborative management (SCCM) is defined as accountable actions that chronically ill individuals implement to maintain their overall health and emotional stability, with combined family and peer input (Riegel et al., 2012; Ryan & Sawin, 2009). The terms *self-care* and *collaboration* are integrated to show the importance of significant others' impact on the management of chronically ill individuals (Riegel et al., 2012). Harper et al. (2014) posited that male AAYAs use resilience processes for self-care management. The methods consist of engaging in health-promoting practices that result in healthy behavior and motivation to seek social support from others (Harper et al., 2014). Recent studies also show that male AAYAs seek to empower their peers who also have HIV by using intrapersonal levels of resilience such as support seeking and providing more substantial emotional support to partners (Harper et al., 2013). Greater exploration and understanding of lived experiences of male AAYAs about the SCCM of their chronic illness, HIV, needs rigorous investigation (Drew, 2001; Riegel et al., 2012; Ryan & Sawin, 2010).

Recent studies show that male AAYAs with HIV collaborate with their peers and use self-care management through various methods. These individuals may cooperate by sharing mobile and smartphones for health information related to their chronic illness (Muessig et al., 2015; Pew Research Center Internet Project, 2014). They also use the internet as a means of social networking, and eHealth, mHealth, Facebook, and text messages to stay connected with their peers (Muessig et al., 2015). The use of these devices and social media may reveal the underlying strength, motivation, and resilience that male AAYAs have as well as the trust that they have established when communicating and sharing self-care ideas with their peers (Kanter et al., 2019; Kirkwood, 2016; Sillence et al., 2017). Analysis of how AAYAs use these devices and what data they utilize and share with peers may provide qualitative information on how AAYAs give meaning to their daily lives (Muessig et al., 2015).

The qualitative research method is based on a naturalistic observation of phenomena and how people assign meaning to their daily lives (Denzin & Lincoln, 2013). I used the qualitative method to explore the lived experiences of AAYAs with HIV related to SCCM. I did so by observing visual cues while conducting semistructured interviews with participants to understand their lived experience and the meaning they attached to SCCM (see Denzin & Lincoln, 2013; Erickson, 2011). Exploring participants' verbalized accounts of their lived experiences through a rigorous qualitative methodological approach may provide insight into the complexity of SCCM (see Ravitch & Carl, 2016).

The results of this study may effect positive social change by encouraging family members and peers with HIV to assist male AAYAs better manage their illness. The results may also inform the development of strategies to decrease the stigma of HIV, help with disclosure of HIV status, improve medication adherence, and foster collaborative communication between individuals (Ryan & Sawin, 2010). In this chapter, I present the background of the study, the problem, and the purpose of the study. The theoretical framework and definitions of terms, the assumptions, limitations, and significance of the study are included in this chapter. The chapter concludes with a summary and introduction to Chapter 2, the review of the literature.

Background of the Study

A literature review reveals that HIV is a chronic disease that affects African Americans at a disproportionate and disparate rate (CDC, 2014) compared to Latinos, Whites, and other diverse groups. By 2018, approximately 1.1 million people are living with HIV in the United States, and AAYAs account for almost half (42.4%) of those living with HIV (CDC, 2019). The CDC (2019) reported that more than 30,000 African Americans are affected by HIV every year, and approximately 30% of these are AAYAs. Male AAYAs are infected ten times more often than White young adult men, and AAYA women are infected with HIV 20 times more frequently than White young women (CDC, 2016). Male AAYAs with HIV are vulnerable and described as marginalized and disparate due to a high percentage of this cohort lacking an awareness of the disease, therefore lacking the ability to take advantage of resources for personal care and treatment for their chronic illness (CDC, 2014; Murphy et al., 2015). Exacerbating this problem, the CDC reported that over 50% of all new HIV infections in the United States are diagnosed in minority young adults, who are a group that practice behaviors that place them at higher risk for HIV (CDC, 2016).

Examples of risky behaviors exhibited by male AAYAs include smoking, consuming large amounts of alcohol, and engaging in unprotected sex (Kipping et al., 2012). A lack of education may affect male AAYAs' decision-making and contribute to their engagement in risky behaviors. Sexual risky behaviors may be defined as having frequent sex with multiple partners, having unprotected sex, and having sex while intoxicated with alcohol or drugs (Haglund & Fehring, 2010). Research has revealed that AAYAs who engage in unprotected, risky sexual behaviors are at a high risk of contracting HIV (Haglund & Fehring, 2010; Kipping et al., 2012; Mellins et al., 2005). Risky sexual behaviors in male AAYAs with HIV may result from knowledge deficits for self-care because of limited or no access to clinics and health care providers who can identify preventative measures for risky sexual behaviors (CDC, 2014).

When male AAYAs become ill from risky sexual behavior, they may seek care from resources within their natural environments, such as peers and family members with HIV (Ryan & Sawin, 2010). The diagnosis of HIV changes their lives by causing fear, denial, and many questions of concern, as well as the immediate need to find someone who can be trusted so that worries and concerns can be shared and questions can be answered (CDC, 2016). The stigma of the disease and fear of discrimination related to disclosure of their status or sexual orientation, as well as fear of rejection and lack of support from family and friends, may prevent AAYAs from seeking appropriate treatment and support from their family and community (CDC, 2016). Stigma and fear of discrimination also may cause male AAYAs with HIV to experience emotional problems, including feelings of anxiety, depression, isolation, suicidal ideation, guilt, and shame (Hall et al., 2017; Logan, 2018). These individuals may choose to be silent and may be reluctant to talk to anyone concerning health issues as a way of protecting themselves from stigma and discrimination (Gillard & Roark, 2013). Understanding the stigma related to HIV in AAYAs continues to be a universal problem because stigma is complex and challenging to understand (Parker et al., 2002).

SCCM is a strategy that is defined as a deliberate act of bringing others, such as family members and peers who have the same chronic illness, into one's care, thus bringing about a collaborative, or team, effort to enforce decision-making for healthy behavior, as relevant to interventions of well-being (Eustace, 2012; Grey et al., 2015). The chronically ill young adult and family members who assist with innovative interventions for optimal health make up the collaborative effort (Filo et al., 2013). A collaborative effort comprised of significant others is essential for the successful SCCM of male AAYAs with HIV. SCCM interventions include stigma and disclosure issues; medication adherence; prevention of HIV transmission; collaboration with family members; communication, sharing, and trust issues; addressing emotional issues; improving self-esteem; and well-being (Hall et al., 2017). Health disparities may result in inadequate SCCM for HIV and impact individuals' access to health clinics, which is relevant to the provision of successful health interventions that may decrease the likelihood of developing AIDS or progressing to death (CDC, 2016).

This study may show that understanding the lived experiences of AAYAs is grounded on contextual information that is based on health disparities (see CDC, 2015). These health disparities may result from unequal access to health care and the inability to access appropriate health care for marginal, minority cohorts who need SCCM interventions (CDC, 2015; Filho, 2013; Marshall et al., 2012; Munhall, 2012). Exploring and understanding the lived experience of this cohort concerning SCCM of their chronic illness needs rigorous investigation (Drew, 2001; Janesick, 2016).

Adequate SCCM means that individuals attempt to initiate and manage their chronic illness care independently and purposefully. They may do so with the advice and help of family members or significant others, some of whom may be affected with the same chronic illness (Ryan & Sawin, 2010). The inability or lack of SCCM for AAYAs may exist because there may be absent, or limited, social networks, as evidenced by poverty, low socioeconomic status, discrimination of racial status, and lack of access to appropriate health care clinics within the community (Ayala et al., 2014). Family members and peers with HIV can assist AAYAs who have HIV by sharing their ideas of self-care through SCCM (Ryan & Sawin, 2010). The literature indicates that a description of SCCM includes successful interventions between family members and peers with HIV and the individual with HIV that may ultimately result in a state of well-being and quality of life for the individual with HIV (Hall et al., 2017).

Nineteen collaborative management behaviors may reduce depressive symptoms that accompany the chronic illness that AAYAs experience (Eller et al., 2010). The 19 cooperative behaviors are healthy activities that significant others with HIV suggest and share with male AAYAs as pertinent to improving their well-being and managing their chronic illness, HIV (Eller et al., 2010). Examples of the 19 collaborative behaviors are communication with significant others such as family, friends, and health care providers who provide support during support group sessions and activities that manage depression caused by living with the chronic illness, HIV (Eller et al., 2010). The collaborative behaviors include activities of daily living that male AAYAs may demonstrate while implementing and expressing their reflective attitude of SCCM (Filho et al., 2013). The 19 collaborative management behaviors may assist male AAYAs with HIV know that HIV is a controllable chronic illness and not a death sentence.

Eller et al. (2010) described six categories of interventions relevant to the 19 collaborative management behaviors that might reduce depressive symptoms for cohorts with chronic illnesses. The six categories are complementary therapies, talking to others, distraction techniques, physical activity, medications, and denial/avoidant coping (Eller et al., 2010). Activities that further serve as a distraction technique to reduce constantly thinking of the adverse effects of being chronically ill include staying busy through working, becoming engrossed in hobbies such as reading and listening to music, and developing new interests and hobbies (Eller et al., 2010; Mitchell et al., 2007). Giving a voice to these individuals may assure their feelings are accepted, valued, and validated, as well as diminish the stress of living with the chronic illness, HIV (Eller et al., 2010).

Problem Statement

In this study, the problem was a lack of knowledge about the lived experience of male AAYAs with HIV and how they manage their illness with the collaborative input of significant others and peers who also have HIV. Research shows that male AAYAs with HIV lack SCCM interventions for their chronic disease. The lack of such interventions impacts their quality of life within their contextual environment as they collaborate with significant others and peers who also have HIV (Ryan & Sawin, 2010). The lack of SCCM for male AAYAs may exist because there may be absent or limited social networks for these individuals because of poverty, low socioeconomic status, racial discrimination, and lack of access to appropriate health care clinics within the community (Ayala et al., 2014). Issues with adequate medication adherence, stigma and disclosure management, mental health issues, prevention of transmission of the virus, and receipt of the correct information on self-care when communicating with family members and peers who have HIV may also reduce opportunities for SCCM (Bekker & Hosek, 2015).

Addressing the SCCM concerns of male AAYAs with HIV is essential because it may affect this population's social and psychological behaviors (Gillard & Roark, 2013) as well as activities of daily living (Reyland et al., 2002). Successful SCCM interventions that involve family members, peers, and the individual with HIV may improve the latter’s well-being and quality of life (Hall et al., 2017). Peltzer et al. (2015) also found evidence supporting the importance of spirituality for SCCM among AAYAs with HIV.

The individual family self-management theory (IFSMT), a descriptive, middle-range theory developed by Ryan and Sawin (2009, 2010), offers a framework for assessing how individuals may manage their chronic illness with the assistance of peers and family members. The theory has been revised to reflect the complexity of self and family management by explicating proximal and distal barriers that are not comprehended well (Grey et al., 2015). Napoleon (2015) also demonstrated how the IFSMT affects individuals, dyads, and family members involved with home parenteral nutrition. As I further discuss in the Theoretical Framework section of this chapter, I used the IFSMT as a lens to explore AAYAs’ communication of their lived experience. Findings from this investigation may highlight issues of disclosure, stigma, emotions, and trust related to SCCM (Ayres et al., 2006; Dillon et al., 2008; Eustace, 2012). This information may be helpful to nurses and other health professionals who provide treatment and care to male AAYAs with HIV.

Purpose of the Study

This qualitative phenomenological study aimed to explore and describe the lived experiences of male AAYAs with HIV and their use of SCCM. Clearly stating the purpose of a qualitative research assists the researcher in eliciting the relevant perspectives from the research participants (Rudestam & Newton, 2015). The phenomenon of interest that I sought to explain was the lived experiences specific to male AAYAs with HIV and SCCM. As Neal (2016) noted, the phenomenon of interest is what the researcher wants to “understand, explain, or describe” (p. 129).

Research Question

What are the lived experiences of male AAYAs with HIV, the perceived support of their families, and their use of SCCM in their daily lives?

Theoretical Framework

The theoretical framework that provided the basis for this study consisted of the IFSMT by Ryan and Sawin (2010) and the transcendental theory of phenomenology by Husserl (Husserl & Moran, 2012). The IFSMT is a descriptive, middle range theoretical framework that has two concepts: self-care and patient education (Ryan & Sawin, 2010). The IFSMT provides a perspective for investigative inquiry and clinical practice as well as clarity for establishing attainable goals and interventions for quality of life (McEwen & Wills, 2014; Ryan & Sawin, 2010).

I selected the IFSMT because its focus on the individual and family members is amenable to examining the lived experience of AAYA men in their daily self-management of HIV. Ryan and Sawin (2010) discussed ways that AAYAs with HIV may manage their chronic illness with the assistance of peers and family members. The IFSMT identifies assumptions, defines concepts, and outlines proposed relationships (Ryan & Sawin, 2014). The IFSMT is a theoretical framework used in the context of individuals and family therapy to combine their knowledge, such as skills and abilities, ways of coping, and self-regulation capabilities, in ways that promote their well-being (Ryan & Sawin, 2014). The components of the IFSMT are context, process, proximal outcomes, and distal outcomes (Ryan & Sawin, 2010). An additional element of IFSMT is called intervention, which consists of information found within the components, contents, and process (Ryan & Sawin, 2014). These components interact to reinforce SCCM for male AAYAs and family members with HIV (Ryan & Sawin, 2010). Chronic illness and impairments such as HIV are within the context component of IFSMT, and health and behavior are identified within the process component of this theory (Ryan & Sawin, 2010). The proximal and distal dimensions are components of the IFSMT that are comprised of quality of life/health state and self-care management behaviors/health care cost, respectively (Ryan & Sawin, 2014).

The context, process, proximal, and distal dimensions contain information that inspires a collaborative effort for SCCM between individuals and families with chronic illnesses (MeEwen & Wills, 2014). Context provides information on the individual’s and family member’s perceptions of an illness, information on the individual and family member's contextual environment, and characteristics (Ryan & Sawin, 2014). The process includes information about knowledge and belief, the ability to self-regulate, and social support availability (Ryan & Sawin, 2014). The components within the IFSMT foster collaborative communication between individuals and family members that is relevant to SCCM of a chronic illness, HIV.

Husserl's transcendental phenomenology is a method for self-reflective transparency of intentionality (Husserl & Moran, 2012; Moran, 2005, 2008). I used this method to comprehend and make inferences about the lived experiences, both verbal and nonverbal, that research participants communicated to me. The awareness of the participant's experience, through the researcher's intuition, engagement with the data, and revisiting the results, is manifested through Husserl's view on bracketing and what is horizontally understood, as relevant to suspending judgments and dismissing assumptions (Allen-Collinson, 2009, 2011; Paley, 1997). Bracketing is when the researcher sets aside the preconceptions that they have of the phenomenon being studied and becomes reacquainted with the data (Fisher, 2009; Tufford & Newman, 2012). Husserl used the theoretical concepts of transcendental, intersubjectivity, and intentionality to explore the consciousness of individuals reporting their lived experiences and facilitating an understanding for the researcher (Drew, 2001; Merleau-Ponty et al., 2010).

Husserl's phenomenology is described as a comprehensive means of understanding everything that is connected to the individual's lived-experiences and shows that the subjectivity of transcendental philosophy is identified as the philosophy of the individual who describes the lived experience (Tassone, 2017). The transcendental phenomenology point of view is based on the culture of the individual and their intersubjectivity (Tassone, 2017). Naturalism, a component of Husserl's philosophical framework, was initially rejected by Husserl because he saw it as going against everything that was needed to support its validity, referring to consciousness as a component of the universe, and seeing naturalism as a negative consequence, which is referred to as a naturalistic attitude that renders the world as unchangeable and easily understood (Moran, 2008). Despite these rejections, Husserl explained, through his transcendental analysis of phenomenology, that a natural attitude, which is observed in daily life experiences, is parallel to the transcendental perspective of a lived experience (Moran, 2008; Tassone, 2017). Husserl suggested that researchers who are implementing lived experience research need to begin a priori and then return to the natural attitude but simultaneously need to limit this continuous universal transcendental approach that may misinterpret the purposeful characteristics of consciousness (Barua, 2007; Moran, 2008).

The paradox of human consciousness is within the world and being for the world, as relative to Husserl's transcendental phenomenology, remains unclear and warrants further research (Moran, 2008). Also, the natural attitude, which is a component of Husserl's transcendental philosophy, maybe Husserl's most successful and most misconstrued worldwide contribution of phenomenology (Moran, 2008). Overall, Husserl believed in the premise that transcendental phenomenology and natural attitudes are integrated (Moran, 2008). He also reminded phenomenological researchers that all lived experiences might be outside of consciousness, in the world; as such, they should consider the inner world and look for things in the consciousness and the world (Sartre, 2012). I provide more details on the theoretical framework in Chapter 2.

Nature of the Study

I used a qualitative, exploratory, phenomenology method to examine the lived experiences of male AAYAs diagnosed with HIV, the perceived support of their families, and their use of SMMT in their daily lives. The phenomenology component for the lived experience report consists of reactions, perceptions, understandings, and feelings of AAYAs with HIV, as they report their lived experience of SCCM. A phenomenological design was appropriate because it may reveal the lived experiences of research participants while in their natural environment (Ryan & Sawin, 2010).

