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# Structures of risk: lived experiences of multi-syndemic clustering in the greater Boston area

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Thesis

**STRUCTURES OF RISK: LIVED EXPERIENCES OF MULTI-SYNDROMIC  
CLUSTERING IN THE GREATER BOSTON AREA**

by

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B.A., New York University, 2014

Submitted in partial fulfillment of the  
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Master of Science

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## **DEDICATION**

For the hardworking health providers and patients with whom I had the pleasure of working. Furthermore, for people who find themselves experiencing syndemics and struggle to manage conditions of risk.

## **ACKNOWLEDGMENTS**

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**STRUCTURES OF RISK: LIVED EXPERIENCES OF MULTI-SYNDemic  
CLUSTERING IN THE GREATER BOSTON AREA**

**NACIELY CABRAL**

**ABSTRACT**

People who experience structural violence are an increased risk for health conditions including HIV and Hepatitis C. Particularly they are at greater risk for experiencing known syndemic interactions between these two chronic infectious diseases. The risks are mediated bio-socially through the ways that structural inequality increases social and biological vulnerability to illness and suffering. Structural inequalities, or experiences of structural violence shape environments of risk; environments of risks increase social and biological vulnerability to the structures of risk promoting syndemic interactions between biological, behavioral, and psychological conditions. The lived experiences of people diagnosed with a combination of HIV, HCV, and mental health conditions (MHC) (e.g., mood disorders and depression) are, however, thus far understudied. Many aspects and consequences of structural violence and social suffering; poverty, homelessness, substance use, lack of access to healthcare, and structural risks for HIV, HCV, MHC and interactions between the three. Through this mixed-methods, primarily qualitative, ethnographic fieldwork with individuals in the Boston area living with HIV, HCV, or both HIV and HCV, or suffering from MHC I ethnographically explore people's perceptions of their vulnerability to these syndemic interactions. I also investigate their experiences of being at-risk for these conditions. Through this process, I seek to illuminate individuals' understandings of the impact structures of risk (i.e.,

substance use, food insecurity and unstable housing) have on lived experiences with HIV/HCV, HIV/MHC, and HCV/MHC syndemics. The perceptions of the lived realities of disease-behavioral-psychological interactions and health consequences are analyzed in the context of substance use. Substance use's biological and social dimensions have a role in promoting syndemic interactions for each of the syndemics experienced within this population. Therefore, substance use is a syndemogenic factor because of its role as a mediator for environments of risks, and as a structural risk factor in all three of these syndemics. These interactions, and consequential health outcomes, in sufferers' own words, enrich the landscape of syndemics research, producing a clearer picture regarding the structures of risks affecting this vulnerable group in the greater Boston area.



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## LIST OF ABBREVIATIONS

AIDS .....	Acquired Immune Deficiency Syndrome
ART.....	Antiretroviral Therapy
ARV .....	Antiretroviral
BU .....	Boston University
BMC.....	Boston Medical Center
CDC .....	Centers for Disease Control and Prevention
CMA .....	Critical Medical Anthropology
CMD .....	Common Mental Disorders
DSM.....	Diagnostic and Statistical Manual of Mental Disorders
EOHHS .....	Executive Office of Health and Human Services
HAART.....	Highly Active Antiretroviral Therapy
HAB .....	HIV/AIDS Bureau
HBV .....	Hepatitis B Virus
HCV .....	Hepatitis C Virus
HIV .....	Human Immunodeficiency Virus
HRSA.....	Health Resources and Services Administration
HSC .....	Hepatic Stellate Cells
IDU .....	Injection Drug Use
IHS .....	Internalized HIV Stigma
INF-Free.....	Interferon-Free

IRB .....	International Review Board
LPS.....	Lipopolysaccharide
MGT.....	Modified Grounded Theory
MHC .....	Mental Health Conditions
MSM .....	Men who have Sex with Men
MWID.....	Men Who Inject Drugs
NKC .....	Natural Killer Cells
PCP .....	Primary Care Provider
PLHIV.....	People Living with HIV
PLWHA .....	People Living with HIV/AIDS
PTSD.....	Post-Traumatic Stress Disorder
PWID .....	People Who Inject Drugs
SNAP .....	Supplemental Nutrition Assistance Program
SAVA.....	Substance Abuse, Violence, and AIDS
TB .....	Tuberculosis
TLR4.....	Toll-like Receptor 4
WWID.....	Women Who Inject Drugs



## INTRODUCTION

*Muffled voices trickle in from the hallway. Django,<sup>1</sup> a female health provider at the hospital-based clinic that offers free HIV and Hepatitis C medication, the X Clinic,<sup>2</sup> freezes. I follow suit. She turns her ear to the door, either to put a name to the voice or to overhear the conversation. MCM,<sup>3</sup> walks in the office, and tells Django he just saw her client in the waiting room of the X Clinic and that the client smells like vodka. She exclaims, “Good! I’ll go see if I can catch him now.”*

*Django turns to me, explaining the client missed his last two case management appointments and desperately needed to renew his health insurance paperwork and reapply for the Massachusetts HIV Drugs and AIDS Program (HDAP) that will pay for his HIV medications. Django opens the door to the hallway and asks me if I want to join their consultation – I accept. She walks into the X Clinic waiting room. I peer through the glass window on the door to the waiting room, but the space appears vacant. Django scans the seemingly empty space; the client’s position at the far-left corner of the waiting room hides him from view. She walks inside and spots Chester, a middle-aged man with chestnut hair and an angular face, swaying in his chair to music emanating from his headphones.*

*We greet him, and she lets out a breath. A twitch of her nose lets me know she can also smell alcohol wafting from him. When Django asks him about his missed case management and primary health care appointments, he replies in Brazilian Portuguese, and in hushed tones. Django later explains to me privately this client can understand English but prefers to speak in Portuguese. Django urges him, in English, to follow her back to her office to complete the HDAP, and a lifeguard certification application she thinks will help him get a job, but he declines. Later, Django explains that Chester refuses to do the re-application with her at that moment because he does not want to lose his spot in the queue waiting for an unscheduled doctor’s appointment. Especially since, he must pay for the doctor-visit co-pays out-of-pocket, pending approval for his state insurance that he has yet to regain. Chester’s scheduled to meet with his mental health counselor after his primary care provider (PCP).*

*“Scheduling multiple appointments for the same day helps save up on transportation costs,” agrees Django in English and then in Portuguese.*

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<sup>1</sup> To protect the privacy of participants, all the names of individuals and organizations are pseudonyms. In the case of “Django,” she only works with clients covered by the Ryan White Program at the X Clinic.

<sup>2</sup> The pseudonym, the “X Clinic,” refers to the hospital-based clinic in the greater Boston where I conducted my eight-month long internship and fieldwork data collection procedures noted in Chapter Two: Methods.

<sup>3</sup> “MCM” is an African-American male health provider at the X Clinic.

*After a few minutes pass, indecision strikes and I awkwardly linger by the bookshelf, because even though I cannot hear nor understand most of their interaction, Django, and the client both graciously allowed me to join. A stack of the February HIVPlus Magazine covers the top of the bookshelf. Then I hear Django switch back to English and urge Chester to renew his HDAP documents before he leaves: “I will see if we have a transportation pass,” she adds, reassuring him that it should also cover the trip to his next appointment. Then, a PCP opens the door from the inside of the X Clinic, a welcoming smile on her lips as she lets Chester know that she can see him now.*

*We return to the private office Django shares with MCM, who then asks, “Did you catch him?” Django answers, “He has an appointment, but I’ll see him afterward... And yeah, I could smell the alcohol on him, because when you are an alcoholic, it does not go away, even if you drink water.” Predicting the forms Chester needs to fill out for the state to pay for his HIV treatment regimen and living expenses; she opens a cabinet and takes out a physical copy of an HDAP application. Then, Django turns to me, “I am trying to help him get a certified lifeguard training from the American Red Cross. [Chester] already has the experience; he just needs to take the exam.”*

*“He needs to get sober first, and the certification costs around \$200,” MCM says in a matter-of-fact tone.*

*“I know... but he needs a job. Hopefully having a job, will motivate him to stop [drinking]...” Django’s voice trails off, and I cannot help but think back to the quote on the whiteboard attached to the waiting room’s wall, next to the knee-high bookshelf, that caught my eye: “The most common way people give up their power is by thinking they don’t have any” by Alice Walker.*

*I think of how aptly this quote describes the circumstances that culminate in the Chester’s compounded experiences of suffering— Excerpt from field note entry, “Shadowing Case Managers” (March 08, 2016).*

As seen in these field notes from early in my time at what I call the X Clinic, where I engaged in participant-observation to learn about the structures of risk that shaped participants’ lived experiences with HIV, Hepatitis C, interactions between both diseases, and other conditions that compounded them, Django hinted that she viewed Chester’s reality of financial precarity as an obstacle that hindered his ability to address his alcoholism, re-apply for state health coverage, or even complete paperwork ensuring access to crucial HIV medications. Especially when Chester used alcohol as a coping

mechanism for the financial and health stress he experienced, or in the vicious cycle of suffering suggested by his reluctance to miss a medical appointment for which he would pay out-of-pocket, to fill out an application that might make the next medical appointment free or more affordable. Chester's alcoholism, as MCM pointed out, further impeded his ability to afford even the \$200 lifeguard review course, much less the costly HIV and HCV treatment therapies.

