Title

A Social, Structural, and Intersectional Analysis of HIV Status Disclosure Among Black Gay and Bisexual Men Living with HIV in the Deep South

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A Social, Structural, and Intersectional Analysis of HIV Status Disclosure Among Black Gay and Bisexual Men Living with HIV in the Deep South

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A Social, Structural, and Intersectional Analysis of HIV Status Disclosure Among Black Gay and Bisexual Men Living with HIV in the Deep South.

Chadwick K. Campbell

Abstract: Forty years into the HIV epidemic, the most impacted group continues to be Black gay and bisexual men, for whom living with HIV comes with a substantial social burden, particularly in communities with high levels of HIV-stigma and homophobia. One way in which this is manifested is in the complex disclosure/nondisclosure process. HIV status disclosure has been, and continues to be privileged in public health research, as it is seen as critical to educating others, reducing sexual transmission, and garnering needed social support. Most of this research has been centered on the individual and has focused on understanding the decision-making process about how, when, and to whom they will disclose. Other research aims to identify barriers and facilitators of disclosure, with the ultimate goal of encouraging disclosure. At the individual level, however, exploring the disclosure process requires an understanding of previous experiences, social environments, and the dynamics of social relationships as HIV risk, diagnosis, and disclosure are each embedded in ongoing social relations. This dissertation takes a sociological approach to understanding the dynamics of HIV disclosure among Black gay and bisexual men living with HIV (BGBM-LWH) in Baton Rouge, Louisiana. BGBM, existing at the intersections of race, class, and sexuality, account for the majority of new infections in the state of Louisiana, and their experiences are embedded in a culture of silence and shame around sexuality and HIV. Thus, their HIV diagnosis and disclosure experiences offer a crucial site for this intersectional analysis which explores disclosure and its outcomes as socially and structurally constituted. Between June 2019 and June 2020, I conducted semi-structured, in-depth, qualitative interviews with 30 BGBM-LWH. I used a grounded theory analysis to explore not only men’s HIV disclosure-specific narratives, but to situate them in the context of their biographies, their social and cultural environment, and their ongoing social and familial relationships.

The results of my analyses are presented in three chapters. First, I illustrate the ways in which HIV status disclosure can result in disruptions to one’s biography and can lead to long-term, negative, and unforseen consequences. These included loss of employment or housing, as well as disrupted social networks, familial relationships, and support systems. Further, I illustrate how their intersectional social locations alongside structural racism, homophobia, and HIV stigma shaped the nature of those disruptions and long-term consequences. Second, I reveal the emotion and emotion work that accompanied men’s disclosure experiences. Men described having to manage and control their own emotions and “dig deep” to get the nerve to disclose. In turn, they described having to manage others’ emotional reactions and feeling a sense of guilt for being the cause of sadness for their friends and family. Lastly, I develop a grounded theory of the social interactions and structures that produce and reproduce HIV stigma on an ongoing basis. These included: the transmission of misinformation at the community level; witnessing or experiencing acts of marginalization at the individual level; HIV criminal nondisclosure laws and sex education policies at the institutional level; as well as silence and gossip at the level of social interactions. This project expands on sociological and public health literatures to produce an analysis of HIV disclosure that places social and structural environment at the center, as opposed to the individual, and offers new sites for research and intervention.

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Chapter 1: Introduction

My Personal Journey to This Work

February 13, 2021, marked 20 years since I was diagnosed with HIV. At the time, I was living in New Orleans, about 60 miles away from my home in Baton Rouge. I had moved there right after high school and was just beginning to acknowledge and accept my gay identity. However, I was beginning my young adult life with little to no real knowledge about how to protect myself from HIV and other sexually transmitted infections. I had also developed a healthy disdain for people with HIV. Around the gay bars of the French Quarter, friends whispered, “I heard he got a **H**ouse **I**n **V**irginia.” Those were the guys we were not supposed to date, sleep with, or even hang out with. Like many of the men in my study, I believed that simply staying away from “those guys” would protect me, that I didn’t need to try to learn more about HIV because that was something that happened to others. As I would soon learn, I was not, in fact, better at choosing “safe” partners than others, and that HIV infects *people* not just *those people.*

After my diagnosis, like many people living with HIV, the prospect of disclosure was a constant thought. I told my three best friends immediately. I am blessed to have friends who are like family to me – people who will drop everything if I need them. I told my family soon thereafter because, while it was uncomfortable and I didn’t want to scare them, I knew that in my family, we don’t keep secrets and we are there for each other unconditionally. I never worried that I would lose them. I never worried that they wouldn’t support me. As I suspected, my relationships with my family members didn’t change much at all. Though, years later, as I was deeply entrenched in HIV prevention work, I slowly began to see how much more complex disclosure is for many other people living with HIV. Moreover, I began to feel as though we

(HIV prevention folks) were, in many cases, advocating that people disclose an HIV diagnosis for the protection of others, without truly valuing how it could change their lives.

I wanted to do this project for my dissertation research because it was my first opportunity to design a study to learn from and about people that I strongly identify with, in the place where I was born and raised. Since my entire family is still in Baton Rouge, I have stayed connected to my hometown and, while I have chosen not to live there, I still have a deep affection for it, despite its flaws. There were things I knew before starting this project that would almost certainly be a part of men's stories. I knew that the city has no real cohesive gay community. I knew that it very recently had the highest new HIV infection rate per capita in the United States and that, despite this, HIV is largely unspoken among its residents. This is, in part, because of the denial that many people live in when it comes to HIV. I knew that when it comes to educational and economic inequality, Baton Rouge's data was worse than national level data. And I knew that the Black family, Black church, and the relations within those institutions in the Deep South would be central. Most importantly, I knew how Black gay and bisexual men are talked about in the literature – as purely sexual beings, whose vulnerability to HIV can be addressed by isolating "risky behavior," and ignoring much of the context that shapes their lived experiences, and the ongoing social relations within which their experiences are embedded. For those living with HIV, disclosure is framed as imperative to protect others and to garner social support, though disclosure decisions, like HIV vulnerability are embedded in those same ongoing social relations.

I tried to keep at the forefront of my mind that while I share several identities with the men I interviewed and have the forementioned knowledge of the city and culture, I was also naïve to many of their experiences. I have spent most of my adult life in the Bay Area where: the culture around sexuality is markedly more liberal; race relations are troubled in many ways, but differ greatly from the South; and knowledge, attitudes, and behaviors around HIV reflect the greater research, education, and activism of the region. Further, I am an academic, and someone who lives a financially stable life in one of the most expensive metropolitan areas of the country. My 16 years in Bay Area culture, my proudly gay identity, and my educational achievement and class status made me an outsider to several of the men in my study, and ignorant of many of the issues they face based on their race, class, sexuality, and HIV status. I was open with participants about my own identities and experiences. As a researcher, who is a part of constructing the research situation (Charmaz 2014), I wanted them to know who I was before they decided to share their sensitive, personal narratives.

My goal was to understand HIV disclosure among the men I interviewed and center their stories in as much of this context as possible. Also, it was, and is, important to me that I honor them and the trust they placed in me by ensuring that I tell their stories with as much compassion as possible, taking care not to use language that blames, stigmatizes, or implies any deviance or pathology in their stories, experiences, beliefs, or decisions. This dissertation was more than a scholarly endeavor – it was an act of love, respect, and activism – as I aim to develop a research portfolio that intervenes on the ways in which *we* are seen in public health research and practice.

Statement of the Problem

Being diagnosed with HIV can be a significant disruption of one's biography, leading to a reimagining of one's identity, relationships, and future (Sandstrom 1990, Wouters and De Wet 2016). Living with HIV comes with substantial social burden, particularly in communities with high levels of HIV-stigma and homophobia. One way in which this is manifested is in the complex disclosure/nondisclosure process. Over the course of the HIV epidemic, disclosure of one's HIV status has been studied by numerous authors (Courtenay–Quirk, Wolitski, Parsons et al. 2006, Gielen, Fogarty, O'Campo et al. 2000, Kalichman, DiMarco, Austin et al. 2003, Paxton 2002). Most of this work has approached disclosure from an individual perspective, exploring the *whys, why-nots, how's,* and, *to-whoms* of disclosure (Cusick and Rhodes 1999, Derlega, Winstead, Greene et al. 2004, Derlega, Winstead, Greene et al. 2002, Obermeyer, Baijal and Pegurri 2011). The ultimate goal of these studies has been to understand the nature of disclosure, encourage disclosure, and intervene on non-disclosure, all in the service of preventing HIV transmission. Though, disclosure itself may serve as an additional biographical disruption because each disclosure poses the risk of altering one's daily existence (Tewksbury and McGaughey 1997), making it a particularly difficult interaction to encourage for many PLWH.

At the individual level, the disclosure process requires an understanding of previous experiences, social environments, and the dynamics of social relationships. For example, negative disclosure experiences, or having experienced unwanted disclosure by others may lead to nondisclosure. Being a member of a social group or a family that one is dependent on for support and survival may require one to keep the information about their HIV status secret to maintain stability and a sense of normalcy (Adam, Corriveau, Elliott et al. 2015, Koku 2010, Rassin 2011). Thus, the disclosure/nondisclosure process is shaped by factors at all levels of society including, but not limited to, laws and policy, societal level stigma, health status, psychological factors, issues around personal safety, one's social environment and network, and interpersonal relational dynamics.

To date, HIV status disclosure is understood largely through public health and psychological frameworks. Much of this knowledge has been shaped around quantitative understandings of relationships between various psychological measures (e.g., depression, anxiety, vengeance) and status disclosure (Abler, Sikkema, Watt et al. 2015, Hays, McKusick, Pollack et al. 1993, Kalichman and Nachimson 1999, Parsons, Schrimshaw, Bimbi et al. 2005). The findings of these studies have been mixed with some finding a significant relationship between the psychological measures and disclosure (Abler et al. 2015, Armistead, Morse, Forehand et al. 1999), while others find no such association. Others, still, find that the association depends on the nature of the relationship between the PLWH, and the person being disclosed to (Clark, Lindner, Armistead et al. 2004, Daskalopoulou, Lampe, Sherr et al. 2017, Zea, Reisen, Poppen et al. 2005). While there is little reason to question that PLWH experience some level of psychological distress associated with their diagnosis, our understanding of the emotional dimensions of living with HIV are limited, not by the quantity of published studies, but by the limited measures and methods used. Indeed, emotions are shaped, in part, by social context, stigma, identity and social location (Hochschild 1979, Hochschild 1990, McCarthy 1989).

Quantitative measures of stigma (e.g., perceived stigma, anticipated stigma, experiences of stigma) have also been employed to understand its relationship to disclosure and non-disclosure. However, little research has attempted to understand these concepts as experienced and navigated using the voices of people living with HIV (PLWH). Sociological studies have shown that HIV stigma is a complex, ongoing, social process that occurs at multiple levels above, beyond, and surrounding the individual level acts of stigma and discrimination that are often measured (Link and Phelan 2001, Parker and Aggleton 2003). For example, HIV criminalization laws, a political context that is hostile toward PLWH and LGBT communities, religious institutions, familial structures, as well as cultural practices and beliefs can each contribute to a stigmatizing environment. Individual-level stigma is often a reflection of the structural and environmental stigma, and thus cannot be effectively addressed only at the individual level. This dissertation employs this more complicated understanding of stigma to understand how it is produced and the role it plays in the disclosure process and the overall lived experiences of men.

Population and Setting

Gay and bisexual men (GBM), and Black gay and bisexual men (BGBM) in particular, continue to account for most new HIV infections in the United States (US), and BGBM in the US south bear a disproportionate HIV disease burden (CDC 2020a, CDC 2020b, State of Louisiana Office of Public Health 2018). Further, southern states have the highest HIV and AIDS diagnosis and death rates (Hanna, Selik, Tang et al. 2012, Reif, Safley and McAllaster 2015). In particular, Louisiana ranks second in new diagnosis rates in the entire US (CDC 2016), with GBM accounting for 65% of all new diagnoses in 2014. The Baton Rouge metropolitan area, where this dissertation research was conducted, has the fourth highest diagnosis rate among metropolitan areas in the US (CDC 2020b). Additionally, there are disparities in treatment and care outcomes. Lower proportions of BGBM living with HIV (BGBM-LWH) are linked and retained in care, are currently on treatment, or reach viral suppression compared to White GBM (Hoots, Finlayson, Wejnert et al. 2017, Millett, Flores, Peterson et al. 2007, Rosenberg, Millett, Sullivan et al. 2014).

Further, in the Southeast region, Blacks are less likely than non-Blacks to be linked to care at any point post-diagnosis (Rebeiro, Ivey, Craig et al. 2017). Thus, BGBM-LWH in Baton Rouge occupy a number of stigmatized social locations in a city with one of the highest rates of infection in the country. In this region, the cultural norm around sexuality and HIV is largely a matter of silence (Foster and Frazier 2008). There are high levels of stigma and homophobia embedded at the community and structural levels (Center for HIV Law and Policy 2020, Reif, Wilson and McAllaster 2018, Sang, Matthews, Meanley et al. 2018, SIECUS 2018) and racial inequalities are more devastating than those at the national level (Conduent Healthy Communities 2020). These are important contextual realities within which the data in this dissertation should be understood.

Theoretical Underpinnings

In each of the three papers in Chapters 2, 3, and 4, substantive theories, relevant to the that paper's focus are discussed. However, three theoretical frameworks were central to the entire project and, to some extent, to each of the three papers. These included: symbolic interaction; stigma; and intersectionality.

Symbolic Interaction

Symbolic interaction (SI) posits that meaning is constructed through social interaction. An essential part of George Herbert Mead's early work on SI (Mead and Mind 1934) was the construction of the self. He argued that the individual is a member of a community, or some group that is a subset of the larger group. The social group, he suggests, can be thought of as the 'generalized other,' and the attitudes of the generalized other represent the attitudes of the larger community. The way the individual begins to understand his place in the community, and form an identity, is by taking on the attitudes of the 'generalized other.' The self is constructed in two phases. First, the "self is constituted simply by an organization of the particular attitudes of other individuals toward himself and toward one another in the specific social acts in which he participates with them." Second, the "self is constituted by an organization of the social attitudes of the generalized other or the social group as a whole to which he belongs." (p. 158) In other words, it is through understanding and taking on the views, beliefs, and actions of the larger community that the individual begins to form his understanding of himself, and his place, within that community. So, through a process of interaction, the self is developed.

Two additional concepts that are particularly relevant to the HIV disclosure process are Mead's discussions of 'verbal gestures' and 'significant symbols' (Mead and Mind 1934). Verbal gestures are stimuli to some type of response. More importantly, the vocal gesture is a stimulus that has the same meaning and evokes the same response in the person talking as in the person hearing it. In this way the verbal gesture, according to Mead, stands apart from other gestures, as we can hear ourselves speaking while we cannot see what our own facial expression is conveying to another person. It is through conversations of gestures, and social interaction broadly, that new objects are created and given meaning. As it relates to this study, in the early 1980s, HIV was a new object that was socially created and given meaning, through interactions of individuals, the medical and scientific communities, the media, and broader social discourse. It is the relationship of the verbal gesture (e.g. self-disclosure of HIV status) to the responses of both the person speaking as well as the receiver of the gesture that makes a verbal gesture, what Mead calls a 'significant symbol' (Mead and Mind 1934).

Disclosure of an HIV positive status is a significant symbol, as the meaning of an HIV positive status is likely shared by the discloser and the disclosee. Disclosing reveals more about oneself than the HIV status itself (e.g., who one is or what one may have done to become a PLWH), and it evokes the same response – often shock, depression, anger, fear, or concern – in both the discloser and the disclosee. The societally shared meaning of HIV is rooted in its association with deviance, and the view of PLWH as a risk to the larger community (Crawford 1994). That meaning has been constructed, altered, and reinforced by individual and the collective society.

Herbert Blumer, building on Mead's work, explicated the main tenets of symbolic interactionism. Blumer described three basic tenets of symbolic interaction. First, human beings act toward objects based on the meaning that they have for them. Blumer suggests that social science has largely focused on factors that contribute to behavior such as stimuli, attitudes, and social position. However, meaning is taken for granted. He argues for meaning to be seen as central in understanding behavior. Second, the meaning of objects is developed through social interaction between people in society. In contrast to understandings of meaning as inherent in the object itself, and psychological understanding of meaning making as a cognitive and perceptive process, symbolic interaction views meaning as the social products of people interacting. Third, meanings are interpreted and modified in an ongoing way by human beings during social interaction. Meanings should not be seen as static. People don't simply apply a pre-established meaning. Instead humans communicate to themselves the thing that they are acting towards, and then based on an analysis of the specific situation in which one finds himself, selects, checks, suspends, regroups and transforms its meaning (Blumer 1969).

SI views society as "arrangements of people who are interlinked in their respective actions," and "seeks explanation in the way in which the participants define, interpret and meet the situations at their respective points" (Blumer 1969:58). There is no inherent meaning to any object, action, or idea. Meaning making is a shared social process, informed by individual experience, knowledge, social position, and unique perspectives. This dissertation takes an SI approach to understanding how HIV disclosure interactions unfold, and how the meaning of an HIV diagnosis is shaped for each person in his own particular context. SI provides a framework to examine how the meaning-making process shaped by men's race, class, and sexual identities. It also assists with an understanding of how community level interactions (e.g., community norms, gossip, marginalization) define what it means to be living with HIV and disclosing one's status.

Intersectionality

Intersectionality is a particularly apt framework for exploring the lived experiences of Black gay and bisexual men living with HIV in the US South. Kimberle Crenshaw originally used the term to describe how race and gender interact to shape the experiences of Black women (Crenshaw 1991). As she argued, "the intersection of racism and sexism factors into Black women's lives in ways that cannot be captured wholly by looking at the race and gender dimensions of those experiences separately" (Crenshaw 1989:1244). While multiple identities (e.g. race, gender, class, and sexuality) intersect at the individual level, they reveal the existence and functions of socio-structural oppression and inequality (Collins 2016, Crenshaw 1989). In the case of BGBM-LWH in Baton Rouge, historical and present-day structural racism, high levels of HIV and sexual minority stigma, and racial economic inequality that exceeds the staggering national data come together the shape their experiences in a way that cannot be explained by any one of these inequities alone. Social life is much too complex and is "overflowing with multiple and fluid determinations of both subjects and structures" to simplify into neat analytical categories (McCall 2005:1773).

An intersectional framework shifts an understanding of multiple axes of inequality from an additive mode, in which oppressions (e.g. racism, sexism, classism) are ranked and added together to quantify "a grand oppression greater than the sum of its parts" (Collins 2016:37), to one that conceptualizes them as simultaneous, multiplicative and co-constitutive. This approach recognizes the interlocking nature of oppressions and incorporates analyses that seek to address the impacts of overlapping marginal identities (Cho, Crenshaw and McCall 2013, Collins 2005, Crenshaw 1991). According to Patricia Hill Collins (2016), additive analyses of oppression, in which race, class, and gender inequalities are simply added up, locks us in a “stance of comparing and ranking oppressions – the proverbial, I’m more oppressed than you” (36). This way of conceptualizing oppression relies on either/or dichotomies in which we are asked to see ourselves as Black/White, man/woman, gay/straight, and then rank our various identities in terms of their salience (Collins 2016). In terms of understanding the ways in which oppressions are manifested, this approach falls short in acknowledging that multiple oppressed identities interlock and co-constitute each other.

Intersectionality is inextricably linked to an analysis of power, more so than identity (Cho et al. 2013). An intersectional perspective requires an acknowledgement of the relationships between identities, and not only acknowledging difference but understanding which differences matter. An intersectional analysis of power helps to understand which differences matter, how they matter, and how they interact (Tomlinson 2013). Indeed, the intersections of race, class, gender, and sexuality create unique experiences and challenges. Others have expanded intersectionality to incorporate additional identities, including age, cultural background and language (Ibrahim and Heuer 2016). Of particular relevance to my work is the concept of geographical identity, defined as one’s sense of attachment to the place they live, and the characteristics of that particular place (Chandler and Munday 2014). As Ibrahim and Heuer argue, “socialization in a specific geographical region has an influence on cultural identity.” In this study, identifying as an HIV positive Black gay or bisexual man is co-constituted with their identity as southerners, their attachment (or lack thereof) to Baton Rouge, and the particular culture of the Southern Black family (Dill 1982, Griffin 2001, McAdoo and Younge 2009).

Consequently, here, I include geography as one of the intersections of identity that help to shape the unique situation in which Black gay and bisexual men living with HIV find themselves.

Intersectionality has been taken up in by a number of HIV scholars aiming to complicate understandings of the HIV epidemic. Celeste Watkins-Hayes argued that “HIV/AIDS is an epidemic of intersectional inequality fueled by racial, gender, class, and sexual inequities at the macro-structural, meso-institutional, and micro-interpersonal levels” (Watkins-Hayes 2014). Some have highlighted the ways in which ‘risk groups’ and simplified, singular understandings of behavior and identity can foreclose the complexities of risk among those who are not members of official surveillance categories (Bowleg 2012, Dworkin 2005, Logie, James, Tharao et al. 2012, Young and Meyer 2005). In *Workable Sisterhood* Michelle Tracy Berger argued that the women in her studies had social locations (e.g. sex work, substance use) that disadvantaged them prior to being diagnosed with HIV, which shaped their experiences as women living with HIV (Berger 2010).

Qualitative findings from a study with Black, heterosexual men, reveal the ways in which their race, gender, and socioeconomic status place in at the intersection of a number of interlocking oppressions. HIV prevention that is informed by the experiences of Black, heterosexual men would have to address high incarceration rates, unemployment, and disproportionately lower likelihood of having health insurance. Importantly, these structural factors, while affecting Black communities generally, do not impact Black men and Black women, or middle-class Black men and poor Black men, to the same degree (Bowleg, Teti, Malebranche et al. 2013). A similar combination of structural factors serve as barriers to BGBM accessing HIV testing and prevention (Levy, Wilton, Phillips et al. 2014). Further, in arguing for the need for intersectionality in HIV prevention, Dworkin (2015) pointed to the ways intersections of race and sexuality can influence the effectiveness of interventions. For example, Black men are more likely to identify their sexuality as something other than gay or bisexual (e.g., same gender loving, heterosexual) and, therefore interventions targeting "gay men" or "men who have sex with men" may fail to reach them.

