Walden University

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Lisa Connors

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Walden University
2023

Abstract

Psychological Distress Following Disenfranchised Grief and Social Support Loss in African American Women Living With HIV

by

Lisa Connors

MA, Liberty University, 2010

MDiv, Howard University, 2006

BSW, University of North Carolina at Greensboro, 1989

Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy
General Psychology (Educational)

Walden University

November 2023

Abstract

Psychological distress can have lasting effects on African American women living with HIV. Research on African American women experiencing psychological distress (anxiety and depression) and living with HIV has focused on coping strategies, religious coping, medical adherence, and quality of life. African American women experiencing psychological distress due to their HIV diagnosis and status may also experience disenfranchised grief and social support loss. This quantitative study determined the extent to which disenfranchised grief and social support loss predicted psychological distress among African American women living with HIV. The integrative theory of bereavement and chronic sorrow theory served as the theoretical foundation. Participants ($N = 70$) completed an online survey using SurveyMonkey. Standard multiple regression analyses were used to evaluate the relative strength of disenfranchised grief and social support loss in predicting psychological distress (anxiety and depression). Results demonstrated that disenfranchised grief and social support loss (family, friends, and significant others) did not significantly predict psychological distress (anxiety and depression) among African American women with HIV. Although the findings in the current study did not demonstrate a predictive relationship between the variables, the theories offer insight for bereaved individuals living with HIV. The results of this study may lead to positive social change by providing information to grief counselors, psychologists, and other advocates to effectively serve African American women living with HIV.

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Dedication

I dedicate this journey to my Heavenly Father- Almighty God. Without my Heavenly Father, there would be no me. It is only by God's grace and mercy. I am truly grateful. Through the love of God, I have learned that God never gives up on you if we allow him to guide us. To my spiritual father and soulmate, Dr. James Connors, and my darling children, Kentrel, Kenterra, Kenton, Kenturah, daughter-in-love, Audrey, and grandchildren, AJ and Aiyanna.

To those not here in body yet are here in spirit, I would also like to dedicate this journey to my ancestors, who paved the way for me. To my beloved grandparents, George and Lucille Hay Goodwine, who never gave up on me and encouraged me throughout my life. Without them, I would not be here. I love you for loving me. To my godmothers, Elsie Madden, and Eliza Williams, what more can I say about you? You took me in and took care of me. You showered me with your love. This dedication is also to my "pops" William "Bobby" Little, who never lied to me, who was always "real" with me, and who never judged me. I love you for being who you were and am grateful for your life and love. To my mother and father-in-love, Lenora, and George Snyder, thank you for sharing your son with me and loving everyone, including me, to my beloved fur-baby, Marley, who was always a constant in my world. I miss all of you, and I know you are proud and looking down on me. I love you ALL!

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The journey took work. Yet, I am thankful for all who played a role in my journey. Your names may not be called. Yet, you know who you are. I am reminded of two scriptures for those coming after me on this journey. 2 Chronicles 15:7 (NIV) says: "But as for you, be strong and do not give up, for your work will be rewarded." Galatians 6:9 (ESV) says: "And let us not grow weary of doing good, for in due season we will reap, if we do not give up."

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Chapter 1: Introduction to the Study

Introduction

African American women are disproportionally infected with HIV (Dale et al., 2018). It is the leading cause of death for African American women between the ages of 24 and 35 (Dale et al., 2018). African American women continue to experience adversities and struggles, such as discrimination, racism, violence, sexual victimization, lower socioeconomic status, residential segregation, and poverty (Dale et al., 2018; Peltzer et al., 2017). Because these issues and problems are burdensome, some individuals forego HIV testing, diagnosis, care, treatment, and management, leading to stigma, disclosure, and psychological distress (Dale et al., 2018; Peltzer et al., 2017). The focus of this study was to determine the relationship between disenfranchised grief, social support loss, and psychological distress among African American women living with HIV. More specifically, I examined disenfranchised grief (loss that cannot be openly acknowledged, socially validated, or publicly mourned) and social support loss (family, friends, and significant others) among African American women living with HIV.

HIV public prevention messaging typically does not consider or acknowledge poverty, institutional racism, disenfranchisement, and gender inequality in the disproportionate numbers of HIV infections among African American women (Gilbert & Goddard, 2007; Peltzer et al., 2016). Research has shown that African American women living with HIV contend with numerous social stressors. Those social stressors include drug use, crime, unemployment, and stigma and discrimination from family, friends, potential sexual partners, and their communities. They also deal with side effects from

HIV medications and increased impact of possible coinfections that may also impact the physical and psychological well-being of individuals living with HIV (Braxton et al., 2007; Dale et al., 2018; Feist-Price & Wright, 2003; Hickman et al., 2013; Hoover et al., 2016; Katz et al., 2013; Peltzer et al., 2016; Phillips et al., 2011; Steward et al., 2008; Watkins-Hayes et al., 2012).

This study expanded the literature on disenfranchised grief (loss that cannot be openly acknowledged, socially validated, or publicly mourned), social support loss (friends, family, and significant others), and psychological distress (anxiety and depression) literature among African American women diagnosed and living with HIV/AIDS. The results from this study may also impact positive social change by informing the development of services to promote bereavement, grief, loss, and psychosocial support to African American women living with HIV. The effects of positive social change include a better understanding of the need for innovative practices to best serve African American women living with HIV as they are grieving their diagnosis and losses. The study results may be used to inform psychologists, counselors, and HIV services and programs for African American women living with HIV.

In this chapter, I review the background of this study and explain the problem. The purpose of the study, along with the research questions, is outlined. An introduction to the integrative bereavement and chronic sorrow theories is provided as the theoretical foundation of the study. The nature of the study, definitions, assumptions, scope and delimitations, limitations, and significance of the study are discussed.

Background

Human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) has impacted the lives of African American women. They account for most new HIV infections, with 66% of the cases being among African American women. (Brawner, 2014; Centers for Disease Control and Prevention [CDC], 2007, 2011, 2018a; Mahadevan et al., 2014; Wolitski, 2018; Wyatt, 2009). When one looks at the diagnosis of HIV/AIDS among African American women, with the primary mode of transmission being heterosexual contact, they are disproportionately affected and diagnosed with HIV at higher rates compared to White and Hispanic/Latina women (Brawner, 2014; CDC, 2018a; Mahadevan et al., 2014; Wyatt, 2009).

In 2016, 4,560 African American women received an HIV diagnosis, compared with 1,450 White women and 1,168 Hispanic/Latina women, representing 61% of HIV diagnoses among all women in the United States that year (CDC, 2018a, 2018b; Wolitski, 2018). Thus, African American women continue to be the fastest growing population infected with and affected by HIV (Rose et al., 2008; Wolitski, 2018; Wyatt, 2009). Black/African American women are still disproportionately affected by HIV compared with other races/ethnicities. Of the total number of women living with and diagnosed with HIV at the end of 2015, 59% were African American, 19% were Hispanic/Latina, and 17% were White (CDC, 2018b). The rate of new HIV infections among African American women is 20 times greater when compared to White women and 5 times greater when compared to Hispanic women (Brawner, 2014; Mahadevan et al., 2014).

Medical advances in HIV care and treatment promote greater life expectancy among individuals living with HIV. Despite these advances and successes, HIV was still the third leading cause of death among African American women between the ages of 25 and 44 in 2007 and the leading cause of death of African American women between 24 and 35 (Peltzer et al., 2016). The results from this study may be used to improve the efficacy of HIV programs and counseling services when working with African American women living with HIV.

Problem Statement

HIV prevention messages have mainly focused on gay White men. Those messages have not considered how poverty, institutional racism, a biased criminal justice system, and gender inequality contributed to disproportionate HIV infections among African American women (Gilbert & Goddard, 2007; Peltzer et al., 2016). When epidemiologists understood the impact of HIV/AIDS among African American women, researchers developed prevention programs to build gender and ethnic pride, promote condom use, link persons living with HIV to care, retain and re-engage them in care, and help them achieve viral suppression (CDC, 2017; Gilbert & Goddard, 2007). These programs included Healthy Love, Sisters Informing Sisters on Topics about AIDS (SISTA), Sister to Sister, and Women Involved in Life Learning from Other Women (WILLOW; CDC, 2017). In addition to the challenges of living with a chronic, life-altering, and debilitating disease, African American women have had to contend with numerous social stressors such as drug use, crime, discrimination, and unemployment (Armistead et al., 1999). Because of highly active antiretroviral therapy (HAART) and medical advances in HIV care and treatment, researchers have concluded that individuals living with HIV are experiencing greater life expectancy (Bottonari & Stepleman, 2009; Smith et al., 2015).

The diagnosis of HIV is emotionally unpredictable, and it has been associated with substantial mental stress and psychiatric morbidity (Hickman et al., 2013; Serovich et al., 2012; Vyavaharkar et al., 2011). Those diagnosed with HIV may face abandonment, ostracism, and secrecy (Corless, 1997; Peltzer et al., 2016; Vyavaharkar et al., 2011). African American women may find it challenging to disclose their status to family, friends, and partners (Serovich et al., 2012; Vyavaharkar et al., 2011). They may not obtain social support, which is an essential resource for effectively coping with HIV disease and possibly minimizing psychological distress (Vyavaharkar et al., 2011). Having judgmental interactions and a lack of support can lead to nondisclosure, withdrawal from social networks, and social isolation (Vyavaharkar et al., 2011). The transformation of HIV into a chronic disease does not prevent African American women from dealing with the shock, psychological stress, and depression of being diagnosed and living with this disease (Vyavaharkar et al., 2011). The ordeal of coping with the trauma and mental stress associated with an HIV diagnosis may dictate a woman's decision about when and to whom to disclose her illness (Armistead et al., 1999). Being diagnosed with HIV also carries a more substantial burden of stigma when compared to other chronic conditions and diseases and has resulted in high levels of social isolation (Smith et al., 2015). The reluctance to disclose African American women's positive status can result in fear of stigma and discrimination, leading to social withdrawal and isolation (Vyavaharkar et al., 2011).

Heterosexual women living with HIV and in long-term relationships are often inhibited or denied the opportunity to acknowledge or grieve their illness (Corless, 1997). The loss of health through sickness or disease is devastating (Pillai-Friedman & Ashline, 2014). Grieving the loss of health and possibly death may facilitate emotional responses, including numbness, denial, pain, frustration, anger, depression, anxiety, fear, helplessness, hopelessness, sadness, loneliness, powerlessness, regret, remorse, never-ending uncertainty, and suicidal thoughts (Peters, 2013). The grieving process becomes more challenging when included with shame, self-blame, secrecy, social stigma, humiliation, other losses, physical declines, and medical treatments (Norris & DeMarco, 2005; Peters, 2013; Winston, 2003).

Pillai-Friedman and Ashline (2014) stated that many breast cancer survivors experienced a lack of acknowledgment or ambiguity surrounding their illness, resulting in disenfranchised grief. Disenfranchised grief is a loss that cannot be openly acknowledged, socially validated, or publicly mourned (Mortell, 2015; Pillai-Friedman & Ashline, 2014; Spidell et al., 2011). Many individuals living with a chronic illness associate loss with death, thus forgetting the grieving process for chronic illnesses and diseases. Individuals often desire to express their loss, thus allowing them an opportunity to accept it and help others understand what they were experiencing (Pillai-Friedman & Ashline, 2014). The loss, lack of expression, and validation often lead to disenfranchised grief (St. Clair, 2013).

African American women are more likely to conceal their feelings of being diagnosed with HIV than their White counterparts (Hickman et al., 2013). This concealment is often due to being stigmatized, the uncertainty about the reactions of others, and the significant impact that disclosing an HIV diagnosis can have on relationships (Corless, 1997; Hickman et al., 2013; Serovich et al., 2007). Not acknowledging their grief and feelings is evident when African American women fail to share or disclose their disease (Winston, 2003). Individuals living with HIV may display disenfranchised grief because of shame, embarrassment, and guilt (Winston, 2003). African American women often feel alone without sharing their diagnoses, experiences, and feelings (Peltzer et al., 2016). African American women may also find that disclosing their HIV status can exacerbate other factors, such as stigma and discrimination, without coping resources available to support them (Corless, 1997; Vyavaharkar et al., 2011; Watkins-Hayes et al., 2012). In some instances, communities of faith or religious institutions may also ostracize individuals living with HIV due to lifestyle issues or stigma (Cotton et al., 2006).

Stigma is a common barrier for managing and treating HIV (Reinius et al., 2017; Steward et al., 2008). Stigma can prevent individuals living with HIV from disclosing their infection (Steward et al., 2008). HIV stigma is socially shared knowledge about the devalued status of people living with HIV. It is manifested in prejudice, discounting, discrediting, and discrimination directed at people perceived to have HIV and the individuals, groups, and communities they are associated with (Jeyaseelan et al., 2013;

Lindberg et al., 2014; Steward et al., 2008). HIV-related stigma is prevalent, affecting the quality of life of individuals living with HIV (Reinius et al., 2017).

Disclosing a chronic and life-threatening illness such as HIV can sometimes lead to adverse changes in an individual's relationships and health (Norris & DeMarco, 2005). Disclosing one's HIV status can also result in stress and cause an internal struggle with how family, friends, and partners may react (Serovich et al., 2012; Sowell et al., 2003). Psychological support and disclosure can give African American women a platform to share their diagnosis and openly grieve without the fear and shame of concealing it (Vyavaharkar et al., 2011). When there is a lack of support, negativity, judgment, and unsupportive people and relationships, women often choose to hide their diagnosis for fear of isolation, discrimination, and rejection (Vyavaharkar et al., 2011). African American women who disclose their HIV status facilitate supportive care and resources in managing the disease by increasing access to medical care and social support (Antoni et al., 2008; Armistead et al., 1999; Serovich et al., 2012; Vyavaharkar et al., 2011).

Religion has also played a role in helping African American women disclose their HIV status (Smith et al., 2015). It has assisted women in coping and living with HIV, and the disclosure of their condition has decreased stress and reduced stigma (Smith et al., 2015). Studies have shown that African American women may experience distress, primarily related to HIV disclosure (Armistead et al., 1999; Comer, 2000; Corless, 1999; Hickman et al., 2013; Serovich et al., 2012; Vyavaharkar et al., 2011). Research also suggests that HIV disclosure results in higher levels of perceived stress and depression (Armistead et al., 1999; Hickman et al., 2013; Jones et al., 2003; Lichtenstein et al., 2002;

Lopez et al., 2012; Prachakul et al., 2007; Vyavaharkar et al., 2011). The lack of disclosure often comes from African American women's roles as matriarchs in families and the belief that African American women are strong and resilient women, in addition to African American women's spiritual values that include faith, prayer, and church connections (McGoldrick et al., 2005; Smith et al., 2015). The ability to openly grieve can become more complex with the strain of health loss and the loss of relationship social support contributing to psychological distress (Corless, 1997).

Disclosing one's status may give women some relief because they no longer need a secret diagnosis. Disclosure facilitates a reduction in depression symptoms as a result of increased opportunities for social support. These findings suggest that self-disclosure and positive coping can be helpful for African American women as they are dealing with psychological distress associated with HIV diagnosis (Peltzer et al., 2016; Peltzer et al., 2017).

Purpose of the Study

The purpose of this quantitative study was to explore the extent to which disenfranchised grief and social support loss (family, friends, and significant others) predict psychological distress (anxiety and depression) among African American women living with HIV. The results from this study may be incorporated into HIV programs that provide HIV care, treatment, and services to women living with HIV.

Research Questions and Hypotheses

The following research questions guided the study:

RQ1: To what extent does disenfranchised grief, as measured by the Witnessing of Disenfranchised Grief scale, relate to psychological distress (anxiety and depression subscales), as measured by the Depression, Anxiety, Stress Scales (DASS-21), in HIV-positive African American women?

H_o: Disenfranchised grief is not a significant predictor of psychological distress.

H_a: Disenfranchised grief is a significant predictor of psychological distress.

RQ2: To what extent does social support loss (family, friends, and significant others' subscales), as measured by the Multidimensional Scale of Perceived Social Support, relate to psychological distress (anxiety and depression subscales), as measured by the Depression, Anxiety, Stress Scales (DASS-21), in HIV-positive African American women?

H_o: Social support loss is not a significant predictor of psychological distress.

H_a: Social support loss is a significant predictor of psychological distress.

Theoretical Framework

Two theoretical frameworks that informed my study were Sander's (Cherney & Verhey, 1996, Sanders, 1999) integrative theory of bereavement and the theory of chronic sorrow (Ahlstrom, 2007; Burke et al., 1999; Lichtenstein et al., 2002). Sander's integrative theory of bereavement contends that individuals move through five phases of bereavement, including shock, awareness of loss, conservation-withdrawal, healing, and renewal (Cherney & Verhey, 1996; Sanders, 1999). The integrative theory of bereavement also motivates and encourages individuals to move through the five phases of bereavement (Cherney & Verhey, 1996; Sanders, 1999). This theory aligned with my research because the integrative theory of bereavement includes phases regarding losses (Sanders, 1999).

The theory of chronic sorrow focuses on recurring losses associated with chronic diseases (Ahlstrom, 2007; Burke et al., 1999). These losses may include control, status, social roles, independence, and identity as a healthy person (Ahlstrom, 2007). This theory addresses episodes of sorrow associated with the diagnosis of chronic disease (Ahlstrom, 2007). This theory aligned with my research, as women diagnosed with HIV experience recurring losses, such as health, relationships, and identity. A more detailed explanation of Sander's integrative theory of bereavement and chronic sorrow theory is presented in Chapter 2.

Nature of the Study

The nature of this study was a nonexperimental quantitative design using survey methodology to examine the extent to which disenfranchised grief and social support loss predict psychological distress among African American women being diagnosed and living with HIV. The research design was appropriate because the goal of this study was to examine the extent to which each independent variable (IV) predicts psychological distress. The IVs/predictors included disenfranchised grief and social support loss (family, friends, and significant others). The dependent/criterion variables were components of psychological distress (anxiety and depression). Data were collected online via self-report instruments completed by African American women 18 years of age or older living with HIV for a year or more. Standard multiple regression was used to evaluate the hypotheses.

Definitions

Human immunodeficiency virus (HIV): HIV is a virus that attacks and destroys the body's immune system. The immune system gives bodies the ability to fight infections (Berger, 2005; CDC, 2021). When the body's immune system is weakened, it has difficulty fighting off certain conditions (American Sexual Health Association [ASHA], 2021). HIV destroys an individual's white blood cells (T cells or CD4 cells), an essential component of an individual's immune system, and it is the virus that causes AIDS (CDC, 2021).

Acquired immunodeficiency syndrome (AIDS): AIDS is the final stage of HIV infection, and it stems from an individual having HIV. It can take many years for an individual to reach this stage (CDC, 2021). The CDC criteria constitute an AIDS diagnosis when individuals have an opportunistic infection, certain cancers, and a low T cell count, they are usually diagnosed with AIDS (CDC, 2021).

Bereavement: Bereavement refers to the experience of a loss of someone close, to which a person is trying to adapt (Worden, 2018).

Chronic sorrow: Chronic sorrow is a healthy, nonpathological state of pervasive, continuing, periodic, and resurgent sadness related to ongoing losses associated with illness and disability (Weingarten, 2012).

Disclosure: Disclosure is the process of revealing a person's HIV status, whether positive or negative (Obermeyer et al., 2011).

Disclosure concerns: Disclosure concerns relate to keeping one’s HIV status secret or controlling who knows (Berger et al., 2001).

Disenfranchised grief: Disenfranchised grief is grief experienced due to a loss that cannot be openly acknowledged, socially validated, or publicly mourned (Corr, 2002; Doka, 2002a; St. Clair, 2013).

Psychological distress: The unique, discomforting emotional state experienced by an individual in response to a specific stressor or demand that results in harm, either temporary or permanent, to the person. It also encompasses depression, anger, sadness, and other negative thoughts and emotions (Peltzer et al., 2017).

Social support: Interpersonal transactions between individuals that foster positive adjustments when dealing with problems (Owens, 2003).

Witnessing disenfranchised grief: The degree to which someone grieving a loss perceives that their grief was witnessed. Witnessing disenfranchised grief also refers to when someone acknowledges the loss and the right of the griever to grieve (St. Clair, 2013).

