RETHINKING HIV STIGMA: LOCATING INTERSECTIONALITY AND AGENCY
IN THE EXPERIENCE OF SOCIAL EXCLUSION

by

Nevia Pavletic
A Thesis
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Committee:

_____ Director

_____

_____

_____ Department Chairperson

_____ Dean, College of Humanities
and Social Sciences

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Nevia Pavletic
Bachelor of Arts
University of Maryland, College Park, 2009

Director: Cortney Hughes Rinker, Professor
Department of Sociology and Anthropology

Summer Semester 2015
George Mason University
Fairfax, VA

DEDICATION

I dedicate this thesis to my parents, Jadranka and Zivko, for their unconditional love and support.

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I would like to thank all those who have helped me, either directly or indirectly, with this thesis. You know who you are. This thesis would not have been possible without your support and encouragement. I am also grateful for anthropology—a discipline that I entered into by pure happenstance but with which I fell in love rather quickly. Anthropology, you have encouraged me to be curious and creative, to think outside of the box, and you have challenged me to reflect more deeply on the intricacies of life and our shared human experience. I am lucky to have found my academic "home" in you. I only wish that we had found each other sooner. Thank you, anthropology. The journey has been awesome, and I hope that I will have another opportunity someday to research and write about the peculiarities of the world we inhabit.

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LIST OF ABBREVIATIONS

Acquired Immune Deficiency Syndrome .... AIDS
Centers for Disease Control and Prevention.. CDC
Human Immunodeficiency Virus.. HIV
Injection Drug Use .... IDU
Joint United Nations Programme on HIV/AIDS……………….…….………….UNAIDS
Men Who Have Sex with Men……………………......………………………….MSM
People Living with HIV or AIDS ....PHA
World Health Organization.. WHO

ABSTRACT

RETHINKING HIV STIGMA: LOCATING INTERSECTIONALITY AND AGENCY
IN THE EXPERIENCE OF SOCIAL EXCLUSION

Nevia Pavletic, B.A.

George Mason University, 2015

Thesis Director: Dr. Cortney Hughes Rinker

The aim of this thesis is to provide a "thick description" of HIV stigma within the United States cultural context, a topic that has received relatively little attention from anthropologists. Since the early days of the epidemic, HIV/AIDS has been symbolically linked with the "dangerous other," and the stigma associated with the disease has had devastating consequences for both individuals and communities. Through a combination of semi-structured interviews, textual analysis, and a literature review, I examine how the embodied experience of HIV stigma intersects with other forms of social exclusion and discrimination, and also how people living with HIV/AIDS (PHA) challenge and resist stigmatization. Specifically, I bring to light how agency is put into practice through the process of disclosure and also through the strategies that PHA employ to transform their illness experiences into a meaningful life narrative. My research builds on the existing scholarship on stigma and structural violence, while simultaneously bringing to light the power of PHA to resist the shame, secrecy, silence, and isolation that usually accompany an HIV diagnosis. I argue that by shifting our interpretive lens towards agency and

subjectivity and away from   vulnerability and passivity, we can begin to view PHA and

other marginalized groups as less Other.

CHAPTER ONE: INTRODUCTION

Secret

We all have our secrets. A few months ago, one of my biggest secrets fell into the hands of a stranger. Literally. On a frigid winter morning in early March 2015, I sat in a lecture hall full of global health professionals, academics, and students at a large private university in Washington, D.C. At the very start of the lecture, the speakers invited the audience to participate in an interactive activity. It went like this. We were each given a slip of paper and asked to write down a secret, something that we would not want anyone to know. Then, we were asked to fold the paper over several times, so that the contents would not be visible, and exchange the slips of paper with the person sitting nearest to us. I reached over to a young woman sitting in front of me; we both grinned nervously as we grabbed each other's secret and clamped it tightly within our fists. I could feel a palpable tension and anxiety in the lecture hall as everyone (reluctantly) began to exchange their papers. I myself began to feel apprehensive knowing that someone else, someone whom I barely knew, was holding one of my deepest secrets in their hands. I could feel my heartbeat speed up and my palms begin to sweat as a wave of panic ran through me: *What will happen next? Will they open the paper? What will they think about me if they find out my secret? I should have just made something up! Something silly, something innocuous…like, "I stole my brother's lunch money when I was eight*." But it was too

late. My secret was already in someone else's hands, and all I could do now was surrender my trust to them.

Although we never opened up the slips of paper (phew!), the point of the exercise, the speakers explained, was to simulate what it was like for a person living with HIV to disclose their status to another person. I am not a person living with HIV, so I cannot fully understand what the experience is like. But I got a sense of the anxiety, the stress, the doubt, the worry that must go on during the process of disclosure; the fear that you will be judged, rejected, or put down simply because of the fact that you are living with a certain virus. For me, this experience was nothing more than an innocuous simulation. For people living with HIV/AIDS (PHA), however, stigma is very much a reality.

The aim of this thesis is to provide a "thick description" (Geertz 1973) of HIV stigma[1] within the United States cultural context, a topic that has received relatively little attention from anthropologists (see Grove et al. 1997; Stanley 1999). Through a combination of semi-structured interviews, textual analysis, and a literature review, I hope to provide a critical analysis of the lived experiences of PHA by focusing on how they challenge stigma, while also shedding light on how other forms of structural violence and discrimination shape the stigma experience.

My thesis is organized as follows: Before presenting my research findings, I provide background information and a literature review in Chapters Two through Four. In Chapter Two, I describe my methodology and provide a brief reflexive analysis of my research. The biology, modes of transmission, and epidemiology of HIV/AIDS are

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[1] In this thesis I use "HIV," "AIDS," and "HIV/AIDS" interchangeably.

discussed in Chapter Three. In Chapter Four, I provide an overview of stigma as it has been applied to research on HIV/AIDS as well as other conditions, drawing primarily on literature from anthropology and related disciplines.

My findings are divided across three chapters. Chapter Five focuses on how stigma is intertwined with other forms of structural violence and discrimination. In Chapters Six and Seven, I examine agency in response to stigmatization. Chapter Six examines how agency is put into practice during the process of disclosure, and in Chapter Seven I focus on how PHA transform their illness experience into a positive life narrative. Chapter Eight, the final chapter, discusses the relevance of my findings for academics as well as those who work in applied settings. Before moving forward, I continue this chapter by providing an overview of my research, elaborating on the stigma concept, and describing my working definition of agency.

Research Problem

In this thesis, I aim to address two gaps in the existing HIV stigma literature. First, few scholars have examined how HIV stigma intersects with other forms of social exclusion, even though PHA often experience multiple forms of stigma simultaneously (Abadia-Barrero and Castro 2006). The tendency in the existing literature has been to view HIV stigma as an isolated "thing" that exists separate from other forms of structural violence. As noted by Parker and Aggleton (2003), the vast majority of the HIV stigma literature has approached stigma from an individualistic perspective, that is, by focusing mostly on the social-cognitive processes through which people form stereotypes about others. This theoretical paradigm has led to HIV stigma interventions that place emphasis

on changing people's negative attitudes and beliefs towards PHA, while ignoring the broader social context that perpetuates stigma in the first place. For the most part, these interventions have been limited in their success because they neglect the influence of larger structural forces that reinforce stigma (Stangl et al. 2013). Although anthropologists have explored the structural dimensions of stigma in other cultural settings, such as Haiti (Castro and Farmer 2005) and Brazil (Abadia-Barrero and Castro 2006), no research, to my knowledge, has ethnographically explored this topic within the US context. Scholars within public health have pointed to the need for research that addresses how multiple forms of disadvantage intersect with the experience of HIV stigma in order to effectively address the problem (Mahajan et al. 2008), and it is my goal in this thesis to expand on this theoretical paradigm of stigma.

Research that addresses intersecting forms of stigma is both timely and important. Link and Phelan (2006) argue that stigma processes have had an immense impact on public health outcomes, an association that has been under recognized because most analyses have focused on a single dimension of stigma (e.g., obesity) and a single outcome (e.g., self-esteem). However, if multiple stigmas were aggregated and multiple outcomes were analyzed collectively, "stigma would be shown to have enormous impact on people's lives" (Link and Phelan 2006:528). In Chapter Five, I use data from semi-structured interviews to illustrate how various forms of stigma and discrimination intersect to create unique and varied experiences of social exclusion. In my analysis, I shift away from the tendency to view stigma as a static and isolated "thing" and instead I

argue that the embodied experience of exclusion extends above and beyond the stigma caused by HIV on its own.

The second gap that I aim to address is the general lack of emphasis on agency in the HIV stigma literature. While structural changes are indeed necessary to combat HIV and its associated stigma, equally significant are the individual ways that each person copes with, struggles against, and finds meaning in their daily experiences of exclusion. In their ethnographic study on the lived experience of stigma among people with schizophrenia, Jenkins and Carpenter-Song argue for reinserting subjectivity into the study of illness, noting that stigmatized persons

> can be **not only exceedingly socially aware but also strategically skilled in response to social assaults on their personhood and survival**. In this respect their existential focus, as well as our interpretive focus, shifts away from the exclusivity of victimization and toward the subjectively perceived possibilities for agency (2008:404 [added emphasis]).

I follow Jenkins and Carpenter-Song by exploring how PHA creatively struggle against and challenge stigmatization, rather than portraying PHA exclusively in terms of the victimization and vulnerability that defines their Otherness. In Chapter Six, I illustrate how agency is enacted in during the process of disclosure, and in Chapter Seven I examine the ways in which PHA transform their illness experiences into a meaningful life narrative. My goal in these chapters is to expand on the ethnographic and theoretical literature on agency and stigma by reframing the stigma experience as a site of struggle and resistance, creativity and change. Through my data, I bring to light how the internal resourcefulness of PHA can be used as a powerful tool for combatting HIV stigma and other forms of exclusion. By focusing on the agency of PHA rather than exclusively on

their vulnerability, we can begin to "[reverse] the tendency to deny subjectivity to the afflicted with the otherizing assumption that 'nobody's home'" (Jenkins and Carpenter-Song 2008:400).

In addition to my specific research questions, a more general goal of this thesis is to contribute to the existing literature on HIV stigma, an issue that has received relatively little attention from anthropologists (see Castro and Farmer 2005; Farmer 1992; Grove et al. 1997; Whittaker 1992). Link and Phelan (2001) have critiqued stigma research for not being rooted in lived experience but rather being informed by the theories of "experts" who have no personal insight into the embodied experiences of stigmatization. Ethnographic approaches can contribute a more holistic understanding of HIV stigma by helping us understand how stigma is connected to larger sociocultural processes and also how stigma is subjectively experienced by those whose lives it affects the most. By using ethnographic approaches, it is my goal in this thesis to shed light on the nuances and complexity of the stigma experience, which I hope will offer a deeper insight into the lived experience of social exclusion and perhaps open the door for new perspectives in how we understand and theorize stigma.

Agency

Since the thematic focus of Chapters Six and Seven is agency, I will briefly outline my working definition of this term. The existing literature on agency is extensive, theoretically complex, and beyond the scope of this thesis. Nonetheless, most scholars would agree that individuals have the ability to make choices in their lives and act on them, although the ability to do so is constrained by various structural limitations. For the

purposes of this thesis, I use Nahar and van der Geest's definition of agency as "people's ability to make choices and act and thus (to some extent) steer their own lives" (2014:382). The authors further suggest that agency should be understood in terms of both resilience and resistance. By resilience, they mean "the ability to withstand adversity and not be crushed by it" (Nahar and van der Geest 20140:382). Resilience "does not really change people's external situation, but rather it enables them to cope" (Nahar and van der Geest 20140:382). They define resistance, on the other hand, as "a more active response to adversity and oppression . . . it is a counterattack (as cautious and subtle as that may be) to change existing conditions" (Nahar and van der Geest 20140:383). In this thesis, I conceptualize agency as both resistance and resilience, recognizing that it is not always in the best interest of individuals to resist hegemonic structures (Ortner 1995).

My focus in this thesis is not on grand-scale forms of resistance that necessarily lead to dramatic and enduring structural changes. Rather, I approach the issue of agency from the perspective that what matters most to people is how to make life bearable today, in this moment, rather than far off into the abstract and distant future. As Scott (1985) has written of peasant resistance, "The goal, after all, of the great bulk of peasant resistance is not directly to overthrow or transform a system of domination but rather to survive— today, this week, this season—within it" (quoted in Nahar and van der Geest 2014:394). Thus, the emphasis on structural change becomes less important when we consider what matters most to PHA in their day-to-day lives. In my sample, PHA employed various strategies to resist stigma, allowing them to reconstruct their lifeworld in ways that are personally significant and meaningful.

Background

  The HIV/AIDS epidemic is one of the world's greatest public health concerns. HIV/AIDS is the sixth leading cause of death worldwide, and the second leading cause of death in low-income countries (WHO 2015). In total, the epidemic has claimed 39 million lives worldwide since the beginning of the epidemic in the early 1980s (WHO 2015). The World Health Organization (WHO) estimates that there are over 35 million people living with HIV globally, with over two million new infections per year (2013). The Centers for Disease Control and Prevention (CDC) estimate that there are more than 1.2 million people living with HIV in the United States, and approximately 50,000 people are newly infected every year (2015). Globally, approximately 1.5 million people die each year from HIV (WHO 2015).

  The pattern of HIV infection tracks along the fault lines of existing social inequalities, as the disease most often affects individuals who are already socially and economically marginalized (Farmer 1992; Parker 2002; Singer 1994). Globally, HIV affects developing nations significantly more than developed ones (Parker 2002). According to the Joint United Nations Programme on HIV/Acquired Immune Deficiency Syndrome (UNAIDS 2012a), sub-Saharan Africa, with an adult HIV prevalence of 4.9 percent, shares the greatest burden of the disease. By contrast, the adult prevalence of HIV is 0.6 percent in North America and 0.6 percent in Western and Central Europe (UNAIDS 2012a). Within the United States, poorer racial minorities carry the greatest burden of HIV infection (Singer 1994; Zierler and Krieger 1997).

  However, HIV is not only an epidemic in a biological sense, but also an epidemic of meanings (Treichler 1987). Since the early days of the epidemic, the disease has been

symbolically linked with the "dangerous other," thereby reinforcing the divide between "us" and "them." The words "HIV and "AIDS" have continually evoked stigmatizing metaphors, bringing up images of immorality, promiscuity, social deviance, pollution, death, sexuality, drug use, and homosexuality, among many others (Sontag 1989). At its core, HIV stigma—and stigma in general—forces us to ask questions about how and why certain people come to be socially excluded and Otherized.

Effective medications introduced in the mid-1990s have transformed HIV from a deadly virus to a chronic and manageable condition.[2] Nonetheless, the stigma attached to the disease continues to have devastating consequences. Although the causes and course of the HIV epidemic vary greatly across cultural settings, combatting stigma and discrimination has been a central component in HIV/AIDS prevention, treatment, and care programs across the globe. Both UNAIDS (2012b) and WHO (2009) have highlighted the importance of stigma reduction in response to the HIV pandemic, and recent research has pointed to stigma as a fundamental cause of health inequities (Hatzenbuelher et al. 2013). Enacted stigma, or discrimination, has led to discriminatory laws and policies targeted at HIV positive individuals, such as travel restrictions and the withholding of medical care (Aggleton et al. 2005). Within family and community settings, discrimination has taken the form of social exclusion, hate crimes, and physical violence against HIV positive individuals (Aggleton et al. 2005; Maman et al. 2006; Varas-Dias et al. 2005; UNAIDS 2012a; Niang et al. 2003). HIV/AIDS stigma also

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[2] Despite the existence of effective therapies, various structural forces limit who is able to access them. In Chapter Three, I elaborate on this point.

influences treatment adherence (Rintamaki et al. 2006; Sayles et al., 2009) and is associated with poor mental and physical health and low social support (Logie and Gadalla 2009). Psychological distress associated with stigma and discrimination may also stimulate the progression of HIV to AIDS (Golub et al., 2003), weaken the immune system (Kemeny and Schedlowski 2007), and cause other adverse health outcomes (Harrell at el., 2003). Despite these common manifestations of stigma, HIV/AIDS stigma remains a very complex phenomenon and, like the epidemic itself, its causes and course vary across (and within) cultural settings.

Before moving forward, it is important to mention at the outset that not everyone who contracts HIV is equally stigmatized. Those who contract HIV through blood transfusions or children who are born to HIV positive mothers have been labeled the "innocent victims" of HIV (Herek and Glunt 1988; Schellenberg and Keil 1995). On the other hand, those who contracted HIV through "immoral" behaviors, such as non-monogamous sex, non-heterosexual sex, or drug use have been viewed as deserving of their fate. As Leavitt (1989) argues, "the implication inherent in the phrase 'innocent victim' (is) that the majority of people with AIDS are 'guilty' victims" (quoted in Schellenberg and Keil 1995:1791). This constructed dichotomy of "guilty" versus "innocent" further serves to reinforce the process of Othering, blaming, and shaming. This is not to say that "innocent victims" do not experience *any* stigma—indeed, they most certainly do. Rather, I bring this point up because it illustrates the fact that stigma against PHA extends far beyond contamination fears, since *how* one contracted HIV may carry more weight than *whether* one has HIV, thereby bringing to light the moral

dimensions of the disease. In Chapter Four, I expand on the connection between morality and stigma.

Defining Stigma

The origin of the word stigma comes from Greek referring to marks or brands made on the bodies of slaves or animals (The New Catholic Encyclopedia 1967, paraphrased in Jones 1987:140). It was not until the 1960s, when sociologist Erving Goffman published his book *Stigma; Notes on the Management of Spoiled Identity*, that the word gained its present-day meaning: "an attribute that is deeply discrediting" that reduces one "from a whole and usual person to a tainted, discounted one" (1963:3). According to Goffman, the stigmatized person "possesses . . . an undesired differentness" which sets them apart from "the normals" (1963:5). Goffman differentiates between three types of stigma: those of the body, such as physical deformations; those of character traits, such as alcoholism and unemployment; and "tribal stigmas"—those associated with "race, nation, or religion" (1963:4). Stigmas can also be visible (such as leprosy or race) or invisible (such as sexual orientation or mental illness).

Scholarly interest in stigma has substantially increased since the 1980s and the concept has been applied widely across the social sciences to various medical and social conditions (Link and Phelan 2001). Most of the existing research on stigma is based on the definition put forth by Goffman (1963). Even though Goffman's analysis emphasized that stigma occurs through social processes, "subsequent practice has often transformed stigmas or marks into attributes of persons. The stigma or mark is seen as something *in the person* rather than a designation or tag that others affix to the person" (Link and

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Phelan 2001:366 [original emphasis]). As such, the vast majority of research on

HIV/AIDS stigma has approached the issue from an individualistic perspective,

conceptualizing stigma as an attribute that exists within a person rather that a social

process through which people come to be excluded and marginalized. However, scholars

within sociology and anthropology have criticized these limited paradigms and have

instead proposed theories of stigma that focus on how the process of stigmatization is

shaped by power and broader forms of social exclusion (Link and Phelan 2001; Parker

and Aggleton 2003).

In this thesis, I draw on Link and Phelan's definition of stigma, which they define

as a process through which "elements of labeling, stereotyping, separation, status loss,

and discrimination occur together in a power situation that allows them" (2001:377).

According to them, the process of stigmatization unfolds across five stages:

> In the first component, people distinguish and label human differences. In
> the second, dominant cultural beliefs link labeled persons to undesirable
> characteristics—to negative stereotypes. In the third, labeled persons are
> placed in distinct categories so as to accomplish some degree of separation
> of "us" from "them." In the fourth, labeled persons experience status loss
> and discrimination that lead to unequal outcomes. Finally, stigmatization is
> entirely contingent on access to social, economic, and political power and
> allows the identification of differentness, the construction of stereotypes,
> the separation of labeled persons into distinct categories, and the full
> execution of disapproval, rejection, exclusion, and discrimination (Link and
> Phelan 2001:377).

The emphasis in their definition is on *power*—that is, it takes power to stigmatize. In

other words, although individuals with less power can negatively label and stereotype a

more powerful group, these actions would not constitute stigma. For example, patients

with mental illness can label their physicians as arrogant "pill-pushers," but we would not

consider the physicians to be stigmatized in this case (Link and Phelan 2006:528).

Similarly, examples of "reverse racism" do not carry the same negative symbolic weight

as racism carried out by whites against racial and ethnic minority groups.[3] In Chapter

Four, I discuss in greater detail the anthropological theories that situate stigma within the

wider social mechanisms of power and inequality.

Before moving forward with my literature review and research findings, in the

next chapter I described my methodology and provide a brief reflexive analysis of my

research.

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[3] Comedian Louis C.K. wittily illustrated this point in his stand-up skit entitled "On
Being White", in which he joked about how there are no words that could hurt the
feelings of a white man. The full skit can be viewed and the transcript read here:
http://genius.com/Louis-ck-on-being-white-annotated.