This dissertation employs an intersectional framework to explore the ways in which BGBM-LWH in Baton Rouge experience these multiple, overlapping, and interlocking identities and their associated stigmas. Indeed, these prejudices and stigmas also have specific regional and local realities, which shape the experiences of GBM in the US south, particularly those living with HIV. There are high levels of homophobia and HIV stigma in the southern region of the US (Reif, Golin and Smith 2005, Southern AIDS Coalition 2012, Truong, Perez-Brumer, Burton et al. 2016, Uselton 2013, Vaught 2004, Whetten and Reif 2006), and in the south, endorsing negative views of gays and lesbians is associated with HIV stigma (Baunach and Burgess 2013). Further, HIV-stigma is negatively correlated with HIV knowledge among African American youth in the Southeast (Kerr, Valois, Diclemente et al. 2014) and evidence suggests a general lack of awareness of the epidemic among African Americans in the south (Foster and Gaskins 2013). An intersectional lens will allow for a more complex understanding of the experience of living with HIV for these men, and HIV status disclosure for those with multiple stigmatized, intersecting identities, generally.

BGBM live in a uniquely inequitable social environment that makes navigating HIV disclosure particularly difficult. For BGBM-LWH in the US South in particular, race, gender, sexuality, HIV-status, and geographic location create a particular intersectionality that undoubtedly affects disclosure as well as their lived experiences more broadly. Like most areas of the American south, Baton Rouge has a long, troubled racial history. Residential segregation has been increasing in the metropolitan area for the past two decades (Frey and Myers 2005, Siegel-Hawley and Frankenberg 2012), and Louisiana has the highest incarceration rate in the nation (Miller and Khey 2017, The Sentencing Project 2018). These structural inequities exist alongside the aforementioned levels of HIV stigma and homophobia. This dissertation expands our knowledge of how these men navigate the HIV status disclosure process, and how their particular social locations shape disclosure outcomes and their overall lived experiences.

Stigma

Erving Goffman's Stigma (1963) is a symbolic interactionist theory of the how stigmas are produced through the actions and interactions of members of a community. It is especially useful in understanding people living with HIV and the social and interpersonal responsibilities that they acquire along with the diagnosis. Goffman describes stigma as "an attribute that is deeply discrediting," (p. 3) and goes further to call for a focus on relationships over and above attributes. In focusing on relationships, we can begin to not only identify the process through which an attribute becomes unfavorable, but under what circumstances and within which bodies it is unfavorable. The social consequences of the stigmatized attribute, and the rationale for those consequences, are aptly highlighted by Goffman's distinguishing of the *normals* from the stigmatized person:

> *By definition, of course, we believe the person with a stigma is not quite human. On this assumption, we exercise varieties of discrimination, through which we effectively, if often unthinkingly, reduce his life chances. We construct a stigma-theory, an ideology to explain his inferiority and account for the danger he represents, sometimes rationalizing an animosity based on other differences, such as those of social class. (p. 5)*

Here, Goffman summarizes the ways in which society *others* the person with a stigmatized characteristic, and then justifies the poor treatment of the person with an ideology. This well describes the view of HIV-positive persons as dangerous and a threat to others, and its disproportional impact on specific social groups (e.g., people of color, gay men, transgender women, sex workers).

Goffman also provides differentiations in terms of how stigmas can be understood. First a person can possess a stigma that is *discredited*, in which the stigma is evident or already known, or one that is *discreditable*, in which the stigma is not known or immediately perceivable. HIV has in many ways moved from discredited, as it was during the height of the AIDS epidemic, to discreditable, as it is now a chronic, manageable illness that can be revealed, or not, at the discretion of those living with the virus. Further, Goffman identifies three different types of stigmas – abominations (physical deformities) of the body; blemishes of individual character; and tribal stigmas of race, nation, and religion. The nature of the HIV epidemic lends itself to HIV positivity falling, potentially, into all three of these categories. First, in some cases, there are visible 'abominations' associated with HIV, such as weight loss, lesions (in the case of advanced stages of AIDS), and facial wasting. Second, the character of gay men, intravenous drug users, sexually "promiscuous" persons, and sex workers are socially blemished and the association of HIV with those blemished characters is at the root of the stigmatization of HIV (Crandall 1991). Lastly, while Goffman's concept of tribal stigmas is concerned with traits that can be transmitted through lineages, I would argue for its expansion to include *social* "tribes." For example, being a gay man, or a sex worker, leads one to be labeled "at risk" for HIV, and leads some to assume that HIV infection is inevitable, both of which are stigmatizing. While these traits are not passed down through lineage, membership in these social tribes comes with similar positive and negative associations as being a member of a racial group.

Stigma as a Social Process: The historical narrative around HIV and AIDS plays an important role in our social understanding of the epidemic. Early on, the Centers for Disease Control and Prevention (CDC) identified groups of people called "high-risk populations," in order to target people in ways that would most effectively fight the spread of HIV (CDC 1989). The "risk groups" that the CDC first identified included people that can be separated into two distinct groups – the *deviants* and the *innocents*. The *deviants* included gay men, people who inject drugs, and heterosexuals from Caribbean and African countries. The *innocents* included blood transfusion patients, infants born to HIV-infected mothers, and health care workers. Consequently, many efforts to decrease the incidence and prevalence of HIV and AIDS have worked in concert with other cultural and political efforts to oppress, subjugate, and control marginal groups of people.

While HIV knowledge has expanded over the past 40 years, the extent to which people have acquired that knowledge and moved beyond stereotypes varies greatly by race, class, and geography (Brown, Serovich, Kimberly et al. 2015, Kerr et al. 2014, Li, Chen and Yu 2016). The particular political, cultural, and social contexts of an illness that is often acquired through societally deemed deviant behaviors (e.g., anal sex; intravenous drug use) have been largely responsible for shaping the social understanding of HIV (Coleman 1986, Crawford 1994, Kowalewski 1988). Indeed, those understandings of HIV and the understandings of PLWH are shared by PLWH. For example, (Bird and Voisin 2013) reported that some BGBM-LWH described having internalized negative stereotypes that they held prior to being diagnosed. The experience of living with HIV is, in part, shaped by a priori negative understandings about

PLWH. Thus, "…coping with every day, HIV-positive life means adopting a stance in relation to these discourses" (Carricaburu and Pierret 1995:71).

Most HIV stigma research has focused on perceptions and the consequences of those perceptions, individual acts of discrimination and rejection, and stereotyping, instead of structural conditions and social processes. Here, stigma has come to be seen a thing that is *in* the person, instead of a label that is attached *to* the person (Parker and Aggleton 2003). More recent work has expanded and complicated Goffman's stigma by shifting our understanding of stigma from a "*kind of thing* – a relatively static characteristic or feature" or a "static attitude" (Parker and Aggleton 2003:14) to a social process (Berger 2010, Crawford 1994, Link and Phelan 2001, Parker, Aggleton, Attawell et al. 2002, Parker and Aggleton 2003, Quinn and Earnshaw 2011). These authors largely place the stigma process in a framework of societal power arrangements. Viewing stigma as a social process, allows for an exploration of how stigma is produced and sustained, and question who has the power to stigmatized and who can be stigmatized because they lack power (Link and Phelan 2001, Parker and Aggleton 2003). Each of these stigma components are a part of a process of social control, which is a key function of stigmatizing individuals and groups, as it creates difference, which is needed to define what is normal, maintain the status quo, and reproduce both dominant status and structural inequalities among the marginalized (Coleman 1986, Parker and Aggleton 2003, Taylor 2001).

Stafford and Scott (1986) argue that by devaluing stigmatized persons, they are positioned as objects of social control which limits their social participation. In the case of stigmas that the person cannot control (i.e., mental illness, or blindness), the reaction to the stigma serves simply to limit the person's social engagement. However, with those stigmatized behaviors, beliefs, and identities over which the person has some control, the stigma reaction goes further. In addition to limiting the person's social engagement, it also functions to discourage others from engaging in the same behaviors, or adopting the same identity (Stafford and Scott 1986). In the case of HIV, individuals are expected not to engage in sex work, injection drug use, gay or bisexual relationships, or promiscuity. Thus, HIV-stigma reinforces "appropriate" behavior and discourages the "deviant" behavior associated with HIV. Individual actions then become a mechanism of social control. Social rejection or quarantine not only separate the stigmatized person from "normal" others, it also encourages the non-stigmatized to limit their interactions with them (Coleman 1986). Lastly, it is critical to recognize the importance of social context. Each of these processes operates differently in different communities, geographies, and time (Earnshaw and Kalichman 2013, Earnshaw, Smith, Chaudoir et al. 2013, Link and Phelan 2001, Mill, Edwards, Jackson et al. 2010, Parker et al. 2002).

Intersectional Stigma: Intersectional stigma employs the framework of intersectionality in understanding the relationships between various stigmas and social structure (Berger 2010). All PLWH share an HIV diagnosis and to some extent, experience HIV-stigma. Though there is great diversity among PLWH, and those who are members of marginalized groups may experience other stigmas related to their race, gender, or other identities (Earnshaw and Kalichman 2013). A number of studies have explored the ways in which HIV stigma and other forms of marginalization come together to shape the lived experiences of PLWH using varying terms including 'layered,' 'multiple,' 'compound,' or 'intensified' stigma (Arnold, Rebchook and Kegeles 2014, Chambers, Rueda, Baker et al. 2015, Doyal 2009, Henkel, Brown and Kalichman 2008, Kowalewski 1988, Nyblade 2006, Reidpath and Chan 2005, Rogers, Tureski, Cushnie et al. 2014). These authors, however, frame their research and findings using an additive approach (Bowleg 2008, Collins 2016), not an intersectional one. These studies describe multiple stigmas in ways that suggest PLWH have to deal with HIV-stigma “on top of pre-existing stigma” (Nyblade 2006:341), and argue for HIV prevention interventions to also address other stigmas lest they might hinder prevention efforts (Henkel et al. 2008). In an intersectional stigma framework, “the ‘piling up’ of stigmas does not result just in a negative effect; it changes and transmutes the relationship between other aspects of identity and HIV/AIDS” (Berger 2010:30). An intersectional view of stigma goes beyond simply acknowledging the experience of multiple stigmas, and suggests that those multiple stigmas are interacting with, and shaping each other.

Michelle Berger ’s analysis of stigma with women living with HIV centers on four stigmas: 1) drug use; 2) sex work; 3) having experienced sexual assault; and 4) HIV stigma. She posits that people with low social status (e.g. women of color, drug-using sex workers, and urban residents) are “already positioned within a set of structurally deleterious social discourses” before they are impacted by HIV (Berger 2010:29). Thus, HIV stigma is interlocking and overlapping (Collins 1986, Crenshaw 1991) with their other, already-stigmatized identities, the cumulative effect of which shape an experience that is unique and different from other groups living with HIV. Indeed, among PLWH who had a history of substance use, Earnshaw, Smith, Cunningham et al. (2015) found that internalized HIV-stigma was only associated with depressive symptoms among those who had the highest levels of internalized substance use stigma. Similarly, other research in China and Thailand has found that AIDS is less stigmatized that injection drug use or commercial sex; and AIDS stigma was lower than the shared stigma of AIDS combined with injection drug use or commercial sex (Chan, Yang, Zhang et al. 2007, Chan, Stoové, Sringernyuang et al. 2008).

Several empirical studies on men and HIV have demonstrated the interlocking nature of multiple marginalized identities. Among BGBM, Bowleg (2013) found that men were faced with interlocking oppressions including gender norms and expectations of masculinity, heterosexism in the Black community, and racial microaggressions in the larger community as well as the White gay community. Gay and bisexual men in the Caribbean have described homosexuality as being heavily scorned in their cultural environment. For them, HIV is "kind of multiplied by twice because of the heavy stigma . . . the level of wrongness and impureness and of how very un-Christian-like you are if you are positive. And if you are gay and you have it, it is worse yet" (Rutledge, Abell, Padmore et al. 2009:26).

Further, men living with HIV and who had a history of incarceration have described the ways in which each of these stigmatized identities led to experiences of judgment and discrimination (Brinkley-Rubinstein 2015). Men described traveling across town to get services or choosing to live on the street to avoid the stigma attached to HIV. Further, they described not being able to find an apartment or get employment due to their criminal records. When describing their internalization of these stigmas, these men described Black people as "dangerous" and HIV as "scary". Further Black men in this study described internalized perceptions of themselves as dangerous because of HIV and incarceration. The authors suggest that it is reasonable to posit that White men LWH and an incarceration history would likely not perceive themselves as dangerous (Brinkley-Rubinstein 2015). In the case of BGBM-LWH in the deep south, high levels of homophobia and HIV stigma, structural racism and heterosexism, traditional gender norms, and religiosity all intersect to form a particular intersectional stigma that men must confront throughout their lives.

To date, understandings of HIV among Black gay and bisexual men have largely focused on sexual behavior and risk reduction, substance use, disclosure (as related to sexual risk reduction and garnering social support), uptake of biomedical prevention strategies such as pre-exposure prophylaxis, as engagement and retention in care. While each of these are important to examine, much less is known about the social and structural realities, outside of the individual, that shape HIV risk, diagnosis, disclosure, and the overall lived experiences of PLWH. Most research starts with exploring the cognitive and psychological measures at the individual level. From a sociological perspective, however, it is crucial to understanding social life and how daily interactions, structures, policies, and community norms constitute those individual level experiences. In conducting the analyses for chapters 2-4 of this dissertation, I sought to answer the following research questions:

Chapter 2

1. What are the intersectional and structural factors that shape the short- and long-term consequences of HIV disclosure among BGBM-LWH?

Chapter 3

1. What is the role of emotions and emotion work in HIV disclosure?
2. How do familial and community norms, social structures, and stigma shape men's emotional responses and the extent to which they engage in emotion work?

Chapter 4

1. What are the social processes through which HIV stigma functions in the lives of BGBM-LWH in Baton Rouge?

Methods/ Overview of Three Papers

Each of my three papers is based on a qualitative sample (N=30) of BGBM-LWH in Baton Rouge, LA. My approach to exploring and understanding their experiences included exploring their lives before and after diagnosis, with a focus on stigma and disclosure. I used a constructivist grounded theory approach to data collection and analysis, which acknowledges the constructed nature of not only social reality, but also the research situation. This includes what both the participant *and* the researcher bring, and do within the situation (Charmaz 2014, Clarke, Friese and Washburn 2017). This is particularly important given my positionality, as described above. As grounded theory emphasizes "actual experiences and practices – the lived doingness of social life" as well as "partiality, situatedness, and multiplicity" (Clarke, Friese and Washburn 2016:124), it was a particularly appropriate methodological approach for the questions this dissertation seeks to address.

HIV disclosure is a deeply personal and may be emotionally fraught. Exploring topics such as these is best suited for open-ended interview questions that allow the researcher to listen to participant narratives and refrain from imposing the researcher's 'expertise.' In-depth qualitative interviews allow the researcher to focus the topic, while making time and space for participant insights to emerge (Creswell 2012). Grounded theory interviewing methods also "conceptualize social life as a process that is the production of the simultaneous shaping of different aspects of social life and human agency" (Cuadraz and Uttal 1999:161). These characteristics of grounded theory were invaluable to understanding participants' complex intersections of experiences, identities, and social positions.

Community Engagement and Recruitment

I engaged in a months-long effort to build connections with members of the community before beginning the recruitment process. I first volunteered at a World AIDS Day event in 2018, where I spent the day helping to set up, serve food, and clean up for a banquet where about 100 community members came together to eat, sing, pray, and honor community members who work in HIV prevention. There, I was able to meet several people who were deeply connected and influential in communities of BGBM in Baton Rouge. Within two minutes of meeting me, one of these men asked me where I was from, why I was doing the research in Baton Rouge, and whether I was also living with HIV. It was in this exchange, and in others, that it became clear that my approach would need to be different for this study. I would need to be as open with the men I recruited as I was asking them to be with me. When I built the web page for the project, I included a biographical statement that included my roots in Baton Rouge, my professional experiences, as well as that I had been living with HIV for 18 years. I also began each interview with these facts about myself. In many cases, I could see a physical shift in participants' body language. They seemed to instantly feel safer with me, and shared stories that they had never told anyone else.

I began recruitment in June 2019. I ran ads on Grindr and attended a biweekly community discussion group each time I went to Baton Rouge. The organizer and facilitator of that group was extremely valuable to my efforts. I participated in those discussions without ever mentioning my research until he prompted me to do so at the end of the gathering. I also placed flyers around town and asked community members and staff at clinics to spread the word. I conducted interviews in several locations, depending on what was most comfortable for the participant. These included a private room or in the garden at the public library, as well as participant's homes or offices. In March 2020, as I was preparing to return for more interviews, Covid-19 restrictions were implemented, and I had to cancel my travel. Consequently, the last 16 interviews were conducted by phone. These participants were recruited via the dating/hookup app, Jack'd, and by word of mouth.

Paper 1: To date, research has framed the potential consequences of disclosure as discrete events that can be measured by asking whether one has experienced a particular reaction or outcome. Though, there is a lack of understanding of how disclosure and its consequences are embedded in ongoing social relations and how negative outcomes have long-term effects. To fill this gap, in the first analysis, I employ and expand on the theory of biographical disruption, which posits that chronic illness disrupts the structures and situations of one's life, and forces a re-examination of one's future (Bury 1982). Most research building on Bury's seminal work focus on the ways in which disruptions are caused by chronic illnesses. Only one study included HIV disclosure as the source of disruption, as opposed to an HIV diagnosis itself (Tewksbury and McGaughey 1998). In this paper, I build on this work by focusing specifically on disruptions resulting from HIV status disclosure.

My analysis adds a structural and intersectional lens in understanding the causes and nature of disruptions. While Tewksbury argues that disclosure is a major source of disruption because it is revealing one's diagnosis that fundamentally changes one's relationships and standing in the social world, no work has explored how those changes are constituted across intersecting axes of oppression, and in a specific geographic context. My findings show that, after disclosing, BGBM-LWH in Baton Rouge experienced: temporary or permanent damage to social and familial relationships, alienation from social networks and support systems; housing instability and job loss; and assaults on the self. Importantly, as I argue, these disruptions were shaped by structural racism, homophobia, HIV stigma, economic inequality, as well as the socio-cultural and structural context of Baton Rouge.

Paper 2: Much research has quantitatively explored the relationships between disclosure and various psychological measures. However, there is a need for research exploring the social nature of emotions and the ways in which they factor into the disclosure process including before during and after disclosure, as well as in the case of nondisclosure. In this paper, I employ the sociology of emotions literature to explore the emotional aspects of disclosing an HIV diagnosis. The sociological study of emotions posits that emotions are social products rooted in interactions with others and lived experiences. "Feelings themselves and their social expression are differently constituted for people whose social relations and social worlds are marked by difference relative to the worlds of others" (McCarthy 1989:57). I also called on the theory of healthism, which argues that, in our society, individuals are compelled to be personally responsible, to behave in ways that reflect a continuous commitment to 'good health,' and to act rationally to maintain health and be a good, moral citizen (Crawford 1980, Lupton 1995:70).

Using these approaches to understanding emotion allowed for my analysis to explore how social context shaped the emotions men experienced and the emotion work (Hochschild 1979) they had to do in order to disclose and to process the outcomes of disclosure. My analysis revealed that emotional responses to HIV diagnoses were shaped by: HIV stigma – which led to feelings of shame, depression, and fears of death; and by healthism – leading to feelings of guilt and personal failure. Further, the emotion work that men engaged in included managing their own emotions after receiving their diagnosis and during the disclosure process, feeling responsible for protecting the emotions of others (by not disclosing or not sharing or discussing details about HIV), and managing the long-term emotional effects of damaged relationships and social standing as a result of disclosing.

Paper 3: HIV stigma is largely explored as though it were a static thing that can be measured, reduced, or eliminated, but there is little understanding of the social processes through which HIV stigma is produced and reproduced. To begin to fill this gap, in paper three, I use a grounded theory approach to analyze the ways in which HIV stigma is produced and reproduced through social interactions and social structures. This analysis expands on previous work on HIV stigma which largely focuses on individual-level cognitive measures of anticipated, enacted, and internalized stigma by incorporated the community and institutional levels. Instead of conceiving of stigmatizing behaviors as manifestations of stigma, in this analysis, I frame them as a part of the ongoing process of how HIV stigma is produced and reproduced. My analysis resulted in a grounded theory model that includes: social interactions – silence, gossip, and rumor; community-level (mis)education – the dissemination of misinformation about HIV through word of mouth and other communication channels; individual-level learning about the social meanings of HIV through witnessing and experiencing acts of marginalization; and institutional level stigmatization through a lack of formal education about sex non-heterosexuality and HIV in the public school system, and in the criminal-justice system by the existence and enforcement of HIV criminal statutes. Importantly structures and interactions at each of these levels interact with and depend on each other for the stigma process to continue.

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CHAPTER 2: Structural and Intersectional Biographical Disruption: The Case Of HIV

INTRODUCTION

HIV disclosure research has largely focused on its potential to reduce sexual risk and garner social support, and its associations with psychological and clinical outcomes for people living with HIV (e.g. Abler, Sikkema, Watt et al. 2015, Kalichman, DiMarco, Austin et al. 2003, Simoni and Pantalone 2004, Waddell and Messeri 2006). Though there are potential negative consequences of disclosure including violence and rejection by friends, family, and potential intimate partners (Hubach, Dodge, Schick et al. 2015, Jeffries IV, Townsend, Gelaude et al. 2015, Radcliffe, Doty, Hawkins et al. 2010), public health literature has overwhelmingly encouraged disclosure as therapeutic, and implied that non-disclosure is an unacceptable choice (Persson and Richards 2008). Indeed, HIV disclosure research treats "disclosure behavior as the 'endpoint' of interest" (Chaudoir, Fisher and Simoni 2011:2). Though, HIV disclosure not a discrete, measurable event, but an ongoing and evolving process that occurs in the context of ongoing social relations (Mayfield Arnold, Rice, Flannery et al. 2008).