The rationale for selecting a phenomenological research design was to examine similarities and differences in the lived experiences of a vulnerable group. How are male AAYAs affected by their HIV diagnosis, the associated stigma, the perceived support (or lack thereof) of their family and peers with similar diagnoses, and their general approach to SSCM? I concluded that other forms of qualitative research were not appropriate for this type of study. Case studies require triangulation of different data sources, which were not available from this group of participants. In contrast, ethnographic studies require that the researcher become immersed in the studied group (Merriam & Tisdale, 2016). Researchers conducting narrative studies tell the participants' stories without attempting to find the themes in the data (Merriam & Tisdale, 2016). I chose a phenomenological design because I wanted a means of exploring participants' lived experiences.

The critical phenomenon investigated was the lived experience of the participants with HIV and their use of SCCM as a strategy for self-care. The literature on self-care management remains complex in understanding how male AAYAs with HIV use SCCM as a strategy for self-care despite the concept itself being studied for approximately 50 years (Ausili et al., 2014). There are several definitions in the literature on self-care. For this study, self-care was defined “as those activities are undertaken in promoting health, preventing disease, limiting illness and restoring health” (Ausili et al., 2014, p 181). Historically, Grey (2006) is identified as the primary author who combined *self-care* and *family management* and presented them to the literature.

I invited six male AAYAs who received treatment at the same clinic to participate in this study. The number of participants for a study is essential to capturing the essence of an investigation. O’Reilly and Parker (2012) suggested that qualitative researchers appropriately select a method from the different available ways and an appropriate number of individuals for the qualitative study. I describe the research method and design in further detail in Chapter 3.

Definitions

Key terms and definitions for the study are as follows:

African American young adults (AAYAs): A group of Americans, aged 18 to 24, who have 100% or partial ethnicity and ancestry from diverse racial groups from Africa (United States Census Bureau, 2017). The term is also used interchangeably with late-stage adolescents (WSU Physician Group, n.d.). The definition of AAYA may also encompass the self-meanings that AAYAs assign to their ethnic group (Romero & Roberts, 2003).

Human immunodeficiency virus (HIV): A manageable chronic disease that attacks the T cells of the body's immune system and decreases the body's potential to combat diseases and infections (Dieffenbach & Fauci, 2009). HIV can become acquired immunodeficiency syndrome (AIDS), the final stage of HIV infection if optimal self-care management interventions are ignored (CDC, 2016).

Self-care collaborative management (SCCM): The responsible behavior that chronically ill individuals use to maintain their physical and emotional stability and health, along with the input of their family and significant others (Riegel et al., 2012; Ryan & Sawin, 2009. Additionally, SCCM is the shared knowledge of cultural and ethnic beliefs, contextual practices, social interactions, and decision-based networking between the individual and the multidimensional behavior, relative to beliefs, feelings, and attitudes, and the collaborative group may offer that (Grey et al., 2006; Riegel & Dickson, 2008; Ryan & Sawin, 2009).

Assumptions

Assumptions are statements that a researcher believes to be true (Ahmad et al., 2018). I had the following assumptions when conducting this investigation. One assumption was that male AAYAs with HIV intend to use SCCM due to their resilience (Seal et al., 2010). I also assumed that the male AAYAs in the study would interact with their families and peers with a similar diagnosis to obtain information regarding the progression of their condition and support during difficult times. In addition, I assumed that the participants would understand the gravity of their situation and be willing to discuss intimate details with me as the interviewer. Another assumption was that AAYAs would answer truthfully about their lived experience with HIV (see Simon, 2011).

Scope and Delimitations

The focus of this study was on male AAYAs diagnosed with HIV and between 18 and 24 years old. I used the IFSMT because it addresses minority AAYAs within the age range that I defined for the study and collaboration with family members. I only involved male AAYAs in the study; I did not interview family members. However, in telling me about their lived experience, the participants conveyed the advice of family members for self-care management. I included only men in the study because men are more at risk for HIV (CDC, 2012). Young men who have sex with men, whether gay, bisexual, or transgender, are the most severely affected individuals with HIV (CDC, 2012).

Delimitations are choices that a researcher makes to limit the scope of a study (Simon & Goes, 2013). I limited the sample to male AAYAs who have HIV, were between 18 and 24 years of age, and were being seen at the same clinic in a large metropolitan area. Another delimitation was the exclusion of all races and ethnic groups other than African American minorities. The study was delimited because the clinic where the research was conducted limits its clientele to marginalized African Americans diagnosed with HIV.

Limitations

Limitations or disadvantages of a qualitative study, unlike quantitative analyses, affect the ability of the study's findings to be transferred to other situations, contexts, and populations (Ahmad, 2018). First, the study was limited to male AAYAs diagnosed with HIV in a single metropolitan area from the same clinic, which has a specific focus and specializes in treating African American adolescents diagnosed with HIV. The findings may not be generalized to African American women with HIV, individuals under 18 or over 24 years who have been diagnosed with HIV, or individuals of other ethnic groups. Second, this study was limited to a specific time frame, and the findings may be different from studies done at an earlier time or those in the future. Third, the labor-intensive process of recruiting, interviewing, transcribing, processing, and analyzing qualitative data is different from that of quantitative research (Simon, 2013). My choice of the qualitative method limited the number of participants in the study and the quantity of data collected. Finally, the data from qualitative studies are based on individual perspectives and cannot be statistically analyzed or used to make any causative claims (Ahmad et al., 2018). The data can be cross-referenced with the findings from quantitative studies and be used to support or elucidate those findings, however.

Significance

The purpose of this study was to investigate the lived experiences of male AAYAs with HIV ages 18 through 24 regarding SCCM. My research topic is significant because it may show how researchers can incorporate an evidence-based theory, the IFSMT, and Husserl’s transcendental theory (Drew, 2001; Ryan & Sawin, 2010) to investigate SCCM interventions. I explored whether the IFSMT can be used to assist individuals in using SCCM for their chronic illness. I used Husserl’s method to understand the lived experience of participants.

The gap in the literature is there are no studies on SCCM of AAYAs with HIV and their lived experience. The gap may result in an inaccurate understanding of how male AAYAs with HIV engage in SCCM of their chronic illness, which shows a need for this study (Gillard & Roark, 2013). Additional gaps in the literature concern issues of trust, stigma, and emotions related to SCCM and specific reasons for disclosure or nondisclosure (Gillard & Roark, 2013). There is a need to study the additional gaps of silence, stigma, and emotions and the reasons for disclosure and nondisclosure because these gaps may impact self-care management of chronic illnesses (Nachega et al., 2012). Although some aspects of SSCM have been studied, "the physical, cognitive, emotional and social processes underlying self-care remain controversial and poorly defined" (Ausili, et al., 2014, p. 180), specifically in AAYAs with HIV (Sawin & Ryan, 2009). The lived experience of AAYAs with HIV and SCCM is difficult to understand and has yet to be universally understood.

Understanding the lived experiences of AAYAs with HIV may provide information on SCCM (Bianchin, 2017; Chenail, 2011; Elopre et al., 2018; Weinstein, 2017) that will help clinicians care for these individuals. Results may reveal what AAYAs with HIV experience in their daily life and what their needs are. With this information, health care professionals may be able to provide optimal care for this population that supports their well-being and activities of daily living (CDC, 2014, 2016; Eustace, 2012; Lynn, 2018).

Results from the study may also effect positive social change by producing new information on the experiences of male AAYAs with HIV that are not currently understood. In this way, the findings of this study may add knowledge to the scientific world regarding SCCM for chronic illnesses and may support additional research on AAYAs with HIV (Napoleon, 2015). This research has implications for social change as relevant to educating male AAYAs with HIV and training clinicians to care for a community of underrepresented AAYAs with HIV and improve contextual environments by engaging and educating individuals with similar chronic illnesses to be leaders and trainers in this area. Critical areas for social change are to train underrepresented individuals with HIV to become advocates within their community and to provide a nurturing environment that contains resources that are accessible and make underrepresented individuals with HIV feel secure (Dang et al., 2015; Husser et al., 2018; Walden University Center for Social Change, n.d.; Zarwell & Robinson, 2017).).

Summary

The major objective of this study was to obtain information from AAYAs with HIV on their lived experience and SCCM. As Ryan and Sawin (2009) noted, the lived experiences of AAYAs with HIV are not well understood. Currently, many AAYAs with HIV lack adequate and effective SCCM for their chronic disease (Lynn, 2018). Insights from the study may help health-care providers to address these concerns among this patient population.

In Chapter 2, I detailed the literature search strategy and theoretical foundation of the study and review key literature. The problem and purpose are restated to show that they are aligned with the study topic. The specific gap within the literature relevant to my study is identified and the theoretical framework to SCCM guiding the study is presented.

Chapter 2: Literature Review

Introduction

The problem is there is a lack of information about the lived experience of male AAYAs with HIV on how they provide self-care management for themselves and how they use advice received from family and peers who also have HIV to assist them with SCCM that may impact their quality of life (Ryan & Sawin, 2010). I addressed this gap in the literature by conducting this study. This research is relevant and needed to provide new information for caregivers who provide care to male AAYAs with HIV. Information on the lived experience of these individuals and SCCM is lacking, and therefore new information can be used as a positive guideline to change the way underrepresented individuals with HIV are treated by clinicians who care for them and by the people whom they interact with on a daily basis as well as provide well-being information for SCCM. Health disparities and inadequate SCCM are related and impact access to health-care clinics. Addressing these issues is necessary to provide successful health interventions for decreasing the likelihood of developing AIDS or progressing to death (Swenderman et al., 2010). Collaboration between significant others with HIV and AAYAs with HIV is needed (Ryan & Sawin, 2014).

The purpose of this qualitative phenomenology study was to explore, understand, and describe the lived experiences of male AAYAs, ages 18 through 24, with HIV and their experiences with SCCM. I gathered data by conducting individual semistructured, face-to-face interviews. Stating the purpose of qualitative research assists the researcher in obtaining explicit consent from research participants to share their perspectives

(Rudestam & Newton, 2015). As indicated in my purpose statement, the intent of my study allowed me to stay focused on how I conducted my investigation. The research question that was addressed was, what are the lived experiences of male AAYAs with HIV, the perceived support of their families, and their use of SCCM in their daily lives? I sought to "understand, predict, explain, or describe" (Neal, 2016, p. 129) the study phenomenon, which was the lived experience of male AAYAs with HIV and SCCM.

A synopsis of the current literature establishes the relevance of the problem. I present a hierarchy of evidence for assessing qualitative health research and design as relative to AAYAs' executive brain function, decision ability, and risky behavior practices that impact their SCCM. I also reviewed literature that shows that male AAYAs with HIV who live in urban environments have limited access to health care that will allow them to manage their HIV through SCCM (Filho, 2013; Marshall & Rossman, 2011). I also address why a qualitative design was appropriate for providing essential information about the concept of self-care management. Information on stigma and disclosure issues in combination with the immature executive brain function of male AAYAs also is vital to understand and is included in this chapter.

I begin the chapter by reviewing the literature search strategy and theoretical foundation for the study. I used the IFSMT framework and Husserl's phenomenology method as the framework for the investigation. The literature suggests that the IFSMT is a relevant framework and can add information to the body of scientific knowledge as appropriate to SCCM (Filo, 2013; Grey et al., 2015; Ryan & Sawin, 2010). Husserl's phenomenological method for understanding an individual's lived experience is relevant for studying SCCM, research indicates (Tassone, 2017). I probe Husserl's philosophy of transcendental, intersubjectivity, and intentionality phenomenology for self-reflective intentionality.

Literature Search Strategy

I used several search engines and databases to gather the best information for this literature review, including CINAHL Plus with Full Text, Cochrane Library, ERIC, EMBASE, MEDLINE, PsycINFO, and SAGE Research Methods, all of which I accessed through Walden University Library. I also searched Google Scholar. Additional databases used were PubMed and the PopLine database, which provides information on diverse populations and health related issues. The years included in my search were 2013-2018. Limited information was available within these years, so I extended my research to include prior years.

The search terms I used included *qualitative methods, health promotion research, qualitative evidence in clinical practice, qualitative research, adolescent brain maturity, executive function in adolescents*, *HIV*, *chronic illness*, *chronic care model*, *self-management*, *IFSMT*, *health promotion*, *stigma*, *stigmatization in HIV*, *disclosure in HIV*, *discrimination in HIV*, *phenomenology*, *Husserl*, *interiority*, *transcendental phenomenology*, *transcendental consciousness*, *naturalism*, *bracketing*, *Husserl grammar*, *interpretive phenomenology*, *father of phenomenology*, *reduction in phenomenology*, and *lived experience*. Because limited research was available on the specific topic of HIV and SCCM, I investigated other sources of literature. The sources consisted of several dozens of articles on self-care management in other chronic illnesses of other age groups and ethnicities.

Theoretical Foundation

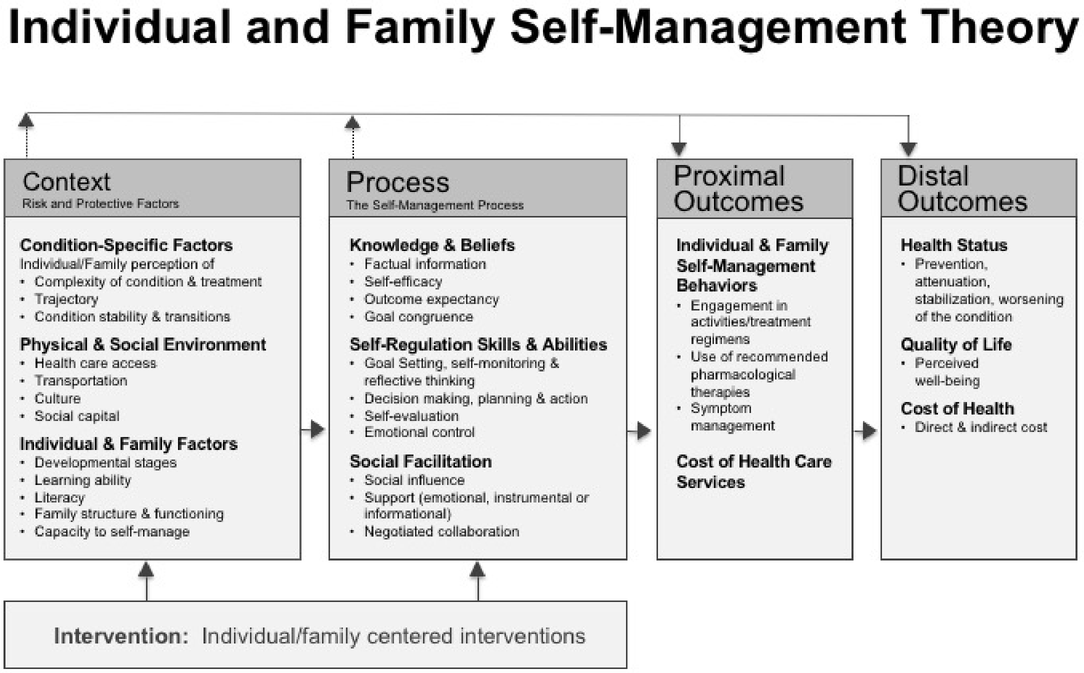
The theories that formed the foundation of this study were the IFSMT, Husserl's transcendental phenomenology, and SCCM theory. Husserl's phenomenology is based on the philosophy of Edmund Husserl (Husserl & Moran, 2012; Tassone, 2017). IFSMT posits a way to describe family relationships and demonstrate how families use collaboration and communication to share important information that is essential in establishing effective relationships and SCCM within family dynamics. SCCM is a part of the IFSMT. Its self-reflective transparency of intentionality and the self-care management that defines SCCM were combined with IFSMT in the research by Ryan and Sawin (2009).

A primary proposition of the IFSMT is that self-management of chronic diseases is fluid and complex in nature, as relevant to its "context, process, and outcomes" (Fawcett et al., 2001). Components of IFSMT are (a) individual, dyads within the family, or the family unit as a whole; (b) explication of context and process components of self-management; and (c) use of proximal and distal outcomes (Ryan & Sawin, 2010). Researchers (Fawcett et al., 2001; Meleis, 1997; Ryan & Sawin, 2010) defined three dimensions of IFSMT as context, process, and outcomes. The context describes influences in the environment that allow the individual and family members to manage their illness; the process provides these individuals with the knowledge needed to exchange information, and outcomes are the self-management results (Ryan & Sawin, 2010). Process refers to how individuals live and exchange information that may improve self-management of their chronic illness and process (Ryan & Sawin, 2010). According to Ryan and Swain (2010), IFSMT shows outcomes of concern related to individuals and families, and improvement of individual and family outcomes translates to improved outcomes for health care practitioners and systems.