CHAPTER TWO: METHODOLOGY

Participants and Interviews

The bulk of my research is based on semi-structured interviews with PHA and people who work with PHA in the Washington, D.C. area. I obtained my sample through a combination of convenience and snowball sampling. Five interviews were with PHA, in which I focused on their lived experiences with HIV and its associated stigma. In November 2014, I attended a conference at a private university in D.C., where I met Brandon,[4] a black gay man in his late 20s, and Hector, a gay Latino man in his early 40s. Through Hector, I was referred to two additional PHA (Elena and Manual). Elena then connected me to Ricky. Four of the PHA were gay men; one was a transgender woman. Three were Latino immigrants (two from El Salvador one from Mexico), one was black American, and one was white American. Their ages ranged from late 20s to mid-40s. Only Ricky had completed college, and he had also completed graduate school. Ricky was also my only white participant. Two participants had a high school diploma only, and two were working towards their bachelor's degree. All of the PHA participants were open about their HIV status; that is, they were currently not hiding their HIV diagnosis from most people in their lives. Most, however, had mentioned being secretive about their diagnosis in the past. All of the PHA participants mentioned experiencing some sort of

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[4] All names of people and locations have been fictionalized.

mental health problems related to their HIV diagnosis, including depression and/or suicidal attempts.

The three additional interviews were with individuals who work with PHA in various capacities, whom I sought out as "experts" to learn more about how stigma affects communities in a general sense. They were found and recruited by searching on Google and reaching out to them through email. One was a physician who works with HIV positive mothers and children in D.C.; one is an employee of a D.C. health organization; and one is an anthropologist whose most recent research has focused on HIV stigma among black women. One of these "experts," Judith, was also HIV positive, but I learned this information only during the interview, so our conversation did not focus on her lived experience of HIV but rather her professional insights from working with HIV positive populations.

During the interviews, the layered dimensions of HIV stigma became strikingly clear to me. I began each interview by asking about participants' demographic background and history with HIV, such as the circumstances surrounding the moment they learned they were positive and their initial reactions to the diagnosis. Soon, I noticed that some of the conversations would spontaneously shift towards discussions of other forms of discrimination that participants and their communities encounter in their day-to-day lives—such as racism, homophobia, and gender-based violence—even if I did not ask them directly about these things. At times, I even found it difficult to talk about stigma, in the sense that participants did not have that much to say about it, but instead preferred to discuss issues related to other forms of social exclusion that permeate their

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lives, such as racism, poverty, gender-based discrimination, and the social inequalities that drive HIV infection rates. I had originally intended to only focus my thesis on agency and resistance. However, these moments during my interviews pointed to the fact that other layers of social exclusion and marginalization are deeply intertwined with the experience of living with HIV. As such, I felt that it was important to integrate these insights into my thesis.

At one point, I was forced to reassess the questions that I had been asking. When I began this research, I thought of agency solely in terms of overt forms of resistance. Thus, for many of the questions that I asked about agency—such as "How do you challenge or resist stigma?"—participants did not have much to say about it and/or had to think deeply before coming up with an answer. Later, however, I realized that agency can occur in more subtle forms, and these less noticeable manifestations of agency only became evident when I went back and analyzed my data in its entirety. For example, I noticed that agency was often enacted through the act of disclosure, even though participants did not necessarily frame these actions as "stigma-challenging." Similarly, I found that PHA often transformed their illness into a positive life narrative by finding meaning and purpose to their experiences. I discuss these forms of agency in greater detail in Chapters Six and Seven.

The interviews took place at various locations, including participants' places of work and local coffee shops. All interviews were completed in March and April 2015. I made an effort to make each interview as relaxing and informal as possible. Although I carried a notepad with me in which I had written down the general themes that I wanted

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to cover, I allowed each conversation to flow naturally while at the same time being

mindful of my main research questions.

All of the interviews were audio-recorded and transcribed by me. The fact that

three of the PHA were not native English speakers made it difficult at times to

communicate and understand each other clearly. I have edited direct quotations only for

clarity and coherency, but not for content. Ethics approval was obtained from the George

Mason University Institutional Review Board.

Literature Review and Textual Analysis

In order to situate my research findings, I conducted a literature review of

HIV/AIDS (Chapter Three) and stigma (Chapter Four), drawing most heavily on the

anthropological literature. I also included epidemiological data on HIV, which was

mostly obtained from the Centers for Disease Control and Prevention and the World

Health Organization websites. In Chapters Six and Seven, I supplement my interview

findings with textual analysis of material written by PHA from websites, blogs, and

online articles in order to obtain greater insight into the lived experiences of PHA.

Vulnerability and Representation

How we represent other people and other cultures has been and continues to be a

highly contested issue within anthropology (Abu-Lughod 1991; Marcus and Fischer

1986). As researchers, we have the power to choose what information and whose voices

to include and exclude. Throughout the research process, my participants, and other

scholars whose work has informed my own, have challenged me to think more deeply

about some of the broader ethical and epistemological issues related to how we represent

the individuals who we write about.

On a rainy afternoon in March 2015 I was wrapping up an interview with Elena, a

transgender Latina in her late 30s, when she boldly but respectfully suggested that I do

not portray her as a victim when I write up my research findings:

> When I do an interview or something like that, I say, "If you're going to ask
> me about my issues or the violence that I [experienced], I can talk about
> that. But I can also talk about my goals that I have met. Or the job that I do.
> I can talk about this . . . But I don't want you to put me like a victim or
> something, because *I'm not*."

At first, Elena's comment made me feel uneasy, as if the authority in that situation had

suddenly shifted. In that moment, Elena was directing the interview, as I was forced to

reflect upon my own privileges and responsibilities as a researcher who has been

entrusted with the task of representing another human life. Elena's comment really struck

a chord with me, as it made me think more deeply about my own preconceptions and

prejudices about what people like Elena—that is, "people living with HIV"—are like. I

came into the interview wanting to know about the various forms of injustice and

discrimination she has endured throughout her life, not only related to her HIV diagnosis

but also as a Latina transgender woman whose life has always laid at the margins, both in

the United States, her adopted country, and her native El Salvador. I wanted her to tell

me about her difficult and painful experiences. But soon I realized that there was so much

more to her life than the suffering she has endured.

More often than not, it seems that social science researchers tend to think about

their participants exclusively in terms of victimization. However, Elena opened my eyes

to the agency and subjectivity that exists within all of us. With every interview after that,

and throughout the remainder of the research process, I could hear Elena's words echo in

the back of my head—the way that she emphatically and somewhat sternly told me that

she was *not* a victim.

Ultimately, it was Elena's comment that encouraged me to reframe some of the

broader goals of my thesis. I began to reflect on how we might be able to write about

other lives in a way that does not ignore their suffering, but at the same time does not

ignore their capacities for agency. Following Lila Abu-Lughod (1991), who has asked us

to consider whether there are ways to "write about lives so as to constitute others as less

other" (1991:142), in this thesis I suggest ways through which we might be able to shift

away from representing PHA exclusively in terms of the victimization that has

characterized their Otherness.

Jenkins and Carpenter-Song have suggested that we focus on illness experiences

within the framework of "fundamental human process" (2008:400), which can prevent us

from creating grand narratives of vulnerability that by their very nature Otherize and

further push certain groups of people into the social margins. The authors argue:

> Calling to mind H. S. Sullivan's maxim that those with schizophrenia are
> "**much more simply human than otherwise," we note that social fears
> and anxieties are shared, at one time or another, by all of us.** The
> struggle is perhaps only more vigorous for those in a situation of mental
> illness. This consideration reverses the tendency to deny subjectivity to the
> afflicted with the otherizing assumption that "nobody's home." It impels
> research toward more explicit attention to **fundamental human processes
> and capacities for subjectivity** in the context of schizophrenic illness and
> recovery, and it opens the door to recognizing that in **certain respects
> schizophrenia can serve as a paradigm case for the study of
> fundamental human processes of everyday life beyond the boundaries
> of affliction** (Jenkins and Carpenter-Song 2008:400 [added emphasis]).

It is within this framework that I hope to reconfigure our understanding of HIV stigma. In Chapters Six and Seven, I argue that the experience of living with HIV can perhaps be regarded as a lens through which we can better understand "fundamental human processes of everyday life beyond the boundaries of affliction" (Jenkins and Carpenter-Song 2008). That is, I hope to expose how the experience of HIV stigma, and the strategies employed by PHA to challenge it, is emblematic of the human condition more broadly, by acknowledging that "social fears and anxieties are shared, at one time or another, by all of us" (Jenkins and Carpenter-Song 2008:400). When viewed from this perspective, we can begin to move our attention away from essentializing notions of vulnerability towards a greater understanding of the shared human condition more broadly.

Reflexivity and Positionality

A reflexive approach in anthropology acknowledges the myriad ways in which the personal experiences of the researcher influence the research process. Throughout the research process, I have been mindful of my own positionality in relation to my research topic, and these considerations have forced me to reflect upon some broader ethical and existential issues.

My motivation to pursue this topic mostly stemmed from a feeling of urgency to choose a topic—*any* topic—so that I could get started on my research as soon as possible and graduate within a reasonable amount of time. At the beginning of graduate school, I had found myself bouncing back and forth between a myriad of possibilities (an ethnography of CouchSurfing? American women's grooming practices? Facebook and

social relationships?), as anything and everything seemed interesting to me. Indeed, too much freedom is often also a curse. As it so happened, during this time a close friend of mine was pursuing research on HIV stigma among youth in South Africa. Through our frequent conversations about her research, I soon decided that studying HIV stigma in the US could be both interesting and have applied value.

In many ways, I came to this research as a complete outsider. I had no prior personal connection to this topic, I had never worked with marginalized populations, and (to my knowledge) I had never met an HIV positive person. Although I have always ideologically aligned myself with human rights causes, I could hardly call myself an activist. And, although I have a professional interest in public health, my life's passions are painting and photography. Throughout the span of my research, however, I began to realize that I was closer to my topic than I had previously thought, in the sense that I too was living with a concealable stigma. I had written this condition down on the piece of paper in the activity that I described in the introduction of this thesis, which is why perhaps I had experienced so much stress at the thought that someone might open the paper. Intuitively, I knew that we would not open the papers, but even the fleeting thought that my condition might be revealed was enough to provoke an acute stress response. It was in that moment that I realized that I was also an insider in some ways. Before this experience, I had not thought much of my condition in terms of stigma. As I progressed with my research, however, I began to notice how my life too had been circumscribed by the stigma of my condition—but perhaps to a lesser degree than those living with HIV. Although I did not disclose my condition to my research participants in

order to maintain professional distance, I felt that my stigma allowed me to establish closeness with my participants who initially felt mysterious and Other to me.

Despite my personal insights into living with a stigmatized condition, I was also an outsider in many ways. As a white, cisgender,[5] straight, educated, upper middle class woman, there were moments where my encounters with my research participants made me acutely aware of my own privilege. For example, I remember feeling so uneasy when I met with Judith in her dilapidated work office in a rundown part of D.C., the part that I never visit and that tourists never see. I felt uncomfortable witnessing the stark inequalities that exist in this "other world" that lies only a few miles from the White House. Furthermore, I felt somewhat guilty knowing that I could leave this "other" world at any moment; that I could come and go as I please, knowing that I can return to the comfort and safety of the well-manicured Maryland suburbs. Those whom I was "studying," however, did not have that luxury.

Being an outsider certainly made me feel uneasy. During the interviews, I often worried about whether I was viewed as a legitimate researcher in the eyes of my participants. I had recurring doubts about whether I could accurately and fairly portray the individuals and communities that I was researching. Indeed, I had no personal experience with HIV, and my life circumstances seemed to be completely different than those of my participants. In order to counteract this uneasiness, at times I would try to assert my credibility by calling attention to the ways in which I was similar to my

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[5] Cisgender refers to people whose biological sex at birth matches their gender identity. That is, cisgender is opposite of transgender.

participants. For example, on different occasions I brought up the fact that I too was an immigrant; that I was knowledgeable about Latin American culture since my spouse is from Mexico; and a few times I tried to communicate with my participants in my broken Spanish. Perhaps these were efforts on my part to minimize the overtness of my outsider status, which I believed might interfere with rapport-building and undermine my legitimacy as a researcher trying to understand an unfamiliar world.

I also began to question the ethics of my own motivations—as well as the motivations of anthropology as a discipline—to pursue research on "vulnerable" and marginalized populations. *Why are anthropologists and social scientists often drawn to the "vulnerable," as if we receive some sort of voyeuristic pleasure by witnessing the suffering and plight of others? Was I contributing to the stigmatization of certain groups by focusing exclusively on their vulnerability and suffering? Is it ethical that I am the one who stands to gain the most from this research—was I merely "using" participants for my own benefit?* Questions such as these often circulated through my mind. I felt especially uneasy knowing that my participants will not be getting any direct benefit from my research, and that I was the one who stood to gain the most. Perhaps it would have been wise for me to follow Nader's (1972) suggestion of "studying up," that is, studying the privileged and the powerful, rather than the disadvantaged and powerless. It is certainly interesting to think about how my research would have been different had I asked questions such as *Why are certain people **unlikely** to get HIV? Why are certain groups **not** socially stigmatized?*

Despite my obvious position as an outsider, I did not feel that that this interfered with my ability to establish trust and rapport with my participants. For the most part, I felt that everyone was eager to share and talk about their experiences with me. Perhaps this would have been less easy had I been a white man. As Brandon had told me during our interview, everyone is socially disadvantaged (or privileged) in some way. My disadvantage, he pointed out, was my gender. In the end, I felt that this "disadvantage" may have reduced some of my "white guilt," and allowed me to abate some of the power inequalities that are inherent in the research encounter.

Co-constructing Knowledge

At times during the interviews, I would become frustrated when a participant would not be direct with answering a question, or would avoid the question entirely and shift the conversation to a new topic. However, I learned to adopt the mindset that ethnographic knowledge is co-constructed by the interviewer and the participant. Kvale (1996) has differentiated between two approaches to the research interview by using the metaphors of the "miner" and the "traveler." The miner approaches the interview with the intention of finding the "buried treasure"—"facts waiting to be culled out and discovered by the interviewer's efforts" (paraphrased in Heyl 2001:370). The traveler, on the other hand, views the research process as a journey through which knowledge and meaning are co-constructed by the interviewer and participant. Kvale (1996:4)

> notes that the original Latin meaning of *conversation* is 'wandering together with'. The route may be planned ahead of time, but will lead to unexpected twists and turns as interviewer-travelers follow their particular interests and adjust their paths according to what those met along the way choose to share (paraphrased in Heyl 2001:371).

Sometimes I would press participants to answer questions regarding their experiences with stigma, but they would not have much to say about it and instead veered the conversation into another direction. For example, at one point I became frustrated when Brandon, who contracted HIV perinatally, insisted that he had not experienced much stigma. My assumption that everyone with HIV must experience some form of stigma was challenged. At first, instances such as these would frustrate me, but later I realized that everything is data, even the information that is omitted. In addition, my conversations with Brandon, Judith, and Elena forced to think more critically about the salience of stigma in certain communities where larger social problems—such as poverty and homelessness—are rampant. By allowing each interview to unfold naturally, I was led to new and unexpected insights that later became integral to my thesis.

The purpose of this study is not to establish objective "facts" about HIV stigma, or to reach conclusions about what certain groups of people are like. Rather, I have approached this thesis with the full acceptance of the notion that all truth is partial (Clifford 1986) and positioned (Abu-Lughod 1991), and that the research that I have presented in this thesis has resulted from the unique interaction between my participants and myself.

In the next two chapters, I turn to my literature review, where I provide background information on the social contours of the HIV/AIDS epidemic and outline anthropological contributions to the stigma literature.

CHAPTER THREE: HIV/AIDS IN THE UNITED STATES AND BEYOND

"Many illnesses that enter the clinic represent tragic experiences of the world." –Nancy
Scheper-Hughes (1990:194)

The purpose of this chapter is to provide background information on the

HIV/AIDS epidemic in order to contextualize my research findings. I begin by outlining

the biology of HIV/AIDS, and then I describe the social epidemiology of the disease

globally and in the United States and place it within the theoretical context of structural

violence. All statistics refer to the epidemic in the United States, unless otherwise noted.

Biology and Transmission

The human immunodeficiency virus (HIV) is the virus that causes AIDS. HIV

attacks immune system cells and is spread through the exchange of bodily fluids, such as

blood and semen. Acquired immune deficiency syndrome (AIDS) develops when HIV

destroys so many of the immune system cells that the body can no longer protect itself

from infections. Thus, people do not die from the HIV virus itself, but rather from the

opportunistic infections and diseases that result from compromised immune function

(CDC 2015a).

In the United States, HIV is most commonly transmitted through male-to-male

sexual contact, injection drug use (IDU), and heterosexual contact (CDC 2015b). Less

common ways of transmission are through blood transfusions, pregnancy/childbirth,

breastfeeding, oral sex, and being pricked or cut by an HIV-contaminated object (CDC 2014). In the United States, men who have sex with men (MSM) account for 63 percent of all new HIV infections, even though they represent about four percent of the U.S. male population (CDC 2014). Heterosexual transmission accounts for 25 percent of new HIV cases; IDU accounts for eight percent; and combined MSM and IDU account for three percent (CDC 2014).

AIDS was first clinically observed in 1981 in the United States among a group of five gay men in Los Angeles who presented with symptoms of an uncommon lung infection ("A Timeline of AIDS"). Later that same year, similar cases around the country began to emerge. The early years of the epidemic were shrouded with fear and uncertainty, as nobody knew what was causing clusters of gay men around the country to suddenly fall ill due to weakened immune systems. It was not until 1983 that scientists discovered the virus responsible for AIDS, which would later become known as HIV (Barré-Sinoussi et al. 1993).

Advancements in biomedicine since the early days of the epidemic have transformed HIV from a deadly, infectious disease to one that is manageable and chronic. When HIV was first discovered in the early 1980s up until the mid-1990s, the chances of HIV progressing into AIDS and a subsequent early death were very likely. However, once effective treatments were introduced, a greater number of people were able to live with HIV and the number of AIDS-related deaths declined drastically after 1996 (Osmond 2003). According to CDC (2006), between 1981 and 1995 there were over 551,515 AIDS-related deaths. Between 1996 and 2000, the number of deaths declined to

228,863; and between 2001 and 2004 deaths declined to 157,468. Since fewer people are currently dying from HIV, there are more people living with HIV today than in the past (NIDA 2012), even though HIV incidence (number of new infections per year) has declined drastically since 1985 (Hall et al. 2008). The incidence of HIV has been relatively stable since the mid-1990s (currently around 50,000), and reached its peak between 1984 and 1985 at about 130,000 infections (Hall et al. 2008).

Although there is no cure for HIV, the disease is highly treatable and preventable. Proper medical treatment can reduce the chances of HIV developing into AIDS (Hogg et al. 1998), prevent HIV transmission (Attia et al. 2009; Muessig et al. 2012), and improve quality of life for HIV positive individuals (Nieuwkerk et al. 2001). HIV is most commonly treated with antiretroviral therapy (ARVs), which reduces the amount of virus in the body. ARVs can also reduce an individual's viral load to "undetectable" levels, which significantly reduces the likelihood of passing HIV on to someone else (Cohen et al. 2011). Similarly, ARVs can be used in the form of pre-exposure prophylaxis (PrEP) by individuals who are HIV negative but at "high risk" for contracting HIV (for example, an HIV negative person who has an HIV positive partner) in order to prevent becoming infected (CDC 2015d). Post-exposure prophylaxis (PEP) can be used up to 72 hours after being exposed to HIV to reduce the chances of infection (CDC 2015e). Therefore, as long as individuals have access to quality medical services and adhere to their prescribed drug regimen, they are generally able to manage HIV infection and prevent further transmission of the virus.

However, in the United States, about one-third of individuals living with HIV are not receiving the medical care they need, which is largely driven by the fact that many people are underinsured or have no health insurance at all (The White House Office of National AIDS Policy 2010). In the sections that follow, I expand on the social inequalities that have shaped the contours of the epidemic in the United States.

An Undemocratic Disease

Although overall HIV incidence in the United States has significantly declined since the 1980s, the incidence among certain groups has increased. HIV has progressively become a disease of poor racial minorities, whereas in the early years of the epidemic the vast majority of HIV cases were concentrated among predominantly white, middle-class gay men. According to the Centers for Disease Control and Prevention (2006), between 1981 and 1995, non-Hispanic white men represented the majority of AIDS cases. However, throughout the 1990s and 2000s, the proportion of AIDS cases represented by blacks and Hispanics increased, as the rate among whites decreased. As noted by Osmond:

> The proportion of new cases in whites (not Hispanic) dropped from 60% in 1981 to 43% in 1996 and to 28% in 2001. The proportion of new cases in African Americans rose from 25% in 1981 to 50% in 2001, and the proportion of Hispanics rose from 14% to 20% (2003).

The rates for heterosexual transmission also increased from five percent in 1983 to 28 percent in 2001. Thus, while HIV has made its way into the "general population"—that is, the non-gay population—those most heavily burdened have been racial minorities.