Assumptions

It was assumed that all participants would meet the criteria for the study and provide honest responses to the survey questions. Due to the stigma of HIV, it was possible that some individuals might not volunteer to participate. However, participants were recruited from support groups and were more willing to share their experiences of living with HIV. In addition, it was assumed that participants experiencing psychological distress would not refrain from participating in the study. Because a convenience sample was used, individuals experiencing psychological distress may have been reluctant to participate or provide honest responses. However, participants were told that the data would be anonymous to help ensure that they were comfortable providing honest answers.

Scope and Delimitation

This study examined the extent to which disenfranchised grief and social support loss predict psychological distress among African American women living with HIV. This study included African American women diagnosed and living with HIV for at least a year. I did not examine women diagnosed for less than a year or women whose experiences had changed over time following their diagnosis. In addition, several factors can influence psychological distress that was not measured with the surveys. Disenfranchised grief and social support loss are not the only variables that might affect psychological distress due to living with HIV. Finally, the mode of transmission was not considered for this study due to the sensitivity of the subject and potential difficulty in recruiting participants.

Limitations

There were several limitations to this study. I focused only on African American women and no other racial and ethnic groups. The purpose of the study was to focus on African American women; therefore, the results may not generalize to other racial/ethnic groups. The use of convenience sampling also limited the representativeness and generalizability of the results. Individuals who belong to HIV support groups may not be representative of the population or those who do not use support groups. However, recruiting participants from online support groups may have allowed for a broader, more diverse sample of African American women.

There are also limitations with survey methodology. Social desirability bias may occur with participants responding to questions in a manner that will represent them favorably. However, participants were informed that the survey was anonymous, which should have reduced that type of response bias. Another limitation was related to research bias. I have had family members who were diagnosed with and lived with HIV; I have worked with African American women living with HIV for many years, and I facilitate an HIV support group for African American women living with HIV. To address possible bias, invitations to participate in the study was sent to the Maryland State Health Department serving African Americans living with HIV and a national organization serving women living with HIV, which oversees a Facebook support group. I addressed bias by using reliable and valid instruments to measure the constructs, thus limiting bias. Participants who volunteered received a link to SurveyMonkey that included an introduction letter and informed consent. I did not have any direct contact with the participants.

Significance

This study expanded the literature related to factors that may contribute to psychological distress among African American women living with HIV. More specifically, the findings from this research expanded the literature regarding the relationship among disenfranchised grief, social support loss, and psychological distress among African American women living with HIV. In a society where HIV is categorized as a chronic disease, individuals are still labeled, stigmatized, and isolated because of their diagnosis (Corless, 1997; Serovich et al., 2007; Serovich et al., 2012; Smith et al., 2015). African American women who have become infected because of drug use and unsafe sexual practices may be blamed because of their choices with the possibility of those choices leading to their infection (Serovich et al., 2007; Serovich et al., 2012; Vyavaharkar et al., 2011).

The results of this study may lead to positive social change by providing information to help grief counselors, psychologists, and other advocates effectively serve African American women experiencing HIV. Understanding African American women's reservation to grieve their diagnosis and seek psychological support and services will potentially give professionals ways to create programs that specifically benefit them physically, emotionally, and spiritually (Brawner, 2014; Laurie & Neimeyer, 2008; Peters, 2013). In addition, understanding the effects of psychological distress in African American women living with HIV makes it possible to provide adequate support by giving them safer spaces to grieve their diagnosis and disclose their statuses, thus minimizing the psychological distress experienced in their lives.

Summary

African American women continue to be disproportionately infected with and affected by HIV. Statistical data suggest that African American women continue to be diagnosed with HIV at higher rates than White and Hispanic/Latina women. Because of their HIV status, African American women often find it hard to grieve their diagnosis, which interferes with their psychological and mental well-being. When stigma, the inability to disclose their status, and lack of social support are present, African American women will decline HIV testing, care, and treatment, leading to adverse changes affecting their relationships and health. Some of those adverse changes can be grief, stigma, lack of support, and the trauma of HIV, which can potentially foster psychological distress. To this end, the study used an nonexperimental quantitative design by administering an Internet-based survey utilizing the SurveyMonkey platform. Understanding the relationship between disenfranchised grief, social support loss, stigma, and psychological distress may help HIV programs develop culturally tailored support groups to combat African American women's challenges while living with HIV. In Chapter 2, I review the integrative theory of bereavement and the chronic sorrow theory to explain how the approaches align with grief, loss, and chronic illness. Some positive and negative outcomes will be discussed, along with factors that predict psychological distress resulting from disenfranchised grief and social support loss. Chapter 2 includes an exhaustive review of the literature related to key variables. Specifically, I will discuss the impact of HIV/AIDS on African American women and review the empirical literature on HIV/AIDS and stigma, disclosure, distress, grief, and social support. Finally, I will discuss the importance of disenfranchised grief.

Chapter 2: Literature Review

Introduction

This study explored the extent to which disenfranchised grief and social support loss (family, friends, and significant others) predict psychological distress (anxiety and depression) among African American women living with HIV. Research on African American women experiencing psychological distress (anxiety and depression) and living with HIV has mainly focused on coping strategies, religious coping, medical adherence, and quality of life (Braxton et al., 2007; Dalmida et al., 2013; Grimsley, 2006; Hickman et al., 2013; Lorenz et al., 2005; Peltzer et al., 2016). There is a gap in the literature regarding the extent to which disenfranchised grief and social support loss predict psychological distress among African American women living with HIV.

In the early years of the HIV/AIDS epidemic, few women were diagnosed with HIV and AIDS (King et al., 2008). Prevention messages targeted gay, White men and failed to acknowledge how poverty, institutional racism, a biased criminal justice system, disenfranchisement, and gender inequality contributed to the disproportionate numbers of HIV infections among African American women (Gilbert & Goddard, 2007; Peltzer et al., 2016). When the epidemiology was understood, culturally tailored and high-impact prevention programs were developed by the CDC (2017) to build gender and ethnic pride, promote condom use, and link HIV-positive individuals to care, retain and reengage them in care, and help them achieve viral suppression (Gilbert & Goddard, 2007). Some of these programs are Healthy Love, SISTA, Sister to Sister, and Women Involved in Life Learning from Other Women (CDC, 2017). Regardless of such programs, African American women still contend with numerous social stressors. Those social stressors include drug use, crime, discrimination, and unemployment, making it more challenging and unbearable to deal with and manage the diagnosis of a chronic, life-altering, debilitating, and potentially fatal disease (Armistead et al., 1999).

With highly active antiretroviral therapy, Bottonari and Stepleman (2009) asserted that an HIV diagnosis was not necessarily a death sentence and individuals living with HIV were experiencing greater life expectancy**.** Despite advances in HIV medication and greater life expectancy, a number of studies have posited that being diagnosed or living with HIV is still traumatic, leading to challenges and adverse outcomes (Braxton et al., 2007; Feist-Price & Wright, 2003; Hickman et al., 2013; Peltzer et al., 2016; Phillips et al., 2011; Smith et al., 2015). Those outcomes include the loss of meaning in life, the lack of formulating intimate partnerships, discrimination, poor health, isolation, depression, mortality, opportunistic infections, secondary HIV transmission, reduced antiretroviral medication adherence, and virologic failure.

Stigma and discrimination by family, friends, potential sexual partners, and communities; internalized stigma; side effects from HIV medications; and increased impact of possible coinfections may also play a role in impacting the physical and psychological well-being of individuals living with HIV (Braxton et al., 2007; Dale et al., 2018; Feist-Price & Wright, 2003; Hickman et al., 2013; Hoover et al., 2016; Katz et al., 2013; Peltzer et al., 2016; Phillips et al., 2011; Steward et al., 2008, Watkins-Hayes et al., 2012). Even with these challenges and adverse outcomes, African American women living with HIV have attempted to find meaning in their lives through narratives, self-awareness, self-efficacy, mindfulness and empowerment interventions, compassionate family members, caring clinical staff, psychological support services, and active community outreach from HIV support organizations (Bottonari & Stepleman, 2009; Brody et al., 2016; Russell et al., 2016).

The purpose of this study was to examine the extent to which disenfranchised grief, social support loss (family, friends, and significant others), and stigma (personalized stigma, disclosure concerns, negative self-image, concern with public attitudes) predict psychological distress (anxiety and depression) among African American women living with HIV. In this chapter, I describe the literature search strategy followed by a discussion of the theoretical frameworks that supported this study (i.e., the integrative theory of bereavement and theory of chronic sorrow). The literature review begins with a discussion of the impact of HIV/AIDS on African American women, followed by a review of the literature on HIV and stigma, disclosure, psychological distress, grief, and social support. The chapter concludes with a discussion of the significance of disenfranchised grief.

Literature Search Strategy

A search of literature consisted of online web research, Google Scholar, online library searches, and databases including PsycINFO, PsycARTICLES, SocINDEX, CINAHL Plus, MEDLine, ProQuest, and PubMed. Government websites included the CDC and HIV.gov. The focus of the literature review reflects peer-reviewed research conducted from 2010 to the present. Search terms for the literature review included the following keywords: *HIV/AIDS HIV statistics*, *HIV-related stigma*, *HIV stigma*, *HIV/AIDS*, *AIDS*, *HIV positive women*, *HIV positive African American women*, *HIV positive Black women*, *African American women*, *Black women*, *integrative theory of bereavement*, *chronic sorrow*, *chronic illness*, *chronic disease*, *social support*, *HIV disclosure*, *psychological distress*, *grief*, *loss*, *bereavement*, and *disenfranchised grief.* The articles reviewed for this study were obtained digitally.

Theoretical Foundation

Sanders' Integrative Theory of Bereavement

Sanders' integrative theory of bereavement developed in 1989 as an extension of Cannon's fight-flight theory, which addresses the psychological, physical, and behavioral responses exhibited in grief (Sanders, 1999). While Cannon's flight-fight theory suggests that a single physiological response is made that contributes to the changes in body function, Sanders' theory indicates that there are psychological forces that operate during the process of grief and has a biological premise that determines the physical well-being of an individual. It provides a basis for the characteristic, initial, and overt response of bereavement. Sanders' integrative theory of bereavement suggests that individuals move through five phases of bereavement: shock, awareness of loss, conservation-withdrawal, healing, and renewal. The theory motivates and encourages individuals to move through the phases of bereavement to facilitate psychological, physical, and behavioral change. This movement during the grief process can be seen as a progression toward homeostasis, resolution, adaptability, and growth (Sanders, 1999). The following sections describe each phase in detail.

During the first phase of Sanders' theory, individuals move in a confused state of disbelief and experience an intense state of alarm. Individuals experience numbness that protects them from intense pain, comparable to adrenaline acting like a self-induced drug. Although shock gives them the ability to go through loss, they can revert to the first phase when confronted with a new loss (Sanders, 1999).

In the second phase, individuals experience the awareness of loss, which forces them to face the reality of their loss (Sanders, 1999). As the numbness of Phase 1 fades, bereaved individuals must come to grips with the loss that has taken place. Also in this phase, individuals expend excessive energy (including crying, angry outbursts, and sleep disturbances) that magnifies the long-lasting stress, which in turn weakens the immune system. This is particularly important for individuals with HIV/AIDS because of the complications associated with a compromised immune system.

The third phase is conservation-withdrawal, during which individuals need to conserve energy (Sanders, 1999). Sanders posited that individuals might feel tired and depressed. They may experience despair, along with feelings of hopelessness and a sense of losing control of everything: life, desires, hopes, and dreams (Sanders, 1999). Sanders suggested that grievers believe that they can do nothing more and that nothing will ever matter again. The first two phases of grief are intense. They leave individuals open to infections and autoimmune diseases, severely compromising the immune system (Sanders, 1999). The conservation-withdrawal phase is a turning point for bereaved individuals. Sanders contended that individuals begin to see new approaches by forming new relationships and rebuilding a life. Additionally, individuals' grief work depends on accepting the loss and consequent changes in their life. The outcome is the redemption of strength and individuals discovering the motivation to move on and move forward to the next phase. Individuals invite healing, with the turning point being the determination to survive and change (Sanders, 1999).

In the fourth phase of healing, individuals gather strength to move forward and recognize the possibility of a new life. Although the process is sporadic and slow, individuals begin to take control and shape their lives in new and different ways (Sanders, 1999). Bereaved individuals gain motivation to develop a new identity by relinquishing old roles and building new ones, forming new ties, and finding new friends and lifestyles. Sanders contended that hope formulates in the fourth phase, and individuals move into the final phase of bereavement.

There is a renewal in the fifth and final phase, where individuals’ pain subsides and they are not the same person as before the loss (Sanders, 1999). Sanders posited that accepting responsibility for oneself lends to the strength necessary to try new things, meet new friends, and begin creating a lifestyle in which emotional needs are met. Bereaved individuals may find it challenging to accept responsibility but soon realize they must take matters into their own hands. When faced with life experiences, individuals develop a new sense of vitality, resulting in the potential to develop into stronger and more confident people than before. While despair has been felt and lifted in the third phase, individuals can move toward a renewed feeling of functional stability (Sanders, 1999).

Cherney and Verhey (1996) applied Sander’s theory to examine the relationship between the number of losses experienced and the intensity of grief among gay men whose HIV status was negative or unknown. Specifically, they examined the relationship between the social and demographic variables (age, educational level, weekly use of alcohol and recreational drugs, weekly use of sedatives, and loss of committed partners) and the intensity of the grief response (anger/hostility, despair, rumination, social isolation, and somatization). Findings revealed that the impact of the loss was mediated through the interaction of specific internal characteristics (age, health, dependency behaviors) and external and situational factors (social support, concurrent crises, stigmatic death, socioeconomic status) of the bereaved as posed by Sander's theory. The external and situational factors lead to the grief process having a significant effect on grieving individuals.

In terms of social and demographic variables, findings revealed that a higher level of education was associated with lower intensity levels on the rumination and somatization subscales (Cherney & Verhey, 1999). These findings suggest that individuals with higher levels of education may be more equipped cognitively to navigate the bereavement process and move through the phases of grief. In relation to alcohol, recreational drug, and sedative use, findings revealed a positive correlation between the number of losses and alcohol and drug use. Participants reporting a loss of a committed partner scored higher in intensity on the rumination and somatization subscales than individuals who did not lose a committed partner. In contrast, participants not in a committed relationship scored higher in the intensity of grief on the despair and social isolation subscales than those who were in committed relationships. There was no correlation between age and the intensity of grief experiences on any bereavement subscales. Individuals who were caregivers scored lower on the intensity of grief on the despair subscale than those who were not caregivers. A one-way analysis of variance was performed to test relationships between individuals in four groups with different levels of social support and the mean scores on each of the five bereavement subscales. There were significant differences between groups on the anger/hostility, despair, and social isolation subscales. Findings revealed that individuals with excellent support were less angry than those with only some support, and those with excellent support were less despairing than those with some or no support (Cherney & Verhey, 1999).

Regarding employment, a positive correlation was found between higher levels of anger/hostility and somatization with unemployed individuals compared to those employed full or part time (Cherney & Verhey, 1999). External moderators (social support and employment status) influencing the bereavement response were consistent with several external and internal mediators presented in Sanders's integrative bereavement theory. Yet Cherney and Verhey (1999) concluded that there was no significant relationship between the number of individual losses reported and the intensity of grief experienced on any dimensions of grief. The findings suggested no significant relationship between the number of losses and the intensity of grief due to the normalcy of death among gay men (Cherney & Verhey, 1996).

In their qualitative study, Smith et al. (2015) investigated the personal stories of 10 African American women living with HIV and the reasons that prompted them to accept their diagnosis. Smith et al. suggested that some women in the interviews experienced grief and loss as defined by Kubler-Ross’ (1993) stages of grief. Smith et al.

focused on the Kubler-Ross model, which, though not identical with Sanders's model, aligns with phases presented in Sanders's integrative theory of bereavement.

Smith et al. (2015) found that African American women living with HIV/AIDS identified their family, community, and church as sources of strength and resilience. The faith community and church promoted connection and encouragement for African American women living with HIV/AIDS. Smith et al. (2015) also argued that the faith community and churches were not totally welcoming of individuals with HIV/AIDS. Although HIV has been deemed a chronic disease, many African American faith communities and churches are hesitant to respond to the HIV/AIDS crisis because of stigma and other religious views. Thus, the faith community and church can present a complicated structure of both stigma and support for individuals living with HIV/AIDS.

Sanders' integrative theory of bereavement aligned with the proposed study. It includes phases regarding losses, and its theoretical approach assists in understanding individual differences in adapting to bereavement (Sanders, 1999; Stroebe et al., 2006). Those individual differences across the course of grief incorporate diverse situations that bereaved individuals may experience (Stroebe et al., 2006). Overall, despite significant losses in life, individuals can move from shock to renewal with resilience and courage (Sanders, 1999; Smith et al., 2015).

Theory of Chronic Sorrow

The theory of chronic sorrow originated with Simon Olshansky in 1962 (Antle et al., 2001; Weingarten, 2012). Olshansky's goal was to explain the recurring waves of grief and challenges faced by parents of children with mental and physical deficiencies as they struggled to cope with the loss of a perfect child (Antle et al., 2001; Eakes et al., 1998). He observed emotions commonly associated with parents' experiences to include sadness, sorrow, fear, helplessness, anger, frustration, and other feelings characteristic of grief (Eakes et al., 1998). The recurring nature of parents' loss of hopes and dreams for their children that could never be realized was assumed to result in continuous grief and chronic sorrow (Eakes et al., 1998: Weingarten, 2012). Olshansky proposed the concept of chronic sorrow as a normal response to living with ongoing losses and long-term periodic sadness among the chronically ill and how their caregivers experience and react to those losses (Ahlstrom, 2007; Lindgren et al., 1992; Northington, 2000; Weingarten, 2012).

Chronic sorrow is the periodic recurrence of permanent, pervasive sadness or other grief-related feelings associated with a significant loss that can be associated with the diagnoses of chronic diseases (Ahlstrom, 2007; Northington, 2000). In the 1980s, there was some interest in the concept, but there was no literature on the concept of chronic sorrow (Weingarten, 2012). Finally, in the 1990s, the concept resurfaced in the context of the nursing profession (Weingarten, 2012). Under the direction of the Nursing Consortium for Research on Chronic Sorrow, research shifted the focus from other loss to self-loss (Weingarten, 2012). The concept has now been validated for individuals experiencing recurring losses as a result of chronic illnesses and diseases, such as amyotrophic lateral sclerosis (ALS), Parkinson's disease, multiple sclerosis, chronic mental illness, and AIDS (Ahlstrom, 2007; Burke et al., 1999; Eakes et al., 1998; Lichtenstein et al., 2002; Lindgren et al., 1992; Northington, 2000). Some of these losses may include control, status, social roles, independence, and identity as a healthy person (Ahlstrom, 2007; Burke et al., 1999; Eakes et al., 1998; Lichtenstein et al., 2002; Lindgren et al., 1992).

In a mixed-methods study, Lichtenstein et al. (2002) examined the relationship between chronic sorrow and social support needs, using narrative interviews and the Center of Epidemiological Studies on Depression (CES-D) Scale among 21 adults living with HIV. The study was conducted through a university-based AIDS clinic in Birmingham, Alabama. The qualitative component included structured, open-ended questions on depression, social support, medication, and health status. When the narrative interviews were completed and transcribed, findings revealed the recurring themes of depression and coping. For the quantitative component, the 21-item CES-D scale assessed symptoms of depression in the prior week. They also examined whether women were more likely to suffer from chronic sorrow than men (i.e., a profound sadness resulting from long-term disability, ill health, or impairment) related to their illness, fear of death, poverty, and social isolation (Lichtenstein et al., 2002). Findings revealed that depression was prevalent among African American women living with HIV due to the stigma and lack of social support as reported through the open-ended questions of the semistructured interviews. In addition, the social processes linked stigma to long-term depression (chronic sorrow) by matching interview excerpts to participants' CES-D scores.