I explored the concept of self-management within the IFSMT to frame the research question. The components that I investigated within the IFSMT were the individual, dyads in the family of the male AAYA, and the total family of the AAYAs as relevant to short-and-long-term goals of SCCM and control of their chronic illness. Looking at the relationships and interactions between male AAYAs with HIV and their families and peers with HIV, as relevant to SCCM, can provide the information needed to understand further the lived experience of male AAYAs with HIV (Verchota, 2014). The IFSMT shows how self-care management is used to define SCCM relevant to exploring the lived experience of male AAYAs with HIV and health outcomes and adding to scientific knowledge of this phenomenon (Grey et al., 2015). Figure 1 illustrates Ryan and Sawin’s revised rendering of the IFSMT, which was the theoretical framework I used to answer my research question.

Figure 1

Individual and Family Self-Management Theory



Note. From *Individual and Family Self-Management Theory* [Revised figure], by P. A. Ryan and K. J. Sawin, 2014, University of Wisconsin–Milwaukee College of Nursing (https://uwm.edu/nursing/wp-content/uploads/sites/287/2020/05/IFSMT_manuscript_no_copyright_07_31_2019-002.jpg). In the public domain.

The IFSMT contributes to and is integrated into past studies related to SCCM of individuals with chronic illnesses (Ryan & Sawin, 2010). The contextual factors of this theory affect self-care management and the process of self-care management and are related to process dimensions (Ryan & Sawin, 2010). Behavioral interventions needed for successful SCCM are explored and may result in additional theoretical concepts needed for SCCM behavior (Lorig et al., 2001). Behavioral interventions may be relevant to SCCM but may be warranted to study at a future date.

Clark et al. (1991) explored certain chronic illnesses to determine if they had identical self-management tasks. Five chronic diseases were evaluated and found to have 12 everyday tasks relative to self-management, including (a) symptom management, (b) taking medication, (c) recognizing acute episodes, (d) having proper nutrition, (e) exercising, (f) not smoking, (g) reducing stress, (h) interacting with health providers, (i) needing information, (j) adapting to work, (k) managing relations, and (l) managing emotions (Clark et al., 1991). Results indicate that the ways a young adult versus an older adult managed their task did not differ. However, the necessities needed for successful self-management were education and community support (see also Bandura, 1997; Ryan & Sawin, 2010). The study provided evidence that the theory was relevant to providing new information on self-management.

In their updated framework, Ryan and Sawin (2014) reflected the complexity of self and family management by explicating proximal and distal barriers that are not well comprehended (see also Grey et al., 2015. Another source that provides information and shows the importance of IFSMT as a theoretical framework is shown in a study provided by Napoleon (2015), who demonstrated how the IFSMT is used to affect individuals, dyads, and family members who are involved with home parenteral nutrition. The AAYAs' communication of their lived experience could suggest that the IFSMT provides a theoretical framework for them and SCCM of their HIV. However, different findings could result instead.

The theoretical descriptive framework, IFSMT, enhances the information on self-management and is used to influence study designs of self-management, as relevant to improving the health of individuals with chronic illness by providing a guide for managing illnesses (Grey et al., 2015). The concept of self-management and the IFSMT are connected because both focus on individuals who have chronic illnesses, families who network with these individuals and have the same illness, and peers who share the same illness and are involved within the same contextual environment (Ryan & Sawin, 2010). The concept of self-management and IFSMT are also connected because they identify the importance of chronically ill individuals being responsible for their own health by engaging in healthy behaviors that they feel will benefit them intentionally (Grey et al., 2015; Ryan & Sawin, 2010). Receiving, sharing, and using such information improves and nurtures the health of these individuals.

Ryan and Sawin (2010) discussed ways that AAYAs with HIV manage their chronic illness with the assistance of peers and family members. IFSMT is a descriptive, middle range theory, of which the individual's assumptions are identified, concepts are defined, and an outline of proposed relationships is revealed (Ryan & Sawin, 2010). Grey et al. (2015) also showed the importance of the IFSMT, focusing on an updated version of the theory that incorporates well-being behaviors that impact the individual and family's daily management of their chronic illness. The revised IFSMT framework reflects the complexity of self and family management of chronic disease by explicating proximal and distal barriers that are not comprehended well by researchers (Grey et al., 2015; McCarty & Grey, 2018). Proximal outcomes indicate an engagement in health behaviors, activities, and treatment, whereas distal outcomes show the quality of life and perceptions of well-being that male AAYAs may experience (Grey et al., 2015). The importance of IFSMT, as a theoretical framework, is supported in a study by Napoleon (2015), who demonstrated how IFSMT was used to influence individuals, dyads, and family members who are involved with home parenteral nutrition.

The central concepts for the framework IFSMT are essential in showing how this theory informs scientific inquiry of self-management (Ryan & Sawin, 2010). The five concepts of the IFSMT are the physical and social environment, individual and family factors, and knowledge and beliefs (McCarty & Grey,2018; Ryan & Sawin, 2010). The five concepts are connected within the IFSMT framework and provide critical information for male AAYAs with HIV (McCarty & Grey, 2018; Ryan & Sawin, 2010). The physical and social environment involves the contextual neighborhood and culture of individuals and barriers and access to clinics. The concept of individual and family factors includes characteristics of the individuals, dyads, and family that increase or decrease self-management.

In contrast, knowledge and beliefs involve self-efficacy and a description of expected outcomes. Characteristics of this theory involving the individual, dyads, and family include cognitive status and processing of information that is received by individuals affected by marginalization, as well as literacy capability and resourcefulness of and for these individuals (Grey et al., 2015; McCarty & Grey, 2018; Ryan & Sawin, 2010). Self-regulation is a concept that includes goal setting, decision behavior, action, planning, and self-evaluation. The fifth concept for the framework IFSMT is knowledge and beliefs of which social facilitation among family, friends, and health care providers are examined (Grey et al., 2015; Ryan & Sawin, 2010).

The second theoretical framework used in my study is Husserl’s transcendental phenomenology for self-reflective transparency of intentionality (Tassone, 2017; Yegdich, 2000). Husserl’s transcendental phenomenology for self-reflective transparency of intentionality assisted in comprehending and making inferences about lived experiences, both verbal and non-verbal, that my research participants communicated to me (Tassone, 2017; Moran, 2008). Through the researcher's intuition, the awareness of the participant’s experiences may manifest through Husserl’s view on bracketing and what is horizontally understood as relevant to suspending judgments and dismissing assumptions (Paley, 1997; Tassone, 2017). The theoretical concepts— transcendental, intersubjectivity, and intentionality —were used by Husserl to explore the consciousness of individuals reporting on their lived experiences and facilitate a better understanding for the researcher (Drew, 2001).

Husserl’s philosophy on phenomenology was used to explore and understand the lived experiences of HIV-infected AAYAs and SCCM (Tassone, 2017). Analyzing an individual’s phenomenon may only be done through the lived experiences that are reported, as noted by the researcher through observing, listening to, and understanding each participant as he is embedded within his complex, contextual environment (Converse, 2012). I may best contribute knowledge regarding SCCM for AAYAs with HIV by applying Husserl’s framework of descriptive transcendental phenomenology because this framework may reveal the awareness and intentionality of inquiries about these individuals’ lived experiences (Lawyer, 2007).

A qualitative researcher in phenomenology must comprehend various aspects and intentions of phenomenology before implementing a phenomenological study (Butler, 2016). Husserl’s transcendental phenomenology for self-reflective transparency of intentionality can assist in comprehending and making inferences about the lived experience, both verbal and non-verbal, that research participants communicate to me (Moran, 2008). Husserl provides explicit, detailed information on lived experience (Tassone, 2017). Husserl viewed his philosophy as unique within itself because he viewed it as an independent point of view, as relevant to owning its own premise of history, psychological stance, and aesthetic framework (Barua, 2007). Through the researcher's intuition, the awareness of the participant’s experience may manifest through Husserl’s view on bracketing and what is horizontally understood as relevant to suspending judgments and dismissing assumptions (Tassone, 2017; Paley, 1997). The theoretical concepts transcendental, intersubjectivity, and intentionality were used by Husserl in many studies to explore the consciousness of individuals reporting their lived experiences and facilitating an understanding for the researcher (Drew, 2001).

Husserl used the term subjectivity of transcendental philosophy in studies to describe the philosophy of the individual who engages in reporting their lived experience (Tassone, 2017). The term represents an explicit description for comprehending a lived experience of the initial person and shows relevance to Husserl’s phenomenological reduction term, which is also called transcendental phenomenology (Tassone, 2017; Yegdich, 2000). The philosophical viewpoint of Husserl is grounded in transcendental consciousness, which reveals the clear thinking of an individual, as relevant to them dismissing all their known knowledge and focusing on the given (Barua, 2007). Husserl's writings suggested that intentional acts may have possessed profound suggestions for intentional insight. However, there were limitations in these writings, relevant to placing too much focus on intentionality and the accompanying mental acts that were needed for intentional objects (Alweiss, 2009; Tassone, 2017). The limitations motivated Husserl to focus his approach and increase his knowledge in the arena of inter-subjectivity and temporality, relevant to a viewpoint of transcendental phenomenology (Tassone, 2017). Transcendental phenomenology, per Heinrich (2003), was referred to as the philosophy of the subject surrounding the lived experience.

The lived experience of AAYAs with HIV may be further explained by understanding how bracketing relates to this phenomenon. Husserl and Yegdich describe their positivist view on bracketing as relative to an individual's lived experience in many ways. Yegdich (2000) concurs with Husserl that bracketing, also called epoch or phenomenological reduction, suspends all judgment within the natural world and draws profound attention to analyzing a pure lived experience. The philosophers also concurred that bracketing is linked to unlearning previous beliefs and linked to the notion that consciousness is deliberate (Moran, 2008; Yegdich, 2000). Both philosophers also felt that the natural attitude and things that are immanently knowable must be bracketed, and this must be done by suspending all ontological commitments regarding the natural world (Yegdich, 2000).

Husserl also wrote about three types of reduction that are important for conducting a true qualitative, descriptive, lived experience. The three types of reduction in phenomenology are phenomenological reduction or epoch, which dismisses all pre-conceived and present judgment about the natural world's existence or non-existence, eidetic reduction, analyzing and mentally picturing whether the phenomena of interest changes, and transcendental deduction, which is thoroughly observing the experience, as relevant to what is suggested by the mind versus what is indicated by the researcher's intuition (Butler, 2016; Linsenmayer, 2011).

Other factors from Husserl's philosophical thinking must be considered as I conduct my research on the lived experience of AAYAs with HIV and SCCM. Husserl also stresses the importance of self-reflection and transformation when doing qualitative research (Butler, 2016). Self-reflection of the researcher must take place so that I am aware of my ego and know that my consciousness is open and always intentional (Jacobs, 2013). Husserl warns the researcher that the downside of a consistent practice of phenomenological self-reflection is that a life change may come, as relevant to the researcher not being able to return to the life as they once knew it (Jacobs, 2013). Therefore, it is suggested that transcendental reflection may prohibit a researcher from returning to their normal life and way of thinking, following the lived experience research, which also shows that natural, conscious life, before this, did not pre-determine the requirements of reflective phenomenology and self-transformation (Brainard, 2007; Brough, 2008; Jacobs, 2013). The knowledge learned through rigorous research of the lived experience of AAYAs with HIV and SCCM adds to scientific knowledge, but I must equip and protect myself by understanding the importance of pre-reflection and transcendental reflection of my data.

Overall, Husserl supported his position that presenting data that is pre-reflective before categorizing it and dismissing all presuppositions that are known about the phenomena being studied would produce an outcome of scientific knowledge that is valid, rigorous, and worthy of phenomenological studies (Bianchin, 2017; McConnell-Henry, Chapman, & Francis, 2009). Qualitative phenomenological researchers may effectively implement the principles of Husserl when considering that they can perform rigorous research because they have the capability to dismiss their natural thinking about specific beliefs and understand reflective behavior is important for researchers to be effective (Lowes & Prowse, 2001; McConnell et al., 2009). The above knowledge and my selected scientific frameworks allowed me to conduct a rigorous research study, discover vital information while allowing me to be secure as a researcher.

The theories that I used for my study are the IFSMT and Husserl's transcendental phenomenology for self-reflection transparency of intentionality because they have been used in scientific studies that contribute to scientific knowledge on self-management and lived experience (Eller et al., 2010; Ryan & Sawin, 2014). Both theories relate to my study because the IFSMT provides information on SCCM and impacts self-management studies, while Husserl's theory includes information on the lived experience of male AAYAs (Denison et al., 2015; Tassone, 2017). These two theories address lived experience and SCCM of the individuals in my study and have been used in similar ways in other studies. Self-management and phenomenology studies of lived experience have been combined in the literature to provide information on how young minority adults manage their chronic illness by using collaborative information from family members with similar illnesses (Sawin, 2014; Tassone, 2017). These theories have been used previously in studies involving self-care and self-management, as well as studies that involve reporting the lived experience of chronically ill individuals and their daily journey of living with their chronic illness (Grey et al., 2015; McCarty & Grey, 2018; Ryan & Sawin, 2014; Tassone, 2017; Yegdich, 2000). A diagram of how these two theories interact to support my theory is in Appendix A.

Conceptual Framework

The concept/phenomenon for my study is SCCM. Dorothea Orem's self-care theory assists in defining the new term SCCM and is defined by Wayne (2014) as a performance of activities for daily living to improve and maintain physical health and well-being to prolong life. I did not use Orem's self-care theory in my study. The two theories that I used in my research are IFSMT and Husserl's transcendental phenomenology for self-reflective transparency of intentionality. Orem's theory is only mentioned as a means of defining SCCM. The term self-care is used interchangeably with SCCM (Lorig et al., 2001; Ryan & Sawin, 2010). My research concept, SCCM, is "a process, a program, or an outcome" (Ryan & Sawin, 2010, p. 218), which has a combination of diverse thinking among individuals, decision-making ability, and factors that impact positive changes in the health outcome of individuals with chronic illnesses. The original term, self-care, was identified by founders of a grand theory in nursing, known as Self -Care Theory, and used as a construct for identifying daily activities of living, such as taking a bath, dressing, or carrying out other independent functions (Wayne, 2012). An intentional independent or collaborative engagement in a person who self-manages illnesses and results in health well-being may result in outcomes of self-regulation, learned knowledge, and cultural practices with beliefs that impact SCCM (Grey, Knafl, & McCorkle, 2006).

Many researchers have contributed to the term self-care, which is referred to as SCCM in my study. One example, a nurse scientist who contributed to writings on self-care is Dorothea Orem, the founder of self-care theory (Wayne, 2012). Wayne (2012) presented Orem's assumptions of self-care by sharing that her assumptions of self-care consisted of engaging with others, as relevant to communicating and connecting within their contextual environment, having the power to act deliberately, by identifying needs and making needed judgments, and using these actions to involve life-sustaining and appropriate SSCM decisions (Wayne, 2012). SCCM, based on Orem's description of self-care, maybe the human agency that is needed to exercise, discover, develop, and transmit information that groups of human beings with similar chronic illnesses need to responsibly care for themselves and others within their contextual group (Ryan & Sawin, 2010; Wayne, 2012).

Additional researchers contributing to self-care, SCCM, are Ryan and Sawin (2010), who provided contributions for self-care by implementing the IFSMT into practice, and Denison et al. (2015), who researched how caregivers and AAYA's with HIV collaboratively worked together to address preventative behavior through health treatments. Two more examples of prolific self-care researchers who contributed to this concept are Eller et al. (2010), who described six categories that are related to 19 collaborative management behaviors, and Filho et al. (2013), who described characteristics of reflective attitudes used by an individual during their activities of daily living (ADL).

Literature Review Related to Key Variables and/or Concepts

SCCM is not a theory but is linked to self-management, which is defined as a complex, multidimensional phenomenon that impacts individuals, dyads within families, and family members, and integrates the theoretical framework, IFSMT (Grey et al., 2015; Ryan & Sawin, 2010). In contrast, *SCCM* is a term that is used to give further meaning and significance to self-management along with the use of this theoretical framework (Grey et al., 2015; Ryan & Sawin, 2010). Researchers in all three studies showed, through qualitative, exploratory, descriptive studies of an AAYA cohort of minorities with chronic illness, how the manifestation of self-care management can be used to impact this cohort and restore their quality of life. The main point of the studies was to explore SCCM practices in chronic illnesses of AAYAs. Based on findings of limited knowledge of self-management and no information around SCCM in AAYAs with HIV, my research is strongly warranted. The literature justifies that the growing problem of increased health disparities and limited self-care management information that surrounds individuals with chronic illness and individuals who experience marginalization results in a negative impact related to how self-management and SCCM are implemented for chronic disease, relevant to HIV (Filho, 2013; Marshall et al., 2012; Munhall, 2012; Ryan & Sawin, 2010; Swenderman, Ingram, & Rotheram-Borus, 2010).

Overall, understanding male AAYAs, related to their lived experience of SCCM, is provided through the lens of this group and reported to researchers who need and use a theoretical framework such as an IFSMT to further understand the research question for their study. There are biases and limitations that I must be aware of when I conduct my study. Replication and transferability are essential factors that may reveal the strengths and weaknesses of studies. A combination of information in research articles provides a platform for developing a framework of inquiry for my dissertation research topic and offsets any opposing view that may have been alluded to as relevant to how SCCM may be viewed.

