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“Hiv Lives with Me”: An Intersectional Analysis of the Successful Navigation of Health Care Services by Sex Workers Living with HIV

Kierra Jones

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“HIV LIVES WITH ME”:
AN INTERSECTIONAL ANALYSIS OF THE SUCCESSFUL NAVIGATION OF HEALTH
CARE SERVICES BY SEX WORKERS LIVING WITH HIV

by

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ABSTRACT

Sex workers living with HIV are affected by pervasive stigma across various life domains because they are situated between two stigmatized identities—their HIV status and as someone who exchanges sexual services for pay. Prior research suggests that not only can stigma hinder attempts to initially access health care services, but it can also foster strained and unwelcoming environments. The purpose of the present study is to illuminate the voices and experiences of sex workers living with HIV as they navigate their specific health care needs. Using an intersectional lens, the aim of this study is to understand the health care experiences (i.e., decision making processes, navigation, and resources) of sex workers living with HIV, which may assist health researchers and practitioners in addressing the specific needs of this marginalized group. This is particularly important given that the current discourse surrounding HIV/AIDS in the United States largely centers “victories” and an “end of the epidemic.” A qualitative grounded theory approach is used to explore the experiences of sex workers living with HIV in accessing health care services and to explicate how they navigate these settings. I conducted six in-depth, semi-structured interviews with sex workers living with HIV (more interviews forthcoming). Participants indicated a need to address internalized stigma that exists within their respective communities, or at multiple community intersections (e.g. being part of both an LGBTQ and African-American community), as a way to introduce individuals into care and maintain it. In terms of health care navigation, all participants were already connected with a regular health care provider and on

treatment regimens, making this a post hoc analysis of the initial introduction into care. Thematic findings demonstrate that part of a successful and sustained care regimen for sex workers living with HIV may require building special, often intimate bonds with health care providers as well as significant others in their lives. Findings also allude to the benefits of affirmative care promote individuals' medical and life successes and encourage sex workers living with HIV to play an active role in their care. This research seeks to reinterpret existing knowledge on HIV as an ongoing social health problem by considering the diverse experiences of sex workers living with HIV and offering suggestions on how to improve the health and health care quality of sex workers living with HIV.

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LIST OF ABBREVIATIONS

ART.....	Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
MSM.....	Men who have sex with men
PrEP	Pre-Exposure Prophylaxis
TasP.....	Treatment as Prevention

CHAPTER 1

INTRODUCTION

Historically, HIV has been deeply stigmatized and associated with behaviors labeled as deviant and/or immoral, such as injection drug use and homosexuality (see Herek, 1999; Herek & Capitano, 1999; Mahajan et al., 2008 for review). This stigma persists today and pervades many social institutions and organizations, including health care settings across a multitude of dimensions (e.g. barriers to accessing care, maintenance of treatment) (see Chambers et al., 2015 for review; Chesney & Smith, 1999; Rueda et al., 2016). Sex workers living with HIV may be particularly affected by stigma when attempting to access health care services because they are situated between two stigmatized identities—their HIV positive status and someone who exchanges sexual services for pay and are consequently disparaged, punitively punished, and often considered “vectors of disease” (Benoit et al., 2018; Forbes, 2015, Global Network of Sex Work Projects, 2015). This poses direct challenges to the HIV care continuum; that is, the series of steps people living with HIV go through to reach a state of viral suppression (Medland et al., 2015), including being connected with a provider and starting antiretroviral therapy (ART).

However, prior research has often overlooked this group, treating sex work and HIV-related stigma as mutually exclusive (Decker, Beyrer, & Sherman, 2014). Further, while this intersection has been explored in low to middle income countries, it has largely been left out of examination in higher income countries, such as the United States

(exceptions include Kalemi et al., 2017; Lawless, Kippax, & Crawford, 1996; Logie et al. 2011; Scambler & Paoli, 2008). Prior research has also most frequently considered HIV in terms of risk or within groups labeled as “high risk,” thus omitting the stigma experiences of those who are already living with HIV. This is particularly important given the current discourse surrounding HIV/AIDS in the U.S., which largely centers “victories” and an “end of the epidemic” (Kenworthy, Thomann, & Parker, 2018). However, some groups may be barred from this reality, largely due to structural barriers (Kurtz et al., 2005; Shannon et al., 2014). This oversight has created a blind spot for public health professionals, social scientists, and policy makers, undermining efforts to make progress in national HIV/AIDS strategy goals. The updated goals for 2020 focus on four key areas: reducing infections, improving access to care, reducing HIV-related health disparities, and achieving better coordination in the national response (Office of National AIDS Policy, 2015). While these goals are progressive and absolutely essential, sex workers are still left out of the “key populations” identified for focus, those being: gay, bisexual, and men who have sex with men (MSM) of all races and ethnicities; Black men and women; Latinx men and women; people who inject drugs; youth ages 13-14; those living in the southern US; and transgender women. At first glance, this list appears quite extensive, but this purposeful omission of sex workers is inimical to the national HIV response as it “perpetuates [sex workers’] invisibility and marginalization in US policy and interventions” (Decker et al., 2015, p.2325).

Globally, sex workers have an estimated 10 times higher risk of contracting HIV than the general population (UNAIDS, 2016). While estimates of both incidence and prevalence are largely unreliable due to sampling and geographic limitations, most

studies indicate high prevalence of HIV among sex workers (Paz-Bailey et al. 2016). These same hurdles that make it difficult to collect demographic and epidemiological data, also inform the challenges we face in collecting more in-depth qualitative information about sex workers living with HIV and the care they receive (or lack thereof). Even so, it is not unreasonable to presume that this group faces extensive challenges navigating health care. If we are to address the exclusion of sex workers living with HIV from public and political discourse and reach the end of an epidemic, it starts with the purposeful inclusion of this group into our research and a steadfast incorporation of their specific needs into national HIV/AIDS strategy goals. Treatment efforts that lack the ability to comprehensively address the particular needs of sex workers living with HIV are inadequate. Failure to consider the unique positionality of sex workers living with HIV is a human rights issue, and in order to continue adequately and efficiently addressing the HIV epidemic, it must be treated as such. With this project, I attempt to provide further understanding of this group's experiences in health care and explicate how they navigate these settings to gain a more nuanced understanding that can inform future health initiatives and sociological work pertaining to the stigmatization of marginalized groups, such as both sexual and racial minorities.

An intersectional lens has proven useful to the aims of this project, and it has also been an essential tool for better understanding the health care experiences (i.e., decision making processes, navigation, and resources) of sex workers living with HIV. Such a framework could be useful to health researchers and practitioners as they address the specific needs of this and other marginalized groups. Because of its explicit attention to power dynamics and emphasis on interlocking identities, an intersectional framework

provides an ideal analytic pathway for interrogating health inequities. Indeed, health scholars have found intersectional approaches beneficial for advancing studies on stigma and health (Hankivsky & Christoffersen, 2008; Hankivsky et al., 2010). Specifically, I use a qualitative grounded theory approach (Glaser & Strauss, 1967) to explore the experiences of sex workers living with HIV in accessing health care services and to explicate how they navigate these settings. Not only do I consider the role of intersectional stigma, but also if (and, if so, how) salient social identities, such as race, gender, and sexuality are meaningfully intertwined in sex workers living with HIV experiences. Through conducting in-depth interviews with sex workers living with HIV, I was able to obtain a clearer picture of this process of navigating health care and of their experiences more broadly.