While Chester's mental health condition (MHC) was not specified (but suggested by his appointment with a mental health counselor), existing literature showed the potential for bi-directional social-psychological interactions between mental illnesses and HIV that can worsen HIV progression to AIDS, and contribute to Hepatitis C disease acquisition, under conditions of poverty. I chose the term "mental health conditions" (MHC) to refer to participants' experiences regarding the combination of MHC they suffer from. Kleinman (2012:118) note mental health is a category that promotes the biomedicalization of adverse consequences of social conditions such as, substance use, HIV-stigma, or family breakdown. Thus, I used MHC as a category encompassing psychological and behavioral conditions that intersect with HIV and HCV in syndemics. Ethnographic accounts such as the one that began this chapter refined my research on the risk environments that produce damaging interactions between disease, behavioral, and structural factors, and pushed me to explore other pathways of interaction in the qualitative data. While this excerpt did not explicitly classify syndemic interactions, it illustrated how participants perceived and experienced risk factors for diseases such as HIV in adverse conditions (e.g., substance use, financial precarity).

My ethnographic investigation of people lived experiences of HIV, and HCV interactions in the greater Boston area began with the following questions: how do structures of risk, as perceived by patients and providers, influence syndemic production? In other words, how do participants (patients and providers from the X Clinic) describe their experiences with syndemic pathways of disease interactions among and between HIV and HCV, and the structures of risk that promote them in the greater Boston area? As I answered these queries, I also paid attention to how they talked about the role overlapping risk factors (social, structural, or biological) played in the production of multiple HIV, Hepatitis C (HCV), and mental health conditions (MHC) syndemics.

My fieldwork focused on people living with HIV (PLHIV), HCV, or both, who received medication, mental health and primary care treatment, and disease management services including social work, at the X Clinic and exploration of how they dealt with day-to-day experiences of disease interaction and the structures of risk that worsened their overall suffering. These types of disease interactions are most often produced and exacerbated by unequal social conditions, such as poverty, unstable housing, food insecurity, structural violence, and stigma, and subsequent conditions of health inequality – producing what are called, in medical anthropology, *syndemics* (Singer et al. 2017). I specifically examined how these factors unfolded in the lives of people living with HIV, HCV or both, in the greater Boston area. Understanding the contexts that drive syndemic interaction and syndemic production is crucial for conceptualizing how disease burden magnifies, and social suffering worsened when a population experiences multiple syndemics or a cluster of syndemics.

I use patients' and providers' *in vivo* perceptions to find the social, psychological, and biological environmental risk factors producing multiple HIV and HCV syndemics within this group of individuals in the greater Boston area. I use Singer's use of the term *syndemic clustering* (Singer 2014b), in which he described a set of risk factors for crack cocaine-related syndemics. However, I expand on the concept because I argue that the same set of risks, or structures of risk, can and do promote multiple syndemics, based on a constellation of interactions associated with the production of multiple HIV and HCV syndemics in the same population. I posit that similar structures of risk promote syndemic pathways of disease/mental health conditions interactions associated with not just HIV/HCV syndemics, but also HIV/Mental health condition (HIV/MHC) syndemics and Hepatitis C/Mental health condition (HCV/MHC) syndemics.

Throughout this thesis, I explore narratives from PLHIV, HCV and in so doing; I determine and articulate the pathways of disease interactions that affected them. I confirmed and found further syndemic interactions between HIV and HCV, and between HIV and mental health conditions, and HCV and mental health conditions, produced and worsened by substance use, unstable housing, and food insecurity. I characterize the structural factors driving the biological/disease/behavioral interactions as structures of risks that facilitated and promoted susceptibility to other biological conditions and worsened levels of affliction within, and building on, a known HIV/HCV syndemic. Participants described how structures of risks, and structural violence, affected their daily lives in different ways, allowing me to analyze the same data to confirm and contextualize multiple syndemics.

Within the context of syndemics, the concepts of *social suffering* (Singer 2005) and structural violence (Galtung 1969) encompasses how unequal health outcomes affect the daily lives of the population. Farmer, Connor, and Simmons use *structural violence* to describe the macro-level power dynamics producing and reproducing conditions of inequality within a population. Importantly, (Farmer et al. 1996:369) defined *structural violence* as the, “large-scale forces – ranging from gender inequality and racism to poverty – which [then] ‘structure’ unequal access to goods and services.” Therefore, structural violence creates adverse conditions where individuals are subject to stigmatization, and discrimination (Parker and Aggleton 2003), which, in turn promote syndemic interactions, and subsequent deleterious health outcomes, especially within HIV-related syndemics (Emard 2016; Singer 2011; 2014b). Structural violence is an apt theoretical concept that frames the structures of risk perceived by my participants.

### **A Syndemic Perspective**

What is appealing about a syndemic approach... is both its explicit emphasis on examining connections between health and [social conditions] and its attention to routes of transmission that affect clusters of interrelated health problems— Mark Nichter (2008:159).

In the mid-1990s, critical medical anthropologist Merrill Singer coins the term *syndemics*, a combination of two words, *syn-* (from the concept of *synergy*) and *-emic* (from the biomedical term, *epidemic*) (Singer 1994; 1996; 2009; Singer et al. 2013; Singer and Clair 2003). Within syndemics, *synergy* addresses worsened health outcomes from the deleterious interaction between “diseases and health conditions of all types (e.g., infections, chronic non-communicable diseases, mental health problems, behavioral

conditions, toxic exposure, and malnutrition),” (Singer 2009; Singer et al. 2017:941). Unlike the term *epidemic*, which describes the spread of one disease (Singer 2009; 2014a), syndemics conceptualizes adverse interactions between multiple entwined diseases, and mental health conditions (MHC) (Singer 2014a). Consequently, these syndemic interactions promote disease clustering within a population and worsens experiences of suffering at the individual level (Gonzalez-Guarda et al. 2011a; Mendenhall 2012b; 2016; Mendenhall et al. 2015; Singer 2009; Singer et al. 2017).

Indeed, syndemics is not synonymous with the biomedical terms, *co-infection*,<sup>4</sup> *superinfection*,<sup>5</sup> nor *comorbidity*.<sup>6</sup> A syndemic identifies unidirectional and bidirectional pathways of disease interactions that shape acquisition and progression of multiple deleterious biological conditions. At the micro-level disease interaction of a syndemic, *co-infection* characterizes one of the multiple pathways for infectious and/or chronic disease interaction (Singer 2009); *superinfection* refers to an interaction when the most virulent genetic strain is dominant (Singer 2009). Lastly, the syndemics framework moves beyond comorbidity because it draws attention to the considerable influence social, cultural, and structural contexts have over disease interaction (Mendenhall 2016; Singer 2009). Consequently, syndemics provide tools for identifying and drawing attention to the biological, psychological, social, and political-economic factors that

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<sup>4</sup> In syndemics, the term co-infection describes the circumstances when two or more diseases, biological conditions, or pathogens *and* consequentially interact (Singer 2009)

<sup>5</sup> Superinfection describes the interaction between two pathogens composed of genetically diverse virulent strands, and a co-infection (Singer 2009).

<sup>6</sup> Comorbidity is a term used in biomedicine to refer to the co-occurrence of more than one disease in an individual (Feinstein 1970).

engender conditions of disparity, facilitate syndemic interactions (Batchelder et al. 2015a; Bulled and Singer 2011; Bulled et al. 2014; Emard 2016; Mendenhall 2016; 2017; Mendenhall et al. 2017; Ostrach and Singer 2012b; Romero-Daza et al. 2012; Singer 2005; 2009; 2010; Singer et al. 2013; Singer et al. 2017; Singer and Clair 2003).

### **Why Syndemics?**

*Patients do not die of HIV. They die of other causes, mostly overdose— “MCM,” a male health provider at the X Clinic (Interview, July 07, 2016).*

In recent years, researchers in public health, and clinical medicine have increasingly become more engaged in syndemics research on human immunodeficiency virus (HIV), substance use, Hepatitis C (HCV) and mental health conditions (MHC) syndemics (DiStefano 2016; Hart and Horton 2017; Loeliger et al. 2016; Morano et al. 2013; Reece et al. 2014; Stall et al. 2015; Tsai et al. 2017; Willen et al. 2017). Health care providers and researchers have long known the impact structural factors have on conditions increasing vulnerability to HIV (Brantley et al. 2017; Ostrach and Singer 2012a; Tallman 2016; Willen et al. 2017), and HCV (Bulled and Singer 2011; Koneru et al. 2016; Oramasionwu et al. 2014; Padam et al. 2016; Thomas 2008).

