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HIV Diagnosis as a Biographical Disruption: A Qualitative Study Among Young Gay and
Bisexual Men Living with HIV

THESIS

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Abstract

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Young black gay, bisexual, and other men who have sex with men (YB-GBMSM) are disproportionately impacted by the HIV epidemic. A positive HIV diagnosis elicits diverse reactions because of the very nature of HIV and its social implications on individuals and their families. Few studies have explored the emotional, and psychosocial effects of a HIV diagnosis on YB-GBMSM. This study seeks to explore the experiences of YB-GBMSM following a HIV diagnosis and their coping mechanisms postdiagnosis in relation to their identity. Semi-structured qualitative in-depth interviews were conducted between May and October 2017 with 28 HIV-positive YB-GBMSM. Participants ranged in age from 18 to 29 years, with an average of 3 years since clinical diagnosis of HIV/AIDS. All participants were receiving ART, and self-reported high adherence level. YB-GBMSM had different experiences following their HIV diagnosis. The process of integrating HIV into their identity post-diagnosis incorporated several levels of identity transition with some participants experiencing full identity transitions and others' partial identity transitions. Resources and coping strategies were mobilized as a form of dealing with the disruptive effects of the HIV diagnosis. Postdiagnosis turning points consisted of a focus on integration of past identity with new identity, social support from family members, friends, HIV community and efforts at normality. Postdiagnosis phase for our participants were characterized by a turning point and focus to survive and thrive. Thus, an in-depth understanding of an individual's connotation and interpretation of a HIV-positive diagnosis and their relevant experiences are crucial for self-management and improved health outcomes.

KEYWORDS: biographical disruption, HIV, YB-GBMSM, coping, identity

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LIST OF ABBREVIATIONS

AIDS: Acquired Immune Deficiency Syndrome

ART: Antiretroviral Therapy

CDC: The Centers for Disease Control and Prevention

HAART: Highly Active Antiretroviral Therapy

HIV: Human Immunodeficiency Virus

MSM: Men who have sex with Men

UNAIDS: The Joint United Nations Programme on HIV/AIDS

WHO: The World Health Organization

YB-GBMSM: Young Black Gay Bisexual Men who have sex with Men

CHAPTER 1: INTRODUCTION

1.1 GLOBAL EPIDEMIOLOGY OF HIV/AIDS

The first cluster of acquired immune deficiency syndrome (AIDS) related cases were reported in 1981, signifying the beginning of the human immunodeficiency virus (HIV) epidemic (KFF, 2021). Four decades later and the HIV epidemic continues to significantly affect the lives of people worldwide. Available data from the Joint United Nations Programme on HIV/AIDS (UNAIDS) reports that since the beginning of the epidemic, 76 million people have become infected with HIV and about 33 million people have died from AIDS-related diseases. Current statistics estimates that there are about 38 million people living with HIV worldwide, of which, Sub-Saharan Africa has been hit the most and accounts for 68% of all people living with HIV (UNAIDS, 2020). The HIV/AIDS epidemic has been recognized as a one of the world's most serious health challenges and a global public health threat (WHO, 2020). Over the years, HIV trends and prevalence have varied around the world, with some countries having generalized epidemic among their population and other countries having the epidemic among specific population groups. However, with the advent of antiretroviral therapy (ART) to treat HIV/AIDS and the widespread availability and accessibility to ART, there has been significant improvements in the survival rates of people living with HIV (Colwell, 2017).

1.2 EPIDEMIOLOGY OF HIV/AIDS IN THE UNITED STATES

The United States (US) has a population of about 330 million people (United States Census Bureau, 2019). The CDC estimates that about 1.2 million Americans are currently living with HIV (amfAR, 2020). Although the size of the epidemic in the US is quite small compared to its overall population, it is such that the epidemic disproportionately affects certain group of individuals i.e.,

racial/ethnic minorities and gay and bisexual men and remains prevalent in certain regions i.e., the South. The disproportionate distribution of the epidemic places the South, which is home to 38% of the US population as the region most affected. In 2017, the Southern states accounted for more than half of all new HIV diagnoses (KFF, 2019). Notably, the South is also home to 21 out of the 25 cities with the highest HIV prevalence among gay and bisexual men (Villarosa, 2017). Primary factors associated with the epidemic in the South include poverty, conservative social and political norms, limited access to healthcare, and high HIV-related stigma. Available statistics show that in 2018, racial disparities in the US epidemic were such that Blacks/African Americans made up 13% of the US overall population yet accounted for 42% of all new HIV diagnoses (CDC, 2021). Likewise, in the same year, gay and bisexual men accounted for 86% of all HIV diagnoses among males, even though they represented only 4% of the US male population (amfAR, 2020). Additionally, still in 2018, young Blacks/African American gay and bisexual men accounted for 42% of new HIV diagnoses, the highest rate of HIV diagnoses that year (AFC, 2021). Following the years since the US HIV epidemic started, the distribution of new cases by age, geographic area and race/ethnicity has significantly changed.

1.3 PROBLEM STATEMENT

Majority of new HIV diagnoses are in young people. The WHO estimates that more than 30% of all new HIV infections occur in young people aged 15-25 years (WHO, 2021). In recent years, while HIV diagnoses have been stable and in some cases decreasing amongst the adult population, there has been an increase of almost 6% among adolescents and young adults in the age group of 13 to 29 (Guilamo-Ramos, Thimm-Kaiser, Benzekri, & Futterman, 2019). In 2017, adolescents and young adults aged 13 to 29 accounted for 41% of new HIV diagnoses and more than one in every five new HIV diagnoses in the US (CDC, 2020). Specifically, young Black gay, bisexual

and other men who have sex with men (YB- GBMSM), are affected the most, bearing a disproportionate HIV burden compared to the other racial groups. In 2017, YB- GBMSM accounted for 52% of all new HIV diagnoses (KFF, 2019). Understanding the unique dynamics of the HIV epidemic among YB- GBMSM in the US is critical to effective treatment and epidemic control. This is because development of self-identity and characteristics occurs in YB- GBMSM lives during adolescence and young adulthood when they are at the greatest chance of getting infected with HIV.

1.4 PURPOSE STATEMENT

The purpose of this study was to explore the effects a positive HIV diagnosis has on the identity and life trajectories of YB- GBMSM in the US and the coping strategies utilized towards post diagnosis identity reconstruction. In this regard, this study aims to explore HIV from the perspectives of YB- GBMSM and, thus, provide context to their experiences.

1.5 RESEARCH OBJECTIVE

The specific research objectives include:

1. To describe the different responses to a positive HIV diagnosis.
2. To explore how YB- GBMSM process and cope with HIV as a chronic illness.
3. To understand the process towards reconciliation of one's pre-diagnosis and post-diagnosis identity to ensure biographical continuity.

1.6 THEORETICAL FRAMEWORK

The theory used to explain the phenomenon being studied was the Biographical Disruption theory. It was developed in 1982 by British sociologist Michael Bury as a framework to describe the experiences individuals diagnosed with a chronic illness faced while dealing with a rupture among

certain aspects of their lives, particularly their identity (Bury M. , 1982). The theory has three dimensions to it:

1. Disruption in one's identity
2. Rethinking one's biography and self-identity
3. Coping through mobilization of resources to repair one's identity

1.7 SIGNIFICANCE STATEMENT

The HIV epidemic in the US is not generalized and if current HIV trends continue, it is estimated that 50% of Black/African American men who have sex with men (MSM) will be diagnosed with HIV during their lifetimes compared to 25% of Hispanic and 9% of White (CDC, 2016). This equates to one in two Black/African American men who have sex with men, particularly young MSM aged 25 to 34 years who will bear the brunt (Avert, 2019). Having HIV doesn't just have health ramifications but also economic, moral, and social repercussions for the individual, their families and the society. This present generation of young adults are the first generations to not know a world without HIV/AIDS and are considered to be at the epicenter of the epidemic, in terms of new cases and opportunities for prevention efforts. Therefore, they represent possibly the greatest chance for epidemic control if they can be reached with the proper programs and interventions.

DEFINITION OF TERMS

This study used several terms that are commonly associated with the HIV/AIDS epidemic and defined them to provide a clear meaning to the terms.

HIV: HIV is a virus that spreads through the body and affects the CD4 cells in the immune system. Over time, if left untreated, HIV infection leads to AIDS.

AIDS: AIDS is the final stage of HIV infection when the immune system has been badly damaged and leaves a person at risk for opportunistic infections.