Early in the epidemic, gay men reported that HIV disclosure was hindered by whether they were open about their sexuality, particularly when high levels of homophobia and HIV stigma were present in their families (Weitz 1990). Heterosexual people living with HIV (PLWH) in Australia felt that non-disclosure avoided opening themselves up to unknown tensions and uncertainty and gave them more control over their lives. For Black gay and bisexual men, and other men who engage in sexual or romantic same-sex relationships, who are living with HIV (hereafter referred to as BGBM-LWH), their multiply stigmatized social location shapes HIV disclosure and its consequences. Disclosing an HIV diagnosis has social meaning which is, in many cases, defined by the association of HIV with deviance, and a view of PLWH as risks to others (Crawford 1994). These social meanings are largely left unexplored, and research has not given attention to what comes after HIV disclosure, *socially* and *structurally,* or what precedes it.

In this article, I employ Michael Bury's (1982) concept of biographical disruption which acknowledges that chronic illness interrupts and alters biography and social relations. Most biographical disruption research has focused on chronic illness itself, and the resulting changes to the individual's life and the lives of their loved ones. Only Tewksbury and McGaughey (1998) acknowledged HIV disclosure as a source of disruption for PLWH. According to Bury (1991) "the notion of biography suggests that meaning and context… cannot easily be separated" (453). Thus, by using the framework of structural intersectionality, which acknowledges that those located at the intersections of multiple marginal identities have qualitatively different lived experiences from those occupying dominant social locations (Crenshaw 1991), this study attempts to situate the HIV disclosure process, its meanings, and its outcomes within the specific contexts in which it occurs. Conceiving of HIV disclosure as a biographical disruption reorients our lens toward the experience of the self *in* illness, and how disclosure can fundamentally shift everyday reality and social relationships. I aim to understand how intersecting oppressions and marginal social locations constitute specific HIV disclosure experiences and consequences for BGBM-LWH.

Disruption to Self and Biography

Sociology has long-explored the impact of illness on identity, describing chronic illness as 'biographical disruption'(Alexias, Savvakis and Stratopoulou 2016, Bury 1982, Bury 1991, Green, Todd and Pevalin 2007, Williams 2000), and as the cause of 'loss of,' 'rethinking of,' or 'assault on' the self (Charmaz 1983, Charmaz 1995, Ciambrone 2001). According to Michael

Bury (1982), biographical disruption is defined by: (1) disturbance of everyday activities; (2) rethinking of the self; and (3) obtaining and engaging resources. The meaning of an illness depends, in part, on its *symbolic significance*, as illnesses have "different connotations and imagery." (Bury 1988, Bury 1991) Thus, "disguising and disclosing symptoms, for example, depends not only on their physical intrusiveness within social context, but also on their positive and negative meanings within a specific set of social relationships" (Bury 1991:453).

Charmaz (1983) conceptualized 'loss of self' as a form of suffering for the chronically ill, as "diminished control over their lives and their futures" can lead to a loss of self-esteem and identity (Charmaz 1983:169). *Discrediting definitions of self* can occur when negative images of self, reflected by others, challenge one's own self-concept. The significance of the discreditation depends on its magnitude, frequency, the situation in which it occurs, and the nature of the person's relationship to the discreditor (Charmaz 1983). As Tewksbury and McGaughey (1998) argue, for PLWH, disclosure may be the most salient process leading to biographical disruption, as it is disclosure, not diagnosis, that changes the nature of interactions and the way others see PLWH, and solidifies the internalization of HIV as a part of the self (Tewksbury and McGaughey 1998).

Most literature on biographical disruption and loss of self explores conditions that lead to physical impairments (e.g., stroke, arthritis, multiple sclerosis) (e.g. Bury 1982, Charmaz 1983, Green et al. 2007, Pound, Gompertz and Ebrahim 1998, Yoshioka and Schustack 2001). Since, under most circumstances, HIV does not initially lead to physical impairment, one is placed in a social "situation at risk of illness," as HIV more often leads to self-restraints such as altering one's behavior, keeping their diagnosis a secret, and mobilizing resources (Carricaburu and Pierret 1995, Ciambrone 2001). Further, HIV presents a situation in which it is unclear whether others will adopt the PLWH's 'definition of the situation;' so the prospects of disclosure and garnering support serve to exacerbate the disruptive nature of the illness (Bury 1991).

Biographical disruption is shaped by social interactions and cultural norms, and "carries particular class- and age-related connotations, as well as gender and ethnic dimensions" (Williams 2000:50). Undoubtedly, for those who experience structural constraints and intersecting inequalities (e.g. high levels of HIV stigma, homophobia, racism, and difficult financial situations), an HIV disclosure can cause a disruption to one's life, which may vary in severity and by socio-cultural context. Ciambrone (2001) described that women living with HIV had experience several other "assaults on self," including intimate partner violence, substance addiction, and losing custody of a child. The frequency and significance of these previous negative experiences, levels of HIV stigma, and their available resources (e.g., financial, social services, social support) influenced women's perceptions of how disruptive HIV was to their lives. Some Black gay men have described having to face racism, homophobia, and HIV-stigma before getting the support they needed (Baumgartner 2014). Thus, homophobia, sex stigma and HIV stigma each contribute to a context in which disclosure is a particularly fraught endeavor; this is especially the case if these are intersecting.

While previous research provides useful theorizing about the ways that a chronic illness diagnosis can disrupt individual biographies, left unexamined are the factors outside of the individual that shape disruptions. As acknowledged by Williams (2000) and others (e.g. Engman 2019, Harris 2009), the nature of disruption differs by demographic and cultural realities. Yet, no study has used an intersectional approach to explore the structural factors that constitute disruptions. In the current analysis, I examine how biographical disruption operates at the individual-level and beyond, including structural and intersectional factors that shape preceding disruptions and constitute the nature of disclosure-related disruptions among BGBM-LWH.

Intersectionality

I take as a necessary starting point, a recognition that the location of BGBM-LWH in Baton Rouge, at the intersection of race, class, gender, sexuality, HIV-status, and geography necessarily shapes their experiences of, and the meanings of disclosure. An intersectional framework shifts the understanding of multiple axes of inequality from an additive mode, in which oppressions (e.g. racism, sexism, classism) are ranked and added together to quantify "a grand oppression greater than the sum of its parts" (Collins 2016:37), to one that recognizes the interlocking nature of oppressions and incorporates analyses that seek to address the impacts of overlapping marginal social locations (Cho, Crenshaw and McCall 2013, Collins 2005, Crenshaw 1989, Crenshaw 1991). Race, class, gender, and sexuality "accompany us in every social interaction" (Veenstra 2011:2) and our experiences differ depending on our social location, time, and place (Bowleg, Teti, Malebranche et al. 2013, Collins 2016).

Structural intersectionality (Crenshaw 1991) is a particularly useful framework for understanding the contours of the HIV epidemic. It is critical to recognize that those with low social status are "already positioned within a set of structurally deleterious social discourses" before they are impacted by HIV (Berger 2010:29). Multiple marginalization (e.g. racism, classism, sexism, and homophobia) can lead to increased HIV vulnerability (Young, Friedman and Case 2005), and barriers to HIV-testing included community-level poverty, HIV stigma, and negative testing experiences, as well as a lack of HIV education in schools and resulting silence around HIV-related issues (Gwadz, Leonard, Honig et al. 2018). Further, higher HIV prevalence in black communities is associated with incarceration and poverty which shape the lives of many Black men in America (Bowleg et al. 2013).

BGBM are made more vulnerable to HIV by housing and economic insecurity, high levels of stigma and discrimination (Parker, Garcia, Philbin et al. 2017), and their intersections with homonegativity and racism (Quinn, Bowleg and Dickson-Gomez 2019). Racial inequality and segregation mean that BGBM are faced with experiences of homophobia and rejection in Black communities, alongside racism from the White LGBT community and society at large (Arnold, Rebchook and Kegeles 2014, Hunter 2010). Further, sexual-minority-based rejection, and internalized homophobia are associated with increased sexual risk, low self-esteem, and depression (Amola and Grimmett 2015, Stokes and Peterson 1998). This experience of exclusion is magnified by an HIV diagnosis, the disclosure of which can lead to rejection from family and friends, as well as from others within gay communities (Hubach et al. 2015, Jeffries IV et al. 2015, Radcliffe et al. 2010).

Lastly, childhood sexual abuse (CSA), is associated with increased vulnerability to HIV, and is more prevalent among gay men of color than among white GBM (Lloyd and Operario 2012, Williams, Wilton, Magnus et al. 2015, Wu 2018). GBM may be made more vulnerable to CSA by gender nonconformity in childhood and, for some, sexual orientation precedes CSA (Purcell, Patterson, Spikes et al. 2007). Qualitative findings from BGBM reveal that CSA can lead to suicidality, social isolation, and other negative mental health outcomes. And some men believed their CSA experience(s) to be the impetus for their sexual identity and behavior (Fields, Malebranche and Feist-Price 2008).

It is this context within which the men in this study come to learn of their HIV diagnosis and navigate the disclosure process. In the analysis that follows, I explore the disruptive nature of HIV disclosure, and how these experiences are constituted by these intersectional inequities.

DATA AND METHODS

Data

Between June 2019 and June 2020, I conducted semi-structured, in-depth, qualitative interviews with 30 BGBM-LWH. Participants were recruited through active (e.g., face-to-face recruitment at community discussion groups for Black LGBTQ people, which focused on a range of topics decided on by the facilitators, and sometimes by participants) and passive (e.g., referrals from well-connected BGBM, advertisements on gay dating apps) strategies. Potential participants called the recruitment line to be pre-screened or completed the online pre-screening questionnaire. I contacted those who completed the online screening survey within 48 hours to tell them more about the study and to answer any questions. Participants were eligible if they: self-identified as Black or African American; were at least 18 years old; were living with HIV; and lived in the Baton Rouge metropolitan area. HIV-status was self-reported by participants during the screening process. Interviews lasted 60 and 90 minutes on average.

Study Setting

This study was conducted in Baton Rouge, Louisiana, a mid-sized city in the US south that, like many other US cities, experiences many structural inequities. Baton Rouge ranks second and fifth in the nation in AIDS and HIV case rates, respectively, and BGBM bear a disproportionate HIV disease burden (CDC 2016a, CDC 2016b, State of Louisiana Office of Public Health 2018). Though, in the region, cultural norms around sexuality and HIV are largely a matter of silence (Foster and Frazier 2008).

Overall, the law and policy context in the US South is hostile to gay and bisexual men and those living with HIV (Adimora, Ramirez, Schoenbach et al. 2014). Sex education is not required in Louisiana (SIECUS 2018), and schools that choose to provide sex education cannot include "any sexually explicit materials depicting male or female homosexual activity" (Louisiana Revised Statute §17:281(A)(3)) and in Baton Rouge, sex education must "emphasize that abstinence from sexual activity is a way to avoid…sexually transmitted disease, including acquired immune deficiency syndrome," (East Baton Rouge Parish School Board 2019). Further, despite the US Supreme Court ruling in Lawrence v. Texas declaring sodomy laws unconstitutional, in 2013 and 2015, men in East Baton Rouge Parish were targeted and arrested under these laws (Garcia 2015, USA Today 2014). And, the city received a score of 40 out of 100 on the Human Rights Campaign's Municipal Equality Index, which attempts to measure the extent to which cities support LGBTQ people through law, policy, benefits, and services (Persad 2019).

In Baton Rouge, health and economic disparities mirror national data. Black people have disproportionately high rates of cancer, diabetes, and HIV, among others (CDC 2013, Conduent Healthy Communities 2020, Nesbitt and Palomarez 2016). Black households have a median income of only $37,350, the lowest of any racial or ethnic group in Baton Rouge while, at $72,414, the median income of white households is nearly double (Conduent Healthy Communities 2020, U.S. Census Bureau 2018). It is also a deeply segregated city (DeWitt and Frey 2018) where Black students account for 78% of public school students (Groeger, Walldman and Eads 2018); and the wealthier, whiter, southeastern corner of the city has recently voted to incorporate a new city with a new school system, which will subtract resources from the mostly non-white East Baton Rouge Parish Schools (City of St. George 2020, Harris 2019). It is this confluence of inequities in which I situate men's narratives.

Data Analysis

All interviews were digitally recorded and transcribed verbatim. Using a grounded theory approach (Charmaz 2014, Corbin and Strauss 1990, Denzin and Lincoln 2003), I conducted initial, open-coding on the first 10 interviews (1/3 of sample) to develop the initial codebook. I subsequently, revised the codebook to eliminate redundancy, and create parent codes. Using this final codebook, I coded all interviews using MAXQDA 2020 (VERBI Software 2019). To explore disclosure as biographical disruption, and the structural intersectionality shaping those experiences, the current analysis focuses on the following parent codes, as well as their relevant sub-codes: childhood and upbringing; family; HIV and/or AIDS diagnosis; HIV disclosure; homophobia; race; and HIV-stigma.

RESULTS

Participant Characteristics

A large majority of men in this sample (83%) identified as gay or homosexual. The remaining 5 participants (17%) identified as bisexual, fluid, or same gender loving. They ranged in age from 18 – 56 (M = 35.21), and on average had been living with HIV for 10.33 years (R = 4 mos. – 32.5 yrs.) (Table 1). All participants had disclosed to at least one other person. At the margins, one participant had disclosed to no one except his doctor and one sex partner, and three participants had disclosed their HIV status publicly. All other participants had disclosed to varying degrees. In the results that follow, the names accompanying participant quotes are pseudonyms. I follow each pseudonym with the participant's age and the length of time since they were diagnosed [e.g., Jonathan (32; 11.33 yrs)].

Table 2.1: Sample Demographics

Age		
Median	34	
Range	18 - 56	
Mean	35.21	
	n	**%**
Sex ID		
Gay/Homosexual	24	83%
Another Sexual ID**	5	17%
Education		
< High School	6	21%
High School/GED	4	14%
Associates/Some College	13	45%
Bachelors	4	14%
Graduate Degree	2	7%
Income		
< $10,000	6	21%
$10,000 - $19,999	7	24%
$20,000 - $39,999	9	31%
> $40,000	7	24%
Employment		
Unemployed	6	21%
Student	2	7%
Self-Employed	2	7%
Employed Part-Time	4	14%
Employed Full-Time	15	52%
Time Since Dx		
0-5 years	6	21%
6-10 years	11	38%
10 -20 years	10	34%
>20 years	2	7%
Mean (Years)	10.33 years	
Range	4 mos - 32.5 yrs	

**Includes Bisexual, Same Gender Loving, and Fluid

Preceding Disruptions

Participant narratives revealed other biographical disruptions that had occurred prior to disclosing their HIV diagnosis. Nearly all (90%; n=27) participants had experienced one or more previous disruptions (Table 2). Over one third (37%; n=11) of men in this sample reported experiences of CSA. Some experienced ongoing, repeated sexual abuse at the hands of one or more family members, while others were victimized by family friends or others in their community. Though most men did not disclose their abuse, those who did were often blamed, not believed, or punished for their perceived sexuality. Further, coming out as gay or bisexual was disruptive for nearly half (47%) of men in this sample. Several lost support from family, were told that they would "get AIDS" by unaccepting family members or were forced to find a new place to live.

Additionally, HIV diagnosis was a significant disruption for the majority (63%) of men in this study. This included confirming some family members' expectation that they would contract HIV because they were gay, expecting to die soon, or having suicidal thoughts after being diagnosed. A few men (n=3) received an AIDS diagnosis either when they were initially diagnosed with HIV, or shortly thereafter, which meant additional embodied disruptions, forced structural changes (e.g., no longer being able to work or afford own home), and being denied the ability to process their diagnosis privately.

Table 2.2: Participant experiences of biographical disruptions

	n	%
Preceding Disruptions		
Childhood sexual abuse	11	37
Coming out as gay or bisexual	14	47
HIV diagnosis	19	63
Disclosure-Related Disruption		
Discredited Definitions of Self	17	57
Damage to social and familial networks	12	40
Negative socioeconomic impacts	8	27
Participants experiencing at least one disruptive impact[a]	18	60
Participants experiencing more than one disruptive impact[b]	14	78
Participants experiencing only one disruptive impact[b]	4	22

[a] Denominator is total sample N of 30
[b] Denominator is men who experienced at least one disruption (n=18)

Disclosure as a Source of Biographical Disruption

Most men (60%; n=18) described disruptions to their biographies once others learned about their HIV diagnosis. Some participants self-disclosed their status and, for some, others shared their status without their consent (i.e., unwanted disclosure). In both cases disruptions included: 1) discrediting definitions of self (57%); 2) disrupted social and familial relationships

(40%); and 3) socioeconomic and structural impacts (27%). While each of these could be discrete and occur independently, in most cases (78%; n=14), participants experienced more than one (Table 2). Importantly, social locations and structural realities were key in shaping the nature of biographical disruption.

Discredited definitions of self. Prior to his diagnosis, Steven (28; 5 mos) had experienced CSA, and when he came out as gay, his mother told him that he "was no longer her son." When he was diagnosed, he worried, "…a lot of people use your information for bad, and really try to harm you…I changed in the world and you never know who your haters are." Darius (23; 4.17 yrs) suffered extreme bullying because of his perceived sexuality and, like several men in this study, coming out as gay led his family to expect that he would "get HIV." When he decided to disclose to his mom, he worried that he would be confirming their fears and that she would "feel like I was just a hoe for a child and just be disappointed at that, which is very hard." When Noah (27; 7.58 yrs) disclosed his HIV-status to a potential sex partner he met earlier that day, "he kicked me out of his house and then he was going around town saying that had HIV… It was hurtful. I actually wanted to hurt myself, but I didn't." In addition to the pain of this unwanted disclosure, people who heard asked him about it, and he denied it, which made him feel "like I told a lie."

Kyle (55; 26.92 yrs) was diagnosed in the mid-1990s. At the time, his family was "scared because my sister thought that we had to use bleach to wash the dishes." Similarly, Brian (35; 9.83 yrs) felt that his family "didn't want to go get educated on HIV." He described his experience while living at home with his parents and his brother.

> …they did make me feel like, damn, I'm really going to pass this to y'all. It's like I'm sitting on a toilet, y'all gotta spray Lysol in y'all cabinet and I'm listening to y'all

> spraying the seat... even washing my clothes, I had to come back and before y'all put y'all's clothes in there y'all had to let it run, or Lysol it. I had to have my own drinking cup, y'all found plastic utensils for me. So that really made me feel like damn, what if I wouldn't have told y'all this, and it's something that I regret because… I don't know but it just really kind of hurt...

Importantly, in contrast to Kyle, the treatment that Brian describes had only ended when he moved out just weeks before I interviewed him in 2019. He had always been extremely close to his family. Though, after his diagnosis, their behavior suggested that they saw him as a threat. Further, these alienating experiences were compounded by his pre-existing perceptions that his parents treated him differently after he came out as gay, and that they preferred to spend time with his heterosexual brother who was able to "give [them] grandkids."

Disruptions to social and familial networks. Trey's (37; 16.25) relationships with his family members were already strained. He had experienced CSA at the hands of a family member, and he struggled with the fact that others in his family continued to be close to the person that abused him. When he lost his job, he lived in shelters around town before moving in with his great aunt, which cause her son to challenge his being there.

> They was saying I had AIDS…and I shouldn't be living there with her… I never had no negativity coming from my family. So, it just hurt me, and it set me back, if they would say something so evil at a time when I needed them so much. And it just hurt my feelings.

Aaron (34; 5.33 yrs) had been previously married to a woman to satisfy his deeply religious family and had subsequently become estranged from them after getting divorced and becoming more open about his sexuality. After he was diagnosed, he disclosed to his mom. She was very emotional which made him feel as though he “really messed up.”

> I snorted cocaine for the first time that very weekend… she didn't want to talk to me, she didn't want to be around me. I just wanted to ease my pain and I thought it was going to ease my pain by telling her, but it made it worse.

Aaron was eventually able to repair his relationship with his mom. Though, as he described, it had a significant impact on him.

When Jonathan (32; 11.33 yrs), who was a member of a gay family, disclosed his status to two very close and trusted friends, one of them told another friend and the information spread throughout his social network. He went on to describe the isolation he felt as a result of this experience.

> [People] didn't want to talk to me because they heard I had HIV… I felt so ... Just ugh… I was talking to somebody ... Well, I guess you can say dating… We talked for a little while after my diagnosis… he found out. He said that he couldn't continue talking to me. Then just all of the weight of the world hit me after… I was like, "All right. I'm out of here." I don't know what I want to do, I don't know what I want to be... See y’all later.

As he describes, unwanted disclosure and gossip led him to lose trust in the people he relied on for support, to feel isolated and, ultimately, to contemplate suicide.

Sam’s (32; 7 years) family had never accepted his sexuality. After seeing him with a high school friend, several family members gossiped and spread rumors about him “hanging out with a faggot.” After, he disclosed his status to his mom, their relationship was damaged after she disclosed his status to other family members.

> What made me feel like I can't go talk to my mama and vent to her about anything and tell her something personal is because when I did tell her about me being diagnosed, I did ask her not to tell anybody. And keep it a secret because I didn't want that being out. And instead of her talking to me about it and letting me know how she felt about it, she went and told one of my cousins, which I don't trust… So that right there caused me not to be able to tell her personally things like this.

Socioeconomic and structural impacts. For some men, HIV disclosure resulted in housing or economic instability. Walter (29; 6.08 yrs) received an AIDS diagnosis at the same time that he was diagnosed with HIV. He felt he needed to inform his employer. He had seen how accommodating they had been for a coworker who was battling cancer and felt that these were people he knew well and trusted.