It is only in the last few decades that HIV, substance use and MHC syndemics have been taken into consideration for prevention, treatment and management of an HIV, HCV or HIV/HCV co-infection within a population (Chasser et al. 2017; Grebely et al. 2013; Harris et al. 2015; Hart and Horton 2017; Himmelgreen et al. 2009; Janjua et al. 2016; Kohli et al. 2014; Padilla et al. 2012; Taylor et al. 2013; The Lancet 2017).

Syndemics are also useful for developing multidisciplinary intervention where



stakeholder (e.g., the sufferers, health providers, primary care physician, mental health counselors, nurses, case managers and additional medical staff) work together to identify structural barriers to treatment, care and social services (i.e., *structural violence*) and reduce experiences of syndemic interaction among PLHIV, HCV or with both.

### *Syndemic Theory*

A crucial component of syndemics as a theoretical construct is the examination of how social, cultural, psychological, and structural factors shape not just the burden of disease from adverse, mutually exacerbating or sequential biological conditions, but also the individual experiences of suffering encountered in a population (Gonzalez-Guarda 2009; Mendenhall et al. 2017; Singer 2009; Singer et al. 2017; Tsai et al. 2017). Thus, biological interactions affecting a disadvantaged community call for employing a syndemic perspective for understanding worsening health outcomes within a population. Indeed, to meet the criteria, a syndemic must discuss the cooperation between two or more epidemics and adverse socio-environmental conditions that intensify the negative health effects of these diseases and produce the interactions (Singer 1996; 2009; 2014a). Singer introduced syndemic theory in the mid-1990s as a biosocial concept within Critical Medical Anthropology (CMA) (Singer 1986). Singer describes CMA as:

[An] examination of the social origins of dis- ease and ill health in light of the world economic system; (2) analysis of health policy, health resource allocation, and the role of the State in Third World nations; (3) re-thinking the contemporary understanding of medical pluralism; (4) development of a critique of biomedical ideology, practice, and structure; (5) attending to the role of struggle in health and health care; (6) re-examination of the micro-level of the individual, including illness behavior and illness experience, within the context of macro-level structures, processes, and relations; and (7) investigation of health and health programs in socialist-oriented countries (Singer 1986:1196).

A CMA perspective considers health in relation to “access to and control over the basic material and nonmaterial resources that sustain and promote life at a high level of individual and group satisfaction,” (Baer et al. 2013:5). In other words, a CMA approach explores health concerns and the suffering at the macro-level, where large-scale systems interact with micro-level factors to promote and perpetuate the political-economic conditions in which they occur (Pfeiffer and Nichter 2008; Singer and Clair 2003).

Rooted within CMA, syndemic theory is essential for the identification and implementation of strategies to overcome conditions of social inequities and the syndemic pathways of interactions that promote adverse health outcomes. Esther Sumartojo (2000) notes how perceptions of risk and acquisition of HIV operate at the macro-level:

At the macro-level, the vulnerability of persons to HIV is influenced by broad social structural characteristics. These ‘core’ or distal causes may be far removed from individuals’ control, but impact their lives through economic inequalities, racism, sexism, discrimination and stigmatization directed towards groups at high risk (Sumartojo 2000:S6).

For example, anthropologist Chaunetta Jones comments on the adverse social conditions ethnographic fieldwork exacerbating health outcomes among people living with HIV/AIDS (PLWHA) in Grahamstown, South Africa: “Economic inequalities and structural barriers have created dire situations that force many PLWHA to choose between their economic security and health security,” (Jones 2011:68). Syndemic theory critically considers the synergistic, mutually exacerbating link between a cluster of biological, social, and cultural factors, rather than only analyzing pathogen-pathogen, condition-condition, or disease-disease interactions in a vacuum (Singer 2010).

Emily Mendenhall outlines how syndemic theory frames three fundamental rules for *clustering*, a core focus of epidemics and its adverse health outcomes in this thesis:

[First] the clustering of two (or more) diseases exists within a specific population; [second] fundamental contextual and social factors are co-constructed with the cluster of these two diseases insofar as they help create the conditions in which two diseases cluster and contribute to the further emiseration of the afflicted and affected; and [third] the clustering of multiple diseases creates the potential for adverse disease interaction, increasing the burden of impacted populations (Mendenhall 2016:3).

Mendenhall's three guiding principles stem from her argument that syndemics theory contributes to biomedical and public health fields by expanding on the concept of comorbidity in a more comprehensive definition – including chronicity and illness interactions in directly applicable ways. Therefore, syndemics offers immediate avenues to pinpoint the biocultural and biosocial contexts and dynamics that drive worsened health outcomes and increase suffering within people living with an HIV/opportunistic disease co-infection (Ostrach and Singer 2012a; Singer 2014a).

#### *Relevant Syndemic Interactions*

Singer further argues that the following four conditions are critical to the nature and progression of syndemic interactions:

[One] interactions between humans and their physical environments, including other species that harbor, transmit, or promote disease; [two] interactions between diseases and human bodies, including our immune systems; [three] interactions among diseases within human or animal bodies; [four] interactions between human social systems – and their structures of inequality – and diseases, often as mediated by the environment (Singer 2014a:198-99).

These four conditions promote multiple pathways or mechanisms of disease interaction.

The following four types of syndemic pathways and mechanisms of disease interaction are of importance: first is the “alterations or damage done to parts of the body caused by

one disease promoting another disease,” (Singer 2014a:203). In other words, biological conditions can leave physiological changes that worsen health outcomes.

Another mechanism of disease interaction addressed in syndemics is: “one disease enhances the virulence of another disease” (Singer 2014a:204). For example, Lin et al. (2008) conducted a study that showed HIV gp120 enhanced Hepatitis C (HCV) virulence by promoting the expression of HCV-regulated transforming growth factor TGF- $\beta$ 1. Another pathway is when “one disease facilitates the contagiousness of another disease,” (Singer 2014a:204). For instance, sexually transmitted infections (e.g., syphilis) cause genital lesions which increase the risk of acquiring and transmitting HIV or additional STIs (Ostrach and Singer 2012a). Lastly, “diseases [and mental health conditions] may interact through behavior,” (Singer 2014a:206). In which case, the social and biological dimensions of engaging in the practice of substance use and needle sharing (Figure 1B) increases the risk of transmitting and acquiring an HIV and Hepatitis C infection (Armstrong et al. 2011; Bulled and Singer 2011; Grund et al. 1996; Iversen et al. 2015a; Rhodes et al. 2003).

The map below shows the prevalence of HCV co-infection among groups of people living with HIV (PLHIV) who experienced heterosexual contact with HCV (Figure 1A), and people who experienced exposure to HCV through injection drug use (IDU) (Figure 1B) in North America.



**Figure 1. Estimated prevalence of HCV co-infection among PLHIV A) who experienced heterosexual exposure to HCV and B) people who inject drugs. (Platt et al. 2016:803)**

Figure 1 is a map from a meta-analysis, which illustrates that PLHIV and who participate in injection drug use suffered from a higher prevalence of HIV/HCV co-infection than PLHIV who experienced heterosexual exposure to HCV (Platt et al. 2016:803). Within a syndemic, injection drug use is a type of substance use that enables HIV and HCV acquisition through participating in risky social behavior such as needle sharing (Figure 1B). In later chapters, literature and my participants describe risky social and sexual behaviors as a structure of risk within HIV and HCV syndemics that promote disease interactions.

### **HIV/HCV Co-infection: “The Twin Epidemics”**

In an HIV/HCV co-infection, these diseases interact via multiple pathways of interactions (Bullied and Singer 2011; Singer 2010); among patients with chronic HCV, also acquiring HIV/AIDS is associated with higher rates of mortality (Bica et al. 2001; Weber et al. 2006). Consequently, individuals diagnosed with HIV/HCV are at a greater risk for hepatic decomposition, and faster rates of fibrosis progression than their HCV mono-infected counterparts (Kim 2014). Multiple studies determined that patients with both have a more rapid rate of progression to cirrhosis than their HCV mono-infected

counterparts (Fierer et al. 2013; Kirk et al. 2013; Osinusi et al. 2009) biologically and structurally syndemogenic. Fierer et al. (2013) conducted a study, which reported a similar progression to cirrhosis among men who have sex with men (MSM) living with HIV and later acquired an HCV infection. Table 1 indicates that as of December 2014, there are 3 million people have Hepatitis C (Kohli et al. 2014) and 25% of the 1.2 million living with HIV in the United States, are dually infected with HIV and Hepatitis C (Centers for Disease Control and Prevention [CDC] 2015).

**Table 1. HIV/HCV dual diagnoses in the United States as of 2014.**

	<b>Diagnosed with Hepatitis C (HCV)</b>	<b>Living with HIV</b>	<b>Dual diagnosis of HIV/HCV</b>
Diagnoses (United States)	3 million	1.2 million	Approximately 25% of people living with HIV have HCV

## **Chapter Overview**

In chapter one, “Background,” I present literature by medical anthropologists and medical sociologists, recognizing the disproportionate impact of syndemics and syndemic pathways of interactions within marginalized and vulnerable populations. To contextualize the topic of HIV/Hepatitis C syndemics for marginalized patients and my related research questions, I focus on HIV and Hepatitis C syndemic pathways of interactions. I outline existing literature on the roles of substance use, MHC, and other structural factors within syndemic models including Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (HIV/AIDS) and substance use (e.g., the SAVA, syringe-mediated and crack-cocaine syndemics). In so doing, I clarify what constitutes a syndemic. Lastly, I evaluate existing literature on how HIV/AIDS and Hepatitis C

syndemics affect people in poverty and other marginalized populations, in the context of social inequities that compound these interactions.