Epidemic: An epidemic is a widespread occurrence of a disease that affects a population, community, or region at the same time.

Identity/Self-identity: How an individual views themselves and defines it to others.

Youth: A period characterized by adolescence and early adulthood, when maturity starts to develop.

CHAPTER 2: COMPREHENSIVE REVIEW OF THE LITERATURE

“If gay and bisexual African American men living with HIV made up a country today, its rate would surpass that of Swaziland, the country with the world’s highest HIV prevalence and all other nations together” (Villarosa, 2017)

Since the beginning of the HIV epidemic, the body of research and existing literature into the epidemic has steadily been growing. Today, the literature consists of a diverse range of topics from stigma to the implications of targeted interventions to achieve epidemic control. This chapter provides an overview of HIV as a biographical disruption, discusses the intersectionality of HIV and other identities, explores coping strategies and reviews two key theories that are the basis of this study (Biographical disruption theory and Lazarus & Folkman transactional model of stress and coping).

2.1 HIV as a Biographical Disruption

Being seropositive or having HIV has been argued in the literature as being a biographical disruption. Bury’s (1982) theory has been explored as an analytical framework for understanding how an individual’s trajectory and identity is threatened following a positive diagnosis (Bury M. , 1982). The premise in which HIV occurs as a biographical disruption starts from diagnosis, where the individual experiences several emotions as a reaction to the diagnosis to the acceptance or denial stage and finally a transition to a new identity which incorporates HIV with other identities of the individual. However, in light of their HIV situation, individuals rework their identities to find meaning in their current situations in an effort at biographical continuity for not only themselves but also their social relationships. A study of HIV positive men found that the study participants had to reinterpret their individual and collective pasts in an attempt at biographical reconstruction of components of their identity that prior to HIV-infection had been built around

other identities. This was done in a bid to attach meanings to their infection (Carricaburu & Pierret, 1995). Another study examining identity transformation for individuals following a HIV diagnosis reported that HIV identities are fluid constructs with no single HIV or AIDS identity, but a range of identities individuals construct and enact. The study findings imply that HIV identities are representations of self in relation to perception of HIV disease, as well as products of individual responses to biographical disruptions encountered at crucial milestones in the identity transformation process. The study outcomes resulted in self identities, that included HIV positive, Living with HIV and Person with AIDS with the outcomes differing in terms of how the study participants perceived and identified themselves as persons with HIV, how HIV was experienced as an illness, and the centrality of HIV in interactions with others (Tewksbury & McGaughey, 1998).

More recent studies have explored biographical disruption in different population of people living with HIV apart from gay men. In the study among HIV positive women in the Dominican Republic, participants had reported a HIV diagnosis as deeply distressful and feeling depressed and worthless. However, a postdiagnosis turning points consisted of a focus on survival and motherhood; social support including their family members, friends, HIV community, which in turn promoted integration and better health outcomes (Paya'n, Derose, Fulcar, Farías, & Palar, 2019). Another study of HIV positive women in South Africa showed similar results with study participants successfully incorporating HIV and its treatment into their life trajectories. The study findings also report that a majority of the study participants felt in control of their lives in relation to their HIV and its treatment although it caused additional disruptions to their everyday life experiences. Thus, they had to continuously negotiate between different roles and identities, depending on the specific context because although ART successfully minimizes the physical

impact of HIV it does not completely eradicate the social and psychological challenges of living with HIV especially in the context of poverty and stigma (Wouters & Wet, 2016). However, not all research report positive biographical reconstruction that incorporate the HIV identity following diagnosis. A qualitative study of HIV individuals in Singapore found that study participants in the aftermath of their diagnosis confronted a future where their previously familiar and benign world has turned hostile against them and challenged their right to coexist with uninfected people. The study findings also found that study participants did not incorporate HIV identity with their other identities but kept it separate from those other identities and selectively using it when appropriate to form a “liveable” identity (Hoa & Goh, 2017).

2.2 HIV as a Chronic Illness

Following the advent of ART, HIV has been reframed from an acute illness to a chronic condition (Mahungu, Rodger, & Johnson, 2009). A chronic illness is defined as “a continuous and long-term health illness that may not be curable”. Living with a chronic illness redefines an individual’s life because they have to adjust and modify themselves i.e., their way of life, identity and social relations with others, to the demands and the treatment of the condition (Casarella, 2020). From the early days, HIV has been characterized with stigma amidst being labelled the “gay-syndrome” and four decades later, this stigma is still a negative element that limits the individual’s adjustment as well as complicates treatment and self-management of HIV (Prati & Pietrantoni, 2015). HIV, unlike other chronic diseases has undefined prognoses and with no cure in the immediate future, positive individuals adapt and learn to live by incorporating ART and treatment options into their lives. Advances in HIV care, particularly highly active antiretroviral therapy (HAART) has led to undetectable viral loads, reconstruction of the immune systems, and significant risk reduction of HIV transmission in positive patients (Deeks, Lewin, & Havlir, 2013). Thus, living with HIV as a

chronic illness requires some sort of normalcy for the individuals, which does not imply a return to their prior lives but learning to cope in a form of biographical continuity (Russell, et al., 2007).

2.3 HIV Resilience among YB- GBMSM

Resilience is defined as the ability to overcome or bounce back after a stressful situation. The context in which resilience is defined is central because it is a complex construct, which may be defined differently in depending on the individuals, societies, and/or cultures (Southwick, Bonanno, Masten, Panter-Brick, & Yehuda, 2014). Several studies have explored resilience among HIV positive YB-GBMSM as a means of coping with the adversities they face in the daily lives. In the literature, resilience is often associated with positive health outcomes (Brewer, et al., 2020), the promotion of well-being (Herrick, et al., 2013) and considered as a buffer against the effects of syndemic conditions on HIV risk and infection (Adeboye, et al., 2017). Resilience is often linked with identity and so the factors that promote the development of resilience among YB-GBMSM are necessary tools to understanding how to moderate resiliency against the various challenges affecting this group. A study of resilience processes demonstrated by young gay and bisexual men living with HIV suggests that study participants build resilience across multiple dimensions, including intrapersonal-level resilience related to individual cognitions and behaviors, as well as interpersonal-level resilience related to seeking support and providing support to others (Harper, et al., 2014). The MARI study found that resilience had a protective effect on HIV among black MSM, especially in the Deep South. In their study, participants with higher resilience had a lower prevalence of condomless anal sex with main sexual partners, participating in a sex party/orgy and having a STI in the past 12 months (McNair, et al., 2018). Similarly, Hussen et al., (2017) reported in their study that resilience factors that lie within the individual such as social support satisfaction, behavioral resilience, ethnic identity, and internalized homonegativity were

significantly associated with cognitive resilience and highlight the importance of positive identity beliefs among YB- GBMSM (Hussen, et al., 2017).

2.4 HIV, Identity, Age and Race/Ethnicity

The intersectionality between HIV, age, race and identity formation has been a crucial factor for understanding the HIV/AIDS epidemic. The existing literature offers potential explanations of the ways in which multiple identities impact the HIV experience regardless of which aspect of the epidemic is being explained. According to the identity theory, individuals have various identities and attach meanings to how those identities are negotiated in their everyday interactions. An assumption of this theory is identity salience, which refers to the possibility of individuals invoking a specific identity across situations (Stets & Serpe, 2013). Several studies that have explored the effects of HIV on identity and argue that the different identities of people living with HIV can't be examined distinctly (Bredström, 2006) (Agénor, et al., 2019). This is because HIV and other identities are interrelated and interdependent, although a hierarchy might exist in the way the individual portrays the HIV identity or how central and significant the HIV identity is to the individual at the given time. Baumgartner and Niemi (2013) in their study reported that HIV identity and other identities were interconnected, and function symbiotically, such that each identity cannot be separated from the other and the other identities depended upon the HIV identity for meaning and clarity. This study adds that the development of a HIV/AIDS identity constitutes a nexus that affects the development and salience of other identities (Baumgartner & Niemi, 2013). The process of identity development and formation can be considered both an individual and social phenomena and a significant part of this process occurs during adolescence when intellectual development allows an individual to create a 'self-theory' constructed around their elements of exposure such as role models and identity options. A crucial identity moment according to

Erikson's theory of psychosocial development is during adolescence, when adolescents navigate life and complexities towards developing their own identities. This identity stage often involves defining certain elements such as sexuality, personality, careers, appearances in establishing one's identity (Hoose, 2020). The importance of the adolescence identity stage cannot be overemphasized because it holds several implications for understanding how a HIV diagnosis at this stage interrelates with the other identities that an individual is trying to form. A key identity, such as adolescence, may fundamentally be threatened by HIV, or maybe a reason for identity continuity and source of self-esteem. A qualitative study of identity development in adolescents living with HIV reported that HIV had an impact on participants values and future goals. The study further reported that participants fell into either diffusion or achievement identity statuses, which in turn impacted their response to having HIV (G. HOSEK, HARPER, & ROBINSON, 2002). Another study of identity formation in adolescence found that middle to late adolescence was a period where most boys and girls started to explore their commitments in an increasingly active manner. The study suggested that for males, early to middle adolescence was a period where they became increasingly more certain about their commitments and in middle to late adolescence was when they first displayed a small increase in reconsideration (Klimstra, Hale, Raaijmakers, Branje, & Meeus, 2010).