The stigma resulted in social isolation, associations with "dirty sex," contagion, and a moral threat among heterosexual communities. On the other hand, findings suggested that men, through open-ended questioning, are often protected from stigma because of their ties to the gay community and their association with health networks (Lichtenstein et al., 2002). Results showed that over half of the participants were depressed, with African American women having significantly higher levels of depression than Caucasian men and women. Seventy-eight percent of all women, regardless of their ethnicity, reported being isolated from society and stigmatized by family and friends, whereas 63% of the men reported being isolated from society, and 18% reported being stigmatized. The lack of support for women (63%) aligned with their inability to share their diagnosis, as discovered through semistructured interviews, for fear of being stigmatized and deemed an outsider. Overall, the diagnosis of HIV can exacerbate the issue of one's status, especially for women who have mourned the loss of their health and relationships. There were significantly higher levels of depression among African American women due to the stigma of being HIV positive, social and financial difficulties, and health care inequities. Chronic sorrow was a significant factor among African American women regarding depression levels. Qualitative insights on social support needs revealed that women were likely alienated from personal and institutional sources of support (Lichtenstein et al., 2002).

Northington (2000) examined the process of chronic sorrow in 12 African American caregivers of school age children with sickle cell disease (SCD) to identify its characteristics and generate a theory to describe its process. Northington (2000) found that the caregivers moved through three overlapping stages: learning about and incorporating SCD into their daily lives, experiencing the sorrow, and doing what is required to move on. The diagnosis was the initial trigger to evoke feelings, including sorrow. Other internal and external triggers began to evoke feelings of sorrow that eventually became chronic. A process of repatterning began as caregivers learned to live with the unpredictable consequences of SCD, which produced the feelings of chronic sorrow. Repatterning behaviors enabled caregivers to “do what you have to do and move on.” For example, when chaos happens in a family system, the system may appear disorganized. For families to have balance, they often find new patterns (repatterning) of adjustment and coping. In addition, feedback loops occur where new experience patterns (repatterning) emerge and lessons are learned from old behavior patterns. As a result, the new patterns facilitate balance in the system. In this case, caregivers will internalize the SCD coupled with emotions involving a feedback loop characterized by a continual readjusting and redefining reality. The redefining of reality is based on pattern-seeking activities and behaviors that allow individuals to cope and make sense of their world. Adjustment to the feelings includes inner strength and support systems. As a result of the adjustments and readjustments, chronic sorrow aids in the growth of the individual via pattern changes (repatterning). This concept aligns with the proposed study as women diagnosed with HIV experience recurring losses, such as health, relationships, and identity (Ahlstrom, 2007). Chronic sorrow has been identified as repeated sadness over time in a situation with no predictable end, external and internal stimuli triggering the feelings of loss, disappointment and fear, progression, and intensification of the sadness or sorrow years after the initial disappointment or loss (Ahlstrom, 2007). While research focuses on the loss of children due to chronic illnesses and disabilities, chronic sorrow aligns with HIV because it is viewed as a response to chronic illness and life-threatening conditions (Doka, 2002b).

The concept of chronic sorrow explains how people may respond to both ongoing and single loss events. Weingarten et al. (2012) and Antle et al. (2001) revealed that families experiencing chronic illnesses considered it a loss. Other losses associated with a chronic illness, especially HIV/AIDS, include parenting roles, loss due to health and financial status due to illness or HIV/AIDS, loss of children who are infected and affected with HIV/AIDS, and loss due to the inability to disclose one's HIV status. Weingarten interviewed four women who explored the macroprocesses that invaded their personal experiences and self-loss by giving examples of how they have coped with illness, experienced painful self-loss, and chronic sorrow. These macroprocesses are loss of bodily functions, loss of relationships, loss of autonomous life, loss of roles, loss of activities, loss of identity, loss of life imagined, and loss of uplifting emotions. In addition, these losses make it very challenging for individuals to do the work of building and revising a self-narrative, which he defines as "an overarching cognitive-affective-behavioral structure that organizes the 'micro-narratives' of everyday life into a 'macro-narrative' that consolidates one's self-understanding, establishes characteristic range of emotions and goals, and guides performance on the social stage of life. A traumatic event often precedes chronic sorrow, and the subsequent realization is that a chronic illness or disability is a person's new reality. Following are the disruptions of these self-narratives: narrative disorganization, dissociation, and disruption. Narrative disorganization is often precipitated by an acute event when the event or illness shatters the self-narrative. There is no longer a level of understanding and meaning in one’s life circumstances. Narrative dissociation diminishes the self-narrative, and the loss is not named or put into words, even to the self. The consequence is a lack of voice and audience. Narrative disruption is when one’s narrative dominates or takes over the self-narrative. She discussed the painful gap between who women have been, who they are now, how they want to be, how they can be, who they dreamed themselves to be, and who they still long to be (Weingarten et al. 2012). Antle et al. (2001) stated that the response of families whose loved one is experiencing HIV, is similar to the death of that individual. Chronic sorrow may be prevalent among families because multiple family members may be infected, and children who are also HIV positive may experience delayed development (Antle et al., 2001). Children, as well as parents, will experience anticipatory grief, depression, anxiety, and self-blame (Antle et al., 2001).

To explore chronic sorrow in families, Antle et al. (2001) examined the experiences of 105 HIV-positive mothers and fathers, including 17 HIV-positive children in the 86 families who participated. Antle reported that parents maintained similar chronic sorrow (anticipatory grief, depression, anxiety, and self-blame) for their infected children, those who lives may be short due to living with HIV. Parents of children with physical and developmental disabilities were reported to be at high risk for psychological distress and physical health problems. It was also reported that mothers of special needs children appeared to be at risk with consistently higher ratings for psychological distress compared to spouses, mothers, or fathers of children without disabilities. In addition, stress symptoms were highest among HIV-positive primary caregivers of HIV positive children. Stigma, discrimination, secrecy, and disclosure were also significant issues for parents living with HIV. Because parents reported concerns that their children would be discriminated against if others knew that family members were HIV positive, many families chose not to disclose their status to their children, thus creating chronic sorrow. Choosing to keep things a secret in the family was a way to protect their children from perceived hardships, concerns about facing death, how parents became infected with HIV, and preparing for the future and guardianship for their children (Antle et al., 2001).

Literature Review Related to Key Variables

African American Women and HIV

Human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) is a public health problem and it has become widespread for African Americans, especially African American women, who account for a majority of new HIV infections and AIDS cases (Brawner, 2014; CDC, 2007; CDC, 2011; CDC, 2018a; Mahadevan et al., 2014; Wolitski, 2018; Wyatt, 2009). Compared to other races and ethnic groups, Black/African American women bear the burden HIV/AIDS diagnosis in the United States with heterosexual contact as the primary mode of transmission (Brawner, 2014; Wyatt, 2009). Black/African American women make up 14% of the total population in the United States but accounted for 66% of HIV/AIDS cases among all women (Mahadevan et al., 2014). This suggests that African American women continue to be diagnosed with HIV at disproportionately high rates compared to White and Hispanic/Latina women (CDC, 2018a; Mahadevan et al., 2014). In 2016, 4,560 African American women received an HIV diagnosis, compared with 1,450 white women and

1,168 Hispanic/Latina women representing 61% of HIV diagnoses among all women in the United States that year (CDC, 2018a; CDC, 2018b; Wolitski, 2018). Thus, African American women continue to be the fastest growing population infected with and affected by HIV (Rose et al., 2008; Wolitski, 2018; Wyatt, 2009).

The Centers for Disease Control and Prevention (2018b) reported that HIV diagnoses among women have declined in recent years with more than 7,000 women receiving an HIV diagnosis in 2016 (CDC, 2018b). Black/African American women are still disproportionately affected by HIV compared with women of other races/ethnicities. Of the total number of women living with and diagnosed with HIV at the end of 2015, 59% were African American, 19%, were Hispanic/Latina, and 17% were white (CDC, 2018b).

Brawner (2014) and Mahadevan et al. (2014) found that the rate of new HIV infections among African American women is 20 times greater when compared to White women and five times greater when compared to Hispanic women. Medical advances in HIV care and treatment promotes greater life expectancy among individuals living with HIV. Despite these advances and successes, HIV was still the third leading cause of death among African American women between ages 25-44 in 2007, and the leading cause of death of African American women between the ages of 24-35 (Peltzer et al., 2016).

Brawner (2014) developed a conceptual model that explored health disparities that influence HIV transmission of among African American women. Brawner conceptualized the intersectionality of behaviors (sexual activity, multiple sexual partners, injection drug use, and noncondom use) and indicators of HIV transmission (percentages of the population with undetectable viral loads and HIV incidence and prevalence rates). The concept of geobehavioral vulnerability to HIV postulates what you do, where you do it, and with whom that increases women's risk for HIV. Brawner discussed the geosocial spaces, which are those geographic areas where people interact, such as census tracts, housing developments, or cities with high HIV prevalence rates and greater probably of being exposed to HIV. This model was developed to explore HIV transmission in the African American population. By examining the relationship between behaviors that transmit HIV and HIV risk, Brawner understood inequities among African American women manifested within individual, social, and structural factors. Brawner suggested that an individual's level of HIV risk occurs within the context of social and structural inequities that outline HIV risk beyond individual influences. In high poverty areas, HIV prevalence rates are higher. Brawner argued that geobehavioral vulnerability to HIV is increased among African American women due to sexual relationships that occur in these geosocial spaces. Future research is needed to test the suggested pathways and explore more comprehensive assessments and prevention programs needed in African American communities.

Phillips et al. (2011) analyzed the lived experiences of HIV-infected women (*N*=280) in the rural southeastern United States, using written notes made by peer counselors during home visits. During each session, the women identified the problem of most significant concern to them, which served as the focus of the peer counseling. There were themes (struggle/effort, stigma/hiding, loss/depression, and independence/dependence) depicting their lived experiences (Phillips et al., 2011). Those themes included struggle/effort with instability being the norm and the women living life in the world on a “roller coaster” with daily waiting, setbacks, striving to survive, fear, and chaos. The women also had physical ailments, including pain, skin eruptions, infections, dental problems, and side effects of prescribed medications. Some women struggled with substance abuse, providing for children, spouses, and other significant others, paying bills, maintaining housing and transportation, obtaining life insurance, and keeping their jobs (Phillips et al., 2011). Stigma/hiding was associated with interpersonal and social systems. When women experienced stigma, they hid their diagnosis from others, especially in the community and family members (Phillips et al., 2011). Loss/depression signifies the women’s loneliness when coupled with the loss of physical integrity and death and desertion of loved ones. Living with HIV made the women more aware of HIV/AIDS deaths within their community. The loss also takes the form of abandonment by family and significant others with depression at the helm of their lived experiences. The many problems faced by women living with HIV (e.g., no housing, no funds, no jobs, no education) led to depression, which intensified their concerns (Phillips et al., 2011). Independence/dependence addresses the women’s desire to be independent and not dependent on others to help or support them. The women strived to be self-sufficient and desired and were motivated not to depend on family or social services agencies. Findings indicated that HIV-positive African American women experienced severe psychological and physiological symptoms coupled with poverty and isolation (Phillips et al., 2011). Additional issues faced by the women included stigma, loss, and depression. The women had complicated life circumstances that reflected a devastating chronic illness, poverty, and abuse (Phillips et al., 2011).

In another study, Peltzer et al. (2016) examined the everyday lived experiences of 11 African American women infected with HIV between the ages of 21 and 35. The authors described how HIV invaded every aspect of their lives as demonstrated in the resulting common themes: living alone with HIV, living with unresolved conflicts, living with multiple layers of betrayal, and living with the everydayness of HIV (Peltzer et al., 2016). Peltzer noted that the women experienced isolation, abandonment, betrayal, and discrimination in their interpersonal and social systems. In addition, women often dealt with the conflict between hope and anguish in their relationships with their children and portraying strength while feeling fragile. The complexities in each area negatively influenced the ability to engage fully in self-care activities. Further research suggested examining psychological distress post-diagnosis, the development of holistic interventions, and research on mass media educational campaigns could reduce HIV-related stigma.

Mahadevan et al. (2014) evaluated an intervention (Project THANKS) that was based on a socio-ecological model built on the empowerment and sustainability of African American women living with HIV. While addressing the barriers leading to recidivistic behaviors and increasing the resolve to stay in treatment, the purpose of the project was to improve overall positive health outcomes among HIV-positive African American women experiencing co-morbidities and other chronic illnesses. Mahadevan implemented the intervention with African American women (*N*=10) living with HIV.

Quantitative and qualitative techniques were used to evaluate the effectiveness of the intervention by assessing the program's effectiveness in increasing the participants' self-efficacy and confidence level in managing health conditions. Mahadevan et al. (2014) found that African American women were less likely to be insured, more likely to receive less than optimal care in organizational settings (such as the emergency room), and more likely to experience lack of continuity in the health care received. Mahadevan et al. (2014) also found that impoverished African American women with HIV tended to be vulnerable to poor health outcomes associated with limited resources, health care disparities due to racial discrimination and oppression, developmental histories marked by poor nutrition and disease, and psychosocial influences such as lack of self-efficacy, powerlessness, stigma, and feelings of social isolation, lack of cultural competency in health care workforce, and lack of transportation or strenuous distances to nearest healthcare facility. These findings suggested that the integration of existing harm reduction services can reduce poor health outcomes among African American women with HIV (Mahadevan et al., 2014).

Stigma and HIV

Erving Goffman introduced the concept of stigma in 1963 (Colbert et al., 2010). He identified three different types of stigma: (a) abominations of the body, (b) blemishes of individual character, and (c) tribal stigma of race, nation, and religion. As the concept of stigma evolved, it became associated with individuals living with HIV. It was manifested through four factors, including prejudice, discounting, discrediting, and discrimination. These attitudes and behaviors create extensive damage to stigmatized individuals. There are varying sources of stigma experienced by people living with or affected by HIV infection. It can be experienced by individuals externally and internally simultaneously, or stigma may be experienced externally or internally separately (Colbert et al., 2010).

Colbert et al. (2010) used Goffman's model of stigma to examine how social support and health status are related to HIV stigma, and how these relationships differed between men and women living with HIV. Participants (*N*=183) in a behavioral randomized clinical trial were analyzed using multi-group structural equation modeling. Stigma, as the dependent variable (DV), was measured using the 40-item HIV-related Stigma Scale with 4 subscales (personalized stigma, disclosure concerns, negative self-image, and concern over public attitudes toward persons living with HIV). Women reported significantly higher levels of stigma than men after controlling for race, history of injecting drug use, and exposure category. HIV-related stigma was negatively associated with social support regardless of gender. The study offered insight into understanding the relationships among gender, health status, social support, and HIV-related stigma. Colbert et al. (2010) found that HIV-related stigma was linked to negative self-perceptions, lower rates of HIV status disclosure, decreased health care utilization, lower rates of HIV and STD testing and disclosure, lower quality of life, and lower medication adherence in men and women. It was suggested that further research with HIV-related stigma should focus on this concept with the entire population of HIV-infected individuals rather than studying the concept with various subpopulations with HIV infection (Colbert et al., 2010).

In their literature review, Darlington and Hutson (2017) investigated 27 scientific articles about HIV-related stigma among women living with HIV/AIDS in the Southern United States. They analyzed the state-of-science regarding HIV-related stigma among women in the Southern United States, identified gaps in the literature, and provided suggestions for future research among persons living with HIV. Some of the main themes observed in the literature were distancing, stereotyping, and intersectionality. Darlington and Hutson (2017) also found that psychological distress and a negative self-image caused by internalized stigma led to a lack of religiosity and traditional beliefs about gender/sexuality. When investigating the literature, stigma was defined as: perceived (negative perceptions before they are experienced leading to limited disclosure and fear of rejection), experienced (social discrimination and rejection), and internalized stigma (one which affects an individual's psychological self-images and value). Perceived, experienced, and internalized stigma have contributed to isolation, depression, medication non-adherence, decreased healthcare access, constrained or high-risk sexual decision-making, negative self-perception, feelings of inferiority, guilt, and disclosure concerns. The effects of stigma have contributed to the trajectory of lives for HIV-positive women in the South by fostering barriers to getting adequate care and increasing HIV transmission to others. (Darlington & Hutson, 2017). Findings in the literature review revealed a sparse and anecdotal understanding of HIV-related stigma among women living in the South, thus revealing that HIV-related stigma poses a significant risk to the physical and psychological well-being of women living with HIV (Darligton & Hutson, 2017).

Dale et al. (2018) argued that Black women who experience microaggressions, which are daily words and behaviors insulting to marginalized groups, led to oppression, trauma, abuse, racial discrimination, and internalized HIV stigma. In their qualitative study. Dale et al. (2018) investigated the experiences of 30 Black women living with HIV related to trauma, racism, HIV stigma/discrimination, gender-related stressors, coping strategies, connections between adversities and medication adherence, and implementing an intervention that met the needs of Black women living with HIV. Because Black women were discriminated against due to their HIV status and race, they internalized stigma (when a person with HIV experiences negative feelings or thoughts about themselves due to their HIV status). The women's experiences of trauma/abuse, HIV stigma, racial discrimination led to depression, anger, resignation, disengagement, and medication nonadherence. Despite facing adversity, the Black women found resilience to continue taking medication despite the trauma, racism, HIV stigma, and gender roles. Findings revealed that having an internalized sense of self, power, and prioritizing themselves and their needs allowed the women to cope with the adversities and adhere to their medication. These findings also suggested that culturally appropriate interventions were needed to improve the lives and health of Black women living with HIV by helping them face and promote self-primacy, self-validation, and self-care (Dale et al., 2018).

Turan et al. (2016) examined whether social isolation (loneliness and lack of social support) and depressive symptoms mediate the relationship between internalized stigma and HIV medication nonadherence among racially diverse women (*N*=1168) living across the United States. Results showed that lower levels of social support and higher levels of loneliness were associated with significantly higher depression, thus mediating the relationship between internalized HIV stigma and lower medication adherence. The effect of internalized stigma on medication adherence was greater for women in racial/ethnic minority groups than for non-Hispanic White women. The results also demonstrated that non-White women living with HIV had significantly lower medication adherence rates and worse health outcomes than White women. Turan et al. suggested that lower levels of social support and higher levels of loneliness may intensify depressive symptoms and predict poorer medication adherence. Biases and social perceptions damage an individual’s social reputation and one’s self-perception, thus facilitating stigma and causing psychological distress (Turan et al., 2016).

In a similar study, Rao et al. (2012) examined the relationship between HIV-related stigma, depressive symptoms, and medication adherence in a cross-sectional study among adults (*N*=720) living with HIV. Results indicated that higher levels of HIV-related stigma were positively associated with more severe depressive symptoms and poorer HIV medical adherence. The study illustrated how depressive symptoms served as a conduit by which HIV-related stigma impacted HIV medication adherence. These findings suggested significant negative outcomes for African Americans living with HIV, which included delays in accessing care and challenged in accessing and adhering to medication regimens. In addition, African Americans living with HIV did not remain in care, did not obtain treatment earlier, and did not adhere to medications well as compared to other ethnic groups living with HIV (Rao et al., 2012).

Katz et al. (2013) also assessed the relationship between HIV-related stigma and medication adherence using a meta-synthesis method to summarize the finding from the studies. Katz et al. (2013) included a total of 75 mixed-design studies (among 26,715 persons living with HIV in 32 countries) in their analysis using an inductive process categorizing themes and organized in a conceptual model spanning intrapersonal, interpersonal, and structural levels. Results indicated that HIV-related stigma influenced medication adherence through adaptive coping and social support. Other factors negatively impacted HIV medication adherence, such as stigmatizing attitudes of others, internalized stigma, and concealment of HIV status. Adaptive coping and social support were critical factors in participants' ability to overcome the structural and economic barriers associated with poverty, thus leading to successful medication adherence. Findings also revealed that HIV-related stigma compromised participants' abilities to successfully maintain medication adherence (Katz et al., 2013). Interventions that could potentially reduce stigma should target multiple levels of influence (intrapersonal, interpersonal, and structural) to maximize HIV medication adherence.