In chapter two, “Methods,” I outline how I conducted a mixed-methods study using participant-observation and open-ended semi-structured interviews to gather data during my 8-month internship at a Hospital-based clinic offering HIV and HCV treatment in the greater Boston area. From ethnographic accounts of the day-to-day experiences from or about 35 people diagnosed with HIV, HCV, or both, 14 are interviews with people living with one or both conditions, and eight are interviews with health providers. For my data analysis, I use modified grounded theory (mGT) data collection and analysis. Importantly, I use syndemic analysis of quantitative factors, and I glean them from the qualitative data that I gathered.

For chapter three, “HIV/HCV Syndemic,” I confirm and contextualize a known HIV/HCV syndemic as experienced by the affected individuals living with HIV, Hepatitis C, or both, in the Boston area. To do so, I present a syndemic analysis of quantitative factors gleaned from qualitative and ethnographic data, collected through participant-observation and in-depth interviews with people living with HIV, HCV, or both, and their providers. I ethnographically illuminate and contextualize the pathways of interaction suggested by the apparent interaction between syndemic factors, by interspersing my analysis with rich, often difficult accounts from the people directly affected and those who care for them. Here I look closely at the effects of HIV/HCV syndemics in a small sample of people (six individuals) who experienced an HIV/HCV co-infection in contexts of substance use, food insecurity, and unstable housing.

In chapter four, “Syndemic Clustering,” I explore how similar structures of risk promote syndemic pathways of disease/MHC interactions associated with not just HIV/HCV syndemics, but also HIV/MHC and Hepatitis C/MHC syndemics. Here, I also illustrate syndemic clustering through two syndemic models. The models reflect the experiences of 15 of the 35 participants whose narratives outline the synergistic interconnectedness between structural conditions such as food and housing insecurity, lack of social support networks, and stigmatization.

In chapter five, “Substance Use Syndemogenesis,” I use participant descriptions of substance use as a key structure of risk that promotes syndemic interactions within all three syndemics (HIV/HCV, HIV/MHC and HCV/MHC syndemics). I present substance use as a syndemogenic factor. Especially since, it seems to drive the production of multi-syndemic clustering among people living with HIV, HCV or both in the Boston area.

I conclude with a confirmation of known HIV and HCV syndemics, demonstrating through participant narrative how they experience syndemic interactions. Throughout, I discuss the concept of syndemic clustering, highlighting how substance use is a key component for syndemic production. Lastly, I recommend further research on structures of risks that promote the development of HIV and HCV supersyndemics within this population.



## CHAPTER ONE: BACKGROUND

Informants described a cycle of hunger, HIV, and sex work, in which food insecurity frequently prompted sex work. Sex work, in turn, generated heightened risk of acquiring HIV, which our informants attempted to manage through eating either healthy foods or any food at all, [to] manage their infection and prevent side effects from their HIV medication. This increased dependence on food created an increased dependence on income generated from sex work— Fielding-Miller et al. (2014:9).

Within known HIV and HCV syndemics, structural violence is a key part of syndemic pathways of interactions. Johann Galtung (1969) coined the term *structural violence*, which operates at a macro-level and refers to the political-economic contexts that prevent individuals from accessing affordable health care and social services – structural violence is intimately tied to syndemics. Structural violence shapes environments of risk that increase susceptibility to interacting diseases, and limit access to or affordability of treatment for them (Ostrach and Singer 2012a; Rhodes 2002; Rhodes et al. 2005; Sumartojo 2000) in the greater Boston area. I argue that researchers using syndemic theory as a framework to explore the impact of HIV and related conditions on sufferers must identify the social and political-economic conditions (e.g., structural violence, and social suffering) that facilitate HIV, Hepatitis C, and mental health conditions (MHC) interactions, and address the exacerbated health outcomes within vulnerable populations (Emard 2016; Mendenhall 2014; Ostrach and Singer 2012a; Romero-Daza et al. 2012; Singer 1996; 2011; Singer et al. 2017; Singer and Clair 2003).

To understand the complex interconnections of HIV, HCV, and mental health conditions, and the consequences of syndemic interactions between them, it is also important to first differentiate between disease and illness. *Disease* refers to the deviation from biological pathways established by Western medicine (Chrisman 1977; Fabrega 1972). Particularly, “an occurrence of disease embodies a cluster of negative deviations in an individual's various interconnected systems (i.e., chemical, physiologic)” (Fabrega 1977:208). *Illness* refers to the “psychological [component] of disease” (Kleinman 1977:118), which involves the sick person's social, cultural understanding of illness, the coping mechanism for these conditions, and the forms of treatment available to the sick person to seek help from. In addition, Fabrega (1977) concludes that illness and disease depend on the social and physical environments of the individual strikes close to syndemics. Therefore, I begin this chapter with a discussion of the literature supporting HIV as a *syndemogenic factor* – likely to result in disease interactions in structural context. Then, I present several known biological, social, psychological, and structural factors and discuss their role within HIV and HCV syndemic interactions. Lastly, I discuss three known syndemics – the SAVA (substance use, violence, and AIDS), syringe-mediated and crack-cocaine syndemics.

### **Special Vulnerabilities, Special Resources**

For those who struggle each day to feed their families, maintain a safe and secure roof above their children's heads, and participate in the local and inevitably global economy, everyday life can be stressful. Understanding the complexities of the causes and consequences of such stress on the health and social well-being of marginalized and impoverished groups is a central goal of medical anthropology— Mendenhall (2016:166).

Known HIV and HCV syndemics research focuses on vulnerable populations (e.g., MSM, women in poverty, people who engage in substance use) who face conditions of structural violence and social suffering, and experience worsened health outcomes (Mustanski et al. 2011; Platt et al. 2016). People living with HIV, HCV, or both conditions, face structural factors (e.g., economic instability, food insecurity, and lack of access to health care and social services) that worsen disease clustering within a population, which in turn, compounds experiences of suffering at the individual level (Romero-Daza et al. 2003; 2005; Singer 2005; Singer et al. 2017). Before addressing the structural factors within known SAVA (substance use, violence, and AIDS), syringe-mediated and crack-cocaine syndemics, it is important to discuss how *structural violence* perpetuates the synergistic cycle of disease and illness clusters within a vulnerable population (Mendenhall 2012a).

### *Structural Violence*

Farmer et al. (1996:369) expanded the concept and defined structural violence as, “the large-scale forces – ranging from gender inequality and racism to poverty – which [then] ‘structure’ unequal access to goods and services.” In other words, structural violence is a term that describes power relationships and how social structures shape one’s ability to access services (Ostrach and Singer 2012a). Therefore, structural violence as a social condition creates adverse situations where individuals are subject to, for example, poverty (Parker and Aggleton 2003) which, in turn, promotes syndemic interactions, and subsequent deleterious health outcomes, especially within HIV-related

syndemics (Emard 2016; Gonzalez-Guarda et al. 2011a; Gonzalez-Guarda et al. 2011b; Ostrach and Singer 2012b; Singer 2014a).

Paul Farmer's description of structural violence further describes the relationship between structural risk factors (e.g., poverty), health, and social suffering with the term *structural violence*. He writes, "Social arrangements... systematically bring subordinated and disadvantaged groups into harm's way and put them at risk for various forms of suffering" (Farmer 2004:307-08). Structural violence encompasses the violence of poverty, social and political marginalization, racism, sexism, and other forms of structured inequalities and their effects on people's lives, health, and agency (Farmer 2003a; 2004). Structural violence shapes vulnerability and resilience and mediates 1) the experience of conflict, 2) individual and social responses to conflict, 3) and hence the health outcomes of conflict. Thus, structural violence robs people of access to resources, creates food insecurities, and strengthens the reciprocal synergism of poverty and poor health (Bourgois and Schonberg 2009). Under these conditions, syndemics builds upon political-economy of health perspective to find and explore the structures of risk that promote excessive health risks and suffering among and within vulnerable, often poor populations.

Gilligan (1997) noted a relationship between mortality rates and those who have experienced structural violence:

The increased rates of death and disability suffered by those who occupy the bottom rungs of society, as contrasted with the relatively lower death rates experienced by those who are above them (Gilligan 1997:192).

In so doing, Gillian made an association between class, income level and mortality rates that suggested poverty as a form of structural violence. Inability to afford HIV or HCV health care treatment and medication further compromises the immune system and promotes disease interactions (Aidala et al. 2016; Batchelder et al. 2015b; Chasser et al. 2017; Mandorfer et al. 2016; Michel et al. 2016; Padam et al. 2016; Reed et al. 2016). Therefore, access to technological and medication advances, as they influence the lived experiences of people living with HIV (PLHIV) and other biological conditions such as Hepatitis C, are also relevant to this discussion.