The literature shows that the lived experience of AAYAs who live with HIV and the family members who collaborate with them provides knowledge of ways to improve the way they handle their daily health (Grey et al., 2015). The theoretical framework IFSMT is used throughout the literature to demonstrate how adolescents with chronic illness can be positively affected by receiving better health when this theoretical framework is used, as relevant to the interaction of individuals, dyads, and families who share the idea of self-care management. Self-care management behaviors that improve the behavior and well-being of chronically ill individuals are identified and shown to improve social, psychological, and SCCM problems Studies throughout the literature suggest that the framework IFSMT is complex in nature but assists in explaining and improving the concept of self-management. The term phenomenology serves as a platform that provides important information for understanding the lived experience of young adults with HIV and for providing information for clinicians who treat these individuals. Phenomenology is used throughout the literature and shows how the underpinnings of the philosopher Husserl’s views are important for understanding the lived experience of individuals with chronic illnesses.

Summary and Conclusions

The IFSMT is important because it provides a perspective for investigative inquiry and clinical practice, as relevant to providing clarity for establishing feasible goals and interventions for quality life (McEwen & Wills, 2014; Ryan & Sawin, 2009). The IFSMT has direct and indirect implications for nursing, as relevant to AAYAs with HIV and SCCM, the nurse, and the natural environment (McEwen & Wills, 2014; Ryan & Sawin, 2010). The IFSMT meets most requirements for a nurse’s metaparadigm as relevant to the following:(a) the concepts and propositions represent a unique perspective for inquiry and practice, (b) the concepts and propositions are global, and there are no redundancies, (c) the concepts and propositions do not represent a specific perspective, and (d) the concepts and propositions do not reflect national, cultural, or ethnic beliefs and values (Fawcett & DeSanto-Madeya, 2013). I used the IFSMT to address the SCCM variable for my study. The IFSMT for my study focused on SCCM and teaching.

Husserl’s transcendental phenomenology for self-reflective transparency of intentionality assisted me in comprehending and making inferences about the lived experience, both verbal and non-verbal, that my research participant communicates to me (Bianchin, 2017; Moran, 2008). Husserl’s view on bracketing, pre-reflection, and self-reflection of data and his philosophical position on phenomenology within a natural environment gave me the best framework for conducting my study (Converse, 2012; Tassone, 2017; Yegdich, 2000). I gained rich knowledge from the data that I collected.

The two theoretical frameworks worked well in describing the outcome of my phenomenological study of SCCM and lived experience of AAYAs with HIV. I am aware that the selected frameworks, being the “current version of the researcher’s map of the territory being investigated,” may need to be altered as my study evolves; however, I do not anticipate this challenge (Rudestam & Newton, 2015, p. 50).

Gaps in research are based on disclosure, stigma, and emotions, and trust issues that are observed within problem statements of chronic illnesses experienced by a minority, AAYAs, as relevant to SCCM (Ayres et al., 2006). Other gaps in prior research involve understanding and building upon strengths of HIV-affected families, relevant to their potential to focus on effective interventions for SCCM of late-stage adolescents with HIV and exploring and understanding what constitutes an HIV family intervention (Eustace, 2012). There is also little known about how social, environmental factors, especially within the context of parent and peer domains, interact and collaborate to promote or reduce SCCM interventions that promote or mitigate sexual risks for this cohort of interest (Dillon et al., 2008). The inability for minorities to SCCM their chronic illness may result in the overlooked, covert psychological state, depression, or isolation experienced, and that needs to be addressed. An additional gap in understanding the similarities and differences of SCCM across developmental stages and interactional relationships among others, and there are gaps in comprehending individual and family interactions and identifying and measuring outcomes that are sensitive to short term behavioral goals that impact health behavior, as relevant to disease status, socio-economic status, and quality of life (Ryan & Sawin, 2010). Despite the above gaps within the literature of SCCM, my study addressed the gap in the literature. The gap, important for my study, is that the literature does not give information on the lived experience of AAYAs with HIV and SCCM. In Chapter 3, I present the methodology that I used to collect and analyze data needed to address the research question. In this chapter, I detailed the population and sample along with data collection procedures that was used.

Chapter 3: Research Method

Introduction

This qualitative phenomenological study aimed to explore and describe the lived experiences of male AAYAs with HIV and their involvement with SCCM. I strove to set aside all preconceived notions, biases, experiences, and personal knowledge of the study topic to provide a valid account of AAYAs and their lived experiences. Chapter 3 includes a discussion of the research design and rationale, my role as the researcher, the methodology I used to collect and analyze the data collected from the interviews, and issues of trustworthiness. Each of these components is instrumental in providing a complete picture of how I conducted my research and the attributes that I possessed and used as the researcher.

Research Design and Rationale

Correctly framing the research question is important to obtain the best descriptive information of participants' lived experiences (Ahmad, 2018). The research question for this study was, what are the lived experiences of male AAYAs living with HIV, the perceived support of their families, and their use of SCCM in their daily lives? The concept/phenomenon under investigation in this study was SCCM, which is the responsible behavior chronically ill individuals use to maintain their physical and emotional stability and health, along with input from their family and significant others (Riegel et al., 2012; Ryan & Sawin, 2009). Additionally, it is the shared knowledge, cultural and ethnic beliefs, contextual practices, social interactions, and decision-based networking between the individual and the multidimensional behavior that the collaborative group may offer (Grey et al., 2006; Riegel & Dickson, 2008; Ryan & Sawin, 2009). The collaborative group in this study consisted of AAYAs with HIV and the family members and peers who have HIV. I integrated the term *collaborative* within the phrase *self-care management* because doing so may demonstrate the importance and need for family members and significant others to assist and network with one another (Riegel et al., 2012; Ryan & Sawin, 2014).

Research has shown that self-care interventions are effective for a wide range of long-term health conditions, and collaborative self-care is a significant determinant of health outcomes (Hua et al., 2017; Riegel et al., 2017). Devising effective self-care strategies or improving current protocols requires understanding the circumstances and perceptions of the complex issues involved. Health care professionals, especially nurses who interact with male AAYAs with HIV, may benefit from this knowledge. I sought to obtain information from male AAYAs with HIV regarding their lived experiences and description of their SCCM activities.

The research tradition for this study was descriptive, qualitative phenomenology. Husserl, the philosopher who founded phenomenology, defined bracketing as a researcher forgetting about previous knowledge so they can be objective while exploring and investigating a present phenomenon related to the lived experience of others (Barua, 2007; Brainard, 2007; Creswell, 2009). Ideas stored subconsciously may be retrieved when using a consciousness that is liberated from the burden of a person's previous individual experiences and ways of thinking (Koopman, 2015). It was important for me to keep Husserl's definition in mind as I conducted my research via face-to-face interviews. Not recognizing the effect of the complexity of human nature that lies within the consciousness may bias a researcher and prevent them from collecting the data honestly and clearly as it presented (Koopman, 2015). Husserl's definition supported the rationale for choosing this research tradition so that my own views would not limit my documenting of the experiences of the AAYAs in my study.

Role of the Researcher

My role as the researcher required me to interview the participants, interpret the data from the interviews, and develop an understanding of the lived experience of the participants. My tasks involved conducting the interviews, transcribing the statements provided, transforming the experiences into words, understanding the experiences from the statements provided, categorizing the codes into themes, and interpreting the themes as they related to the phenomenon being studied (Sanjari et al., 2014). My additional roles included monitoring and limiting any research bias while developing my capability as a listener and documenter (Sanjari et al., 2014). Expanding my competence in the qualitative method, collecting and analyzing data, and presenting my findings were also part of my duties.

In addition to the Husserl philosophy, I also used structured observation to guide the development of my research study strategy. Structured observation is a positivistic view as it applies to qualitative research methodology, where the events are observed in their natural setting and recorded by an independent observer (McCoyd & Kerson, 2006). This approach allows for the collection of data about the subjects as if they were not being observed, and it provides information that other methods would not. The field notes from my structured observation provided me with a thorough description and added more details to the information that was communicated verbally (Lindorff & Sammons, 2018; Mulhall, 2002).

I had no personal or professional relationship with any of the participants, nor was I in a supervisory or instructor-type relationship that involved power over the participants. As the researcher for this project, who conducted the interviews, interacted with the subjects, and collected information from them, I realize that I do have biases related to my study. I managed my biases by acknowledging that I have them, recognizing what they are and learning of their potential impact on my research, and making a deliberate effort to externalize them in favor of objectivity. I took additional steps to manage my biases by having the transcriptions produced by a professional transcription company via a Sony digital recorder, with the approval of participants (see Scholten et al., 2018). Information on the signed confidential consent form addressed all ethical issues related to confidentiality and justification of incentives (Brown et al., 2018; U.S. Food and Drug Administration, 2018).

Methodology

Participant Selection Logic

The participants for the study were AAYAs, ages 18 to 24 years, who had HIV and were outpatients at a metropolitan area clinic, providing care specifically for AAYAs with HIV. The sampling strategy was a nonprobability convenience sampling based on participants who were available from the clinic and agreed to sign up for the study (Sanders et al., 2012). The criteria on which participant selection was based were as follows: AAYAs who were HIV positive and were outpatient clients of an adolescent clinic and who volunteered to participate in the study upon signing an informed consent provided. The purposive sampling involved approaching potential candidates as they exited the clinic, informing them about the nature of the study, and requesting their participation.

I was able to recruit six participants and interviewed them to the “point of redundancy” (p. 220), the definition of saturation (Rudestam & Newton, 2015). The number of participants I interviewed was based on meeting saturation and thus verified my sample size. The number of participants needed for qualitative interviews, per Latham (2013), is five to 10, with a minimum of five participants. All six of the participants were asked the same interview questions, and their responses were documented via the use of a tape recorder. All participants were clients at the clinic who consented to be interviewed for my study. The potential participants met the study criteria because they were from the same clinic, and all had the diagnosis of HIV. I did not screen participants because they were purposefully selected from this specific clinic; however, I asked their age to ensure that they were 18 to 24 years old. I posted flyers at the entrance to the clinic, with details about the study, for prospective participants as they left their clinic appointment. The participants who wanted to participate in the study contacted me by my cell phone number that was included on the flyer. The individual, confidential, unstructured interviews took place over the phone because of the current COVID-19 pandemic crisis.

My sample size was six participants, male, between ages 18 and 24. Patton (2015) suggested that phenomenology studies require no fewer than six participants when conducting qualitative interviews. On the other hand, Creswell (2013) recommended anywhere between five to 25 participants, while Morse (1994) recommended six research participants when conducting qualitative interviews. Overall, there are no specific numbers for implementing qualitative research interviews as recommended by the experts, and this is reflected in the variety of sample sizes observed in the published research on qualitative data throughout the literature (O'Reilly, 2012; Patton, 2015). The sample size needed for qualitative data is not specific but is based on the amount of time that the researcher is prepared to dedicate to the data collection process, the resources that are available, and the specific objectives of the particular qualitative study (Patton, 2015).

Saturation is met when adding research participants to the study does not result in additional information or perspectives on the phenomenon (Creswell, 2013). Initially, I decided on a sample size of 10 to 15 participants as being an adequate starting point for acquiring in-depth, rich accounts of the reported lived experience of the participants whom I interviewed (see Patton, 2015). The strategy that I used to determine the sample size for my phenomenology study was based on the aforementioned saturation concept (Creswell, 2013). However, I also recognized that six participants as the working minimum number for qualitative interviewing might provide an acceptable level of saturation in the collected data (Morse,1994; O'Reilly, 2012). I felt confident that my chosen sample size and strategy were sufficient and that the quality and quantity of the information provided were appropriate to address my research objective.

Instrumentation

For this study, I used the same data collection instrument for each participant, a semistructured interview guide with one interview question (see Appendix B). A Sony digital recorder was used to record the audio responses, and an observation sheet was used to take field notes after the interview. Following the interviews, I received a written transcription of each interview recorded from a professional transcription company. The information was based on the responses to the official interview question and the information the participants shared in response to the additional prompts (see Appendix B).

I conducted all the interviews over the phone and recorded them for accuracy and to reduce bias. The interview began with the participants identifying themselves and responding to questions about their demographics (e.g., age, gender, and job). To collect the study data, I used one open-ended question, "Please tell me about your experience of HIV and SCCM." Also, I explained the terminology of SCCM. To maintain consistency in how the interviews were conducted, I was the only person collecting the data. The data came from recorded responses to the interview question I asked each research participant. Recordings were sent to a professional service for transcription. Following the receipt of the transcripts, transcripts were reviewed alongside the recordings to ensure the accuracy of the recording. The data were analyzed through hand-coding as I read the transcripts several times. Using a Microsoft Excel spreadsheet, I recorded the codes and themes that I assigned from each transcribed interview. My data collection included a semistructured interview and field notes and was an ongoing process (see Creswell, 2013).

Procedures for Recruitment, Participation, and Data Collection

I scheduled an appointment to meet with the director of the clinic and asked permission to recruit participants for interviews. I subsequently received permission to recruit research participants from the director of the clinic. My phenomenological research method consisted of an in-depth interview. The semistructured interview consisted of an individual, confidential interview with one open-ended question, “What is your lived experience with HIV and SCCM?” The response to this question provided information about the ideas, opinions, and lived experiences of the research participants. Each interview lasted 15-45 minutes. I asked the participant to tell me about their day when they did not understand my question.

The interview question was based on my comprehension of matching research context and research question. I formulated the research question to provide an understanding of the phenomenon, as well as allowing participants the opportunity to provide a well thought of and honest response (Maxwell, 2013). There was no follow-up plan for data collection. The initial interview reflected my only meeting with each individual participant. Data were gathered from my observations recorded at the end of each interview in the form of memo notes. These notes were combined with the transcripts of the audiotaped responses of the participants about their individual lived experiences.

For this phenomenological study, I selected the Husserl methodology because of its reported effectiveness at obtaining confidential, lived experience information from vulnerable participants living with chronic illness, such as HIV (Abalos et al., 2016;

Gutland, 2018; Janesick, 2016). As intended, the interview provided vital information about research participants' lived experiences regarding critical scenes from their life stories and personal reflections of daily experiences as a minority adolescent living with HIV (Janesick, 2016). To ensure quality, trustworthiness, credibility, and a reduction in research bias, I audio recorded the conversation between the interviewee and myself, wrote memo notes during the interview, and used a professional, impartial transcription service to transcribe the recording of each interview.

The interview prompts that I used during each interview were related to my research question and were based on findings throughout the literature that are pertinent to underrepresented minority AAYAs living with HIV and their particular SSCM experiences. Predetermined interview prompts were used during the interviews. I only used questions from my interview prompt when the individual had difficulty expressing their thoughts or could not think of anything to say when I asked the one question. I sought to establish a trustful, friendly, collaborative, interactional relationship with the interviewee by telling them something about myself and asking me questions and addressing any concerns they had. I understood the importance of adhering to the interview script when asking questions and asking related qualitative interview questions to receive a complete account of participants' lived experiences. I reminded interviewees that all information and communication between us was confidential and would be securely stored. I was also mindful that, as the qualitative, phenomenological interviewer, I was also an instrument and, as such, I should not allow my unconscious biases to influence the data being shared with me or what I would eventually collect. I made every effort to ensure that my qualitative research was based on integrity, honesty, and an understanding of my personal biases (see Maxwell, 2013).

I would have conducted face-to-face interviews, but because of the social distance recommendation imposed due to the COVID-19 pandemic, I conducted my interviews over the phone using an audio recorder. The face-to-face interview format would have helped to provide structured observation, which is ideal for qualitative phenomenology interviews (McCoyd & Kerson, 2006). The advantages of face-to-face interviews outweigh the disadvantages inherent in interviews to collect data for qualitative research (Beck, 2005; Eagan et al., 2006). However, a cutting-edge finding challenges the biases of electronic interviews and shows unique opportunities for meaningful, collaborative interactions that give voice to research participants when using electronic interviews versus face-to-face interviews (Novick, 2008).

Data Collection

The data collection procedure consisted of (a) the use of a Sony Digital Recorder to record everything the participant told me over the phone during the interview, (b) responses of the participant during individual, confidential interviews, (c) information from field notes and memo notes, and (d) information retrieved from the Sony Digital Recorder and transcription as related to the entire interview. I presented and organized my qualitative data by identifying codes, reduced these codes into themes, and summarized and presenting data into a narrative or graphic form (Creswell, 2009).

Data Analysis Plan

The data that I collected was based on my research question: What are the lived experiences of male AAYAs with HIV and SCCM? This was the only question I asked the participants. I had two interview prompts that were used when the participants were having difficulty expressing their thoughts in words. My qualitative research question shaped my data analysis because it provided the focus for my study and provided the direction for a rigorous inquiry and eventual interpretation of the findings for my phenomenon of interest. My analysis was based on adherence to my selected frameworks and methods of reflexive viewpoint (Agee, 2009). The data that I collected are strongly connected to my research question because it provides information on comprehending how participants view their lives related to their HIV diagnosis and SCCM they experienced (Adams, 2008; Agee, 2009). The two interview prompts that I used (asking about their day and advice received from family or friends) are found in Appendix B.