In another study, Turan et al. (2017) examined the association between perceived community stigma, internalized stigma, and mental health outcomes among 203 adult participants living with HIV (130 Black, 73 White). The associations between perceived community stigma and interpersonal outcomes (i.e., social support, trust in physicians) were mediated by internalized stigma and anticipated stigma (perceived community stigma). Turan et al. also examined the extent to which perceived community stigma and affective, cognitive, and mental health outcomes (self-esteem, depressive symptoms, avoidance coping, self-blame) predicted internalized stigma. Using two subscales of the revised HIV Stigma Scale of perceived stigma in the community (concern with public attitudes) and internalized stigma (negative self-image), Turan et al. found that higher levels of perceived community stigma were associated with higher levels of internalized stigma, thus resulting in lower medication adherence. The associations between perceived community stigma and interpersonal outcomes (social support, trust in physicians) were mediated by internalized stigma and anticipated stigma (perceived community stigma leads to internalized stigma, which leads to anticipated stigma, which in turn leads to interpersonal outcomes). These findings suggested that perceived HIV-related stigma in the community may cause people living with HIV to internalize stigma and anticipate stigmatizing experiences, resulting in adverse health and psychosocial outcomes (Turan et al., 2017).

Lindley et al. (2010) assessed stigma in the faith community using cross-sectional surveys from 20 churches that included 1,445 parishioners, 61 pastors, and 109 care team members, measuring HIV-related knowledge and stigmatizing attitudes. Results indicated that members of faith communities were knowledgeable about HIV transmission, the importance of consistent condom use, and regular HIV testing. However, males and older parishioners were significantly less knowledgeable and had significantly higher levels of HIV-related stigma compared to females and younger parishioners. In addition, pastors and care team members at the churches had significantly more HIV knowledge and had significantly lower levels of stigma-related attitudes than their parishioners (Lindley et al., 2010). In a related study, Derose et al. (2016) examined possible predictors of HIV stigma among church-affiliated populations, and HIV stigma and associated stigmas regarding same-sex sexual relationships and drug addiction among 1235 congregants in 11 churches. The researchers measured constructs related to stigma, including discomfort interacting with people with HIV, feelings of shame if you had HIV, fears of rejection if you had HIV, and feelings of blame towards people with HIV (Derose et al., 2016). Results indicated that significantly lower levels of HIV stigma were associated with knowing someone with HIV and higher levels of HIV stigma were linked to someone who was homosexual or had a drug addiction. These findings suggested that it is important for faith communities to address issues of sexual orientation and drug addiction to minimize HIV stigma (Derose et al., 2016).

In their mixed-methods study, Sangaramoorthy et al. (2017) interviewed older HIV positive Black women (n=35) and assessed their experiences with perceived and experienced HIV stigma, retention in care, and medication adherence. Using interviews and the Multidimensional Measure of Internalized HIV Stigma Scale, Sangaramoorthy et al. found that older Black women experienced high levels of HIV stigma compared to other racial and ethnic groups. These findings suggested that the stigmatizing of HIV often leads to rejection by family and friends and internalized feelings of guilt and shame compared to other racial and ethnic groups. HIV stigma was intensified for older Black women due to experiences of marginalization in health care that hindered retention in care and medication adherence. These findings also suggested that despite increased public awareness, community perceptions of HIV and negative stereotyping of persons living with HIV continued to be highly stigmatized (Sangaramoorthy et al., 2017).

McDoom et al. (2015) also found that stigma was a factor for older Black women with HIV that influenced the degree of engagement in care with a healthcare provider. In their qualitative study with 20 older Black women, McDoom et al. (2015) examined how experiences with stigma and social support facilitated or inhibited engagement in HIV care. While social support encouraged older Black women to engage in care, stigma inhibited their ability to do so. Taken together, these studies confirmed that providers should be consistent in ensuring that Black women's illness is not stigmatized by understanding the various changes in women's lives as they deal and struggle with stigma and disclosure while in engaging in HIV care (McDoom et al., 2015; Sangaramoorthy et al., 2017).

In a qualitative study, James-Borga and Frederickson (2018) explored the lived experiences of older Back women living with HIV. James-Borga and Frederickson interviewed 10 Black/African American women over the age of 50 to gain a deeper and more holistic view of older African American women's experiences living with HIV. James-Borga and Frederickson found that seven essential themes associated with their lived experiences were interconnected: knowledge as empowerment, concealing while revealing, hypervigilant awareness regarding HIV stigma, maintain relationality, caring while being cared for, emotional ebb and flow, and self-transcending and becoming. The interrelationship and overlapping of the themes suggested the complexities of the women's daily lives, pointing out how HIV stigma was still a critical issue in the lived experiences of individuals living with HIV (James-Borga & Frederickson, 2018).

In another qualitative study, Saki et al. (2015) assessed the perceived experiences of stigma and discrimination among HIV patients and their role in receiving health care services. The main themes in the study were multidimensional stigma, rejection, discrimination, and insults in health services (Saki et al., 2015). Results indicated that discrimination was one of the outcomes of stigma, which led to barriers for patients not accessing services. Participants in the study revealed that their experiences were associated with degradation and insults from health professionals. These findings suggested that stigma can be a deterrence to getting needed care and treatment (Saki et al., 2015).

Davtyan et al. (2016) suggested that stigma stemmed from judgmental views about particular lifestyles, fear of becoming infected, and ignorance about HIV transmission. In their qualitative interpretive phenomenological study with 10 African American and Latina women, Davtyan et al. (2016) investigated experiences of stigma through a community-based participatory method using documentary photography. Results indicated that the women were stigmatized by healthcare professionals and often judged and blamed for contracting HIV as a result of moral fault. Results also indicated that the women's experiences with HIV stigma were associated with depressive symptoms, diminished quality of intimate relationships, and difficulty disclosing HIV status due to anticipated stigma, which influenced relationship dynamics in the context of power and gender. Davtyan et al. (2016) concluded that a lack of education and cultural myths were key triggers for HIV stigma, whereas fear of intimate relationships, depression, and nondisclosure of HIV were consequences of stigma.

In a follow-up study, Davtyan et al. (2017) argued that approximately 30 percent of individuals living with HIV have experienced stigma associated with their illness. Many of these individuals have experienced stigma within healthcare settings, which has contributed to an adverse effect on individuals engaging care and health outcomes. Davtyan et al. investigated how healthcare workers conceptualized HIV stigma, using a grounded-theory approach. Results indicated that stigmatizing attitudes and behaviors exhibited by healthcare workers were seen with HIV patients in many forms, including visible discomfort, inferior treatment, patient avoidance, and care refusal. Other behaviors demonstrated towards individuals with HIV included irrational anger, blatant discrimination, physical distancing, minimal eye contact, hostility, disrespect, and reduced attention. These behaviors were directed toward individuals living with HIV and could lead to unfavorable health outcomes for them. Davtyan et al. concluded that HIV-related stigma in healthcare settings presents a major challenge for individuals living with HIV. Davtyan et al. also found that stigmatization directed toward individuals with HIV was attributed to healthcare workers' lack of awareness, lack of experience with HIV community, education and training, personal actions, and intuitional and organizational practices that can be perceived as prejudicial. HIV-related stigma was also triggered by limited contact with HIV individuals, which led to reduced opportunities for clinical education and practice for nonspecialists, unnecessary referrals, and provider detachment from HIV individuals (Davtyan et al., 2017).

Disclosure and HIV

Obermeyer et al. (2011) defined disclosure as the process of revealing a person's HIV status, whether positive or negative. Disclosure is considered a way to uncover the HIV epidemic, along with it being a critical step toward ending stigma and discrimination against people living with HIV and AIDS (Obermeyer et al., 2011). There has been much debate about disclosure because of its link to individuals’ confidentiality and privacy. In a review of the literature on HIV disclosure, Obermeyer et al. (2011) assessed the extent to which health facilities and health workers facilitated disclosure. Obermeyer et al. (2011) found that disclosure is difficult, and few people keep their status completely secret. The levels of disclosure are generally high, but lower levels are documented among certain populations, mainly with parents dealing with prenatal care. Obermeyer stated that disclosure is a way for individuals to divulge their status, thus leading to the ending of stigma and discrimination against people living with HIV and AIDS. Obermeyer et al. (2011) also found that disclosure was significantly higher in high income countries of Europe and the United States, with some variation among low and middle-income countries. Obermeyer et al. (2011) concluded that women disclosed and received disclosure more frequently than men. However, pregnant, and married women experienced challenges with partner disclosure. These findings show that decisions regarding what information to disclose, to whom, and when are selective across diverse settings (Obermeyer et al., 2011).

Sowell et al. (2003) also examined how disclosure of HIV status is decided and the internal struggle initiated by learning that one is HIV infected. In their qualitative study with 322 African American HIV-infected women residing in the Southern Unites States, Sowell examined women's level of disclosure to various groups and how these disclosure decisions were made. Results indicated that many of the women had disclosed to close family and friends, sex partners, and health care professionals. The level of disclosure was to at least one parent, followed by husband, siblings, friends, other relatives, and children (Sowell et al., 2003). The disclosure of one's status in relationships can leave African American women vulnerable to stigma and discrimination, and possibly put them at risk for loss of employment, housing, health insurance, custody of her children, interference and disruptions in relationships, rejection, abandonment, and stigmatization and discrimination of a woman's children. Overall, the findings suggested that African American women must consider the impact on resources and support when weighing the benefits and negative consequences of disclosing their HIV status (Sowell et al., 2003).

Yonah et al. (2014) examined HIV disclosure among 270 HIV positive adults attending care and treatment clinic at Sekou-Toure hospital in Mwanza, Tanzania. The results showed a high rate of disclosure of HIV, though delayed disclosure was noted in a small proportion of participants. Negative outcomes following disclosure of HIV status were also reported by participants. These findings suggested that increased efforts are needed to promote disclosure of HIV serostatus in Tanzania through health education and awareness for HIV prevention, and the maintenance of health for people living with HIV, their spouses, and the community, and its role in reducing HIV transmission. Dibb (2018) agreed that individuals must weigh the risk of experiencing stigma against the potential of receiving positive support when considering disclosure of HIV status. Dibb argued that the decision to disclose or not has been described as a dilemma where the individual weighs the risk of experiencing stigma (discrimination and feelings of shame) against the potential of receiving positive support. The reluctance to disclose one's status is informative as there is evidence that non-disclosure is linked to poorer health whereas disclosing has been found to be associated with positive aspects for health such as a better perception of physical health, lower depression scores, and better mental health. In this cross-sectional survey with 75 adults living with HIV, Dibb (2018) explored whether posttraumatic growth was positively related to adjustment, perceived stigma, and disclosure regret. Results showed that all participants had disclosed to at least one person with posttraumatic growth significantly and positively associated with life satisfaction. Life satisfaction was negatively associated with depression, disclosure regret, and perceived stigma. Individuals with more depressive symptoms perceived more regret after disclosing, and those who perceived more stigma from others also reported lower life satisfaction. Posttraumatic growth was significantly correlated with disclosure regret, indicating that individuals who perceived more regret after disclosure perceived less posttraumatic growth. Disclosure regret was negatively associated with diagnosis and mental functioning and positively associated with depression and perceived stigma. Perceived stigma was negatively related to psychological and physical functioning and positively associated with depression, disclosure regret, and disease severity. Overall, disclosure regret and perceived stigma were significantly positively associated, indicating that the higher the perceived stigma, the more the individual regretted disclosing their status to others. These findings suggested that the relationship between posttraumatic growth and subjective measures of adjustment may be crucial for interventions aimed at supporting persons living with HIV (Dibb, 2018).

Disclosure to Family and Friends

Simoni et al. (2000) examined HIV disclosure among Hispanic women of African descent and non-Hispanic women of African descent to determine if HIV disclosure was related to social support and psychological adaptation. Results showed significantly higher rates of HIV disclosure to partners, friends, mothers, and sisters with significantly lower rates of disclosure to brothers, father, relatives, and nonrelatives (Simoni et al., 2000). Bivariate analyses revealed that disclosure was significantly related to greater frequency of HIV-related social support, although not directly to lower depressive symptoms or mood disturbance scores. In addition, disclosure rates were positively associated with the use of healthier coping strategies (i.e., spiritual resilience, constructive cognitions, and community involvement). Multiple regression analyses indicated satisfaction with social support mediated the relationship between adaptive coping and psychological distress. These findings suggested that HIV disclosure leads to more successful and positive adaptation to HIV/AIDS.

Serovich et al. (2007) posited that the decision to disclose HIV status to friends, family, and sexual partners is selective because it may present complications in all areas of an individual’s life. Serovich et al. (2007) conducted a 15-year longitudinal study of 125 single HIV-positive African American adult women to determine the occurrence and timing of HIV disclosure. Serovich et al. (2007) found that women were significantly more likely to disclose their HIV status to mothers and sisters within the first seven years of their diagnosis compared to fathers and brothers. Thus, Serovich et al. (2012) argued that for African American women, disclosure of their status is done selectively. Serovich et al. (2012) also compared the rates of women's HIV disclosure to family and friends and the possible influences of social networks and relationships on the time-to-disclosure of HIV status. Results indicated that during the first month after diagnosis, family of origin, partners, extended family, friends, and children had been disclosed to by the participants. While a larger proportion of friends were disclosed to during the first month after diagnosis, disclosure more likely occurred with family of origin two years after the diagnosis. In addition, sexual partners (current and ex-partners) were more likely to be told immediately with the trajectory of disclosure increasing over time (Serovich et al., 2012). Women's desire to disclose their status immediately after diagnosis to past and current sexual partners was to protect sexual partners from possible infection, to encourage testing, to encourage them to seek support, and to alleviate blame for possible infection due to disclosure law requiring disclosure (Serovich et al., 2012).

Armistead et al. (1999) examined the patterns of disclosure to significant others among 100 HIV-positive African American women in a longitudinal study. They assessed who they disclosed to, predictors of disclosure, and the relationship between disclosure and psychological functioning. Results demonstrated that women disclosed their diagnosis to different individuals at varying rates with mothers being more common, followed by disclosure to partners. Disclosure to children and fathers was less frequent. The findings suggested that disclosure to a partner significantly related to women's psychological functioning, resulting in fewer symptoms of depression in women who disclosed their HIV status to their partners compared to those who had not (Armistead et al., 1999). In a related study, Vyavaharkar et al. (2011) examined the relationship between social support, HIV disclosure, and depression among African American women, hypothesizing that self-disclosure may help decrease depression and improve the quality of life among African American women living with HIV. Results indicated that HIV disclosure and the social support variables (perceived availability of support, sources of support, and satisfaction with support) were negatively related to depression symptoms. HIV disclosure was positively associated with each social support variable (perceived availability of support, sources of support, and satisfaction with support). Overall, social support variables were significantly negatively associated with depression. Higher social support, whether perceived or actual, and greater satisfaction with the support available to African American women can minimize the effects of psychological stress associated with being HIV-positive and result in better adaption and lesser depression (Vyavaharkar et al., 2011).

Geiger et al. (2016) also examined HIV status disclosure in a sample of African American adults living with HIV (*N* = 262) to social contacts, the relationship of such disclosure to other potential predictors of engagement in medical care, and the independent significance of such disclosure as a predictor of engagement in medical care. Disclosure of HIV status to family members and friends was shown to be positively associated with higher levels of social support and lower levels of life stress. These findings suggested that the disclosure of HIV status to social contacts plays an important role in successful engagement of persons living with HIV in medical care. At baseline assessment, many of the women (46 %) reported they had not disclosed their HIV status to others. Engagement in medical care was assessed 45 and 90 days after enrollment in the study. Participants who disclosed their HIV status were significantly more likely to engage in HIV medical care (78 %) than persons who did not disclose their status (66 %).

Amutah (2012) argued that disclosure to family and friends may be inhibited due to fear. In a qualitative study with 10 HIV positive women of color in Washington, D.C., Amutah explored barriers to social services, mental health issues, and experiences of discrimination. Results of the study showed that the women experienced numerous social and mental health issues related to the diagnosis. The issues they experienced were fear of disclosure to family and friends. The study also pointed out the need for mental health services to address unresolved issues regarding their diagnosis. During the study, the women had reservations about disclosing their HIV status for fear of being judged (Amutah, 2012).

Disclosure to Sexual Partners

Hudson (2008) conducted a study to examine HIV disclosure to an intimate sexual partner by HIV positive African American women. The assumption was that non-disclosure of HIV status to primary and/or non-exclusive sexual intimate partners is a common occurrence. Hudson (2008) examined the relationships between adult romantic attachment style and HIV disclosure to an intimate sexual partner when coupled with perceived HIV stigma, shame-proneness, and psychological functioning. Results showed that HIV disclosure to an intimate sexual partner was significantly predicted by adult romantic attachment style. The most significant finding was that adult romantic attachment style was inversely associated with the likelihood that HIV positive women would disclose their status to an intimate and/or significant sexual partner (Hudson, 2008). More specifically, the results indicated that African American women who had a secure attachment style were twice as likely to disclose HIV positive status to an intimate sexual partner compared to women with a preoccupied attachment style. Also, those with a preoccupied attachment style were twice as likely to disclose HIV positive as those with a dismissing-avoidant attachment style, who were then twice as likely to disclose as those with a fearful-avoidant attachment style (Hudson, 2008).

Hood et al. (2020) examined whether partner disclosure status and HIV conspiracy beliefs conjointly moderated the relationship between HIV-testing attitudes and HIV-testing behaviors among 119 Black women aged 18-25 years. It was found that HIV conspiracy beliefs and partner disclosure moderated the relationship between attitudes and HIV testing at one-month follow-up. When partner disclosure was low, women with more negative attitudes toward testing and higher conspiracy beliefs were significantly less likely to get tested than those with negative attitudes and lower conspiracy beliefs. These findings suggested that conspiracy beliefs did not relate to testing outcomes when testing attitudes were positive (Hood et al., 2020). Smith et al. (2017) argued that HIV disclosure depends on relationship quality. Smith et al. explored perceived relationship quality and its influence on HIV disclosure outcomes in a cross-sectional study with 95 HIV-positive adults. Results showed that higher levels of perceived relationship quality were significantly related to more positive disclosure outcomes. Those positive outcomes were good relationship dynamics, such as trust and disclosing one's status. Higher levels of perceived negative relationship quality resulted in more negative disclosure outcomes. Their findings indicated that the quality of relationship of intimate partnership plays a vital role in disclosure and disclosure outcomes (Smith et al., 2017).

While there may be benefits to disclosing HIV diagnosis, Kennedy et al. (2015) argued that women living with HIV are also hesitant to disclose their HIV status due to the inability to receive social support, access other reproductive health services, and negotiate safer sex in current unhealthy and violent relationships. Disclosure in intimate partner violent relationships could be a barrier, thus perpetuating violence, abandonment, relationship dissolution and stigma, loss of children, or loss of their home (Kennedy et al., 2015). Kennedy reviewed 1080 published citations and over 2200 conference abstracts before 2015 that examined interventions to facilitate HIV status disclosure of women who feared violence or were experiencing violence. Kennedy founded very few articles on the impact of partner violence on disclosure. The results yielded two studies that ultimately met the inclusion criteria. The inclusion criteria were: 1) published in a peer-reviewed journal, presented as an abstract at a scientific conference, or presented as a grey literature report prior to the search date of 1 April 2015; 2) comparative study (including either pre/post or multi-arm comparison groups) assessing one or more interventions to facilitate safe disclosure of HIV status for women living with HIV who fear violence or who disclose that they are currently experiencing violence compared with no intervention or standard of care; and 3) measures one or more of the following outcomes: disclosure, violence (physical, sexual, emotional), fear of violence, other adverse events (e.g. relationship dissolution, abandonment, job loss, loss of children, loss of access to services, etc.) or positive outcomes (e.g. feelings of individual empowerment, safety, partner involvement, better physical health for self and children, HIV care and treatment engagement, adherence to antiretroviral treatment, etc.). One of the studies published evaluation results in 2015, but the evaluation results addressing the safer disclosure component have not yet been published. Findings revealed that intimate partner violence continued to be a significant barrier to disclosure for women who feared violence. It has not been adequately addressed in current approaches related to HIV testing, treatment, and care services in healthcare settings. These findings suggested that interventions that facilitate safe HIV disclosure for women who fear violence or experience violence are limited.