Mendenhall (2012a; 2014) expanded on the role of structural violence in lived experiences with syndemics, applying the medical-anthropological concept of *social suffering* (Kleinman et al. 1997) to syndemics research by developing the combined theoretical framework of *syndemic suffering* to refer to lived experiences of interactions between violence, poverty, diabetes, depression, immigration, and substance use among Latina women in Chicago.

In other words, syndemic suffering links structural violence to interwoven socially and structurally driven adverse biological conditions, such as diabetes and depression (Mendenhall 2012a; 2014; Mendenhall et al. 2015), producing increased suffering illuminated by ethnographic research on syndemics. Therefore, syndemics research reflects the unique, and neglected, health needs of people at-risk for acquiring multiple infectious diseases and experiencing suffering.

### *National and State HIV & HCV Medication Programs*

A specific form of structural violence can be seen in the denial or delaying of access to health care (Ostrach and Cheyney 2014), which can particularly affect people at risk for HIV/HCV syndemics. In 1990, Congress passed the Ryan White Comprehensive Resources Emergency Act to increase health care services for people living with HIV (PLHIV) (Johnson and Morgan 2007). Established in 1990, revamped in 1996, and reauthorized and amended in 2000, the Ryan White Program financially assists PLHIV with needed medications at the state level, protecting their right to access HIV treatment and medication (Johnson and Morgan 2007). The U.S. Department of Health Resources and Services Administration (HRSA) and HIV/AIDS Bureau (HAB) administer the Ryan White Programs (Cope et al. 2016). The national HIV/AIDS Drug Assistance Program, which functions under the Ryan White Program in each state which participates, including Massachusetts, is a financial “safety net” for low-income PLHIV (Bassett et al. 2008). These programs are crucial for improving access to HIV medications among vulnerable populations experiencing financial precarity.

In Massachusetts, people living with HIV who earn a gross annual income that below 500% of the US federal poverty level (FPL), or about \$60,300.00 or less as of 2017, are eligible to enroll in programs such as the Massachusetts HIV Drug Assistance Program, HDAP, which is the local provider for Ryan White Program services (HDAP 2016). However, Massachusetts recipients must also have health insurance – for many Ryan White Program beneficiaries in Massachusetts, this is MassHealth, a state Medicaid program that provides health care services for low-income residents living at or below

185% of FPL (Freyer 2016; Gross et al. 2016). HDAP is thus a “payer of last resort” for HIV-related medication co-pays, for those who cannot afford them (HDAP 2016). Even if an HIV-positive person in Massachusetts succeeds in getting HDAP coverage, they may need assistance from covered physicians, nurse practitioners, social workers, and/or case managers to understand their treatment regimen, manage any co-occurring (or syndemic) conditions, and to navigate state health insurance systems to receive related care. While HDAP, as the Ryan White Program provider in Massachusetts provides HIV medications to eligible participants, it does not provide Hep C treatment, to people living with both HIV and HCV, or to people who acquire an HCV infection after already living with HIV, as is common. People with HIV who also need HCV treatment must rely on MassHealth or other health insurance for their any needed HCV treatment.

Given that HIV/HCV co-infected individuals have a higher chance of dying of liver disease (Kirk et al. 2009; Lin et al. 2013; Sohn 2016) or liver cancer (Ryerson et al. 2016; Sarkar et al. 2015; Sogni et al. 2016; Stanaway et al. 2016), the Ryan White funded clinics are, however, expected to provide and to improve access to HCV treatment for HIV/HCV co-infected individuals (Cope et al. 2016). Treating HCV before treating HIV, among people living with both, slows down the progression of liver fibrosis before it becomes fatal (Arends et al. 2015; Fierer et al. 2013; Hernandez and Sherman 2011; Miyamura et al. 2016; Thomas 2008). HCV therapy followed by highly active antiretroviral therapy (HAART) has yielded a reduction in fibrosis progression and cirrhosis-related mortality (López-Diéguez et al. 2011; Macías et al. 2006).

An evaluation of Medicaid policies for reimbursement of sofosbuvir, a drug used in treatment for HCV, showed that individuals with advanced fibrosis had limited access to HCV therapies (Barua et al. 2015). One contraindication was a person's substance use status (Davis and Rodrigue 2001; Harris et al. 2015) and the other was a person's existing mental health condition (MHC) (e.g., depression and anxiety disorders) (Goossens et al. 2016; Johnson et al. 2002; Johnson 2003; Mark et al. 1998). These conditions thereby limit the eligibility criteria of therapies for HCV (Barua et al. 2015). This was because "old" HIV/HCV therapy (i.e., using PEGylated interferon (PEGIFN) and ribavirin (RBV) with joint antiretroviral therapy (cART) increased the chances of developing exacerbated psychological conditions (Blacklaws et al. 2011). Unfortunately, Mehta et al. (2005) note that the measurement for liver disease is not uniform and can be too costly; medications for HCV therapy cost more than \$1,000 (Harper 2015). Thus, some individuals experience limited access to HCV treatment therapy (Mandorfer et al. 2016), even when they are at demonstrably higher risk for HIV and HCV interactions for the very reasons that limit their treatment options.

Although states continue to place disease-related and financial restrictions on HCV therapies it was not until August 2016 when negotiations between MassHealth and Gilead Sciences, Inc., a pharmaceutical company, resulted in a rebate, which lowered the price of Harvoni, a first-line medication for HCV treatment (Executive Office of Health and Human Services [EOHHS] 2016; Freyer 2016). On October 2014, the U.S. Food and Drug Administration (FDA) approved Gilead Sciences' Harvoni to treat HCV genotype 1 infections (Raedler 2015). Harvoni is an interferon-free (IFN-free) combination of the



drugs ledipasvir and sofosbuvir (Gritsenko and Hughes 2015). Unlike ribavirin, Harvoni is a once-a-day oral combination that does not need to be co-administered, making it more efficient than the “old” HIV/HCV therapy regimen (Gritsenko and Hughes 2015; Raedler 2015). Therefore, using “new” interferon-free (IFN-free) and direct-acting antivirals (DAA) to treat and cure HCV, among people also living with HIV, is a preferred treatment regimen for HIV/HCV co-infected individuals (Cope et al. 2016).

### **Human Immunodeficiency Virus – The Perfect Syndemogenic Factor**

HIV/AIDS is caused by a lentivirus that destroys the host immune system and is characterized by its rapid mutation and reproduction (Condon and Sinha 2008:6-7). The virus replicates via the division mechanisms of particular cells in the immune system, as well as some glial cells and nervous system neurons; they have to be cells with cell-surface receptors capable of interacting with the viral envelope protein (Lodish et al. 2007:159). If not treated with antiretroviral, and carefully managed, the virus quantity increases in the blood, simultaneously destroying CD4+ cells—T-lymphocytes from the host immune system (Condon and Sinha 2008). This process enhances the risk of the host acquiring a co-infection (e.g., of tuberculosis, sexually transmitted diseases (STDs), and malaria) (Singer 2010).

A huge body of literature demonstrates the syndemogenic nature of HIV, in interaction with other diseases and conditions including sexually transmitted infections (Adimora et al. 2006; Cheney et al. 2014; Fenton et al. 2014; Gruskin et al. 2007; McLellan-Lemal et al. 2012; Singer et al. 2006), mental health conditions (Altice et al. 2010; Brown et al. 2000; Bulled and Singer 2011; DiStefano 2016; Eisenberg and Blank

2014; Gonzalez-Guarda et al. 2011a; Illangasekare et al. 2014; Iversen et al. 2015b; Johnson 2003; Mustanski et al. 2007; Senn et al. 2010; Wyatt et al. 2002), and malnutrition (Bulled et al. 2014; Everett and Wieland 2012; Himmelgreen et al. 2012; Ostrach and Singer 2012b; Romero-Daza et al. 2012; Singer and Clair 2003). More than 40 years ago, Scrimshaw et al. (1990) discovered the “nutritionally acquired immunodeficiency syndrome” which refers to the process in which malnutrition negatively affects the immune system’s ability to fight off disease at the cellular level. Later, Chandra (1997) noted the cyclical and synergetic interaction between malnutrition and infectious agents and named the synergetic relationship “nutrition-infection complex.” Indeed, HIV disease is remarkably syndemogenic (syndemic-causing) particularly because of how the HIV pathogen destroys the immune system, increasing the risk of acquiring a co-infection and promoting deleterious health outcomes within unjust social environments (Singer 2010; 2014a:208).