CHAPTER 2

THEORETICAL FRAMEWORK

2.1 DEFINING STIGMA

Goffman's (1963) classic definition of stigma as "the phenomenon whereby an individual with an attribute which is deeply discredited by his/her society is rejected as a result of the attribute" (6) provides the foundation for my understanding and use of stigma throughout this project. This interpretation of stigma aligns with how stigma is commonly defined and conceptualized in the current health literature (Scambler, 2009). Further, I approach stigma from a social determinants framework in which social conditions and forces (i.e. stigma) are thought to influence the ways in which individuals operate throughout the social world and, therefore, impact health and health outcomes (Braveman & Gottlieb, 2014; Hatzenbuehler, Phelan, & Link, 2013; World Health Organization, 2008). With this framing in mind, stigma can operate on micro, meso, and macro levels, and it can be both internal to and external of any individual person, making this an appropriate sociological phenomenon for study. This is also particularly relevant for study among groups who may experience a plethora of barriers to everyday functioning and life due to the pervasive nature of the stigmatization of relegated, demonized, and/or misunderstood identities.

In acknowledging the shortcomings and ambiguity of its conceptualization and measurement in most studies (see Fitzgerald-Husek et al., 2017 for review; Link & Phelan, 2001; Parker & Aggleton, 2003), I aim to situate stigma as a nuanced and

complex process that fluctuates within different social contexts and from group to group. Because the term stigma has been adopted across various disciplines and its conceptualization is often vague, Link and Phelan (2001) attempt to explicate five specific components of stigma: labeling, stereotyping, separation, status loss, and discrimination. In doing so, stigma is also situated as rooted in larger power structures given that power “is essential to the social production of stigma” (p. 375) (see also Watkins-Hayes, 2014 for review).

Link and Phelan’s iteration of the components of stigma has implications for the present study because this conceptualization moves away from more simplistic individual-based models of stigma and toward models that include consideration of social inequalities which “requires us to think more broadly about how some individuals and groups come to be socially excluded, and about the forces that create and reinforce exclusion in different settings” (Parker & Aggleton, 2003, p. 16). I make a point to displace some of the emphasis on the use of individual-based models of stigma here because, as I hope to expound upon in later chapters, stigma is an interactional process, and while it can and is internalized by individual beings, it is wholly required that we consider the continued reproduction of stigma at the group and larger societal levels. Drawing from these configurations of stigma has better informed my data analyses and allowed for the exploration of stigma using an intersectional lens, particularly as it applies to the health of sex workers living with HIV and health care as a social institution.

2.2 INTERSECTIONALITY

Intersectionality is a framework first introduced by Kimberlé Williams Crenshaw (1991), a professor of law and critical race theorist, to more fully consider how race, gender, and class intersect in the lives of women of color to differentiate their experiences from those of white women. Since its initial development by Crenshaw, scholars across a multitude of disciplines have adopted intersectionality as a primary analytic framework and for the past thirty years, intersectionality has been a leading framework within feminist scholarship, underlining the importance of not advancing single-issue politics and analyses (for an overview, see Grzanka, 2018). Crenshaw demonstrates how the interconnectedness of identities can significantly impact access to resources, exclusion from social justice and political movements, and interpersonal experiences.

Individuals cannot be reduced to just one identity because identities are inextricably linked and their intersections overdetermine experiences of various forms of privilege and discrimination. For example, the resources of rape crisis centers are primarily geared for helping victims pursue legal action, yet other needs might be more immediately salient for some women of color who experience rape, such as medical resources and housing opportunities (Crenshaw, 1991). Drawing upon intersectional frameworks is an imperative component of the study herein as these frameworks hinge upon the idea that intersecting identities are meaningfully intertwined with salient social positions and forms of stigma, therefore suggesting that complex interactions must be considered to develop a cogent and comprehensive model for how sex workers living with HIV navigate health care and health care systems.

For too long scholars, have relied too heavily on gender as a lone social determinant of health and access to health care resources, but intersectionality directly confronts the limitations of such approaches (hooks, 2014). Intersectional health scholars note that health research still tends to “give too much primacy to gender over other key determinants” (Hankivsky et al., 2010, p. 1; also see Wyatt et al., 2013), and further this minimal focus undermines the potential for analyses to be more thorough and holistic (Bredström, 2006). Consequentially, certain groups are excluded from mainstream health research and its potential benefits (Hankivsky & Christoffersen, 2008; Hankivsky et al., 2010). HIV research reflects similar limitations in its approaches to understanding and explaining stigma, health care, and access to health care resources (Bowleg et al., 2013; Logie & Gadalla, 2009).

There is often an embedded assumption that if HIV-related stigma is properly tackled, then barriers to care will disappear, yet this is not necessarily the case for sex workers living with HIV who face multiple forms of stigma at the intersection of their various identities (Mahajan et al., 2008; Scambler & Paoli, 2008). Researchers have expressed a dire need to include substantive consideration of the importance of power structures in their research on health and health care (Hankivsky & Christoffersen, 2008; Hankivsky, 2010). In doing so, they draw upon intersectional frameworks to “inform a more complete and nuanced understanding of health determinants” (Hankivsky and Christoffersen, 2008, p. 272). Because of its explicit attention to power dynamics and emphasis on interlocking identities, intersectionality provides a necessary framework for explicating health inequities and their various connections to stigma.

CHAPTER 3

LITERATURE REVIEW

ART was introduced in the mid-90s, catalyzing the transition of HIV from being a terminal illness to a largely manageable chronic condition in countries like the United States. The references in the following literature review were purposely chosen to provide the most current information and to account for shifts in societal perceptions surrounding HIV and sex work-related stigma. With the exception of some germinal theoretical pieces, all articles were published in or after 1996.

Readers may also note that I use “HIV” to refer to both HIV and AIDS throughout this paper. This is because AIDS is the progression of HIV infection into its third stage which is characterized by a drop in CD4 cell count below 200 cells/mm³ (CDC, 2017). This is typically where we see more complications and opportunistic infections along with increases in mortality rates; however, AIDS is still the same virus. The decision to use the term HIV was made in line with the UNAIDS (2015) terminology guidelines. It was also made to reflect the CDC’s (2014) revised surveillance case definition in which diagnostic advances have made it such that HIV is classified into five stages (e.g. “HIV stage 3”), and there is no longer differentiation between adults and youth. That being said, I do not want to minimize the ways in which illness is socially constructed and the different meanings that may be ascribed to HIV and AIDS because there is most definitely power in distinguishing between the two.