2.5 HIV and Coping

Coping has been extensively studied in the literature as either a potential mediator or disrupter following a positive HIV diagnosis. Several coping theories have been developed that provide explanations regarding how individuals deal with the impact of a HIV diagnosis. One of such widely used theory and framework is the Lazarus and Folkman (1984) transactional model of stress and coping. According to this theory, a person deals with stress through two phases: cognitive

appraisal and coping. The cognitive appraisal phase includes a primary reappraisal of the stressful event and a secondary appraisal of resources that can be mobilized to cope with the stressful event. The coping phase then attempts to moderate the demands caused by the stressful event. Lazarus and Folkman (1984) classify coping into two categories: problem-focused coping, which involves the individual changing certain elements of the stressful event by directly managing the stress and emotion-focused coping, which involves modifying the emotions that are attached to the stressful event. Thus, in other words, problem-focused coping is used when the individual feels the situation is modifiable whereas, emotion-focused coping is used when the individual knows the situation is not changeable (Lazarus & Folkman, 1984). A meta-analysis of 63 studies published from 1990 through 2005 investigated which types of coping are related to psychological and physical well-being among people with HIV. The study reported that direct action such as problem focused coping and positive reappraisal were correlated with better outcomes across physical and emotional health categories while disengagement forms of coping such as behavioral disengagement and use of drugs and alcohol to cope were associated with poorer health outcomes (Moskowitz, Hult, Bussolari, & Acree, 2009).

Similarly, a study of HIV seropositive gay men found that changes in cognitive coping skills such as positive reframing, changes in social support, active coping, and acceptance of HIV during a cognitive behavioral stress management program were significantly associated with low distress and improved psychological well-being and quality of life (Lutgendorf, et al., 1998). Another study that examined the role of coping as a mediator of dysfunctional attitudes and depression associated with HIV diagnosis among positive symptomatic MSM found that the use of adaptive coping strategies such as active coping was associated with lower depression, whereas use of maladaptive strategies such as denial was related to higher levels of depression (Penedo, et al., 2001). Cruess

et al., (2002) in their study of cognitive behavioral stress management and HIV infection among HIV positive gay men reported that participants who changed their use of a number of important coping strategies, particularly, their use of active coping and seeking social support showed increased self-efficacy and decreased distorted and dysfunctional attitudes (cognitive, appraisal processes) over time. In addition, the acceptance and positive reinterpretation and growth as coping strategies increased participants perceptions of social support attachment, guidance, reassurance of worth (Cruess, et al., 2002).

Recent studies of the effects of coping on psychological adaptation in individuals with HIV consistently reported that approach coping strategies such as seeking support and acceptance are correlated with better health outcomes. A study of coping and psychological wellbeing among HIV positive men who have sex with men found that cognitive coping strategies such as positive refocusing and reappraisal served as predictors of low depressive symptoms while catastrophizing and other blame were associated with high depressive symptoms. This study also reported cognitive coping strategies had a stronger influence on well-being than the behavioral coping strategies and that withdrawing effort and commitment from unattainable goals, and reengaging in alternative meaningful goals, in the situation where preexisting goals could no longer be reached, was an effective way to cope with being HIV positive (KRAAIJ, et al., 2008).

Several other studies have examined the role of religion and spirituality in coping with HIV as a chronic illness. Trevino et al., (2010) in their study of religious coping among HIV positive patients found that participants who had reported relying on positive religious coping as a source of comfort and support had positive outcomes, including greater self-esteem and spirituality and improvements in well-being over time. On the other hand, participants who had reported spiritual struggle were often associated with negative outcomes, such as poorer quality of life, higher levels

of HIV symptoms, and higher levels of depressive symptoms (Trevino, et al., 2010). A similar systematic review exploring religion and spirituality's influences on HIV syndemic among MSM found that studies with more racially and ethnically diverse samples reported positive effects of religion and spirituality on the health of MSM of color than for white MSM implying that that religion and spirituality may be more beneficial for the health of MSM of color (Lassiter & Parsons, 2016).

CHAPTER 3: MANUSCRIPT

Contribution of the Student

This manuscript has been prepared for submission to the Journal of Acquired Immune Deficiency Syndromes (JAIDS). I, Maryam Bello, contributed to this manuscript chapter through writing, analysis, theoretical framework and figure/table development.

3.1 ABSTRACT

BACKGROUND: Young black gay, bisexual, and other men who have sex with men (YB-GBMSM) are disproportionately impacted by the HIV epidemic. A positive HIV diagnosis elicits diverse reactions because of the very nature of HIV and its social implications on individuals and their families. Few studies have explored the emotional, and psychosocial effects of a HIV diagnosis on YB-GBMSM.

OBJECTIVE: To explore the experiences of YB-GBMSM following a HIV diagnosis and their coping mechanisms postdiagnosis in relation to their identity.

METHODS: Semi-structured qualitative in-depth interviews were conducted between May and October 2017 with 28 HIV-positive YB-GBMSM. Participants ranged in age from 18 to 29 years, with an average of 3 years since clinical diagnosis of HIV/AIDS. All participants were receiving ART, and self-reported high adherence level.

RESULTS: YB-GBMSM had different experiences following their HIV diagnosis. The process of integrating HIV into their identity post-diagnosis incorporated several levels of identity transition with some participants experiencing full identity transitions and others' partial identity transitions. Resources and coping strategies were mobilized as a form of dealing with the disruptive effects of the HIV diagnosis. Postdiagnosis turning points consisted of a focus on integration of past identity

with new identity, social support from family members, friends, HIV community and efforts at normality.

CONCLUSION: Postdiagnosis phase for our participants were characterized by a turning point and focus to survive and thrive. Thus, an in-depth understanding of an individual's connotation and interpretation of a HIV-positive diagnosis and their relevant experiences are crucial for self-management and improved health outcomes.

KEYWORDS: biographical disruption, HIV, YB-GBMSM, coping, identity

3.2 INTRODUCTION

Globally, the HIV/AIDS epidemic has shown tremendous progress in stabilizing, however silo HIV epidemics such as among men who have sex with men (MSM) have been on the rise. In the United States, the Centers for Disease Control and Prevention (CDC) approximates that 69% of all new HIV diagnoses in 2018 were among gay, bisexual and other men who have sex with men (GBMSM) (HIV.gov, 2021). Racial disparities among GBMSM are such that Black/African American GBMSM are the most impacted, accounting for about 25% all new HIV diagnosis and 39% HIV incidence among all MSM (KFF, 2020). Additionally, of concern is the increasing HIV incidence among young Black/African American GBMSM (YB- GBMSM), aged 13-24 years, who accounted for 52% of all new HIV diagnosis among all MSM in this age group (KFF, 2020).