Both blacks and Hispanics have been disproportionately affected by the HIV epidemic. Although blacks represent only 12 percent of the US population, they

represented 44 percent of new infections in 2010 (CDC 2015b). Hispanics represent 16 percent of the US population, but accounted for 21 percent of all new infections in 2010 (CDC 2015b). Among women, the racial discrepancies become all the more striking. Although black women represent only 13 percent of the US female population, they account for 64 percent of all new infections among women (Kaiser Family Foundation 2014).

In certain "hot spots" around the country, the HIV epidemic has taken its greatest toll. In Washington, D.C., for example, 2.5 percent of the population is living with HIV (D.C. Department of Health 2013). The city's black residents are the most affected, representing 75 percent of all people living with HIV, even though they represent only 48.6 percent of the city's total population. The HIV prevalence rate among black men (5.7 percent) is more than double the overall prevalence, and black women represent 92 percent of all HIV cases among women.

Racial inequalities are also evident in HIV health outcomes. Compared to whites, blacks are more likely to die from HIV infection, representing 55 percent of all HIV-related deaths (CDC n.d.). The death rate among black men is around 22.5 percent, whereas it is 2.5 percent for white men (CDC n.d.). Furthermore, blacks are less likely to be prescribed antiretroviral therapy (Gebo et al. 2005; Palacio et al. 2002); less likely to be engaged in care and less likely to have adequate care (Shapiro et al. 1999); and less likely to have "undetectable" viral loads (Mugavero et al. 2009).

As these statistics demonstrate, the burden of HIV in the United States has fallen most heavily on ethnic and racial minority groups. Thus, Merrill Singer has rightfully

referred to AIDS as "an undemocratic disease" since it disproportionately affects certain populations, as opposed to other illnesses, such as influenza, which are distributed throughout the population more or less equally (1994:945). The reasons for these discrepancies in HIV infection across racial lines can be explained within the framework of structural violence, which I explain further in the next section.

Critical Perspectives on HIV

The significance of the HIV pandemic extends far beyond matters of biology, medicine, and science. The disease is also a cultural artifact, bringing into sharp focus the linkages between various forms of power and inequality that have become manifested at the level of individual bodies (Schoepf 2001). As within the United States, it is the disenfranchised and marginalized populations of the global South that have been the most burdened by the disease (Parker 2002). For example, sub-Saharan Africa is home to nearly 71 percent of all people who are living with HIV, where nearly 1 in 20 adults are infected (WHO 2015). The reasons for these discrepancies in HIV infection can be explained within the framework of structural violence. As Parker and Aggleton argue,

> Every society is shaped by large-scale social forces that together define structural violence. These forces include racism, sexism, political violence, poverty, and other social inequalities that are rooted in historical and economic processes that sculpt the distribution and outcome of HIV/AIDS. Structural violence predisposes the human body to pathogenic vulnerability by shaping risk of infection and also rate of disease progression. Structural violence also determines who has access to counseling, diagnostics, and effective therapy for HIV disease. (2005:54-55).

In other words, structural violence infiltrates individual lives through various mechanisms, making them not only more vulnerable to HIV infection about also less likely to receive adequate care. For example, even though effective HIV medications

exist, these therapies are often out of reach for many individuals because they are either uninsured or underinsured. Furthermore, psychosocial stressors such as poverty and racism can reduce immunity (Kemeny and Schedlowski 2007), and therefore render certain individuals more prone to HIV infection.

Some scholars have argued that AIDS is a disease of modernity, emblematic of the consequences of increasing inequalities worldwide due to neoliberal economic policies that have placed significant financial burdens on the countries of the South and the poor within industrialized countries (Parker 2002). According to Parker:

> These structural factors, which shape the HIV/AIDS epidemic within the contours of specific societies, even in the resource-rich industrialized countries, are the same factors that shape the global epidemic, particularly in the resource-poor and often economically dependent countries of the developing world (2002:334).

For example, structural adjustment programs imposed by international financial institutions have forced certain countries to reduce spending on social welfare programs, such as health and education, while also pushing them into greater debt, thereby reducing their resources to effectively address the spread of HIV in their countries (Parker 2002). Within the United States, the economic policies of the Reagan administration, which championed an increase in military spending and tax reductions for the wealthy, were accompanied by cuts in welfare programs and opposition to raising the minimum wage, which pushed many people, especially minority women, into poverty (Zierler and Kreiger 1997). The forces of racism, sexism, homophobia, and many other social "insults" (Quesada et al. 2011) accompanied these structural-level changes, which rendered certain populations more vulnerable to HIV infection.

Much of the anthropological literature on HIV/AIDS is situated within the broader theoretical context of critical medical anthropology (Farmer 1992; Quesada et al. 2011; Singer 1994), which seeks to expose the ways in which structural forces create situations of vulnerability for HIV infection. Critical medical anthropologists have criticized prevailing public health responses to the HIV crisis for being too focused on the individual. These individualistic approaches are indicative of the larger neoliberal discourses on health, which assume individual responsibility and rationality in one's decisions regarding personal health while shifting accountability away from government and social institutions, which Petersen has referred to as the "privatization of risk management" (1996:52). As Schoepf notes,

> The currently dominant biomedical model incorporates capitalist economic assumptions about health resulting from individually chosen lifestyles. It leaves little scope for understanding how behaviors are related to social conditions, or how communities shape the lives of their members (2001:339).

For example, the circulation of "information" on HIV, an approach that has been unsuccessful in reducing HIV transmission (Schoepf 2001), assumes that everyone will make the right decisions if only they have the "right" knowledge about HIV and how it is transmitted. As such, public health approaches have mostly focused on reducing risk "behaviors" while ignoring the social contexts that make certain behaviors more likely to occur. In addition, the focus on health "disparities" within public health obscures the underlying causes of inequality by making it appear as though certain ethnic and racial groups are inherently diseased by linking them with illness, rather than exposing the social conditions that can create these disparities in the first place.

Critical anthropological perspectives suggest that health and illness are configured through various levels of oppression—at the level of race, class, and gender, and, more distally, at the level of political and economic structures (Farmer 1992; Holmes 2013), thereby challenging the perspective that HIV is solely caused by certain "risk" behaviors and lifestyles. Instead, critical medical anthropologists seek to expose how social and political contexts create situations of structural vulnerability that limit life choices, thereby creating "risk environments" (Rhodes et al. 2005) where certain "behaviors" are more likely to occur (Quesada et al. 2011). For example, some individuals might turn to injection drug as one way to cope with the daily stresses of poverty and racism, which in turn increases the likelihood of HIV infection (Singer 1994). Others might seek out sex work as a way to make ends meet, which oftentimes intersects with gender-related power dynamics, as some people may be less able to negotiate condom use with their clients. More often than not, these vulnerabilities tend to be overlapping and reinforcing. As Quesada and colleagues argue,

> Structural vulnerability . . . applies to the poor, the medically uninsured, the sexually stigmatized, people of color, the disabled, the incarcerated and those with drug and alcohol problems. Experiences of vulnerability, however, are only partially shared across populations as they are shaped unevenly by specific status attributes (i.e., gender, age, ethnicity, etc.), conditions (i.e., legal status, economic and living conditions, etc.) and individual serendipity (2011:5).

Thus, not only do structural forces make certain individuals more likely to contract HIV because of the constraints placed on their agency, but these forces often work synergistically to create intersecting and layered experiences of vulnerability.

The HIV epidemic in the United States should not be regarded as a peculiar, isolated incident that has unduly burdened racial minorities. Rather, the disease represents one in a series of multiple afflictions that disproportionately fall on the shoulders of marginalized communities, afflictions which Singer has referred to as "syndemics"—"the set of synergistic or intertwined and mutually enhancing health and social problems" (1994:933). HIV requires us to think more deeply about power and inequality, and how and why certain individuals become more likely than others to experience various forms of social suffering throughout their lives (Farmer 1996). Thus, it is necessary that we conceptualize HIV within the wider theoretical context of structural violence, which asks us to consider "how various large-scale social forces come to be translated into personal distress and disease" and the mechanisms by which they "become *embodied* as individual experience" (Farmer 1996:261[original emphasis]). Castro and Farmer (2005) argue further that structural violence can also be used to understand how HIV stigma operates. In the next chapter, I expand on the link between stigma and structural violence.

CHAPTER FOUR: STIGMA

In addition to HIV/AIDS, anthropologists have addressed stigma across a wide range of medical conditions, including leprosy (Barrett 2005), chronic pain (Jackson 2005), epilepsy (Kleinman et al. 1995), schizophrenia (Jenkins and Carpenter-Song 2008), male infertility (Inhorn 2004), involuntary childlessness (Nahar 2014), cervical cancer (Gregg 2011), and abortion (Kumar 2009). What sets the anthropological literature apart is that it examines stigma from the perspective of those individuals who actually experience it. In other words, anthropologists have approached stigma as an embodied, *lived experience* in a particular local world at a particular moment, instead of a universal phenomenon that is identical across contexts. By using ethnographic methods to study stigma, anthropologists are able to provide a holistic interpretation of stigma in terms of its subjectively experienced meanings and its connection to individuals' broader sociocultural context.

In this chapter, I provide a literature review of the stigma concept as it has been used by anthropologists to analyze HIV/AIDS and other conditions. First, I provide an overview of the existing ethnographic research on HIV stigma. Then, I outline anthropological theories that link HIV stigma with structural violence. Finally, I outline the cultural metaphors of HIV/AIDS that have proliferated throughout the course of the epidemic in the United States. Although my regional focus is the United States, I

incorporate literature from other cultural settings, as there is a dearth of anthropological

literature on HIV stigma, and stigma in general.

Functions of Stigma

Some stigma theories suggest that stigma fulfills specific functions in a society.

Evolutionary psychologists have argued that stigma serves as a self-protective response

to perceived threats. Kurzban and Leary (2001) have put forth the argument that social

exclusion is ubiquitous across all human cultures, even among non-human animals, for

various reasons in order to ensure evolutionary fitness, that is, species survival. Avoiding

individuals who carry contagious diseases is one pathway through which this is

accomplished (Kurzban and Leary 2001). As such, HIV stigma can partially be attributed

to contamination fears associated with a potentially deadly infectious agent. However,

contamination fears do not fully explain why HIV is so stigmatized, since there are other

fatal infectious diseases that do not carry nearly the same negative symbolic weight as

HIV, such as Ebola or tuberculosis. Furthermore, the development of effective HIV

therapies in the mid-1990s has transformed HIV in the United States into a manageable

chronic illness rather than a fatal disease that noticeably degrades the human body. Thus,

fear of contamination may be a less salient source of HIV stigma in the US than it was

previously. It is possible, however, that despite these advancements in biomedicine, the

image of death and suffering associated with HIV has continued to linger in our

collective memory.

Certain conditions can also be threatening in a psychological and moral sense. As

argued by Yang and colleagues (2013), stigma is a highly moral experience as the

stigmatized condition in question threatens what matters most to individuals in a particular cultural setting. For example, first-onset psychosis threatens the American cultural values of self-reliance, independence, and the need to establish intimate bonds, which are all central components of adolescence or early adulthood—the developmental period when most initial psychotic episodes occur (Yang et al. 2013). The authors note: "Stigma, we hypothesize, *threatens the loss or diminution of what is most at stake, or actually diminishes or destroys that lived value*" (Yang et al. 2013:1530 [original emphasis]).

Along similar lines, Jean Jackson (2005) argues that one reason why chronic pain patients are stigmatized is because their condition threatens our culturally-defined categorical distinctions between mind and body. Chronic pain—which is subjectively real yet undetectable by biomedical instruments—creates liminal creatures out of patients because they "transgress the categorical divisions between mind and body and confound the codes of morality surrounding sickness and health" (Jackson 2005:332). They are viewed as "out of place," betwixt and between, thus threatening the "naturalness" of our culturally accepted notion of Cartesian dualism, thereby bringing to light the limitations of biomedical authority. In other words, chronic pain patients challenge the prevailing social order.

HIV, like other sexually transmitted diseases, disrupts core American values concerning sexuality—that is, that the only morally "correct" way to have sex is within the context of heterosexual marriage. Alan Brandt (1988) draws parallels between the moral panic caused by sexually transmitted diseases in the first half of the twentieth

century, which were associated with the wave of new immigrants who threatened to "pollute" the middle-class with venereal diseases. He notes, "AIDS raises a host of concerns traditional to the debates around venereal infection, from morality to medicine, sexuality and deviancy, prevention and intervention" (Brandt 1988:425). However, at the same time, Brandt argues that "AIDS is different" because "it has threatened our sense of medical security" (1988:425). Around the time AIDS became an issue, fears about epidemics had long been erased from the collective memory of Americans, but the AIDS epidemic rekindled these fears. Thus, in many ways, AIDS dismantled our trust in scientific experts to protect the public from infectious diseases. Once again, the prevailing social order had been challenged.

In a more general framework, stigma may also function to provide a sense of order and security among the general public by separating "the normals" from a dangerous and polluting Other. According to Mary Douglas, cultural beliefs about pollution, dirt, and cleanliness are ubiquitous throughout all human societies, and their purpose is to maintain social order In *Purity and Danger*, she argues,

> Ideas about separating, purifying, demarcating and punishing transgressions have as their main function to impose system on an inherently untidy experience. It is only by exaggerating the difference between within and without, about and below, male and female, with and against, that a semblance of order is created (Douglas 1966:5).

When viewed through this lens, stigma may not only function to protect people from obvious threats, but it may also serve to create a "semblance of order" within the midst of life's chaos.

Stigma and Agency

Anthropologists' contributions (e.g., Gregg 2011; Grove et al. 1997; Nahar and van der Geest 2014; Whittaker 1992) have also helped reframe the stigma experience as a site of agency and struggle rather than focusing exclusively on victimization. In this literature, the stigmatized are not merely regarded as victims of misfortune, but also as creative actors who have the ability to make choices and intervene in their own destiny. This research forces us to consider the various contours and manifestations of agency and resistance in the context of stigma, and also the ways in which individuals strive to make meaning of their experiences of social exclusion.

While the concept of agency is oftentimes equated with resistance, agency does not necessarily have to be reduced to it. Jenkins and Carpenter-Song (2008) examined how individuals who have recovered from mental illness employ strategies in order to deflect and resist the stigma they encounter. Even though the strategies they use are examples of agency, they are not necessarily forms of resistance but instead serve to make life more bearable for the sufferer (e.g., avoiding socializing with others who have a mental illness; attempting to "pass" as normal). Gregg (2011) makes similar observations based on her research on women with cervical cancer in Brazil. Rather than challenging stigma, some of the women embraced stigmatizing metaphors of their illness as a way to affirm their adherence to existing cultural norms, thereby asserting their belonging to the wider community from which they were otherwise excluded on the basis of their stigmatized illness. Gregg concludes,

> I would caution, then, that before we rush to "belabor" metaphors, or to assume that stigma will be resisted because it seems clear that it should be

resisted, we pause to consider what else, what other uses metaphor, even stigmatizing metaphor, may serve in lives of the ill (2011:81).

Similarly, Nahar and van der Geest (2014) propose the idea of resilience as agency. In their study on the stigma of involuntary childlessness among women in Bangladesh, they found that some women actively chose to tolerate abuse by their husbands as a way to prevent divorce and abandonment, which may result in worse consequences for the women in the long run than outwardly resisting stigma. Perrson and Richards (2006) challenge the view that "coming out" as HIV positive is always beneficial. In their study of HIV stigma and disclosure among heterosexuals living with HIV in Australia, they found that disclosure was not helpful because HIV had no "cultural resonance" among heterosexuals and thus they did not have a platform where they could share their experiences with others in a way that is meaningful and beneficial. On the other hand, "non-disclosure was the key to 'normalcy,' the key that ensured life would go on as if nothing had changed even though everything had" (Persson and Richards 2008:76). As this body of research highlights, it is sometimes not in the best interest of actors to resist or challenge stigma because in certain instances they may have more to lose if they do so, while conversely they might be better able to protect themselves if they do not challenge stigma.

Anthropologists have also examined how PHA assert their agency by creating empowering identities for themselves in the face of stigma (Grove et al. 1997; Persson 2005; Stanley 1999; Whittaker 1992). Whittaker's (1992) study of HIV stigma in Australia examined how seropositive individuals invert common negative metaphors of AIDS as a way of resisting stigma—for example, by defining AIDS as "simply a virus"

rather than viewing it as a punishment. Whittaker notes, "This counter discourse of [HIV] among positive people transforms them from objects of the medical gaze into active subjects" (1992:388). Similarly, Persson's (2005) research on the bodily visibility of HIV medication side effects among gay men in Australia suggests that the PHA can transform stigmatizing labels generally associated with HIV into empowering identities, thereby leveraging their HIV status to create a stronger sense of community.

A few anthropologists studying HIV stigma have addressed how social capital influences agency in response to stigmatization. In their study of HIV positive white, middle class women, Grove and colleagues (1997) argue that symbolic capital allows some women to have more control over the management of stigma, and thus evade the blame often associated with HIV infection. In contrast to other PHA with less social capital (i.e., those who fall into the traditional "risk groups"), white middle-class women are better able to elicit sympathy from others and evade ostracization from the community when they disclose their HIV status since they were "innocent victims," that is, they had primarily become infected through their long-term partners rather than through "promiscuous" sex or drug use. Similarly, Stanley (1999) explored how white middle class women manage HIV stigma, and found that women were able to manage their stigmatized identity by invoking spiritual rhetoric, such as reframing their infection as a "blessing," "calling," or a "gift from God."

Structural Violence

Anthropologists have encouraged an epistemological shift away from overly individualistic theories of HIV stigma, and have instead situated stigma within the

broader theoretical context of structural violence (Abadia-Barrero and Castro 2006; Castro and Farmer 2005; Parker and Aggleton 2003). These scholars argue that stigma represents as an outgrowth of various social structures of power and domination, and that stigma reinforces, reproduces, and legitimizes existing social hierarchies and inequalities. As Parker and Aggleton argue,

> Ultimately . . . stigma is linked to the workings of *social inequality* and to properly understand issues of stigma and discrimination, whether in relation to HIV and AIDS or any other issue, requires us to think more broadly about how some individuals and groups come to be socially excluded, and about the forces that create and enforce exclusion in different settings (2003:16 [original emphasis]).

In other words, stigma is a part and parcel of the larger issue of social exclusion. This view holds that stigma is a social process, rather than a static "thing," through which "othering" occurs and hegemonic structures are reproduced. Some scholars also suggest that stigma can most effectively be challenged by community mobilization and resistance on the part of the stigmatized (Parker 1996; Parker and Aggleton 2003). Such approaches towards HIV/AIDS stigma may be more effective than simply trying to change attitudes—which has been the focus of most HIV stigma interventions thus far—as they have the potential to radically transform the social structures that produce stigma in the first place (Parker and Aggleton 2003).

The reality that stigma is configured along the fault lines of power and domination is most evident in the fact that stigma disproportionately affects individuals who are already marginalized—based on their class, race, gender, sexuality, or citizenship. As Castro and Farmer (2005) argue, among HIV positive individuals, women and minority groups are at increased risk to become victims of stigma, while individuals

living in poverty—regardless of race or gender—are the most likely to experience stigma. Conversely, the possession of social capital may help certain individuals cope and more effectively "manage" their "spoiled identity" (Grove et al. 1997; Stanley 1999). Thus, one's position in the social hierarchy can influence the way that stigma is experienced.

Stigma in Contexts of Poverty

Some scholars working in sub-Saharan Africa have suggested that HIV stigma may be linked with economic productivity (Tsai et al. 2013a). Because AIDS seriously undermines individuals' capacity to engage in physical labor, it thus renders them incapable of contributing economically to the family and community. In turn, their perceived "uselessness" within the community is what drives the stigmatization of AIDS (Tsai et al. 2013:1). Tsai et al. (2013) suggest that one way to reduce HIV/AIDS stigma in this context would be to provide livelihood interventions to reduce poverty, such as socioeconomic support, but also provide effective AIDS treatment so that patients can return to being economically productive members of their community. Similarly, research from sub-Saharan Africa (Tsai et al., 2013b) and Brazil (Abadia-Barrero and Castro, 2006) suggests that greater access to effective HIV treatment may reduce HIV/AIDS stigma by improving self-efficacy and therefore economic productivity.

Castro and Farmer (2005) have taken a critical stance on the strong emphasis on stigma reduction within the context of HIV/AIDS treatment and prevention. Their research on AIDS in Haiti led them to conclude that stigma "has become . . . one more argument used to walk a slow walk to fight the pandemic" (Castro and Farmer 2005:53). The authors argue that lack of access to effective HIV treatment, poverty, and social

inequality—not stigma per se—are driving HIV infection rates. Abadia-Barrero and

Castro have made similar observations based on their research among HIV positive

children and adolescents in Brazil:

> Our data shows that a child's experience of stigma may be that of being a poor, black, orphan, pre-adolescent girl coming from poor northeastern Brazil and living with HIV in a specific support house and not only about being a 'child living with HIV' (2006:1225).