#### *Biological Factors: Accelerated Liver Fibrosis Progression*

HIV and HCV promote hepatic fibrosis of the liver. Since HIV compromises CD4+ T cell function, these immune cells become depleted, and result in a higher viral load. This reduces CD4+ cells’ ability to stimulate Natural Killer (NK) cells (Glässner et al. 2013). Inactive NK cells thus cannot inhibit fibrosis among HIV/HCV co-infected individuals, resulting in accelerated fibrosis progression (Miyamura et al. 2016). Additionally, with a depleted CD4 + T cell quantity, the autoimmune response becomes compromised, which also depletes the lymphoid tissue of the intestines. In doing so, the host is more susceptible to bacterial infections (Lin et al. 2013). A compromised

autoimmune system cannot protect against exposure to lipopolysaccharide (LPS), a part of the Gram negative bacteria that can begin hepatic fibrogenesis.

People diagnosed with HCV have higher levels of LPS (Sandler et al. 2011), suggesting that HIV/HCV co-infected individuals have a compromised autoimmune system that does not protect against cirrhosis (Balagopal et al. 2008). The resulting higher levels of LPS bind to Toll-like receptor 4 (TLR4) on human hepatic stellate cells (HSC), thereby activating HSC and promoting hepatic fibrosis (Miyamura et al. 2016). In other words, an HIV/HCV co-infection worsens the level of affliction (e.g., accelerating scarring of the liver) as well as increasing susceptibility and vulnerability to other infectious agents or psychological conditions.

Furthermore, excessive alcohol use decreased HIV and HCV treatment efficiency, which then accelerated development of AIDS via changes in CYP2E1 and CYP3A4 activity (Kumar et al. 2012). This association must be noted because approximately one fourth of people newly diagnosed with HIV engage in the practice of excessive alcohol consumption (Barve et al. 2010). Additionally, Wit et al. (2002) report higher hepatotoxicity in HIV/HCV co-infected individuals undergoing highly active antiretroviral therapy (HAART) who also abuse alcohol. The report suggested that excessive alcohol use among vulnerable HIV/HCV co-infected individuals undergoing HAART resulted in possible harmful liver and autoimmune condition.

Importantly, structural and social inequalities shaped the harmful social and political-economic and behavioral conditions which then increased a population's vulnerability for HIV, HCV, and MHC syndemic interactions (Bruce et al. 2011; Emard

2016; Kelso et al. 2014; Mendenhall 2012a; Mendenhall et al. 2017; Meyer et al. 2011; Operario and Nemoto 2010; Romero-Daza et al. 2012). As such, the structural factors described below were crucial for the development of syndemic pathways of interactions between HIV, HCV, and MHC.

*Structural Factors: Syndemic Interactions*

Bulled and Singer (2011) identified the social and structural factors that facilitated syndemic pathways of disease interaction between HIV and HCV, and the subsequent worsened experiences of suffering. They found that age drove syndemic interactions because younger individuals were more likely to financially depend on someone who is more experienced with substance use practices. Engaging in the practice of drug use at an early age increased the risk of drug sharing and syringe sharing practices over a longer length of time (Grund et al. 1996; Olsen et al. 2013; Palmateer et al. 2010; Rourke et al. 2011; Strike et al. 2004). Given the deleterious health consequences of substance use and HIV/HCV co-infection discussed earlier in this chapter, the length of time an individual engaged in illicit substance use practices further promotes hepatocellular fibrosis progression (Miyamura et al. 2016) and development of AIDS (Kumar et al. 2012).

Traditionally, literature focused on how gender inequalities promoted worsened health outcomes among people living with HIV and HCV. Literature explored how men who inject drugs (MWID) forced or coerced their female partners into injection drug use, increasing women's vulnerability for an HIV, HCV, or HIV/HCV co-infection (Iversen et al. 2015a; Iversen et al. 2015b; Olsen et al. 2013; Scott et al. 2013). Recently, Ellen Tuchman (2015) conducted a qualitative study revealing that some women who were

inexperienced in the practice of substance use sought out or relied upon experienced women for access to drugs and syringe paraphernalia. Tuchman (2015) found that the women who were more experienced with illegal or excessive substance use controlled the access to clean syringe paraphernalia, which increased the risk of acquiring HIV among inexperienced women. As Tuchman hinted, gender, social networks and the amount of experience influenced access to drug and syringe paraphernalia, which further exacerbated health risks among women at risk for an HIV, HCV or HIV/HCV co-infection.

People living with HIV, HCV or both who experienced conditions characterized by structural violence and social suffering may have also experienced racism (Linton et al. 2016). Racism increased the risk of internalizing the social negative stereotypes regarding their ethnicity on top of the interactions racism has with substance use as social factor (Friedman et al. 2016; Kelso et al. 2014; Mokotoff 2011; Rhodes et al. 2005; Sanders-Phillips 2002; Wilson et al. 2014; Woerner et al. 2016). Additionally, the location of residence stands for the environment of risk driving syndemic interactions (Bulled and Singer 2011). A lack of access to health care, and unstable housing increases vulnerability for acquiring an HIV and/or HCV infections (Riley et al. 2015). Riley et al. (2015) found that impoverished women who experience unstable housing are at risk for engaging in substance use. Bungay et al. (2010) conducted an ethnographic study and found that women living with HIV who experienced unstable housing took part in crack-cocaine use as a coping mechanism for the emotional and physical pain.

Unstable housing indicates inability to afford housing expenses, which then suggests financial instability and potential food insecurity. In 2001, the United Nations Subcommittee defined food insecurity as “the limited or uncertain availability of nutritionally adequate, safe foods, or the inability to acquire personally acceptable food in socially acceptable ways.” Limited access to food services further compound health outcomes among PLHIV because food insecurity coupled with HIV increases the risk of medical hospitalizations and emergency room visits (Weiser et al. 2013). Lastly, PLHIV who experience unstable housing also engage in substance use practices, which not only affect the risk for an HIV/HCV co-infection, but also the development of mental health conditions (Kalichman et al. 2014; Kalichman et al. 2015). PLHIV, HIV or both face conditions characterized by poverty; poverty then drives multiple syndemic interactions, producing disease clusters and suffering (Mendenhall et al. 2017; Ostrach and Singer 2012a; Singer 2014b; Tsai et al. 2017).

### **Known HIV and HCV Syndemics**

Ever since the 1980s, awareness of HIV/AIDS and its compounding effects on co-infections is growing – yet co-infection and syndemic interactions are not the same (Singer 2010). The HIV and viral Hepatitis C (HCV) co-infection are notoriously known as the “Twin Epidemics” because the viruses share similar transmission qualities (Highleyman 2003). Syndemic researchers go beyond co-infection or shared routes of transmission to show how HIV and HCV, and structural risk factors for both illnesses, intertwine and interact to increase the burden of suffering for people affected by both. Therefore, to best understand the syndemic conceptualization for exacerbated health

outcomes in marginalized populations, it is imperative to also explain the pathways of disease interaction.

### *The SAVA Syndemic*

Singer (1996) recognized the first syndemic – the SAVA (substance use, violence, and AIDS) syndemic among low-income inner-city Puerto Ricans residing in Hartford, Connecticut in the United States. During a longitudinal study using community-based methods, Singer noticed the harmful effects of poverty, inequitable health care, high employment precarity, housing insecurity, interpersonal violence, and substance use on the AIDS epidemic. Initially identified after exploring the multidirectional relationships between substance use, interpersonal violence, and AIDS in the context of inner-city poverty and discrimination, Singer’s syndemics theory outlined the role of social problems as they work in conjunction to exacerbate all three threats to health simultaneously. The SAVA syndemic linked infectious diseases (HIV/AIDS) with behavior-associated diseases (substance use), and interpersonal factors (violence victimization, especially intimate partner violence), in the context of social conditions (poverty and discrimination) that compounded the disease interactions (Singer 2009). Following recognition of the SAVA syndemic example, the Centers for Disease Control and Prevention (CDC) acknowledged the value of a syndemics orientation for its potential to influence how infectious diseases (e.g., HIV, tuberculosis, viral Hepatitis C, and sexually transmitted infections (STDs) were perceived and treated as multifaceted health phenomena (Fenton et al. 2014).

### *Syringe-mediated Syndemics*

Syringe-mediated syndemics describe the multiple biological and structural pathways of interaction in HIV/injection drug use (IDU) syndemics. Specially those interactions that stem from HIV's ability to compromise an individual's immune system, which then increases the risk of acquiring a disease and produces disease interaction between HIV and Hepatitis C. In an HIV/HCV co-infection, the diseases interact via multiple pathways of interaction (Bulled and Singer 2011; Singer 2010). Bulled and Singer (2011) analyzed the known literature and statistics, considering the biological pathogen-pathogen interaction that can occur in a syringe. Due to the nature of syringes being conductors of diseases, the sharing of needles among people who inject drugs (PWIDs) increase the risk of multiple pathogen-interaction, which then, worsen morbidity and mortality rate among this population (Bulled and Singer 2011; Singer 2010). For example, Dumchev et al. (2009) conducted a study of an acetylated opioid mixture made from poppies in Ukraine (i.e., hanka) revealed its use among people who inject drugs have a prevalence of HIV infection of 14% and a prevalence of HCV infection as 73%. The population in Ukraine who injected drugs had a 12.1% change of acquiring an HIV/HCV co-infection (Dumchev et al. 2009). As such, this study suggests that there is something either biological, social, political or economic that makes this population disproportionately affected.