3.1 HIV-RELATED STIGMA

The negative effects of HIV-related stigma in health care have been well-documented (Barroso & Powell-Cope, 2000; Chesney & Smith, 1999; Henkel, Brown, & Kalichman, 2008; Herek, 1999; Herek & Capitanio, 1999). The manifestation of stigma affects people living with HIV through institutionalized discriminatory acts in various settings and even in the form of individual threats and acts of violence (Herek, 1999; Parker & Aggleton, 2003). Overall, stigma is detrimental to physical, mental, and emotional health. Furthermore, it contributes to delays in testing and care, exacerbating the epidemic further (Baral et al., 2014; Chesney and Smith, 1999). Delays in testing can mean subsequent delays in treatment and less effective care in the long run, limiting quality of life and hindering the optimistic and much sought after “end of the epidemic” goals (UNAIDS, 2016). This is problematic for an age in which the best treatment is also considered prevention (Treatment-as-Prevention or TasP).

Briefly, TasP approaches encourage testing and treatment as key routes to minimizing new HIV infections (World Health Organization, 2012). Because there is strong evidence to suggest that HIV cannot be transmitted if a person has reached a state of continued viral suppression (e.g. SMART clinical trials), the use of TasP is an effective option in tackling the spread of HIV. For example, PrEP is medication (e.g. widely known as TRUVADA) that can be taken to block the transmission of HIV in serodiscordant partners (CDC, 2015). However, there are certain limitations that come with this model: Namely, initially gaining access to PrEP is dependent on willingness to express or disclose the need for PrEP to a provider and the trust one has in said provider (Underhill et al., 2015). It is also evident that more privileged individuals may reap

benefit from PrEP use, while other marginalized groups do not get the same access either for lack of knowledge or not being offered PrEP as an option during health care visits. Of course, this is problematic for the current social and political response to sex workers living with HIV, as there is a disconnect between our key populations and strategy goals and the means and resources to reach them.

Gender and ethnicity differences in HIV-related stigma may be associated with overall stigma levels (Loutfy et al., 2012; Mburu et al., 2014). As noted in earlier pages, we have most often focused our attention on the gendered dynamics of HIV-stigma. For example, Loutfy et al. (2012) found higher stigma scores on the Berger stigma scale among female and non-white persons. This study's findings suggest the need to explore HIV-related stigma along with other demographic variables, expanding beyond an additive approach and toward a more intersectional model. Other researchers emphasize delineation of the complex and complicated relationships between identities, particularly among members of minority groups, as imperative for understanding stigma and discrimination processes in the context of HIV (Doyal, 2009; Logie et al., 2018; Rice et al., 2018). For instance, Doyal (2009) found that for a sample of migrant women living with HIV, moral and social expectations are associated with stigma and discrimination processes. The women were often "faced with complex sexual and reproductive choices" in a culture that values motherhood and maternal responsibilities. Some felt constrained by this motherhood role and found it highly distressing in times when they were unable to perform these responsibilities.

These gendered expectations of roles and responsibilities do not just impact women's stigma experiences. Culturally bound ideas about masculinity and femininity

also play a role in HIV-related stigma. Mburu et al. (2014) notes that ideas of masculinity influence both health-seeking and support-seeking behaviors for Ugandan men living with HIV. Because to engage in these behaviors is culturally regarded as feminine, particularly in the way of social support, this hindered men's engagement in their health care. Although this hindrance in health-seeking behavior was not something I was able to pick up on in the present study, I do note the intricate and complex ways in which masculinity is tied with homophobia in the stigma experiences of participants.

3.2 SEX WORK-RELATED STIGMA

Researchers have also studied the effects of sex-work-related stigma on health and access to health care. Prostitution stigma has been posed as a fundamental cause of social inequity, specifically on the meso level (e.g. health care) (Benoit et al., 2018). Additionally, Lazarus et al. (2012) note that occupational stigma (defined as hiding involvement in sex work from friends, family, or community) also operates as a barrier to health care. In fact, this type of stigma remained both “significantly and independently associated with increased barriers to health access...irrespective of” other controlled factors (5). This finding suggests that sex work stigma, alone, is enough to limit access to care regardless of other factors at play. Similarly, sex workers were less likely to disclose their occupational status to health care providers (also see Logie et al., 2011). Yet they did have frequent contact with health services which may be good news in terms of the HIV care continuum. These findings indicate the need to reassess how we treat sex workers even after they have navigated through any initial barriers to care. Successfully gaining access to care does not always equal continuing access to high-quality care.

3.3 AT THIS INTERSECTION

Research examining both HIV and Sex work stigma is not as robust and thorough as it could be. Assessments of stigma are largely quantitative, relying on Berger's stigma scale (or a modified version of it) and survey data (see Fitzgerald-Husek et al., 2017 for review). For example, survey studies largely utilize developed internalized stigma scales, thus leaving out other forms of stigma. The present study aims to qualitatively address multiple forms of stigma. Qualitative studies have begun to explore experiences of overlapping stigmatized identities and also started to engage with an intersectionality framework (Hankivsky, 2008; for examples, see Logie et al., 2011; Mburu et al. 2014). To date, there is limited empirical inquiry into the intersectional identities of sex workers living with HIV, their everyday experiences, and how they navigate health care specifically. The study herein empirically investigates these intersections and looks directly at experiences in health care.

Collins, von Unger, and Armbrister (2008) utilize an intersectional approach to understand how multiple identities for women suffering from severe mental illness might influence HIV risk. While they did not study sex workers specifically, the findings may be applicable as this is one of relatively few studies to include a direct assessment of women's sexual practices. Internalization of the intersecting stigmas these women faced was reflected in their increased risk for both sexual abuse and HIV infection. Women's sexual relationships were often compromised because the felt stigma "hamper[ed] [their] chances of finding a partner and maintaining a satisfying sexual relationship" (Collins, von Unger, and Armbrister, 2008, p. 393). For example, many women were put in vulnerable positions within their relationships because their partners sought outside

sexual relationships, or they were not able to negotiate condom use. Yet, an interesting finding is that these women also actively resisted the stigma and “align[ed] themselves with identities that bestow[ed] dignity and respect, such as the “church ladies” and “good girls” (2008, p. 395).

In a qualitative study of women living with HIV in Canada, Logie et al. (2011) explored many different intersecting identities. Participants reported being treated differently in primary care; for example, one woman reported that doctors would unnecessarily test her for infections. However, similar to Collins et al. (2008), the authors also found positive coping strategies that existed within the group, such as resilience at the micro level and challenging stigma at the macro level. The narrative around sex work has long been one of vulnerability and lack of agency (Dworkin, 2005); however, individuals can and do exercise resistance in a system that criminalizes, demonizes, and objectifies them (Collins et al., 2008).

Kalemi et al. (2017) presents findings not fully congruent with past research. In a study of the self-esteem of HIV+ sex workers who had been exposed in the media and incarcerated for intended transmission of HIV in Greece, the majority of women completely disregarded comments about their profession. Kalemi et al. suggest that after dealing with sex work stigma for so long, public exposure did not carry negative self-esteem effects because of their self-efficacy and ability to cope. However, many of the women were not aware of their seropositive status and this became a major source of worry for them.