The procedure for coding was manual coding. I decided on a deductive coding technique as I read through the data to get a general idea of the information. Thematic coding was used to find meaning between the information provided in each transcript because it defined and brought out patterns that are essential and necessary for understanding phenomena (Maguire & Delahunt, 2017; Vaismoradi et al., 2013). As the researcher, I took direct responsibility for doing my data collection and data analysis; however, I also consulted with Dr. Uohna Thiessen, a research analyst, for guidance (see Rudestam & Newton, 2015).

I selected codes after each individual interview following a careful analysis of the interview transcript, and the codes were then grouped into themes based on those from the literature. The themes were developed after all codes were listed. The data were analyzed to find meanings from the developed themes related to the research question. I inspected the themes for fidelity and consistency by making a comparison with the interview transcription of the recorded interview. Hand coding is used by many researchers and may facilitate ease for establishing additional themes that assist in understanding information provided by the transcription (Basit, 2003; Saldana, 2015). Hand coding was used instead of NVivo due to the benefits of cost containment and because numerous researchers use it.

I analyzed the data from each interview by finding codes that evolved from each interview transcription. I listened to each audiotape and compared it with the transcription that resulted from the individual audiotape recording. I verified the major responses from the participants by repeating them back to them at the end of the interview. I did this to give them an opportunity to clarify or make changes to what they said if it communicated something other than what they intended. I then looked at the list of codes from each transcript, compared them, and developed themes, keeping the idea of a saturation point in mind. Data analysis was completed when I interpreted the themes and found the meaning of the lived experience that the participants reported.

The validity of my qualitative data shows credibility, trustworthiness, confirmability, and dependability as evidenced by the following eight steps of validity strategies: (1) triangulate diverse data sources to further establish themes, (2) use member checking to determine the accuracy of findings by taking the outcome descriptions and themes back to the participant for final comments, (3) use detailed, thick description of shared experiences and themes, (4) clarify bias that I may have brought to the study, (5) present negative or discrepant information that is contradictory to the themes, thus allowing the account to become more realistic, (6) spend prolonged time in the field with the participants, (7) use peer debriefing, which involves an interpretation beyond the researcher, that enhances the accuracy, and (8) use an independent, external auditor to review my entire project (Creswell, 2009). Awareness and implementation of most of these steps resulted in my research being rigorous and thorough, as well as facilitating efficient analysis of my data.

The software that I used for the analysis was Microsoft Excel because of cost containment, the size/quantity of my data, and ease of use (Bree & Gallagher, 2016). I am aware that analyzing qualitative data can be a daunting task, but I took on the challenge. I understood the possibility of a discrepant case, in which a reported experience may significantly differ from the experience of the majority. The unexpected knowledge that I received strengthened my findings and provided important information about my phenomena. Unique contributions from discrepant cases in qualitative data analysis add to the credibility of the findings (Barbour, 2001). Based on these findings, discrepant cases in data analysis should be welcomed and reported as innovative knowledge for scientific inquiry.

Overall, I used the transcriptions that were provided from my Sony Digital Recorder following each individual unstructured interview. I developed codes following each unstructured interview, and from these codes, I then categorized the codes into groups which developed into themes. I investigated the feasibility of using **NVivo** Data Analysis, but I chose to use Microsoft Excel along with consultation services due to cost containment. My research question is appropriately aligned with the data collected, and there were no discrepant cases.

Issues of Trustworthiness

Threats to Validity

There are some concerns about the validity of a qualitative study and whether the findings are trustworthy and substantial. The subjectivity of the responses raises doubts about whether the results are results being dependable, having credibility, confirmability, and having transferability (Lincoln & Guba, 1985; Rudestam & Newton, 2015). I was conscientious of threats to credibility when conducting and reporting the findings of my research. The experience of responding to interview questions about an individual's lived experience may impact the amount of information that the participant gives or withholds. With this in mind, I was careful to use a consistent set of semistructured interview instruments. My approach was differed only based on the vernacular of the individual and their understanding and ability to communicate what they were feeling. As some were more educated and understood the meaning and the intentions of the question, while some need to have the question clarified and the terminology explained. My awareness that selection can interact with history, maturation, or instrumentation helped to take action to minimize threats to trustworthiness. The potential adverse outcome portrays the ability of a single threat to interact with other threats and thereby giving multiple threats a more profound effect.

To establish transferability in my study, I followed rigorous protocols in my research methodology to ensure that I captured the essence of the message they wanted to communicate (Morse, Barrett, Mayan, Olson, & Spiers, 2002; Rudestam & Newton, 2015). This was especially critical because my study participants were all male AAYAs with HIV, an already especially vulnerable population. Unfortunately, the stigma and nondisclosure issues and the emotional and psychologically hurt suffered at the hands of a clinician who they do not trust; who approaches them in the wrong way; and who does not show compassion, love, and kindness when conducting the interview is well-known. To collect information that was truly reflective of their experience and that of others like themselves, I maintained a professional attitude while still conveying that I cared about each of them as a person. I surmised that if they believed that they were making an essential contribution to the field of study, they would be more inclined to share the truth.

The other issue about which I was concerned was that of my gender. Would the male AAYAs with HIV not appreciate an AA female asking them about their lived experience? However, I assured each participant that they were all free to decline the request to be interviewed by a female interviewer. Additionally, my study's issues were viewed suspiciously, and the participants not seeing the worth and, as a result, being tainted by selection bias. Would those whose lived experience increased their mistrust of the system not even bother to volunteer? In that case, only those still trusting of the system would volunteer, and their views would dominate the findings, limiting the transferability of the results. Again, here I explained the purpose and intention of the study and tried to convey the importance of being given a voice to share their experience on behalf of themselves and others with similar experiences.

I sought to establish dependability for my study by receiving interviewee training. This was done in addition to recording and transcribing data in an orderly and universally consistent manner (Rudestam & Newton, 2015). Consistency in the way data was collected and the way they were handled allowed the same study condition to be consistent and reduced the potential for interviewer or measurement bias (Altheide & Johnson, 2011). Cross-checking data via triangulation also supported this effort to minimize the errors that are inherently a part of all qualitative type research (Rudestam & Newton, 2015).

Confirmability, which refers to the objectivity in qualitative research, is established through reflexivity. Steps that I took to assure confirmability of my research were to identify and examine my biases and assumptions about participants honestly and realize that these biases may influence my research (Berger, 2015). Examining my own background, I realized the areas where my unconscious bias could affect the research process. I documented these and reviewed them before and after the data analysis process. Doing so helped me ensure that the research findings were based truthfully on the participants' narratives without influencing my opinions.

Agreements to gain access to my participants and the data collected were obtained from the Institutional Review Board (01-05-21-0601432) at Walden University. There were ethical concerns regarding the recruitment of my participants because they were a minority, stigmatized by their HIV status, their double vulnerability added to the already sensitive nature of my topic. I informed my participants that they were free to withdraw from the study at any time, as indicated on the signed consent form. My flyer also had my contact information so that interested participants could call me at their own discretion. Each participant received a $20 electronic gift card from SkyRocket when they completed the interview.

All the participants were told that any information shared during the interviews was confidential, that no individually identifiable information would be included in the final dissertation. I am the only one who had access to the confidential data, and all data were stored in a locked container kept in my home. I told my participants that all their audio information was secure, and my phone and recorder with the confidential data was always locked, except for recording during the interviews. According to present guidelines at Walden University, all data was to be kept for five years regarding the disposal of research data. There is no conflict of interest because I do not work at the clinic where I conducted my research.

Ethical Procedures

When conducting any type of research, following ethical guidelines is critical to the participants' safety and that of the researcher. A mandate that pertains to nurses and other health professionals conducting research and others is to abide by the ethical principles of nonmaleficence, beneficence, autonomy, justice, and confidentiality (Silva & Ludwick, 1999). Nonmaleficence, per Silva and Ludwick (1999), refers to assuring that no harm comes to a participant. Every attempt must be made to prevent psychological damage that may result from the betrayal of a trusted bond. Silva and Ludwick (1999) defined ethical concerns as (a) beneficence refers to preventing and removing harm and promoting good within the intimate bond between the researcher and participant; (b) autonomy refers to the research participant having a right to self-determination regarding making decisions about the information that is released to the researcher without being coerced; (c) justice and fairness alludes to the participant being made aware that needed resources may be available on a confidential basis, and; (d) privacy is an asset and a right that belongs to each participant, whereas, confidentiality is also a right that indicates that personal information is used only for the purpose intended. I made every effort to abide by the mandates mentioned above required of a researcher, paying particular attention to principles of nonmaleficence, beneficence, autonomy, justice, and confidentiality.

There are several codes that address ethical challenges such as protection of privacy, minimizing harm, and respecting the shared experience of others, as required by the national institute of health (NIH) (National Institute of Health, 2006). Firstly, the United States Code of Federal Regulations (Department of Health & Human Services, 2005) directives to researchers and review boards provide a protocol to follow that protects the confidentiality and privacy of the participants involved in the specific research. Secondly, the National Institute of Health Guidelines for the Conduct of Research Involving Human Subjects requires a protective mechanism to be put in place that assures the confidentiality and other delicate concerns of research. Such a mechanism enforces the protection of a research participant’s confidentiality, protecting privacy, and personal respect (NIH, n.d.; Rudestam & Newton, 2015). Thirdly, the American Sociological Association's (ASA's) Code of Ethics is yet another code that serves as an oath to the community, and mandates that the researcher obtains consent, address confidentiality before the research endeavor, and that the participant knows that the researcher protects all confidential information by removing any identifiers that may reveal true identities (ASA, n.d.). Fourthly, the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule of April 2003 does not have an actual effect on the implementation of the researcher's work, but it plays a role in the researcher's ability to retrieve the participant's protected health information (PHI), relevant to making the researcher accountable for, and adhering to HIPAA Privacy Rules (Silva & Ludwick, 1999). I used the Code of Ethics and HIPPA guidelines as well as that from the ASA to assure that my research was conducted responsibly.

I continually experienced ethical dilemmas while conducting my research and will continue to do so when disseminating much-needed data of my participants' lived experiences through in-depth interviews (Silva & Ludwich, 1999). Ethical challenges always persist, as relevant to protecting participants' identities, and portraying the rich data that is obtained, disseminated, and added to scientific knowledge (NIH, 2004). I am aware that challenges exist within this realm. Thus, I continue to follow present protocols for protecting my research participant, assuring respect, and giving them free will to control what happens to their data.

The vulnerable individuals I researched were protected regarding confidentiality, HIPAA guidelines, personal rights, privacy, and respect. All procedures for the interview were explained to the research participant on an individual, confidential basis. The IRB approval, confidentiality statement, and consent form were explained and, appropriate consent was given to me prior to implementing the interview. The research participants were allowed to ask questions and had the freedom to decide to no longer be involved in the study at any point during the process. The research participants were informed of the results of the study and a reminder that their name was not be included in the study. All confidential interview information provided by each participant was stored and locked on my personal computer (PC) with a confidential password that is only accessible by the primary investigator (PI). Symbols were be used in the place of a participant's name to assure integrity and confidentiality. Each research participant's privacy, dignity, and respect were maintained during all stages of the study protocol.

Summary

The researcher's unconscious biases profoundly affect the outcome of a study, especially one that involves sharing personal information. The methodology, instrumentation used, and implementation process may also affect how the investigation is perceived and received by other scholars who may want to use the findings or replicate the research and add to scientific knowledge (Janesick, 2016; Sanjari et al., 2014). Procedures that involve the recruitment of research participants and details regarding the data collection and analysis process play an essential role. Issues regarding trustworthiness, relevant to research transferability, dependability, and confirmability, are strategies that must be addressed when implementing research on a scholarly level. Ethical procedures regarding the treatment of participants, the IRB approval, and the treatment of data before and after the research experience are also key components of a successful research experience. Guided by all these principles, I interacted with the participants and carried out the data collection process to ensure they are confidentiality while collecting valid and reliable information.

Chapter Four describes activities performed after IRB approval in documenting and analyzing the data collected to answer the research question and present the findings. Observations and reports of the actual setting and details of the data analysis implemented is the focus of chapter four. The characteristics of the participants and evidence of trustworthiness portrayed is also be presented.

Chapter 4: Results

Introduction

In Chapter 4, I present the results of the qualitative analysis of data from the interviews conducted with six male AAYAs who had been diagnosed with HIV. The male AAYAs who participated in the study were all receiving treatment at the same clinic in a large urban area. The participants had volunteered to participate in the study, understanding they would receive an e-gift certificate for $20. The purpose of this qualitative phenomenological study was to explore and describe the lived experiences of male AAYAs with HIV and their experience of SCCM. Stating the purpose of a study assists the researcher in conveying the perspective of the research participants (Rudestam & Newton, 2015). The methodology for the research was phenomenology, which I used to "understand, explain, or describe" (Neal, 2016, p. 129) the experiences of this particular group of young men. I aimed to collect the information in their own words and to analyze and report an accurate representation of the SCCM of male AAYAs with HIV (Neal, 2016). One overarching research question was addressed in this study: What are the lived experiences of male AAYAs with HIV related to the perceived support of their families and their use of SCCM in their daily lives?

Research Setting

The setting for this study was initially intended to be at the clinic where the AAYAs were seeking treatment for the HIV/AIDS condition symptoms. However, because of COVID-19, I switched from face-to-face interviews to virtual interviews, which I audio recorded. The participants were either in their homes or at a secure remote computer where they contacted me to start the interview. I was in the privacy of my home office, also using a secure computer. To further assure the confidentiality of the participants, the interviews were only audio recorded, without any video recording.

Demographics

All the interviews with the six AAYAs lasted between 10 to 45 minutes, with the same general questions being asked and the occasional predetermined probes used to elicit additional information. The general interview question was "What is the lived experience of AAYAs with HIV and SCCM?" One suggested probe was "tell me about your day." Although the AAYAs were not asked specific demographic questions, all stated that they were between 18 and 24 years of age and officially diagnosed with HIV. None of the participants were employed full-time, and none were attending any type of school. The participants were asked about their living conditions. Although their answers were vague, none appeared to be living in their family homes, and one indicated that he was living in a motel, doing odd jobs to pay the rent. The others did not state unequivocally where or under what conditions they were living at the time of the interview. That information, nor any other personal information, was probed further during the interviews.

Data Collection

A total of six AAYAs participated in the study by engaging in virtual one-on-one interviews with me. Originally, I had planned to conduct the interviews at the clinic where the AAYAs were receiving treatment for their HIV. Due to COVID-19's social distancing advisements, face-to-face interviews were replaced with virtual one-on-one interviews. The six AAYAs had read the informed consent form and agreed to participate. Interview times had been established at the convenience of the participants. At agreed-upon times, the participants contacted me by telephone to start the interview. The interviews were audiotaped with no names or identifying information included. The shortest interviews lasted 15 minutes, and the longest interview lasted 45 minutes. I reviewed the audiotapes prior to sending them for transcription to verify that no identifying information was included. The transcribed interviews were compared to the audiotapes to assure the accuracy of the transcription.

Data Analysis

I recorded the participants' interviews and had each of them professionally transcribed for analysis. Each of the AAYAs was assigned a pseudonym to assure their confidentiality would be maintained in the final report. The names that are used are Ron, Charlie, Dave, Bobby, Ben, and Henry. Quotes from each of these participants were be used in discussing the themes and ascribed to the individual based on the assigned pseudonym. The transcribed interviews were read and reread before the start of the analysis and to get a sense of the whole of the message. The transcripts were reread after listening to audio to get the timbre or the emotional context from the voice of the speaker of the words that were shared.

Theme Coding

The general approach for qualitative analysis used in this study consisted of a hybrid of deductive and inductive reasoning. General themes that were derived from the literature served as the initial guide, and from those, the related themes that evolved were used to begin the coding process. I completed thematic coding by reading the text and searching for words, phrases, or sentences that describe or express their feelings about their experience of SCCM. The original themes included family and peer support systems, medications, self-care, physical health, mental health, education, economics, and guilt, and they were used to categorize the comments. After arranging comments into these themes, I read the comments again. Some items were reassigned to another comment, deleted when it was determined that the comment was not reflective of the theme or left where it was. Empty themes, such as education, were eliminated.

Theme Development

After all the comments were codified, I then categorized them into specific themes. Some new themes were created, and some were eliminated. For example, although family and peer support systems were initially separate categories, they were merged because some of the AAYAs did not separate their idea of a family from those of their peers when discussing support systems. I joined medication with self-care as these two themes appeared to be regarded as the same by the participants. Physical and mental health were divided into two separate categories, as they were discussed as two distinctly separate but important themes. Eventually, all the comments were placed in themes that most closely resembled the sentiments being expressed.

Inferring Meaning

After categorizing all the comments into relevant themes, I reread them for comprehension and message. The comments within each theme were read and reread to capture the content and context and determine the meaning behind the participants' words and the relevance to the research topic. During this process, there was an additional reshuffling of some comments as they were moved to other themes, while some others were eliminated due to an absence of relevance to the research question. This iterative process continued until the themes that emerged were clear and were specifically addressing the issue be addressed in the research question. In examining the interviews, although a few comments were irrelevant, none of the cases appeared to be divergent. Although there were some minor areas of differences, all of the AAYAs in the study were similar in the way they coped with their condition, HIV.