More recent research has shown that women may be afraid to disclose their HIV status when there is potential violence in the relationship. Hampanda and Rael (2018) explored the relationship between intimate partner violence against women and their HIV status disclosure behaviors. They evaluated how the severity, frequency, and type of violence against postpartum HIV-positive women affected status disclosure within married/ cohabiting couples. Hampanda and Rael administered a cross-sectional survey to 320 HIV-positive postpartum women attending a public health center for pediatric immunizations in Lusaka, Zambia. Survey data captured women’s self-reports of various forms of intimate partner violence and whether they disclosed their HIV status to the current male partner. Multiple logistic regression models determined the odds of status disclosure by the severity, frequency, and type of violence women experienced. Findings revealed a negative dose-response relationship between the severity and frequency of intimate partner violence and status disclosure to male partners with physical violence having a more pronounced effect on status disclosure than sexual or emotional violence. Findings also showed the majority of the women (92%) living with HIV reported disclosing their HIV-positive status to their current male partner, which is similar to disclosure rates observed in other similar settings among long-term committed couples. Postpartum women living with HIV who knew they were HIV positive for more extended periods (i.e., before their most recent pregnancy) were significantly more likely to disclose their status to their current male partner than more recently diagnosed women. Before engaging in optimal health behaviors and notifying significant others of their HIV diagnosis, newly diagnosed women needed more time to adjust to their diagnosis psychologically. This finding underscores the importance of quality counseling, particularly for newly diagnosed women, to include HIV counselors' ability to evaluate the pros and cons of disclosure among women and support some women's decisions not to disclose.

Psychological Distress and HIV

Zhu et al. (2018) posited that chronic illnesses and functional limitations were associated with an increased risk of suicide ideation among adolescents and older adults. Chronic disease and disability were also determinants of high psychological distress. Zhu et al. (2018) suggested that psychological distress was positively related to suicide ideation among the elderly population, having a direct and mediating role in suicidal patients among adolescents. While this study addressed psychological distress in elderly and adolescents, Zhu et al. (2018) concluded that individuals with higher levels of disease burden were more susceptible to psychological distress. Because HIV is a chronic disease, there is potential for psychological distress for individuals diagnosed and living with the disease. For example, Olley (2006) explored the prevalence and changes in psychiatric morbidity at baseline and after 6-month follow-up among recently diagnosed HIV-positive women. Results indicated that women exhibited psychiatric conditions at baseline and follow-up such as major depression, dysthymia, and post-traumatic stress. After six months, there were changes in coping, suggesting a decline in denial, self-blame, and ventilation, yet effective use of acceptance, emotional support, positive reframing, and planning (Olley, 2006). Results also included a change in coping behaviors among HIV-positive female patients, shifting from maladaptive coping behaviors to more adaptive ones. The high prevalence of major depression found among the women at baseline is consistent with the lifetime prevalence of mood disorders observed among HIV-positive and at-risk populations (Olley, 2006).

In a mixed-methods study with 490 women who were at risk for or infected with HIV/AIDS and with varying histories of violence and trauma, Brumsey et al. (2013) assessed the relationship between HIV status, psychosocial resources, substance use, and psychological distress. The study examined the association between cumulative exposure to traumatic events and the psychological distress common to posttraumatic stress, nonspecific anxiety, and depressive symptoms, and how problematic substance use and impaired psychosocial resources mediate the association between trauma burden and psychological distress. Results indicated that the experience of multiple types of traumatic events of childhood and adult sexual abuse and non-sexual trauma were related to higher levels of posttraumatic stress, anxiety, depressive symptoms, and nonspecific distress, especially when traumatic events were experienced in both childhood and adulthood. Brumsey found that social support was more strongly associated with psychosocial resources among HIV-positive women than HIV-negative women. Brumsey et al. (2013) found that anxiety associated with psychological distress was significantly higher for HIV-positive women than for HIV-negative women. This result indicated that HIV-positive women reported significantly more anxiety symptoms than HIV-negative women, which is consistent with previous studies showing higher mood and anxiety disorders rates among HIV-positives than the general population (Brumsey et al., 2013).

Hickman and colleagues (2013) examined the role of religious coping in psychological distress and adjustment among 141 HIV-positive African American women. Cross-sectional analyses showed that negative religious coping (being angry, mad at God) was associated with poorer mental health and functioning and greater perceptions of stigma and discrimination. Longitudinal analyses revealed that greater negative religious coping at baseline significantly predicted greater changes in mental health in a negative direction after 12 months. Positive religious coping (prayer, connecting with God) was not associated with any measures of psychological well-being, nor did it predict any mental health outcomes at 12 months. Participants who experienced high levels of HIV-related stigma and reported high levels of positive religious coping were significantly less depressed than those who reported lower levels of positive religious coping. Results indicated that African American women living with HIV were typically contending with other issues, such as mental health disorders and problems, and were significantly more likely to conceal their feelings of being diagnosed with HIV than their White counterparts. Hickman et al. (2013) also found that higher negative religious coping was associated with poorer psychological functioning and adjustment. Higher levels of negative religious coping were significantly correlated with greater depression and psychiatric symptom severity, decreased social support from friends, and a greater perception of discrimination. Higher levels of negative religious coping were also significantly correlated with poorer mental health and clinician-rated functioning, and greater perceptions of stigma, whereas positive religious coping was not related to psychological well-being. These results suggested that for African American women living with HIV, negative religious coping was a more salient determinant of psychological distress than positive religious coping was of psychological health (Hickman et al., 2013).

Despite the challenges and complexities that HIV-positive African American women experienced in everyday life, they can actively engage in managing their health. In a qualitative study with 22 HIV positive African American women, Peltzer et al. (2016) examined the experiences of African American's women's psychological distress and the use of coping strategies. Following an HIV diagnosis, Peltzer found that the African American women experienced significant psychoemotional suffering, which negatively influenced the African American women's daily lives, their abilities to attend to their health, and their relationships with significant others, families, and their communities (Peltzer et al., 2016). Psychological distress was exacerbated among African American women who had children because of the possibility of their children being without them. Isolation based on the fear of stigma and concerns about disclosure contributed to suffering. While psychological distress was evident in African American women, they used spiritual and religious practices to cope. Disclosing one’s status also gave the women relief because they no longer had to maintain a secret diagnosis, facilitating a reduction in depression symptoms as a result of increased opportunities for social support. These findings suggested that spiritual and religious practices were helpful for African American women in coping with psychological distress associated with HIV diagnosis (Peltzer et al., 2016).

In a similar study, Peltzer et al. (2017) explored the lived everyday experiences related to psychological distress among 11 African American women living with HIV. After learning of their HIV diagnosis, participants experienced significant experiences of distress, which included depression, sadness, and suicidal thoughts. Other experiences included emotional suffering, negative contextual factors resulting from everyday experiences of living with HIV, and stigma, which facilitated loneliness and isolation. Psychological distress obscured African American women’s ability to manage HIV. In addition to hindering the management of the disease, it contributed to experiences of anger, anxiety, suicidality, and other negatives feelings and thoughts. Peltzer et al. (2017) discussed an overarching pattern. That is, results indicated that when living alone with HIV, the women felt alone with few individuals to share their feelings and no one to understand their lived experiences, *even with* support from families or significant others

(Peltzer et al., 2017). Results also indicated that living with unresolved conflicts, in which the multiple roles of caregiving for self and others, could negatively influence women's health. In addition, living with multiple layers of betrayal resulted in stigma and discrimination negatively impacting interpersonal (family and friends) and social systems (community and health care systems).

While Peltzer found that spiritual and religious practices were a great source for coping with psychological stress associated with HIV diagnosis, Jones et al. (2003) argued that family stress was a meditating factor between HIV diagnosis and psychological distress. Jones et al. examined the association between stressful life events, self-reported health, and depressive symptoms in a longitudinal study with 72 inner-city, low-income African American women living with HIV. Results indicated that family stressors fostered a significant decline in women's self-reported health, along with depressive symptoms mediating the link between family stress and self-reported health. In addition, stressful events negatively impacted HIV positive African American women's perception of their health producing more physical symptoms. Based on these findings, it was presumed that family stress results in a decline in self-reported health among African American women that may be detrimental to their quality of life. Further clinical implications suggested that health care professionals working with African American women living with HIV should assess and monitor family stressors and provide appropriate referrals for women coping with higher levels of family stress. In addition, researchers should examine family-based prevention and interventions for clients and families (Jones et al., 2003).

Because African American women are usually the caregivers of others living with HIV and matriarchs in their families, they are sometimes reserved about sharing their feelings or emotions with others for fear of displaying their weaknesses (Watson-Singleton, 2017). Watson-Singleton (2017) asserted that African American women have been perceived as possessing strength in the family dating back to slavery. Despite the perceived notion of strength, African American women have lost their ability to show sadness, depression, and hopelessness (Watson-Singleton, 2017). Being a strong black woman carries a set of expectations that fosters negative outcomes, such as depression, anxiety, and binge eating (Watson-Singleton, 2017). Watson-Singleton examined perceived emotional support and the link between the strong black woman schema and psychological distress among HIV negative African American women. Participants (n=158) ranged in age from 18 to 59 years. The strong black woman schema was hypothesized to be inversely related to perceived emotional support, perceived emotional support would be inversely associated with psychological distress, and perceived emotional support would mediate the relationship between the strong black woman schema and psychological distress in HIV negative women. Results indicated that perceived emotional support was partially linked to the strong black woman schema and psychological distress. Being a strong black woman was also significantly related to decreased perceived emotional support and increased psychological distress (Watson-Singleton, 2017). This study demonstrated that Black or African American women are strong and are assumed to have the ability to overcome many adversities in their lives (Watson-Singleton, 2017).

African American Women, Grief, and Support

Historically, African American, or black women have not been given a platform to grieve (Laurie & Neimeyer, 2008). Much of this has been attributed to slavery, racism, and oppression. Post-slavery has depicted women community leaders as actively fostering kinship bonds to strengthen the community and effect social change. African American women have demonstrated strength and resilience and have always been perceived as a guiding force in getting family through crises (Laurie & Neimeyer, 2008).

When there is a death or loss in their lives, African American women generally grieve privately, spend less time talking about the death or loss, and are less likely to seek professional help than Caucasian women (Piazza-Bonin et al., 2015). The idea of being vulnerable and weak hinders their motives for the professional help that may be readily available and offered in their communities (Piazza-Bonin et al., 2015). Because there are specific expectations in the African American community about grieving, women may not be comfortable discussing their feelings and emotions with others (Piazza-Bonin et al., 2015). These expectations include surviving amid challenges, moving past the mourning stage, maintaining previous social roles, and being the “fixer” of others’ issues and problems (Piazza-Bonin et al., 2015; Sharpe & Boyas, 2011).

Harrison et al. (2005) compared the coping mechanisms for three Caucasian women and four African American widows experiencing grief and bereavement. Harrison et al. (2005) found that African American widows utilized more support from family, friends, and other relatives when compared to the Caucasian women who needed more support with financial problems and control over their lives. The African American widows also utilized religion, spirituality, and belief in God as a significant coping strategy for dealing with the loss (Harrison et al., 2005).

Because African American women are usually the caregivers of others living with HIV and matriarchs in their families, they are sometimes reserved about sharing their feelings or emotions with others, thus displaying their weaknesses (Watson-Singleton, 2017). Peltzer et al., (2016) posited that African American women try to hide their weaknesses behind a wall of strength. These findings suggest that women may not be at liberty to discuss emotional vulnerabilities. Watson-Singleton (2017) agreed that African American women had been perceived as possessing strength in the family dating back to slavery.

There are variations of bereavement among cultures and ethnicities. To this end, Schoulte (2011) and Laurie and Neimeyer (2008) recommended that counselors understand cultural differences and diverse practices related to loss among people of color and be more empathetic to the unique needs and challenges of African Americans seeking counseling and treatment. Schoulte (2011) stressed that counselors should allow clients to share what their experiences mean to them. African Americans’ grieving experiences do not reflect those of Caucasians, and the traditional theories of bereavement do not fully capture the cultural differences associated with the way in which African Americans grieve (Laurie & Neimeyer, 2008). In their study of 1,581 bereaved African American and Caucasian undergraduate psychology students, Laurie and Neimeyer (2008) examined African American students’ experience of grief. Laurie and Neimeyer found that African American students were less likely to get professional help following the death of a loved one due to the strength and support of other family members than Caucasian students. This was due to historical implications dating back to slavery and a level of mistrust for counseling professionals. African Americans also have significant within-group differences (racial and ethnic differences), which may be influenced by geographical location, social class, family influences, and spiritual beliefs (Schoulte, 2011).

Family Support

While families may seem to be a source of support for African American women, Owens stated that families can also contribute to the stress of women living with HIV. Owens (2003) identified the value of family as a source of support when family members need help, and African American families are likely to be the first source of support when dealing with a crisis. In this qualitative study with 18 African American women living with HIV, Owens investigated ways in which families provide support or foster stress among women living with HIV. Owens found that African American families were a source of strength when individuals are dealing with HIV/AIDS. Owens (2003) also found that the African American women emphasized stress pertaining to family members not listening to their concerns of becoming sicker. The inability to communicate with family members, a family’s denial, a family’s grieving process, parents’ struggle with their limitations and an inability to undo the unfortunate, and families’ inability to communicate the shame, guilt and anger associated with a family member living with HIV/AIDS are factors that cause stress for an individual living with HIV/AIDS (Owens, 2003).

Social and family support within African American communities is prevalent when dealing with grief and bereavement. When mourning, African Americans have different rituals and larger social networks than Caucasians (Piazza-Bonin et al., 2015). The strength drawn from family members and friends was attributed to spiritual and other faith-based practices, such as prayer. To this end, Sharpe and Boyas (2011) explained that many African Americans forfeited attending church or formalized religious services and often focused more on private prayer to God to help them cope with grief and bereavement. While these authors agreed on the importance of social and family support as well as spirituality and spiritual practices to help African Americans experiencing grief and bereavement, there was some difference in the form of spiritual and faith-based practices utilized by African Americans. These differences included religious beliefs, holistic forms of healing, communal spiritual traditions, messages, rituals, and activities taught by ancestors (Sharpe & Boyas, 2011). Burke et al. (2010) argued that the lack of social support can exacerbate the pain of the loss. When supporters fail to welcome, walk alongside, and help the bereaved process the grief, it leads to grief that goes unnoticed, unvalued, and unacknowledged (Burke et al., 2010).

Spiritual Support

Sharpe and Boyas (2011) explained that many African Americans forfeited attending church or formalized religious services, often focusing more on private prayer to God to help them cope with grief and bereavement. In this qualitative study, Sharpe and Boyas examined the coping strategies of African American survivors of homicide. Interviews were conducted with 8 African American family members (ages 18-82) of homicide victims. Survivors were recruited from the Massachusetts Office of Victim Services and from homicide survivor support, school, and community groups throughout the New England area. Interviews were conducted using open-ended questions derived from coping, support network, grief, and bereavement literatures. Results indicated that the primary coping strategies utilized by African American survivors of homicide victims were spiritual coping and meaning making, maintaining a connection to the deceased, collective coping and caring for others, and concealment. While these authors agreed on the importance of social and family support as well as spirituality and spiritual practices to help African Americans experiencing grief and bereavement, there was some difference in the form of spiritual and faith-based practices utilized by African Americans. These differences include religious beliefs, holistic forms of healing, communal spiritual traditions, messages, rituals, and activities taught by ancestors (Sharpe & Boyas, 2011).

In their study with 308 African American women living with HIV, Braxton et. al. (2007) explored the role of spirituality in psychological health. Braxton et al. (2007) found that spirituality played a role in helping HIV-positive Black women sustaining psychological well-being. Braxton also found that spirituality enhanced an individual’s ability to cope with negative life events, and decreased levels of depressive symptoms. This finding suggested that spirituality served as a protective factor for Black women’s psychological well-being.

Spirituality is often an integral part of the health and well-being of African American women living with HIV/AIDS (Dalmida, 2011; Dalmida et al., 2012). Prayer, meditation, and reading the Bible are common practices for women living with HIV

(Dalmida et al., 2012). Historically, African American women have reported feeling that spirituality provided them with improved health, healing, and a second chance in life, despite their illness (Dalmida et al., 2012). Utilizing spirituality or spiritual beliefs can be significant when experiencing the grief of living with HIV. It reduces stress, anxiety depression; while increasing life satisfaction, optimism, and quality of life (Dalmida, 2011; Dalmida et al., 2012).

Spirituality and spiritual beliefs can be sources of strength and also sources of conflict. Individuals living with HIV are faced with various challenges of grief, loss, meaning, purpose, and death (Cotton et al., 2006). Cotton et al. (2006) and Dalmida (2006) found that spirituality was central as HIV individuals explore purpose and meaning in life. In their study, Cotton et al. (2006) examined associations between spirituality/religion and a number of demographics, clinical, and psychosocial variables over 12 to 18 months. The authors argued that there can be adverse effects of spirituality for individuals living with HIV. For example, some women reported being ostracized from faith communities or religious institutions due to their illness (Cotton, 2006). In their study, Burke et al. (2011) investigated whether religious coping predicted psychological distress in 46 African American homicide survivors. Burke et al. (2011) argued that individuals may struggle with finding comfort in spirituality because of their anger towards God for the loss. Individuals may question their faith, religious community, and even God (Burke et al., 2011). Engagement in traditional spiritual activities or with other parishioners does not always provide sufficient bereavement support that addresses spiritual progress and psychological functioning (Burke et al., 2011). Burke et al. (2011) found that bereaved African Americans experiencing a loss from homicide had higher positive and negative levels of religious coping than individuals experiencing grief from terrorism or medical illness. Although this study was not related to HIV diagnosis, it highlighted African Americans' inability to always find solace in spirituality or spiritual practices for handling grief and loss in their lives.

In a mixed-methods study, Bailey et al. (2013) explored the cognitive process of black mothers (*N* = 48) in finding meaning and building resilience following loss of their children to gun violence. Bailey et al. (2013) pointed out that the mothers' grief process was stressful and complex, along with them finding meaning and purpose out of the deaths. Bailey et al. (2013) also concluded that the mothers could not totally make meaning out of the deaths due to the loss of social support, perceived treatment by police, and race-based stigma associated with gun violence. Yet, black mothers experiencing the loss of a child though gun violence were able to understand their loss, process meaning of the death, and interact with others (Bailey et al., 2013).

Sharpe et al. (2014) reported that African Americans often feel deprived when grieving the death of a loved one. When loved ones die, African Americans are generally preoccupied with many aspects of the death, including managing their grief and helping others cope with grief (Sharpe et al., 2014). In their study with African American family members of 44 homicide victims, Sharpe et al. (2014) examined the effects gender, length of time since death, the trauma of experiencing the death, and the use of coping strategies to current grief reactions. Results showed that African Americans often suppressed their emotions or relied on spiritual, collective, and shared coping resources to help them manage their grief due to the lack of resources that may be available to this population (Sharpe et al., 2014). Sharpe et al. (2014) also found that African American women had higher levels of current grief than African American men when facing the loss of a loved one.

Disenfranchised Grief

Disenfranchised grief is grief experienced as a result of a loss that cannot be openly acknowledged, socially validated, or publicly mourned (Corr, 2002; Doka, 2002a; St. Clair, 2013). Individuals often desire to express their loss, thus giving them an opportunity to accept it and help others understand what they were experiencing. The lack of expression and validation of the loss often leads to disenfranchised grief (Lawson, 2014; Mortell 2015; St. Clair, 2013). Losses also often carry social stigma. Individuals may feel shame involving their losses, thus unable or unsure about expressing those losses openly (Mortell, 2015). They may not receive validation, sympathy, or consideration that may be afforded others who have experienced losses (Mortell, 2015).

Doka (2002b) stated that individuals experiencing disenfranchised grief may have intense reactions to loss that society and others do not honor or acknowledge (Doka, 2002b). Individuals experiencing loss do not have a right to grieve the loss since others do not recognize it as a valid cause of grief (Doka, 2002a). Doka (2002a) also reported that the persons experiencing the loss are not believed to be capable of grief or when circumstances of the loss are dismissed, and stigma of the loss inhibits the grieving person from seeking or receiving support. Finally, grief can be disenfranchised when the way the person grieves is not perceived by others as appropriate (Doka, 2002a).