3.4 PROVIDERS AND PROGRAMS

In a study of medical and nursing students in Canada, Wagner et al. (2017) attempted to assess a model of overlapping stigma, including variables such as racism, homophobia, and sexism. They found that among this group of providers, stigma against sex work accounted for a large percentage of variance in their model of “overlapping stigma” to predict HIV-related stigma. This indicates that “health care providers may marginalize individuals engaged in sex work and prevent open and honest discussions of health concerns” (2017, p. 372) (see also Wagner et al., 2014). Interestingly though, sexism did not contribute to HIV-related stigma, and “this distinction demonstrates that high HIV-related stigma does not necessarily equate to high stigmatizing attitudes and behaviors in all areas” (p. 373). This supports an intersectional approach in that we might expect sexism to also be significant if looking through a purely additive lens.

In a review of the challenges in developing HIV programs for sex workers, Wilson (2015) points to various needs for their effective delivery. First, these programs should be developed based on robust evidence of what works to access sex workers living with HIV and retain them in care and in ways that prioritize sex workers and includes those engaging in various forms of sex work (for example, services for male and transgender sex workers are often lacking). Wilson highlights why the need for continued research into effective programming that is sensitive to stigma is so important.

Mountain et al. (2014) maintain that continuing adherence to ART, and retention in ART programs, for sex workers living with HIV is imperative to effectively respond to the needs of this population and to curb the HIV epidemic. The same concerns have been echoed in The Lancet series on sex work and HIV, in which addressing HIV among sex

workers is regarded as a top research priority. The authors emphasize the need for community-based and peer-led programs; call for increased funding for research in this area; discuss drastic policy reform to end discriminatory laws/practices against sex workers that contribute to their continued marginalization and endangerment; and reframing sex work as a legitimate occupation (Beyrer et al. 2015, Das & Horton, 2015; Kerrigan et al., 2015).

This literature demonstrates the need to implement training on stigma reduction and stigma reduction tools in health care. Health care systems are currently limited in their ability to adequately reach and respond to sex workers' health needs due to the continued stigmatization and damaging social construction of sex work. Thus, it is necessary to include those living with HIV into these programs for the continued progression of our national HIV response and to gain a better understanding of the needs of this groups as opposed to the current emphasis on those who are "at-risk." This will also provide a more nuanced perspective to health care and treatment services for sex workers living with HIV, not only benefitting quality of life among sex workers living with HIV by addressing these underlying social processes at work, but also advancing scholarship to inform future research on intersectional stigma and health literature.

CHAPTER 4

PURPOSE

4.1 PURPOSE AND AIMS

The purpose of this project was to illuminate the voices and experiences of sex workers living with HIV as they navigate their specific health care needs. In particular, the study discussed herein explores their subjective understandings of health and well-being, as well as their navigation of health care and health care systems in the context of multiple stigmatized identities, examining the specific intersection of HIV-status and sex-related work or exchange for pay. Current understandings of how this group navigates care successfully are vague or underdeveloped, thus this project aims to explicate this process more clearly in hopes of aiding future health goals and initiatives that target sex workers living with HIV. Community-based and sex worker-led health organizations and programs are sparse across the United States. These findings may be considered in the implementation of new strategies in caring for sex workers living with HIV, particularly in areas in which quality, inclusive care is currently inadequate or unavailable. Many researchers point to findings in the current literature as an avenue to suggest decriminalization of sex work, and while this is an important and ambitious goal, it may be impractical for the current political climate and the direction of social policy in the United States. It is my understanding that future research can help to empower sex workers living with HIV in findings ways of navigating this process more smoothly through ethnographic and participatory action research.

Using a qualitative grounded theory approach (Glaser & Strauss, 1967; Strauss & Corbin, 1998), I have identified and developed a set of themes to provide an overview of how sex workers living with HIV may successfully navigate health care, specifically by employing an intersectional lens throughout my analyses. By interviewing sex workers living with HIV using a semi-guided conversation structure, I was able to obtain a clearer picture of how they navigate and experience health care settings. One of my goals as a researcher was to avoid characterizing sex workers living with HIV as a solely vulnerable group, stripping them of power and agency over their bodies, health, and well-being. The methodology described in detail in the following pages has aided greatly in this task. It allowed for a more organic emergence of my themes and ultimately facilitated the participants telling their own stories. That being said, this study was guided by an intersectional lens, meaning that what I have developed is largely attuned to what I could discern regarding both the meaning and impact of these identities and the constant daily-life interactions of the participants.

4.2 RESEARCH QUESTIONS

In order to gain further insight into the experiences of sex workers living with HIV, this research project was guided by the four following interrelated questions:

- (1) Do sex workers living with HIV experience intersecting stigmas related to their sex worker and HIV status?
- (2) If so, what patterns emerge looking across salient social positions, including race, gender, and sexuality?
- (3) How might the intersecting stigmas experienced by sex workers living with HIV influence the ways in which they navigate health care services?

(4) What are the protective resources and strategies sex workers living with HIV use to navigate health care services?

In keeping these questions broad, I was able to situate diverse individual experiences into seven overarching themes, which can then be used by researchers, health professionals, and community/organization leaders to better understand and advance the well-being of sex workers living with HIV through easing this process of navigation and in helping aid in future quality of care. Readers may note that the findings herein are preliminary, and as such, these questions remain important for future inquiry.

Particularly, discerning patterns between experiences based on the intersections of identities was difficult due to the size of my sample. Further emphasis should also be placed on the roles of protective resources and strategies outside of the health care setting. Resources and support are a critical concern for this group, and the themes developed in the following chapters do not address the extent of external support and strategies available to sex workers living with HIV.

CHAPTER 5

METHODOLOGY

The study herein draws from a qualitative grounded theory approach (Glaser & Strauss, 1967; Strauss & Corbin, 1998). Qualitative grounded theory approaches move beyond simple description and are most often used to generate conceptual models or theories about a specific process and/or interaction (Creswell & Poth, 2018). With further data collection and thematic analysis, I aim to develop a conceptual model detailing this process of successfully navigating health care. However, I only present the preliminary themes that have emerged at this point in time. While my research topic and questions are well-suited for the generation of conceptual models and theory, a modified, constructivist formulation of grounded theory was also considered given the flexibility it affords (Charmaz, 2000).

In a constructivist approach, more emphasis is placed on the individual participants in which participants and researcher(s) work to “co-construct” the findings. Social constructions, power dynamics, and positionality of the researcher are all imperative aspects of the research process to reflect upon (i.e. reflexivity), as Charmaz confronts the notion of complete objectivity in the construction of shared realities. As Charmaz writes, constructivist grounded theory “assumes the relativism of multiple social realities, recognizes the mutual creation of knowledge by the viewer and the viewed, and aims toward interpretive understanding of subjects’ meanings” (Charmaz, 2000, p. 510).