A positive HIV diagnosis, especially when unexpected, can have serious psychological and emotional implications on the individual and their lives. Life changing moments are often characterized after a positive diagnosis that involve the reassessment of one's biography, where the individual seeks to understand the period before the diagnosis and that after the diagnosis. In the era of widespread availability of antiretroviral therapy (ART), there has been a paradigm shift of HIV care and management from an acute illness to a chronic illness (Deeks, Lewin, & Havlir, *The End of AIDS: HIV Infection as a Chronic Disease*, 2013). However, while medical advances in HIV/AIDS treatment options and management can aid in assuaging the complex and multifaceted responses to a new HIV diagnosis, it can still be difficult to accept and adjust to one's HIV status, especially at a young age. This is due to the fact that HIV is a highly stigmatized illness and is so intertwined with religious, moral, and social beliefs of society (Mahajan, et al., 2008). Hence, as young people living with HIV seek to thrive in the midst of these medical advances,

through transitioning or incorporating a new identity to an existing one, it is important to note that certain characteristics of that individual's identity are left scathed by the diagnosis particularly regarding issues of sexuality (Starks, Kelsey, Rosania, & Getz, 2020). Several qualitative studies focused on HIV diagnosis have reported responses to a diagnosis to be traumatic, tense and distressing (Okal, et al., 2020) (Kutnick, et al., 2017). Barkish et al. referred a HIV diagnosis as "being at a dead end", "having the feeling of falling" and having "a shift in life" (Gh.Barkisha, Jalali, & Jalali, 2019). HIV diagnosis has been described as a transition (Lam, Fidler, & Fosterb, 2017), an interruption in the structure of individuals' lives (Hutchinson & Dhairyawan, 2018), and a biographical disruption (Alexias, Savvakis, & Stratopoulou, 2016).

Theoretical understanding of HIV identity post diagnosis can be conceptualized using Bury's (1982) biographical disruption framework. Michael Bury introduced the concept of "biographical disruption" in 1982. This, he notes as the result of a disruption caused by a chronic illness which leads to an interruption of an individual's present life and ongoing situation. According to Bury, biographic disruption affects an individual through three processes, which are: (i) an interruption from one's previous identity due to the realization of a new situation i.e., HIV diagnosis in this case; (ii) changes in the individual's social relationships that occur during the biographic disruption altering the dynamics of their relationships with others, where some relationships are lost and some are improved; and (iii) a redevelopment of one's self-identity, where the individual attempts to reconcile their future identity with their past one through the utilization of resources (Pranka, 2018). Because of the disruption from a sudden and unanticipated onset of a chronic illness, the individual affected is forced to rethink their biography and self-identity, ultimately resulting in the mobilization of resources to respond to the disruptive event. In this case, the HIV diagnosis is

referred to as the disruptive event. The fundamental belief underlining the biographical framework is the personal impact of illness from the moment of the disruption to assumptions about the future. The belief is that self-identity relies on the continuity of an individual's narrative, implying stability and hence the disruption or interference with daily activities and relationships leads to anxiety and uncertainties. HIV diagnosis, being the disruptive event signifies change and thus poses a prospective problem to the maintenance of one's narrative (Bury M. , 1982).

Several studies have explored identity and the self among individuals living with HIV and have noted that identity is an important factor that contributes to psychological functioning, treatment decisions and HIV self-management (Swendeman, Ingram, & Rotheram-Borus, 2009). Acceptance or rejection of certain elements of an illness invariably affects how the individual sets out to restructure their biography and identity. Kutnick et al. in their mixed methods study highlighted that the process of incorporating HIV and ART into one's identity post diagnosis is not an automatic experience but one that involves several stages of identity transition, including HIV diagnosis, post diagnosis disclosure and non-disclosure, positive living and efforts at healing and normalcy (Kutnick, et al., 2017). How people living with HIV reshape their identities influences their decisions to engage in care and appropriate HIV self-management. Certain coping mechanisms after a HIV diagnosis to deal with the disease and the stigma, are associated with health outcomes. Lazarus and Folkman defined coping as, "the cognitive and behavioral efforts made by an individual in managing a stressful situation" (Lazarus & Folkman, 1984). Lazarus and Folkman's stress and coping theory highlights how an individual cognitively appraises a stressful situation as either having some personal significant and exceeding the individual's practical and/or emotional resources (Lazarus & Folkman, 1984). Different stressful situations require different

types of coping mechanisms. For example, cognitive avoidance has been associated with increased stress in people living with HIV over time whereas proactive behavioral coping mechanisms have been associated with better health outcome and disease progression.

How YB- GBMSM experience and cope with an HIV diagnosis is not well explored, particularly in the context of their own stories and circumstances. In addressing these existing literature gaps, this qualitative study sought to explore the many ways in which positive HIV diagnosis impacts the identity, and behavior of YB- GBMSM living with HIV in the metro Atlanta area. The burden of HIV in the Southern region of the US is relatively high, accounting for highest HIV incidence rates in the US. Among YB- GBMSM, reported HIV transmission is mostly driven by unprotected sexual activity and the infection rate has been disproportionately increasing among this group (KFF, 2020). In addition to exploring the impacts of an HIV diagnosis on identity and behavior among YB-GBMSM, this study investigates how men cope with the diagnosis and self-manage their condition. Exploring how YB- GBMSM process and cope with HIV as a chronic illness is essential toward understanding their use of resources, circumstances linked to disclosure, available support networks and development of effective interventions that can lead to successful treatment outcomes of people living with HIV.

3.3 METHODOLOGY

3.3.1 Qualitative study design

This qualitative analysis used data derived from a larger study which aims to develop and test an intervention to improve social capital and engagement in care among YB-GBMSM living with HIV in Atlanta, Georgia (Hussen, et al., 2018). The study was conducted in Atlanta for a number of reasons: Atlanta is one of the metropolitan cities in Georgia, which has become an epicenter of the HIV epidemic (Wheatley, 2020); various groups of young black men who have sex with men could be included; the sample would be sufficient for data analysis to inform intervention strategies given allocated resources and time frame; and communications between researchers and participants could be maintained since they were all in the same area. A semi-structured qualitative in-depth interview guide was developed between the research team and inputs from a youth advisory board (YAB) comprised of nine YB-GBMSM living with HIV. The interview guide was divided into five domains, which include:

- I. Early life experiences
- II. Social network composition
- III. HIV stigma, disclosure and gay identity
- IV. Using social capital
- V. Reciprocity.

3.3.2 Study participants

All twenty-eight (28) study participants were recruited through a brief screening process. The study team, and the YAB members provided referral for eligible study participants, explaining the study aims and providing information. Participants were 1) aged between 18-29 years; 2) HIV

positive; 3) reported any history of sex with men; 4) were of Black/African American race; 5) self-identified as male gender.

3.3.3 Data collection

Semi-structured qualitative in-depth interviews were conducted between May and October 2017 by selected study team members and YAB members. Both selected team and YAB members were trained in qualitative research methods. A majority of the interviews were conducted by two of the study team members, who self-identify as Black and gay (one male and one female). Interviews lasted 1.5-2 hours and took place in either a private room at the clinic, or an alternative location which was more accessible to the participant. Interview questions were open ended, intended to stimulate discussion followed by probes (Box 1). Additionally, participants completed a brief demographic questionnaire before each interview. Interviews were audio-recorded using a digital recorder, and recordings were transcribed verbatim by a professional transcriptionist. Transcripts were stored on a secure computer network with permissions restricted to only study members and labelled with codes (e.g., 'YM1 Transcript'). Likewise, after each interview, the research team members convened, debriefed, and subsequently adapted the guide to accommodate emerging themes. The research team concluded that thematic saturation had been achieved after all the interviews were conducted. Once the interviews were completed, participants received written information about the study and a \$50 gift card as a token of appreciation for participating.

Table 1: Excerpts from interview guide

Box 1: Example of interview guide questions

Participants (men who have sex with men)

- Tell me about how you found out that you had HIV?
- Can you tell me about some experiences (either good or bad) that you've had sharing your HIV status with others?
- How has your relationship with your family changed since your childhood?
- Are you active in any organizations that are specifically for Black gay men, gay men, or people with HIV? If yes, which ones and what is that like? If no, why not?

3.3.4 Data Analysis

Demographic Data

The study participants demographic data were imported into RStudio, a quantitative analysis software and were analyzed using to produce various descriptive statistics, including sample size, measures of variability, measures of central tendency, and percentages. These descriptive statistics are displayed in Table 1 in the results section.

Thematic Analysis

Data was analyzed using two theoretical frameworks: Bury's biographical disruption concept and Lazarus and Folkman coping strategies. The findings of this study applied Bury (1982) concept of biographical disruption to analyze and categorize themes describing how unanticipated HIV diagnosis and acquisition plays a role in an individual's life by altering their social relationships and individual identity (Pranka, 2018). Lazarus and Folkman's coping strategies were used to complement the third process of the biographical disruption by categorizing resources used by

participants to cope with their diagnosis. For the purpose of this study, resources and coping strategies will be used interchangeably.