Evidence of Trustworthiness

To foster trustworthiness, I considered the four components of trustworthiness, credibility, transferability, dependability, and confirmability while collecting the data and addressing the research questions. According to Rudestam and Newton (2015), credibility is established by focusing on these important components in the qualitative study process. To bolster trustworthiness and encourage the participants to feel relaxed and at ease, I gave permission to participants to take as much time as needed to respond during their interviews over the phone, allowing them time to think about their answers and making sure to carefully listen to what they said, even if it was off topic. I assured each of the participants that as a Black woman and mother of three, including a Black male, I would be earnest in reporting their responses in a way that would minimize the stigma and bias that they had already experienced. The objective was to get the participants to share their concerns openly, understand that there were no wrong answers, and believe that their information was safe.

Equally as important as trustworthiness and credibility are the issues of transferability and dependability, features that are reinforced by demonstrating an adequate level of rigor to the research process (Morse et al., 2002; Rudestam & Newton, 2015). To strengthen dependability and transferability, I enrolled in an interviewee training course prior to starting the data collection. Based on what I learned, I took steps to ensure that the interview process was consistent by asking the same interview question and using the same probes in a similar manner across all the interview sessions. I did so to guarantee consistency in my interaction with the participants and collect the data. My goal was to make the findings as dependable as possible; should the study be repeated by someone else, the results would be the same. Although I tried to guide the respondents to remain on topic, I was careful to allow them some freedom to expand on their responses if they wanted to. I also recorded the interviews consistently and used the same transcriber for each of the interview recordings to assure uniformity in that part of the process as well (Altheide & Johnson, 2011, Rudestam & Newton, 2015).

Finally, I established confirmability, which is defined as objectivity in qualitative research (Berger, 2015), through flexibility and reflexivity. To ensure that my role as researcher created a safe space for the participants to share their stories, I also took steps to keep my own biases at bay. Prior to the interviews, I used a reflexive journal to examine any thoughts I had that could have had an adverse effect on the conversation. This process facilitated the acknowledge of my biases and the steps that I could take that would prevent them from influencing the interview and the data collection (Berger, 2015). The activity of reflexive journaling was effective, I believe, in minimizing the effect of researcher bias, both during the data collection and the data analysis stages of the research process.

Results

All the data used in the analysis for this study are based on the participants' responses to the research question as presented to them during the interview. The research question was- what are the lived experiences of male AAYAs with HIV, the perceived support of their families, and their use of SCCM in their daily lives? After careful review of the data and coding in meaning units into themes, analysis of the data resulted in the emergence of six main themes. These themes included (a) support systems, (b) self-care, (c) physical health, (d) mental health, (e) economics, and (f) guilt. Each of the themes was deemed independent of each other, with little or no overlap across the themes.

Theme 1: Support Systems

After analyzing the data, the first theme that emerged related to SCCM was that of family/peer support. The consensus among the group was that a support system was essential to their physical and emotional well-being. For half of the group, that support came from family members, and for the other half support came from friends, peers, or confidants. Of the three who identified family members as the main source of their support, two named their mother, and one named his grandmother. Ron stated, "My mom is just a very supportive mother who helps me here and there when she can." Like Ron, Bobby also shared that his mom was supportive of him. According to Dave, "My daughter is a big part of my motivation. I am a full-time dad for my five-year-old daughter that I love and care for." He went on to add that his grandmother was a big part of his support system and that she was the one sitting next to him when he received the news about his HIV-positive status.

Those who did not have the support of their family members were their friends who fulfilled that role. A few of the participants indicated that they had partners whom they were close to, and these partners were the ones who provided support during difficult times. Dave, the young single father, stated that he had the help of his grandmother and that of a supportive partner. He noted the following about his partner, who is HIV negative: "My partner is very supportive, makes sure I take my meds, I take care of my health, I eat right, and I stay on top of things." Dave also indicated that his best friend of more than 16 years was aware of this HIV status and was also very supportive. Like Dave, Bobby also indicated the presence of a supportive male presence in his life, indicating, "My partner is a huge support to me, . . . so I can say I have a pretty good support system."

For some in the group, it was their friends and peers who served the role of the supportive network that they valued. For example, Dave indicated that his friends are his confidants, and not only can he confide in them, but he can also count on them for help when he needs it. Ben stated that he has four friends, and although he is not sure if they are aware of his HIV-positive status or not, he feels that he can talk to them regularly. As he puts it:

> I have four other friends I talk to daily, and I don't know if they have HIV because it is none of his business and his status is none of their business. If

> my friends know I have it, they never said anything about it cause it's none of their business.

Ben relayed that he does get together with these individuals and share stories about where and how they got infected with HIV. He added that these events have a positive impact of serving as a bonding moment among them. Ben was also in the process of developing a new friendship with a potential partner who, according to him, could end up being supportive. In contrast, Bobby said that he does not have any friends who provide support, despite him knowing several persons who are also HIV positive. Charlie admitted that he was only able to confide in his friends about his condition a year after he was initially diagnosed. He expressed that his friends seemed accepting as they "were cool" with the information he shared about himself, and he was able to use that as an opportunity to educate them about HIV disease and what it's like to be HIV positive. Henry indicated that he had no family members as part of his support circle, but he confided in his friends like Ben. According to him, "I have a few positive friends. We get together and try to encourage each other and support each other. We share each other's stories and learn from each other."

Theme 2: Self-care

All six participants recognized the need and had therefore implemented some type of regime for themselves as part of their daily self-care initiative. In general, they all began their morning with some kind of routine. The general order of tasks involved first waking up, then taking a shower and brushing their teeth, followed by eating something for breakfast and taking their medications. Both Charlie and Ben had an addition to their mourning routine that was similar to each other. They both started their mornings by smoking marijuana (weed) and ritually burning sage throughout their homes. Charlie said, “I wake up every morning, have my Biktarvy pill, brush my teeth, smoke a joint, then smoke another one.” Ben stated, “[I] smoke weed and burn sage throughout my house several times throughout the day.” These two young men said that they felt that the ritual of burning sage in their homes was intended to chase away evil spirits and negative vibes and to maintain a healthy atmosphere. They both expressed the idea these two activities (smoking marijuana and burning sage) were an essential aspect of their self-care as patients living with the anxiety of an HIV-positive diagnosis.

As part of their regular routine, all the participants reported incorporating their belief in God as part of their self-care. They mentioned things like “praying” or “talking to God” habitually, and some even reported attending church frequently. Most agreed that these religious or spiritual practices assisted them with their overall self-care. All had some form or another of these religious practices as part of their daily activities to help them manage their other day-to-day activities. Another example of self-care mentioned was spending time alone in the practice of mediation, but others preferred spending time and talking and sharing carefully selected individuals that they trusted.

On the more traditional side, there were references to self-care that included self-medicating with Ibuprofen when experiencing body aches or other types of physical pain. There was also mention of different practices that were important to their health, such as the importance of staying hydrated or of participating in some form of physical or extracurricular activity. All participants indicated that they believed that they had some measure of responsibility for their self-care and self-management. Despite their diagnosis, ultimately, their health was up to them.

Theme 3: Physical Health

All the participants verbalized that they felt relatively healthy despite their HIV diagnosis. They also acknowledge awareness of the steps they should take to remain as healthy as possible. They knew they needed to drink plenty of water to stay hydrated, take their medications daily to slow the disease progress, and generally practice good hygiene to support their immune system to keep the HIV from progressing to AIDS. Ron recognized what aspect of his health he needed to focus on to impact his physical health positively. He was quoted as saying, “I’m not the healthiest, I’m overweight, I’ve been overweight all my life and trying to get better with my health and my weight. I also don’t eat the healthiest.”. Charlie said, “I lay down and rest throughout the day.” Charlie understood the positive effect that rest would have on his already compromised body. Dave said that his HIV viral load is now at an undetectable level. As a result, he was even more motivated to take care of his body so that he remains in the “undetectable” category. All participants indicated that keeping their bodies healthy by medication compliance, eating healthy, making healthy choices, and collaborating with support people can have an optimal and profound effect on their physical health.

Theme 4: Mental Health

Like their concerns for their physical health, issues of mental health appeared to be a major part of the lived experience of all six AAYAs. Most of the participants reported experiencing occasional bouts of depression, feeling isolated, or frequent feelings of sadness, or feelings of mistrust of those around them. These emotional issues were sometimes complicated by illegal drugs use and abuse. As Ron stated:

> Since I was diagnosed with HIV, I had mental issues, deep depression, and using drugs because of all the pressure and feelings rushing through my head when I first got diagnosed. However, I'm grateful that I'm alive every day. I talk to a therapist from the place that I go to, and I try to read and keep my mind busy with productive and healthy things.

Charlie, however, had a more positive perspective as he reported:

> I don't know of anyone else dealing with what I'm dealing with, so I'm the single soldier over here. I also feel that it's not the end of the world, and I gotta deal with it because I'm stuck with it. It's a life-or-death situation, but it doesn't have to be.

Dave described his emotional experience as that of an internal battle taking place inside himself. He added that this internal struggle started when he began to take his antiviral medication for the disease. According to him, there was a period of disbelief about his diagnosis, and that he was at a loss about what was happening. He went on the exclaim, however, like Charlie, he has a more positive outlook now and that:

> This battle, in my eyes, is making me a better warrior, a stronger person, a better individual, a better role model for my daughter to look up to, to give my daughter inspiration that no matter what life throws you, you can make it through life.

For Bobby, his mental health issues were complicated by the problems of his physical health; Bobby said, “I get a lot of headaches and some days are not good at all. I don’t know if the pain is tied to my condition.” On the other hand, Ben is more proactive as he acknowledged his mental issues and talked about the steps that he took to deal with them. He says:

> I feel sad and depressed sometimes, but I write music and play music to get stuff off my head. I see my Sperm Donor sometimes, but I don’t speak to him. I barely talk to my parents, and they don’t check up on me. My mom knows my status but doesn’t check on me, so I just keep my business personal.

Overall, all six AAYAs mentioned some form of coping mechanism to combat the toll of their HIV status on their mental health. Examples of coping included self-reflection and contemplation of their situation, but some chose, at times, to improve their mental state by getting “dolled up and looking pretty” so they could feel good about themselves. Other activities discussed as means to gain mental ease or peace of mind were painting, singing, and other positive distractions that took their minds off their present state of illness. Henry was the one who shared the conviction that a selfless perspective helped him by saying, “I cope with my mental status by knowing that there are people out there that’s not HIV positive that go through way more struggles.”

Theme 5: Economics

Five AAYAs were employed at the time of their interviews but did not reveal any details about their place of employment or what type of work they did. Ron, who considered himself employed but only on a part-time basis, was also dealing with homelessness while trying to look for a steady job every day. He shared that he did get the occasional side jobs and that this allowed him to live in motels. He went on to specify his plans for his future by saying: “I’m trying to get into college, but I don’t know how to apply for the FAFSA. I can get food stamps when I live in a motel.” Among those that were employed, Dave, the single father, said, “I have a support team for resources.” Charlie stated, “I know that there are people and resources out there because it’s something I have to figure out on my own.” Ben was the only one not working and considered himself as a homebody. Although the six AAYAs had economic struggles, they also implicated that they were aware of resources available to them and that they were taking or needed to take steps to access them.

Theme 6: Guilt

Beyond the emotional dilemma that they all experienced from time to time, five of the six young adults dealt with feelings of guilt and shame because of their HIV status. Ron’s guilt seemed to lead to self-loathing as he stated, “I feel almost gross for what happened to me and for letting it happen. I take full responsibility for not being safe as I should have been...it takes two to tango.” As Charlie put it, “I think this is the worst-case scenario of my mom having a gay son even though she still doesn’t know my status.” The tone of the responses of five of the six AAYAs suggested that they might have had feelings of insecurities and did not want to be judged by others. One aspect of living with the disease that exacerbated their shame was the number of medications required to take daily. They expressed apprehension about having to explain why they take so many pills every day. Dave expressed concerns about wanting to be “mentally ready to have the conversation with my six-year-old daughter re why I’m taking these medications, inform her about my status, and educate her on what I know about HIV.” Some of the responses indicated that there were feelings of guilt arising from their mistreatment of others and that their condition might a form of punishment for being mean to others. Bobby dealt with his guilt by using drugs (marijuana) as an escape, as stated, “I smoke weed to get my mind off of things.” Henry’s position was different from the other five, as he said, “I’m not ashamed to have HIV because I didn’t choose it, it chose me. My opinion is HIV chooses people; therefore, they should not be ashamed to be HIV positive.”

Summary

Chapter 4 has presented the results of the thematic analysis of interviews of six AAYAs diagnosed with HIV on their illnesses. Six themes emerged from the study, including support systems, self-care, physical health, mental health, economics, and guilt. Three participants reported support from family, especially their mothers, was particularly important. Others reported help from their partners or friends, while one reported no support system. The AAYAs indicated they were taking their medication and trying to be physically fit in terms of self-care. Ben smoked joints after taking his medicine, and both Ben and Charlie burned sage to ward off evil spirits. All the AAYAs indicated that they were meditating, self-medicating with Ibuprofen when experiencing body aches, staying hydrated, being involved in extracurricular activities, and communicating with carefully selected individuals that they trust to some extent.

They all reported that their individual self-care management was their responsibility. In addition to taking medications as prescribed by their physicians, they were all trying to take care of their physical health. Mental health was a problem for all the AAYAs in the study. They had feelings of depression, sadness, and loneliness. They knew they had to develop coping strategies to manage their mental health. Examples of coping strategies they were using included self-reflection, making themselves look attractive, participating in painting, singing, and positive distractions to take their minds off their present state of illness. Henry stated, “I cope with my mental status by knowing that there are people out there that’s not HIV positive that go through way more struggles.”

Five of the six AAYAs were working, but none were in good shape economically. One was homeless, and another was living in a motel, doing odd jobs to pay his rent. Guilt was the last theme that emerged. Each of the AAYAs felt some degree of guilt about their condition, but most were able to voice their responsibility in the diagnosis. According to Henry, “I’m not ashamed to have HIV because I didn’t choose it, it chose me. My opinion is HIV chooses people; therefore, they should not be ashamed to be HIV positive.”

The six themes that emerged from the analysis of these findings were not novel, but there were some unique perspectives that make them exceptionally informative for the group being represented. This chapter detailed these peculiarities and the meaning and relevance for the nursing profession and other health care intervention strategies. While several studies have involved HIV-positive patients, there are few on the issue of the lived experience of young Black men who are members of this group. The themes emphasize the need for more studies in this area to find their voice and take care of their self-care and, ultimately, their health outcomes. The final chapter of this dissertation (chapter five) provides a critical evaluation of the findings related to previous studies and the implication for related studies in the future, and its potential positive social impact.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this study was to obtain information on the lived experiences of male AAYAs with HIV and their use of SCCM. I intended to collect the information using semistructured, face-to-face interviews with the participants; however, because of the COVID 19 pandemic, the interview format was changed to phone interviews only. I conducted each individual interview by phone from my home, with the interviewee at a remote location. I was able to listen to the lived experience of the six male AAYAs in response to the interview question, and the audio from each interview was recorded. According to my review of the literature, information on the lived experience of these individuals and SCCM lacks. The information obtained in this study may provide health-care providers with valuable insight into this vulnerable group.

One objective of this research was to share the perspectives of male AAYA with health-care professionals and inform policymakers and other stakeholders about the challenges faced by AAYAs living with HIV. This information can then be used to develop protocols and guidelines that bring about positive changes in the way that health-care professionals give care to these individuals and address their needs according to their perspective. Ultimately, this study’s findings may help reduce the stigma that these young men live with and give voice to their struggles and humanity.

After the interviews, I sent the recorded product to a professional transcription service that transcribed the recordings into text. I applied the deductive approach to the written text to categorize the responses based on themes from the literature. From the aggregation of the responses, six themes were developed to further understand the lived experience of the AAYA with HIV and SCCM. The six themes were (a) support systems of family and peers, (b) self-care, (c) physical health, (d) mental health, (e) economics, and (f) guilt.

Support Systems of Family and Peers

All six of the young men interviewed deemed having a support system of some kind to be important. For half the group, it was both family members and friends that filled the role support systems; for the other half, their support came, not from family members, but only from significant others or from their friends. In the family-member support group, it was their mothers (Dave and Ron) or grandmothers (Dave) who provided the much-needed support. These three young men also had the support of their close friends (partners and best friend for Dave, best friend for Ron, and partner for Bobby). The three who were without any support from their family did not have any partner support either. Their network was made up of their friends, and they depended solely on them. It should be noted that for this group, the idea of the friendship relationship appeared more causal than the best friend type of relationship described by Ron or Dave. For Ben, Charlie, and Henry, the friends were mostly people they would “hang out with,” some of whom were not aware of their HIV status (Ben), or if they did, they were being educated by the AAYAs. In the case of Charlie, it took a whole year to tell his friends, and then when he did, it was more of an educational opportunity and less of a bonding one.