Data for this study consist of interview transcripts and field notes from observations. All data were treated to rigorous and ongoing analysis. Another unique feature of grounded theory is memoing, a process in which the researcher actively engages with the data and writes down ideas as they emerge. This was a crucial component of my research process as it aided in both the organization of my data as well as the creation and comparison of themes and concepts that emerged. It also helped me to keep track of some of the problems that arose during the recruitment and interview processes, which are detailed below.

5.1 DATA COLLECTION

The target population for this study was: adult individuals (18+); living in the United States; who have participated in some form of sex work (broadly defined as the exchange of sex or sexual services for money or goods) within the past 24 months; and who have an HIV-positive diagnosis. Recruitment efforts began in November of 2018 and are still ongoing. Interviews began in February of 2019. By purposive sampling, (a strategy in which participants are selected based on shared characteristics), through HIV support services, clinics, and online platforms (e.g. Twitter, Craigslist, and other target sites) in the Southern United states, I was able to recruit initial participants for study. From there, I passed along my information to those identified key informants, so as to employ a snowball sampling technique to continue participant recruitment. As this is an ongoing project, I will continue to interview participants until I reach a point of data saturation in which no new themes emerge. Because grounded theory also involves theoretical sampling, I made numerous attempts to target specific individuals who were missing from my data (women participants, specifically). Future efforts will be made to

directly engage with this population. Because I have been embedded in this field and have built a network and professional relationships, I will continue to lean on this resource to facilitate access to this marginalized and relatively hidden population.

5.2 PARTICIPANT DEMOGRAPHICS

Because I sought to understand the realities of sex workers living with HIV, and the specific stigmas they experience navigating health care access, an open-ended dialogue with research participants allowed for flexibility in responses and elaboration when necessary. I recruited six individuals for in-depth, individual interviews. Two of these participants were local and, as such, I was able to conduct one-on-one, in-person interviews with them. The remaining four participants, while still located in the Southern United States, were located farther from the researcher, necessitating the use of video and teleconferencing technologies. Utilizing Zoom software, I was able to conduct video interviews with three participants and telephone interviews with one participant.

Participants were informed of their ongoing voluntary consent and right to discontinue participation at any time during the course of the study. The names used within the following pages are pseudonyms to help maintain participant privacy and confidentiality. I was able to provide resources and information to participants about both local and national certified medical professionals and/or hotlines in the event of any feelings of distress; however this was not needed and most participants expressed a sense of relief upon being able to share their stories. For instance, at the end of all interviews I asked if there was anything important I missed or anything else participants just wanted to share. Brendon stated, “it's opened up doors and really was, you know, I was able to, you know, kind of reflect which I already do very often, but it was nice to you know be

able to verbalize.” Another participant, Jordan, stated, “my biggest thing that I wanted to do with this one [this question] is thank you.” Upon completion of a one-on-one interview, each participant received a \$25 gift card for their willingness to share their stories and participate.

Five participants identified as male and one identified as female. As I discuss later, the female participant was not able to give a complete interview, and I have less than 20 minutes of useable data from her. Participants ranged from 26-57 years of age, with the majority of participants (n=3) in their mid-30s. All participants belonged to racial minority groups, with five of the six identifying as Black or African American. The remaining participant identified as Biracial. All participants self-identified on the LGBTQ spectrum, with three identifying as bisexual and the other three as gay. Racial and sexual identity proved to be particularly important throughout my analysis, as many participants recalled ways in which various identities, such as sexual identity or race, influenced ways in which they formed and/or maintained relationships and groups they resonated with. Participants had varying ideas of what “sex work” or “involvement in the sex industry” entailed. Although my recruitment flyers specified a timeframe (“In the last 24 months have you exchanged sexual services for money or goods or otherwise worked in a sex industry?”), upon interviewing I found that some individuals had previously been involved in sex work, but outside of the 24-month time frame. Of the two participants who were no longer involved in sexual exchange for pay, one was out for roughly six years and the other was undetermined. In terms of the type of sex work in which participants engaged, their responses varied from “prostitution” or “street walking” to holding “sex parties” in which the participant, Kindrick expressed that it was “beneficial

financially.” He was able to “[pay] the mortgage over a year, just from the parties (laughter).”

I chose to include participants who fell outside of the specified timeframe because, as I started collecting data, I realized that they still shared similar stories in terms of health care, although details were not as fresh. In the future, I will consider placing more measures to ensure that participants fall within the explicit outlined criteria, such as an online screening surveys or quick telephone screenings. While this data is still valuable in itself, screening tools would be beneficial to future projects that transpire from this.

5.3 DATA ANALYSIS

Interviews were recorded with the consent of each participant. Interviews were later transcribed, verbatim, through the transcription service, Rev.com. I then cross-checked each transcript with its associated audio file (Zoom video recordings also provide an isolated audio file) to ensure fidelity of recorded audio to the written content of transcripts. To ensure my participants’ ongoing privacy and safety, digital data were de-identified by assigning pseudonyms to each participant and a codesheet linking participants’ actual and pseudo names are securely stored under password protection. Any potentially-identifying data or information is accessible only to myself.

Once interviews were transcribed and checked for accuracy, they were analyzed using the constant comparative method (Bogdan & Biklan, 2009). This method is characterized by continuously combing through collected data, coding, and analyses with aims of constructing a “grounded” theory. This process also involves theoretical sampling, an ongoing process for this project. Because of the interwoven structure of an

intersectional analysis, this method is complementary (and I might say, necessary) to gauging complexity in the health care navigation process. Each transcript was then read twice to gain holistic familiarity with the dataset prior to attempts to identify important themes and establish categories. Because each individual interview was transcribed soon after completion, this aided in my ability to gradually gain familiarity with the data, while simultaneously collecting new data. I then began my thematic analysis. I have conceptualized coding to exist as part of the analytic process but not the entirety of it. Therefore, during various stages of coding, I was also actively thinking about the analysis of these codes (what they mean or do not mean, changes throughout the data). This process begins with my initial attribute coding. At the first stage, I read over interview transcripts, simply making note of descriptors and characteristics (including demographic information) of participants using NVIVO attribute coding. Next, during the open coding process, I browsed the transcript data to find any significant statements and “major categories of information” (Creswell & Poth, 2018, p. 85). The data points within these codes looked different for each transcript but with some overlap. For example, I open coded “Feelings about Status” as a major category to compile the various ways participants currently felt about their status. Others included “Positive Disclosure Experiences” and “Intimate Partner Support.” Following attribute and open coding, I conducted axial coding, which allowed me to identify relationships between my codes and identify any existing patterns. I was able to related codes such as “Homelessness” and “Loss to HIV” (e.g. death) under the broader category. Lastly, I was able to hone in on commonalities across the participant sample and also note stark differences that emerged in the process of selective coding to help assemble the overarching storyline.