Transcripts were imported into QSR NVivo 12, a qualitative data analysis software to organize the study data for coding and thematic analysis. This particular qualitative software was utilized because of its simplicity in analyzing text, coding and categorizing data, identifying themes, and organizing data segments. Prior to coding, transcripts were read and re-read allowing for thorough understanding of the data, identifying potential themes and fostering the inductive process. With inputs from an already existing codebook, codes were amended to include a combination of inductive codes from the data and the guiding theoretical framework. An iterative process was used (i.e., labeling, coding) several times, to amend the codebook, including newly emerging themes not specifically addressed within the interview guide, each time refining the coding process. The coding process was complete once it was clear that the data were sorted into appropriate categories and the amended codebook was then applied to all transcripts. Quotes that best described the themes from transcripts were presented in the results, whilst making sure to incorporate examples illustrative of all study participants. Finally, thematic saturation was important to the credibility of this study and this was informed based on how completely understandable each theme was given the data presented. The researcher concluded that seeking additional study data would have diminishing results for the study, because, it would add little or nothing to the nuance of the themes in the data already collected and analyzed.

3.3.5 Ethical consideration and approval

Participants interviewed for this study were given oral information about the study prior to consenting to participate in the study, including the option to decline to answer questions or end their participation at any time during the interview. Study participants anonymity was ensured by

assigning an identification number (YM1-YM28) with no names or personal information collected. The institutional review board at Emory University and the Grady Research Oversight Committee reviewed and approved this study.

3.4 RESULTS

3.4.1 Sample Characteristics

A total of 28 young MSM living in Atlanta were interviewed for this study. Participants were aged between 18 and 29 with a median age of 24.5 years and were all African American, including two who identified as both African American/Latino and African American/American Indian (Table 1). More than half (57%) of the participants had at least some college, associate's or technical degree, and a fourth (27%) reported an annual income of less than or equal to \$40,000. Self-reported viral load status was undetectable for majority of participants (24) with three participants reporting detectable viral loads and one person unsure of their status. The length of time living with HIV ranged from less than 1 to 11 years, with a median of 3 years. In addition, more than two-thirds of the men (85.7%) identified their sexual identity as homosexual, same gender loving (SGL) or gay and the rest (14%) considered themselves as bisexual or verse.

Table 1: Participants Demographics

Characteristics	Category	Participants (n=28)
Gender, % (n)	Male	100% (28)
Age, years, mean (SD)	18 - 25	23 (1.95)
	26 - 35	27.6 (0.7)
Ethnicity, % (n)	African American	92.9% (26)
	African American/Latino	3.6% (1)
	African American/American Indian	3.6% (1)
Education, % (n)	High School Diploma/GED	28.6% (8)
	Some college, associate's or technical degree	57.1% (16)
	Bachelor's Degree	14.3% (4)
Sexual Identity, % (n)	Homosexual, Gay or SGL	85.7% (24)

	Bisexual	7.1% (2)
	Verse/Versatile	7.1% (2)
Annual Income, % (n)	x <20,000	57.1% (16)
	20,000< x <40,000	28.6% (8)
	40,000< x <60,000	10.7% (3)
	Not Reported	3.6% (1)
Undetectable viral load, % (n)	Yes	85.7% (24)
	No	10.7% (3)
	Unsure	3.6% (1)
HIV diagnosis, median (range)	Years diagnosed with HIV	3 (0 -11)

We present our analysis by describing the major themes that emerged as a result of the biographical disruption following HIV diagnosis. We report participant response to their HIV diagnosis, HIV disclosure and coping strategies post HIV diagnosis. The integration of HIV into one's identity is illustrated with two case studies in the final section. Figure 1 shows the conceptual framework following biographical disruption and coping strategies from this study, which are explained in detail below.

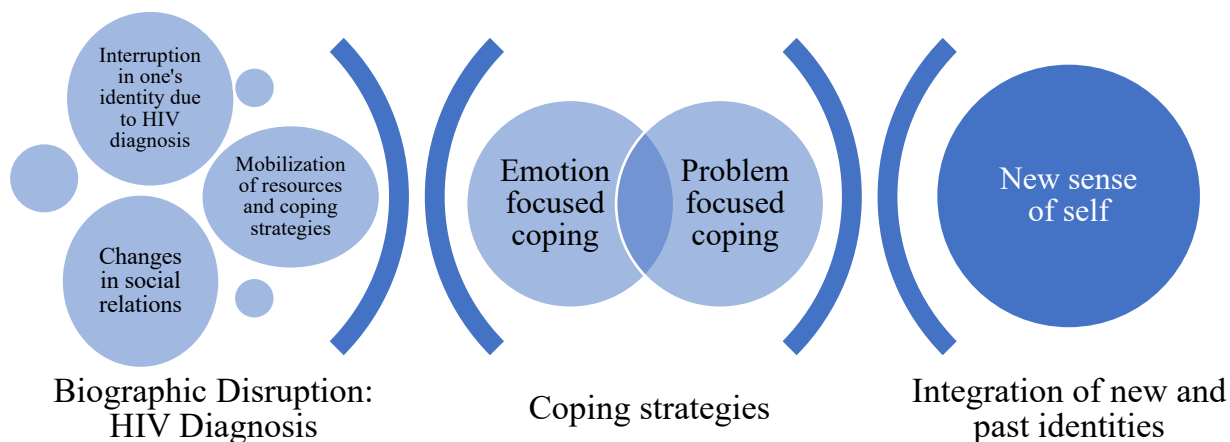


Figure 1: Conceptual framework: Integration of one's identity post HIV diagnosis

3.4.2 Response to HIV diagnosis

Understanding how participants responded to their HIV diagnosis is important because it involves the first step in integrating it into their new identities and underlines subsequent changes in individual's life trajectories post HIV diagnosis. From our results, we found out that for the majority of the participants, awareness of one's HIV status and acceptance was not as easy as going from being HIV negative in one instant to being positive in the next. Instead, these participants had experienced a wide range of emotions from anger, fear to relief about status, accompanied by questions on the possible source of their infection and how they became infected. Below one young participant describes finding out about his status:

...Um, I got tested, the tests kind of – it came back negative. But they advised that I should come back because it was a faint line there so, you know, they weren't too sure what was going on there. But I went and did what I needed to do and then it was time for me to get tested again to continue working for the company that I was with. And when I got tested, that's when the test came back positive. Um, which in a sense, you know, I'm thankful that they're procedures were the way they were because had I not gone and got tested or they required that we get tested on a regular basis, I probably would have found out much later than when I actually did. (Participant 4, Age 29)

Post HIV diagnosis was attributed to new changes in their biographies with participants' altering them to adjust to their new identity. Participant 11 below provides an example of such situation:

..I did OraQuick and it came out preliminary positive, like this can't be. This can't be, I didn't tell my best friends that night. Then Monday, no Sunday, my best friend had called me, and he hadn't heard from me all day because I kinda seemed down

because it was the weekend, like what's wrong with you? I was like, I don't know, I have HIV, I'm like, I'm not really sure because it was the OraQuick. So like, the following Monday he picked me up from work and went to emergency care and did a blood test and it came out, you know, positive. I didn't cry because I knew it takes two to tango because I knew it was my fault as well. [...]It changed me. [...]But in the back of my mind, you know, taking that medication every day, oh my God, I have to take this forever, that's the only downfall of the virus. (Participant 11, Age 27)

While majority had expressed shock or anger at their diagnosis, a few participants had mentioned having some inkling that they might have HIV either due to high-risk situations they had been involved in or due to recent knowledge that their present or previous partner was positive and so they might have transmitted it to them. Below, one participant details how his partner had infected him:

I: All right, so tell me more about how you found out that you had HIV?

P: Um, I mean, I heard, I got news that someone that I was messing around with had it and I went to the doctor. (Participant 14, Age 25)

Additionally, time from diagnosis to acceptance ranged from instantly in the case of some participants to months or years later in the case of others. Participants who took more time in accepting their diagnosis cited feeling healthy and not having symptoms that indicated that they had been infected with the virus and hence were living with HIV.

..But, you know, things happen. So yeah, initially it was really, really a shocker. And again, I felt like I let myself down. I let my family down. I put myself into an “in denial” state for a long time, two years. To where I didn't think that I had it. I

told myself I didn't have it and I just carried on as if that was the case that I didn't have it. Nobody could tell, I couldn't tell. I no longer had symptoms, I wasn't feeling weird, I wasn't feeling sick, I wasn't looking sick. So, it's just like, "Oh I'm fine. I'm cured. It's a miracle." That's how I was looking at it to be very, very honest with you. But reality hit back in when I infected my ex and we had to go get retested and they told me I was positive. It was kind of like Déjà vu. Like it was kind of like, "Okay now I'm back to life and this is real." (Participant 24, Age 23)

Furthermore, reaction of being a statistic was often common with participants associating themselves to the narrative of being black, gay and acquiring HIV.