> …they handled it horribly, because they didn't know how to deal with someone who was positive… within the management and the hierarchy they were like, 'well if it comes out, we don't want the other employees feeling like they're not protected, or like we didn't consider their safety.' So, them having that fear factor, I think ultimately led me to resign as well because it was a tense atmosphere because of that.

Similarly, Reggie (30; 9.25 yrs) made the choice to leave both his job and his apartment. Though, for him, the decision came after an angry ex-boyfriend printed flyers revealing personal information, including his status, and placed them around the neighborhood.

> It's like everyone at work saw these flyers, everyone in my apartment building saw these flyers and it's just like, "Whoa." If I would walk to work and if everyone that's on the street, now they all know… that destroyed me. Like internally I just felt, no one would

> ever pretty much want to deal with me. I still like, worked at my job for maybe a good two to three weeks and then I just couldn't do it anymore.

Importantly, this experience was particularly traumatic, as it came only a short time after he had begun to feel more comfortable being open about both his sexuality and his HIV status.

Other men described having similar experiences in which they chose to move or were kicked out of their homes after others learned of their diagnosis. Sam's (32; 7 years) family expressed discomfort with his diagnosis and his mother, who did not accept his sexuality, refused to allow his boyfriend visit, and he no longer felt welcomed.

> I could have stayed there. I could have made a padding on the floor or slept on the couch, but because of their fears of me having it, and them not knowing what to expect, I just ended up going to stay at other people's house, and in my car.

Nathan (30; 1.08) had been living with his sister until a representative from the health department came to inform him that one of his sex partners had been diagnosed with HIV. He went to get tested and was diagnosed with HIV. "My sister is at home, waiting on the news... I didn't know how to come out and tell her that. So, once she put two and two together… She told me that I had to leave." Because he couldn't afford a place of his own, he lived in a hotel for several months before moving in with a friend. Previously, his sister had also kicked him out when he was 17, after she learned he was gay.

Structural and Intersectional Nature of Biographical Disruption

As BGBM-LWH in Baton Rouge, the men in this study were located at the intersections of race, class, geography, sexuality, and HIV status, making them particularly vulnerable to disclosure-related biographical disruption. Tyrone (35; 13.92 yrs) summed up what his social location meant for his life:

> I don't feel like I'm accepted with the intersections mind you. If I didn't have HIV, okay. If it was straight, I would probably be fine. I say that being a black, gay male, living with HIV in Baton Rouge is hard.
>
> *Interviewer: Yeah. What makes it hard?*
>
> People understanding you. Where you're coming from. Your personal situation… I'm traumatized by certain white people. I know other people that just don't even deal with white people... So just racially that's just one thing. Talk about being gay? This is Louisiana. We're just now getting comfortable with things… if we were white back in 2014-15, if I was white, I would have been fighting for marriage equality, right? But being black, we wasn't worried about that. We wasn't worried about no marriage equality… fuck marriage equality. I need a house. I need some food right now. That's what being black and being HIV positive in Baton Rouge is like.

While a large majority (66%) had completed at least some college, nearly half (45%) earned less than $20,000 annually, and less than one quarter earned $40,000 or more. Lower income levels made these men more vulnerable to housing insecurity, which can initially increase vulnerability to HIV (Parker et al. 2017), and place them in greater need of social and financial support from family and friends after diagnosis. Indeed, for some, losing employment meant a near immediate loss of housing. For some who lived with family members, negative reactions to their sexuality or HIV diagnosis led to sleeping in the car, finding a new place to live on a tight budget, or sleeping in shelters. Lastly, as Walter described mistreatment at work because of an HIV diagnosis can also lead to loss of income, benefits, and housing. While state and federal law prohibit discrimination based on HIV status, these cases are difficult to prove, and require legal representation, to which many do not have access (Center for HIV Law and Policy 2020).

A lack of HIV-knowledge in their families and communities made being diagnosed particularly difficult. Most were diagnosed in the era of HAART, rapid testing, increased scientific knowledge about HIV, and nearly half (44%; n=13) were diagnosed after PrEP was approved for prevention. Though, evidence suggests a general lack of awareness of the epidemic among African Americans in the south (Foster and Gaskins 2013). Reflecting the data on sex education in Lousiana, these men entered young adulthood with little information about HIV. Jonathan (32; 11.33 yrs) "never really paid attention to [HIV]. I think we talked about it in health class… but it's like, all you learned [was] what it was. That was it." Similarly, for Darius (23; 4.17 yrs), "there was never a thought. It was never brought up in school, which they have sex education… they got into STDs, but they never got into HIV or AIDS or anything like that. Never." The majority (53%; n=16) of men in this sample were diagnosed with HIV by the age of 24. Of those, 10 (or 62.5%) were diagnosed by age 21. The lack of information is also reflected in the belief by their parents that being gay necessarily leads to HIV, as well as in family members using disinfectants, and giving men their own silverware.

Lastly, hegemonic HIV stigma and homophobia were key in shaping the disruptions for some men. Three men believed that they contracted HIV during CSA experiences in their adolescence. In each of these cases, these men also had traumatic associations of CSA with their sexuality, as each of them had either been punished for causing their own victimization or believed that the CSA experiences were the cause of their same-sex attraction. After Walter's (29; 6.08 yrs) father learned that he was raped by his cousin, he "…beat me because I was quote unquote 'bringing gay into his household.'" As he believed that this rape was the source of his infection, disclosure was particularly difficult. When his father questioned how he contracted HIV, it brought back to mind his rape and his father's reaction. He decided it was "less work to let him believe it was [a blood] transfusion than to go down that road again." For others, disclosing their HIV diagnosis came after a long period of time in which family members had prayed that they would choose a different "lifestyle," Further, a majority of men reported that within the gay community, HIV-stigma could lead to being ostracized, rejected by potential partners and, most perniciously, unwanted disclosure and gossip.

DISCUSSION

This study explored HIV disclosure experiences of BGBM-LWH in Baton Rouge, Louisiana using the frameworks of biographical disruption and structural intersectionality. Men's narratives illustrated several ways in which HIV disclosure manifested as disruptions to their biographies. First, disclosure led to discrediting definitions of self, which were particularly impactful as men identified with those doing the discrediting (e.g. family and friends) and because of the intensity of those experiences (Charmaz 1983). Second, men experienced disturbances to their familial and social relationships, some of which were temporary, while for other men, relationships were fundamentally and permanently altered. Lastly, some men were faced with a loss of housing or employment after disclosing their HIV diagnosis. Importantly, for all men who described HIV disclosure as a disruptive experience, that disruption manifested in multiple ways, with one (e.g., disrupted family relationships) often leading to another (e.g., housing instability).

These findings complicate our understanding of the disclosure experience for BGBM and expand on the concept of biographical disruption by including structural and intersectional factors that shape preceding disruptions and constitute the nature of disclosure-related biographical disruption. For some BGBM, rejection by family after disclosure may also be influenced by non-acceptance of their sexuality, and the disclosure experience may be shaped by previous experiences of CSA or other traumas. Further, for many GBM of color, the ballroom community and other "gay family" structures provide safety and support for many who do not receive acceptance in their biological families and can play a critical role in HIV prevention and care (Arnold and Bailey 2009, Bailey 2009, Young, Jonas, Michaels et al. 2017). Rejection in this context is more significant than simply losing a friend. In Jonathan's case, unwanted disclosure led him to leave his gay family and contemplate suicide.

Previously, authors have suggested that biographical disruption may not be applicable when illness is anticipated or when one has had prior disruptive experiences (Pound et al. 1998, Wouters and De Wet 2016). In the case of HIV, Ciambrone (2001) suggests that the impact of HIV may be lessened by previous negative life events. According to Wouters and De Wet (2016), these findings suggest that "biographical disruption holds an implicit assumption that illness enters lives which have been relatively untouched by crises" (537). Though, for PLWH and other stigmatized illnesses, biographical disruptions can result, not only from the diagnosis, but also from events that occur within the illness experience (e.g., medication side effects; hospitalizations; disclosure), and the social contexts in which they occur (Nowakowski 2016, Nowakowski and Sumerau 2019, Tewksbury and McGaughey 1998).

My findings highlight that the *symbolic significance* of HIV within specific communities, and the intersectional social identities of those receiving the diagnosis is determinative in how previous negative life events accumulate and interact with HIV diagnosis and disclosure. In the context of high levels of HIV stigma and a long history of institutionalized homophobia and racism, deeply religious culture of the deep south (Persad 2019, Reif, Wilson and McAllaster

2018, Reif, Sullivan, Wilson et al. 2016), HIV diagnosis and disclosure were still significantly disruptive events. Indeed, those previous disruptive events (e.g., CSA, coming out) did not reduce the disruptive nature of disclosure, but helped to shape the disclosure experience. For example, some men who had a disruptive coming out experience were told that they would "get AIDS" because they were gay. In those cases, disclosing an HIV diagnosis meant confirming those warnings and fears and reifying the homophobia and HIV-stigma that link HIV to being gay. In addition, GBM are more likely to experience CSA (Fields et al. 2008, Williams et al. 2015), and may be targeted because of gender non-conforming behaviors (Purcell et al. 2007). For men who believe their CSA experience was the source of their HIV infection, disclosing an HIV diagnosis means revisiting that trauma, and possibly struggling to answer questions about how they contracted HIV, particularly if they had not disclosed their CSA.

In Baton Rouge, sex education is not required in schools and, for schools that choose to offer it, abstinence must be encouraged, homosexuality is not to be discussed explicitly, and little detail is provided on HIV (East Baton Rouge Parish School Board 2019). Consequently, BGBM, who account for the majority of new infections in Baton Rouge (State of Louisiana Office of Public Health 2018), entered young adulthood and began to engage sexually with little to no practical information about how they could prevent contracting HIV. Lastly, for Black men in general, and the Black men in this study specifically, "social risks (e.g. losing housing and family support) are directly linked to men's intersecting identities as Black, sexual minority, and (mostly) of low socio-economic status" (Parker et al. 2017:333). Thus, men in this study were particularly vulnerable to negative socioeconomic outcomes of disclosure to those they depended on for support. Applying a structural intersectionality framework allows men's experiences to be situated within an understanding of cumulative inequalities and societal structures; and, thus, HIV-disclosure among BGBM is not understood as micro-level intra- and interpersonal experiences.

There are limitations worth noting. The current sample was a convenience sample and was recruited in a mid-sized city in the deep south. Thus, the views and experiences of the men in the study reflect their particular social and cultural realities. Additional studies are needed to explore HIV disclosure as biographical disruption among BGBM men in other geographical locations. Additionally, HIV status was self-reported. Due to the high levels of stigma in the community, no HIV testing, or documentary verification of status was obtained. Lastly, the distance between some experiences and the present could lead to recall bias.

Overall, the narratives of men in this study illustrate deeper, disruptive, and more lasting implications of HIV disclosure for some who occupy multiple stigmatized identities. That men suffered aggressive assaults on self that led some to consider suicide or to leave the stability of their home highlights that the rejection, social isolation, and discrimination that has been documented fails to reveal what these experiences *mean* in the lives of PLWH. Further, the potential for disruption depends on the symbolic significance of HIV in one's particular community, and the social locations (e.g., race, gender, SES) occupied by the person disclosing. In order to move beyond treating disclosure as a behavioral endpoint, or as a predictor of sexual behavior or psychological outcomes, it is critical that analyses in HIV disclosure research are situated within PLWH's particular structural context. This will provide deeper understanding of the real-world meanings of disclosure, as well as the structural and intersectional factors that constitute the experiences and the consequences, particularly for members of marginalized groups.

There are implications that emerge from this study’s findings. First, biographical disruption, resulting from HIV disclosure is shaped by intersections of the social location occupied by the PLWH, and the particular structural, social, and geographical context in which it occurs. This furthers the point that biographical disruption is a stronger theoretical framework when, instead of only exploring the ways that chronic illness impacts one’s identity, the intersection between illness and identity is centered (Williams 2000, Wouters and De Wet 2016). Further, HIV prevention efforts that aim to increase HIV disclosure as a strategy for increased social support, improved clinical outcomes, or reduction of HIV transmission should account for the factors that are preceding and cumulative, outside of the individual, that also constitute the disclosure process and its outcomes. In some cases, disclosure may be more detrimental to overall well-being, particularly in high stigma settings, and for those with intersecting marginal identities and limited resources. HIV disclosure is a complex social interaction. Future research must go beyond considering disclosure of a stigmatized illness or identity as a predictor or outcome of singular measures. Other aspects of one’s biography, identity, and social location constitute these experiences and their outcomes and, therefore, must be incorporated into any exploration of these interactions.

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CHAPTER 3: Emotions and Emotion Work Before During and After HIV Disclosure Among Black Gay and Bisexual Men Living with HIV

INTRODUCTION

In the United States, the highest rate of new diagnoses is among Black gay and bisexual men (BGBM) (Linley, Johnson, Song et al. 2020). Importantly, BGBM face intersecting social and structural stigmas along the axes of race, sex, class, and HIV status, among others (Bowleg 2013, Quinn, Bowleg and Dickson-Gomez 2019). These inequalities constitute BGBM's vulnerability to HIV infection and, subsequently, their experience of living with HIV. In spite of these realities, public health research and policy has privileged HIV status disclosure for people living with HIV (PLWH) as a moral, legal, and responsible choice to protect others, and as an effective strategy to educate, reduce stigma, and obtain social support (Daskalopoulou, Lampe, Sherr et al. 2017, Derlega, Winstead, Greene et al. 2004, Kalichman, DiMarco, Austin et al. 2003, Lehman, Carr, Nichol et al. 2014). Framing disclosure in this way reveals an understanding shaped by a public health model that emphasizes behavior change, risk reduction, and personal responsibility (Sandset 2019).

Public health messages and interventions focused on HIV status disclosure view PLWH as rational actors who should make safe and responsible choices from the set of options prescribed by public health (Adam, Corriveau, Elliott et al. 2015, Sandset 2019). However, in everyday reality, there are many other factors (e.g., ethics and morality, fear, the nature of relationship) that shape disclosure (Adam et al. 2015:395). The illness disclosure process inherently requires 'emotion work' (Hochschild 1979), as one can face stigma and attacks on the self (Bird and Voisin 2013, Tewksbury and McGaughey 1998), and has to: manage their own emotional reactions to their status; process the legal and social expectations of disclosure;

evaluate their environment and relationships to determine how to proceed; and educate, console, and protect others (Charmaz 1991, Clifford, Craig and McCourt 2019, Kilty and Orsini 2019, Yoo, Aviv, Levine et al. 2010).

Few papers to date focus on the emotion work involved in HIV disclosure. Chin and Kroesen (1999) found that, among, Asian and Pacific Islander American women, disclosure was influenced by fear of being stigmatized and not wanting to burden or disappoint others. AIDS service organization staff members described encouraging PLWH to disclose as long as they feel it is safe to do so. Though, as one man in that study argued, "that's oversimplified because we're not talking about trauma; we're not talking about all of the other things that people living with HIV deal with every day" (Kilty and Orsini 2019:274). Women living with HIV in Jamaica confronted the shame and alienation as a result of social perceptions of HIV, and were encouraged to disclose to their children despite their desire to protect their children and to be seen as "good and responsible mothers" (Clifford et al. 2019:246). Further knowledge is needed to understand the full experience of disclosure and the ways social position, and intersecting inequities create a situation in which management of emotions is critical to the disclosure process.

BGBM face overlapping oppressions in addition to HIV status due to their social locations, which determine what emotions are felt and how they must be expressed and managed (Hochschild 1990). No sociological study has examined the emotional nature of HIV status disclosure and its consequences among BGBM. Narrow rational, moral, and personal responsibility frameworks fail to account for the fact that oppressive structures (e.g., racism, homophobia, HIV-stigma) create difficult circumstances under which disclosure happens and limit an understanding of resulting emotions and the work needed to manage them. HIV is a social phenomenon (as well as a biological one). Thus, as emotions (e.g., fear, shame, depression, anxiety) are central to understanding disclosure, it is critical to examine their role in disclosure, and their socially and structurally constituted nature.

In this paper, I employ Hochschild's emotion work, and the framework of healthism, to explore the emotional aspects of HIV disclosure decision-making, the act of disclosure, and the aftermath of disclosure for Black gay and bisexual men living with HIV (BGBM-LWH). Current knowledge of HIV disclosure largely does not account for emotions and disclosure's embeddedness within particular social, cultural, and structural contexts that shape disclosure processes, experiences, and outcomes. Sociological thinking on emotion work can begin to shift the approach of disclosure research and interventions by situating HIV disclosure in existing social and structural relations. Doing so can provide new approaches that focus addressing structural inequities that constitute the emotional nature of disclosure, instead of intervening on individual disclosure processes.

Framing Rules, Feeling Rules, and Emotion Work

Emotions are shaped and defined through social interactions and lived experiences. "Feelings themselves and their social expression are differently constituted for people whose social relations and social worlds are marked by difference relative to the worlds of others" (McCarthy 1989:57). Emotions: depend on how one defines the situation; emerge from social relations; are influenced by internal impulses and external events, because our perceptions and interpretations are also influenced by both; and function within the frameworks of our cultural and structural environment (Shott 1979). The interactional theory of emotion work draws attention to the social world, its organization, and the role of social structures in shaping our emotional responses and displays (Hochschild 1979). Emotion work is about evoking a certain emotion or feeling (e.g., to try to feel brave, happy, or responsible) or suppressing a feeling (e.g., to try not to feel angry or selfish). This work is can be done: 'by the self on the self'; 'by the self upon others'; or 'by others upon oneself'.

Underlying emotion work are *framing rules* which determine how people define social situations, and *feeling rules* which guide the way one *should* feel in a given situation based on the frame that defines the situation (Hochschild 1979). Dominant public health ideology suggests, for example, that an HIV diagnosis may be defined as the result of "risky behavior." In turn, it would be fitting for a BGBM to have feelings of guilt or shame. Here, these feelings may be what he should feel, and he *should* also feel a responsibility to disclose. In this case, the emotion work that follows would be working up the courage to disclose despite these feelings, or to overcome those feelings altogether. If, however, the same man's HIV infection was the result of a sexual assault, infidelity, or a blood transfusion, then what he *should* feel may be anger, sadness, or betrayal, but likely not guilt. Importantly, however, in these alternative frames, he may still feel shame. Though, the source of that shame would be societal HIV stigma, not a sense of having done something "wrong." The current public health approach conceives of emotion in terms of measurable indicators of psychological distress (e.g., suicidal ideation, depression, anxiety). Though, emotions such as shame, guilt, betrayal, and anger, and the social and structural inequities that are largely constitute one's emotional response to an HIV diagnosis are unaccounted for.

Further, the nature of emotions and the feeling rules governing them are, in part, shaped by social position (Hochschild 1990). Racial/ethnic and class strategies – "persistent lines of feeling and action" (129) – through which we adapt to situations, are determined by existing ideologies and our relative social location. "Given an individual's placement in the race or class hierarchy, we can ask about what feeling rules make sense to them, and what ways of managing emotion will seem necessary or right" (137). For the men in this study, some racial strategies are rooted in sociological and historical determinants of Black family life. During slavery, the formation, maintenance, and functioning of Black families were controlled by slave owners (Dill 1988). Indeed, families at different locations in the social hierarchy have different levels of access to the institutions that support families (Zinn 1990). The Black family has been and continues to be a source of strength within a racially oppressive system. Thus, survival of Black families has long required cooperation, collectivism, and mutual interdependence (Dill 1982, Jewell 2003, Pastrana Jr 2016, Staples 1971, Zinn 1990). As Larry Griffin (2001) argues:

> Black southerners, certainly, were never permitted by whites to be "individualists," and they seldom, if ever, relied on the socially unanchored self… Few groups in American culture have been more "communitarian" – in terms of identity, patterned sociability, perceived grievances, proposed solutions, and disciplined organization and collective action – than African Americans in the South (68).

Thus, it is critical that emotion work in BGBM's HIV disclosure narratives be centered in an understanding that recognizes their membership in Black southern families. In addition, BGBM are overburdened with disclosure, due to disproportionate representation in the HIV epidemic, and societal expectations of ethical and responsible health behavior. This expectation of personal responsibility to maintain health and protect the community is a particularly heavy burden for people living with a stigmatized illness and must be considered in analyses of disclosure and emotions.

Healthism

Healthism is a cultural belief system in which individuals are compelled to behave in ways that reflect a continuous commitment to 'good health' (Crawford 1980). Individual responsibility is core, as "healthism is an ideology which requires either the self-restructuring of attitudes, emotions, and behaviors, or the intervention of healers to help accomplish the same" (375). In post-industrial society, there has been an increase in the salience of 'health' in the ways people identify and organize themselves, and achieving health becomes a moral endeavor. As Deborah Lupton argues, the ideal body is one that is civilized and "subject to highly conscious and rational control" (Lupton 1995:70). Further, she posits that medical conditions are subject to moral judgments based on ideas such as individual responsibility. Those moral judgements are translated into public health messages and those who are at risk are seen as irresponsible and irrational. Disease is linked to moral qualities (Greco 1993), and those who expose others to harm are thought of as sinners who not only threaten health, but threaten the social body.

Societal norms and discourses define a healthy identity in contrast to what, and who, is unhealthy (Crawford 1994). For example, "HIV/AIDS comes to be seen as the other of this 'healthy' self: an 'unhealthy' other who is perceived not only as a physical danger, but as an equally threatening and dangerous identity" (1348). In this way, healthism is a dividing practice providing a basis upon which people can be distinguished and stigmatized (Crawford 2006). Further, being a good and moral citizen involves a responsibility not to place the community at risk. As public health frames sexuality in terms of risk, and epidemiologic 'risk groups' continue to be the first step in managing that risk, those deemed 'at risk' or who are seen as 'a risk' to others are 'responsibilized' and managed through self-regulation or government intervention (Kinsman 1996). In this framework, nondisclosure "marks a deficient subjectivity that shirks its obligation to truth" (Persson and Richards 2008:76). The individual responsibility framing comes with moralism and blame and, by not acknowledging the socially constructed nature of individual behavior, reproduces a disabled subjectivity (Crawford 1980).