Mortell (2015) reported that disenfranchised grief is associated with secrecy and shame, and the absence of public acknowledgement and support make it difficult for individuals attempting to process their losses. Mortell (2015) pointed out five components of grief that are considered to be disenfranchised. These components include: (a) that the relationship not recognized and may include homosexual and extramarital relationships, as well as relationships between ex-spouses; (b) the loss is not acknowledged and perceived as insignificant (e.g., miscarriages, abortions, or the death of a pet); (c) the griever is excluded and they are perceived as being incapable of understanding death or of experiencing grief (e.g., children, mentally ill individuals, older adults, developmentally disabled individuals); (d) the circumstances of death because some deaths carry stigma or evoke anxiety (e.g., AIDS deaths, executions, suicides) and grievers may be disenfranchised because such deaths inhibit the expression of grief or social support; and (e) if the expression of grief conflicts with social expectations it can cause disenfranchisement. For example, an individual may show no or excessive emotion, or may act out his or her grief through socially unacceptable behaviors (e.g., excess anger, substance abuse).

While disenfranchised grief is associated with death, it can be associated with other losses such as stigmatized losses (Doka, 2002b). Stigmatized losses are losses heavily influenced by culture to include the way individuals grieve, how individuals behave after the loss, how they come to think and feel about the loss and the manner in which it may be appropriate to grieve (Brosnan, 2013; Gill & Lowes, 2014; Pillai & Ashline, 2014). The loss of health through illness or disease can be devastating (Pillai &

Ashline, 2014). Many individuals associate loss with death, thus forgetting the grieving process for individuals faced with illnesses and diseases. Pillai and Ashline discussed the relationship between breast cancer and sexuality, and how grieving sexual losses can lead to disenfranchised grief. They also stated that many breast cancer survivors experience a lack of acknowledgment or ambiguity surrounding their illness, resulting in disenfranchised grief. Having breast cancer prohibits women from acknowledging loss in their lives, and lack of acknowledgement surrounding breast cancer may result in disenfranchised grief (Pillai-Friedman & Ashline, 2014). Pillai-Friedman and Ashline (2014) found that various treatments for breast cancer survivors could significantly affect their quality of life, resulting in severe loss. Family members, friends, and intimate partners, health care providers, and psychotherapists may not understand this ambiguous loss (Pillai-Friedman & Ashline, 2014). They concluded that this form of grief may be disenfranchised grief, which is grief that is precipitated by a loss that cannot be socially sanctioned, openly acknowledged or publicly mourned.

Gill and Lowes (2014) agreed that grief is not only associated with death, but can also occur following other significant losses, including loss a relationship, a limb, or loss of one’s health. Loss of health is not as tangible as the death of a loved one yet is as significant due to the loss of independence, autonomy, control, freedom, preferred treatment, lifestyle and hopes and expectations for the future. In their qualitative, longitudinal study, Gill and Lowes explored participants’ experiences of renal transplant failure in the first-year post-graft failure. A sample of 16 participants (8 recipients, 8 significant others) from a regional renal transplant unit and three District General

Hospitals in South-West England. Data were collected through a series of three recorded, semi-structured interviews in the first-year post-renal transplant failure. Gills and Lowes found that the grief process is unique and depends on the person, their circumstances, and the nature and extent of the losses. Non-death losses were viewed as less intense than losses related to death (Gill & Lowes, 2014). The right to grieve is not often allowed, thus creating further issues and problems for the individuals affected. Gill and Lowes (2014) also reported that disenfranchised grievers will not usually seek out social support because none is available or if support is available, it is believed that support is not necessary. Family members, friends, and health care professionals do not always understand the experiences of transplant failure or the feelings associated with grief and loss. Because of this, they fail to provide support, help, or advice, which further complicates the experiences of the patient, and contributes to disenfranchisement (Gill & Lowes, 2014). This confirms that disenfranchised grief is not valued as grief, making it more challenging to seek support and help for persons experiencing losses.

Gill and Lowes (2014) also found that participants experiencing renal failure grieved the loss of their previous life and imagined future, resulting in feelings of grief, loss, sadness, and guilt. The conflict between how things were, how things are, and how things should be were significant and appeared to be the primary source of grief, loss, sadness, and depression (Gill & Lowes, 2014). The authors stressed that family members and health professionals lacked the ability to understand the significance of loss and the grieving process among this population (Gill & Lowes, 2014). While family members lacked the ability to understand the illness' significance on the patient, its impact was significant on the spouses (Gill & Lowes, 2014). They experienced similar emotional reactions while dealing with the patient's illness, to include ongoing fear and concern for their partners, potential changes in marital roles, relationships and responsibilities, stress, and anxiety (Gill & Lowes, 2014).

Disenfranchised Grief and HIV

Individuals living with HIV experience numerous changes and adjustments in their lives, including stigma, discrimination, and prejudice (Peters, 2013). People living with HIV and those grieving HIV-related deaths are finding it more difficult to grieve the loss of loved ones. Peters (2013) explained that grief counseling has not been effective in meeting the needs of individuals living with HIV. Although the diagnosis of HIV does not carry an immediate death sentence, individuals are often concerned about an impending death. Grieving the loss of health, and ultimately death, may elicit emotional responses, including numbness, denial, pain, frustration, anger, depression, anxiety, fear, helplessness, hopelessness, sadness, loneliness, powerlessness, regret, remorse, never ending uncertainty, and suicidal thoughts. Peters (2013) concluded that the grieving process becomes more challenging when it is coupled with shame, self-blame, secrecy, social stigma, humiliation, other losses, physical declines, and medical treatments.

Summary and Conclusions

African American women are disproportionately infected with HIV/AIDS, and they experience a number of negative consequences associated with their diagnosis. Some of these negative experiences include loss of relationships with family, friends, significant others, stigma, psychological distress, and disenfranchised grief. As African

American women work to address the psychological pain of being diagnosed with and living with HIV, it is essential to understand other experiences while coming to terms with being diagnosed with and living with HIV. Other common experiences include discrimination, loneliness, and social isolation. Examining disenfranchised grief, social support loss, and stigma among African American women living with HIV can better inform support programs and services that address psychological distress issues. The proposed study fills the gap in the literature by examining the extent to which disenfranchised grief, social support loss, stigma, predict psychological distress among African American women living with HIV. In Chapter 3, I discuss the research design and methodology, sample and sampling procedures, instrumentation and operationalization of constructs, data analysis plan, threats to validity, and ethical considerations.

Chapter 3: Research Design and Methodology

Introduction

Being diagnosed and living with HIV can be challenging. African American women continue to be marginalized and disproportionately infected with and affected by HIV. The lack of support and the ability to grieve one's illness and the intensified stigma associated with HIV can lead to anxiety and depression. The purpose of this study was to examine the predictive relationship between disenfranchised grief, social support loss, and psychological distress among African American women living with HIV. More specifically, I evaluated the relative strength of disenfranchised grief and social support loss (family, friends, and significant others) in predicting psychological distress (anxiety and depression). In Chapter 3, I describe the quantitative research design and statistical measures utilized in the study. This chapter includes the description of the sample and sampling procedures, participant inclusion and exclusion criteria, recruitment procedures, data collection, reliability and validity for the specific measurement tools, data analysis plan, threats to validity, and ethical considerations.

Research Design and Rationale

The study was quantitative with a nonexperimental correlational survey method. Standard multiple regression analysis was used to determine the extent to which disenfranchised grief and social support loss (family, friends, and significant others) predict psychological distress (anxiety and depression) among African American women living with HIV. Standard multiple regression is a method used to determine the value of a DV based upon the value of two or more IVs (Sheposh, 2020). Multiple regression provides a way to understand the relationship of a set of IVs to a DV. It also helps guard against making inaccurate conclusions based on partial correlation (Sheposh, 2020). Edmonds and Kennedy (2017) asserted that the most common form of nonexperimental research is the survey approach. Surveys are used to observe trends, attitudes, or opinions of the population of interest (Edmonds & Kennedy, 2017). The research design generalizes, leading to predictions, explanations, and understandings. DVs are also identified, which are presumed to be influenced by the IVs (Sheposh, 2020; Smith, 2014). In this study, the predictor variables included disenfranchised grief and social support loss. The dependent/criterion variables were components of psychological distress (i.e., anxiety and depression). Thus, two standard multiple regression analyses were conducted: one analysis to predict anxiety, and a second analysis to predict depression.

Methodology

Population

The target population for the current study was African American women living with HIV. Based on CDC data, Blacks/African Americans remain disproportionately affected by HIV. In 2018, Blacks/African Americans accounted for 42% of new HIV diagnoses and 13% of the population (CDC, 2020). Black/African American women are disproportionately affected by HIV compared with women of other races/ethnicities. Of the total number of women living with and diagnosed with HIV at the end of 2015, 59% were African American, 19%, were Hispanic/Latina, and 17% were White (CDC, 2018b).

Women accounted for 24% of the 18,160 AIDS diagnoses in 2016 and represented 20% of the 1,232,346 cumulative AIDS diagnoses in the United States from the beginning of the epidemic through the end of 2016 (CDC, 2018b). In 2018, 37,968 people received an HIV diagnosis in the United States and dependent areas. Of the 37,968 people receiving an HIV diagnosis, 3,758 African American women were infected via heterosexual contact, 1,109 Latino women were infected via heterosexual contact, and 956 White women were infected via heterosexual contact (CDC, 2020).

Sampling and Sampling Procedures

A convenience sample of African American women living with HIV in the United States were recruited. It was a posting that described the study to potential participants. The sample within Facebook group that supports women living with HIV was a national online social media platform. I also provided that posting to the Maryland Department of Health Faith and Community Partnerships, whose staff emailed the post to members who belonged to the group. The inclusion criteria for participants in the study included the following: (a) African American women living with HIV in the United States, (b) over 18 years of age, and (c) currently diagnosed with HIV for over a year.

A power analysis was performed using G*Power 3.0 software to calculate the minimum recommended sample size for linear multiple regression using a fixed model and R^2 deviation from zero (Faul et al., 2007). The parameters included in the power analysis were an alpha level of 0.05, four predictor variables, a medium effect size of .20, and statistical power of 0.95 (Faul et al., 2007). The power analysis resulted in a minimum recommended sample size of 98 participants. Previous research examining perceived social support and well-being among HIV positive African American adults reported a medium effect size (e.g., Williams & Smith, 2009).

Procedures for Recruitment, Participation, and Data Collection

After approval from the Walden Institutional Review Board (IRB), I posted a description of my study (and SurveyMonkey link) on the Facebook group for the Positive Women’s Network—USA (PWN-USA) to recruit African American women with HIV. The Facebook membership engagement coordinator of PWN-USA approved my request to recruit participants. PWN-USA is a national membership body of women living with HIV and allies that exists to strengthen the strategic power of all women living with HIV in the United States. It was founded in 2008 to develop a leadership pipeline and policy agenda that applies a gender lens to the domestic HIV epidemic grounded in social justice and human rights. The PWN-USA Facebook group has approximately 3000 members with over 8000 followers.

I requested permission from the chief of the Office of Faith Based and Community Partnerships for the Prevention and Health Promotion Administration under the Maryland Department of Health (MDH) to recruit women for my study through their email distribution list. They emailed the description of the study and the Survey Monkey link (similar to the Facebook post) to the members of the group in an effort to recruit women for the study (Appendix A). The MDH serves individuals throughout the state. I chose the MDH because of accessibility and the department’s provision of services and support to women living with HIV.

When participants clicked on the SurveyMonkey link, the first page displayed the informed consent form (which was approved by the Walden University IRB). Each participant was asked to click “Agree” on the informed consent form to begin the survey.

The surveys were completed in the following order via SurveyMonkey: (a) demographic questionnaire (Appendix C), (b) the Witnessing of Disenfranchised Grief Scale (Appendix D), (c) Multidimensional Scale of Perceived Social Support (Appendix E), and (d) the modified version of the Depression, Anxiety, and Stress Scale-21 (Appendix F) .

The consent form described participation procedures, the voluntary nature of the study, and risks and benefits of participation, and it indicated that the data being collected would be anonymous and confidential. Contact information for me and for the Walden University participant advocate were provided should participants have questions about the research or participant rights. After the informed consent was provided, participants were screened for eligibility. Potential participants who did not meet the inclusion criteria were led to a “thank you” page restating the participation requirements and my contact information. Eligible participants completed the survey. It took approximately 35 minutes to complete all the survey items. Upon survey completion, participants were directed to a “thank you” and debriefing page where they would receive information about the specific nature and purpose of the study.

Instrumentation and Operationalization of Constructs

Demographic Questionnaire

The brief demographics questionnaire (Appendix C) assessed information including gender, age, race, and HIV status (how long they had been living with HIV diagnosis). The demographic questionnaire took approximately 5 minutes to complete.

Witnessing of Disenfranchised Grief Scale

The Witnessing of Disenfranchised Grief (WDG) scale was used to assess the degree to which someone who was grieving a loss perceived that their grief was witnessed. Witnessing disenfranchised grief refers to when someone acknowledges the loss and the right of the griever to grieve. A loss that is perceived as being witnessed should result in a decrease in grief symptoms. The WDG consists of 22 items. Participants endorse statements about themselves (e.g., “My feelings are easily hurt when I feel that others do not accept me”; “I try hard not to do things that will make other people avoid or reject me”) using a 5-point Likert-type scale ranging from 1 (*strongly disagree*) to 5 (*strongly agree*). The WDG has a possible range of scores from 17–85, with higher scores indicating higher levels of perceived witnessing of their loss (St. Clair, 2013). The WDG takes approximately 10 minutes to complete. The WDG is in the public domain, and I was given permission to use the WDG scale by the author (Appendix D).

Reliability and Validity

The reliability of the WDG was assessed using Cronbach’s alpha, and St. Clair (2013) reported an alpha of 0.91. This result demonstrated a high internal consistency. Construct validity was first demonstrated with a factor analysis, and results demonstrated that the 22 items represented a single dimension with item factor loadings that ranged from 0.40 to 0.78. Additional construct validity was established by correlating the WDG with a measure of actual grief response (the Texas Revised Inventory of Grief). The result showed that higher scores on WDG resulted in significantly lower scores of actual grief response. This result demonstrated that when participants had stronger perceptions that grief was witnessed, they had more positive feelings about the loss and remained engaged in their lives and support systems. In addition, the WDG scores were correlated with scores on the Center for Epidemiologic Studies Depression Scale (CES-D). The results also showed significant negative correlations between the WDG and components of depression (r values ranging from -.15 to -.18, $p < .05$). This result indicated that having a loss witnessed resulted in significantly reduced symptoms of depression. Taken together, these results demonstrate that the WDG is a reliable and valid instrument measuring the perceived level to which a loss was witnessed.

Multidimensional Scale of Perceived Social Support

The Multidimensional Scale of Perceived Social Support (MSPSS) was used to measure an individual’s perception of the availability of various types of social support, and how much they received outside social support from family, friends, and significant others (Zimet & Farley, 1988). The MSPSS consists of 12 items with a 7-point Likert-type scale ranging from 1 (*very strongly disagree*) to 7 (*very strongly agree*). The MSPSS consists of three subscales—family, friends, and significant others—with each subscale containing four items (Wongpakaran et al., 2011; Zimet, 1988). The MSPSS takes approximately 5 minutes to complete. The MSPSS is in the public domain, and I requested permission from the author (Zimet, 1988).

Reliability and Validity

Zimet et al. (1988) assessed the internal consistency of the MSPSS using Cronbach’s alpha and found the following: significant other subscale (.91), family subscale (.87), friends’ subscale (.85), and total scale (.88). Zimet et al. also assessed test-retest reliability over a 2- to 3-month period. The test-retest reliability coefficients (*r*) were as follows: significant other support subscale (.72), family support subscale (.85), friends support subscale (.75), and total scale (.85).

Construct validity was first demonstrated with a factor analysis on the original 24 items, and results demonstrated a three-factor solution (Zimet et al., 1988). The factor item loadings for the significant other subscale ranged from .74 to .92. The factor item loadings for family subscale ranged from .81 to .84. The factor item loadings for the friends subscale ranged from .79 to .86. Construct validity was also assessed by Zimet et al. (1988) by correlating the scores on the MSPSS subscales and scores of depression and anxiety (Hopkins Symptom Checklist). Scores on the family support subscale were significantly inversely related to both depression ($r = -.24$, $p < .01$) and anxiety ($r = -.18$, $p < .01$). Scores on the friends support subscale were significantly inversely related to depression ($r = -.24$, $p < .01$) but were not related to anxiety. Scores on the significant other support scale were significantly inversely related to depression ($r = -.13$, $p < .05$) but were not related to anxiety. Zimet et al.'s results demonstrated good internal consistency and test-retest reliability as well as moderate levels of construct validity.

In a more recent study, Williams and Smith (2009) reported construct validity for MSPSS in a study examining the relationship between social support, psychological well-being, and immunological measures among African Americans living with HIV. Specifically, they found that scores on the Beck Depression Inventory-II (BDI-II) were negatively correlated with scores on the MSPSS. The results demonstrated that participants with high levels of depression were more likely to have low perceptions about social support and more likely to have high levels of anxiety (Williams & Smith, 2009).

Depression, Anxiety, and Stress Scale

The Depression, Anxiety, and Stress Scales (DASS) measured the severity of a range of symptoms for anxiety and depression (Lovibond & Lovibond, 1995). The original DASS consists of 42 items with a 4-point Likert-type scale ranging from 0 (*did not apply to me at all*) to 3 (*applied to me very much, or most of the time*) over the past week. The DASS consists of three subscales (depression, anxiety, and stress), with each subscale containing 14 items.

For my study, I used the DASS-21 (Henry & Crawford, 2005). The DASS-21 measured the dimensions of anxiety and depression. The DASS-21 consists of 21 items with a 4-point Likert-type scale ranging from 0 (*did not apply to me at all*) to 3 (*applied to me very much, or most of the time*) over the past week. The DASS-21 consists of the same three subscales as the long version, with each subscale containing seven items. The DASS-21 takes approximately 10 minutes to complete. The DASS is in the public domain, and I requested permission from the author (Henry & Crawford, 2005).

Reliability and Validity

Lovibond and Lovibond (1995) assessed the reliability of the DASS using Cronbach’s alpha and found high internal consistency: depression subscale (.91), anxiety subscale (0.84), and total scale (.92). Construct validity was first demonstrated with a factor analysis on the original 42 items, and a three-factor principal components solution was found (Lovibond & Lovibond, 1995). The items on the depression subscale had factor loadings that ranged from .45 to .80. The factor item loadings for the anxiety subscale ranged from .20 to .64. Construct validity was also assessed by Lovibond and Lovibond by correlating the scores on the DASS subscales and scores of depression (using the BDI) and anxiety (using the Beck Anxiety Inventory [BAI]). Higher scores on the DASS depression subscale were significantly related to higher levels of depression on the BDI ($r = .74$, $p < .0.05$). Higher scores on the DASS anxiety subscale were significantly related to higher levels of anxiety on the BAI ($r = .81$, $p < .0.05$). Lovibond and Lovibond (1995) reported good internal consistency and moderate levels of construct validity. Combined, these results demonstrate that the DASS is a reliable and valid instrument for assessing anxiety and depression.

Henry and Crawford (2017) assessed the reliability of the DASS-21 using Cronbach's alpha and found high internal consistency: depression subscale (.82), anxiety subscale (0.90), and total scale (.88). Construct validity was established using principal components factor analysis, which results in the same three-factor solution (anxiety, depression, and stress). The authors demonstrated convergent and discriminant validity by correlating scores on each subscale of the DASS-21 with two independent measures of anxiety and depression. The results were identical to those of Lovibond and Lovibond (1995). Scores on the DASS-21 depression subscale were significantly related to higher levels of depression on the Hospital Anxiety and Depression scale. Scores on the DASS-21 anxiety subscale were significantly related to higher levels of anxiety on the Hospital Anxiety and Depression scale. Together, these results demonstrate that the DASS-21 is a reliable and valid instrument measuring anxiety and depression.