I: So how did you deal with it?

P: I didn't. I didn't deal with it until last year. It kind of you know, broke me down but, you know, I got over it.

I: In what ways did it break you down?

P: In ways that I felt I couldn't ever, I felt that I wasn't normal anymore. I felt like I had become a statistic, a gay, got HIV and I live in Atlanta and I'm black. It was just like, damn! (Participant 1, Age 28)

Nonetheless, all participants eventually accepted their status, with full or partial integrations of this newly formed identity with their present and proceeded to either disclose the situation with their social relations or not.

3.4.3 HIV status disclosure: Changes in individual's social relations

Disclosure of HIV status was often not easy after diagnosis as cited by participants but was somewhat necessary to effectively manage their identity. Reasons to disclosure varied among

participants depending on the kind of relationship they had with whom they were disclosing too. Friends and family members were often times cited as being those with whom early disclosure happened with either because they were with the participant when they received their status, or they were the ones they called for support after receiving their diagnosis. Positive reactions and support from these family members and friends towards their diagnosis eased their feelings about their new status and helped with their coping.

..My whole family knows; both my mom and my dad's side know. And that was probably one of the most – it was the scariest part for me, for my father's side to know. Because, of course, my dad is Jamaican so he don't – like him finding out I was gay, and I was positive, I mean when he found out it broke his heart. Like he said that he had to stop on the side of the road from working and he just broke down. So that kind of broke my heart because I was kind of – I didn't want him – I don't want you to have to worry about me. I'm okay, like I went all this time without you knowing and I'm okay. My mom's side, they gangstas. And I wasn't really worried about them. They are like okay, cool, what do we need to do? If you need anything, if you need to call us, call us. So, they handled that situation quite well.

(Participant 13, Age 25)

On the other hand, participants who were reluctant to disclose or chose to selectively disclose with their social relations backed their decisions with reasons such as ignorance from others regarding HIV, fear of social consequences i.e., rejection. which emanated from personal experiences that were not good. Additionally, only a handful had mentioned not disclosing to their family members. Disclosure with casual or sexual partners was on a need-to-know basis depending on if the relationship was perceived as being serious or had potential to develop into something serious.

3.4.4 Coping strategies post HIV diagnosis

Following their HIV diagnosis, all participants reported adjustment to their HIV status through various coping mechanisms. Lazarus and Folkman (1984) coping framework consisting of emotion focused coping and problem focused coping were used to present themes (Miodrag & Hodapp, 2011). The themes that were emergent under the emotion focused coping were personal spirituality and faith, acceptance of HIV status prior to diagnosis and cognitive reappraisal of the situation, whereas the themes that emerged under problem focused coping were seeking professional help and using social networks.

Emotional Focused Coping

Personal Spirituality and Faith

Majority of participants identified as being brought up around the church during their early years. Following their sexual identity or HIV status disclosure, most of them mentioned not going to churches anymore or believing in the whole organized religion idea because of their negative experiences i.e., gay bashing, judgmental church folks etc. In its place, they formed their own understanding of faith and God and how through that connection, they were able to deal with their HIV diagnosis. They describe how their spirituality gave them a sense of purpose in life, especially with coping with issues of guilt, shame and grief associated with HIV. Two participants describe their spirituality and faith as:

Because I feel like I should have been dead; all the shit I've been through, I should have been dead and gone a long time ago. But God, like that's what it boils down to, but God! Because at the end of the day, I feel as though he got me on this earth for a reason and I may not know it or completely see it yet, but God has a reason

and a purpose for everything and that's why I'm still here. So, I would say my faith is pretty strong, even this day and I ain't going to say there's day I don't talk to Him because there is. There's days when I might forget to, there's days when I might want to cuss Him out, you know what I mean? But the end of the day, but God, is the reason why I'm still here. (Participant 20, Age 25)

...Mmm. I have been written off by everybody else. HIV for me, personally, symbolizes that God thought enough about little ole me to give me a chance to love myself, to give me a chance to give back as much as I could. God thought enough about me to be able to give me one more chance to serve him to the best of my ability instead of calling me home. As much as I would love for you to give me my wings and call me home now, he thought enough to know that I had the strength to push in spite of it. (Participant 5, Age 24)

Acceptance of HIV status prior to diagnosis

A few of the participants reported noticing changes in their body and researching to understand what was going on with them. This may be due to the fact that they possibly indulged in some high-risk behaviors, and suspected they had HIV hence preparing themselves by seeking information about HIV, indicating a measure of acceptance on their part about their status even before clinical confirmation. This helped them to cope with their diagnosis. The quote below illustrates this:

I guess it was more about just me doing what I needed to do to get, I guess, back healthy I would say. I had already dealt with it mentally and I was pretty much at

terms with it before I even found out by the doctor. So, it's kind of just growing used to going to the doctor and taking medication I guess. Like, I guess, just like opening myself up to the fact that it was actual reality. (Participant 16, Age 18)

Cognitive reappraisal of HIV situation

Majority of the participants expressed how after dealing with the initial reaction to their HIV diagnosis, they developed a shifting attitude towards HIV/AIDS influenced by factors such as the availability of antiretrovirals (ART), pre-exposure prophylaxis (PrEP), and undetectable viral loads etc. Participants commonly cited how HIV was now longer regarded as a death sentence as opposed to the earlier days of the virus and compared it to having other health conditions that could be managed through ART treatment adherence.

I mean, I'm on my meds. I'm good. It is what it is. I just stick with it as a baby that I have to take care of. [...] I got to feed, eat, take my meds, make sure I do my bloodwork and stay on top of it. So, to me it's just like any other regular illness now how I try to think about it. If I have high blood pressure, take a pill. (Participant 6, Age 27)

Following a reappraisal of their situation, ART adherence was high among participants, having successfully integrated taking their medications into their everyday routine. Setting phone alarms, verbal reminders from support system, and putting pill bottles in places where participants are prompted to take them were among methods used to manage their medications and ensure adherence.

I set an alarm in my phone or put the bottle somewhere that I see every day or get a pill case that has Monday, Tuesday, Wednesday, Thursday, Friday, and put them

in there and that way you don't really have to think about it. (Participant 14, Age 25)

Participants also noted that being HIV positive had made them more health conscious especially in terms of their overall well-being. Below the response of a participant elucidates this:

Um, I'm taking my meds every day and I'm undetectable. You know, I feel like HIV is a blessing and a curse. It's like okay, well, you have a virus, but you are more in tune with your body than the average HIV negative person. Like, people who believe they are HIV negative or who are, they are not as self-cautious as someone who is HIV positive. You know, like you can ask a person, you can ask a straight guy, or you can ask a person who believes they are HIV negative or who is HIV negative, when was the last time you went to the doctor? And they would say, 'Well the last time I went to the doctor was a while, like six months ago.' And you can ask somebody who is HIV positive, like, 'Well I go to the doctor once a month.' Or, 'I go to the doctor every two months, or three months,' but they are more actively at the doctor than people, you know, who are not aware or who are negative.

(Participant 2, Age 23)

Additionally, knowing or seeing older healthy and successful HIV positive MSM confirmed to them that it was achievable to live a good and healthy life.

...I was just like, you are awesome, and you're funny, and you're intelligent and you have insight on a lot of things and you have been doing this for a long time and you are 50 something and you're great, and you look great. You took care of yourself and you're not falling apart, and this is what HIV looks like in 20 years, or in 30 years. You don't have to look – it was very – I think another reason why

they both impact me so is because they are both HIV positive and they both are representative of who I am most likely going to become. Their interest, who they are, the fact that they are black, gay, and have HIV, the fact that they live in Atlanta, and that's not all there is to it, but it's enough to be like this could be me, this might be me. I kind of want this to be me. But a better me. (Participant 18, Age 22)

Problem Focused Coping

Seeking professional help

A few participants sought out professional help from clinical staff in coping with their diagnosis. Reasons for this included that participants believed that they possessed more knowledge about HIV and there was a high level of confidentiality about the services they provided. The advice, compassion and medical information received from nurses, caseworkers and counsellors were useful in alleviating the anxiety that came with the situation with even simple statements like not too worry giving participants succor. Reassurances by their doctors that enrolling in care and taking their ART would halt the progression, helped make adjustment to the situation better.