Furthermore, Macías et al. (2006) conducted a study of 135 individuals living with HIV and HCV who had undergone liver biopsies for three years, concluding that 28% progressed into the next stage of fibrosis, 16% pressed by two stages of fibrosis, and



at least 13% developed cirrhosis. Netski et al. (2008) performed a study which associated higher levels of HCV vireo among people living with HIV than those who are HIV-negative. Two other studies noted the relationship between higher levels of HCV viral loads and increased risk for HIV progression to AIDS (Daar et al. 2001; Kovacs et al. 2010). These studies show that individuals dually infected with HIV and HCV experience worsened health outcomes than those who are living with a mono infection of either disease.

### *Crack-Cocaine Syndemics*

Singer (2014b) found a crack-cocaine syndemic, where crack and cocaine use lead to worsened health outcomes among its sufferers. In this article on infectious disease syndemics of crack-cocaine, Singer first used the term *STI clustering* (which I also employ in relation to structural risks that produce multiple interactions related to HIV and HCV), to describe the syndemic relationships between crack, cocaine, STIs (e.g., genital herpes, chlamydia, and syphilis), interpersonal violence, and poverty (Singer 2014b). Singer also outlined that, like syringe-mediated syndemics (Bulled and Singer 2011), crack cocaine syndemics result from and facilitate the spread of sexually transmitted infections (STI). Thus, increasing the likelihood of disease interaction between HIV and other STIs, as well as with other infectious and chronic illnesses.

For instance, Singer (2014b) notes that crack and cocaine syndemics explore worsened symptoms and hindered access to treatment among individuals who may also be infected with tuberculosis (TB). Particularly, crack-cocaine syndemics address how conditions of substance use promote the risk for an HIV or HCV co-infection. Cocaine

increases the production of catecholamines, biogenic amine neurotransmitters that include dopamine, epinephrine (adrenaline) and norepinephrine (noradrenaline), consequentially depleting the amount of these molecules (Brooks 2015; Lodish et al. 2016). As such, prolonged cocaine use may result in depression (Brooks 2015), which alludes to pharmacological effects substance use has on the mental health condition and HIV risk of the sufferer (Eisenberg and Blank 2014; Gonzalez-Guarda et al. 2011a; Loftis et al. 2006; Walkup et al. 2008). Lastly, syndemics research highlights the progression of HIV viral load, thereby increasing vulnerability to opportunistic diseases, especially since substance use, and food and housing insecurity all affect the sufferer's mental health and ability to adhere to HIV medication (Kalichman et al. 2014; Singer 2014b; Surratt et al. 2015; Turan et al. 2017; Whittle et al. 2016).

## CHAPTER TWO: METHODS



**Figure 2. Entrance to the X Clinic.**

*I fix my collar as I adjust my volunteer badge, which dangles, from my neck before opening the door to the X Clinic. The waiting room lays empty except for the magazines neatly stacked on top of the knee-height table nearest to the entrance through which I pass. I make eye contact with a dark-haired woman – her straight black bangs fall neatly on her forehead, concealing her eyebrows. I tap my badge to the door and wait for it to turn green. I start to panic a little, as it does not open; the little red light taunts me. I peek my head toward the front desk, smile and wave to catch the attention of the Front Desk staff, signaling to my badge and asking if they could please open the door. She disappears from my line of sight, and the light turns green, allowing me entrance into the X Clinic. I pass by the glass window and nod and smile with what I hope is gratitude towards the Front Desk staff that buzzed me in. I walk to the back of the X Clinic, and right*

*before the getting to the EXIT door at the very end of the corridor; I make a left and see that Sam, the mental health counselor's room is open. I knock and peek my head in. Sam is sitting facing her desk and she twists to see who it is although she does not stop typing. When she sees that it is I, she smiles, swivels her chair to stand and face me. I greet her and shake her hand. She tells me she is excited to have me here as she glances at the clock and motions for me to follow her out the door.*

*She tells me that her 9 AM patient just arrived and asks if I would like to observe her appointment, if the patient allows me to sit in, that is. I eagerly nod my head, clutching my bag behind me to hide my enthusiasm. A nurse stands by the door that would not let me into the X Clinic before, and smiles in greeting, saying hello to someone not in my line of sight. She waits there, by the door to the X Clinic, and I, not wanting to crowd them, stand by the door to the Front Desk, wishing that I could have a place to drop my coat and bag before meeting the patient. Sam introduces me and I greet the female patient, "Rose," bowing my head slightly, a nervous smile twitching the corners of my lips when I meet the patient's eyes and say hello. I notice Rose wears a bright red hoodie, with white letters on the front, worn-out jeans, and black sneakers. Her thin brown hair is pulled back in a ponytail. She merely glances at me, acknowledging my presence for the slightest of seconds, lips quickly twisting in dislike (I think) before she dismisses me. Rose follows Sam to her office, and I trail behind, unsure if I could sit in during the appointment. Once at the office, Niki informs Rose and me that I am only here for five minutes and that I will not stay for the entire duration of the appointment. At that, Rose seems to relax slightly into her chair – her shoulders slump as she adjusts her elbows to rest on top of her knees. She sits in the middle of the chair, as if uncertain if she wants to stand up or lean back on the chair completely. Disappointment threatens to unravel my smile, at her discomfort, and I do my best not to show it. Rose sits directly across from Sam, who faces Rose, her back to the darkened computer screen as they begin to exchange pleasantries, inquiring about each other's family.*

*Rose sits at my right, while Sam sits at my left and I do my best to pay attention to their exchange. Rose talked about how her daughter had her sixth child, and I congratulated her on the new family member. At that moment, she turns to face me, under the office's lighting, I get a closer look at the bags under her eyes, and her mouth set in a straight line. It was then that I realized that having a new family member may not exactly be a cause for celebration as she gives me a slight nod, one side of her mouth twisting again, in something like a "nothing I can do now" gesture, her eyes moving upward to a spot above my head. After a few seconds of silence, I ask if she has many granddaughters and she says she has a few and talks about how she is now in the search for a new place to live because even though she carries two jobs, her home is too crowded to relax there. The room falls into silence once more, and I begin to grow nervous, thinking I had over-stayed my welcome by accidentally maybe bringing up a sore topic. My eyes*

*search Sam's face, focused on Rose, as if waiting patiently until the Rose was ready to speak. After a few more seconds, I grow more self-conscious, and I get a distinctive feeling that Rose is not willing to discuss more of her private life with me in the room. Uneasiness grips my stomach and I am not sure if I did something for the patient to not like me.*

*I look at the clock and notice my five minutes are up and even If I wanted to stay, I did not want to take time from an appointment by making it more difficult for Rose to talk about what was important to her. I exclaim that I am so sorry and that it was a pleasure meeting Rose. I gather my bag and coat and walk the two steps out of the office, the soft click of the lock sounds behind me as I close the door and make my way to an empty office room next to the Triage Station in the hallway. I found myself unsure of where to put my stuff and about how to proceed— Excerpt from field note entry, "Searching for a Site" (March 01, 2016).*

Here I detail the events that resulted in a seven-month search for an internship, and then fieldwork position, at a community-based organization offering services to people living with HIV, HCV or both. The first site where I offered to volunteer, a community health center with a specific HIV and HCV program, I was only able to attend twice with each visit lasting up to 2 hours; I spent these hours hashing out the details of volunteering requirements and the paperwork needed to complete to join the organization. However, there were scheduling conflicts and unexpected requirements that made it difficult to confirm a position. After my acceptance as a volunteer with, my would-be supervisor informed me that the organization could no longer support a volunteer position because it was undergoing staffing and organizational changes, including ending the HIV/HCV program for lack of a program coordinator, and that this meant they would be letting go all related volunteers.

Suddenly without a site I had waited patiently to confirm, and limited opportunities to volunteer in the Boston area with my desired population of individuals

living with both HIV and HCV, I thought back to when I first visited the site from which I had just been released:

*We walk into an office space. A dark-skinned woman with a complicated dread pattern with streaks of purple and a silk purple blouse sits at her desk found next to the door we walk through; she looks up when a Staff member opens the door all the way to let me in. I do a quick wave hello as the Staff member introduces me – “this is Naciely, a current BU Masters student interested in volunteering for us. She is interested in HIV, women, and stigma.” I open my mouth to explain, respectively, that stigma is not what I was focusing on and that he forgot to say Hepatitis C as well, but as I try to speak, I stammer and end up just saying hello once more. The woman in the silk asked me if I was nervous and I nodded, as I replied, “Yes, sorry.”*

*“Don’t be! Relax,<sup>7</sup> this is not an interview!” she exclaims as she turns her focus to her computer screen after a quick beep, which I assumed indicated that she had a new email message. This comment completely baffles me because all this time I thought that this was an interview... Therefore, I just laugh awkwardly. Slowly, I nod as I feel my cheeks go from hot to scalding from embarrassment— Excerpt from field note entry, “Site: First Attempt” (Field note, October 29, 2016).*

That encounter had made me feel like I was next in line at the grocery store and I had just realized someone had replaced all my cash with monopoly money. I wanted to make the best impression possible, but as I debated over how I should correct the person who was introducing me, not only had I missed my chance to explain I was interested in Hepatitis C, I had also lost track of the change in a conversation I was to take part in.