Selective coding is the process of exploring existing codes for patterns and relationships through the open and axial ties to narrow down to a core concept(s). This process is much more researcher-fueled in the description and generation of concepts. That storyline is one that consists of mostly positive experiences in health care, yet influenced by a plethora of life circumstances and characteristics. These commonalities are referred to as my broad themes.

As part of the analysis process, I also explored any conflicting statements or ideas expressed in the interviews. These conflicting statements also indicate areas for future study, as they were not incorporated into the themes reported here. Lastly, memoing also became a useful tool for me as I conducted interviews over the course of a few weeks. I was able to keep track of the data and individual details of participants. Memos were also helpful in browsing the paper copies of transcripts that had not been uploaded into NVIVO software yet. That is, prior to coding with NVIVO software, I was able to browse the print transcripts and create memos for anything important to come back to or think through. I was also able to use this information to help inform directions for later interviews.

CHAPTER 6

FINDINGS

In starting this project, my intentions were to maintain a targeted focus on aspects of health care and health care navigation for sex workers living with HIV, as evidenced by the latter half of my question guide (see APPENDIX A). However, after I conducted several pilot interviews and fully engaged and interacted with participants, I realized the necessity of probing about other life domains and applying an intersectional lens to all domains, rather than just with regard to identity characteristics. As a researcher and sociologist, I would be remiss to ignore the overspill of other life domains into accessing health care and maintaining care. A grounded theory approach provided flexibility throughout the research process. I was attuned to the factors that influenced the data collection and analysis process in particular, such as interview protocol. This helped to refocus themes and assess the happenings in the data. Thus, in the following pages, I also report three overarching themes from the life experiences of participants with the aim of shedding light on the influential and interconnected nature of these life factors with health and health care experiences. These three themes also later inform four predominant themes directly related to health care experiences. I will then specifically discuss these themes based on what I discovered through analysis of the interview data. I want to emphasize that the following themes are still preliminary findings and subject to change with continued theoretical sampling and data collection.

6.1 LIFE THEMES

Adverse Experiences.

The first life theme evident in my data is the presence of adverse experiences across the life course, such as homelessness, financial insecurity, sexual abuse, and prior drug use or “addiction.” While this finding is not necessarily novel in the literature (particularly within public health research pertaining to people living with HIV), the majority of participants (n=6) shared these adverse experiences as being particularly influential for their current lives and many used this as a segue into talking about their HIV diagnosis. For example, Jordan, a 30-year-old African-American male was diagnosed after experiencing sexual abuse as a young teenager. In sharing his HIV story, Jordan stated, “I was in love with a thug” at 13-years-old. After further probing, Jordan stated that he had been sexually abused as part of a gang initiation for his lover at the time. During his hospital stay after this encounter, Jordan found out that he was HIV positive.

Another participant, Carl, a 57-year-old African-American male, recounts his internal dialogue when discussing these adverse experiences, “you're gonna catch that sooner or later if you don't change your risky behaviors.” The risky behaviors to which he was referring were “unprotected sex” and “drug use.” Carl found out about his HIV status after spending time in a detention center for a misdemeanor charge. Tiana, the only female participant in my sample, expressed some hardships to me before ending our call rather abruptly. She mentioned that one of her small children was having difficulties with a feeding tube and had to go to the emergency room. While, I cannot be sure of the scope of Tiana’s hardships and a lot of her experience living with HIV, I share this as an

example of the adversity and many life distractions that have made accessing this population difficult.

Adverse life experiences such as sexual abuse, gang involvement, illegal drug use, and engagement with carceral systems were littered throughout most of the interviews I conducted. The significance of many of these experiences was that individuals often found out about their diagnoses as a consequence of their engagement with some other negative life circumstance. This also means that, for some participants, their entrance into HIV care (which is generally discussed as a positive life circumstance in the existing literature) was filtered through the lens of other negative life experiences. Through this theme of adverse experiences, I was able to document either a voluntary or involuntary introduction to HIV-related care for participants, which I took into account when developing the model. A voluntary entrance into care occurs when a participant volitionally seeks out medical care for ailments or perceived health problems. Involuntary care typically occurs when an individual enters into care through some adverse life experience(s) that would require them to receive medical care. To pull from the example above, Carl was introduced to medical care only after he spent time in a correctional facility, at which point he was tested and found out.

Intersectional Stigma.

The second life theme that emerged was the prevalence of stigma relating to several intersecting marginalized identities in their respective communities, or intersectional stigma. This thematic finding emerged more than once (n=3), without any specific prompting on my behalf. Those who were vocal about the existence of this stigma were also very critical of their communities for perpetuating stigma. For instance,

when I asked Kindrick, a 44-year-old African-American male, about his involvement in sex work, he stated that he would *never* call himself a sex worker. In trying to gauge why that was, he responded:

They can say all they want that it's one of the oldest of professions, but that is one of the worst stigmas that can be attributed to you in this community. It's, it's the combination of African-American, gay, and then HIV positive, but to add *that* [sex worker] moniker on top of that, it's like, “Okay, *really? Are you really serious?*” You would get that kind of feedback or blowback from the general population. In the LGBT community, you know, that would just further enrage the heterosexual community that's already homophobic.

In this statement, Kindrick makes it clear that the combination of these marginalized identities (e.g. African American, LGBT, HIV+, and sex work involvement) was a major source of stigma both specifically within African American communities and within LGBT communities, as well as exogenous of them. Further, he later alludes to the fact that sex work, for many, is a much more concealable status than certain other statuses he claims or holds, such as being an African American male. He jokingly claimed, “if this were not confidential, I would deny it.”

Echoing some of Kindrick’s statements about the way stigma operates within his own community, Brendon, a 30-year-old African-American male described how gay men can often perpetuate stigma around HIV through the “outing” of other people’s statuses and a general lack of privacy:

But, until we break down that barrier of seeing it as so negative and trying to you know, um, both and that goes for the gay community as well as straight community. Many times people in the gay community are worse than straight because they are online posting people's statuses, posting videos and doing all of this foolishness and it's really just feeding into the negative stereotypes that people already hold.

Further, multiple participants mentioned that people often avoid finding out their HIV status altogether, and/or refrain from disclosing their status to partners, for these very reasons. Stigma that exists within these personal life and social community spheres was sometimes much more pertinent to the participants than stigma that came from outside these spaces.

Perseverance and Reframing.

In spite of these documented negative experiences and life stories, participants often spoke positively and even optimistically about their current situations. The third life theme to emerge from analysis of interview data is one of perseverance and reframing. Many participants had come to terms with their diagnoses, and some were looking optimistically towards a future cure for the virus. For example, Carl had completely reframed his outlook on HIV and what it means to live with the condition: Well I, when I say I can live with it, I've since had a change of mindset on that. I don't need it to live. It needs me to live, you know... You know, I, I hear a lot of people say I'm living with HIV. I don't

live with HIV. HIV lives with me, you know...Because I don't need it, it needs me to live. It needs my blood to survive.

Although not every participant had such strong reframing of what it means to be living with HIV, most had reached a point in which they were comfortable with their status and shared the ways in which they live with it in their daily lives.