Um, I guess you could say, um-- I don't really know, outside of friends and family, um, I mean, I would say my psychiatrist, because I can literally talk to her about everything and anything. And she pretty much gives me advice and she's kind of like my training wheels, I like to call her. Like, she's there and she's like-- when I feel like I'm losing balance or focus, she kinda like gets me right back together and holds me in place. So, yeah, I'd say her. (Participant 8, Age 18)

Using social networks

Social support from family, friends and HIV networks helped participants integrate their new status with their identity. Participants mentioned receiving emotional, financial and material support from these social networks. While not all family and friends who knew participants' status were supportive, those who accepted and stuck with them provided encouragement to them to seek care and assisted in self-management of HIV by reminding them to take their medicines or escorting them to their clinical appointments. One participant recalls how his grandmother has warned and made sure none of his family members were going to stigmatize him by actions such as not sharing utensils etc. One young man captures how his support system help him with coping below:

Well uh-uh. The funny thing is, is that I can only say after a year of being HIV positive, the one thing that I know that has kept me in I guess you could say a happy place with the occasional frustration, I mean you get down, you think about it sometimes but knowing that I have that support there, that's what kept me going. Like that's what's kept me going. I think I'd be a very different person right now. I don't think I would have made half the strides that I've made in 12 months from finding out. I probably would still be stuck hadn't I had those people around me that you know, have just continuously just supported me. I have a lot of support and I'm very thankful because I'm lucky, a lot of people don't. (Participant 3, Age 25)

HIV networks support was described by participants as providing them with a new sense of worthiness and belonging. Connecting and becoming members of these positive networks, interactions with other positive individuals and participating in their different activities provided

them a network of people whom they shared similarities with. These interactions improved their knowledge about the disease and boosted their confidence to feel better equipped to deal with their situations. Support statements like “I’m not alone in this”, or “you will get through” were often mentioned as being received from peers and others in these networks. A few participants went further in these network groups to reciprocate the support received by serving as outreach and advocacy people in these networks to encourage others living with HIV to initiate care promptly, empower them with HIV knowledge and providing them with guidance and support. This involvement provided purpose to their lives, feelings of fulfillment and motivation to keep moving and coping with their diagnosis. Subsequently, following regular relations with network members’, many had learnt to manage their situations.

..Support because you have so many people in the field with HIV, from people working at the health department to people like [..], they can lead me the right way to be in my better treatment, better care, things of that nature. (Participant 11, Age 27)

3.4.5 Transition from HIV negative to positive: Post diagnosis identity

Reconciliation of one’s self-identity following the biographic disruption process and normalizing their lives was expressed by all participants in this study. We use brief case studies to illustrate two different experiences post diagnosis. For context, the case studies include certain narrative of participants’ experiences prior to HIV, as well as post diagnosis and linkage to care. The names used for the case studies are pseudonyms, and any identifying elements have been modified to ensure confidentiality of participants. The first case illustrates Jamal, who’s embraced his new identity and has used that as a career path and the second case study shows Kevin, who on the

other hand, sought to maintain his biographic continuity, not allowing his HIV diagnosis to be his new identity.

Case study 1: Jamal, age 25 (embraced HIV and integrated it into post diagnosis identity)

Jamal was raised in the South and described having a good relationship with his family. He was diagnosed with four years prior to the interview and contracted the virus from his partner at that time. He has totally embraced his diagnosis and integrated into his identity. Post diagnosis, he sought a career path in HIV by volunteering at an AIDS foundation so that he could change that narrative that young black gay men can't be productive in the society because they're living with HIV. His social relationships post diagnosis have improved with his family and friends and he believes his support network which is inclusive of family, friends and HIV support groups help him in coping with HIV.

Case study 2: Kevin, age 22 (embraced HIV but doesn't consider it post diagnosis identity)

Kevin was raised in Georgia and has a strained relationship with his family since coming out as gay and HIV positive. He was diagnosed with HIV three years prior to the interview and had threatened to commit suicide following his diagnosis. He has had multiple transition phases towards integrating HIV and ART into his identity and feels that just because he is a black gay man with HIV, that does not define his identity. Following his diagnosis, his social relationships with friends have been affected and he does not consider that he has any social support or resources that he has been able to mobilize. In regard to his HIV and self-management strategies, he sometimes forgets to take his drugs and says his diagnosis only bothers him when it comes into play with his sexual activities.

These two case studies illustrate different identity transformation post-HIV diagnosis. Jamal, with full disclosure, has completely integrated a new HIV identity and started to make a career out of his HIV status. He now primarily associates with other people with HIV because it's comfortable for him and he can be himself. From this, we clearly see HIV as having disrupted his biography, but he has adapted to its presence and made it a central element of his identity which helps to support his health. Kevin on the other hand, his HIV diagnosis meant a biographical disruption, with neither incorporation of a new identity postdiagnosis nor adaptation to his identity. His failing to embracing his identity is evidenced by the establishment of everyday realities in which his health status is not a dominant theme. By not embracing his HIV identity, Kevin hasn't fully moved beyond the devastating diagnosis to fully accepting the biographical disruption as positive. These different responses have implications for biographical continuity and better health outcomes.

3.5 DISCUSSION

This qualitative study explores the experiences of young black GBMSM living with HIV as a chronic illness in a high prevalence setting. The concepts of Bury's (1982) biographical disruption theory were applied and this has been used to describe the experiences of individuals as they are diagnosed with a chronic illness and explain their life trajectories as they respond and adapt to this chronic illness (Harris, 2009) (Faircloth, Boylstein, Rittman, Young, & Gubrium, 2004). We found that our study participants each had their different reaction to their HIV diagnosis, which were influenced by several factors such as prior knowledge of HIV and ART, HIV risk taking behaviors, current life situation and socioenvironmental factors. In addition, the data from the interviews suggests that the past experiences of the participants impacted their present lives and reactions to their diagnosis. For those whose biographies had been marked by adversity and hardship such as experiences of sexual, emotional and child abuse, their diagnosis was more distressing. Likewise, through our analysis, we found that participants whose HIV diagnosis was preceded by some prior illness or had thoughts of being infected did report initial surprise and distress at their diagnosis but were more accepting of their status unlike those whose diagnosis was unanticipated and so they had a much harder time in accepting their HIV status. This finding correlate with previous research in individuals who had experienced psychosocial issues or traumatic events over their life course and in the years preceding their HIV diagnosis (Gourlay, et al., 2017). However, a common similarity among our participants' reactions was that the process towards accepting one's HIV status was not an automatic process; in that our participants did not think of themselves as HIV negative in one moment and then HIV positive in the next moment unlike some situations where transition of individuals from a certain context to another is seamless. Rather, our study participants needed time to process their diagnosis, understand when and how they became

infected, and the likely source of their infection. This time to process their diagnosis often had an effect on how they accepted their HIV status, engagement in care and disclosure or non-disclosure to their friends, family and partners.

Similar reactions to HIV diagnosis have been reported from research among other minority populations in high prevalence settings. In their study of HIV individuals in Swaziland, Horter and fellow researchers reported that the process involved with accepting one's HIV diagnosis varied depending on the individual's context and was not automatic with some individuals often experiencing non-acceptance for longer periods of time (Horter, et al., 2017). Kutnick et al in their study of African American/Black and Hispanic high-risk heterosexuals also reported that their study participants who had no expectation of a HIV diagnosis were slow in accepting their status. In contrast, those who diagnosis precipitated a crisis, or there was prior suspicion of an HIV diagnosis, met the information with acceptance (Kutnick, et al., 2017). Another study of men living with HIV in Nigeria found that participants were more likely to accept their HIV diagnosis if it was preceded by diagnosis of immediate family members than if the diagnosis was preceded by one's own experience of illness (Okoror, Falade, Walker, Olorunlana, & Anaele, 2016). Accepting and adapting to a chronic illness depends largely on how the individuals interprets that illness.