In other words, multiple forms of oppression render individuals more vulnerable to

stigma and intensify their experiences. For many people suffering from HIV globally,

stigma is but one socially inflicted "insult" (Quesada et al. 2011) among a legacy of

multiple insults. Combatting stigma will require that these intertwining forces of social

exclusion that produce stigma in the first place be addressed, because stigma is "both a

cause and consequence of inequality" (Castro and Farmer 2005:58).

Metaphors of HIV/AIDS

As cultural critic Paula Treichler (1987) observed in her essay *AIDS,*

Homophobia, and Biomedical Discourse: An Epidemic of Signification, numerous

meanings have been attached to the word AIDS, both in official sources and through

rumor. Some examples of this include the following beliefs about AIDS: that it is "a

fascist ploy to destroy homosexuals," that it is "the price paid for anal intercourse," and

that it is a disease that "threatens to wipe out the whole world." (These are just a few of

the nearly forty conceptualizations of AIDS that Treichler lists in her essay.) The fact that

there have been so many meanings attached to AIDS, argues Treichler, attests to the

word's "enormous power to generate meanings" (1987:31).

However, metaphors do not appear by happenstance, or at random. Rather, they develop out of existing hierarchies of power and inequality. Parker and Aggleton suggest that Pierre Bourdieu's (1977) notion of symbolic violence is useful for understanding how stigma operates within society to legitimize "othering" and social exclusion:

> 'Symbolic violence' describes the process whereby symbolic systems (words, images and practices) promote the interests of dominant groups as well as distinctions and hierarchies of ranking between them, while legitimating that ranking by convincing the dominated to accept existing hierarchies through processes of hegemony . . . [which] is achieved via a complex interlocking of political, social and cultural forces which organize dominant meanings and values across the social field in order to legitimize the structures of social inequality, even to those who are the objects of domination (2003:18).

Symbolic violence accounts for how domination is reproduced through symbolic linkages, and also how those who are oppressed come to accept their domination as normal and "natural," making resistance to these structures less likely and more difficult. In the case of HIV stigma, symbolic violence is perpetuated through cultural metaphors that have circulated through society. These metaphors, in turn, reinforce existing hierarchies by making these hierarchies appear natural and legitimate. For example, linking HIV with certain "risk groups" (e.g., drug users, blacks) is a form of symbolic violence, as such linkages make it appear as though these groups are inherently diseased and Other, thereby further legitimizing their social marginality.

Since the early years of the epidemic in the 1980s, AIDS has been synonymous with the "dangerous Other," and these symbolic linkages have proliferated within both scientific and lay discourses (Sontag 1989; Treichler 1987). AIDS was viewed as an "exotic" and "alien" disease, threatening to pollute the American public. The condition

was shrouded with much uncertainty and mystery. A popular theory in the United States was that AIDS originated in Africa. As Susan Sontag argues,

> . . . illustrating the classic script for plague, AIDS is thought to have started in the "dark continent [Africa]," then spread to Haiti, then to the United States and to Europe . . . The subliminal connection made to notions about a primitive past and the many hypotheses that have been fielded about possible transmission from animals (a disease of green monkeys? African swine fever?) cannot help but activate a familiar set of stereotypes about animality, sexual license, and blacks (2001:139-40).

These beliefs about the origins of AIDS construct the disease as stemming from the dangerous and threatening Other that will contaminate the rest of society, thereby reinforcing the divide between "us" and "them."

Initially, AIDS was considered a "gay disease" among scientists, and its transmission was often attributed to their hedonistic "lifestyle" of promiscuity and recreational drug use. Indeed, before the name AIDS was officially chosen, some scientists unofficially adopted the name gay related immunodeficiency disorder (GRID) in 1982 (Altman 1992; Kher 2003). As Steven Seidman (1988) argues, "AIDS . . . provided a pretext to reinsert homosexuality within a symbolic drama of pollution and purity" (quoted in Epstein 1996:78). In the biomedical literature, the gay male body was frequently portrayed as "sexually potent and adventurous" (Treichler 1987:65). In an article entitled "AIDS: The Latest Scientific Facts," which was published in 1985 in the science journal *Discover,* John Langone noted that AIDS is "largely the fatal price one can pay for anal intercourse" (quoted in Treichler 1987:37).

In addition to gay men, other "deviant" and "immoral" populations were considered responsible for spreading AIDS, such as sex workers and intravenous drug users. Alan Brandt argues,

> AIDS, like other sexually transmitted diseases in the past, has been viewed as a fateful link between social deviance and the morally correct. Such fears have been exacerbated by an expectant media. "NO ONE IS SAFE FROM AIDS," announced *Life* in bold letters on its cover. Implicit was the notion that "no one is safe" from gays and intravenous drug abusers. The disease had come to be equated with those who are at highest risk of suffering its terrible consequences (1988:428-29).

Furthermore, AIDS was stigmatized due to it being a sexually transmitted disease (Brandt 1988) and thus evoked metaphors of "pollution" (Sontag 1989:17). For example, Bryan Turner (1984) argues, "with regard to sexually transmitted diseases in general, the diseased are not seen as 'victims' but as 'agents' of biological disaster" (paraphrased in Treichler 1987:64).

AIDS discourses have also constructed the solution to AIDS as a purely individual and behavioral endeavor (Brandt 1988). That is, there is a widespread belief that HIV infection rates could be curbed and eradicated if only individuals adjusted their behavior accordingly and acted "morally." This point of view ignores the larger sociopolitical forces that drive the epidemic, and thus serves to reinforce AIDS stigma, as it "blames the victims" for their poor health. For example, public health initiatives overemphasize the role of individual "risk behaviors" in HIV transmission—which sends the message that individual decisions are responsible for incidence rates—while giving less attention to the myriad social inequalities that constrain life choices and limit opportunities.

Another source of HIV/AIDS stigma comes from its association with suffering, death, and decay. As Sontag asserts, AIDS is "the generic rebuke to life and to hope" (1989:19). Indeed, AIDS has come to signify not only social deviance, but also social "uselessness" that comes with being seen as chronically ill and beyond help, and thus "socially dead" (Niehaus 2007; Sontag 1989). As with Jackson's (2005) chronic pain patients discussed above, perhaps we can even regard AIDS patients as occupying a liminal space, that is, dead-yet-alive, "corpses that live," thus transgressing prevailing boundaries between what constitutes dead and alive. The metaphor of death is perhaps less salient in the present-day United States than it is in parts of the global South where an HIV diagnosis is more likely to lead to disfigurement, disability, and premature death due to insufficient resources for HIV treatment and care in contexts of dire poverty (Farmer 1992). Nonetheless, AIDS in the United States is still a "deeply problematic signifier" (Treichler 1987:70) that carries profound social and cultural consequences.

These metaphors bring to light the multidimensionality of HIV stigma. Indeed, the sources of HIV stigma are multiple and complex, spanning across the biological, cultural, and moral dimensions. In the next chapter, I turn towards my research findings where I illustrate how the experience of HIV stigma is deeply interconnected with and shaped by other forms of social exclusion.

CHAPTER FIVE: "WE FACE FIVE TIMES THE DISCRIMINATION": INTERSECTIONALITY AND THE STIGMA EXPERIENCE

In this chapter, I explore how HIV stigma is intertwined with other forms of social exclusion (other "stigmas") by presenting findings from interviews. Instead of dividing the data into themes, I decided to separate each section by participant in order to highlight their unique experiences. Each section is more like a narrative or case study so to give each participant a voice. My goal is to highlight the uniqueness of each narrative in terms of layered forms of discrimination, while at the same time not losing sight of the structural violence that links these narratives together. I conclude the chapter by discussing the importance of approaching stigma from the standpoint of intersectionality (Crenshaw 1991).

Elena

I met with Elena one dreary March afternoon at her work office in a predominantly Latino neighborhood in D.C. Elena is a transgender woman in her late 30s who has been involved with HIV activism for many years. She immigrated to the United States from El Salvador in 2009, and has been living with HIV since 1999. She first came to the country illegally, but was later able to obtain legal status by seeking asylum based on her gender identity. Our conversation revolved around her personal experiences and the experiences of her wider community (transgender Latinas) in both El Salvador and the United States. Elena recounted the difficulties her community faces in her home country:

> You know in my country, it's really hard for us to live as transgender
> because they don't know anything about it, and we're always just like
> something weird for them, like, "no, you're a gay guy" or "you're a woman,
> but you're different." So it's really hard, because if you don't do what the
> heteronormatives say, you're excluded from the society. No work, no
> education, no nothing . . . We are facing transphobia, and discrimination,
> and violence because of who we are.

Elena went on to mention that transgender people are also marginalized from the LGBTQ

subculture as well, because they are viewed as lying outside of the normal in terms of

transgressing gender categories. Even here in the United States, Elena explained, there is

persistent discrimination against transsexuals, especially when it comes to applying for

work.

For Elena and her community, the issue of gender discrimination is further

complicated by vulnerabilities related to immigration status. Elena told me that many of

her "sisters" (other transgender Latinas) in the D.C. area resort to drugs, alcohol, and sex

work to get by, and they stay in unhealthy relationships because they do not have access

to work since many of them are undocumented immigrants. Thus, they are less able to

negotiate safe sex with their partners, which increases their risk for HIV. Elena recalled,

"They don't fight for their rights. Because they are not confident. Because we are fleeing

from this violent country, and when you come here and you don't have papers, you don't

have anything, so you become more afraid." Being undocumented makes people

particularly vulnerable, as sexual partners can threaten to call immigration if they do not

do as they are told:

> There's a lot of drugs, alcohol, and sex work in this community. And it's
> really hard for my sisters to leave these kind of men. So, they have to be
> in this unhealthy relationship because they don't have access to work,

because they might be undocumented, and they cannot change the name[6] on the documents to go and look for a job. Maybe they're not passable—that's the term that we use, when you are able to pass as a woman.

Elena's experience speaks to how structural vulnerabilities related to gender identity, immigration status, race/ethnicity, and socioeconomic status intersect to create multiple and layered experiences of exclusion that extend far beyond her HIV diagnosis alone. Thus, Elena was right to state, "we face five times the discrimination."

Hector

Hector is also from El Salvador and he, like Elena, came to the United States illegally in his mid-twenties to escape a civil war back home. Hector is in his early forties and learned that he was HIV positive almost a decade ago. When he first came to the United States, Hector experienced multiple forms of discrimination: "When we got to the Promised Land, I experienced a different kind of rejection and discrimination. I mean, I've been stigmatized for being an immigrant, gay, Latino, not speaking English—or not speaking it well, my looks." He told me about the difficulties he experienced when he came out as gay, which was relatively late in his life, in his mid-20s. At this point he already had a wife and children. In his culture, coming out is considered a "gringo thing," and it is the norm for gay men to stay in the closet their entire life and have "normal" families. He recalled that being a gay Latino man is particularly difficult because of the prominence of religion in their culture. From a young age, he was inculcated with the belief that homosexuality is a sin that is punishable by going to hell. When he finally

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[6] Elena is referring to the fact that transgender individuals may keep their original birth names on their legal documents, which do not reflect their new gender, making employment discrimination more likely.

came out about his sexual orientation, his church pastor told him, "God hates him." His

family called him names as a young child, and by the time he was three years old, Hector

believes that "the damage was already done." That is, he believed that all of these forms

of exclusion that he experienced within his family and in the wider society had a lasting

impact on his self-esteem and the way he viewed himself. He told me that the stigma of

being gay and the negative messages he had received "become a part of who you are" and

"run through our veins."

Hector has been involved with HIV work for many years. He told me about an

intervention that he helped out with, which seeks to challenge the "inner scripts" that

vulnerable populations have been living with their entire lives,

> Inner scripts mean the negative messages that we have been programmed to
> believe over the years as a result of discrimination, racism, immigration in
> our case, homophobia, machismo—all those sort of negative messages that
> we actually learn   over the years, or heard over the years . . . Because
> we hear those inner scripts that we have made our own. We heard them at
> church, in our religion, our culture, our families, our jobs. We have been
> bombarded by those messages from all directions.

Hector used this anecdote to connect what he had experienced personally with the

experiences of others in similar situations. Eventually, Hector explained, these negative

messages become internalized and affect one's self esteem, which in turn cause one to

enter into abusive relationships, abuse drugs, and become vulnerable to HIV infection.

Regarding his HIV diagnosis, he said that a part of him believed that he "got what [he]

deserved." He recalled:

> Even though I didn't completely understand it, I had already internalized
> and absorbed [those messages], and made [them] my own. Running through
> my veins, you know. I guess all those messages maybe eventually made me

more vulnerable . . . I wonder whether I was even looking for what I deserved, unconsciously.

Hector understood his vulnerability in terms of the effects his religion and culture had on him from an early age, which ostracized him for being gay. In Hector's narrative, religious beliefs and homophobia intersect with the experience of being a Latino immigrant in the United States. Hector's experiences bring to light how various forms of discrimination intersect. His narrative regarding his experience with HIV is intimately connected with his experiences with other forms of social exclusion that have permeated his life.

Ricky

Ricky is a white gay man in his early thirties who recently moved to D.C. after completing graduate school in another state. Ricky was the only participant who was white and born in the United States, with a middle-class background and a university degree. Thus, in terms of his social demographics, he was different than the other participants. The majority of my conversation with Ricky focused on his personal experiences with stigma and living with HIV. This contrasted with the other interviews, where much of the conversation revolved around other forms of social injustice and discrimination in participants' personal lives and their wider community. Nonetheless, Ricky did mention how the identity of being gay influences the experience of HIV stigma:

> I think that as a community, we're told that, you know, as gay men, or men who have sex with men, we're conditioned, I believe that we're conditioned, 'cause you know, that's just a fact. To me, it's a fact. When you think about HIV you think about gay men, and now recently people think about black

women, but they think about black women in relation to having sex with, you know, men who have sex with men.

Young, young Ricky, had barely been sexually active. Not many risk factors. First time I went to get tested, they did everything but wear HAZMAT suits when they came in. And so, every time I would go to a doctor—whether I was going to get tested or not—whatever the medical visit was, when they found out I was gay, they would then jump to all these wild conclusions, and order testing…and give me printouts from WebMD of superviruses and all this crazy shit, and so, when that happens, over and over, when all your experiences, personal experiences in healthcare…

For Ricky, the stigma of having HIV was applicable to him even before he became infected, simply because he came from a social group (homosexuals) that has historically been associated with the virus. Ricky expressed that these experiences have caused him to distrust medical professionals, and created much anxiety for him when he would go to the doctor.

Brandon

Brandon is a black man in his late twenties who has lived in D.C. his entire life. He is currently working towards his bachelor's degree at a local university while simultaneously holding a job as a community health worker serving HIV positive individuals in the District. He contracted HIV through birth, and he does not feel that he has experienced too much stigma because he is considered an "innocent victim." Similar to Ricky, however, he expressed the view that gay men are conditioned to think they will get AIDS: "People think like, 'Well, it's inevitable, I'm gonna get it anyways, so I'm just gonna decide when I'm gonna get it' . . . Or they just assume because of being gay, that it's going to be inevitable that somebody will have it. And it's not always true."

Since stigma was not a big part of Brandon's experience, our soon turned toward the rampant inequalities facing his community, which he views as responsible for the surging HIV rates among blacks. For him, stigma was a "micro issue," since there are so many other forms of social injustice plaguing the black community that perpetuate a range of disparities—including HIV rates. Brandon recalled: "Stigma is a symptom of something else, you know? So these structures that we have created are the reasons why stigma around HIV exists. I mean, in D.C., why is it that the poorest neighborhoods are separated by a body of water?[7]" Brandon went on to discuss his personal experiences of living and growing up in D.C., which he calls a "tale of two cities" due to the fact that the city is heavily segregated by class and race. He himself lives in one of the poorest areas of the city, and he mentioned several problems facing residents in these communities, such as the issue of food deserts and the neglected public education system. Brandon continued:

> At the end of the day, what people do worry about, especially in the communities I come from is, "Am I gonna leave my home, and come back to my home today?" That's what they worry about. "And if I don't get home, is it gonna be because I've been murdered, shot, killed, whatever," you know? And those are the things that people really are thinking about.

For Brandon, the issue of HIV and its associated stigma was a relatively minor problem for his community in comparison to the other daily challenges they face. In an ironic yet humorous tone, he went on to express his frustration at the rampant injustices that plague black communities:

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[7] The Anacostia River separates South East Washington, the poorest part of the city, with the wealthier parts of the city.

I mean, how come African Americans have the highest rate for everything? I mean, can we not be the highest rated for every damn thing? Can somebody else take this one? Why are African Americans always on the top of the list of health disparities? Or crime? Or unemployment? That says something about the *structure*. The systems that are in place against African Americans.

When I asked him about what he thinks is the biggest factor driving the HIV epidemic in the District, his response was curt and without hesitation: "Racism."

Brandon's narrative highlights how the issue of HIV stigma, and HIV more broadly, is really an issue of syndemics (Singer 1994). That is, HIV is just one form of social suffering out of many that plague black communities in D.C. and elsewhere in the United States. Conceptualizing HIV as a syndemic rather than merely an epidemic emphasizes the need for a holistic course of action—one that seeks to address the various structures of inequality that create the conditions for HIV to spread in communities such as Brandon's.

Judith

I met with Judith, an employee of a local health organization, to learn about the stigma faced by HIV positive black women in the District. She was the first person I interviewed, and I came into her office with a bunch of questions prepared about HIV stigma among black women. Although she touched on the issue of stigma, our discussion mostly focused on the structural inequalities in the black community that render black women particularly vulnerable to contract HIV. She discussed various systems of oppression that lie at the heart of the epidemic among black women, and that the poverty experienced by the women also further stigmatizes the disease. I could sense the desperation and frustration in her voice as she listed the multiple forms of oppression

faced by the black women that her organization serves, whose lives are dominated by

poverty, poor healthcare, inadequate housing, and they come from neighborhoods with

failing education systems. She also noted that about 80 percent of the women served by

her organization report injection drug use: "If I open these curtains [in her office],

sometimes you might see people shooting up out there. It's a huge problem." Judith

continued:

> If you take any one of those disparities and explore them, even outside of
> HIV, those are huge disparities that need to be overcome before the HIV
> battle can be won. If you ask me how you get rid of HIV in our community,
> get rid of poverty. You know, how do you do that? Where do you begin?
> So, that's why I differentiate. In that movement [the gay HIV movement],
> there was somewhere they could begin. There was support where you could
> begin . . . And it's just amazing because of that whole web of disparities that
> interlink with HIV, and that's why it will be much harder to get rid of HIV
> in the African American community [than in the white gay community].

My conversation with Judith extended far beyond the discussion of HIV stigma, and even

beyond the issue of HIV. Although I had asked specific questions about stigma among

the women she serves, somehow these larger social issues came to dominate our

conversation. Although I did not get the opportunity to speak directly with any of

Judith's clients, her account brings to light the vast and seemingly endless social

inequities and systems of oppression that perpetuate HIV among black communities.

Intersectionality

As these vignettes illustrate, the stigma of living with HIV is often compounded

by other stigmas—that is, other forms of discrimination and social exclusion. Thus, I

have found it useful to conceptualize stigma in terms of *intersectionality*, which is helpful

for understanding how stigma experiences are varied and unique, but also how these

experiences are structured by intersecting forms of structural violence. Kimberle

Crenshaw (1991) proposed the concept of intersectionality to theorize how gender and

race oppression intersect to create unique experiences of disadvantage for women of

color, in a way that extends above and beyond the experience of each identity on its own.

She argues:

> The problem with identity politics is not that it fails to transcend difference,
> as   some critics charge, but rather the opposite—that it frequently
> conflates or ignores intragroup differences. In the context of violence
> against women, this elision of difference in identity politics is problematic,
> fundamentally because the violence that many women experience is often
> shaped by other dimensions of their identities, such as race and class
> (Crenshaw 1991:1242).

HIV stigma can be understood in a similar light: an individual's experience of stigma "is

often shaped by other dimensions of their identities" (Crenshaw 1991:1242), including,

but not limited to, their race, class, gender, country of origin, and sexual orientation.

Furthermore, these various identities often intersect to create unique and layered

experiences. For example, four out of five of my research participants were gay men, yet

they all had unique experiences of HIV and stigma due to their personal histories related

to their immigration status, experiences with war and conflict, race, cultural background,

and social class. Thus, the tendency to lump the experiences of "gay men" into one

category does not adequately capture how multiple layers of structural violence shape the

course of the subjectively perceived stigma experience.

Although Crenshaw conceptualized intersectionality solely in terms of

disadvantage, I would extend the definition to include intersecting forms of privilege.