Overwhelmingly, extant literature has investigated HIV disclosure by assessing whether one has disclosed, to whom they have disclosed, to how many or what proportion of one's social or familial network one has disclosed, and how others reacted (CITE). Little is known about emotion work and HIV disclosure among BGBM, particularly situated in the context of the US south, and understood within the personal responsibility frames that dominate HIV prevention research. In this analysis, I explore how Black gay and bisexual men living with HIV, in a city located in the Deep South, experience disclosure. Specifically, I elucidate the emotion work required before during and after HIV disclosure or nondisclosure. As my findings illustrate, a sociological exploration of emotion work and disclosure moves beyond seeing HIV disclosure as a discrete event. Here, I incorporate emotions as lived and experienced, and as shaping disclosure experiences within ongoing social relations. This sociological approach will expand understandings of emotions and disclosure to shed light on potential community-level and structural interventions to reduce the negative emotional effects of HIV diagnosis and disclosure for PLWH.

METHODS

Data

Between June 2019 and July 2020, I conducted in-depth, semi-structured interviews with 30 BGBM in the Baton Rouge, Louisiana Metropolitan Area. In-depth interviews allow the researcher to focus the topic, while making time and space for participant insights, and substantial experience with the subject of focus, to emerge (Charmaz 2014, Creswell 2012).

Grounded theory interviewing methods also “conceptualize social life as a process that is the production of the simultaneous shaping of different aspects of social life and human agency” (Cuadraz and Uttal 1999:161).

Participants were recruited using passive (e.g., flyers at clinics and doctors’ offices, advertisements on gay dating sites), and active (e.g., announcing the study at community events). Additionally, participants were referred by well-connected community members and by previous participants. Men were either screened by phone or completed an online screening survey. Eligible participants: self-identified as Black or African American cisgender men; were over the age of 18; engaged in sexual and/or romantic relationships with other men, resided in the Baton Rouge metropolitan area, and were living with HIV. I conducted all interviews, which lasted between 60 and 90 minutes, on average. Approximately, the first half (n-14) of interviews were conducted in person. Due to Covid-19 restrictions beginning in March 2020, the additional 16 interviews were conducted by phone or internet. All interviews were digitally recorded and transcribed verbatim.

Analysis

I conducted open coding on the first third of interviews in order to develop the initial codebook. Interviews were coded simultaneously with ongoing data collection (Charmaz 2014). Subsequently, I eliminated redundancy and categorized codes into parent codes. Interviews were coded MAXQDA 2020 (VERBI Software 2019). To answer the research question on the role and management of emotions in the disclosure process, the current study draws on following codes: disclosure philosophy; disclosure circumstances; emotion management; disclosure reactions; disclosure regrets; social support; protecting self; protecting others.

RESULTS

To illustrate the emotional experiences and the work participants engaged in to manage emotions, and the structural realities shaping emotion work, I first describe framing and feeling rules that were reflected in the way men described emotion and emotion work around disclosing their HIV status. Then, I describe the emotional nature of disclosure as reflected in men's narratives. These narratives are described in three broad themes: (1) Emotion work on the self; (2) Simultaneous emotion work on the self and on the other; and (3) Emotions after disclosure. The names used throughout are pseudonyms, followed by the participant's age and time since diagnosis, rounded to the nearest year [e.g., Martin (30; 4)].

Disclosure Framing, Healthism and Feeling Rules

Men's narratives reflected two predominant framing rules organizing their emotional responses to receiving an HIV diagnosis, and the emotional processes involved in subsequently disclosing it. First, within an HIV-stigma frame, an HIV diagnosis is one of the worst, if not the worst thing that an individual can receive. Importantly, the HIV-stigma frame both contributed to, and was amplified by other intersecting stigmas (e.g., racism, homophobia), and a general lack of education about HIV in men's families and larger communities. The HIV stigma frame organizes feeling rules in which the appropriate feelings are those of devastation and shame, as well as fear of one's impending death, and the negative reactions expected when others learn of their diagnosis.

Within the frame of healthism, the appropriate feeling for the person who is diagnosed with HIV is one of responsibility for contracting the virus. Public health messages emphasizing "higher risk of infection" for BGBM, campaigns that ostensibly teach BGBM how to protect themselves, and the decades-long associations between HIV and homosexuality defined an HIV diagnosis as a personal failure, and something about which one should feel guilt. In this frame, disclosure is loaded with one's perceived inability to maintain the boundary between the *self* and *unhealthy other*. This sense of not having succeeded in remaining a healthy, responsible, moral citizen shaped men's emotional processes around disclosure.

Reflecting both the healthism and the HIV-stigma framing rules, Darius (23; 4) described how he felt after his diagnosis:

> I never really broke down like I feel like I should have after I found out the news… It was devastating news to anybody, that was just devastating news, and for it to be a part of my life, and for me to have played a role in it. I couldn't blame nobody but myself. My had playing a role in there, I feel like I should have broken down or I should have cried more, or I should have been in a darker place than I was. Maybe because that's what you see on TV or that's what you see other people experience. But one night… it felt like I could just feel the infection running through my veins. And that's when I really just felt the low. That's when I really was just I don't want to do this, I don't want to be here, I don't want to have to go through this… I thought rejection was going to be a bad thing, I should have learned my lesson about having unprotected sex…

Here, he illustrates a number of the feeling rules within the two frames. First, that depression, sadness, and distress are *the* ways to feel about an HIV diagnosis, as it is necessarily "devastating news." While, for many BGBM, receiving an HIV diagnosis is still a traumatic experience (Mgbako, Benoit, Iyengar et al. 2020), in other settings and structural circumstances (e.g. knowing others with HIV; having strong support networks, knowing treatment has improved the life course and health of many), others react calmly and without fear for how HIV will impact their lives (Bilardi, Hulme-Chambers, Chen et al. 2019). Importantly, Darius described learning that an HIV diagnosis is “devastating” from witnessing the experiences of others, which is one way in which HIV stigma and fear are perpetuated. Further, the role of personal responsibility ideology is prominent in both his guilt for having contributed to his HIV infection and is his belief that he “should have learned [his] lesson.” Each of these frames are present in the ways in which men describe their emotions and emotion work around HIV status disclosure.

Emotion Work on the Self by the Self

Emotions felt before, during, and after disclosure were shaped, in part, by expectations and obligations around disclosure that men felt compelled to meet. These were informed by familial and cultural norms, ideological realities which shape *patterned entitlements* – gestures that individuals feel are owed to oneself or to others (Hochschild 1979) – as well as public health messaging, and criminal law. Men believed that their families were entitled to disclosure and transparency. Reflecting the central support role of mothers in Black families (McAdoo and Younge 2009, Stack 1975, Zinn 1990), and the closeness of Black families in the south (Griffin 2001), some men were members of families in which secrecy about major life events was not the norm. Others were accustomed to telling their parents – their mothers in particular – about numerous pieces of personal information, what was happening in their lives, and their well-being. Though, accompanying the disclosure process was the long-standing and persistent association of HIV with homosexuality (Crawford 1994) leading to a sense of having failed or disappointed their parents. Perceiving disclosure as something men owed their families, and their efforts to meet this ‘entitlement’ came with considerable emotional stress.

Darius’ (23; 4) anxiety about disclosing to his parents began immediately after his diagnosis,

> …how was I going to tell my mom, the person that I live with, the person that raised me. Lord Jesus, she tried her best….so hard and now I've got to tell her that this one thing that we was all so afraid of when I first came out of the closet, I've got to come in here and tell her it happened.

As his quote illustrates, his understanding was not that he could consider whether to tell his mother, but that he had to. Here, he also highlights a sense of failure in confirming that being gay would lead to HIV infection. Similarly, Andre (37; 11) disclosed his diagnosis to his mother because she was "the only person I could confide in," and during this disclosure experience, he felt "hurt. I felt like I let her down."

Despite having a family that was generally open with each other about life challenges and health issues, Charles (26; 6) described a feeling of guilt and failure as something that kept him from disclosing to his family for more than a year.

> It was just the simple fact that it's me being the gay cousin, the gay one of the family, telling y'all that, 'Well, damn, I've fallen victim to the statistic. I have contracted HIV. Now, I'm a statistic and I hate to come to tell y'all this, but I have'… But I know I didn't want to hold that from them anymore.

Eventually, he turned to his mother when he could no longer handle it on his own: "I was crying and I think I had a bad day at work, and I was like, 'I need someone.' I was hyperventilating and couldn't breathe. I said, 'I have to tell my mom'." He went on to describe that "the type of family we have, if one person's hurt, we're all hurt." After telling his mom, he received supportive phone calls from his grandmother and aunt, whom his mother told of his diagnosis.

These narratives illustrate the crossing of the boundaries between the moral, personally responsible, healthy citizen, and the 'unhealthy other' (Crawford 1994). The strength of the ideological commitment to this imaginary boundary lies in the senses of guilt and failure for having brought HIV into the worlds of their family members. Indeed, Darius', Andre's, and Charles' narratives each point to the belief that they and their families shared – that the boundary between them and HIV was homosexuality. Thus, the emotion work involved in disclosing was largely shaped by having crossed that ideological boundary.

Other men didn't specifically discuss that same sense of failure but, still, had to engage in emotion work on themselves in order to disclose. Craig (34; 9) returned to work after being diagnosed and had to control his feelings to meet his work obligations.

> …the next chapter in my life, was living with this and accepting it and coming to terms with it. It's almost like mourning in a way, but I had to put that off. I needed to finish up my job, I needed to finish doing what I was there to do. People could tell that something was wrong with me, something was off in my demeanor and my attitude, but for me it was just important to finish up my year… It took a couple days; I told my mom. I sat down one night, it was a Sunday I want to say, and I told my mom... I sat her down and told her. I cried, and I told her. She gave me a hug and everything. Then, the next morning I think she had slept on it. She started asking questions, and they were questions that I didn't want to answer because I wasn't out to my mom. So, I didn't want to tell her how this had happened or how I thought it had happened.

Here Craig speaks to the challenges he faced after his diagnosis. Disclosing to his mother was both emotionally difficult and opened the door to questions that may have revealed his sexuality which, at that point in his life, he was not prepared to discuss with her.

Chance (34; 1) learned of his HIV positive status shortly after his mother died. This left him with one parent, and he felt he needed to share it “with someone I know loves me,” though it was a daunting task.

> …it was kind of hard. It wasn't hard telling him, the hardest thing was pulling myself together to tell him, I really had to dig deep inside of me and take a couple of breaths before I let the words come out of my mouth.
>
> ***Interviewer: Was that about fear of his reaction or was that because you were still trying to process it?***
>
> I was still trying to process it. I didn't want to break his heart all over again. We still grieving from mama. He's grieving hard because his baby still breathing. I just didn't want to break his heart all over again, but I had to get that off my chest.

For Chance, the emotion work he had to do on himself prior to disclosing was harder that the disclosure itself. Further, as his diagnosis and disclosure occurred at a time of grief for his family, his narrative illustrates how important context is in constituting the need for and nature of emotion work. As these narratives illustrate, men did experience negative emotions around their diagnosis. Though, these emotions did not prevent disclosure. Instead, they engaged in a process to work on overcoming and suppressing their emotions in order to disclose, which in many cases led to a need to do emotion work on behalf of those to whom they disclosed.

Doing Double Duty: Emotion Work on the Self and on the Other

BGBM’s narratives revealed that managing other's emotions necessarily occurs simultaneously with emotion work on themselves. Some men chose to withhold details or chose non-disclosure either because talking about it was too hard, or because they believed that some people in their families wouldn’t be able to handle the information. Though, not telling their loved ones required them to manage their own emotions associated with keeping a secret. Jamar (32; 9) described his decision after seeing his cousin's emotional response to his disclosure:

> Lord, she cried more than I did. She was like, "Well, if you all need anything just let me know." And I was just like, I wouldn't bother her with that. I would never bother her with that… With any of, any feelings or emotions or any issues I was having pertaining to my diagnosis. I didn't want them to deal with that. I never spoke... It's more of an emotional thing. It's more so on me running from the conversation.

Thus, for Jamar, not discussing the details of his diagnosis is a strategy that both spares others from having to process the information and spares himself from the guilt he felt after seeing his cousin's reaction.

Keith (29; 6) chose to withhold his status from his grandmother because "I believe it will kill her." Though, "It hurts and I feel when I'm around her, I feel bad. I don't like holding it from her," he was willing to tolerate the painful nature of keeping a secret from her because he didn't want her to worry. At the time of my interview with him, Eugene (45; 17) had been living with HIV for more than 17 years. Though, he had chosen not to disclose to his friends and family because he didn't want to worry them. He described what it was like for him to keep his status from them for so long:

> Well, I mean, for the most of it, it hurts because I really would love to tell my mom. But I also don't want to stress her out. Because she would fall under the category of one of those people that's not 100% educated on it. Majority of the people in my family, all they feel or think or know is that if you have it, you're dying. They think if you have it, you're dying. I mean, a lot of people are uneducated with it. So, majority of people I know that does not have it, they feel like if you get it, you're dying. If you catch anything that's

> incurable, you're going to die from it. That's pretty much everybody's presumption on that case… I don't want any of my family to know, because I don't want to stress them out. Because they love me dearly. Them to know that, would hurt them badly.

Here, Eugene describes keeping this information from his mother as something that “hurts.” Though, to protect his family, he is willing to experience that hurt. Further, we can see here that his emotion work and nondisclosure are shaped, not by a belief that his family wouldn’t support him, but by the presence HIV-stigma and a lack of knowledge about HIV.

Reggie (30; 9) did not disclose to his family for seven years. During that time, keeping that secret took a toll on him that eventually led him into a deep depression.

> I had a crisis last year where I was going into a depression, and my sister called me, and she broke down because I was not talking to anyone. Like I said, I try to keep communication with them a lot. I had pretty much stopped talking to them, I stopped talking to all my friends… She had left this very long, passionate voicemail, and I still didn't even call her back and respond to it because I just I felt like I couldn't. Because, well, I had found out I was HIV positive in February 2011, and I had kept that in for so long. I didn't tell my family when I found out until last year. Because I felt like I didn't want them to be concerned or over worry about me.

Reggie’s narrative reveals an additionally challenge for those who choose nondisclosure to protect others’ emotions – that the emotion work may ultimately prove unsustainable.

Several men described working to managing others’ emotions related to their diagnosis. This involved comforting others after disclosure, feeling a sense of guilt for upsetting their loved ones, refraining from discussing details with others, or choosing not to disclose to protect others. After Tyrone (35; 14) disclosed to his parents, he felt guilt for having upset them; and because of his commitment to his family, and the fact that his parents had always been there for him, he owed it to them to help them deal with the news.

> I had to reassure them like they reassured me when I was a child. That's just how it works… They didn't abandon me when I was small. They could have when I was gay. ‘He's gay.’ Put me out or whatever. They could have done that… But they didn't, so I didn't… I felt like it was my responsibility as their child…

Craig (34; 9) disclosed to a few friends just a day or two after his diagnosis. When several of them cried in response to his disclosure, he felt compelled to comfort them despite not having processed it for himself and not knowing much about what his health and future would look like.

> It was tough, I didn't like seeing them cry… I hated that. I didn't want to see them cry because of me. I reassured them, "I don't know what's going to happen, but everything is going to be okay. I'm still the same person." Yeah, it was really tough seeing them react the way that they did, and I didn't expect that… I wish I had spared them from that and just kind of had time to process, deal with it myself, and then have those conversations. I think in those types of moments, I wanted to protect them. So, even if things weren't going to be okay, they didn't need to know. I didn't want them to worry about that. So, it was just my natural response to be like, "Everything's going to be okay.”

For these men, there were multiple emotional exchanges involved in their disclosure. For each of them, disclosing involved emotion work to manage others. Tyrone had been diagnosed more than a year before his told his parents because it was just “too much” for him, and Craig presented a composed and stoic self to his friends though he had been crying for days. The reactions of Tyrone’s parents and Craig’s friends conveyed love, concern, and fear which led each of them to feel a sense of guilt for causing the emotional pain and did what they could to try to comfort them through it, setting aside their own emotional process, at least for that moment.

Emotions after disclosure

HIV focused public health literature has overwhelmingly examined disclosure as discrete events without acknowledging the emotion work involved thus limiting the content of interventions and the definition of the public health problem. As disclosure is “embedded in the process of ongoing social interactions over time” (Mayfield Arnold, Rice, Flannery et al. 2008:87), the emotion work doesn’t end after the information about one’s status has been revealed. Literature has documented rejection by family, friends, and sexual partners. Though, even if disclosure does not lead to rejection, it still transforms social relationships. Indeed, men who chose to disclose their HIV status to the people close to them also described emotional work that followed those disclosures.

> …it was like the happiest before I found out because I was close to my family. I found my family… Y’all wanted to do stuff. The spirit in me after them knowing that I have HIV was like, now it's something that I won't even expect my family to do… I don't know but it just really kind of hurt. ~Brian (35; 10)

After Sam disclosed his status to his mother, he later found out that she told other family members that he didn’t want to know about his diagnosis. He was also treated differently by other members of his family who were afraid to have him around. Subsequently, his relationship with his mother suffered. He describes that the experience “caused me not to be able to tell her personally things,” and he felt as though his mother “has no happiness for me at all. It hurts.”

Other men described telling partners, friends, and sex partners who insulted them, broke off relationships, or disclosed their status to others in the community. This led to bouts of depression, anxiety, or suicidal ideation, which men had to process, overcome, and learn to manage the resulting scars (see chapter 2). These narratives illustrate an important aspect of (non)disclosure – that once the decision has been made to disclose or conceal the information about one's HIV diagnosis, the emotion work does not end. Thus, in addition to central to the decision-making process and the act of disclosure itself, emotions are a central part of what comes after. In each theme of these findings, men's narratives reveal the emotion work that was required of them before during and after disclosure, and the extent to which social and structural factors shaped their own emotional reactions to being diagnosed and the reactions of those to whom they disclosed. This highlights the need to expand public health interventions focused on HIV disclosure which will be discussed in the next section,

DISCUSSION

This qualitative analysis explored how Black gay and bisexual men living with HIV experience disclosure, engage in the emotion work required before, during, and after disclosure, and how those experiences and related emotion work are situated in ongoing social and familial relationships. These findings challenge the common practice of measuring HIV disclosure as discrete events (e.g., Who have you told?; How did they react?; Is disclosure related to psychological outcomes?), and provides a more nuanced understanding of the emotional nature of disclosure, what it means in the moment and what it requires in an ongoing way. As is illustrated in men's narratives, the type of emotion work required was shaped by familial and cultural norms, experiences of trauma (e.g., incarceration, childhood sexual abuse), and the presence of high levels of HIV-stigma and homophobia. Men in this study engaged in the difficult emotion work needed to disclose despite these existing structural inequities. In contrast to most extant HIV disclosure literature that applies rational frames to understanding and intervening on nondisclosure (e.g. exploring risks and benefits, assessing self-efficacy, and developing disclosure strategies) (Cao, Wong, Chang et al. 2019), my findings situate HIV disclosure in particular structural contexts and recognize its place within ongoing social relations (Mayfield Arnold et al. 2008).

Given that BGBM are disproportionately affected by the HIV epidemic (Linley et al. 2020), much focus has been placed on understanding the potential roles of HIV disclosure in sexual risk reduction (e.g. Bird, Eversman and Voisin 2017, Okafor, Li, Hucks-Ortiz et al. 2020, Simon Rosser, Horvath, Hatfield et al. 2008), or garnering social support and improving clinical outcomes (Carnes, Carey, Gelaude et al. 2020, Greene, Carpenter, Catona et al. 2013, Wohl, Galvan, Myers et al. 2011). In the framings of these studies, emotions are explored as psychological constructs that can be quantitatively measured and assessed as predictors and outcomes of the aforementioned variables. Further, these studies largely research and discuss BGBM as almost purely sexual beings, evidenced in the hegemonic use of "Black men who have sex with men (BMSM)," which erases varying identities and sexual behaviors, and does not account for political and social context, or how different identities shape how men engage in social interactions (Carrillo and Hoffman 2016, Garcia, Parker, Parker et al. 2016, Young and Meyer 2005). Indeed, this approach obscures their relative social positions and lived experiences as Black gay, bisexual, queer, fluid, and same gender loving men (the sexual identities of men in this study), who are living with HIV. Contextualizing our understanding of disclosure among these men within their particular social and political contexts is necessary in order to see their emotions more sociologically – as lived, experienced, managed, and situated in beliefs and symbols, not only as objects to be measured (Bericat 2016, Francis 2006, McCarthy 1989).

My findings illustrate particular frames - namely HIV-stigma and healthism – within which emotion work was done. Within the ideological frame of HIV-stigma, the feeling rules suggest that an HIV diagnosis should be "devastating" or that disclosing their diagnosis to one's loved one will "kill" them. Indeed, for most of the men in this study, being diagnosed was devastating, with some withdrawing from the social world and others becoming suicidal (Campbell 2021; see chapter 2). Though, research has documented a range of emotional reactions to an HIV diagnosis from shock, depression, and suicidality to seeing it as no big deal and being ready for action (Bilardi et al. 2019, Hult, Maurer and Moskowitz 2009). These differences highlight the ways that 'interpretive frameworks' help us to define a situation (Hochschild 1990). With connections to others living with HIV, strong support networks, and fewer negative associations with HIV, receiving an HIV diagnosis can be seen as 'no big deal' (Bilardi et al. 2019).