Through participant narratives, it was evident that living with HIV as a chronic condition had long-term implications for their lives both from the disease itself and also from negotiating everyday challenges. Their experiences of living with HIV were simply not just the experience of living with an illness, but rather the impact on their trajectories and lives prior to the diagnosis. This is due in part to the fact that they had been confronted with a chronic condition, at a young age, which

had been considered a “death sentence” before the advent of ART (Nkosi & Rosenblatt, 2019). Reflecting on the unusual flow of their trajectories and trying to give meaning to their own biography, participants had to fully incorporate this new reality into their biographies in an attempt for normalcy and biographical continuity. As participants accepted their new realities, for some, transitioning to a new self-identity, that integrated all aspects of HIV most especially ART into their lives meant that they created a new identity for themselves that centered on their diagnosis and for others, the transition was partial with certain aspects of their identities redefined and others reinforced. By relating the present situation to their reconstructed pasts, participants could endow their present life with meaning and incorporate HIV self-management in their daily lives (Russell & Seeley, The transition to living with HIV as a chronic condition in rural Uganda: Working to create order and control when on antiretroviral therapy, 2010) (Russell, et al., 2016). For instance, few participants who already had certain pre-existing conditions felt that although their diagnosis did cause a disruption in their lives, they simply had to arrange their lives to include HIV now since they were used living with an illness. For them, it was a form of a biographical continuation or few others who also did report that their HIV diagnosis was disruptive, but since they were already involved in activism concerned with the LGBTQT community as black gay men, their status created a means to also get actively involved with HIV/AIDS initiatives happening around them thus reinforcing their sense of identity in terms of their sexuality and community. For the most part, all of our study participants had incorporated HIV and its treatment into their life trajectories by the time this study interviews were conducted.

Overcoming a biographical disruption depends on the individual’s narrative reconstruction and the various resources and social support that they can mobilize. Using Lazarus and Folkman (1984)

coping theory, we were able to categorize the coping strategies mobilized by our participants into emotion-focused and problem-focused. We found that our study participants mobilized their social networks and capital to deal with their diagnosis. Social support in terms of practical, emotional, or informational assistance that our participants received from their family, friends and HIV network groups were sources of support that helped mitigate the emotional distress associated with their diagnosis and living with HIV. From our analysis, we see a salient association between living with HIV as a chronic illness and individuals' network of social support. We also found that social networks were positively linked to better health outcomes for our participants. In their study of HIV-positive gay men in the United Kingdom, White and Cant (2003) explored the relationships between health, well-being, and social support among HIV-positive gay men and found that social support played a major role in their lives and improved health and well-being (White & Cant, 2003). Several other studies have demonstrated the link between social support and improved health outcomes for both HIV positive gay African American men and other groups of HIV positive individuals (Forouzan, Shushtari, Sajjadi, Salimi, & Dejman, 2013) (Li, et al., 2017) (Saleh, Berg, Chambers, & Operario, 2016). HIV network organizations were also an important resource for our participants in embracing their new identities as positive individuals. These networks provide individuals an opportunity to be themselves where they could network, socialize and engage with other positive individuals. These kind of engagements enable positive individuals have a better understanding of their disease, a sense of belonging and increase their confidence and realization that they can live healthy and productive lives. This finding is consistent with other studies that have also described HIV positive individuals feeling reinvigorated and full of renewed hope and confidence that they can lead healthier lives after being in HIV networks and learning more about HIV/AIDS (Bateganya, Amanyeiwe, Roxo, & Dong, 2015).

Another coping strategy that was pervasive throughout our interviews was faith and spirituality. Spirituality and faith in a higher being was expressed by all participants regardless of their religion identity. Interestingly, more than two-thirds of our participants had been raised in or around black churches however following their disclosure of their sexual orientation, they all mentioned that they had stopped going to church due to the stigma and judgments from church folks. Participants expressed that they had and felt a personal connection with God through spiritual practices, such as praying, meditation, reading the Bible etc. and this helped them make sense of their diagnosis, continue in their life biography and HIV self-management practices. These findings of ours align with other research that support the positive relationship between spiritual practices and emotional and mental well-being for HIV positive individuals. In their study of HIV positive African American women, Dalmida et al. (2009) found that spirituality was important to the quality of life of their study participants (Dalmida, Holstad, DiIorio, & Laderman, 2011). Spiritual and religious practices have also been identified as important coping strategies for psychological distress (Szaflarski, 2013).

Overall, the cumulative process of a biographical disruption, its effects on social relationships and identity can be distressing to the individuals experiencing. However, this can be overcome through a reconciliation of one's previous identity with the new identity that has emerged during the biographical disruption process through the mobilization of resources and support. In our study, the postdiagnosis phase for our participants were characterized by a turning point and focus to survive and thrive. This positive reappraisal of their current situation motivated them to engage in HIV care and treatment and self-management practices.

3.6 STRENGTHS AND LIMITATIONS

This study had some major strengths including include its theoretical foundation in medical sociology, the richness and depth of the study information collected, which covers a wide range of common themes among participants transcripts. Participants were exclusively recruited from the Atlanta metropolitan area, came from mostly southern backgrounds and were black, and focused on a key population of public health significance in the United States and so there may be some possibility that our findings can be applied to MSM in diverse cities, like Atlanta or similar international contexts, with sizeable MSM populations. However, the study had some limitations. The period during which the interviews took place in relation to HIV diagnosis of participants may have informed some recall bias. Although participants disclosed personal information that were considered sensitive, and precautions were taken i.e., adequate training of interviewers so they could create an environment of trust that allowed the participants to speak freely, we cannot totally rule out the possibility of a social desirability bias. Additionally, Likewise, our study might have had some participant bias since YB- GBMSM who had more disrupting HIV diagnosis might not have been likely to participate and discuss the effects of their diagnosis on their biographies. Finally, study participants were interviewed at a single point in time and so we might not have fully captured the full biographical disruption around participants lives and trajectories.

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CHAPTER 4: CONCLUSION, PUBLIC IMPLICATIONS AND RECOMMENDATIONS

4.1 CONCLUSION

Medical advances in HIV/AIDS research and the ability to live with HIV now as a chronic illness has given people living with HIV a new lease on life. However, an unexpected positive HIV diagnosis can still be distressful and cause life-altering moments. Responses to HIV were not heterogenous and acceptance of HIV status is crucial to self-management and ART adherence. This study utilized the biographical disruption framework to conceptualize the effects and coping strategies after an HIV diagnosis. Our study findings show the need to address living with HIV/AIDS holistically among young Black GBMSM living with HIV in their own narratives and experiences. Finally, our study did not explore HIV as a biographical disruption in terms of reproductive outcomes and sexual functioning among our participants and so this can be a focus area for future studies to explore.

4.2 PUBLIC HEALTH IMPLICATIONS

The first AIDS related report of five gay men with *Pneumocystis carinii* pneumonia (PCP) was published in 1981. However, this report omitted the documented case of a gay African American man, who had both PCP and cytomegalovirus (Villarosa, 2017). This omission probably thought to be insignificant at the time has since demonstrated how years of negligence, inequity and several other factors has led to this disproportionate epidemic among black communities particularly young Black GBMSM. This study contributes to the existing literature by highlighting the need for deeper analysis of the experiences of young Black GBMSM living with HIV that takes race and age at diagnosis into greater account. This is particularly important because exploring the

significance of identity, particularly during adolescence and young adulthood, provides an opportunity to bridge the existing research gaps in understanding why the HIV epidemic still persists among this group. Likewise, the inclusion of young Black GBMSM in the literature and understanding of HIV/AIDS emphasizes the need for the development of culturally appropriate interventions for them.

4.3 RECOMMENDATIONS

This study contributes to the understanding of the impact of a positive HIV diagnosis on the life trajectories of young Black GBMSM and how they cope following their diagnosis. The recommendations based on the findings comprise:

- i. more research that explores the intersectionality of the identity development process for young Black GBMSM beyond the individual level. In our study, some participants had discussed the different way in which they felt that several identities i.e., racial, gay, and HIV-positive identities interacted to become this one identity that they acknowledged for themselves. Young Black GBMSM are at the intersection of pervasive and continuing stressors such as dealing with HIV as a chronic illness, homophobia, racism, and poverty, just to mention a few and not just one-time disruptive events. Therefore, it is important to recognize that these adversities cannot be essentially addressed by only efforts that seek to increase resilience solely at the individual level.
- ii. the development of integrative approaches in healthcare and socio-environmental settings that serve positive young Black GBMSM, particularly towards communicating their needs and assisting them to empower themselves such as the Brothers Building Brothers By Breaking Barriers intervention by Hussen et al., (2018) (Hussen, et al., 2018).

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