That is, a person's subjective experience of HIV stigma can be shaped by their access to

various forms of social capital, as Grove and colleagues (1997) have suggested in their ethnographic study on HIV among middle-class white women. These women, the authors argue, were able to protect their "moral career" despite their HIV status because of their possession of various forms of symbolic capital (e.g, white, educated). Thus, individuals with more social capital may have qualitatively different experiences of stigma than those who have less, and they might also have greater ability to deflect or abate the stigma that is attached to them. For example, in my conversation with Ricky (my only participant who was American, white, and highly educated), I got the sense that his lived experience of social exclusion was qualitatively different from other participants whose lives were marked by multiple forms of social marginalization due to their ethnicity, immigration status, and gender identity.

Adopting the framework of intersectionality can help us understand how and when gender identity (or race, or class, etc.) combined with race (or class, sexual orientation, etc.) influences the lived experience of HIV/AIDS stigma, and how these webs of disadvantage and privilege might hinder or facilitate opportunities for agency. My goal is to encourage a view of stigma as occurring at the nexus of various identities, and I believe that anthropological approaches can useful for capturing the complexity of the stigma experience. By emphasizing intersecting identities in discussions of HIV stigma, we will be better able to account for and understand how multiple webs of disadvantage and privilege operate synergistically to create varied experiences of exclusion. To borrow from Abadia-Barrero and Castro, I argue that for many PHA the experience of stigma and social exclusion is not just about "being a person with HIV,"

but rather it is about being an immigrant/black/transgender (or any other combination of identities) who is *also* living with HIV (2006:1225).

Discussion

The vignettes presented above illustrate how the lived experience of HIV stigma is deeply intertwined with and influenced by other forms of social exclusion. As Castro and Farmer have noted, "stigma is often just the tip of the iceberg" (2005:53), indicative of other forms of structural violence that influence not only who will become infected with HIV but also the subjective experiences of living with the virus. This holistic perspective is important, because it reveals how multiple forms of discrimination and stigma are often co-occuring. It seems that there has been a tendency in the HIV stigma research to focus on how HIV stigma on its own influences health-seeking behavior, mental health, health outcomes, and other indicators. However, the human experience is much more complex than this. Link and Phelan (2006) have pointed to the need to address the impact of combined stigmas, rather than focusing on one stigma alone, because it is ultimately these combined experiences of exclusion that shape life outcomes and individual health.

Although I was unable to tease apart the exact mechanisms through which intersectionality operates to shape the lived experience of HIV stigma, it is possible that one pathway is through the stress caused by perpetual exposure to social injustices, such as poverty and racism, which have been shown to increase psychological suffering (Belle Doucet 2003). Intersecting forms of disadvantage might have a snowball effect, where each additional layer of discrimination further reduces a person's ability to effectively

cope with the emotional and psychological stress of an HIV diagnosis. Hector's account reflects this mechanism. He recalled that the messages that stigmatized individuals hear their entire lives—from their families, communities, and the larger society—eventually become internalized "inner scripts" that negatively impact one's self-esteem. In turn, low self-esteem makes one vulnerable to engage in behaviors that increase the likelihood of HIV infection. Thus, various forms of structural vulnerability can influence psychological health, which makes one more likely to get HIV and also less able to cope with the stigma in the case that they contract the virus. At the opposite end, some people might be better equipped to cope with and manage their "spoiled identity" if they possess one or more forms of symbolic capital, as Grove and colleagues (1997) have suggested.

It is also important to consider the overall salience of stigma when there are more immediate issues at hand, such as poverty, homelessness, and neighborhood violence. Judith, Brandon, and Elena discussed at length the multiple forms of discrimination and injustice facing their communities. Brandon even described stigma as a "micro issue" in the black community—that is, in his view, there were many more pressing social problems than HIV or stigma that needed to be addressed in his community, such as neighborhood violence and racism. These observations force us to consider whether these broader social problems perhaps deserve more attention than HIV stigma in contexts where "managing" one's spoiled identity is perhaps a less urgent priority than finding a place to sleep at night.

My conversation with Ricky (my only white and highly educated participant), on the other hand, focused almost entirely on his personal experience with stigma. He did

not mention any larger social problems facing his community. In this sense, intersecting or layered forms of discrimination may not only influence the subjective experience of stigma, but they also force us to consider whether interventions to reduce stigma might be more salient in certain communities than others. For example, the issue of stigma might be more salient to a person who is HIV positive but otherwise relatively privileged. However, for someone who is living in extreme poverty, overcoming HIV stigma might be less of a concern than finding money for food.

Although the connection between structural violence and stigma cannot be overemphasized, at the same time we must not lose sight of the opportunities for agency in the lives of PHA. In the next two chapters I focus on the active subject, who has generally been absent in HIV stigma research. Specifically, I focus on how PHA respond to and challenge their stigmatized identities in a way that is personally meaningful and significant, thereby "[shifting] away from the exclusivity of victimization and toward the subjectively perceived possibilities for agency" (Jenkins and Carpenter-Song 2008:404).

CHAPTER SIX: TO TELL OR NOT TO TELL? NAVIGATING THROUGH THE POLITICS OF DISCLOSURE

Anyone who has ever revealed a personal secret has likely experienced both the relief of getting something off of one's chest, and also the anxiety and stress of keeping something hidden from the rest of the world. Similarly, disclosing one's HIV status can either be extremely rewarding or awfully devastating, or even a combination of both. At one end, disclosing one's HIV status provides an opportunity to challenge stigma and reclaim ownership of a negative label by transforming it into a tool of empowerment (Paxton 2002). At the opposite end, the moment of disclosure is laden with anxiety and vulnerability, as it can expose PHA to intimate partner violence (Gielen et al. 2000), interpersonal rejection (Derlega et al. 2004), and criminal prosecution (Galletly and Pinkerton 2006). Thus, it is not surprising that some PHA deliberately choose not to disclose their status in order to protect themselves both physically and emotionally. Furthermore, knowing when and how to disclose is anything but easy. PHA often struggle with decisions regarding whether to disclose, when to disclose, how to disclose, and to whom to disclose. The reasons for doing or not doing any of these things are complicated and vary from person to person. Nonetheless, in each case, PHA act with their own best interests in mind in order to protect themselves from assaults on their dignity.

In the present-day United States, HIV differs from other stigmatized conditions—such as quadriplegia or epilepsy—in the sense that it is an invisible condition. That is,

there is usually no way to know whether someone has HIV or not just by looking at them.[8] Through disclosure, PHA deliberately make their illness "visible," which can have both beneficial and devastating consequences. The aim of this chapter is to explore how PHA negotiate the meanings, consequences, and benefits of disclosure in various social situations, and I illustrate how disclosure is a means through which agency is put into practice—either through resilience or resistance. By focusing on the lived experience of stigma within the context of disclosure, I hope to reinsert subjectivity into theoretical discussion on HIV stigma, thereby counteracting the tendency to portray PHA exclusively in terms of victimization.

Coming Out

Across many stigmatized conditions, there is an importance placed on disclosure and "coming out." Indeed, being secretive about one's condition reinforces shame and powerlessness, and Smart and Wegner (2000) have referred to the secrecy surrounding one's identity as "private hell" (quoted in Corrigan et al. 2013). Despite the fact that HIV is "invisible," having a concealable stigma carries many negative psychological consequences. Fear and anxiety arise when there is a possibility that the stigma might be revealed (Pachankis 2007), and inhibiting one's emotions through secrecy can lead to increased psychological stress. On the other hand, openly identifying with one's stigmatized group can positively impact self-esteem (Jetten et al. 2001). As noted by Major and O'Brien, "Groups can provide emotional, informational, and instrumental

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[8] However, Persson (2005) has pointed out the paradox that HIV medications sometimes produce visible side effects, thereby literally "marking" people as HIV positive even though these medications have allowed them to maintain their physical health.

support, social validation for one's perceptions, social consensus for one's attributions, and a sense of belonging" (2005:405). Along similar lines, Corrigan and collaborators (2013) argue that GLBTQ who embrace their identities report less stigma, and have better health outcomes, improved relationships, and greater personal achievement. As this literature suggests, being open about one's HIV diagnosis can potentially counteract the exclusion and isolation often experienced by PHA.

In a two-minute introductory video published on the webpage for the Speak Out Campaign, part of the organization Greater than AIDS,[9] several gay men of color share their experiences of living with HIV, and they provide reasons as to why they "speak out." Here are some of the excerpts:

> Man 1: "In everything that I've been through, the people that I've come in contact with—my mentors, my friends—who've been affected, they've all been the reason as to why I speak out."
>
> Man 2: "I speak out for people of my past, people of my current, people of my future."
>
> Man 3: "I speak out because I don't want other people to suffer in silence."
>
> Man 4: "In the end, I know that there are a lot of others out there who are also afraid, and that's why I speak out."

The key theme that links these excerpts together is that there is a sense of urgency to help others who are in similar situations. Speaking out in this sense is empowering because it gives meaning to one's suffering by transforming misfortune into purposeful action.

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[9] Visit "Greater than AIDS" here: http://www.greaterthan.org/

In another video by Greater Than AIDS entitled "Speak Out: Let's Bring HIV Out of the Closest,"[10] several gay men recall their experiences of living with HIV and being gay:

> Man 1: "I feel like being open about my status and sharing that I am HIV positive with other people is a second 'coming out.'"

> Man 2: "If coming out as HIV positive is parallel to coming out as a gay man, then I can completely understand, because I hid my sexuality from myself and the world for so long, and I felt so alone."

> Man 3: "That's why Speak Out is so amazing to me, because it helps me see that our experience is not all that different. The community we belong to is the same community."

These quotes highlight the fact that speaking out creates a greater sense of community, of feeling connected with others who are in a similar situation, thereby breaking through the feelings of loneliness and isolation that an HIV diagnosis usually brings.

The above quotations are an example of what sociologist Manuel Castells (1997) has termed *project identities*. Project identities "are formed when social actors, on the basis of whatever cultural materials are available to them, build a new identity that redefines their position in society and, by so doing, seek the transformation of the overall structure" (paraphrased in Aggleton et al. 2003:12). By speaking out about their HIV status, PHA work towards reducing stigma around HIV by transforming it into a positive identity from a "spoiled identity." Furthermore, speaking out makes one's illness visible, which "gives meaningful expression to their story, thus challenging the anonymity [and] powerlessness" (Persson 2005:241) of carrying a stigmatizing label.

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[10] The video can be viewed here: https://www.youtube.com/watch?v=87I7LcFYXGE

The importance of speaking out was also emphasized by all of my research participants. Hector noted the benefits of speaking openly about his status at work to challenge stigma among his colleagues. He has also shared his personal experiences of living with HIV with others in his role as a HIV counselor, and was invited to speak publically on World AIDS Day at a local university, which he says has helped "heal" him.

For Elena, disclosure was important because it allowed her "to show that [HIV is] not something horrible, or that you're gonna die from it." She also recalled: "When I decided to disclose after five years of silence, I remember going to this support group, and then I got involved in my own group. So, I guess this is part of the importance of disclosure, because you can do a lot of things for your community, and it's going to help you." Elena also told me about the importance of reaching out to others about HIV and educating them, by showing them that you can live a good life with HIV: "When we talk about [our experiences as HIV positive people], it will enable someone to become successful. Because they will be able to say, 'Oh, I can be that person. I can be *better* than that person'. " Both Elena and Hector found disclosure important because it allowed them to help others, and thus allowed them to integrate an unfortunate experience into a meaningful life narrative.

For Ricky, disclosure was cathartic and necessary in order to maintain a healthy identity. Around the time when he first learned about his diagnosis, Ricky felt compelled to disclose to everyone around him. He told me that one day while he was in class, he impulsively just began disclosing to his peers in graduate school because he just had to

"get it out." He felt that holding on to his secret was not compatible with his sense of self. According to Ricky,

> Disclosure plays a huge role in a person's life moving forward. Imagine just keeping a secret from people that you care about. Some people are really good at keeping secrets. Some people hold secrets their whole life and that doesn't bother them. Other people don't like to keep secrets and have a hard time doing that. I have a hard time doing that…I'm always trying to be as transparent as possible, and I wasn't able to do that holding that secret.

Ricky also recalled that it was important for him to speak out in order to protect himself and his partners in the context of dating.

As these examples show, speaking out and being "open" about one's HIV status is one way through which PHA challenge the stigma that surrounds the disease. Bringing one's HIV status out in the open has may benefits, as it can foster a sense of community, counteract loneliness and isolation, provide mental health benefits, and dismantle the self-stigma and shame surrounding the illness.

However, Persson and Richards (2008) have critiqued prevailing discourses that have hailed HIV disclosure as necessary for psychological health, while simultaneously labeling nondisclosure as a deficiency. In their study of disclosure among heterosexuals in Australia, they found that for many participants "non-disclosure was the key to 'normalcy,' the key that ensured life would go on as if nothing had changed even though everything had" (Persson and Richards 2008:76). Furthermore, for disclosure to have any meaning, the authors argue that there must be a platform on which it can be shared with others. In the case of the heterosexual HIV community, however, HIV had "no cultural resonance," which created experiences of isolation in response to disclosure rather than a sense of greater connection with others. As one respondent put it, "In the straight world,

HIV makes you so foreign" (Persson and Richards 2008:77). Thus, the benefits of "coming out" must be carefully weighed against the possible consequences of disclosure, which I describe in the sections that follow.

'You got infected the right way'

In terms of HIV stigma, sometimes *how* you contracted the virus is more relevant than the fact that you have HIV. In their study of HIV stigma among white middle-class women, Grove and colleagues (1997) argue that these women were able to protect their "moral career" (Goffman 1963) when they disclosed how they contracted HIV because of the various forms of symbolic capital that separated them from traditional HIV "risk groups." For example, one of the women recalled that she contracted HIV even though she had slept with only one man her entire life. Other women in the study contracted it from their husbands. In the words of one woman, " 'You got infected the right way, so you're okay. And someone else got infected the wrong way so they aren't. This way of thinking perpetuates discrimination' " (Grove et al. 1997: 334). By disclosing the details of how they contracted HIV, women with significant symbolic capital were able to protect themselves from stigma because they contracted HIV "the right way," that is, through monogamous, heterosexual sex rather than through "immoral" behavior such as injecting drug use.

This vignette contrasts from an anecdote recounted by Ricky. Ricky told me about an incident that occurred a few months back with the man with whom he is currently dating. When they first started dating, Ricky hesitantly disclosed his HIV status, and his partner accepted him for it. However, one night during a phone conversation, he asked

Ricky "how he got [HIV]," a question to which Ricky took great offense. Ricky's

response to his boyfriend's question is worth quoting at length:

> I was like, "You know what, I really like you, but I'm gonna tell you right now, the way you're asking me this, I'm not comfortable answering your question. Because look, I'm not an IV drug user, and we both know that I got it from unprotected sex" . . . I can admit that I was defensive . . . I stood up for myself, and I stood up for other positive people, but in that moment I was like, "The way you're asking me that is making me feel very guarded, and the reason why you're asking me is because you've taken the experience that I've been living for the last three years, and you're just taking that all the way down to the least common [denominator]: the sex act, and the shame around that sex act.

> . . . He interrupted me: "Well, I have other friends that are positive. I'm very supportive, and they feel very comfortable telling . . . because my one friend, he was in a relationship, and his boyfriend cheated on him." I said, "I'm gonna stop you right there, because look, your friend got cheated on by his boyfriend, and they were having unprotected sex, so his boyfriend contracted HIV through that. So you're comparing me to that. So, what I'm getting from this is, he was an innocent victim, because he didn't know that his boyfriend was cheating on him. I, however, hooked up [with a random person] . . ."

> I told him: "I hope that that answers your question, and furthermore, I want to know from you, does the fact that I hooked up with someone make me more deserving of contracting HIV than him? 'Cause the last I checked, the vast majority of people who contracted HIV, they don't *want* to contract HIV." And I said, "and furthermore, I'm not the only person who has had sex without using protection." I said, "I don't know you that well, but I can guarantee with pretty good certainty that you've made mistakes in your life before, and I'm gonna guess that some of them may have been related to sex." So, I said, "the difference is I contracted HIV, and you didn't . . ."

Although Ricky's boyfriend did not reject Ricky because of his HIV diagnosis, the

stigma came afterwards when he asked Ricky *how* he got infected. That is, Ricky was put

in an uncomfortable situation where he was asked to openly disclose the fact that he

contracted HIV through "promiscuous" sex—thus linking him with the shame and

"immorality" associated with non-monogamous sex. Although it is unclear whether his

boyfriend was intentionally stigmatizing Ricky (even Ricky acknowledged that his partner had good intentions), the fact of the matter is that stigma was enhanced when questions arose regarding the mode of transmission.

Ricky's experience contrasts from the accounts of the white, middle-class women from Grove and colleagues' (1997) study who contracted HIV "the right way," and whose disclosure regarding mode of infection served to protect their "moral career." This juxtaposition of experiences highlights how disclosure can have varied meanings and consequences for different people, and also how the ability to manage stigma can vary based on one's possession of symbolic capital.

I did not ask any of my participants how they contracted HIV, as I felt uncomfortable doing so and felt that it was not relevant to my research questions. However, it is worth noting that Brandon divulged the fact that he contracted HIV through birth at the very beginning of our interview, even though I did not solicit this information from him. He told me that he feels that he has not experienced much stigma, and he attributes this to the fact that he falls into the "innocent victim" category. I found similar patterns elsewhere (e.g., from reading about PHA's experiences on blogs and websites), where individuals who contracted HIV through birth were open and direct about how they became infected, as if this information somehow served to protect their identities by separating them from the "guilty victims" of HIV. On the other hand, I have yet to hear or read of an account by someone outwardly stating (without being asked) that they contracted HIV through non-monogamous sex or drug use.

These examples illustrate how disclosure can have different consequences for different people. In the cases where HIV was contracted "the right way," disclosing the mode of HIV transmission can serve to separate oneself from "immoral" others, thereby protecting oneself from stigma while simultaneously reinforcing stigma against those who do not fall into the "innocent victim" category (Grove et al. 1997). However, if you contract HIV the "wrong" way, disclosing the mode of transmission can reinforce stigma. Although Ricky experienced stigma when the issue of mode of transmission was brought up, he resisted the stigma by calling his boyfriend out on his tactless and stigmatizing question. For other people, however, disclosing mode of transmission can be a way to reduce the stigma that is usually associated with HIV by distancing themselves from "immoral" others.

Disclosure, Law, and Violence

The decision of whether or not to disclose one's HIV status extends far beyond the fear of interpersonal rejection and shame. In the United States, disclosure has also become a legal issue. Many, but not all, US states have laws that criminalize non-disclosure.[11] That is, PHA can be charged with a crime—ranging from misdemeanors to felonies—if they know they are HIV positive and expose another person to HIV, regardless of whether or not they had an intention to inflict harm. According to the Center for HIV Law and Policy:

> Currently there are 32 states and 2 US territories that explicitly criminalize
> HIV exposure through sex, shared needles, and, in some jurisdictions,

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[11] For an interactive map of HIV criminalization laws by state, visit http://www.cdc.gov/hiv/policies/law/states/index.html. Washington, D.C. does not have explicit HIV criminalization laws, although Virginia and Maryland do.

through "bodily fluids", including saliva. In these cases, neither proof of the intent to transmit HIV nor actual transmission is required. Sentences for HIV-positive persons convicted of HIV exposure are typically very harsh and disproportionate to the actual or potential harm presented in the facts of the case, perpetuating the stigma that HIV-positive people are toxic and dangerous. Studies show that these HIV-specific statutes and prosecutions have absolutely no effect on behavior, and in fact undermine public health goals (2010).

Not only do these laws perpetuate stigma, they also send the message that it is better not to get tested, since these laws only apply to people who are aware that they are HIV positive. Furthermore, HIV criminalization laws put HIV positive people in a precarious position. On the one hand, they may be putting themselves at risk to experience violence if they disclose their status to an intimate partner. On the other, if they do not disclose, they risk being charged with a serious crime.

Various forms of structural vulnerability can further complicate disclosure. I asked Judith about how HIV criminalization laws make women vulnerable to domestic violence. She recalled:

Last year, the first homicide in D.C. was a woman who was stabbed. She was one of our clients. It was not specific whether he stabbed her because of her HIV status, but given the history that we have had here, it was probably very closely related. And we have had other women who, especially with the housing situation, who go back and forth from shelters, and end up taking space at their partner's, and they become very vulnerable to violence because of their HIV status . . . D.C. does not have any specific HIV criminalization laws, but that doesn't make you exempt. You can still be criminalized because of that. So that, I think, enhances the vulnerability for violence, because you end up staying in a violent situation if he suggests that he may sue you for exposure, or something like that.

Judith's quote brings into focus the mechanisms by which HIV disclosure, structural vulnerability, and the law intersect to create situations where certain individuals become vulnerable to experience violence. In these situations, opportunities for agency are

constrained due to various forms of oppression that work synergistically. Furthermore, the fact that such laws exist perpetuates the message that PHA are somehow equal to malicious criminals and thus deserving of their fate in the case that things do become violent, which further perpetuates symbolic violence against PHA.