Alongside HIV-stigma is the framing of healthism, which positions health as an ideal goal and erects an imaginary boundary between moral, healthy people and those who fail to behave responsibly to protect their health and the health of others. Disclosure and other 'risk reduction' strategies are social processes that happen within racialized, classed, sexualized, and gendered contexts (Adam et al. 2015, Flowers, Duncan and Frankis 2000, Kinsman 1996, Petersen and Lupton 1996). As BGBM are over-represented in HIV incidence and prevalence, the burden of responsibility falls on their shoulders more than others (Siconolfi, Halkitis and Moeller 2015). The logic of individual responsibility, where people are expected to stay *healthy* and not become a risk to the larger community, risks "sliding into victim blaming" (Crawford 2006:411), and the extent to which this is true is shaped by social perceptions based on one's social location, and our social understandings of HIV. Further, in the context of the HIV epidemic, when members of pathologized groups (e.g. gay men, people who use drugs, sex workers) contract HIV, it is seen as the result of something inherently immoral or dysfunctional about those individuals (Crawford 1980, Crawford 1994). This ideology suggests that an HIV diagnosis *should* lead BGBM to feel a sense of guilt and failure for having "fallen victim to the statistic," in Charles' words. This extends healthism beyond its focus on what a responsible, moral person should do, to include how one should feel. Indeed, several men described feeling "guilty" or as though they "let down" their family members. Disclosing meant that, in addition to coping with their diagnoses, they had to manage emotions associated with confirming their family's belief that they would eventually contract HIV because they were gay.

These findings also highlight the importance of the Black family for many BGBM. Men described their families as their support systems, as people that "I know love me," in Chance's words. They disclosed their HIV diagnoses to their loved ones not because there was an absence of stigma or because they expected solely positive responses, but because they felt that their families deserved to know, and that *their* families would stick together. In another paper, I quote Walter describing the reasons he didn't disclose his experience of CSA: "I was taught the sanctity of the family was more [important than] what I was going through... So I decided not to bring it up" (Campbell 2021, see Chapter 2). The difficult emotion work that these men engaged in reflects the long-established role of Black families, particularly in the south, as a safe haven in a racist world (Dill 1982, Griffin 2001, Zinn 1990). As a result of what they were taught about family in their upbringings, BGBM were willing to shoulder the emotional burdens of nondisclosure to protect members of their families or, in the case of disclosure, managing and comforting others and facing negative reactions.

Findings from this study have practical implications for how future research and interventions approach HIV disclosure interventions. First, in most of men's narratives, psychological distress (e.g., depression, anxiety) was not a barrier to disclosure. Instead, men disclosed to friends and family despite their fears and depression and, in some cases, because they were experiencing depression. Importantly, Black people in the Deep South have deep attachments to family and may not feel that keeping such important information from their families and, in particular, their mothers. Disclosure interventions have not accounted for these cultural variations in how men approach disclosure and have focused on increasing disclosure self-efficacy, estimating possible responses to disclosure, and weighing risks and benefits (Conserve, Groves and Maman 2015, Greene et al. 2013, Serovich, Laschober, Brown et al. 2018). Existing disclosure interventions have not accounted for the emotional burdens and the emotion work required for disclosure. These interventions have started from the assumption that disclosure is inherently positive. Though, the findings of this study highlight that disclosure is more complex, and that emotions are central before, during, and long-after disclosure. Interventions that aim to assist PLWH in identifying potential reactions from those to whom they plan to disclose (e.g., Greene et al. 2013) must consider that long term consequences of disclosure cannot necessarily be foreseen.

Indeed, it is critical to recognize that disclosure is embedded in ongoing social relations. Disclosing one's HIV status to others is an interaction that is shaped by the existing nature of relationships, which involve support as well as conflict and, thus shape the emotions that accompany disclosure decision-making. Further, disclosure (or nondisclosure) doesn't just lead to the immediate reaction of the person or persons being disclosed to. Disclosure can fundamentally change the way other see and interact with the person disclosing (Tewksbury and

McGaughey 1998). Years after his diagnosis and disclosure to his family, Brian described feeling that he was the happiest before his family knew about his diagnosis. His relationships were fundamentally changed. The emotions that accompanied his family's knowledge of his status, and the associated emotion work were ever present nearly 10 years after his diagnosis and disclosure.

HIV disclosure interventions must adapt to specific contexts and communities. Intervening at the community level to increase knowledge around HIV, including at the institutional level (e.g., formal sex education, including HIV education, in public schools) would serve to shift the environmental context in which disclosure occurs. As noted by Bilardi et al. (2019), strong social support networks, HIV health literacy, and knowing others with HIV can lead to better coping with an HIV diagnosis, while having little knowledge, or out of date knowledge about HIV can lead to feelings of shock and devastation. As I have noted elsewhere (see chapter 4), men also described a process of HIV stigma including silence, gossip, the spread of misinformation within the community, and a lack of formal education about HIV. It is within this stigma context, the emotions accompanying HIV diagnosis and disclosure are determined. These findings suggest that future efforts should push beyond individual level interventions to address the structural, cultural, and social factors that constitute an environment in which the emotions associated with disclosure are shame, fear, and depression.

The current analysis has limitations worth noting. This was a convenience sample recruited in a mid-sized city in the Deep South. Thus, the narratives and perspectives of BGBM reflect particular social and cultural realities, and emotion work during the disclosure process likely differs across race, gender, sexuality, class, geography, and their intersections.

Additionally, HIV status was self-reported. Due to the high levels of stigma in the community, no HIV testing, or documentary verification of status was obtained.

Conclusion

Generally, receiving an HIV diagnosis is a difficult and emotional experience. Though, for those who are located at the intersection of multiple stigmatized identities, the experience is additionally influenced by their social locations. Previous research has documented the potential negative consequences of disclosure, including negative psychological outcomes. Though, these studies overwhelmingly leave unexplored the emotional *experience,* the work that must be done within that experience, and how these are shaped by social and structural realities. It is critical that future research exploring disclosure includes an analysis of emotions as lived and experienced, and that the management of emotions associated with HIV disclosure are shaped by overlapping existing social inequities.

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CHAPTER 4: A Grounded Theory of Social Processes That (Re)Produce HIV Stigma

INTRODUCTION

Black gay and bisexual men (BGBM) continue to bear a disproportionate burden of new HIV diagnoses in the United States (CDC 2020a). One structural reality, HIV stigma, has played a significant role in higher rates of infections among BGBM, and contributes to disparities in diagnosis, treatment, and care, for BGBM living with HIV (BGBM-LWH) (Jeffries IV, Townsend, Gelaude et al. 2015, Overstreet, Earnshaw, Kalichman et al. 2013, Reif, Wilson and McAllaster 2018). In qualitative studies, BGBM have described a need to guard their privacy as a result of gossip and unwanted disclosure in their communities and internalizing pre-existing negative ideas about HIV once they were diagnosed (Bird and Voisin 2013, Bird, Eversman and Voisin 2017, Jeffries IV et al. 2015). Further, some explained that, in their communities, HIV was seen as a judgement for immorality, and that members of their families and broader communities had rejected them and perpetuated negative ideas about HIV (e.g. HIV is a death sentence) and people living with HIV (PLWH) (e.g., PLWH are tainted, nasty, sick) (Arnold, Rebchook and Kegeles 2014, Bird and Voisin 2013, Bogart, Dale, Christian et al. 2017, Jeffries IV et al. 2015).

Quantitative HIV stigma research has focused on measuring cognitive, individual-level stigma mechanisms including perceived (i.e., awareness of stigma), anticipated (i.e., expectation of stigma), enacted (i.e., negative reactions or discriminatory treatment), and internalized (i.e., acceptance of negative ideas about HIV and PLWH) stigma (Bauermeister, Muessig, LeGrand et al. 2019, Earnshaw, Smith, Chaudoir et al. 2013, Sang, Matthews, Meanley et al. 2018). Among BGBM-LWH, these various stigma mechanisms are associated with uptake of prevention strategies, nondisclosure, poor medication adherence and lower retention in care, as well as increased depression and anxiety (Balaji, Bowles, Hess et al. 2017, Bogart, Wagner, Galvan et al. 2011, Brewer, Hood, Moore et al. 2020, Eaton, Earnshaw, Maksut et al. 2018, Miller, Janulis, Reed et al. 2016, Overstreet et al. 2013, Sang et al. 2018). Importantly, these individual level constructs have also been taken up in qualitative studies, in which participant narratives largely agree with quantitative findings (Arnold et al. 2014, Bird and Voisin 2013, Bird et al. 2017, Jeffries IV et al. 2015, Quinn, Voisin, Bouris et al. 2017).

Resulting from these individual-level analyses, most interventions which aim to reduce HIV stigma emerge from public health and have relied on individualistic social-cognitive approaches to: improve HIV knowledge; increase awareness, acceptance, and compassion toward PLWH; as well as to improve self-image and coping among PLWH (see Brown, Macintyre and Trujillo 2003, Sengupta, Banks, Jonas et al. 2011, Stangl, Lloyd, Brady et al. 2013). Though, in a recent systematic review of stigma interventions, Dunbar, Labat, Raccurt et al. (2020) identified just two interventions in the United States that aimed to reduce HIV stigma among BGBM. In one of those studies, HealthMPowerment, an mHealth intervention for young BGBM created an online space for young men to discuss stigma related information and experiences (Bauermeister et al. 2019). The authors found that while stigma declined over time, changes in perceived, anticipated, and experienced HIV stigma differed according to education level, HIV status, and whether participants described having experienced HIV stigma. The second study implemented an HIV prevention intervention for young BGBM in the House Ball Community (Hosek, Lemos, Hotton et al. 2015). The authors measured similar stigma mechanisms, with the addition of internalized HIV stigma, and found only a nonsignificant decline in stigma. While addressing the effects of stigma on the mental and physical well-being of PLWH is crucial, the social processes through which stigma is produced must also be addressed.

Most HIV stigma research begins with Goffman's conception of stigma as a mark or characteristic that results in reduced social value for people with that characteristic (Goffman 1963). Despite Goffman's call for a "language of relationships," there has primarily been a focus on individual perceptions and the consequences of those perceptions – individual acts of discrimination, and rejection. According to Parker and Aggleton (2003), that research has proceeded "as though stigma were a static attitude rather than a constantly changing (and often resisted) social process has seriously limited the ways in which stigmatization and discrimination have been approached in relation to HIV and AIDS" (14). Importantly, as noted by several authors, only when people have more power than others can they engage in the process of stigmatization (Gilmore and Somerville 1994, Link and Phelan 2001). PLWH, as a group, possess less social power than those who are not and, many groups who occupy a marginal social status prior to receiving an HIV diagnosis (e.g., people of color, gay men, sex workers, people who inject drugs) have even less power to resist stigmatization (Berger 2010, Gilmore and Somerville 1994, Parker, Aggleton, Attawell et al. 2002). Indeed, research has shown that HIV/AIDS stigma is layered onto other stigmatized identities (e.g. injection drug use (IDU), homosexuality, commercial sex (CS)), such that "disease stigma of HIV/ AIDS is a derivative of the negative meanings attached to IDU and CS, and not the other way around" (Chan, Yang, Zhang et al. 2007:9).

Stigma occurs through social relations in which some are made to feel superior while others are devalued and excluded (Parker and Aggleton 2003). This exclusion is reproduced through social relations and, thus, stigma should be viewed through its relationship to social structures and power relations (Link and Phelan 2001). As argued by Mead and Mind (1934), the self is constructed by taking on the attitudes of the social group, which is learned through social interactions. Thus, one-on-one and community level gossip, for example, helps to create social meanings and to determine appropriate social behaviors (Fine and Rosnow 1978). Further, "stigma emanates from many societal and individual systems whose interconnections cannot be divorced from one another. They coexist in a dynamic relationship in which there is an interplay across, for example, the media, the community, and the individual" (Pescosolido and Martin 2015:102). Indeed, beyond the individual, cognitive processes typically explored in public health HIV stigma research, stigma occurs at multiple levels including the intra-personal, interpersonal, community, and structural (e.g., laws, policies, and institutions). Further, the stigmatization process is ongoing and involves not only labels and stereotypes, but also actions.

To date, our understanding of HIV stigma among BGBM has remained at an interpersonal and intrapersonal level using social psychological measures. To date, no theoretical conception of HIV stigma focuses exclusively on social interactions and structures as a part of an ongoing process through which HIV is stigmatized, and not simply as manifestations of stigma. In this paper, I begin to fill this gap with a grounded theory of the ongoing process through which HIV stigma is produced and reproduced based on the narratives of BGBM-LWH in the deep south. This theoretical model refocuses attention away from individual beliefs and attitudes, and toward social interactions, institutions, and structures. In viewing HIV stigma in this way, research and interventions focused on stigma can more so focus on structural inequities and community level interactions.

Study Setting

Southern states have the highest HIV and AIDS diagnosis and death rates (Hanna, Selik, Tang et al. 2012, Reif, Safley and McAllaster 2015). Louisiana and Baton Rouge rank fourth in the rate of new diagnoses among states and metropolitan areas in the US, respectively, with GBM accounting for 60% of all new diagnoses in 2018 (CDC 2020b, State of Louisiana Office of Public Health 2018). In addition, there are disparities in treatment and care outcomes. Lower proportions of BGBM living with HIV (BGBM-LWH) are linked and retained in care, are currently on treatment, or reach viral suppression compared to White GBM (Hoots, Finlayson, Wejnert et al. 2017, Millett, Flores, Peterson et al. 2007, Rosenberg, Millett, Sullivan et al. 2014). Further, in the Southeast region, Blacks are less likely than non-Blacks to be linked to care at any point post-diagnosis (Rebeiro, Ivey, Craig et al. 2017).

In the South, the cultural norms around sexuality and HIV are largely a matter of silence (Foster and Frazier 2008). Indeed, heterosexism, sex-stigma, and HIV stigma are embedded structurally, particularly in the public school system. In the state of Louisiana, sex education is not required at any grade level (SIECUS 2018), and any school that provides sex education cannot include “any sexually explicit materials depicting male or female homosexual activity” (Louisiana Revised Statute §17:281(A)(3)). Further, in the East Baton Rouge Parish health education standards, very little specific guidance is provided for HIV education, and abstinence is emphasized in the health standards for grades 8 – 12. While, for grades 9-12, the standards include methods of transmission and symptoms of HIV, they also include stigmatizing language such as “analyze the cost of medicines to treat HIV and other STDs/STIs and how these illnesses affect a person’s ability to attend school or maintain employment” (East Baton Rouge Parish School Board 2019).

Further, HIV stigma was a major motivation for HIV criminal laws, and, in turn, these laws reinforce HIV stigma. Louisiana incarcerates its citizens at a higher rate than any other state in the US (Carson 2020), and has implemented specific laws criminalizing HIV non-disclosure (Lehman, Carr, Nichol et al. 2014). In the state, intent to infect is not required for prosecution, and behaviors such as mutual masturbation and spitting, which have minimal risk of transmission are included among those for which one can be prosecuted (Center for HIV Law and Policy 2020).

METHODS

Between June 2019 and July 2020, 30 BGBM-LWH from the Baton Rouge, Louisiana Metropolitan Area participated in semi-structured, in-depth interviews. Qualitative interviews are an effective method for focusing the domains of the interview while allowing participant insights, and lived experiences related to the subject of focus to emerge (Charmaz 2014, Creswell 2012). Grounded theory interviewing methods also "conceptualize social life as a process that is the production of the simultaneous shaping of different aspects of social life and human agency" (Cuadraz and Uttal 1999:161). Interview domains included: childhood and adolescence; family dynamics during childhood and adulthood; current relationships; HIV diagnosis experience; social support; romantic and sexual relationships; community norms regarding sex and sexuality; health and healthcare; HIV stigma; and HIV status disclosure.

Data Collection

Participants were recruited using a number of strategies including: flyers at clinics and doctors' offices; advertisements on gay dating sites; announcing the study at community events; and referrals by well-connected community members and previous participants. Men were eligible if they: self-identified as Black or African American cisgender men; were over the age of

18; engaged in sexual and/or romantic relationships with other men; resided in the Baton Rouge metropolitan area; and were living with HIV. Interviews lasted between 60 and 90 minutes, on average. Half of the interviews were conducted in person, and due to Covid-19 restrictions, half were conducted by phone or internet. All interviews were digitally recorded and transcribed verbatim.

Analysis

I conducted open coding on the first third of interviews in order to develop the initial codebook. In line with a grounded theory approach, data analysis began during, and continued throughout the data collection process (Charmaz 2014). Subsequently, I eliminated redundancy and categorized codes into parent codes. I coded all interviews using MAXQDA 2020 qualitative software (VERBI Software 2019). While coding interview transcripts, I wrote extensive memos to identify and explore emerging themes. Analysis of text segments coded with the 'HIV stigma' code revealed clear patterns of social behaviors and interactions. Men's narratives illuminated the ways in which the HIV stigmatization process functioned in their communities. To answer the research question on how HIV stigma is produced and reproduced at the intrapersonal, interpersonal, community, and structural levels, the current analysis focused on the following codes, from which a theory of an ongoing process of HIV stigmatization emerged: HIV stigma; HIV silence; gossip; fear; euphemisms for HIV; pre-diagnosis HIV attitudes; sex education; and HIV criminalization.

RESULTS

Men in this sample ranged in age from 18 – 56 years old (M=35.21) and had been living with HIV for an average of 10.33 years (R=4 mos – 32.5 yrs). Twenty-eight men were born and grew up in the Baton Rouge Metropolitan Area. Two-thirds (66%) had at least some college education, and the majority were employed full-time. A large majority (83%) identified as gay/homosexual; the other 17% identified as bisexual, same gender loving, or fluid. At the time of their interviews, all men reported being on treatment and having an undetectable viral load, and three had received an AIDS diagnosis at some point since they had been living with HIV.

Analyzing men's narratives regarding the treatment of HIV and people living with HIV, in their community, revealed an interconnected and interdependent set of processes at several levels making up an ongoing process of HIV stigmatization (Figure 1). These included: 1) Social Interactions – silence, euphemism, and gossip; 2) Individual – witnessed and experienced marginalization; 3) Community Interactions – a process of (mis)education; and 4) Social Institutions – laws and policies carried out within the education and criminal justice systems. Each of these represent one component of a process that is ongoing, with each component relying to some extent on the others to perform its role in the process. A theoretical model representing this process and the relationships between the components is shown in Figure 1. In the results that follow, I describe each component and its role in the process of producing and reproducing HIV stigma. The participant that provided each representative quote is identified by a pseudonym, his age, and the number of years he had been living with HIV at the time of the interview (e.g., Martin (30; 4)).

Social Interactions: Silence, Euphemism, and Gossip

Men's narratives depicted a symbiosis between silence, the use of euphemisms for HIV, and gossip. These functioned together to structure an environment in which HIV is not to be discussed, save for its use as a tool of shame and social control. Existing levels of HIV stigma in the community provided the foundation for these interconnected social actions, and their uptake served to perpetuate the stigmatization process. Each featured prominently in men's narratives, which described a general practice of silence in their families and communities, and when HIV was discussed, it was often cloaked in euphemistic terms that allowed the virus to remain unnamed. Euphemisms did not stand out as a prominent discrete subtheme. Instead, as illustrated in the following, these euphemisms for HIV (e.g., “situation,” “that shit,” “that gangsta,” “the stuff”) feature prominently and are woven throughout narratives of silence and gossip.

Silence

Several men described the role of silence around HIV in their families. This was true for men who had disclosed their diagnosis as well as those who had not. Tyrone’s (35; 14) family was supportive after his disclosed his diagnoses. Though, HIV was not a comfortable topic of discussion. After learning for the first time that his viral load was undetectable, he felt “blessed” and was excited to tell his mother. She responded, “‘shhh. Don’t talk about that so much.’ She felt that it was a parent-son thing that not everyone should know about.” As was clear in the narratives of several men, discussing details of HIV was not comfortable for them or their family members, even when those family members were aware of their status. Shawn (42; 14) described that he does talk to his grandmother about his health: “we talk about it all the time, as far as my health-wise. But she really doesn't *really* talk about it. We don't really talk about it in depth.”

To be sure, some men preferred not to talk about HIV with their families, generally speaking, or specific members of their families. For example, Kyle (55; 27) described having told his sisters about his diagnosis many years ago. However, it is something that they do not discuss, and have never discussed. I asked what it was like to have his family never discuss his health. “It's fine with me. It's very good with me because that doesn't define me as a person. It's just something we don't talk about.” Similarly, after disclosing to his cousin, Jamar (32; 9) described that they “had the understanding, we knew, we just never talked about it again.”

Men also described that, outside of their families, HIV is largely a topic that is not to be discussed. Some men felt this was because HIV is seen as something that only affects other people. As Darius (23; 4) described, “I feel like if you're not affected by it, or if anybody in your family is not affected by it, most people here aren't concerned. If it doesn't concern them, they don't care.” Tyrone (35; 14) suggested that there are two options around HIV in the community – either one does not speak of HIV at all, or one speaks of it only using stigmatizing euphemisms.

> In Baton Rouge I don't think people really talk about it like that. I've heard people talk about it, they talk about it, like “that shit” or “that gangsta”, they talk about it like that still… I don't think people talk about HIV… Not even in general… just a regular gay person? Probably so because it's a gay culture thing. But a straight person, probably not because it's been a part of our culture since the beginning of time, even though it's not a gay disease. It's just weird because it's been a part of our culture. The people in Baton Rouge, it's a part of their culture too.

He further highlights what he sees as a perceived cultural separation between heterosexual and gay communities in terms of living with HIV. For the heterosexual community, HIV is seen as only affecting gay men and, therefore, there is no need for them to discuss it.

Others highlighted the role of existing stigma in preventing education about HIV and discussing it openly.

> We didn't hear about it at [college] ... You know? It was nothing. It was like no one to model yourself after. There was nobody. There was no nothing. HIV was just this unspoken truth that carried a whole lot of bad shit with it. You know?... There's still the stigma. They're still living in that stigmatizing, demeaning world with HIV of what TV and the public portrays it to be opposed to what science tells you. (Jonathan, 32; 11)

Two other men explained why they believe it is a taboo subject. "… if they do talk about it, it's negative… Because, I don't know, I guess it's a subconscious thing with people, because it has this big, negative look on it… so people just don't like to deal with that. (Nathan, 30; 1)

> Everybody's just walking around like zombies to me because they're like ... They know we're up here, statistically, but they're like, 'It don't affect me.' You know? Go walking around like it doesn't affect them…
>
> *Interviewer: Yeah. So, people don't ... Do people talk about HIV?*
>
> Hell, no… They're afraid. They are afraid. They are afraid. (Kyle, 55; 27)

When it comes to disclosure, some men described a culture of just keeping a positive diagnosis to oneself. "They hide it down here… It's like, they don't tell. They don't tell you…To cover their ass? I really don't know. (Bryce, 18; 4 mos)

As each of these men describe, HIV is largely treated as a topic that should not be discussed, and conversations about it come with great social risk in the community. Indeed, even in the context of our interviews, the word HIV was rarely uttered by most participants, illustrating that they were in the practice of talking about HIV using euphemisms in place of the letters.