The nature of the support provided by those with family members and close friends as support was different from those with only friends. This high-quality, meaningful support consisted of reminders to take medication and to take care of themselves in general. And the idea that there were people in their lives that they could count on was expressed with words like “huge support” or “very supportive.” The latter group did not use these kinds of words; instead, they simply referred to getting together or “being cool” about their diagnosis or to persons with whom they “got together” to chat occasionally. Without family members or a significant other or partner, the support system was weak. The ones who had it expressed gratitude, and the ones who did not adopt a more “it is what it is” type of attitude while hoping that things would change. As Ben expressed, he is currently at the beginning stage of a new intimate relationship and thinks his potential partner may be a source of support for him in the future.

Self-Care

All six participants implemented some type of self-care routine to take care of themselves. Most (four out of the six) began their morning routine with showering, brushing their teeth, eating their breakfast, and taking their medications. Incidentally, three of those four were the ones with family and partner support. By contrast, Ben and Charlie, who had no family or partner support, started the morning out by smoking weed and burning sage. And even though Charlie mentioned still taking his medication (in between his first and second joint), they both seemed to be using the marijuana habit and sage burning ritual to make up for any loneliness that might greet them in the morning.

They felt that these activities were positive self-care habits. They also both talked about needing to drive away “evil spirits” from their respective dwelling places.

All the AAYAs had a religious or spiritual upbringing and said they were incorporating their belief in God into their daily prayer or meditation or at least weekly church routine. The consensus was that these religious practices were an effort to take care of their whole (physical, mental, and emotional) self and might be helping them to maintain a disciplined attitude to their other more secular practices. Along with their regular morning routine (for Ron, Dave, Bobby, and Henry) or the marijuana smoking (for Ben and Charlie), the participants also mentioned other habits, such as regular water consumption for staying hydrated or the use of ibuprofen for the physical aches and pains and drink. Few talked of the importance of taking part in regular exercise or extracurricular activities to maintain their physical and mental health. Recognizing the importance of these activities and engaging in them are two different things, and it was not clear if it was simply the former or both for the participants. They all did, in their way, express a sense of ultimate responsibility and autonomy regarding their health and the need to take charge of their self-care management.

Physical Health

All the participants verbalized that they felt somewhat healthy, aside from being diagnosed with HIV. They were all aware of their need to drink plenty of water, take their medications daily, and practice good hygiene to keep their disease progressing. And for a few, they recognized that there was even more that they could do on an individual basis to improve their health conditions and increase the quantity and quality of their life. Ron knew that he needed to lose weight to be healthier, and Charlie knew that resting regularly would protect him from stress and boost his immune system.

Fortunately for Dave, his HIV viral load was now regarded as undetectable, and he believed that it is up to him to take care of his health so that he could remain that way. As a young father, he has a solid reason to stay healthy and alive, and with the continued support of his grandmother and partner, he believes he can. But Dave is not the only hopeful; all participants indicated that keeping their body healthy by complying with medication protocols, eating healthily, making healthy choices, and collaborating with their health-care providers and those in their support network might have an optimal and profound effect on their physical health.

Mental Health

Like their physical health, mental health appeared to be a significant concern among the AAYAs in the study. They all reported periods of occasional moderate to severe depressive feelings, feelings of isolation, sadness, and distrust. Even though Ron has the support of his mother and his best friend, he was the one who talked about the deep depression he experiences and how he uses illegal drugs to try and nullify those feelings. For him, the news of his HIV-positive status was devastating, but things have gotten better. He talks with a therapist and tries to use something other than drugs to keep his mind busy, which has helped. Charlie was also sad, and not knowing any other HIV-positive patients himself made him feel isolated. He oscillates between feelings of loneliness and being stuck on one hand and his feeling that it does not have to be a death sentence if he does not want it to be.

Dave’s emotional struggles were also generated by feelings of hopelessness and denial in the beginning, but he was able to turn those feelings around to believe that the experience has strengthened him. He now considers himself a survivor, one who could be a source of inspiration for other, especially his daughter, about perseverance and grit. Ben was the only one who, in addition to recognizing his mental susceptibility, has been proactive in putting in place some measures to help him combat his depression. He believes that he has learned to channel his feelings of loneliness and isolation into more creative and positive activities that hopefully make him feel better about life and himself.

> I see my sperm donor sometimes, but I don’t speak to him. I barely talk to my parents, and they don’t check up on me. My mom knows my status but doesn’t check on me, so I keep my business personal. I feel sad and depressed sometimes, but I write music and play music to get stuff off my head.

Overall, all six AAYAs in the study were aware of the challenge to their mental health posed by dealing with the disease and found various coping methods. Some used drugs (marijuana) to escape the loneliness, and others used self-reflection to help find some peace of mind. Most used coping techniques with less negative consequences, which impacted their quality of life positively, such as engaging their artistic side by painting, singing, or playing music.

Economics

Five AAYAs in the study were working at the time of their interviews but chose not to reveal any details about their employment. No details were provided about the housing circumstances of the others, but they did not mention being homeless. Ron was dealing with homelessness while also trying to find steady employment. Fortunately, side jobs allowed him to live in motels, and he had dreams of attending college someday. Both Dave and Charlie mentioned access to financial support when needed. Charlie, like Ron, was aware of other sources of financial support but seemed intimidated or daunted by the prospects of pursuing those resources. Both Dave and Charlie mentioned that they believed that it was their responsibility to do so and felt that the outcome was up to their efforts. Overall, the young men thought their financial situation was critical or that they were in extreme financial distress.

Guilt

Five of the six young adults had feelings of guilt related to their HIV status. Ron not only felt guilty but expressed feelings of self-loathing, stating, "I feel almost gross for what happened to me and for letting it happen….."Charlie did not share his HIV status with his mother because he believed that this was the worst-case scenario for his mom- not only was her son gay, now he was also HIV positive. The general tone of the responses from five AAYAs suggested feelings of deep insecurities about their condition. Those feelings were from fear of being judged by others for their sexuality and the resultant disease brought on by their ostensibly immoral lifestyle. Their responses indicated that they were also concerned that their condition was a result of them being punished for having been mean to others in the past. However, none of the young men I interviewed seemed to want to share more details or expand on that idea, at least not with someone they did not know well. Henry voiced the opinion that his HIV status was not punishment but more of the result of fate or lot in life, and there was not very much anyone could do about it.

A few participants were very concerned about their medication routine, which is so extensive (several pills every day) that it is difficult to conceal from anyone close to them. Dave was concerned about explaining this to his daughter when she is old enough and has some realization of his daily routine. He spelled out the enormity of the daunting task of explaining why he takes so many pills, why he is HIV positive, and what it all means.

Link of Themes to Literature

In this qualitative phenomenological study, I explored and described the lived experience of male AAYAs with HIV and their use of SSCM. Like other researchers conducting similar studies, I sought to obtain a clear perspective of the research participants to explore their lived experiences as AAYAs (Rudestam & Newton, 2015). The specific concept/phenomenon of interest that I examined was the lived experiences of male AAYAs with HIV and SCCM (Neal, 2016). The published literature on self-care management so far have excluded a focus male AAYAs with HIV despite this concept being studied for approximately 50 years (Ausili et al., 2014). There is very little information on their self-care or their lived experience as it relates to living with a chronic illness. The phenomenological component for the lived experience report addressed the reactions, perceptions, understandings, and feelings of AAYAs with HIV, as their lived experience of SCCM. A phenomenological design was appropriate because it can reveal the lived experiences of the research participants based on their unique perspectives (Ryan & Sawin, 2010). The rationale for selecting a phenomenological research design was to examine the lived experiences of this vulnerable group, as experienced from the first-person point of view. The objective was to gain insight into participants' perception of the acceptance of their diagnosis, the stigma associated with having HIV, the perceived support of their families and peers, and the use of SSCM in their daily lives.

Other forms of qualitative research methodology may have been used but were not suitable for this type of study. Case studies require triangulation of data (Ravitch et al., 2016), which was not available from this group of participants as only the AAYAs themselves were interviewed. Similarly, ethnographic studies, which require the researcher to become immersed in the group being studied (Ryan et al., 2010), were not an option for reasons of anonymity and security of participants. And finally, the narrative approach, where the participants tell their stories without an attempt by the researcher to find patterns and themes in the data (Merriam & Tisdell, 2016), would not have provided information directly related to the research question on which the study is based. The Husserl's phenomenology appropriately allowed for a focus on the individual and their e

The importance of support from friends and family is one of the main themes that emerged from this study. This finding mirrors Wallace's (2013) research that emphasized the need for nurses to advocate for family involvement in the design of their interventions for HIV/AIDS patients. She also concluded that it is critical that this involvement should span the lifetime of the disease trajectory and should be based on an interdisciplinary perspective. Similarly, Hussen et al. (2018) reported on the resilience that is fostered when HIV patients can break barriers and build collaboration, not just among themselves but with members of their communities. Hussen et al. (2018) developed a community-based participatory approach that leveraged the power of social capital and was thereby successful in positively impacting the health behaviors and physical and mental health outcomes of the HIV participants in the study.

The other theme that was present for all the participants in some way or another was the guilt that came from the stigma they experience in their everyday lives. The issue of stigma is a prevailing one and a most common theme coming out of HIV studies (e.g., CITE). The stigma that these patients are subjected to is real and damaging, but its elimination or maybe the reduction could significantly impact their self-care engagement. In the Intervention for Seropositive Injections-Research and Evaluation (INSPIRE) study involving HIV patients who were also drug users, researchers (Gwin et al., 2007) found that the program and the appraisal, information, and mostly the emotional support were instrumental in the positive changes experienced by the participants. The changes were reflected in their reduced drug use, the more responsible sexual practices, and ultimately, higher level of participation in health care utilization (Gwin et al., 2007).

Although my study is not new in highlighting the issues of stigmatization, as Nachega et al. reported in 2012, some 30 years after the onset of the pandemic, the stigma, isolation, and discrimination associated with the disease persisted. That study also reported on the depression and loneliness that result from this ingrained stigmatization. The researchers also pointed out the significant difference in HIV disclosure status, with 100% of the North American patients in the study reported disclosing their status.

However, this is contrasted by what my study found; despite it being a much smaller size, only half of the subjects in this present study were not open to disclosing their HIV status. This difference emphasizes the difference between the lived reports from general studies and the lived experience studies that focus on smaller groups, like the AAYAs.

According to Filho et al. (200), promoting, educating, and proactive engaging in self-care is a critical health outcome of HIV-positive adolescents, and that the strategies developed should specifically include the challenges of their sociocultural environment. An observational study by Gillard and Roark (2013) reported that effective self-care starts with a valuation of intrinsically motivated oneself, but that must be supported by those who understand and care about HIV patients. For the young HIV patients especially, who are still undergoing significant emotional and psychosocial development, compound with the issues of identity and sexuality, this can make dealing with the disease more overwhelming and even devastating (Ayers et al., 2006). This underscores the importance of identity affirmation that can only come from the family, the love, and the communities supposed to nurture them. When these factors are missing, the young person is less likely to engage in any self-care, and if they do, it will be less than optimal (Eustace, 2013).

The theme of self-care, or the lack thereof, and physical and mental health is not unique to the AAYAs in this study. A seminal study that looked at the lived experience of young AAYA women found that the isolation and abandonment they experienced in their interpersonal and social networks often deprived them of distraught and without any desire to live or any ability to participate in their self-care (Peltzer, 2014). These women (ages 21 to 35) had the added burden of being HIV positive and being women, and sometimes young mothers, with children for whom they were responsible. Unlike the AAYA men in this study, most of these women contracted the disease in a heterosexual encounter, and the betrayal that the HIV status represented had several layers of complexity to an already highly challenging situation. The AAYAs in this study did not have to deal with any of those issues, as they were all living as gay men at the time of the interview. It would be interesting, however, to understand the role the method of disease infection plays in the feelings of guilt and self-loathing some gave expression to (Peltzer, 2014). What the AAYAs did have in common with the women was the issue of economics and financial support, which apparently is a common thread in the lived experience of a large percentage of the HIV-positive community.

All the themes were fell into two main categories, the emotional burden of feeling deserted (needing support, feelings of guilt, depression, and loneliness, and loss of trust) and the material burden of the need to care for their physical for and provide for their physical needs. The interconnectedness of these themes and their similarities with those from other studies highlights the reality that HIV is very much a chronic illness, like all others. And like any other chronic illness, the needs of HIV patients are like other chronic illness sufferers. The physical, mental, psychological, social, and financial needs must all be included in any intervention strategy. Additionally, the self-management emphasis that is part of the services for other diseases must be included in the HIV patient treatment response. Like so many studies on the subject with other patient populations, the need remains for educating the public and reducing the still present and prevailing stigma associated with the disease. As Swenderman (2018) puts it, if this is not done, these prevention and wellness services were not be utilized no matter how well designed.

The key findings in my research indicated that the AAYAs use SCCM for dealing with living with their HIV status. The information that surfaced fell into six main categories— support systems, self-care, physical health, mental health, economics, and guilt —all common among the group. The support systems, when present, usually consisted of a mother, grandmother, and partner. There was no mention of fathers or grandfathers or aunts, uncles, cousins, or any other type of relatives as part of their support network. For most AAYAs with HIV, a few trusted friends and peers at work served as a supportive network once disclosure was shared with them. Five of the six (all except Bobby) mentioned friends as part of their support, even if the support was merely a casual friendship. Some were fortunate enough to have both family support, as well as support from their friends, and Dave had his grandmother, his partner, and his best friend. It should be noted that the ones that had the most support tended to be the more ones with the more extroverted (i.e., more talkative) and that the measure of the support received reflected the individual's natural characteristics and was not related to their disease status.

Care for their physical and mental health appeared to be an important concern that was shared by all the participants. They all had some form of regimen or had implemented daily practices and activities of daily living to assist them with their self-care management of living with HIV. Examples of self-care were daily hygiene, adhering to their medication regime, drinking enough water to stay hydrated, and trying to eat nutritiously. Some AAYAs with HIV engaged in other activities that impacted their self-care and mental health, such as praying and attending church, smoking weed, burning sage throughout their living quarters, playing music, and taking on the art of cooking and even by trying to help the self-esteem of others by learning the art of cosmetology.

Early studies reported that patients living with HIV often incorporate some form of spirituality in their lives to help them make sense of their circumstances, to try and find meaning in their otherwise hopeless situation or find emotional strength to face their inevitable demise (Cotton, 2006 & Lorenz, 2005). Later researchers also found was that higher levels of spirituality or belief in a higher power were associated with favorable outcomes, including improvement in their physical conditions as well as in their sense of well-being (Szaflarski, 2013). Other studies confirmed the central role of various spiritual practices in helping HIV patients, especially minorities and youth in dealing with the stressors (Arrey et al., 2016 & Doolittle et al., 2018). A multi-study review found that prevention programs that combine primary prevention (condoms and oral pre-exposure prophylaxis) with things like prayer, mediation, yoga, reported the highest positive protective behavior changes (Vigliotti et al., 2020). Spirituality in any form helps with the mental, emotional, and physical aspects of living with a chronic disease, such as HIV.

All participants stated that they dealt with periods of depression, guilt, and feelings of isolation at some time. Most were resilient and recognized the need to reach out for support from their network or to try and engage in some type of extracurricular activity that could take their mind off their present status. All participants were reasonably healthy and were able to take charge of their physical self-care themselves. They voiced that they knew where to receive community help, but only through people with whom they had developed a trustful relationship. All participants except for one were employed, but they did share any details about their employment. Only one person was homeless and but admitted that he knew how to seek help through the community.

Interpretation of the Findings

Persons who are gay or lesbian are subject to stigmatization, even more so when dealing with other discrimination issues such as race. The emotional and psychological offenses they are subjected to by clinicians and other health care professionals who show no compassion, providing care for them is well-documented (Elopre et al., 2018; Oeur, 2016; Todman, 2012). What is not well-documented is their perception of these experiences and their own lived experience of male AAYAs with HIV. This study presents the findings on the disparity, marginalization, and nondisclosure issues that male AAYAs experienced when dealing with their families, community, and peers, as expressed in their voice. Focusing on this marginalized group's ability (or lack thereof) to engage in SCCM required dealing with their chronic illness confirmed the previous research about the covert psychological state, depression, or isolation these men face and their reactions (Ayres et al., 2006; Eller et al., 2010; Harper et al., 2014).

Previous studies have reported the importance of family and community in the shared responsibility of dealing with chronic illness and the SCCM required (Denison et al., 2015; Eustace, 2013; Grey et al., 2015; Ryan et al., 2010). Similarly, this is the first theme to surface in this study- the high value placed on support from family and friends and how it is related to all the other themes. When the right kind of support is in place, the AAYAs are more likely to be actively engaged in their own self-care and enjoy better physical and mental health. Like in other studies, this study emphasized the role of caring friends, family members, or partners in helping the patient stick with their routines. They also give them a reason to want to take care of themselves and live more responsibly.