During my interview with Elena, she told me about an instance where disclosure was connected to violence. When she stopped at a "safe house" in Texas once she (illegally) crossed the border into the United States from her native El Salvador, a man who did not know that she was HIV positive raped her. She recalled, "It was horrible. And I was thinking, 'Can I tell him that I'm positive? Maybe that's gonna stop this.' And then I was like, 'No, he's gonna kill me.' I was having this in my mind. So, I just asked him, 'if you're gonna do something, please use a condom.'"

Being aware of the stigma that exists around HIV within her culture, Elena anticipated that her disclosure might lead to a disastrous outcome. Thus, she decided that it was best not to disclose at that moment. Elena also mentioned that a previous partner threatened to kill her if she "gave him something [HIV]." At the time, she knew she was HIV positive but decided to keep quiet about it because her boyfriend had a history of being sexually and physically abusive with her. In these two instances, Elena's primary concern was to protect herself from potential violence rather than actively resist stigma. This is reflective of what Nahar and van der Geest (2014) have called resilience. Elena chose her own course of action, and acted upon her choice, which exemplifies her agency. From my research, I have gathered that PHA act with their own best interests in mind when they reach decisions about disclosure, even though the outcome of their

choices is, ultimately, uncertain. Elena and women in similar situations are not merely victims towards whom stigma "happens," but rather they are creative actors who struggle against and resist assaults to their personhood. When we view stigma in this light, we can begin to shift our focus away from the exclusivity of victimization by bringing the active subject into our view.

Dating

For HIV positive gay men,[12] concerns about disclosure arise when it comes to deciding when and how to disclose to a potential or current intimate partner. As Gorbach and colleagues (2004) found in their study on HIV disclosure patterns among MSM in Los Angeles and Seattle, the reasons for disclosure to sexual partners are complex and influenced by various factors. For example, men were less likely to disclose their HIV status to casual sex partners than to partners for whom they had romantic feelings. Other reasons given for non-disclosure included having a low viral load, rejection fears, drug use, and feeling that it is "nobody's business." Reasons given for disclosure included fears of arrest and fears of transmission.

Another issue involves knowing when to disclose: Is it better to disclose at the very beginning of a relationship? Or should you wait until things are getting serious? Further, should you only disclose within "serious" relationships but not random hookups? Such dilemmas are common for PHA, as they frequently have to navigate through the process of disclosure while trying to decide what is the best course of action to take.

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[12] Although this may also be true for people of other identities, the data in this section focuses on the experiences of gay men

Ricky told me that he had experimented with "a wide range of approaches [for disclosure], and got a wide range of responses." At one point he decided to post his HIV status on Grindr[13]:

> I was having a hard time meeting guys, because I didn't know when to tell, so I'd experienced a broad range of reactions when I told them…I just didn't know when; if you're going to hook up with someone, when do you tell them? If you're going on a date with someone, when do you tell them? I was trying to navigate that, right. So, I just put it out there, like, have you heard of Grindr, the mobile app? . . . Yeah, so I had Grindr and stuff, so I put it [HIV status] on my app, I just put it on there, so I used it like a pre-screener, but I experienced a significant amount of rejection because of that, right . . . They just don't reply back, or they reply back really rudely. So, when I would take it [HIV status] off, I would get a lot of responses, but when I would put it on there, I would get like, really shitty responses. So, that was like a self-study, right?

Ricky's "experiment" with Grindr made him acutely aware of the interpersonal rejection that he will have to face if chooses to be open about his status. Since he became HIV positive, Ricky struggled with deciding how and when to disclose. He recalled an instance where the timing of his disclosure led to a bad (and potentially violent) outcome:

> I was out at a bar in Annapolis, because I was living in Annapolis, right, and I met this guy there, and he ended up coming home with me. And I didn't plan on engaging in any risky behavior, but we were in my bedroom and just making out or whatever, and he asked me, "You're not HIV positive, are you?" And I said, "Well, yeah, I am." And he was like, "*WHAT?*" And we can laugh about it, but he got like---he didn't get physically aggressive, but the attitude quickly changed, and he started to insinuate and I was setting him up, and I deescalated the situation and said, "I'm not setting you up" blah, blah, blah, "but you asked a question and I gave you the answer." And he ended up leaving. And, I thought, later, and I told myself after that experience, I would never let that happen again, that I would put myself in that situation, to where this stigma would be so strong that it would potentially put me at risk.

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[13] Grindr is a mobile dating application for gay and bisexual men

After this experience, Ricky decided that he would disclose to his partners as soon as possible in order to prevent a potentially violent situation from unfolding. Ricky admitted that he had not disclosed a few times in the past, but he did not feel good about it because of his personal beliefs. Now, he always discloses at the outset and says that he would not be able to "sleep at night" if he did not disclose upfront.

However, Ricky explained that his friends have different views than him regarding disclosure. One of Ricky's friends believes that if you are just "hooking up" with someone from Grindr, you do not have the obligation to disclose your status as long as your viral load is undetectable. Another friend believes that people should not disclose at the beginning of a relationship, because it will lead to automatic rejection, whereas if one waits for the other person to get to know them more intimately, then they will be more likely to stay with them despite their positive HIV diagnosis.

Brandon had a very different interpretation of "rejection." Brandon says he is very open and comfortable about his status. He has it posted on his Facebook profile, and he recently went on national television to tell his story of living with HIV on a popular cable channel. Although he mentioned being rejected from dates because he is HIV positive, he did not view this as stigma per se:

> I have been told that people don't want to date me because I'm positive. And that's OK. That's perfectly fine, you know? You have a preference, you have a choice, you know? I don't own it as, like, "Oh, he doesn't like me because I'm positive, oh my God." I don't get that dramatic about it. But, I mean, I don't like you because your hair is a color I don't like. You know? . . . Is that stigma? Um, not so much. It's your preference.

For Brandon, being rejected because of his HIV status was a matter of personal "preference" rather than stigma, as he felt that it was the same thing as being rejected

because someone does not like your physical appearance. Perhaps this reframing of rejection as a personal "preference" is one way to mitigate the emotional impact of stigma.

Patrick Ingram, an HIV positive young gay black man, publishes his own blog about his experiences of living with HIV. In a video, he provides guidance and recommendations for others on how to navigate the dating scene. In terms of disclosure, he advises that people disclose by the third date:

> I recommend at least by the third date be prepared to tell someone about your status. One, because you do not get connected, or he doesn't get too connected to you. Because imagine if you have been dating someone for six months, you're falling in love, and then they break that news to you. It's like, wow. Like, "what else are you hiding?" So, that's kind of a major thing. I would say after about three dates, my recommendation, you tell them about your status. Um, but yeah, rejection, it could be that perfect guy, who is just everything that you want, but when they hear those three letters—HIV—they run for the hills. Expect it. Expect rejection. It happens, and it's gonna hurt. I promise you it's gonna hurt. But would you rather hurt for a little bit, or hurt for a long time hiding a secret?

Others, however, believe that it is better to disclose as soon as possible in order to protect oneself from getting hurt even more once a deeper intimacy has already been established. In an op-ed piece[14] published by *The Huffington Post,* Tyler Curry recalls his insights and experiences with disclosure and dating. Curry writes:

> The danger of the "third date rule" is that it allows for feelings to develop, albeit little baby ones. Disclosing your status once a semblance of trust has formed is like placing a loaded gun in front of a person and asking them not to shoot you with it.
>
> …

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[14] The full article can be read here: http://www.huffingtonpost.com/tyler-curry/when-is-the-right-time-to-disclose-your-hiv-status_b_2915880.html

> …I believe in divulging my status before I even agree to the first date. I am not invested before the first date. I haven't begun to scribble their name on my desk pad, incessantly stalk their Facebook wall and wonder if the feelings are mutual. In fact, revealing my status before a first date spares both parties' feelings and satisfies both of our choices.

Thus, even though disclosing at the outset might lead to hastier rejection, it may prevent more hurt in the long term since feelings of intimacy and attachment usually take some time to develop. This contrasts to the views of Ricky's friend, who believes that disclosing too early can scare potential partners away, while they might have been willing to stick around despite the diagnosis if he waits to disclose once the other person "gets to know him" more intimately.

Some HIV positive men commented (in response to Curry's article) that they only date positive men because they do not want to risk transmitting the disease to another person. In these instances where partners are seroconcordant (couples who are both either HIV negative or HIV positive), the risks associated with disclosure are minimized since rejection and/or violence are less likely to occur based on HIV status. In this way, stigma management is manifested through avoidance strategies; that is, avoiding situations where one could potentially be rejected.

These accounts illustrate the various ways that agency asserts itself during the act of disclosure in the context of dating. The process of disclosure involves carefully weighing one's own personal and moral values with the desire to protect oneself from interpersonal rejection and possibly even violence. Disclosure is further complicated by the precariousness of human behavior; that is, everyone will react differently to the news that a partner is HIV positive. This creates even more anxiety and uncertainty for PHA,

as one can never be certain about how their intimate partner will react to the news. Nonetheless, PHA carefully navigate through the process of disclosure, illustrating that PHA "can be not only exceedingly socially aware but also strategically skilled in response to social assaults on their personhood and survival" (Jenkins and Carpenter-Song 2008:404).

Conclusion

In this chapter, I have portrayed PHA not as mere victims of misfortune, but rather as creative actors who direct the course of their own lives. Decisions regarding disclosure are never easy. Nonetheless, PHA do not just "sit there" while stigma is projected "on to" them. Rather, they carefully negotiate the risks and benefits of disclosure and decide which course of action is best while taking into consideration the circumstances that they are in. With this, I have given voice to the active subject, which "reverses the tendency to deny subjectivity to the afflicted with the otherizing assumption that 'nobody's home'" which "impels research toward more explicit attention to fundamental human processes and capacities for subjectivity" (Jenkins and Carpenter-Song 2008:400). This is not to ignore the limitations of structural vulnerability on individual lives, but rather to expose the opportunities for struggle, creativity, and change *despite* the confines of structure. Viewed in this light, we can begin to see PHA not merely in terms of the victimized and marginalized others, but rather as human beings, not all that different from ourselves, who must maneuver through the precariousness of life just as we do. In terms of the cases presented here, the issues surrounding disclosure are reflective of the all-too-human reality that "social fears and anxieties are shared, at

one time or another, by all of us" (Jenkins and Carpenter-Song 2008:400). When we

begin to regard the subjective experiences of HIV as reflective of "fundamental human

processes," perhaps we can begin to minimize the distance between "us" and "them." In

the following chapter, I continue this dialogue by turning to the ways in which PHA resist

stigmatization by transforming their experiences of HIV/AIDS into narratives that are

personally meaningful.

CHAPTER SEVEN: TRANSFORMING THE ILLNESS EXPERIENCE

"HIV doesn't come with good things," Elena recalled. "No. You make those

things happen." Elena's observation speaks to the human capacity to transform

misfortune into an opportunity for growth and change, and in this chapter I explore how

PHA renegotiate their "spoiled" identity by integrating their HIV diagnosis into a positive

life narrative. Given the fact that HIV/AIDS stigma largely operates through the symbolic

violence of metaphor (Sontag 1989; Treichler 1987), the ability of PHA to transform

these meanings into something positive is one way through which stigma can be resisted.

By focusing on how PHA "[integrate] HIV disease into a personally meaningful

framework" (Stanley 1999:117), my aim in this chapter is to reframe the experience of

HIV stigma in terms of both individual agency and as a site through which "fundamental

human processes" unfold (Jenkins and Carpenter-Song 2005).

"Positive" Discourse

One way through which PHA have transformed the meaning of HIV is through

discourse. As Whittaker has noted, PHA resist stigma through "counter discourses"

(1992:386) by inverting the stigmatizing metaphors that are usually associated with the

disease. For example, by reframing HIV as "simply a virus," and by actively intervening

in their treatment and care, PHA are able to reposition themselves as "heroes in a brave

struggle" rather than as vulnerable victims (Whittaker 1992). Elena also transformed the

meaning of HIV by saying that it is "just a virus" and "is not a disability," thereby minimizing the negative symbolic weight of an HIV diagnosis:

> So when you know that HIV is just a virus in your system, and that you can take your medicine and live a normal life, that's something that a lot of people don't know . . . what people don't know is that you can be productive in your community. You can be productive to society. You have a normal life like everyone else . . . I mean, it's not a disability. At least not for me.

In a similar way, I have found that PHA have reclaimed ownership of the HIV label by attaching new meanings to the word "positive." Elena, for example, told me that "if you learn how to live positive, not just in your blood but in your spirit, you're gonna live a beautiful life." In this way, Elena creatively altered the meaning of the word "positive." Similarly, one website called "The Poz+ Life"[15] (which features blogs about written by PHA) has as its subtitle "Positivity is Everything."

Ricky also invoked discourse as a way to transform his experience with HIV. He recalled how a quote by a recently deceased HIV positive friend had inspired him to live his life to the fullest: The quote read: *In the end, HIV was my beginning, not my end.* Ricky says that this quote has been his mantra and has motivated him to live the best life possible, as he "has no other choice."

As these examples illustrate, PHA are engaged in an active "struggle for rhetorical ownership" (Sontag 1989, quoted in Whitaker 1992:386), but also a symbolic ownership, of HIV, by transforming the meanings and metaphors generally associated with an HIV diagnosis. In the following sections, I illustrate further how PHA transform

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[15] Visit the website here: thepozlife.com/

"the stereotypes, roles, and constructions of HIV" from "stigmatizing to affirming"

(Whittaker 1992:389).

Helping Others

As journalist-epidemiologist Elizabeth Pisani cleverly observed, "You never hear

of a flu activist, or a syphilis activist, or even a cancer activist. But 'AIDS activist' trips

off the tongue nicely" (2009:161). Since the early days of the epidemic in the United

States, AIDS and activism have been intimately intertwined. Grassroots AIDS advocacy

groups have successfully fought for access to medicines, and have played a significant

role in "credibility struggles" by challenging biomedical knowledge about the disease and

directing the course of clinical research for HIV/AIDS therapies (Epstein 1996).

Aggleton and colleagues (2005) describe similar success stories in Latin America, where

PHA have successfully organized and initiated lawsuits for access to antiretroviral

therapies.

Within my research sample, all six of the HIV positive individuals were involved

in HIV/AIDS work in one way or more. Some were even involved prior to learning about

their HIV diagnosis, but even in these cases their diagnosis played an important role in

their current line of work. Ricky, for example, had been an HIV/AIDS activist for many

years prior to receiving his own diagnosis. Once he was diagnosed, he told me that his

experiences as a patient have helped him in his professional practice as a social worker,

as it has given him greater insight into the personal struggles PHA face day to day, which

has allowed him to better train healthcare providers who work with PHA. I asked

Brandon, who currently works as a community health worker with PHA in the District

while working towards his bachelor's degree, how he got into this line of work. He

recalled that when he found out he was positive at age 16 (he was infected perinatally),

he was forced to reassess his life's purpose:

> Everything that I'm doing now is an example of how you can take something so devastating, or what's considered devastating, and flip it on its head and do amazing things with it. But, I didn't set out to be in this field. I set out to be an actor, that's all I wanted to do! You couldn't give me another career [laughs]. That's what I wanted to do; that was my aim; that was my goal. So, when I discovered that I was positive that's when I realized, "Oh, acting is not as important to me anymore."

Brandon has also spoken publically about living with HIV, and has appeared on popular

cable network talk shows in an effort to educate others about HIV prevention and reduce

the stigma around the disease.

Hector, who works as a health educator at a Latino HIV organization in the D.C.

suburbs, told me that he really enjoys his job. He said his goal now was to help other

people. He recalled:

> Since I have started working there I have only given five positive results. And it's been a year. And people are probably between the ages of 18 and 21 maybe, they're really young, you know. So, it has felt really good to know that I can actually help someone. And there were times when I found it helpful to come out to them, I'm like "No, no, it's OK, you can be healthy, you can be married, you can be happy" and whatever, you know?

Hector has also spoken publically about living with HIV at events, which he says has been

helpful in his own healing process.

Elena recalled that HIV has "opened many doors" for her by giving her the

opportunity to grow professionally:

> It opens doors for me because I was getting well-known in the community in a good way, because [before] I was known as the party girl, the crazy lady, a lot of things, so, the HIV changed me and gave me another

opportunity to do something good. And that's what I did. I created this [support] group *Ma Nueva Familia*, "My New Family" in English. After that I was meeting with other organizations in [San Salvador]. So, that helped me grow and helped me to give my own group everything that I've learned through the opportunities that I've had, like going to workshops and conferences, going to meetings. So, it really helped me become a leader, mostly.

Elena became involved with HIV work while she was still living in El Salvador, and continues to do so here in Washington, D.C. where she helps youth who are at risk for, or living with, HIV. Even though she kept her diagnosis a secret for several years, and at one point tried to kill herself because of it, she recalls, "So, in the end I felt that HIV wasn't that bad for me, because it opened so many doors for me and for my HIV community." Like Elena, Manual also recalled that HIV "opened doors for him in many ways," in that he was able to help others with HIV, experience new and exciting things, and meet celebrities at HIV fundraising events, such as Elton John and Evan Longoria, and Miss Universe. Manual recalled:

When I was diagnosed with [HIV], I thought that everything was going to be for me *out*. . . . But, at some point, when I started working, when somebody gave me the opportunity to work with the Latino community I said, "Wow. I can work. I can do that." And because of [HIV], I've met people from different levels. Government, entertainment, business, you mention it. I was having dinner with them at one table, Miss Universe . . . So HIV allowed me to meet a lot of people. The international people, the local people, federal people . . . Honestly, that's what I say, "Oh, wow, HIV," and then I try to talk to HIV like my good friend. 'Cause I say, "Listen, you are in my system now so we have to work *together*."

Stanley (1999), in her study of white women's stigma management techniques, found similar observations. The women in her study were able to rebuild their moral identities by engaging in AIDS work in various capacities. Stanley paraphrases Lifton (1979), noting, "a sense of having a special message to spread or a mission to accomplish is

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common among terminally ill persons who devote themselves to public cause"

(1999:111). She comments further:

> Transforming shame and helplessness into activism or advocacy is an interactive and ongoing process reinforced by practice. Initially devastated and ashamed by their own serostatus, these women, over time, adopted a more empowered AIDS identity. Through a commitment to educate others, a sense of purpose and power is channeled and reinforced (Stanley 1999:109).

Transforming the negative symbols often attached to the HIV/AIDS label by integrating

HIV into a meaningful framework allows PHA to better able to cope with their illness

and transcend the stigmatizing metaphors that are generally associated with an AIDS

diagnosis. As Stanley notes, "Whereas the dominant discourses [of HIV] devalue

identity, reconstructing AIDS as a chance to make a worthwhile contribution confers

value" (1999:109). In my sample, PHA actively reconstructed the meaning of an HIV

diagnosis by finding a greater purpose in their illness experiences. Hector summed this up

well when he said, "Listen [HIV], you are in my system now so we have to work

together."

Personal Growth and Transformation

All of my research participants expressed some form of personal growth or

transformation that came out of their HIV diagnosis. Elena recalled how living HIV has

helped her with her character growth:

> [HIV helped me in] my personal life; being more healthy, not partying like I was doing in the past, and being confident in myself, being respectful towards others. So, I think it made me put my feet on the ground, and made me put some goals in my life, like being with my family, being with my friends most of the time in a good way. It helped me a lot, not just professionally but personally.

For Ricky, one way of coping with stigma was to see what kind of lesson he could gain from it. He recalled an experience he had when he moved to D.C. after finishing his master's degree. While Ricky was a graduate student, he was able to utilize the clinic on campus. However, once he graduated, "[he] had to go to the dedicated HIV clinic … [where he] got treated with the same shitiness that all the other HIV patients got treated." Ricky said that he felt disrespected by the clinic staff. For example, he was told not to eat beforehand but then ended up having to wait for an additional hour after his scheduled appointment, and he had to deal with the "snarky health nurse." He recalled that the stigma he experienced in the clinic was very anxiety provoking and distressing. He expressed similar frustration in another incident when he attended a clinic that was staffed by medical students who did not know much about HIV, and Ricky had to provide the students with the education about the virus. I asked Ricky whether his frustration was because he felt that he was not getting the quality of health that he deserved. He responded:

> I try to be real careful to not tap into those areas of privilege that I have and feel entitled, like I *should* be getting better than what I'm getting. That was a very humbling experience for me too, because I've always thought of myself as an advocate and an activist, and I've checked a lot of areas of my privilege. But then when I had to go be a patient at the clinic I had to go to, it was a *whole* other level of checking my privilege, and checking my entitlement. It made me really acutely aware of any type of entitlement that I thought I had … It forced me to acknowledge those things. So, that was a great learning lesson. Every time I've encountered stigma and shitty things, I've tried to really think about what lesson I can get out of that. Like, "Did that help me examine my privilege? Did that help me validate who I am and that I'm doing the right thing?" So, being positive has really taught me that level of insight, which I didn't have before.