Participants also discussed how their medical regimens were relatively straightforward, in that most participants had a daily medication regimen and regular provider visit schedule. As Carl notes, this made it easier to just keep moving along as “life goes on.” This is a finding that contrasts with earlier literature in which medication can be (and still is) a source of anxiety and stigma, as old treatment regimens required multiple medications, often with distressing side effects and lifestyle modifications. Medication has also been posed as a potential source of “outing” one’s status to close family or friends, yet this was not indicated in the collected data.

Each of these three life themes—adverse experiences, intersectional stigma, and perseverance and reframing—have implications for the broader process of navigating care of which I develop below.

6.2 HEALTH CARE THEMES

In identifying these broad life themes, I was also able to hone in on themes relevant to participants’ navigating health care in particular and what this process looks like in their daily lives. I first introduce the idea of voluntary vs. involuntary entrance into care, which is a theme I would like to explore in future research. It consists of the idea of a volitional entrance into care or contingent entrance due to life circumstance. I then

discuss health care-related themes and how they appear to operate in the lives of sex workers living with HIV in this sample.

Voluntary vs. Involuntary Entrance to Care.

Because participants were introduced into care through multiple pathways, I found it important to note the difference between voluntary entrance into care and involuntary entrance. For example, some participants reported “knowing their bodies” or knowing that something was wrong, and so they willingly went to a care provider to find answers. As noted by Darius when asked if he had ever avoided seeking care: “No, ‘cause I notic[e] things going on with my body. I was like, I need to go in and see the doctor. That's how I [knew] I got diagnosed....And, anytime I felt like I had an STD, or my body was telling me, I went and I got everything checked out. But no, I never avoided going to um, to see like any type of health care provider.” Other individuals, such as Carl and Jordan, found out they had HIV due to other life circumstances in which they were released into the care of individuals, a term I’ve labeled involuntary entrance into medical care..

I cannot say with any certainty that differences exist between individuals who take different routes into care. There may be differences in the ways in which a voluntary entrance vs. involuntary entrance impacts the coping abilities one has and the strength of reframing following a new diagnosis, but I was not willing to create a theme around this, because I don’t have enough conclusive support for that. All participants expressed difficulty in coping upon first finding out. However, those who entered into care involuntarily (i.e. Jordan and Carl), had strong exclamations about themselves and the

reframing of the statuses they held. This is definitely an aim for a future research project(s) in which potentially the way one enters into care stimulates later coping abilities, self-concept, and perseverance.

6.3 SUCCESSFUL AND SUSTAINED MAINTENANCE OF CARE

The remainder of the health care navigation process and what appears to be a successful and sustained maintenance of care (i.e. all participants reported being on a regular medication regimen and half reported having an undetectable viral load), appears to be influenced by three themes: 1) intimate bonds with providers, 2) openness and willingness to share with health care providers, and 3) playing an active (or proactive) role in care.

Intimate Bonds with Providers.

Upon initial analysis of interviews, I was intrigued by one recurring theme, and that was the tendency for participants to describe their relationships with their medical provider in familial terms. This type of assessment speaks to the intimate, but also complicated relationships that participants often form with their providers. For example, Kindrick mentioned (of his new primary provider), “She and I have a brother/sister kind of rapport because I talk shit and she tells me what the hell I'm gonna do and what I'm not gonna do, and so, (laughs) it works for us.” This type of bond suggests regular interactions and a level of optimal comfort may yield such relationships. Future research should take into account the specific meanings given and participants’ accounts of interactions.

In another instance, after disclosing his prior drug use and involvement in sex work with his doctor, Carl described his doctor’s response as one of “a parent scolding a

child.” After probing about Carl’s feelings towards this experience, Carl stated that it was a “good scolding,” one that was meant to be encouraging. While I, as a researcher, interpreted this initially as a potential source of stigma, additional probing revealed that this was not Carl’s interpretation of the experience and I found it interesting that Carl spoke so positively of this interaction with his health care provider.

This finding of participants using familial terms to describe their interactions with health care providers may also point to health care providers serving as potential key social-support resources in addition to their roles as a necessary gateway to life-sustaining medical treatment. For example, in Jordan’s case, his support from his doctor extended outside of the medical office. Because of other health complications, Jordan’s former employer, current partner, and doctor all had a meeting together to figure out the best way to support his ongoing medical needs. He explained:

And you know, my doctor came. He came and popped up. And I come out there, "Mr. [Jordan]." He said, "Come here, let me talk to you downstairs." And my boyfriend was downstairs and my manager, and we all sat down and we talked.

Openness and Willingness to Share with Providers.

A second theme related to the health care navigation process is openness and willingness to share with providers. Most participants spoke of freely disclosing their involvement in sex work or past drug use to their providers. When asked to say more about why they chose to disclose to their health care providers or not, many cited the need to be open and honest with their doctors in order to get the best quality care. Others stated that they were not shy about disclosing because “they’ve [providers] have heard it

all before.” This was particularly true for participants living in southern US cities, in which they perceived HIV and sex work involvement as being more common. This finding is somewhat contradictory to what we would expect if stigma operates through health care in ways that have been outlined in previous literature (Chesney, 1999; Mahajan et al., 2008; Scambler, 2009; Scambler & Paoli, 2008).

This may be due to the fact that many participants were older and had been living with HIV for an extended period of time. Age itself might not matter much, but time living with the condition could play a role in how comfortable one is with oneself, and subsequently the ability to communicate otherwise personal or secret information with another. However, Jordan noted, with regard to his open-book personality and willingness to share his experiences:

In the African American community, because we’re always taught: “Nah, don't say that too loud or just keep it on the low.” And, no. (laughs) That's a microwavable life. That's how I call it, a microwavable life... Anything worth having is worth fighting for and fighting through. I don't want anything quick. (laughs) Because it don't last that long.

Active and Proactive Engagement in One’s Own Health Care.

Lastly, participants in the study were both actively and proactively engaged in their medical care. Many participants explained that they always prepared for their health care provider visits by making a list of questions and concerns they had. They were also very knowledgeable about HIV and its effects on the body and were unafraid to bring up concerns or questions to their providers about new ailments or new treatment plans.

Health care providers were reportedly supportive of these efforts and often offered encouraging and affirmative care. For instance, several participants noted their provider's ability to encourage them to keep personally involved in their own care. As Carl noted, his present provider was willing to spend the time to explain anything he did not directly understand: "He'll break it down and just say, 'You are good. You're going to be around to be 100!'"

The above quote is indicative of the provider's role in affirmative and encouraging care that I alluded to in earlier pages. We also see cross-over into how this affects participants' responses. Some participants were willing to share their CD4 counts and viral status with me, expressing an active participation in their care and wanting to maintain and gain knowledge of their bodies and HIV in general.