As Zarwell et al. (2018) concluded, the social support provided by a network also serves as a most needed outlet for the emotional strain of dealing with the disease. According to the findings, the patients who have significant others with whom they could be open and honest are less likely to resort to not so helpful means of dealing with their troubled emotions. The difference was seen in those who chose to smoke marijuana or other more dangerous drugs or other risky behavior, which only compounded the physical and mental health issues in the long run as a means of dealing with the emotional issues. As Dillon et al. (2008) reported, the contrasted is observed with those who had caring relatives or friends and chose to practice playing music, pray, or engage in some other more positive activity that made them physically, mentally, or emotionally stronger.

The stigma of the disease is not limited to the physical and mental challenges but extends to almost every aspect of their young lives. According to Hall et al. (2016), along with the intervention programs, stigma reduction efforts should be an important factor in the retention of patients in the treatment program and the eventual success of the health outcomes. The difference between having a job or some type of financial or economic support was significant. Though only admitted to by one of the AAYAs in the study, the issue of homelessness is a significant challenge for young gay men (Muessig et al., 2015). And attempting to maintain a consistent SCCM while dealing with no steady source of income, or unemployment, or no permanent place of abode is challenging for anyone, more so for a young man coping with a chronic illness. Other studies have revealed that these factors a key in determining the health outcomes, as it relates to the quality and quantity of life for HIV patients.

Omer, Lovering, and Al Shomrani, (2014) revealed that disclosure issues to be a significant determining factor in the stress related to the guilt and dread experienced by HIV-positive individuals, who fear stigmatization, discrimination, judgment, and rejection by the friends and families. Unfortunately, this fear can cause these individuals to isolate themselves from those that care about them to shield themselves. But this serves to also separate them from the family and the community that could be a source of support, and they need. The young men in this study touched on the issue of the guilt they feel, brought on by feelings of self-reproach for their situation, maybe because of their sexual orientation or what they believe was punishment for their past wrongdoing. What is clear from these findings is that these young men need an outlet to share these feelings to be addressed, and hopefully, they either be given the opportunity to make amends or be relieved of these burdens.

The direct and indirect consequences of the significant issues of a supportive network, self-care, physical and mental health, economics, and guilty are revealed in this study. The participants were all aware of the shortcomings in their personal experience as it relates to these factors. Some were more proactive in dealing with the problems; others were resigned to like with the situation for as long as it existed, believe that there was not much they could do. In agreement with the findings on resilience reported by Hussen et al. (2018), young HIV patients may see that their situation was a test; others believed themselves to be warriors for having survived and wanted to inspire others. The themes convey the complexities of their challenges and how they negatively affect their abilities to provide themselves the appropriate level of SCCM they require in dealing with their chronic illness. This emphasizes the need for a holistic approach in supporting them, one that includes their physical and mental health, as well as the engagement of their families and communities.

Health disparities and inadequate SCCM are related and could influence access to health-care clinics and receiving health-care interventions that could decrease the likelihood of developing AIDS or progressing to death (Swenderman et al., 2010). A synopsis of the literature showed that the marginalization of male AAYAs with HIV, who live in urban environments with limited access to health care, are underrepresented as relevant to receiving health care that allows them to manage their HIV (Filho, 2013; Marshall & Rossman, 2011). The literature also suggested that the Individual and Family Self-Management Theory (IFSMT) used to frame my research question can and add vital information to the body of scientific knowledge as relevant to SCCM for AAYAs (Filo, 2013; Greyet al., 2015; Ryan & Sawin, 2010). Husserl's phenomenological method for understanding an individual's lived experience as relevant to SCCM and providing first-hand information could guide developing a practical treatment approach to reduce the disparity and improve intervention programs to reach the vulnerable group (Tassone, 2017).

Overall, Ron, Charlie, Dave, Bobby, Ben, and Henry are products of an urban, marginal, disparate environment, where minorities with HIV need SCCM from peers and or family members that they trust. The IFSMT is a theory that posits a description of family relationships and demonstrates how families use collaboration and communication to share important information, which is essential in establishing effective relationships and SCCM within family dynamics. This makes SCCM an indispensable part of IFMT. Husserl's philosophy on phenomenology promotes exploring and understanding the lived experiences by a direct investigation by analyzing and units of consciousness and intentional experiences of the persons in question (Tassone, 2017). The IFSMT and Husserl's phenomenological method was used to guide the research methodology and interpret findings in my research. This approach focused primarily on the individuals while giving voice to their perspectives of their social support. According to the scientific conceptual frameworks, the results provided unique insight into the emotional and practical issues of coping with a long-term health issue that is unique to this group and adds to the body of the literature.

Limitations of the Study

Though the findings from this study were valuable, some limitations could affect its transferability beyond the participants. A possible limitation is related to the small sample size used in this study, as there were only six AAYAs interviewed, which was at the lowest end of the recommended range. Saturation, however, was met when I interviewed the six participants. With qualitative inquiries, the appropriateness of the sample depends on both the size and composition of the samples. The required sample size is smaller than quantitative analysis, as the validity issues are guaranteed not through statistical significance but the principles of saturation and trustworthiness. Given the specific scope of the study, the data collected for the AAYs responses sufficiently representative all of the critical topics and therefore considered to have generated thematic saturation.

While phenomenological research designs generally use small samples, their transferability depends on the richness and volume of information collected and intensive analysis of the data. In this study, the young men were open and honest; few were more forthcoming with their responses than others. Along with additional participants or the inclusion of other clinics, maybe subsequent follow-up interviews would have provided a greater volume of information. However, the accuracy, relevancy, and data support the information's density and, therefore, its transferability to similar contexts and populations, i.e., young African American young adults dealing with HIV-positive status.

The other limitation to findings was that errors might have been introduced by response or social desirability bias. The reactions of the AAYAs may have reflected what they thought I wanted to hear and not what was occurring in their lives. These young men have suffered the consequences previously, may have become guarded in what they said and how they said it to avoid the stigma of having HIV and gay. Using the open-ended question and simplifying and clarifying as much as possible while avoiding any assumptions and using the predetermined probes when required was helpful. This setting and the freedom to provide honest answers without any negative ramifications and the assurance of anonymity and security of their response, hopefully, ensured that the information provided was a sincere reflection and the findings are valid. However, the results of my qualitative study cannot be generalized because qualitative studies are not generalizable. Transferability is possible in qualitative studies, but my analysis showed that transferability might not be potential because my qualitative research design is specific to the participants in the sample. Because of this, my study findings may not be transferable to other chronic illnesses.

Despite all the precautions taken in the research methodology design and in the research process, limitations were not eliminated. An already challenging data collection process was further challenged by the COVID-19 pandemic. This made face-to-face interviews impossible and may have subconsciously exacerbated the levels of stress experience and that reported by the young men in the study. Any attempts at replicating this study at another time or another location may be challenged by the absence of the many known and unknown effects of the current pandemic. It should be noted that, like other qualitative studies, these findings were not analyzed statistically, and while there may be a correlation between the themes, causation is implied.

Recommendations

Research is needed to add to the body of knowledge on HIV and its effects on the lives of male AAYAs who are diagnosed with this chronic condition. A longitudinal study is needed to follow AAYAs for several years following diagnosis to determine how their physical, emotional, and social lives change over the years with this diagnosis. The respective roles of physical health and even economics have been widely explored as it relates to the lives of HIV patients. The less commonly studied issues highlighted in the findings in this study, as family support, mental health, and guilt, could be used as variables in the hypotheses for quantitative studies measuring patient health outcomes. These themes can also be used in studies related to the variation in the effectiveness of intervention strategies (Miller, 2010). My study could be used effectively to guide quantitative research. A quantitative study using valid, reliable instruments could examine the relationships between self-efficacy, locus of control, and their use of SSCM in managing their chronic conditions and the long-term outcome for the patients. Included in such as study could be variables such as age to quantify the differences in the teenagers' perceptions (18- & 19-year-olds) versus those of the young men in their twenties. A more extensive phenomenological study of male AAYAs could use participants from several clinics in urban and suburban areas to determine if socioeconomic status or neighborhood influences SCCM for these young men.

Implications

With the nature of health care changing to focus more on the whole person and collecting qualitative data, studies like this will become more critical to nursing research. The shift in focus to address the medical factors and include the non-medical factors of health, namely, the social determinant of health, is not new. More recently, however, the focus has been to, along with the individual's emotional and socioeconomic factors, acknowledge the role of their social environment. Studies such as this one that is based on FIMST and that include aspects of the subjects of SCCM bring sociodemographic to the forefront. This approach provides an advantage for exploring the lives of these disenfranchised groups in a way that is based on their lived experience and not on variables determined by the researcher to be significant (Gladstone, 2017; Grey et al., 2015; Napoleon).

As a Black female health care worker, I may have had an advantage in recruiting these young men, as they may have been more trusting of me to protect not just their identity but also the importance of their stories. However, the reverse may also be true, as they may unconsciously see me as representing the community that betrayed them, both professionally and societally. This dynamic, and others related to self-reporting, is worth exploring, comparing, and contrasting for different genders, races, and identities. However, the importance of proper training in ways to interact with, while leveraging technology and the virtual era, in collecting meaningful personal data from this most underrepresented, cannot be overstated (Kirkwood, 2016). Given the damaged relationship that some of these AAYAs already have with health professionals, all future interactions must be positive ones.

There is still a lot more research to be done and more information to be gathered about the SCCM of these AAYAs. For now, what they have shared will be of benefit to other young men like themselves, who feel forgotten, unheard, and devalued. The immediate implications include informing the health care community about their struggles. Hopefully, this will be translated into providing them with services appropriate to their physical, emotional, and financial needs. Beyond, this study may inspire other researchers to consider the powerful potential of phenomenological type investigations, which gives precedence to the human experience of the participants in their research. These types of studies can only answer questions about the emotional challenges faced by marginal groups such as these AAYAs. And given the opportunity, and under the right circumstances, as other researchers have found, they are more than willing to share (Latkin et al., 206; Peltzer, Domain, & Teel, 2015).

Positive Social Change

The implications for positive social change for a study such as this are manifold, potentially benefiting the AAYAs themselves, enlightening the family members and loved ones, and informing the health care professionals with whom they interact. Results of my study affect positive social change by guiding family members and peers with HIV in the ways that they can lend support to the AAYAs to help them better manage their illness through SCCM. It can also help their nurses establish an environment that is friendly and non-threatening to male AAYAs with HIV patients. Understanding the physical and emotional challenges they face and how their loved ones can make could bring about an effective joint effort between all involved. When parents or partners, or friends realize that the disease affects the patient's body and mind, they can be more compassionate in their attitude towards them. This could go a long way in minimizing some of the trauma of the stigma these young men live with daily.

The results of this study revealed that the young men in the AAYAs community face numerous challenges physical, emotional, and financial. The findings could guide the development of strategies that decrease the stigma of HIV and assist with disclosing their HIV status to friends and family members and affect collaborative communication between individuals (Ryan & Sawin, 2010). Improving the communication between family members and trusted peers could help increase the positive use of SCCM in

AAYAs with HIV. Additionally, protocols could be put in place to help the AAYAs improve medication adherence and other aspects of their SCCM. Different types of community support can be implemented for ongoing assessment of the services needed and those that are available and adequately promoted to assist male AAYAs with HIV. The consensus among the AAYAs interviewed is that they are peripherally aware of additional resources that could be utilized but that there were hurdles involved in know exactly what those services were and what was required in qualifying for them. Programs are needed that provide opportunities for AAYAs with HIV to talk about their lived experience while managing their chronic illness. This is where the nurses providing care can make a difference. The nursing community can implement these programs that educate the AAYAs and their loved ones and provide an outlet for them to share their concerns and be informed of available resources.

The findings of this study, though limited, are a meaningful insight into the lives of these AAYAs and the areas where the medical community, mainly the nursing community, could take the lead in effecting positive changes. Nurses have always been actively involved in improving the physical, mental, and social conditions of their patients. An example of the initiative of nurses includes devising plans for establishing support groups. That could serve as support groups for AAYAs with HIV. These ad hoc groups could consist of volunteer nurses, physicians, clergy, student nurses, med students, pharmacists, and an open invitation to AAYAs with HIV who reside within the community. Recruitment of individuals for this community-based participatory group will be implemented by posting flyers with monthly meeting dates and the purpose of the meeting. Locations of flyers were placed in schools, adolescent centers, stores, churches, and other areas of outreach that are accessible to the youth within the community. Incentives such as socks, gift certificates, and gift packages of food items and miscellaneous items could be offered to AAYAs for their participation in these monthly meetings. Participants who attend the monthly meetings will be trained on SCCM goals to outreach and educate their peers who have HIV. The nurse could collaborate with vaccine clinics, free food giveaway endeavors within the community, and other available sources within the community to advocate and provide easy access for the AAYAs with HIV. The nurse should also assess the demographics of the AAYA and include their family members and significant peers as collaborative resources for information if allowed.

A ripple effect throughout other urban and even suburban communities may result from the activist-type effort from the nursing community on behalf of the AAYAs. Nurses involved in community nursing know how to use their advocacy influence by networking and connecting with resource centers available within the urban community. Connecting with and being a member of community-based participatory research provides valuable support for this kind of outreach program. This includes programs, complimentary food giveaways, activity centers for exercise, free educational programs, and free clinics that give access to the community AAYAs (Neal, 2016). These synergistic efforts between nurses, family members, and other stakeholders and community leaders to form ad hoc committees for the purpose of advocating for the

AAYA with HIV and SCCM can effect significant positive social changes that improve the lives of the AAYAs and strengthen the community in which they live.

Conclusion

The challenges faced by male AAYAs with HIV, primarily related to their lived experience of SCCM, manifest in several different ways. Providing them with a platform to voice their experiences is a vital part of the approach to solving these challenges. Being allowed to talk about daily problems encountered may provide self-empowerment, increased knowledge, increased self-esteem, independence, and a sense of well-being for the AAYA man with HIV and his SCCM. The opportunity to share personal experiences with their friends and family members, their peers who also have HIV, and other community members is still lacking. The AAYA man with HIV still can live a fulfilling life and a voice in how they can best meet their SCCM needs. Research, documenting, and analyzing reports of their lived experiences are paramount for exploring and understanding how the AAYA man copes with the condition and how it can be improved. The findings of this study emphasize the need for a supportive social network for providing for their economic needs, for assistance with optimizing their physical health, and for minimizing the mental trauma of their social stigma. It also highlights the need for increased research in this arena that may optimally impact public health policies that deal with marginal minorities who, like so many others, bear the burden of health disparities resulting from their racial or sexual orientation, or both compounded by their HIV status.

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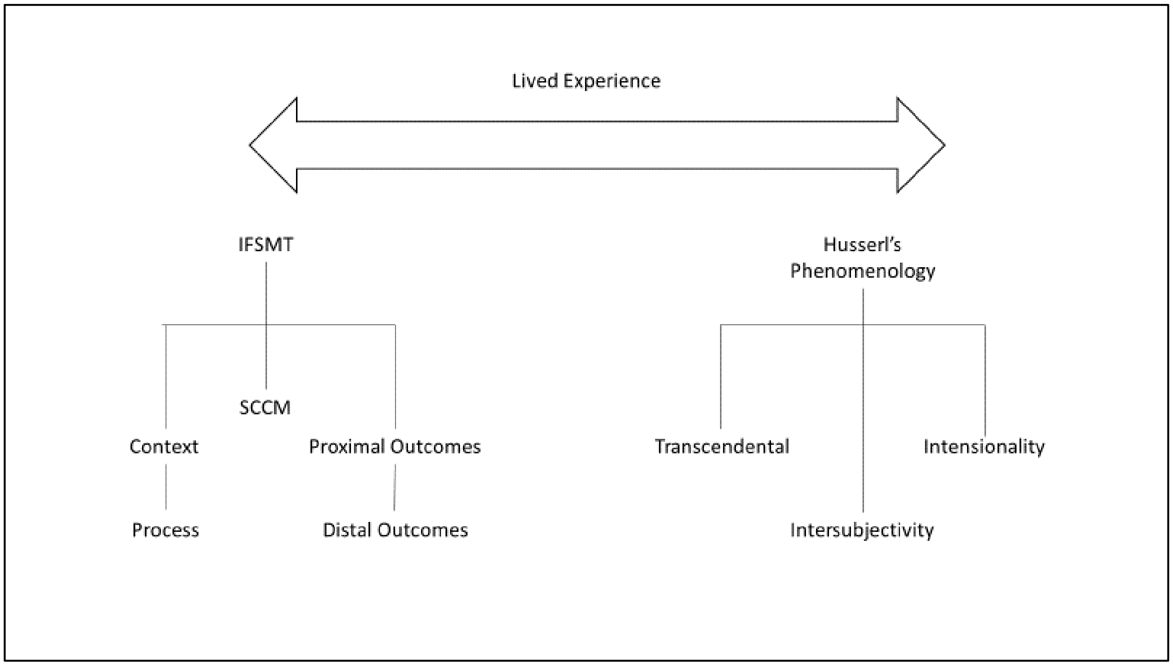
Appendix A: Comparison of Phenomenology Models



Appendix B: Interview Guide

Interview Question

What is the lived experience of AAYAs with HIV and SCCM?

Possible Interview Prompts:

1. Tell me about your day?
2. Tell me what information your family members/peers with HIV give you to help you manage your illness?