For Ricky, finding meaning in his experience of stigma in healthcare settings was one way to cope. Rather than dwelling on the negative, he reframed the experience as an opportunity to grow as a person and look at the big picture. Ricky also mentioned that his HIV diagnosis "forced [him] to be more accountable to [his] own health and to [his] own well-being." He recalled,

> I knew I *had* to graduate, I *had* to get a good job, I couldn't spend time kind of doing whatever, like I had to stay focused on my goals. So that I could keep my health insurance, so that I could keep alive.

Ricky also mentioned that his HIV diagnosis has strengthened his existing relationships, and forced him to get rid of "toxic" friends. He noted, "When you go through a tough experience with someone, and you're able to succeed through that, and you can positively navigate through that, it brings you closer together."

Similarly, Hector reframed some of his stigma experiences as an opportunity for character growth. He recalled the emotional pain that he felt when some of his ex-boyfriends would act hurtfully towards him, for example, by threatening to tell his family about his HIV diagnosis. He told me that in a few cases, these people who were mean to him ended up contracting HIV themselves later on. Hector explained,

> I don't say that to celebrate it, just to mention how ironic life is. Because usually people who do that [treat others hurtfully] are people who are struggling themselves . . . with other things. Including, you know, not using condoms, or having unprotected sex with random people. And they feel lonely. So, this has been healing for me.

By recognizing that people who behave hurtfully are often struggling with their own issues, Hector was able to minimize the pain of some of the interpersonal stigma that he has encountered.

Brandon, who says he does not internalize the stigma that is projected onto him,

recalled:

> In terms of the stigma that may have been projected on me, I just learned to really look at the bigger picture, you know? There's purpose in all of it. Purpose in everything. And because I know that, I knew that my first purpose was to be an actor, and then I discovered that no, that's not my purpose, my purpose is to do what I'm doing *now*, it allows me to just really be resilient, in terms of when stigma is directed toward me, I feel enough resiliency in myself to know not to attach it to myself.

By finding purpose a meaning in his present experience as an HIV positive person,

Brandon was able to deflect some of the negative connotations associated with being HIV

positive.

Acceptance

Existing literature has pointed to the correlation between self and other

forgiveness and increased mental and physical health (e.g., Lawler et al. 2005; Toussaint

et al. 2001; Wilson et al. 2008). Both Elena and Ricky mentioned that forgiveness of

oneself and others has played a big role in their ability to overcome stigma. I mentioned

to Ricky that I got the sense that he had learned to better cope with his self-stigma since

he first learned about his diagnosis three years ago. He told me that although he had made

progress in the first two years, he noticed that he was still being self-deprecating towards

himself. He went on to tell me that forgiveness has played an important role in the

healing process for him:

> So, one of the people that knows me really well told me, "You're not gonna be able to fully move forward with your life until you are able to forgive yourself." And I kind of [already] told myself that, but hearing that from someone else really drove that point home. Being able to forgive yourself— it sounds really easy, right?—but being able to forgive yourself, it was a lot . . . So, once I realized that I just needed to fundamentally forgive myself,

that's when I really dug into that deep hurt, and I was trying to work on the healing of that. So most days more often than not, I feel fine about where I am right now, because I know that being positive has forced me to be better . . . But I had to learn to forgive myself. And that's what I told those two people [friends who recently got HIV], "You're not gonna [understand] this today, because you're still in shock today, but I just want you to plant this seed of remembering to allow yourself the amnesty to forgive yourself." So, that's what's really helped me.

I asked Elena what has helped her reach a point where she could accept herself and move on with her life despite the HIV diagnosis. She replied:

I guess forgiven people. The mean people. And forgiven myself for not having this chance to talk with people [about her HIV diagnosis] like this first five years. Because those five years, it's like I was dead. Because I didn't talk about it. I was doing drugs, I was doing alcohol.

When I asked Manual how he thought stigma could be eradicated, he replied:

I think that everything begins with self-esteem. Loving yourself. Educating yourself . . . But the biggest issue again is self-esteem. It's *you*. And you can make the difference if you want to make it. It's you, because if you don't want to do anything nothing is gonna happen. But if you want to move your fingers, *something* is going to be moved. *Yes*. So most definitely it's *you*. Self-esteem.

Manual did not frame his experiences in terms of forgiveness, but instead framed it as an issue of self-love and self-esteem. However, both forgiveness and self-love fall under the umbrella of "self-acceptance," which is associated with increased mental and physical well-being (MacInnes 2006). By invoking such quasi-spiritual rhetoric, Manual, Ricky, and Elena were able to reframe their experience illness within a positive framework.

Conclusion

Reflecting on these last two chapters, I hope that I have succeeded in carrying out Elena's request to not portray her and other PHA as victims. The emphasis that I have given to individual agency does not negate the difficulties and challenges PHA must

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endure, and it has not been my intention to trivialize the impact of stigma or any other challenges that an HIV diagnosis brings. Indeed, all of my participants, to various degrees, mentioned that living with HIV has been challenging because of the stigma associated with it. All had personally dealt with rejection in one form or another, from intimate partners, family, friends, or their wider communities. My goal, rather, has been to reframe the stigma experience as a site of struggle and resistance, thereby giving a voice to the active subject who has thus far been absent in the existing HIV stigma literature. This reconfiguration of the stigma experience has important implications for both research and policy, as it points to how PHA might be able to effect change for themselves and their communities through collective empowerment. Furthermore, locating agency in the stigma experience allows us to move away from grand narratives of victimization, thereby minimizing our tendency to Otherize.

In this chapter, I have illustrated how PHA counteract the stigmatizing metaphors that are usually attached to HIV by transforming the rhetorical and symbolic meanings of the disease. I borrow from Jenkins and Carpenter-Song to suggest that PHA are "much more simply human than otherwise" (2008:400). By this I mean that PHA's experiences of social exclusion are emblematic of the human experience more broadly—that is, the inevitability of suffering and misfortune in the lives of all sentient beings, and our shared desire to find meaning in these experiences. "Integrating HIV disease into a personally meaningful framework" (Stanley 1999:117) is emblematic of the response to the illness experience more broadly, or other life-changing events that shatter our previously held notions of selfhood. We are ultimately meaning-seeking beings, and our psychological

ability to adapt to change and cope with adversity can sometimes mean the difference between life and death. In his book *Man's Search for Meaning,* based on his three year experience in Nazi concentration camps, Holocaust survivor Viktor Frankl quotes Friedrich Nietzsche: "He who has a why to live for can bear almost any how " (Frankl 1985:109). Frankl attributes his survival to his capacity to find meaning in every moment, even in the grips of dire physical and psychological suffering. With this in mind, we can reframe the experience of living with HIV as a lens through which we can better understand "fundamental human processes" (Jenkins and Carpenter Song 2008:400), in the sense that the importance of finding meaning in one's life is a universal phenomenon, and especially so when faced with suffering.

In the next and final chapter, I outline the broader significance of my research and I suggest recommendations for the way forward.

CHAPTER EIGHT: SIGNIFICANCE AND RECOMMENDATIONS

As I sit at my desk writing up this final chapter, I cannot help but ask myself, *So what? What is the broader significance of this research? Who will it benefit?* In the sections that follow, I discuss some ways that I believe this research could be of practical significance, for both scholars who research HIV stigma and individuals who work in more applied settings.

Methodological Recommendations

Ethnographic methods, such as those used in this thesis, have the potential to contribute significant insights to the theoretical understanding of stigma. While a significant portion of the HIV stigma literature has approached stigma as a measurable "thing," my research has brought into focus how the experience of stigma is both highly situated and unique. The embodied experience of stigma itself cannot be quantified or measured through scales and surveys. Rather, the experience of stigma is a process: it is dynamic, fluid, and highly complex, varying across time and space, and changing throughout a person's lifespan. Fiona, a medical anthropologist, elaborated on this point:

> I think it's just public health's way of narrowing down stigma to a scale. I think that's the problem with a lot of these public health driven initiatives. I mean, that's how they happen, that's how community health organizations *have* to operate, that's how they get their funding, you know? But, that's how most people are trained, and so I think that's OK, but I don't think it's reflective of how women think about stigma and marginalization and discrimination and disempowerment. All of that is stigma. The whole cycle of it all is what stigma is, and so, that's how I feel, but that's not how you would talk about [stigma].

Fiona's observation speaks to the broader tension that exists between the search for objectivity in the social sciences and the inherent complexity of human experience that renders it difficult to quantify. As Paul Farmer has noted, "the experience of suffering . . . is not effectively conveyed by statistics or graphs. The 'texture' of dire affliction is perhaps best felt in the gritty details of biography" (1996:262-63). By shifting our methodological focus toward lived experience, we can better understand how structural violence exerts itself within individual lives by giving a voice to those who experience stigma directly. In this way, we can allow PHA to speak for themselves, instead of speaking for them under the cloak of scientific objectivity.

Capturing the subjectively experienced dimensions of HIV stigma will also require that we discard our proclivity for generalization. Feminist anthropologist Lila Abu-Lughod argues that generalization is problematic because it is "part of a professional discourse of 'objectivity' and expertise" and is thus "inevitably a language of power" (Abu-Lughod 1991:150). I suggest that individual experiences of HIV stigma can best be captured by moving away from broad generalizations of certain groups of people that assume "homogeneity, coherence, and timelessness" (Abu-Lughod 1991:152) and instead focus on the subjectively perceived experiences of each individual on their own terms, what Abu-Lughod (1991) refers to as ethnographies of the particular. This approach will allow us to see how each individual experiences HIV stigma within the context of their own unique lifeworld, thereby steering away from generalizations that construct the fictitious Other.

Theoretical Recommendations

Despite the obvious social and cultural dimensions of stigma, I believe that it is important not to lose sight of the biological functions of stigma and exclusion. Anthropologists have problematized the notion of a pure, "natural" world that exists beyond human involvement, and their critiques point to the fuzzy boundaries between "nature" and "culture" (Cronon 1996; Sagoff 2003). In other words, nature and culture are mutually enhancing and interdependent, rather than discrete and separate entities. While the focus of this thesis has been the sociocultural and symbolic dimension of HIV stigma, it is important not to lose sight of the perspective of critical medical anthropology that "nature is shaped by society no less than society is shaped by its encounter with nature" (Singer 1994:942). Keeping in mind these biological perspectives on stigma can contribute to our understanding of disease stigma since aversion to death and disease is partly a biological response.

Our understanding of stigma could also be expanded if studies begin to focus on the psychological benefits of disclosure for HIV positive individuals. My research points to the potential benefits of "coming out" about one's diagnosis, and other literature has pointed to the benefits of coming out among people with mental illness and those who identity as GBLTQ. Disclosure has the potential to be personally transformative and cathartic, and the power of PHA to direct their own healing should not be underestimated. In retrospect, I wish I had spent more time discussing disclosure with my research participants; however, I only realized the potential significance of disclosure when I had already completed my fieldwork and began the analysis process. I recommend that future

research on HIV stigma focuses on the nuances of disclosure, and what the consequences and benefits this might have for various individuals across various contexts.

Finally, I believe that it may be useful to shift focus away from HIV stigma on its own and instead focus on how HIV stigma intersects with other stigmas to shape people's experiences of exclusion. As I have described in my research, PHA often experience multiple forms of stigma and discrimination simultaneously that extends above and beyond the stigma of being HIV positive. I agree with Link and Phelan (2006), who have pointed to how layered forms of stigma adversely shape life outcomes and health. They suggest,

> If future research is to capture the full impact of stigma related processes the agenda needs to be broad. We run a real risk of underestimating the overall impact of stigma by parceling our efforts up into "the stigma of this and the stigma of that." While some specialization of this sort is both necessary and desirable it will be important to at least keep a broader vision so that the overall impact of stigma on public health is not lost (Link and Phelan N.d.).

In other words, thinking about how HIV stigma influences life chances will require that we also include multiple and intersecting forms of stigma in our analysis. Although it has been the tendency of science and biomedicine to parse out discrete variables and quantify their effects on experience, the fact of the matter is that human experiences are extremely complex and shaped by multiple variables simultaneously. This synergy can best be captured by research that gives authority to situated and embodied knowledge rather than scientific "objectivity" that is detached from lived experiences (Haraway 1991).

Recommendations for Public Health and Policy

As my research has shown, there is no universal stigma experience. The experience is shaped by intersecting forms of structural violence, and also by individual personality traits—that is, some people may be "naturally" more resilient to adversity than others. My first recommendation for public health is that interventions aimed at tackling HIV stigma be mindful of the fact that there is no "magic bullet." Rather, interventions must operate at multiple levels while taking into consideration that everyone experiences stigma differently.

In addition, in some contexts it may be wise to place less emphasis on HIV stigma and instead focus efforts on the root causes of social exclusion that perpetuate social marginalization and HIV infection in the first place. In my view, stigma may serve as a distraction from the "real" and more enduring problems that plague our society. Reducing poverty, improving public education, and tackling racism and gender discrimination may be more effective in reducing HIV infection than addressing stigma on its own (or at all).

Finally, although structural-level interventions to reduce HIV stigma are extremely important for long-term change, it is my view that these approaches are less relevant for PHA in their immediate, day-to-day lives. As I have described in my research, finding meaning and purpose in misfortune and suffering is a universal human reaction to adversity. By becoming involved with HIV activism, advocacy, and other meaningful work, PHA are able to transform their illness experiences into a positive life narrative by finding greater meaning and purpose in their diagnosis. Furthermore, sharing one's personal story with others can be therapeutic and cathartic, and also create a sense of community with other PHA. As Aggleton and colleagues (2003) argue, community

mobilization among PHA can be an effective and powerful way to not only tackle stigma, but also to change the structural forces that drive HIV infection rates in the first place. As such, being open about one's HIV status, and speaking out either individually or collectively, are means through which PHA can build a greater sense of community, thereby mitigating the powerlessness, isolation, and shame that usually surrounds an HIV diagnosis. I recommend that community health organizations reach out to and encourage PHA to become involved with HIV activism and advocacy, thereby providing a platform through which they can have their voices heard while simultaneously dismantling the shame and secrecy of stigma. At the same time, however, disclosure should not be regarded as a panacea for stigma, or even necessarily the best option for everyone (Persson and Richards 2008).

Final Words

I hope that this thesis has brought to the light how an anthropological approach, through both theory and method, can broaden our collective understanding of HIV stigma, and stigma in general. Anthropology is unique in the sense that it has been called "the most scientific of the humanities and the most humanistic of the sciences," thus giving us the freedom to transcend the limitations of "objectivity" and encouraging us to think critically and creatively about the world we inhabit. Examining HIV stigma through an anthropological lens allows us to engage more deeply and compassionately with the individuals and communities that we write about, and it also enriches our understanding of how stigma is part of the greater human experiences of illness, social exclusion, and suffering, but also of agency, resilience, healing, and transformation. It is my hope that

the anthropological literature on HIV stigma will continue to grow and eventually lead to

new insights into how we think about stigma and various other forms of social exclusion.

REFERENCES

Abadia-Barrero, Cesar Ernesto, with Arachu Castro
    2006   Experiences of Stigma and Access to HAART in Children and
    Adolescents Living with HIV/AIDS in Brazil. Social Science & Medicine
    62:1219-1228.

Abu-Lughod, Lila
    1991 Writing Against Culture. *In* Recapturing Anthropology: Working in the
    Present. Richard G. Fox, ed. Pp. 137-162. Santa Fe: School of American Research
    Press.

Aggleton, Peter, with Richard Parker, and Miriam Maluwa
    2003   Stigma, Discrimination, and HIV/AIDS in Latin America and the
    Caribbean. Inter-American Development Bank.

Aggleton, Peter, with Kate Wood, Ann Malcolm, and Richard Parker
    2005   HIV-Related Stigma, Discrimination and Human Rights Violations: Case
    Studies of Successful Programmes. Geneva: Joint United Nations Programme on
    HIV/AIDS (UNAIDS).

Altman, Lawrence
    1982   New Homosexual Disorder Worries Health Officials. New York Times,
    May 11. http://www.nytimes.com/1982/06/18/us/clue-found-on-homosexuals-
    precancer-syndrome.html, accessed 15 June 2015.

Attia, Suzanna, with Matthias Eggera, Monika Muller, Marcel Zwahlen and Nicola Low
    2009   Sexual Transmission of HIV According to Viral Load and Antiretroviral
    Therapy: Systematic Review and Meta-Analysis. AIDS 23(11):1397-1404.

Barre-Sinoussi, Francoise, with Françoise, Jean-Claude Chermann, Fetal Rey, Marie
Therese Nugeyre, Sophie Chamaret, Jacqueline Gruest, Charles Dauguet et al.
    1983   Isolation of a T-lymphotropic Retrovirus from a Patient at Risk for
    Acquired Immune Deficiency Syndrome (AIDS) 220(4599):868-871.

Barrett, Ronald
    2005   Self-Mortification and the Stigma of Leprosy in Northern India. Medical
    Anthropology Quarterly 19(2):216-230.

Belle Doucet, Deborah

        2003   Poverty, Inequality, and Discrimination as Sources of Depression Among
        US Women. Psychology of Women Quarterly 27(2):101-113.

Bourdieu, Pierre
        1977 Outline of a Theory of Practice. Cambridge: Cambridge University Press.

Brandt, Allan M.
        1988   AIDS and Metaphor: Toward the Social Meaning of Epidemic Disease.
        Social Research 55(3):413-432.

Brown, Lisanne, with Lea Trujillo and Kate Macintyre
        2001   Interventions to Reduce HIV/AIDS Stigma: What Have We Learned?
        New Orleans: Horizons Program/Tulane School of Public Health and Tropical
        Medicine.

Castells, Manuel
        1997   The Power of Identity. Oxford: Blackwell Publishers.

Castro, Arachu and Farmer, Paul
        2005   Understanding and Addressing AIDS-Related Stigma: From
        Anthropological Theory to Clinical Practice in Haiti. American Journal of Public
        Health 95(1):53-59.

The Center for HIV Law and Policy
        2010   Positive Justice Project: HIV Criminalization Fact Sheet.
        http://www.hivlawandpolicy.org/resources/positive-justice-project-hiv-
        criminalization-fact-sheet, accessed June 2, 2015.

The Centers for Disease Control and Prevention
        2006   Epidemiology of HIV/AIDS: United States, 1981-2005.
        http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5521a2.htm, accessed May
        30, 2015.

        2015a About HIV/AIDS. http://www.cdc.gov/hiv/basics/whatishiv.html,
        accessed May 20, 2015.

        2015b HIV/AIDS Basic Statistics. http://www.cdc.gov/hiv/statistics/basics.html,
        accessed May 20, 2015.

        2015c HIV Transmission. http://www.cdc.gov/hiv/basics/transmission.html,
        accessed May 20, 2015.

        2015d HIV/AIDS Basic Statistics: PrEP.
        http://www.cdc.gov/hiv/basics/prep.html. Accessed July 3, 2015.

2015e HIV/AIDS Basic Statistics: PEP. http://www.cdc.gov/hiv/basics/pep.html. Accessed June 20, 2015.

N.d.   Mortality Slide Series. http://www.cdc.gov/hiv/pdf/statistics_surveillance_hiv_mortality.pdf, accessed June 23, 2015.

Cohen, Myron S., with Ying Q. Chen, Marybeth McCauley, Theresa Gamble, Mina C. Hosseinipour, Nagalingeswaran Kumarasamy, James G. Hakim et al.
2011   Prevention of HIV-1 Infection with Early Antiretroviral Therapy. New England Journal of Medicine 365(6): 493-505.

Corrigan, Patrick W., with Kristin A. Kosyluk, and Nicolas Rüsch
2013   Reducing Self-Stigma by Coming Out Proud. American Journal of Public Health 103(5):794-800.

Clifford, James
1986   Introduction: Partial Truths. *In* Writing Culture: The Poetics and Politics of Ethnography. James Clifford and George E. Marcus, eds. Pp.1-26. Berkeley: University of California Press.

Crenshaw, Kimberle
1991   Mapping the Margins: Intersectionality, Identity Politics, and Violence Against Women of Color. Stanford Law Review 43(6):1241-1299.

Crocker, J., with Major, B., and Steele, C.
1998   Social stigma. *In* The handbook of social psychology, Vol. 2. D.T. Gilbert, and S. T. Fiske, eds. Pp. 504-553. Boston: McGraw-Hill.

Cronon, William
1996   The Problem with Wilderness; or, Getting Back to the Wrong Nature. *In* Uncommon Ground: Rethinking the Human Place in Nature. William Cronon, ed. New York: W.W. Norton Company.

Derlega, Valerian J. with Barbara A. Winstead, Kathryn Greene, Julianne Serovich, and William N. Elwood
2004   Reasons for HIV Disclosure/Nondisclosure in Close Relationships: Testing a Model of HIV-Disclosure Decision Making. Journal of Social and Clinical Psychology 23(6):747-767.

District of Columbia Department of Health
2013   Annual Epidemiology & Surveillance Report. HIV/AIDS, Hepatitis, STD, and TB Administration (HASTA).

http://doh.dc.gov/sites/default/files/dc/sites/doh/publication/attachments/2013%20Annual%20Report%20FINAL-2.pdf, accessed November 10, 2014.