Data Analysis Plan

Data collected from Survey Monkey platform will be uploaded into the Statistical Package for Social Sciences (SPSS) version 25.0 for data analysis. Multiple regression is designed to assess whether one continuous DV can be predicted from a set of independent (or predictor) variables, or how much variance in a continuous DV is explained by a set of predictors (Cohen & Cohen, 1983). Multiple regression provides a way to understand the relationship of a set of IVs to a DV. Standard multiple regression will be used to determine the extent to which disenfranchised grief and social support loss (family, friends, and significant others), predict psychological distress (anxiety and depression) among African American women living with HIV. Two standard multiple regression analyses will be conducted: one analysis to predict anxiety, and a second analysis to predict depression. Assumptions for multiple regression will be tested in SPSS prior to the regression analysis (i.e., normality, linearity, homoscedasticity, multicollinearity, and independence of residuals). Normality will be tested using the Shapiro-Wilk test and Q-Q plots. Linearity will be examined using scatterplots. A scatterplot of residuals will be used to test for homoscedasticity. Multicollinearity will be tested using Variance Inflation Factor (VIF) values, and independence of residuals will be examined using the Durbin-Watson *d* test. The following research questions and hypotheses will be addressed.

Research Questions

The primary focus of this study is to determine the extent in which disenfranchised grief, health and social loss, and stigma influences psychological distress in African American women living with HIV. The following research questions will guide the proposed study:

RQ1: To what extent does disenfranchised grief, as measured by the Witnessing of Disenfranchised Grief scale, relate to psychological distress (anxiety and depression subscales), as measured by the Depression, Anxiety, Stress Scales (DASS-21), in HIV positive African American women?

H_o: Disenfranchised grief is not a significant predictor of psychological distress.

H_a: Disenfranchised grief is a significant predictor of psychological distress.

RQ2: To what extent does social support loss (family, friends, and significant others' subscales), as measured by the Multidimensional Scale of Perceived Social Support, relate to psychological distress (anxiety and depression subscales), as measured by the Depression, Anxiety, Stress Scales (DASS-21), in HIV positive African American women?

H_o: Social support loss is not a significant predictor of psychological distress.

H_a: Social support loss is a significant predictor of psychological distress.

Threats to Validity

Quantitative research is described as more reliable and valid than qualitative or mixed methods approaches because of the objective data collection processes (Creswell & Creswell, 2018). However, quantitative research also has threats to both external and internal validity. External validity refers to the extent to which the research can conclude that the results apply to a larger population (Creswell & Creswell, 2018). That is, the results are generalizable. One possible threat to the external validity of the proposed study is the sampling method. I will be using a convenience sample in this study. This non-random sampling provides weaker external validity and is more likely to be biased than random samples (Trochim & Donnelly, 2008). However, to improve generalizability I will be recruiting from social media site (Facebook) with thousands of members across the United State and a state agency that serves my specific population of interest (African American women who are HIV positive).

It is also likely that some African American women may be reluctant to participate/or withdraw from the study because of the stigma and/or psychological distress they are experiencing. On the other hand, women who might have more social support and who are in better physical and mental health may be more likely to participate. Any of these issues could impact the results and misrepresent the population of African American women living with HIV.

An internal threat to the validity of the study may be the degree to which participants are honest in their responses to the survey items. The participants may be reluctant to report negative experiences related to living with HIV. For example, this could be related to the stigma they encounter, or even the level of psychological distress they are experiencing. However, the fact that I am using reliable and valid measures of each construct should reduce the likelihood of participants not being honest. In addition, the survey is anonymous and confidential which increases the likelihood of honest responses.

Another threat to validity has to do with the nature of the study. The study will be quantitative with a nonexperimental correlational survey method. While my design and multiple regression analyses may reveal significant relationships among the predictor and outcome variables, it cannot be implied that the variables are causal. It is difficult to draw causal relationships in quasi-experimental designs, including correlational designs (Tabachnick & Fidell, 2013). In addition, my study will be examining the relationship among the predictor and outcome variables at a single point in time. Those relationships among the variables may not be stable over time and could vary depending on factors such as the health status of the individual. The health status of the individual, while not a factor in this study, could impact levels of psychological distress. Similarly, there may be other factors that will not be measured in the present study which could impact psychological distress (e.g., coping styles, disease status, etc.). Thus, disenfranchised grief and social support loss cannot be determined as the only factors contributing to psychological distress among African American women who are HIV positive.

Because I will be examining perceived anxiety and depression in African American women living with HIV, participants may feel uncomfortable answering the questions or may not be interested in providing such information.

Ethical Procedures

This study will be approved by the Walden University Institutional Review Board (IRB) prior to data collection. Because participants will be asked about personal information pertaining to HIV, the proposed study may pose some risks because of the sensitive and confidential nature of surveying women living with HIV (National Research Council, 2014). The consent form will advise participants that answering questions surrounding their diagnosis could possibly lead to discomfort. If participants experience any feelings of discomfort during the completion of the surveys, a phone number will be provided to connect them with referral and linkage to local community resources (the National HIV/AIDS/Hepatitis C nightline at 1-800-273-2437; 211 that provides access to resources in their local communities; the National HIV/AIDS hotline at 1-800-232-4636 that is available 24/7 with information and referrals to local hotlines, testing centers, and counseling). The consent form and debriefing page will provide national resources should they need additional support from participation in the study.

Participants should not feel pressured to participate in the study because it is voluntary. Participants can withdraw at any time. If they do withdraw from the study, there will be no negative consequences and data will be kept confidential. All information collected from participants will be completely confidential. No names or identifying information of participants will be collected. Data downloaded from SurveyMonkey into SPSS for analysis will be stored on a password-protected computer accessible only by me. Data will also be stored for a minimum of five years on a password-protected flash drive in a secure and locked safe that will only be accessible by me.

Summary

My goal in conducting this study is to expand the literature by studying the extent in which disenfranchised grief and social support loss among African American women living with HIV predict psychological distress. I will use an online survey platform to collect data from African American women living with HIV. The surveys will be used to measure disenfranchised grief and social support loss (significant other, family, friends), and anxiety and depression. A survey method using SurveyMonkey will be utilized.

Standard multiple regression will be used determine the extent in which disenfranchised grief and social support loss predict psychological distress among African American women living with HIV. In Chapter 4 I will discuss the data collection procedures and analysis. The results from the multiple regression analyses will also be presented.

Chapter 4: Results

The purpose of this study was to determine the extent to which disenfranchised grief and social support loss (family, friends, and significant others) predict psychological distress (anxiety and depression) among African American women living with HIV. Disenfranchised grief was measured with the WDG scale (St. Clair, 2013), social support loss was measured with the MSPSS (Zimet & Farley, 1988), and anxiety and depression were measured with the DASS-21 (Henry & Crawford, 2005). Two standard multiple regression analyses were used to answer the research questions regarding the extent to which disenfranchised grief and social support loss predict anxiety and depression among African American women living with HIV. The remaining sections of Chapter 4 include the research questions and hypotheses, data collection procedures, and summary of demographic data for the sample, followed by a discussion of the statistical assumptions and the results of the standard multiple regression analyses.

Research Questions and Hypotheses

The following research questions guided my study:

RQ1: To what extent does disenfranchised grief, as measured by the Witnessing of Disenfranchised Grief scale, relate to psychological distress (anxiety and depression subscales), as measured by the Depression, Anxiety, Stress Scales (DASS-21), in African American women living with HIV?

H_o: Disenfranchised grief is not a significant predictor of psychological distress.

H_a: Disenfranchised grief is a significant predictor of psychological distress.

RQ2: To what extent does social support loss (family, friends, and significant others' subscales), as measured by the Multidimensional Scale of Perceived Social Support, relate to psychological distress (anxiety and depression subscales), as measured by the Depression, Anxiety, Stress Scales (DASS-21), in African American women living with HIV?

H_o: Social support loss is not a significant predictor of psychological distress.

H_a: Social support loss is a significant predictor of psychological distress.

Data Collection

After approval from the IRB at Walden University, data collection began on June 18, 2022, and ended on May 20, 2023, via SurveyMonkey. Initially, participants were not paid to complete the surveys. However, I offered a nominal fee to complete surveys due to recruitment challenges. I could not accurately determine the response rate for this study. Three hundred three individuals were interested in completing the survey; however, 70 participants finished the survey without missing data or outliers. Demographic data included age group, gender (cisgender or transgender female), ethnicity, and how long the individual had been living with HIV. The participants varied in age, with most in the 18- to 24-year-old group (*N* = 46, 65.7%). There were variations in gender, with most participants being cisgender (assigned female at birth and identifying as female; *N* = 69, 98.5%). There was no variation in race/ethnicity; all women identified as African American/Black. Table 1 provides a demographic summary for age group and gender.

Table 1

Frequency Table for Age Group and Gender of Participants

Demographic variables	*N*	%
Age groups		
18–24 years old	46	65.7
25–34 years old	18	25.7
35–44 years old	3	4.3
45–54 years old	1	1.4
55–64 years old	1	1.4
65 years old	1	1.4
Gender		
Cisgender	69	98.6
Transgender	1	1.4
Total (*N* = 70)	70	100

While all women were African American/Black, I relied on a convenience sample, which may have limited generalization of the results. The average time it took participants to complete the survey was 8 minutes. Some participants spent less than 8 minutes completing the surveys, which could indicate that little effort or thought was given to reading and responding to the questions. That might also impact the validity of the data.

Results

Descriptive Statistics

Seventy participants were included in this study. Means and standard deviations were calculated for the predictor variables related to disenfranchised grief and social support loss. Social support loss subscale scores ranged from a minimum of 4 to a maximum of 28 for significant others, family, and friends. In addition, the disenfranchised grief score had a minimum of 22 and a maximum of 102 (*M* = 42.85, *SD*

= 11.79). Table 2 provides the means and standard deviations for the predictor variables. Means and standard deviations were also calculated for the outcome variables related to psychological distress (depression and anxiety). Table 3 provides the means and standard deviations for the outcome variables.

Table 2

Means and Standard Deviations for the Predictor Variables

Predictor variables	*M*	*SD*
Disenfranchised grief	42.85	11.79
Social support loss		
Significant other	21.91	4.51
Family	21.35	4.68
Friends	20.84	4.90

Table 3

Means and Standard Deviations for the Outcome Variables Related to Depression and Anxiety

Components of psychological distress	*M*	*SD*
Anxiety	12.90	5.36
Depression	12.98	5.51

Evaluation of Statistical Assumptions

I examined the values for skewness and kurtosis to determine whether or not the data for each variable were normally distributed and if the data set contained any outliers. The skewness value of a normal distribution is 0, implying symmetric distribution. Outside the normal range is an absolute skewness value > 2, or less than, or equal to -2.

When the kurtosis is > 3 or less than or equal to -3, then the variable's distribution is not average (Field, 2013). The Shapiro-Wilk test was conducted to test for normality, and the results of the tests indicated that the data for each variable were significant, suggesting nonnormal distributions. However, Williams et al. (2013) noted that multiple regression analyses are a robust test and permitted when variables are not normally distributed as long as there are normal distributed errors. Therefore, the data were considered to have met the requirement of normality required to use parametric analysis. Table 4 presents the results of the Shapiro-Wilk test for normality, skewness, and kurtosis.

Table 4

Normality Testing for Study Variables

Variables	Statistic [a]	*df*	*P*	Skewness	Kurtosis
Disenfranchised grief	.795	70	< 001	2.44	9.23
Social support loss					
Significant others	.853	70	< .001	-1.80	5.48
Family	.885	70	< .001	-1.50	3.48
Friends	.826	70	< .001	-1.81	4.20

[a] Shapiro-Wilk test of normality.

Assumptions for standard multiple regression were tested (i.e., multicollinearity, normality, homoscedasticity, and independence of residuals). Multicollinearity was assessed by examining the variance inflation factor (VIF). The VIF values were below 10, and the tolerance scores were above 0.2. Therefore, the assumption of multicollinearity was met. The VIF scores and tolerance scores of the predictor variables are shown in Table 5.

Table 5

Multicollinearity Predictor Variables for Disenfranchised Grief and Social Support Loss

Predictor variables	VIF	Tolerance
Disenfranchised grief	2.57	.388
Social support loss		
Significant others	1.97	.506
Family	2.21	.452
Friends	1.88	.530

The Durbin-Watson *d* test was conducted to examine independence of residuals. The Durbin-Watson test results for the two regressions, using the four predictor variables (i.e., disenfranchised grief, social support loss significant others, social support loss family, and social support loss friends), were 1.195 for depression and .905 for anxiety, demonstrating that the assumption of independent residuals was met.

To assess homoscedasticity between the independent and dependent variables, I examined the scatterplots. The linearity assumption and homoscedasticity showed that the error was constant along the values of the DVs. The scatterplots for all variables demonstrate that data points are close to or on the line for each variable. Therefore, the assumption of homoscedasticity was met. Figures 1 and 2 present the residual scatterplots for homoscedasticity for each of the DVs.

Figure 1

Scatterplot for Depression Subscale

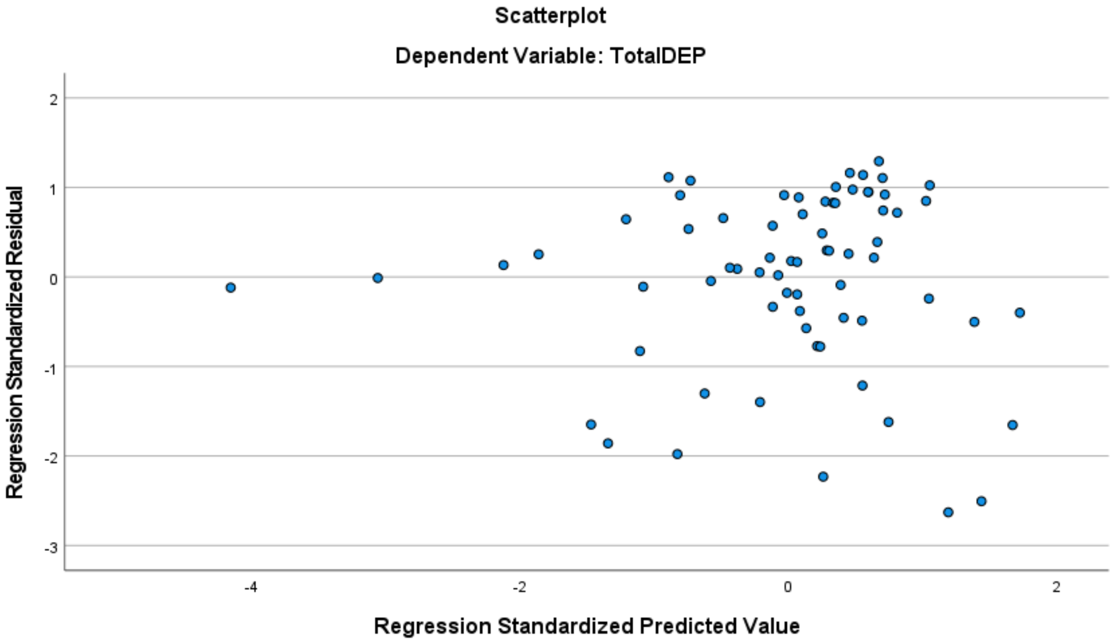
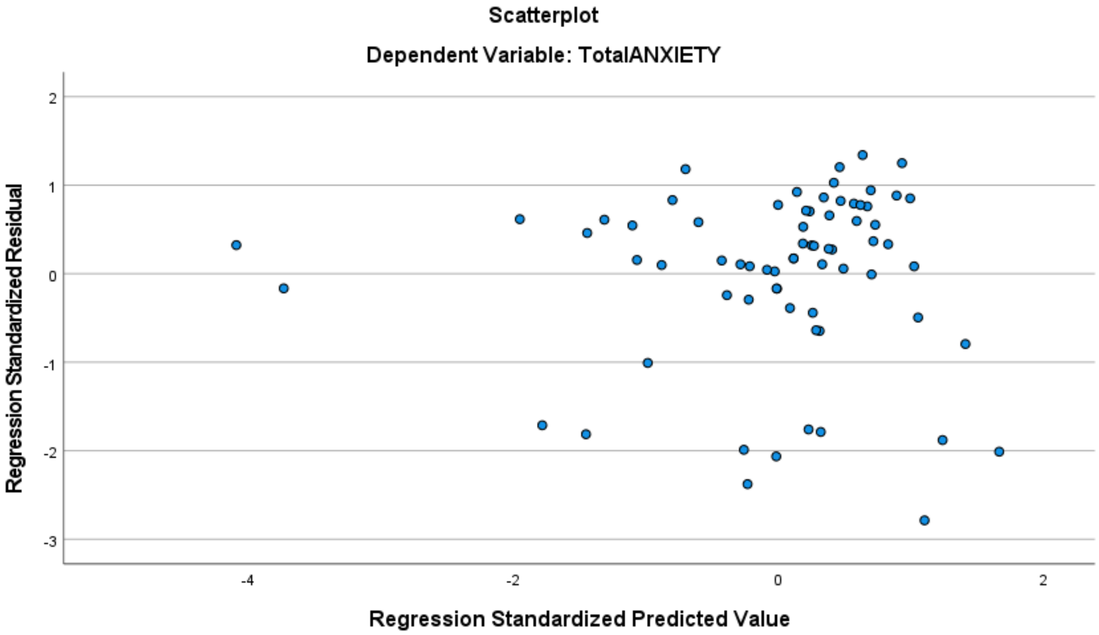


Figure 2

Scatterplot for Anxiety Subscale



Cronbach’s alpha was measured to assess internal consistency. A reliability coefficient of .70 or higher is considered acceptable (Greg & Mallory, 2003). Cronbach's alpha for disenfranchised grief was above .70, showing acceptable internal consistency of .894. Cronbach’s alpha for the subscale scores for social support loss ranged from .829 for significant others to .857 for family. In addition, Cronbach’s alphas for outcome variables were .878 for anxiety and .898 for depression (see Table 6).

Table 6

Cronbach’s Alpha for Disenfranchised Grief, Social Support Loss, and Anxiety and Depression

Variables	Cronbach’s alpha
Disenfranchised grief	.894
Social support loss	
Significant others	.829
Family	.857
Friends	.854
Anxiety	.878
Depression	.893

Standard Multiple Regression Analyses

Predicting Psychological Distress: Depression

The research questions explored the extent to which disenfranchised grief and social support loss (family, friends, and significant others) predicted psychological distress (depression). The results showed that the overall regression model was not significant, $F(4, 65) = .932$, $p = .451$, $R^2 = .05$. The results showed that none of the IVs significantly predicted depression. Disenfranchised grief ($b = -.004$, $\beta = -.009$, $p = .964$), social support loss significant others (*b* = -.026, β = -.021, *p* = .901), social support loss family (*b* = -.130, β = -.111, *p* = .540), and social support loss friends (*b* = -.169, β = -.151, *p* = .365) were not significant predictors of depression. Therefore, I failed to reject the null hypothesis. The standardized and unstandardized regression coefficients for all of the predictor variables are shown in Table 7.

Table 7

Regression Coefficients for All Predictors (Outcome Variable for Depression)

Predictor variables	*b*	*SE*	β	*t*	*p*
Disenfranchised grief	-.004	.090	-.009	.045	.964
Social support loss					
Significant others	-.026	.207	-.021	.125	.901
Family	-.130	.211	-.111	.616	.540
Friends	-.169	.186	-.151	.912	.365

Predicting Psychological Distress: Anxiety

The research questions explored the extent to which disenfranchised grief and social support loss (family, friends, and significant others) predicted psychological distress (anxiety). The results showed that the overall regression model was not significant, $F(4, 65) = 1.622$, $p = .179$, $R^2 = .09$. The results showed that none of the IVs significantly predicted anxiety. Disenfranchised grief (*b* = -.024, β = -.053, *p* = .780), social support loss significant others (*b* = -.067, β = -.056, *p* = .737), social support loss family (*b* = .149, β = .130, *p* = .461), and social support loss friends (*b* = .224, β = .205, *p* = .211) were not significant predictors of anxiety. Therefore, I failed to reject the null hypothesis. The standardized and unstandardized regression coefficients for all of the predictor variables are shown in Table 8.

Table 8

Regression Coefficients for All Predictors (Outcome Variable for Anxiety)

Predictor variables	*b*	*SE*	β	*t*	*p*
Disenfranchised grief	-.024	.086	-.053	-.281	.780
Social support loss					
Significant others	-.067	.197	.056	-.337	.737
Family	.149	.201	.130	.741	.461
Friends	.224	.177	.205	1.26	.211

Summary

The results from the multiple regression analyses demonstrated that disenfranchised grief and social support loss (family, friends, and significant others) did not significantly predict psychological distress (anxiety and depression) among African American women living with HIV. The multiple regression analyses demonstrated that disenfranchised grief predicted no significance in psychological distress. In addition, social support loss indicated no significance in psychological distress. In Chapter 5, I interpret the findings in the context of Sanders' integrative theory of bereavement and theory of chronic sorrow, discuss limitations, and provide recommendations and implications for positive social change.