CHAPTER 7

DISCUSSION AND CONCLUSION

Some of the themes that emerged from my data directly point to an intersectional framework as being a useful analytic tool. Many participants spoke of the stigma they felt and experienced in life as being related to not one, but multiple identities. Despite stigmatizing experiences in other life domains, participants in my study largely reported positive experiences related to health care and health care providers. This was an interesting finding and one that could be interpreted in multiple ways: First, one might argue that because sex workers living with HIV may not have the language to talk about and recognize instances of stigma in health care, that these go unrecognized. While this is possible, it is unlikely (given that participants displayed the ability to communicate very well about their life experiences and, specifically, stigma experiences in their personal lives) and potentially reflective of a troubling “false consciousness” approach to understanding underprivileged people’s experiences and narratives. This finding could also be due to the nature of my inquiry and the questions I posed to each participant. In general, however, I received positive responses from participants about their health care experiences. When asked what, if anything, they would alter about their health care experiences, more than one interviewee stated that there was nothing they would suggest to make it better.

The above suggestions speak to mostly methodological hurdles, however there are also social/cultural explanations for this positive finding to exist: Intersecting stigma in

everyday life has left some participants with minimal resources and support networks, and as such, participants may have developed feelings of indebtedness and gratitude toward individuals in their social networks who are able to demonstrate even modest degrees of care and provision of health resources. It is also possible that racialized and classed interactional norms generally proscribe deference, respect, and expressions of gratitude from those of lower social status to those of relatively higher social status. While this is generally true in most patient-provider health care interactions, its extent may be magnified when patients are multiply marginalized. It is quite possible that a number of these explanatory mechanisms may be at play simultaneously.

This research was 1) intended to expand on the current knowledge of experiences of sex workers living with HIV by bringing together two mostly divergent streams of literature—stigma experienced by individuals living with HIV and stigma experienced by sex workers; 2) create new knowledge by applying an intersectional feminist lens to the experiences of sex workers living with HIV; and 3) reinterpret existing knowledge on HIV as an ongoing social health problem by considering the diverse experiences of sex workers living with HIV and offering suggestions to improve the health, health care access, and health care quality of sex workers living with HIV.

Implications

There are several implications for these findings: First, working with this population may require a non-normative approach to health and health care. My findings indicate that sex workers living with HIV may benefit from more hands-on, culturally competent and inclusive care and through establishing good rapport with health care providers. This includes that health care providers be willing to engage with individuals

on a personal level, offering up both advice and affirmation for the successes that patients reach or sustain (e.g. viral suppression, un-detectability). A couple of participants spoke about requirements for the amount of time a provider must spend with each patient living with HIV. While this timing requirement varies from state to state, it could aid in patient-provider interactions tremendously, especially in patients whose complex and multi-faceted lives require more in-depth probing and understanding.

These patient-provider interactions also point to the need to do more empowerment work with sex workers living with HIV through their care, which occurs not only through HIV education, but also in the reframing of health workers as a resource and support system. Providers lent both encouragement and support to participants in ways that appeared to help foster and maintain relationships and embrace the intricacies of their personal lives.

Limitations and Future Directions.

A few methodological limitations exist within this study. First and foremost, the number of participants recruited is very low. While a goal of this study's findings was not to claim generalizability, this small number of participants does generate concern for the saturation of my themes, given issues with the theoretical sampling of women in my sample. Future iterations of this study will aim to collect larger amounts of data, with the goal of recruiting at least 20 participants. Efforts need to be made to recruit female participants in the future, and it may be beneficial to reach beyond HIV-related and support organizations. Because these spaces are often marketed towards gay men (or a stereotype or perception exists that they are, anyways), this may be directly influencing participants I am able to recruit from these spaces. Although these findings are not

generalizable to larger populations living with HIV or even to other sex workers living with HIV, the experiences and life events demonstrated herein are some of the subjective realities of these particular participants.

Similarly, speaking to the points above, the aims of this project were to develop a sound intersectional analysis that took into consideration the variety of pathways in which salient social positions and identities intersect to influence health care navigation experiences among sex workers living with HIV. This idea was complicated by some of the homogeneity in my sample, specifically in terms of race and sexual identity. Yet, the findings here are telling, and do not necessarily require a between-group comparison to be useful. Considering women respondents were less responsive to recruitment and interviewing attempts than men, this could point to the utility in an intersectional feminist analysis in later work.

Lastly, participants in this sample spoke overwhelmingly positively of their experiences in health care, yet prior research suggests that sex workers living with HIV, in general, would struggle with this process due to structural barriers and stigma. There is possibility that a selection effect systematically skewed the data, in that participants doing well in terms of health, were both more able and willing to respond and participate in the study. While future project plans aim to help tackle issues of sampling, the current implications for care still stand as this framework is effective in this small group.

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APPENDIX A
INTERVIEW GUIDE

The following list of questions was used as a guide for individual interviews. Where appropriate, the interviewees were probed to expand upon their answers.

1. Age:
2. Gender:
3. Sexual Orientation:
4. Relationship status:
5. Race/Ethnicity:
6. Education Level:
7. How would you describe your financial situation?
8. Can you talk about your current living situation?
9. How did you come to be diagnosed with HIV?
 - a. When did this occur?/How long has it been since?
 - b. What was your reaction?
10. Who, if anyone, have you disclosed this status with?
 - a. Why have you or have you not chosen to disclose this with _____?
 - b. Do you feel supported by those whom you have disclosed with?
11. Are you aware of any laws about HIV here in South Carolina? If so, can you talk about what you know?

12. Part of the criteria for participation in this study, was that you must have been involved in some type of sex work/sex exchange currently or in the past. Can you talk a little bit about why this description fits you?
13. Are you currently still doing this work? How long have you/did you work(ed) in the sex industry?
 - a. Has this been continuous employment?
 - b. What is the main type of work you do/did?
14. How did you come to this line of work?
15. Who, if anyone, knows that this is/was your occupation?
 - a. Why have you or have you not chosen to disclose this with _____?
16. Have you ever avoided seeking care when you needed it?
 - a. If so, when and why?
17. What would you say are your greatest health concerns?
18. Do you have a regular health care provider?
 - a. If so, how did you become associated with _____?
 - b. If not, why not?
19. Do you do anything to prepare for a doctor/clinic visit?
 - a. If so, what does that process look like?
20. Walk me through the last time you went to see any health care provider.
 - a. What was that experience like?
21. How are you typically treated when you see doctors/physicians?
22. Does your doctor know of your current or past involvement in sex work?

23. Do you think being involved in sex work affects how you're treated or the care you receive?
24. Are you happy with your medical treatment?
- a. If so, why?
 - b. If not, what would make it better?
25. Do you use complementary medicine or other modes of treatment? (e.g. acupuncture, massage therapy, reiki, yoga, etc.) If so, what form? For how long?
- a. What made you interested in _____?
26. What do you think is the biggest problem facing sex workers living with HIV when it comes to health care?
27. What would you recommend to the community in terms of how they can best support newly diagnosed people in getting into HIV-care?
28. What would you recommend to programs in terms of how they can best support newly diagnosed people in getting into HIV-care?