Another way in which silence functioned as a tool of stigma was illustrated by men who described their own silent reactions in the face of stigma, as a way of protecting themselves. Chance (34; 2) described what it is like for him to hear negative conversations about stigma in his community.

> I hate it man, it makes me want to go into a shell. It makes me feel like there's an elephant in the room. Especially being at the barber shop and places like that, and they bring up these conversations, and they end up talking about HIV or it ends up coming up

> somewhere. People start talking in a negative way it makes you feel like the elephant in the room because I'm living with this every day, but I can't just bust out and tell you all that I'm living with this, and I'm beating this. I'm fighting. I'm undetectable, my numbers look good, and I don't have to do nothing but wake up and take these two pills every day. It could be anywhere, in conversation with somebody at the bus stop, hearing other people on the bus in conversation, or just in the grocery store, anywhere people tend to have these conversations, even around my homegirls and stuff like that. I got one homegirl she was mad with her baby daddy, and she made a joke, 'I wish I could find a guy who got that shit because I would pay him to bite him.' I was like girl what?
>
> *Interviewer: How do you respond to stuff like that?*
>
> Chance: You don't, you get quiet because I don't want to say too much…. I get quiet and just back the hell away from the situation.

Chance illustrates not only what it feels like for him to hear these negative things as a person living with HIV, but also the difficulty in challenging stigma as it could place him at greater social risk.

Similarly, when I asked Eugene (45; 17) how he responds to hearing negative comments about HIV, he responded,

> ... when I hear people say that stuff? I don't react because that's their life. I mean, I don't react at all. I don't feel the need or see the notion to react because it's... I mean, you're going to run into that. You're going to have those problems, so I just don't react.

And Bryce (18; 4 mos) described that, "I don't entertain it. I just go on with business. It's not my conversation. Just step away." When I asked him what he believed would happen if he were to speak up to challenge the negative things he heard, he responded: "Rumors, that's how they spread. Rumors from 'Oh, he's the sweetest thing, now he got it.'" For these men, silence is an act of self-protection and a strategy of resilience. Challenging stigma comes with social risks that they have determined to be too high of a cost. In this way, stigma self-perpetuates, as one social process of stigmatization – rumor and stigmatizing language – activates another process – silence.

Gossip

In contrast to men's narratives of silence, men described social interactions in which discussions of HIV in their community were largely centered around rumor and gossip. When I asked what they hear being said about HIV in the community, nearly every participant described negative talk about people living with HIV. Noah (27; 8) described previously thinking HIV was "a disgusting disease." When I asked where he learned to think about HIV in that way, he said "It was just a group of friends talking… They were saying like, 'Oh he got this shit,' and all that." These euphemisms were prominent in men's descriptions of the kinds of gossip they hear about HIV. David (43; 14) explained that he hears a mix of positive and negative.

> I have a neighbor; she says things like 'My son has HIV and he's doing great, and it doesn't really affect him.' But there's other people around who are like 'Oh, that one from around the corner, he got that stuff. He got HIV, stay away from him.'

Being seen seeking care was often the genesis of gossip about one's status. As Louis (57; 14) described, "Some people they hear, 'Oh, I heard that he was at the clinic the other day, so that mean he has HIV.' And that doesn't mean that they have HIV, but you're being frowned upon because somebody said it…" And as Brian (35; 10) explained,

> a lot of people don't want everybody to know, because people like to talk, like to expose. People just be afraid to open up. The first time going to the doctor, to the clinic, I was

> shocked when I walked into that room. Because I'm like, damn, I don't want nobody to know that I have HIV and most places like on [X] street, when you go on that block, they know that certain area that's for HIV people. Once you hit that block and everybody look... or somebody at the urgent care side, they looking like, "Damn, I didn't know that person had such and such."

A number of men described ways that an HIV positive status could be weaponized in the community. For example, Jamar (32; 9) described that it is common for people to be accepting and supportive until you "piss them off tomorrow and then now all your business out on the street." Steven (28; 6 mos) and his partner are both living with HIV. Though he had not yet disclosed his diagnosis to his family. When they were having a conflict, his partner disclosed his status to his family to get back at him. "I didn't tell my family that I had HIV. [My partner] did. He told them out of anger and stuff like that because he was mad." Michael (48; 16) described trusting people he wanted to date, who then disclosed his status to others.

> I [would] find somebody that I really like. You're investing time into getting to know them. You getting all these feelings. You getting worked up because you find somebody and you really like them. You know what I mean, when you finally disclose, then they're the ones that's going to go out there. They're going to spread your business, too. It's not just to one person. It's going to be a whole group of people.

Further, Keith (29; 6) explained how one's social status shifts once they are diagnosed:

> When a person is diagnosed, they become ... to the person from the outside looking in, they become the person that's spreading it. No one knows what goes on behind closed doors but when it comes out, and the people here have this thing about exposing people.

As illustrated above by Chance, Eugene, and Bryce, men often "just get quiet" when they hear gossip about HIV to avoid becoming a target. Thus, this culture of rumor and gossip not only furthers the stigmatization of HIV, but also serves to reinforce more silence around HIV.

Witnessing and Experiencing Acts of Marginalization

At the individual level, one of the most salient themes in men's stigma narratives was that many of them had developed their understanding of what HIV meant in their families and communities by witnessing and experiencing acts of marginalization. These experiences reinforced the belief that people with HIV were bad and risky to be around, both in terms of their potential to transmit the virus, as well as the likely damage that will be done to one's own social standing. Steven's (28; 6 mos) mother had been diagnosed with HIV years before his own diagnosis. He described the way his siblings treated her after she was diagnosed.

> …my sisters, they kind of kept they distance and they were treating her kind of bad. Like my other sister actually didn't want my mom inside the house. [My sister] used to sleep in the garage and stuff like that... it's like they were treating her awful, you know what I'm saying? I'm saying like 'damn… like she got this, and this is the way they treating her.' Like, 'damn, if I get this, it make me feel like y'all gonna treat me like that!'

For Steven, watching the way his siblings treated his mom was instructive – it taught him that having HIV was bad and resulted in being alienated by others, even those closest to you.

Similarly, Marcus (27; 4) described witnessing the poor treatment of PLWH: "I've seen where people be actually telling people, 'Get away from me. You got that shit,' like, just crazy stuff." When I asked him if he thought he would be treated that way if people knew he was living with HIV, he responded, "Oh, I know I would if I said it." Nathan (30;1) described watching his family members interact with people they believed to have HIV.

> The people in my family, they kind of treat HIV like COVID-19… I have watched them, how they have treated other people that they thought they had HIV. They was very cautious… they cleaned up behind those people at all times. People would use the bathroom, they was right behind the people cleaning it. Shit like that. I watched this stuff happen. In my head, it's like, I don't want to go through that.

Importantly, as Nathan states clearly, watching people be treated this way left a clear impression and the expectation that people would treat him similarly.

Rodney (56; 33) was diagnosed in 1987 and had witnessed the worst days of the epidemic. During the early 1980s, he was caring for his partner who had been diagnosed with AIDS.

> He had cancer, whatever, you could tell. You know a person that has AIDS, you know that type. [My aunt] wanted me to come over and mow grass, but I was taking care of him at the time. I said, 'Well you'll have to come lay in the bed,' because he was almost dead. [My cousin] said, 'Oh no [Rodney], I don't want nobody… He can't lay in the bed,' That that was one experience that kind of tripped me out. Or people thinking you can catch it from laying in a bed or something. People was like that back then… it just stayed that way with me. I just, and I think that's how it all really began. People were scared of you.

The way people were treated back then was etched into his memory, and at the time of his interview, in 2019, he still feared being labeled with "gay and AIDS." He believes that he will be treated a certain way and held tightly to those stigmatizing ideas. He was so committed to secrecy around his status that he hoped not to have a prolonged illness at the end of life so that no one would ever know. "I just hope I drop dead."

Others described experiencing these marginalizing social interactions when the negative treatment was directed at them personally. Shawn (42; 14) described how his friends reacted and how it impacted him long term.

> My trust level is off. I don't trust a lot of people. I'm not going to come to a lot of people. I'm not going to trust a lot of people with my business because of what I experienced dealing with HIV… my classmates at school knew I had HIV, and they got scared of me. People wouldn't talk to me. That affected me. So, I learned not to let people get too close. But I also learned that people will let you down as well... [they were] scared to touch me, and thought I was going to infect them, and stuff like that.

Several men had experienced family members treating them as though they feared them, including not wanting them in the house, or bleaching household items they used (see chapter 2). As Michael (48; 16) explained: “You had your own families that were serving you with plastic plates and stuff like that.” When I asked if he was describing his own family, he responded, “Right. They were buying certain products to make sure and clean the toilet. It was bad.”

In some cases, the marginalization of HIV was performed by celebrating the idea of being HIV negative. For example, when Darius (23; 4) was diagnosed, he was worried about telling his friends because he previously had another sexually transmitted infection that required several treatments. When he told his friends about that diagnosis and treatment, their responses were “Well you know, thank God it's not ‘that.’" He described it as “heartbreaking… when I actually had to come back and tell them, ‘Well, it is.’" Walter (29; 6) had been increasingly ill with no confirmed cause. His coworkers and boss were aware that he had been having health problems. He finally received an HIV diagnosis at his doctor’s office in the middle of his workday. When he returned,

> I clocked back in, went to my boss and she was like, ‘Okay, so it's not HIV?’ was the first thing she said. And I was like, no, it's not. And so, she gave me like a high five and a hug and everything and I was just like, oh my God, how am I supposed to tell these people? I don't know why there was so much riding on it not being HIV.

Walter’s and Darius’ experiences illustrate how the messages conveyed by celebrating *not* having HIV are similar to those conveyed by explicitly negative statements about HIV.

Community (Mis)Education

At the level of community interactions, word of mouth communications were key in disseminating erroneous and stigmatizing information about HIV. This form of (mis)education, particularly given the lack of formal education (which I discuss in the next section), shapes a belief that one should avoid people with HIV and, if diagnosed with HIV, one should not expect to live much longer. James (27; 8) described that he had learned “nothing about how [HIV] works; more that it was bad. It was something that you don't want to do, you don't want to have. It was like a death sentence. It was like it was over with.” Similarly, Trey (37; 16) said he believed his life was over when he was diagnosed, “because that's just the stigma with AIDS. You get AIDS, you die. That's all I knew. That's all I ever was told.” The narrative that HIV = death had a particularly negative impact on Sam (32; 7).

> From what I had known about it, AIDS was deadly, it was the worst thing to ever happen for anybody. There's no cure for it. You get down, your immune system starts to shut down, your body starts to shut down and you just become a vegetable, and then you just die… I didn't want any of my family members to see me like that… And then I didn't want to have to go through the fact of people just knowing that I had it…

Sam had considered suicide immediately after receiving his diagnosis, because he did not want to put his family through the horrible demise that he expected for himself.

When I asked Marcus (27; 4) where he got the idea that HIV was a death sentence, he replied, “my circle that I was hanging with…So that's just how it was presented to me. ‘You going to die tomorrow if you got it.’” Some described other negative and inaccurate information. Eugene (45; 17) had been told, “You know you can catch that by them touching on you.” Walter’s only knowledge about HIV was from word of mouth. “If someone spits on you, you can get it from them. It's so much bad information out there and people believe it because it's just word of mouth or they heard it from somebody they trust.”

Nathan’s (30; 1) understanding of what it meant to have HIV was based on having heard that people with HIV are “sick, they dying, stuff like that at first... they say they dying, some people, they call them dead. ‘They dead,’ whatever, stuff like that.” After receiving his own HIV diagnosis, all those thoughts shaped his outlook on his future. These inaccurate perceptions didn’t simply exist in the minds of people in their communities. They were being actively transmitted. Importantly, the spreading of such ideas contributes to the silence and gossip that was so prevalent in men’s narratives, illustrating how interactions at various levels intersect furthering the HIV stigma process.

This (mis)education is, in large part, driven by stigma and, at the same time, stigma stands as a barrier to HIV education. From Steven’s (28; 6 mos) perspective, HIV stigma “detours them away from actually wanting to know more about it…” Louis (57; 14) explained:

> I think there's still a lot of ignorance here in Baton Rouge, when it comes down to HIV. And sometimes, I just feel like people, they just have a one-track mind and that's what they learned and what they first heard about HIV is what they will retain. Then they don't

> broaden their knowledge scientifically or none of that. They just feel, 'Oh well. I know such and such died of HIV.' So, they think everybody who has it is going to die of HIV.

Chance (34; 2) wished "people get [the stigma] out their heads. If they were more educated about it but you can't make someone learn something they don't want to learn. Some people just got stuck in their ways."

As Louis and Chance both illustrate, the stigmatizing ideas that people learned earlier in the epidemic were cemented in the minds of some people who are unwilling to learn about HIV or believe it isn't relevant to their lives. As Walter (29; 6) explained:

> I feel like a lot of people don't do a lot of research on their own about it because they just feel like, "Oh, it's never going to happen to me." Or this and that, and then they just hold onto those negative stereotypes without having done any research to dispel them or to put themselves in situations where they can speak to people with it and know that this is not something like, it's not a death sentence…

Social Institutions: Public Education and Criminal Justice

Sex Education

Reflecting the embeddedness of structural HIV stigma and heteronormativity within state and local sex education policies, most men described learning very little about HIV, and nothing about non-heterosexual sex. These policies reflect deeply embedded stigma that creates an environment in which gay and bisexual men are not equipped with the information they need to protect themselves. Jamar (32; 9) pointed specifically to the impact of the lack of comprehensive sex education.

> There was never a thought. [HIV] was never brought up in school, which they have sex education, but I don't think they… yeah, they got into STDs, but they never got into HIV

> or AIDS or anything like that. Never. Now that I look back, I'm like, we were doomed from day one.

Charles (26; 6) explained that he had a similar experience:

> They didn't, actually come to think, like they didn't touch on it. The base that they touched on was how to put on a condom and pregnancy. That's all they touched on, was pregnancy. It's like they skipped out over all the diseases and just with like pregnancy and condoms and how to put on the condom. That's about all the Sex Ed that was given.

As Jamar and Charles explain, the topic of HIV was left unaddressed.

Several men described the lack of information they received that was relevant to non-heterosexual behavior, and the ways HIV stigma and homophobia intersected in these classes. For example, when I asked Carl (39; 20) if he learned anything about gay sexuality and HIV, he responded, “Oh, not at all, no. That was not even a subject. It just pretty much talked about the basic STDs and how you make a baby and how the sperm and egg, all that kind of stuff, the basics.” Similarly, Brian (35; 10) explained:

> I know when I was in high school and in the health book, they had HIV… they had AIDS and all that in the health book, but this is stuff that wasn't talked about. I can only talk about going to [high school] in my club when we was required to pass health. This is areas that didn't get discussed… Everything from been getting a baby, parenthood, all that was being discussed. In the health book that got skipped over, HIV always got skipped over. Even sex, you'll do how to make a baby, but after that it was no consequences behind it. That got skipped over… I felt like if I had known about that in high school or if my parents would have sit down and really talked to me and said that we

> accept the fact that you're gay. I felt like if I had knew that more about it, then I could have been more protected for myself.

For Sam (32; 7), the intersection of HIV stigma and homophobia were more explicit.

> I remember being educated in school, and just in high school they taught sex education for a little while. [The teacher] was telling us about AIDS, syphilis, gonorrhea and all that stuff. And he was like, AIDS is deadly. He thought it was a gay person disease. He said gay people brought it over here. I felt like it was a bad thing.

As Carl, Brian, and Sam illustrate, there was both a lack of information about HIV, a focus on conception, but he no information relevant to their sexuality. Further, like Jamar, Brian highlights how this lack of information left him unprepared to protect himself.

HIV Criminal Law

Just over half of men had ever heard of HIV nondisclosure criminal laws. Though in most cases their knowledge of those criminal statutes was limited. Several participants learned about HIV disclosure criminal laws from news reports of criminal cases. "I think it was an article or something about it, where somebody had got intent to distribute AIDS, or something like that. And I read an article about it." (Trey, 37; 16) Similarly, David (43; 14) also said he knew about HIV criminal laws "from the news, I found that out." And Eugene (45; 17) had:

> mostly seen a lot of news and things like that. People also had it and do not tell somebody, and end up sleeping with them or whatever, whatnot, and giving it to them.
>
> I've actually seen people go to jail for actually giving it to them, giving it to other people.

Importantly, several media analyses have shown that reporting on these cases serves to further stigmatize HIV and PLWH, and to regularly employ homophobic and racialized tropes when discussing defendants (Campbell, Rojo, Khanna et al. 2020, Persson and Newman 2008, Shevory

2004). In each of these quotes from Trey, David, and Eugene, there is stigmatizing language used in describing these laws (e.g., “distribute AIDS”; “giving it to them”). Further, David went on to describe what he believed these laws meant for him. “…it means whether I feel comfortable about it or not that I need to make sure I [disclose] for legal reasons.”

Noah (27; 8) first heard about nondisclosure laws when someone from the public health department called him, after his diagnosis, to inquire about partners that may need to be notified. I asked him what he thought when he heard about them and he simply responded, “scary! I mean they shouldn't take people to jail for not telling people that they have HIV.” Nearly all men who were aware of these laws agreed with Noah that criminal punishment was unfair to PLWH. Keith’s (29; 6) concerns about the effects of these laws highlights their stigmatizing and oppressive nature.

> …for the person who was raped, for the person who was born with [HIV] – so I'm born into a world where I have to tell everybody this or I go to jail, but I was born with this. I didn't contract this; I didn't go out there and just get it. I was born with this. I was born into a world ... I can't love anyone just to love them. I always have this hanging over my head that I can go to jail if I don't say this.

His concern about having your status “hanging over your head” illustrates the way that PLWH are burdened by these laws, and fear what could happen to them if they don’t meet the societal and legal expectations.

In addition, the existence of these criminal disclosure laws can also be used as a weapon against PLWH. A number of men described ways the laws have been used against themselves or others. During his interview, Rodney (56; 33) was cautious in discussing his status and his experience of these laws. He believes that he has been targeted and set up to be arrested under criminal nondisclosure statutes.

> Probably about three years ago. I met somebody online and it was a very, very, very sexual conversation about what we was going to do to each other… I went to the hotel to meet him… Then he said he was over across by the bank [in the same parking lot]. 'I'm just standing by the dumpster over there. Come meet me over there.' So, I pulled in there and I saw a person standing back there all dark color. I said something ain't right about this, so I hurried up and backed out. And then I saw some other people… So, I feel it's some type of set up. Then after that I got phone calls that I was going to get arrested and all kinds of stuff. That I was passing AIDS around and just all kinds. They had my license plate number and called me and said I was going to get arrested and all kinds of stuff. It was a set up.

Importantly, Rodney had never met this man before and did not end up meeting him, as he describes. Nontheless, these phone calls and threats terrified him and caused him to stay home and not meet new people for several months.

Shawn (42; 14) explained that he knew other people who have been threatened with these laws.

> I've had people around me, or friends that I know that have been threatened about not disclosing status and things like that. So, yeah, I've heard that… Maybe that's part of some of the reason why I don't tell certain people that I'm not close to about me being positive… because not everyone has good intentions. I've learned over the years, not a lot have good intentions when you tell them certain things. That's why I'm not very open to

> everyone about me being positive… I think [the laws are] silly. I think it's more a deterrent to keep people from being more open about it.

Shawn's concerns were realized for one of Carl's (39; 20) friends.

> I have friend of mine who was in a contentious relationship with someone. He told his partner his status and everything. And they broke up, and he lied and said he didn't tell him. And he went to jail for that for a little while.

Others lived with the fear that someone could use their status against them because these laws exist. The potential to be arrested or the invocation of nondisclosure laws as a threat decreases the likelihood of disclosure and more open discussion around HIV. Walter (29; 6) explained, clearly, how he believed nondisclosure laws were a barrier to better communication about HIV.

> I feel like HIV criminalization pushes us so far back in reference to how much we've grown and how much we've sacrificed to get to the point where we can actually have conversations about it, openly without ramifications. I do feel like the criminalization does add a fear factor back to things, especially for those that are positive because in the court of law as I see it, it's our word versus their word. And the law system has tended to take their side more often than not. And proving that you have disclosed is a very difficult thing to do in court and to show that you did not have the intent to transmit the virus to anyone else is again very subjective… I get the intent of the law to make people disclose cause I would hate for someone to knowingly transmit the virus to somebody else on purpose… But I don't know if the laws they have in place protect those people who are positive and protect those that are not. Right now, I feel like it's just protecting those people who are not positive.