Douglas, Mary
    1978   Purity and Danger: An Analysis of Concepts of Pollution and Taboo. London: Routledge.

Epstein, Steven
    1996   Impure Science: AIDS, Activism, and the Politics of Knowledge. Berkeley: University of California Press.

Farmer, Paul
    1992   AIDS and Accusation: Haiti and the Geography of Blame. Berkeley: University of California Press.

Farmer, Paul
    1996   On Suffering and Structural Violence: A View From Below. Daedalus 125(1):261-283.

Frankl, Viktor
    1985[1946] Man's Search for Meaning. Simon and Schuster.

Galletly, Carol L., with Steven D. Pinkerton
    2006   Conflicting Messages: How Criminal HIV Disclosure Laws Undermine Public Health Efforts to Control the Spread of HIV. AIDS and Behavior 10(5):451-461.

Gebo, Kelly A., John A. Fleishman, Richard Conviser, Erin D. Reilly, P. Todd Korthuis, Richard D. Moore, James Hellinger et al.
    2005   Racial and Gender Disparities in Receipt of Highly Active Antiretroviral Therapy Persist in a Multistate Sample of HIV Patients in 2001. JAIDS Journal of Acquired Immune Deficiency Syndromes 38(1):96-103.

Geertz, Clifford
    2000[1973] The Interpretation of Cultures. New York: Basic Books.

Gielen, Andrea Carlson, with Linda Fogarty, Patricia O'Campo, Jean Anderson, Jean Keller, and Ruth Faden
    2000   Women Living With HIV: Disclosure, Violence, and Social Support. Journal of Urban Health 77(3):480-491.

Goffman, Irving
    1963   Stigma: Notes on the Management of a Spoiled Identity. New York: Simon & Schuster.

Gorbach, Pamina M., with J. T. Galea, Bita Amani, A. Shin, C. Celum, P. Kerndt, and M. R. Golden

    2004   Don't Ask, Don't Tell: Patterns of HIV Disclosure Among HIV Positive Men Who Have Sex with Men with Recent STI Practising High Risk Behaviour in Los Angeles and Seattle. Sexually Transmitted Infections 80(6):512-517.

Golub, Elizabeth, with J. Astemborski, D. Hoover, J. Anthony, David Vlahov, and Stefanie Strathdee

    2003 Psychological Distress and Progression to AIDS in a Cohort of Injection Drug Users. Journal of Acquired Immune Deficiency Disease 4(1):429-434.

Gregg, Jessica L.

    2011   An Unanticipated Source of Hope: Stigma and Cervical Cancer in Brazil. Medical Anthropology Quarterly 25(1):70-84.

Grove, Kathleen A., with Donald P. Kelly, and Judith Liu

    1997 "But Nice Girls Don't Get It": Women, Symbolic Capital, and the Social Construction of AIDS. Journal of Contemporary Ethnography 26(3):317-337.

Hall, Irene, with Ruiguang Song, Philip Rhodes, Joseph Prejean, Qian An, Lisa M. Lee et al.

    2008   Estimation of HIV Incidence in the United States. JAMA 300(5):520-529.

Harrell, Jules, with Sadiki Hall, and James Tallaferro

    2003   Physiological Responses to Racism and Discrimination: An Assessment of the Evidence. American Journal of Public Health 93(2):243-248.

Hatzenbuehler, Mark L., with Jo C. Phelan and Bruce G. Link

    2013   Stigma as a Fundamental Cause of Population Health Inequalities. American Journal of Public Health 103(5):813-821.

Herek, Gregory M., with Eric K. Glunt

    1988   The Epidemic of Stigma: Public Reactions to AIDS. American Psychologist 43(11):886-891.

Heyl, Barbara Sherman

    2001   Ethnographic Interviewing. *In* Handbook of Ethnography. Paul Atkinson, Amanda Coffey, Sara Delamont, John Lofland, and Lyn Lofland, eds. Pp. 369-383. Sage.

Hogg, Robert, with Katherine V. Heath, Benita Yip, Kevin J. P. Craib, Michael V. O'Shaughnessy, Martin T. Schechter et al.
>   1998   Improved Survival Among HIV-Infected Individuals Following Initiation of Antiretroviral Therapy. JAMA 279(6):450-454.

Holmes, Seth
>   2013   Fresh Fruit, Broken Bodies: Migrant Farmworkers in the United States. Berkeley: University of California Press.

Inhorn, Marcia C.
>   2004   Middle Eastern Masculinities in the Age of New Reproductive Technologies: Male Infertility and Stigma in Egypt and Lebanon. Medical Anthropology Quarterly 18(2):162-182.

Jackson, Jean E.
>   2005   Stigma, Liminality, and Chronic Pain: Mind-Body Borderlands. American Ethnologist 32(3):332-353.

Jenkins, Janis H., with Elizabeth A. Carpenter-Song.
>   2008   Stigma Despite Recovery. Medical Anthropology Quarterly 22(4):381-409.

Jetten, Jolanda, with Nyla R. Branscombe, Michael T. Schmitt, and Russell Spears
>   2001   Rebels with a Cause: Group Identification as a Response to Perceived Discrimination from the Mainstream. Personality and Social Psychology Bulletin 27(9):1204-1213.

Jones, Christopher P.
>   1987 Stigma: Tattooing and Branding in Graeco-Roman Antiquity. Journal of Roman Studies 77:139-155.

Kaiser Family Foundation
>   2012 Fact Sheet: The HIV/AIDS Epidemic in Washington, D.C. http://kaiserfamilyfoundation.files.wordpress.com/2013/01/8335.pdf, accessed November 5, 2014.

Kemeny, Margaret D., with Manfred Schedlowski
>   2007   Understanding the Interaction between Psychosocial Stress and Immune Related Diseases: A Stepwise Progression. Brain, Behavior, and Immunity 21(8):1009-1018.

Kher, Unmesh

    2003   A Name for the Plague. Time, March 31.
http://content.time.com/time/specials/packages/article/0,28804,1977881_1977895
_1978703,00.html, accessed July 2.

Kleinman, Arthur, et al.
    1995   The Social Course of Epilepsy: Chronic Illness as Social Experience in
Interior China. Social Science & Medicine 40(10):1319-1330.

Kumar, Anuradha, with Leila Hessini and Ellen M.H. Mitchell
    2009   Conceptualising Abortion Stigma. Culture, Health & Sexuality 11(6):625-
639.

Kurzban, Robert, and Mark R. Leary
    2001   Evolutionary Origins of Stigmatization: The Functions of Social
Exclusion. Psychological Bulletin 127(2):187-208.

Kvale, Steinar
    1996   Interviews: An Introduction to Qualitative Research Interviewing.
Thousand Oaks, CA: Sage.

Lawler, Kathleen A., with Jarred W. Younger, Rachel L. Piferi, Rebecca L. Jobe,
Kimberley A. Edmondson, and Warren H. Jones
    2005   The Unique Effects of Forgiveness on Health: An Exploration of
Pathways. Journal of Behavioral Medicine 28(2):157-167.

Leavitt, D.
    1989   AIDS. The New York Times Magazine, pp. 28-32, 80-82

Lifton, Robert J.
    1979   The Broken Connection. New York: Simon and Schuster.

Link, Bruce, with Jo C. Phelan
    N.d.   On Stigma and its Public Health Implications.
http://www.stigmaconference.nih.gov/LinkPaper.htm, accessed July 3, 2015.

    2001   Conceptualizing Stigma. Annual Review of Sociology 27:363-385.

    2006   Stigma and Its Public Health Implications. The Lancet 367(9509):528-
529.

Logie, Carmen, with Tahany Gadalla
    2009   Meta-Analysis of Health and Demographic Correlates of Stigma Towards
People Living With HIV. AIDS Care 21(6):742-753.

MacInnes, Deborah L.
    2006   Self- Esteem and Self- Acceptance: An Examination into their
Relationship   and their Effect on Psychological Health. Journal of Psychiatric and
Mental   Health Nursing 13(5): 483-489.

Mahajan, Anish P., with Jennifer N. Sayles, Vishal A. Patel, Robert H. Remien, Daniel
Ortiz, Greg Szekeres, and Thomas J. Coates.
    2008   Stigma in the HIV/AIDS Epidemic: A Review of the Literature and
    Recommendations for the Way Forward. AIDS 22(Suppl 2):S67.

Major, Brenda, with Laurie T. O'Brien
    2005   The Social Psychology of Stigma. Annual Review of Psychology 56:393-
    421.

Maman Suzanne, with Elizabeth King, Avni Amin, Claudia Garcia-Moreno, Donna
Higgins, and Amolo Okero
    2006   Addressing Violence Against Women in HIV Testing and Counseling: a
    Meeting Report. Geneva: Department of Gender, Women and Health, Department
    of HIV/AIDS, World Health Organization.

Marcus, George E., with Michael M.J. Fischer
    1986   Anthropology as Cultural Critique. Chicago: The University of Chicago
    Press.

Muessig, Kathryn E., with M. Kumi Smith, Kimberly A. Powers, Ying-Ru Lo, David N.
Burns, Andrew E. Grulich et al.
    2012   Does ART prevent HIV transmission among MSM? AIDS 26(18):2267.

Mugavero, Michael J., with Hui-Yi Lin, Jeroan J. Allison, Thomas P. Giordano, James H.
Willig, James L. Raper, Nelda P. Wray et al.
    2009   Racial Disparities in HIV Virologic Failure: do Missed Visits
    Matter? Journal of Acquired Immune Deficiency Syndromes 50(1):100-108.

Nader, Laura
    1972   Up the Anthropologist: Perspectives Gained from Studying Up. In Reinventing
    Anthropology. Dell H. Hymes, ed. Pp. 284-311. New York: Pantheon Books.

Nahar, Papreen, with Sjaak van der Geest
    2014 How Women in Bangladesh Confront the Stigma of Childlessness: Agency,
    Resilience, and Resistance. Medical Anthropology Quarterly 28(3):381-398.

Niang, Cheikh I., with Placide Tapsoba, Ellen Weiss, Moustapha Diagne, Youssoupha
Niang, Amadou M. Moreau, Dominique Gomis, Abdoulaye Sidbe Wade, Karim Seck,
and Chris Castle

2003   'It's Raining Stones': Stigma, Violence and HIV Vulnerability Among
Men Who Have Sex With Men in Dakar, Senegal. Culture, Health & Sexuality
5(6):499-512.

Niehaus, Isak
2007   Death Before Dying: Understanding AIDS Stigma in the South African
Lowveld. Journal of Southern African Studies 33(4):845-860.

Nieuwkerk, Pythia T., with Elisabeth H. Gisolf, Monique H.E. Reijers, Joep M.A. Lange,
Sven A. Danner and Mirjam A.G. Sprangers
2001   Long-term quality of life outcomes in three antiretroviral treatment
strategies for HIV-1 infection. AIDS 15(15):1985-1991.

Ortner, Sherry B.
1995   Resistance and the Problem of Ethnographic Refusal. Comparative studies
in Society and History 37(1):173-193.

Osmond, Dennis H.
2003   Epidemiology of HIV/AIDS in the United States.
http://hivinsite.ucsf.edu/InSite?page=kb-01-03, accessed May 20, 2015.

Oxford Dictionaries
2015 "stigma," accessed July 10, 2015,
http://www.oxforddictionaries.com.mutex.gmu.edu/us/definition/learner/stigma.

Pachankis, John E.
2007   The Psychological Implications of Concealing a Stigma: A Cognitive-
Affective-Behavioral Model. Psychological Bulletin 133(2):328.

Palacio, Herminia, with James G. Kahn, T. Anne Richards, and Stephen F. Morin
2002   Effect of Race and/or Ethnicity in Use of Antiretrovirals and Prophylaxis
for Opportunistic Infection: A Review of the Literature. Public Health Reports
117(3):233-251.

Parker, Richard
1996   Empowerment, community mobilization and social change in the face of
HIV/AIDS. AIDS 10(Suppl 3):S27-S31.

2002   The Global HIV/AIDS Pandemic, Structural Inequalities, and the Politics
of International Health. American Journal of Public Health 92(3):343-346.

Parker, Richard, with Peter Aggleton

        2003   HIV and AIDS-Related Stigma and Discrimination: A Conceptual
Framework and Implications for Action. Social Science & Medicine 57:13-24.

Paxton, Susan.
        2002   The Paradox of Public HIV Disclosure. AIDS Care 14(4):559-567.

Persson, Asha
        2005   Facing HIV: Body Shape Change and the (In) Visibility of Illness.
Medical Anthropology 24(3):237-264.

Persson, Asha, with Wendy Richards
        2008   From Closet to Heterotopia: A Conceptual Exploration of   Disclosure and
'Passing' Among Heterosexuals Living with HIV. Culture, Health, and Sexuality
10(1):73-86.

Petersen, Alan
        1996   Risk and the Regulated Self: The Discourse of Health Promotion as
Politics of Uncertainty. Journal of Sociology 32(1):44-57.

Pisani, Elizabeth
        2009   The Wisdom of Whores: Bureaucrats, Brothels, and the Business of AIDS.
London: Granata Publications.

Quesada, James, with Laurie Kain Hart, and Philippe Bourgois
        2011   Structural Vulnerability and Health: Latino Migrant Laborers in the
United States. Medical Anthropology 30(4):339-362.

Rhodes, Tim, with Merrill Singer, Philippe Bourgois, Samuel R. Friedman, and Steffanie
A. Strathdee
        2005   The social structural production of HIV risk among injecting drug
users. Social Science & Medicine 61(5):1026-1044.

Rintamaki, Lance S., with Terry C. Davis, Silvia Skripkauskas, Charles L. Bennett, and
Michael S., Wolf
        2006   Social Stigma Concerns and HIV Medication Adherence. AIDS Patient
Care and STDs 20(5):359-368.

Sagoff, Mark
        2003   Genetic Engineering and the Concept of the Natural. *In* Genetic Prospects:
Essays on Biotechnology, Ethics, and Public Policy. V.V. Gehring, ed. Lanham,
MD: Rowman and Allenheld.

Sayles, Jennifer N., with Mitchell D. Wong, Janni J. Kinsler, David Martins, and William
E. Cunningham

    2009   The Association of Stigma with Self-Reported Access to Medical Care and Antiretroviral Therapy Adherence in Persons Living with HIV/AIDS. Journal of General Internal Medicine 24(10):1101-1108.

Schellenberg, E. Glenn, with Janet Mantler Keil and Sandra Lipsitz Bem
    1995   "Innocent Victims" of AIDS: Identifying the Subtext. Journal of Applied Social Psychology 25(20):1790-1800.

Scheper-Hughes, Nancy
    1990   Three Propositions for a Critically Applied Medical Anthropology. Social Science & Medicine 30(2):189-197.

Schoepf, Brooke G.
    2001   International AIDS Research in Anthropology: Taking a Critical Perspective on the Crisis. Annual Review of Anthropology 30:335-361.

Scott, James C.
    1985   Weapons of the Weak: Everyday Forms of Peasant Resistance. Yale University Press.

Seidman, Steven
    1998   AIDS and the Discursive Construction of Homosexuality. *In* The new American Cultural Sociology. Philip Smith, ed. Pp. 47-59.

Shapiro, Martin F., with Sally C. Morton, Daniel F. McCaffrey, J. Walton Senterfitt, John A. Fleishman, Judith F. Perlman, Leslie A. Athey et al.
    1999   Variations in the Care of HIV-Infected Adults in the United States: Results from the HIV Cost and Services Utilization Study. JAMA 281(24):2305-2315.

Singer, Merrill
    1994   AIDS and the Health Crisis of the U.S. Urban Poor; The Perspective of Critical Medical Anthropology. Social Science & Medicine 39(7):931-948.

Smart, L. with Wegner D.M.
    2000   The Hidden Costs of Hidden Stigma. *In* Social Psychology of Stigma. Heatherton T.F., Leck R.E, Hebl M.R., Hull J.G., eds. Pp. 220-242. New York: Guilford Press.

Sontag, Susan.
    1989   AIDS and Its Metaphors. New York: Farrar, Straus and Giroux.

    2001   Illness as Metaphor and AIDS and its Metaphors. Macmillan.

Stangl, Anne L., with Jennifer K. Lloyd, Laura M. Brady, Claire E. Holland, and Stefal Baral
>   2013   A Systematic Review of Interventions to Reduce HIV-related Stigma and Discrimination From 2002 to 2013: How Far Have We Come? Journal of the International AIDS Society 16(Suppl 2):1-14.

Stanley, Laura D.
>   1999   Transforming AIDS: The Moral Management of Stigmatized Identity. Anthropology and Medicine 6(1):103-120.

A Timeline of AIDS
>   N.d.   https://www.aids.gov/hiv-aids-basics/hiv-aids-101/aids-timeline/, accessed June 5, 2015.

Toussaint, Loren L., with David R. Williams, Marc A. Musick, and Susan A. Everson.
>   2001   Forgiveness and Health: Age Differences in a US Probability Sample. Journal of Adult Development 8(4):249-257.

Treichler, Paula A.
>   1987   AIDS, Homophobia, and Biomedical Discourse: An Epidemic of Signification. AIDS: Cultural Analysis/Cultural Activism 43:3170.

Tsai, Alexander, with David R. Bangsberg and Sheri D. Weiser
>   2013a   Harnessing Poverty Alleviation to Reduce the Stigma of HIV in Sub-Saharan Africa 10(1):1-6.

Tsai, Alexander, with David R. Bangsberg, Mwebesa Bwana, Jessica E. Haberer, Edward A. Frongillo, Conrad Muzoora, Elias Kumbakumba, Peter W. Hunt, Jeffrey N. Martin, and Sheri D. Weiser
>   2013b   How Does Antiretroviral Treatment Attenuate the Stigma of HIV? Evidence from a Cohort Study in Rural Uganda. AIDS Behavior 17:2725-2731.

Turner, Bryan A.
>   1984   The Body and Society. New York: Basil Blackwell.

The World Health Organization
>   2009   HIV Testing, Treatment and Prevention: Generic Tools for Operational Research. http://www.who.int/hiv/pub/operational/or_generic_tools.pdf, accessed September 20, 2014.

>   2013   Adult HIV Prevalence (15-49 years), 2012 By WHO Region. http://www.who.int/gho/hiv/hiv_013.jpg?ua=1%20UNAIDS%20Global%20Repo rt%20 01, accessed September 20, 2014.

2015   Global Health Observatory (GHO) Data: HIV/AIDS.
http://www.who.int/gho/hiv/en/, accessed May 20, 2015.

UNAIDS
2007   The Greater Involvement of People Living with HIV (GIPA).
http://data.unaids.org/pub/BriefingNote/2007/JC1299_Policy_Brief_GIPA.pdf,
accessed October 25, 2014.

2009   HIV Testing, Treatment and Prevention: Generic Tools for Operational
Research. http://www.who.int/hiv/pub/operational/or_generic_tools.pdf,
accessed September 20, 2014.

2012a   Global Report: UNAIDS Report on the Global AIDS Epidemic 2012
http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2
012/gr2012/20121120_UNAIDS_Global_Report_2012_with_annexes_en.pdf,
accessed September 20, 2014.

2012b   Guidance Note 2012: Key Programmes to Reduce Stigma and
Discrimination and Increase Access to Justice in National HIV Responses.
http://www.unaids.org/en/media/unaids/contentassets/documents/documen
t/2012/ Key_Human_Rights_Programmes_en_May2012.pdf, accessed
September 20, 2014.

Varas-Diaz, Nelson, with Irma Serrano-Garcia and Jose Toro-Alfonso
2005   AIDS-Related Stigma and Social Interaction: Puerto Ricans Living With
HIV/AIDS. Qualitative Health Research 15(2):169-187.

Zierler, Sally, with Nancy Krieger
1997   Reframing Women's Risk: Social Inequalities and HIV Infection. Annual
Reviews of Public Health 18:401-36.

Whittaker, Andrea M.
1992   Living with HIV: Resistance by Positive People. Medical Anthropology
Quarterly 6(4):385-390.

Wilson, Tobi, with Aleks Milosevic, Michelle Carroll, Kenneth Hart, and Stephen
Hibbard.
2008   Physical Health Status in Relation to Self-Forgiveness and Other-
Forgiveness in Healthy College Students. Journal of Health Psychology
13(6):798-803.

Yang, Lawrence Hsin, Arthur Kleinman, Bruce G. Link, Jo C. Phelan, Sing Lee, and
Byron Good.

2007   Culture and Stigma: Adding Moral Experience to Stigma Theory. Social Science & Medicine 64(7):1524-1535.

BIOGRAPHY

Nevia Pavletic received her Bachelor of Arts degree in Sociology from the University of Maryland, College Park, in 2009. Born in Croatia, she currently lives with her family in the D.C. metropolitan area. Some of her favorite things include travel, painting, film photography, laughter, documentary films, and enjoying the simple pleasures of life.