Chapter 5: Discussion, Conclusions, and Recommendations

The purpose of this study was to determine the extent to which disenfranchised grief and social support loss predict psychological distress in African American women living with HIV. Previous research on African American women experiencing psychological distress (anxiety and depression) and living with HIV has focused on coping strategies, religious coping, everyday lived experiences, and the strong Black woman schema (Brumsey et al., 2013; Hickman et al., 2013; Peltzer et al., 2016; Peltzer et al., 2017; Watson-Singleton, 2017). However, disenfranchised grief and social support loss as potential factors that contribute to psychological distress have not been examined. Results from the multiple regression analyses demonstrated that disenfranchised grief and social support loss (family, friends, and significant others) were not significant predictors of psychological distress (anxiety and depression) among African American women living with HIV.

Interpretation of Findings

Disenfranchised Grief

Women living with HIV are often inhibited or denied the opportunity to acknowledge or grieve their illness or loss of health through sickness or disease (Corless, 1997; Pillai-Friedman & Ashline, 2014). Many individuals associate loss with death, ignoring the grieving process for individuals with illnesses and diseases. Grieving the loss of health facilitates emotional responses, including numbness, denial, pain, frustration, anger, depression, anxiety, fear, helplessness, hopelessness, sadness, loneliness, powerlessness, regret, remorse, never-ending uncertainty, and suicidal thoughts coupled with shame, self-blame, secrecy, social stigma, and humiliation (Gill & Lowes, 2014; Norris & DeMarco, 2005; Peters, 2013; Winston, 2003). When family members, friends, and health care professionals do not understand, validate, or acknowledge feelings and emotions associated with grief and loss, this can lead to disenfranchised grief. Disenfranchised grief is experienced due to a loss that cannot be openly acknowledged, socially validated, or publicly mourned (Corr, 2002; Doka, 2002a; St. Clair, 2013). As a result of disenfranchised grief, individuals may not receive support, help, or advice, which further complicates the experiences of the individual.

The results from the current study showed that disenfranchised grief was not a significant predictor of psychological distress. In the context of the current study, individuals often desire to express their loss, which is loss of health, relationships, and other losses associated with a diagnosis of and living with HIV. Losses, mainly nondeath losses, carry social stigma where individuals experience secrecy and shame. The trajectory of loss can be changed by giving individuals a voice to express losses openly and receive validation, sympathy, or consideration when experiencing losses. This can create a space for those experiencing disenfranchised grief to receive support and care (Doka, 2002a; Mortell, 2015).

Living with HIV results in losses that are not tangible, such as loss of health, independence, autonomy, control, freedom, preferred treatment, lifestyle, and hopes and expectations for the future (Gill & Lowes, 2014). The right to grieve is not always supported, thus creating further issues and problems for the individuals impacted by loss (Gill & Lowes, 2014). The loss can also take the form of abandonment by family and significant others. The many problems faced by women living with HIV (e.g., lack of housing, finances, employment, education) often lead to psychological distress (Phillips et al., 2011).

It is clear from previous research that living with HIV results in disenfranchised grief due to being inhibited or denied the opportunity to acknowledge or grieve the illness or loss of health (Corless, 1997; Pillai-Friedman & Ashline, 2014). My results showed that disenfranchised grief was not a significant predictor of psychological distress. I propose that there may be other factors that contribute to psychological distress among African American women living with HIV. For example, the current study did not measure the time living with HIV as a predictor variable. The only criterion was that participants had to be living with HIV for at least 1 year. Individuals newly diagnosed with HIV experience both physical and emotional challenges (Owusu, 2022). There may also be problems dealing with finances or finding adequate care. These issues may be all the more impactful for African American women who live in communities with limited resources or face higher levels of stigma and isolation. This initial diagnosis and adjustment period of navigating medical and behavioral care and treatment may be a significant contributor to anxiety and depression among African American women diagnosed with HIV.

It is also possible that living with HIV for longer than a year provides an opportunity for individuals to develop effective coping mechanisms to deal with the psychological impact of their initial diagnosis. In addition, the longer someone is living with HIV, the more likely they are to be provided with or find resources, such as case managers, counselors, physicians, and support groups to help with the loss, grief, and distress. In addition, being virally suppressed could also be a contributing factor related to anxiety and depression; viral suppression is defined as having less than 200 copies of HIV per milliliter of blood by consistently taking HIV medicine (U.S. Department of Health and Human Services [HHS], 2022). It can also make the viral load so low that it does not appear in a standard lab test, referred to as an undetectable viral load. In this instance, the possibility of having significant anxiety and depression is reduced because it means that the individual is undetectable, and undetectable means untransmissible (HHS, 2022).

Social Support Loss

Families are often the first source of support and strength for African American women living with HIV (Owens, 2003). The strength drawn from family members and friends is also attributed to spiritual and other faith-based practices (Piazza-Bonin et al., 2015). Social and family support within African American communities is prevalent when dealing with grief and bereavement (Owens, 2003; Piazza-Bonin et al., 2015). In previous studies, social support was significantly and negatively associated with depression among African American women living with HIV (Dibb, 2018; Jones et al., 2003; Kennedy et al., 2015; Peltzer et al., 2016; Vyavaharkar et al., 2011). However, the results from the current study showed that social support loss was not a significant predictor of psychological distress. It is possible that social support loss is more likely to occur after initial diagnosis. Previous research has shown that women are more likely to disclose their HIV initial diagnosis than men (Obermeyer et al., 2011) and that when

African American HIV-infected women disclosed to close family and friends, sex partners, and health care professionals, it left them vulnerable to stigma and discrimination (Sowell et al., 2003). According to Sowell et al. (2003), it also put these women at risk for loss of employment, housing, health insurance, and custody of their children, as well as interference and disruptions in relationships, rejection, abandonment, and stigmatization and discrimination. Thus, social support loss may be more likely to occur after initial diagnosis and disclosure, again resulting in higher levels of psychological distress. African American women living with HIV for longer than a year may be more likely to restore relationships with family, friends, and significant others, finding support among other social networks and faith-based groups.

Interpretation of Findings and the Theoretical Framework

Sanders' (1999) integrative theory of bereavement addresses the psychological, physical, and behavioral responses exhibited in grief and indicates that psychological forces operate during the process of grief, with a biological basis that determines the physical well-being of an individual. Sanders suggested that individuals move through five phases of bereavement: shock, awareness of loss, conservation-withdrawal, healing, and renewal. According to Sanders, this process motivates and encourages individuals to move through the phases of bereavement to facilitate psychological, physical, and behavioral change. The movement during the grief process can be seen as a progression toward homeostasis, resolution, adaptability, and growth (Sanders, 1999). This theoretical approach assists in understanding individual differences in adapting to bereavement that, across the course of grief, incorporate diverse situations that bereaved individuals may experience. Despite significant losses in life, individuals are believed to move from shock to renewal with resilience and courage (Sanders, 1999; Smith et al., 2015; Stroebe et al., 2006).

The last three phases of loss indicate that individuals begin to see new approaches by forming new relationships and rebuilding a life, especially the work done in accepting the loss and consequent changes in one's life, where individuals discover the motivation to move on and move forward to the next phase. Individuals invite healing, with the turning point being the determination to survive and change (Sanders, 1999). In the fourth healing phase, individuals gather strength to move forward and recognize the possibility of a new life. Although the process is sporadic and slow, individuals begin to take control and shape their lives differently (Sanders, 1999). Bereaved individuals gain motivation to develop a new identity by relinquishing old roles, building new ones, forming new ties, and finding new friends and lifestyles. Sanders (1999) contended that hope formulates in the fourth phase, and individuals move into the final phase of bereavement.

There is a renewal in the fifth and final phase, where individuals' pain subsides, and they are not the same person as before the loss. Individuals accept responsibility for themselves, which lends to the strength necessary to try new things, meet new friends, and create a lifestyle in which emotional needs are met. Bereaved individuals also accept responsibility by taking matters into their own hands. When faced with life experiences, individuals develop a new sense of vitality, resulting in the potential to develop into stronger and more confident people than before. Individuals can move toward renewed functional stability (Sanders, 1999).

The theory of chronic sorrow describes sorrow as the periodic recurrence of permanent, pervasive sadness or other grief-related feelings associated with a significant loss that can be associated with the diagnosis of chronic diseases (Antle et al., 2001; Weingarten, 2012). While research has focused on losing children due to chronic illnesses and disabilities, chronic sorrow also explains living with HIV (Doka, 2002b). The concept of chronic sorrow explains how people may respond to both ongoing and single loss events, including chronic illness and disclosure of one's HIV status, specifically HIV/AIDS (Ahlstrom, 2007; Northington, 2000). In previous studies, researchers found the themes of depression and coping among African American women living with HIV. The stigma is due to the HIV diagnosis, while depression and lack of social support are outcomes of stigma. The current study explored the theory of chronic sorrow associated with disenfranchised grief and social support loss. While not measured in the current study, those losses may include bodily functions, relationships, autonomous life, roles, activities, identity, imagined life, and uplifting emotions (Weingarten et al., 2012).

These results do not fully support the assumptions of the theory of integrative bereavement or the theory of chronic sorrow associated with African American women living with HIV. Although the findings in the current study did not demonstrate a predictive relationship between the variables, the theories offer insight for bereaved individuals living with HIV. When viewing the phases of bereavement, it is assumed that

African American women living with HIV have moved through some of the phases of bereavement, thus leading to psychological, physical, and behavioral changes and a progression toward homeostasis, resolution, adaptability, and growth (Sanders, 1999). In the current study, phases of bereavement were not assessed. Thus, disenfranchised grief and social support loss may impact psychological distress, depending on the specific phase of bereavement African American women living with HIV are experiencing. In the theory of chronic sorrow, the periodic recurrence of permanent, pervasive sadness or other grief-related feelings associated with a significant loss can be related to the diagnosis of HIV (Antle et al., 2001; Weingarten, 2012). Again, the current study focused on African American women living with HIV for at least 1 year. I hypothesized that those grief-related feelings may be more prevalent during initial diagnosis and adjustment. This insight suggests that newly diagnosed women may be more impacted and affected with bereavement and sorrow than those living longer with HIV.

Limitations of the Study

There may be limits in generalizing the results to all African American women living with HIV due to convenience sampling. Convenience sampling (also known as availability sampling) is a specific type of nonprobability sampling method that relies on data collection from population members who are conveniently available to participate in the study. Because I used nonprobability convenience sampling, it is possible that the sample does not represent the population of African American women living with HIV (Tabachnick & Fidell, 2013). The women who volunteered to participate were participants living with HIV and were offered a nominal incentive to complete surveys via SurveyMonkey. The average time it took participants to complete the survey was 8 minutes, with some taking even less time. This may indicate that little time or thought was given to questions or responses. There were also no assessments to verify whether participants had any other mental, cognitive, or physical conditions that could impact the surveys. In addition, the number of years living with HIV was not assessed, nor whether or not participants received any additional services or support pertaining to being diagnosed or living with HIV.

Similarly, data that addressed any treatment for mental health issues participants may have experienced were not collected. These factors may have influenced anxiety and depression results. Other limitations of the study were social stigma, including reluctance to disclose one's experience or shame and blame associated with one's diagnosis. There are other limitations in the study associated with psychological distress that were not measured, including how long participants were living with HIV, viral load, coping styles, disease status, and stigma.

Recommendations

Previous researchers have provided evidence that disclosure of HIV to significant others, family, and friends may result in a lack of support, and disfranchised grief is often associated with secrecy and shame, thus facilitating the inability to grieve one's diagnosis, health, and HIV status. It is recommended that future research examine other factors related to psychological distress and stigma. In previous studies, stigma was a significant factor or occasion for anxiety and depression among African American women living with HIV. Therefore, stigma should be examined as a possible predictor for anxiety and depression among this group. Another recommendation is to examine the timeline after initial diagnosis. A longitudinal study examining disenfranchised grief, social support loss, and psychological distress with newly diagnosed African American women may identify specific time periods where disenfranchised grief and social support loss are factors that contribute to psychological distress. A final recommendation is to conduct a qualitative study on the experience of disenfranchised grief among African American women living with HIV.

Implications

The current study found that disenfranchised grief and social support loss were not significant predictors of psychological distress among African American women living with HIV. This is not to say that participants were not experiencing psychological distress. Thus, it is important to offer support or other programs, such as palliative and hospice care, partner services, counseling, and grief and loss support groups to African American women living with HIV. Offering these services may lead to increased education about disenfranchised grief, co-morbidities, quality of life, and coping skills needed for African American women living with HIV.

The results of this study may lead to positive social change by providing information to grief counselors, psychologists, and other advocates to effectively serve African American women living with HIV. Disenfranchised grief and social support loss may be important factors for some African American women living with HIV, depending on the time since initial diagnosis. Understanding African American women's reservation to grieve their diagnosis and seek psychological support and services will potentially give professionals ways to create programs that specifically benefit them physically, emotionally, and spiritually (Brawner, 2014; Laurie & Neimeyer, 2008; Peters, 2013). In addition, understanding the effects of psychological distress in African American women living with HIV makes it possible to provide adequate support by giving them safer spaces to grieve their diagnosis and disclose their status, thus minimizing the psychological distress experienced in their lives.

Conclusion

HIV/AIDS is a chronic disease. African American women are disproportionately infected with HIV/AIDS and experience several negative consequences associated with their diagnosis. These negative experiences include losing relationships with family, friends, and significant others, stigma, psychological distress, and disenfranchised grief. As African American women work to address the psychological pain of being diagnosed with and living with HIV, it is essential to understand other experiences while coming to terms with being diagnosed with and living with HIV. Other everyday experiences include discrimination, loneliness, and social isolation. Examining other adverse experiences and factors among African American women living with HIV can better inform support programs and services that address psychological distress issues. Positive social change may occur with the continual development of services to promote bereavement, grief, and psychosocial support to African American women living with HIV.

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Appendix A: Invitation to Participate in Research for Webpage Administrators

Date:

Dear [redacted]

My name is Lisa Connors, and I am a doctoral student at Walden University pursuing my PhD in Psychology. I am requesting your assistance in my recruitment efforts for my dissertation. The purpose of the research study is to examine the relationship between disenfranchised grief, social support loss, stigma, anxiety, and depression for African American women living with HIV. Participants will be asked to complete an online survey that includes a demographic questionnaire and four self-report measures that will take approximately 45 minutes to complete.

I am seeking African American women, who are 18 years or older, and who have been diagnosed and living with HIV for 12 months or longer. Upon approval of my proposal by Walden University, I am requesting permission to post an invitation for participants to participate in my research study on your organization's online or social media page or for you to post on my behalf. Also, if you would feel comfortable distributing the announcement to any list serves or email lists you may have access to, I would greatly appreciate it.

If you have questions about this research study, you may contact me directly at [redacted]. I would greatly appreciate your help in the recruitment process. Thank you in advance for your time and consideration. If you have questions or concerns, please do not hesitate to reach out to me. I look forward to hearing from you soon.

Respectfully Submitted,

Lisa Connors, Doctoral Student
Walden University

Appendix B: Invitation to Participate in Research Announcement

My name is Lisa Connors, and I am a dissertation student at Walden University. I am conducting a research study with African American women living with HIV to examine disenfranchised grief, social support loss, stigma. I am seeking African American women, who are 18 years or older, and who have been diagnosed and living with HIV for 12 months or longer

If you would like to participate in the study, please complete my survey via this SurveyMonkey link: (Weblink). This is a voluntary study. There will not be any compensation for participating. A benefit of your participation may be the contribution of new information to help improve the services and programs for African American women grieving loss and experiencing stigma. Please feel free to share this announcement on your page in order to reach potential participants. Thank you for your time and consideration.

Respectfully Submitted,

Lisa Connors, Doctoral Student
Walden University

Appendix C: Demographic Questionnaire

Instructions: Please provide a response for each of the following demographic questions:

1. What is your age? ________

2. How do you identify [i.e., gender]?
    - Cisgender Female (assigned female at birth and identifies as a woman)
    - Transwoman (a woman who was assigned male at birth)
3. Which ethnic or racial category do you identify?
    - ○ Black or African American
    - ○ Multiracial (one or more race)
    - ○ Other Race
4. Have you been HIV positive for over a year?
    - Yes
    - No {if the answer is "no", please STOP HERE} {if the answer is "yes", proceed to question 2}
5. Are you able to consent to this proposed study?
    - Yes
    - No {if the answer is "no", please STOP HERE} {if the answer is "yes", proceed to question 4}
6. Have you been diagnosed with a severe mental health disorder in the last year? A severe mental health disorder includes schizophrenia and schizoaffective disorder, major depression, and bipolar disorder.
    - **Yes**

- **No**
- Prefer Not to Answer {if the answer is “yes”, please STOP HERE} {if the answer is “no”, you are eligible to participate in the proposed study} {if you prefer not to answer, please STOP HERE}

- **If you do not meet the criteria for participation in the study, I want to say thank you for agreeing to participate in the study.**
- **If you meet the criteria for participation in the study, I want to say thank you for taking the time to complete the surveys.**

Appendix D: Witnessing of Disenfranchised Grief Scale Permission Letter

Re: WDG scale

[redacted]

Lisa Connors <lisa.connors@waldenu.edu>

Hello Lisa,
I am happy for you to use the WDG scale. I do not have copies of the study for distribution. Good luck. I am so glad that others are looking into disenfranchised grief.
[redacted]

On Fri, Apr 28, 2017 at 2:47 PM, Lisa Connors <lisa.connors@waldenu.edu> wrote:

Good afternoon [redacted]

It was a pleasure speaking with you today! Thank you for allowing me to use the WDG scale for my research study. Is it possible to get a copy of the study from you?

I look forward to speaking with you again!

Have a wonderful day, and weekend!

Best,

Lisa Connors, Doctoral Candidate
Walden University

Appendix E: Multidimensional Scale of Perceived Social Support

Hello [redacted]

My name is Lisa Connors, and I am a Ph.D. student at Walden University. I am currently working on the proposal for my dissertation on the relationship between disenfranchised grief, social support loss, and stigma in African American women living with HIV. I am seeking permission to use your scale in my research from the following article:

Zimet, S.G. & Farley, G.K. (1988). The multidimensional scale of perceived social support. Journal of Personality Assessment, 52(1), 30-41.

I will be happy to share the results from my research with you when it is completed. If you have questions, please feel free to email me at lisa.connors@waldenu.edu.

Thank you in advance for your time and consideration.

Sincerely,

Lisa Connors, Ph.D. in Psychology Student
Walden University
lisa.connors@waldenu.edu

Appendix F: Depression, Anxiety, Stress Scales-21

Hello [redacted]

My name is Lisa Connors, and I am a Ph.D. student at Walden University. I am currently working on the proposal for my dissertation on the relationship between disenfranchised grief, social support loss, and stigma in African American women living with HIV. I am seeking permission to use your scale in my research from the following article:

Henry, J. D., & Crawford, J. R. (2005). The short-form version of the Depression Anxiety Stress Scales (DASS-21): Construct validity and normative data in a large non-clinical sample. British Journal of Clinical Psychology, 44, 227–239.

I will be happy to share the results from my research with you when it is completed. If you have questions, please feel free to email me at lisa.connors@waldenu.edu.

Thank you in advance for your time and consideration.

Sincerely,

Lisa Connors, Ph.D. in Psychology Student
Walden University
lisa.connors@waldenu.edu

Appendix G: National Resources

Organization: HIV.gov

Website: HIV Testing Sites & Care Services Locator

Telephone Number: 1-866-415-8051 (toll free)

Organization: Mental Health America

Website: Finding Help | Mental Health America (mhanational.org)

Telephone Number: 1-800-969-6642 (toll free)

Organization: SAMHSA's National Helpline

Website: www.samhsa.gov/find-help/national-helpline

Telephone Number: 1-800-662-4357 (toll free)