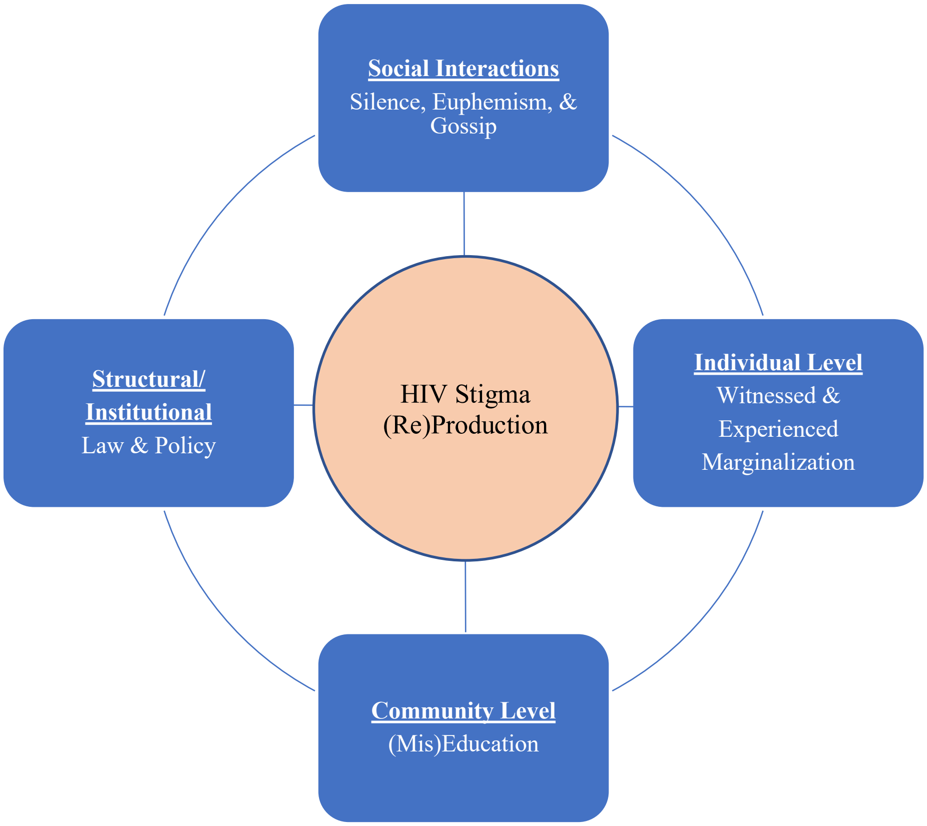

Figure 4.1: Model of Ongoing Process of HIV Stigmatization

DISCUSSION

In the current analysis, I examined the social relations through which the process of stigmatizing HIV occurs. Men described that HIV is a topic largely left unspoken in their communities and families, and when it is discussed, it is normally in the form of gossip using euphemistic terms for HIV. Misinformation about HIV is spread through community level interactions, while social institutions further stigmatize HIV by criminalizing non-disclosure and restricting formal education about sexuality and HIV in the classroom. To date, our understanding of HIV stigma has described these social interactions as manifestations of stigma and have focused on cognitive measures of HIV stigma's impact on individuals (Earnshaw et al. 2013). The narratives of men in this study suggest that these are not simply how HIV stigma is manifested. Instead, they are critical aspects of the ongoing and ever-changing social process of stigmatizing HIV. Framing HIV stigma in this way shifts the focus from perceived, enacted, and anticipated stigma as stigma mechanisms, which only allow for individual-level intervention, to the interactions and processes at multiple levels of social world. Thus, my findings push beyond the individual level to include the levels of social institutions, social interactions, and community; and highlight the ways in which the social processes at these various levels work together to produce and reproduce HIV stigma.

Public health studies have provided much evidence of the negative effects of HIV stigma on mental health, retention in HIV care and clinical outcomes, disclosure, and sexual behavior (e.g., Balaji et al. 2017, Bird et al. 2017, Eaton et al. 2018, Overstreet et al. 2013, Quinn et al. 2017). Though, a sociological analysis allows for an emphasis on the ways that the realities of the social world come from “thoughts and actions, and is maintained as real by these” (Berger and Luckmann 1966:20). The grounded theory resulting from this analysis provides a model of HIV stigma that centers actions, interactions, and structures from which HIV stigma originates and through which it is reproduced. Importantly, each component of this stigma process interacts with, and is somewhat dependent on the others. For example, community (mis)education processes persists in part because of the lack of formal education about HIV and sexuality in the East Baton Rouge school system (East Baton Rouge Parish School Board 2019, SIECUS 2018). That lack of education about HIV perpetuates silence around HIV (Gwadz, Leonard, Honig et al. 2018), as does the fear of HIV criminalization. These findings are in line with several other authors who describe the ways that HIV criminal laws perpetuate HIV stigma (Burris and Cameron 2008, Cameron 2009, Federman, Holmes and Tremblay 2011, Hoppe 2017, Jürgens, Cohen, Cameron et al. 2009, Kane and Mason 2001). Further, the acts of marginalization that men witnessed or experienced result from community (mis)education, silence, and gossip; and the lessons learned from these experiences sustain as there no formal HIV and sex education to counter the beliefs that undergird this mistreatment.

This study has limitations worth noting. First, findings should be seen in as representing a convenience sample of Black gay and bisexual men in the Deep South region of the United States. Thus, the theory of an HIV stigma process is one that emerged from that particular context and would likely differ in samples of different demographic groups in different geographic regions. Additional research needs to be conducted to explore the stigma process in other social contexts. Second, HIV status was self-reported and not confirmed through testing or documentation.

Important implications emerge from these findings. First, framing HIV stigma as an ongoing process embedded in social interactions and institutions provides new spaces in which to intervene. Efforts to reduce stigma that focus exclusively on individual beliefs and attitudes are critical, though they do not address interconnected social processes. It is not necessary for individual people to engage in stigmatizing behavior toward PLWH to be participants in the process of stigmatizing HIV. "We are all enmeshed in a complex web of problematic relationships that grant our mirror images full human subjectivity while stereotyping and objectifying those most different from ourselves" (Collins 2016:36).

However, in the US, stigma interventions overwhelmingly focus on the interpersonal and intrapersonal levels, and there is a dearth of community-level stigma intervention research (Rao, Elshafei, Nguyen et al. 2019, Stangl et al. 2013). Existing community-level interventions have largely extended strategies used at the individual-level (e.g., building empathy, providing correct information about HIV, teaching about the negative effects of stigma) to the community (e.g., Frye, Paige, Gordon et al. 2017, Frye, Paige, Gordon et al. 2019, Payne-Foster, Bradley, Aduloju-Ajijola et al. 2018) Indeed, as these findings illustrate, some members of men's families, and social networks actively participated in marginalizing behaviors. Though, as important are others who simply remain quiet or encourage silence, but see PLWH as "other," and likely fail to recognize their role in the HIV stigma process.

Second, the role of institutions is largely absent from HIV stigma research and intervention. Men's narratives point to not only stigmatizing behavior by individual people but highlight the critical role of HIV criminal laws and sex education policies. Intervening at the structural level is crucial to disrupting processes such as community (mis) education, and the silence and fear that men describe because of draconian HIV nondisclosure statutes. Lastly, it is worth restating that HIV stigma is not a "static attitude" but a "constantly changing (and often resisted) social process" (Parker and Aggleton 2003:14). Thus, quantitative measures, thus far, have failed to capture the reality that HIV stigma means something different in each place and to each person depending on the social context, and that it is continuously being produced. Future HIV stigma interventions must include strategies that aim to interrupt the social processes through which it is reproduced.

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CHAPTER 5: Conclusion

In this dissertation, I explored HIV status disclosure among a group of Black gay, bisexual, fluid, and same gender loving men in Baton Rouge Louisiana. This work was informed by medical sociology, sociology of emotions, stigma theory, sociology of the Black family, Black feminism, and intersectionality, allowing for multiple ways of framing questions about men's disclosure experiences. Throughout this study, I critiqued and challenged public health framings of HIV status disclosure by removing from the equation the taken for granted associations between disclosure and sexual risk behaviors, psychological distress, and social support, among other variables. Instead, I centered men's experiences and took a neutral position on the question of disclosure – that disclosure and nondisclosure are equally valid, agentic choices for BGBM-LWH. This contrasts with much of the public health literature on disclosure which privileges disclosure over nondisclosure and intervenes to increase disclosure. In this study, I have shared men's narratives with a particular focus on the structural, social, and environmental realities that shape their lived experiences and the HIV disclosure/nondisclosure process.

Key Findings, Implications, and Contributions

In *chapter 2*, I reframe HIV disclosure as a source of biographical disruption. Previous research has described the potential negative consequences of disclosure including losing friends, being insulted, being rejected by family, experiencing violence, having people avoid them and exclude them from social events, and being rejected by potential intimate partners (Courtenay–Quirk, Wolitski, Parsons et al. 2006, Evangeli and Wroe 2017, Gielen, Fogarty, O'Campo et al. 2000, Simoni and Pantalone 2004, Vanable, Carey, Blair et al. 2006). Though, these studies have framed consequences as discreet (though sometimes repeated) events. By employing Bury's theory of biological disruption (Bury 1982), I argue that disclosure experiences, and their outcomes, are embedded within the full context of one's life and biography, and cannot be analyzed as stand-alone events.

I identified two main themes: preceding disruptions and disclosure-related disruptions. Preceding disruptions included surviving childhood sexual abuse (CSA), coming out as gay or bisexual, and receiving an HIV diagnosis. These were crucial to understanding men's HIV disclosure narratives, as these previous biographical disruptions had long-term impacts on how men saw themselves, their relationships, and how they engaged in the social world. These also played a major role in shaping their disclosure experiences. In some cases, men contracted HIV through CSA, which meant that disclosing an HIV positive status was retraumatizing and raised questions about the source of their infection that they were uncomfortable answering. In others, HIV disclosure confirmed warnings from parents and others, after they came out, that being gay meant that they would "get AIDS". Disclosure-related disruptions included: 1) discredited definitions of self when, for example, family members acted as though they were afraid by disinfecting things they touched, and not wanting them to sleep in the house; 2) Disrupted familial and social networks, and support systems; and 3) loss of jobs or housing. Importantly, I also emphasize the intersectional and structural nature of these disruptions and argue that these must be seen, not as discreet negative experiences, but as disruptions to their lives with lasting implications for their biographies.

These findings expand on sociological theories of illness, the self, and biographical disruption by centering the moment at which others become aware of the chronic illness diagnosis. This acknowledges that, at this stage of the HIV epidemic, HIV itself is not necessarily the reason for a disrupted biography. While Tewksbury and McGaughey (1998), were the first to identify HIV disclosure as a source of biographical disruption, their work focuses on how disclosure alters how others see PLWH, and how PLWH sees themselves. I expand on their work by elucidating not only the effects on self and identity, but also extending the theory to apply to the social and structural consequences of disclosure. Further, I show how structural inequities such as racial economic oppression, heterosexism, HIV stigma, and racial oppression constitute the social environment and social relations in which disclosure decision making, experiences, and outcomes occur.

My application of the biographical disruption framework makes an important contribution to the public health literature. Previous work hasn't adequately accounted for the ways in which these experiences can interrupt one's life trajectory and have long-lasting effects. Importantly, for some men, the positive outcomes of disclosure like social support, for example, were ultimately short lived. Several existing disclosure interventions aim to assist PLWH in considering possible reactions during the disclosure decision-making process. Though, in many cases, the longer-term negative outcomes cannot be predicted. Future HIV disclosure research should fully incorporate social and structural context and consider the long-term outcomes of disclosure, not only those that can be predicted and measured. This is an important shift in how we think about the risks of disclosure, as it acknowledges that those negative consequences may be more severe and impactful than has previously been appreciated.

Further, this paper responds to calls from S. Williams (2000) and others (e.g. Engman, 2019; M. Harris, 2009), for exploring the ways in which biographical disruption differs by demographic and cultural realities. My work does this and adds an intersectional lens to exploring the impacts of these differences. Intersectionality is increasingly being employed in public health. Though structural intersectionality which recognizes that people located at the intersections of race, class, and gender, have qualitatively different experiences (Crenshaw 1991), is largely missing in public health HIV research. In this chapter, I bring a structural intersectional approach to highlight the ways in which the experience of HIV disclosure and its consequences are constituted by men's social locations.

In *chapter 3*, I employ literature on the sociology of emotions and discuss the emotional aspects of HIV status disclosure. In contrast to the extant literature on disclosure and individual-level psychological measures, I frame the emotions associated with disclosure as socially constructed through healthism and personal responsibility narratives (Crawford 1980, Crawford 2006, Lupton 1995) community norms, familial and social relationships, structural inequities, and stigma. The ideology of personal responsibility and the imperative to maintain health led men to feel a sense of guilt and failure for contracting HIV. This created an emotional backdrop to disclosure in which disclosing to one's mother, for example, was burdened with the feeling of having let her down.

I describe how men had to perform emotion work (Hochschild 1979) on themselves in order to garner the courage to disclose their diagnosis, to hold back their emotional responses in order not to scare others. Others chose to disclose but not to discuss details or decided not to disclose because they felt that it was too much of an emotional burden for themselves or their loved ones. Men were willing to do this emotion work, in part, because they believed that they owed it to their families to inform them about their health. The collective nature of Black southern families is such that secrets about one's well-being are not common. Men also did emotion work on those to whom they disclosed by, for example, comforting them and telling them that everything would be ok, even when they didn't necessarily believe it. I argued in chapter 2 that disclosure and its outcomes cannot be seen as discrete events, and my findings suggest that neither can the emotional aspects of disclosure. I found that the emotion work continued long after disclosure, included managing the emotions resulting from some of the disruptions in chapter 2.

In calling on the sociology of emotions, I offer a new approach to understanding how emotions are constituted and managed before, during, and after disclosure experiences. Unsurprisingly, men in my study described experiencing many of the forms of psychological distress most commonly measured in public health research on disclosure (e.g., anxiety, depression). Though, this paper goes beyond these to elucidate the context that shapes their emotions and emotion work. This adds to the sociology of emotions literature and refocuses public health literature toward understanding not just whether people experience psychological distress and how it is associated with disclosure, but also what social and structural forces constitute their emotions.

Further, I extend the framework of healthism to include the ways that one should feel in addition to what they must do to be a moral, ethical, and healthy citizen. Healthism has typically centered the activities and behaviors that one is expected to engage in to remain healthy and to not be a threat to others. My findings suggest that healthism describes not only what gay and bisexual men must do to prevent HIV infection, but also how they should feel if they fail to meet those moral obligations. Feelings such as shame, guilt, and failure must be managed, in part because these emotions drive the need and the obligation to comfort others who express sadness once they learn of one’s diagnosis. This highlights that the emotions associated with disclosure are constituted by social context, and that context is what must be confronted in order to address the negative emotions that accompany disclosure.

In *chapter 4*, I developed a grounded theory of social processes through which HIV stigma is produced and reproduced. These findings center interactions and structures, in contrast to much research which focuses on individual, cognitive-level measures of stigma. Those individual-level understandings of stigma offer only the ability to intervene at the individual level, while my findings provide potential community and structural-level targets for intervention. The theory includes four components, each representing a different level of analysis. First, at the level of social interaction is the trio of *silence, euphemism, and gossip*. Men describe how, in their communities, HIV is not discussed openly and when it is talked about, it is in the form of gossip and euphemistic substitutes for HIV (e.g., 'that shit,' 'that stuff') are regularly used. Second, at the level of community interaction is *community (mis)education*, which describes the ways that incorrect or outdated information is spread through informal communication channels. Third, at the individual level, men described *witnessed or experienced acts of marginalization* through which they learned the social meanings of HIV – that PLWH should be avoided and that they are a threat to others, ideas that some later internalized about themselves. Lastly, at the institutional level, HIV stigma is reproduced through the existence and enforcement of HIV criminal nondisclosure statutes, and through the absence of formal sex and HIV education in the public school system. Important to the theory is that each of these components interacts with and is somewhat dependent on the others.

Men's narratives describing HIV stigma were illuminating, as it became clear during my data analysis process, that what was occurring was larger than individual level rejection and discrimination. During my interviews, I would ask men what kinds of things they heard about HIV in the community. In the words of one man, "What you mean? Negative things… come on. You know!" These stigma processes were so deeply embedded in their worlds, some responded as though it was unthinkable that I would need them to tell me. While there are many articles that describe similar stigma narratives as the men in my study, this paper builds from sociological literature framing stigma as a social process that is embedded in social and power relations and contributes a new structural and interactional analysis of the production and reproduction of HIV stigma.

These findings have significant implications for public health. To date HIV stigma interventions have aimed to reduce stigmatizing beliefs about PLWH and to reduce internalized stigma among PLWH. Similarly, community level interventions aim to shift beliefs and values at the community level using education to combat misinformation and contact with PLWH to encourage compassion and reduce fear. My findings suggest that, while changing beliefs and values is worthwhile, it is not enough to disrupt the exchange of misleading and stigmatizing information transmitted through community interactions. As men described, in some cases, their own friends and family members participated in these stigma processes while, simultaneously, loving them and offering some level of social support. Thus, it isn't necessary for one to consciously hold negative views of PLWH to participate in the process of reproducing HIV stigma.

Future HIV stigma interventions must go beyond individual cognitive measures of stigma and focus on the processes that can be the targets of community-level interventions. Further, approaching HIV stigma in this way complicates the associations between HIV stigma and clinical outcomes. Existing approaches assess levels of internalized or perceived stigma among PLWH, and whether they are associated with clinical outcomes. In my study, men described that community gossip can start after one is seen going to a clinic that others associate with HIV. It is not just the perception or anticipation of stigma, but an effort to prevent being the target of gossip that serves as a barrier to care. More upstream public health interventions focused on structure and interrupting the community interactions that reproduce stigma should accompany – and may potentially prevent the need for – interventions to *reduce* stigma at the individual level.

This dissertation builds on an interdisciplinary body of literature on the experience of living with HIV, HIV status disclosure, and HIV stigma. Each of these papers engages with sociology and public health, specifically, and aims to challenge some of what we "know" about HIV disclosure. Few sociological studies have taken up the question of HIV status disclosure and none have done so with gay and bisexual men of color. My findings highlight the impacts of structural inequities on those with intersectional identities who are living with HIV. For example, while in recent years, the rate of new HIV diagnoses has been declining in Baton Rouge, the city's infection rate remains the fourth highest in the nation. Black gay and bisexual men account for the majority of new infections in the state of Louisiana (State of Louisiana Office of Public Health 2018). While individual-level prevention and care interventions alongside community-level anti-stigma efforts have some positive effects, there are several structural inequities that should be addressed in Baton Rouge.

The city is highly segregated by race (DeWitt and Frey 2018), and racial economic disparities are more pronounced than at the national level, with a White median household income that is nearly double the median household of Black households (Conduent Healthy Communities 2020). More than 70% of the students in the East Baton Rouge public school system are Black (Groeger, Walldman and Eads 2018), and within that school system there are strict limits on what can be taught to students about sexuality and limited information is provided about HIV (East Baton Rouge Parish School Board 2019, Louisiana Revised Statute §17:281(A)(3)). Each of these contributed to men's experiences living with and disclosing their

HIV positive status, including the nature of biographical disruptions, their emotions and emotion work, and the process of HIV stigma production. Additional work on the HIV epidemic is needed by sociologists who study social inequality to help elucidate more of the roles of social and structural processes in driving HIV infections among marginalized communities at intersectional social locations. This work would provide critical knowledge that can be used to address the needs of Black gay and bisexual men, particularly those who live in communities with high levels of homophobia and HIV stigma, like Baton Rouge and other areas of the Deep South.

Future Research Directions/ Next Steps

When I first conceived of this project, my understanding of HIV disclosure and HIV stigma were heavily shaped by my work in public health and my knowledge of public health research on HIV, HIV stigma, and HIV disclosure. The more sociological approach of this dissertation shifted my focus toward more structural concerns, and the results of the data analysis have raised several additional questions and areas of research. I would be interested in furthering my work on understanding HIV stigma processes and exploring the feasibility of a quantitative measure of an HIV stigma process that focuses on structures and interactions, instead of individual perceptions of stigma. I would also be interested in continuing to explore the ways in which one's life can be disrupted by the various aspects of the illness experience, particularly for those with a stigmatized condition.

I plan to publish each substantive chapter of this dissertation in peer reviewed academic journals. Chapter 2 has been provisionally accepted for publication in *Social Science and Medicine,* with only minor suggested revisions and I plan to submit chapter 3 to *Sociology of Health & Illness.* I also plan to make an additional theoretical contribution to the healthism literature in an additional manuscript. In that paper, I will argue that expectations of disclosure by PLWH exemplifies how those who fail to maintain the boundary between healthy and unhealthy are subsequently burdened with a new set of behaviors that they must engage in to be healthy, moral citizens. Lastly, I will submit chapter 4 to AIDS and Behavior or the American Journal of Public Health.

I would like to expand on my dissertation research in the next 1-2 years by going beyond the city of Baton Rouge to other cities in the deep south. I want to focus more specifically on elucidating the roles of racism and other oppressions, and their intersections in the high rates of infection among BGBM and in the lived experiences of those who are living with HIV. This research will broaden the lens through which we explore the intersections of HIV, gender, sexual orientation, and race, and help to reframe the focus of interventions to reduce HIV infections. I would do this, in part, by using a life course perspective, allowing for an examination of the cumulative factors that increase vulnerability to HIV, beginning in childhood and continuing into adolescence and adulthood. I began to do this in my dissertation which provided important insights such as the impact of childhood sexual abuse and other traumas on their HIV related experiences. This research would also be grounded in geographically specific historical and present day racial, economic, and social realities.

Lastly, I plan to write a book based on my dissertation with the aim of giving honor and voice to my participants. The focus will be to provide a fuller picture of the BGBM men in my project. The hyper focus on sexual behavior in HIV research obscures much of what is contributing to infections among BGBM. In my dissertation, the factors that contributed to infections included: lack of HIV-knowledge due to stigma and sex education policies; childhood sexual abuse; grief, depression, and loneliness; unstable housing; poverty; and substance use. Interventions focused on sexual behavior modification would likely not have prevented these infections, especially since some contracted HIV when they were sexually abused as children, and a large majority contracted HIV within a few years of entering adulthood. I want the book to tell the story of these men’s lives – how strongly they identify with their families, religion, and culture; how the environment they live in is structured to systematically oppress them economically, politically, and spiritually. I want to tell the stories of their childhoods and lives, to illustrate that those who suffered trauma and those who had great childhoods both faced the same challenges when it came to being BGBM, and when it came to sexuality and HIV. And lastly, argue for a fundamental shift in the way we approach HIV.

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