What was worse than the embarrassment I felt that day was the disheartening email I received in December 2015, mere hours before my birthday, telling me that my approved volunteer position had become unavailable as soon as it had begun, because the program supervisor for the program I would be working with had left abruptly.

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<sup>7</sup> Underlined sections within quotes or field notes represent the words and phrases participants emphasized with inflections in their voice.

Unfortunately, I learned this while reading an email on my phone, while I was waiting at the site, expecting to start my first day in the internship:

*I sit in the open space where multiple people in pale blue or black jeans and hoodies lounge around, talking amongst themselves; some watch the TV screen above them in the corner. Pictures of smiling faces litter the wall. I feel out of place and over-dressed in my dark slacks, suede boots, red silk blouse and cardigan sweater; I avoid eye contact with the other individuals because I am not sure about what I would even say to them or if I could talk to them. I am anxious because I feel like I everyone is staring at me. To keep me occupied while I wait [to start my volunteer hours], I get up to take a closer look at the pictures. I read one of the notes next to the closest photograph, a portrait of a young man with curly hair smiling directly at the camera. The sadness and somber tone depicted in the note contrasts with the seemingly happy individual to which the note corresponds to; the note talked about how the person and the photo will never be forgotten and how they hope that he is in a better place now. That is when I realize that this is a mural of individuals that are no longer with us due to an overdose. I continue to read other notes, which, like the first, is surrounded by sadness despite the happy looking portraits of people next to it. In the middle of reading my fifth note, Staff member comes out of the back room, and signals me to go to where she is, behind the door that separates the "common area" and the "back area" reserved only for those that work at the organization. I stand in the doorway, caught between the work space meant only for employees and the common area when Staff member informs me that unfortunately, they cannot take anyone at the moment— Excerpt from field note entry, "Site: Second Attempt" (Field note, February 22, 2016).*

Luckily, another manager there interested in my research focus referred me to the site where I eventually volunteered and succeeded in carrying out my fieldwork – a place I call the X Clinic. The X Clinic is a Hospital-based clinic providing HIV & HCV treatment in the greater Boston area.

After trying many other options, the X Clinic accepted me as an intern. I felt elated, and as the old saying goes, the third time is the charm. I could not wait to begin the process of building rapport with the organization staff and the patients that frequented it. I had a phone interview with a member of another organization that worked closely

with the X Clinic, after being connected with her through the site where I had thought I would volunteer, and she also referred me to the X Clinic. It was not until much later, during one of the staff meetings at the X Clinic, that I met the woman who had so graciously introduced me to Sam at the X Clinic. I could not help but profoundly thank her when she pulled me to the side and introduced herself, asking me how I liked working at the X Clinic.

### **Original Research Plan**

Through my ethnographic research, carried out at the X Clinic, I sought to understand how people living with HIV, HCV, or both, and who attended the X Clinic, perceived the structural risk factors affecting their day-to-day lives. I wanted to identify structural risk factors from participants' experiences of living with HIV and HCV syndemics, and of being at-risk for disease clustering and increased suffering. With the guidance of my internship supervisor, and participant-observation interactions with health providers and individuals living with HIV, HCV, or both, I broadened my research scope to include ethnographic accounts from both men and women, rather than just women, as had at first thought I might. I aimed to explore participants' perceptions of their vulnerability for structural risk factors that promote syndemic pathways of disease interactions.

Fundamentally, this is a syndemics and modified Grounded Theory (mGT) project designed using mixed-methods approaches. I posed the following research questions, to explore the structures of risk affecting a marginalized population:



*How and why do people living with HIV, HCV, or both, in the greater Boston area, experience their risks for HIV and HCV syndemics?*

*How do people perceive and experience these diseases, and interactions between them, under adverse conditions?*

*Furthermore, how do structures of risk, as perceived among patients and providers, influence syndemic production?*

In other words, I wanted to know how patients and providers describe risk environments and structures of risk for syndemic pathways of disease interactions, in the greater Boston area. Guided by the theory of syndemics explored within Medical Anthropology, my open-ended research questions reflect the overall purpose of the study, which was to ethnographically investigate HIV/HCV syndemics in the greater Boston area.

This project was originally conceived to explore how women, as a marginalized population, and their health providers, understand how the prevalence and interaction of HIV and HCV infections, co-infection, vulnerability, and susceptibility are exacerbated by cultural, gender-specific, and socioeconomic barriers to the reduction of risk behaviors, health care access and social services (Cachay 2014; Grebely et al. 2013; Mehta et al. 2005; Moore 2011; Oramasionwu et al. 2014; Ostrach and Singer 2012a; Robinson and Moodie-Mills 2012; Wolfe et al. 2010). In so doing, I had hoped to increase social science, medical anthropology, ethnographic, and syndemic understandings of the structural factors and lived experiences that shape disease interactions and risks for HIV and HCV syndemics, for marginalized women in the Boston area. As my research design and preliminary recruitment began, however,

participant-observation at the X Clinic quickly demonstrated that I needed to expand the sampling strategy and focus of the study to include all X Clinic patients living with HIV, HCV, or both, and their providers, to fully examine the structures of risk for interactions between HIV and HCV.

### *Initial Planning and Recruitment Strategies*

I employed mixed-methods ethnographic data collection methods at the X Clinic over a period of eight months (March through October 2016). I gathered data from participant-observation interactions in the form of field notes journaling, where I maintained a daily reflective and private journal used to collect de-identified ethnographic field notes. I employed purposive, opportunistic, expert, and convenience, sampling strategies to gather ethnographic, quantitative, and interview data. I also observed how patients living with HIV, HCV, or both, interacted with their mental health providers or primary care providers, or social workers, or in the X Clinic food pantry.<sup>8</sup> I also had many opportunities to directly interact with eligible participants, as a volunteer (Spanish) translator, HDAP re-application facilitator, and ad-hoc patient navigator, at the X Clinic.

I originally planned to use purposive and opportunistic sampling strategies to recruit participants with whom I would have built rapport. I planned to conduct semi-structured, open-ended interviews in English and Spanish, and I expected each interview to be up to an hour long. I expected to distribute recruitment flyers in Spanish and

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<sup>8</sup> Of the 35 participants who shared their experiences with HIV, HCV or both, 11 reported experiencing food insecurity. Of the 11 individuals experiencing food insecurity, 7 were women, and 8 were men. See Table 2.

English at the X Clinic. I originally intended to focus most my data collection on direct interactions with X Clinic patients, and to merely triangulate the findings with some key informant interviews with providers.

### **Approved Research Activities**

The Boston University Medical School Institutional Review Board (IRB) determined my revised <sup>9</sup> protocol exempt in the spring of 2016. The secondary IRB protocol I was nevertheless required to also submit to the X Clinic's parent hospital's IRB was determined expedited and approved on August 31, 2016. The IRB approvals included permission to analyze field notes I had been collecting since the beginning of the internship. Altogether I collected ethnographic accounts of the day-to-day experiences of a total of 35 people diagnosed with HIV, HCV, or both, directly from them, or from their X Clinic providers (Table 2) to quantify syndemic factors. Following IRB approval, I conducted in-depth interviews with 14 people living with one or both conditions, and with eight health providers.

From March through October 2016, I completed three shifts per week in the X Clinic. While volunteering in the site, I wrote down quick short-hand field note observations. I conducted participant-observations during pre-clinic hours, conference calls, weekly staff meetings, and monthly presentations, and while interacting with patients and shadowing their appointments. I would transcribe these de-identified notes, uploading them to NVivo after hand-coding them within the week; I transcribed open-

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<sup>9</sup> The Boston University Medical School IRB determined the initial project protocol EXEMPT and approved it on March 15, 2016; the amended protocol was approved July 5, 2016.

ended interviews from the formal IRB-approved study period within the week to capture the most accurate depiction. I developed my code-book using existing literature, field notes, and preliminary transcripts and I would revise it whenever I had new codes or new connections between codes. I spent a great part of the summer reading multiple forms, documents and guidelines on the X Clinic's IRB site in efforts to meet all the requirements and specifications. I also expanded my reading and research notes on my bibliography, by reading about HIV, substance abuse and mental health.

*Revised Recruitment and Enrollment Strategy: Version 1*

I only had access to de-identified information from participants eligible for the project. Thus, prior to, during and after the research study, I did not have access nor keep any identifiable characters such as names, telephone numbers, or electronic mail addresses. For the second version of IRB protocols required by the X Clinic's parent hospital, I wrote a more detailed oral consent statement, which I relabeled as the "research pamphlet" per the X Clinic IRB requirements. I further revised my IRB protocol to elucidate more detailed procedures to de-identify and store the gathered data. However, the version varied from the original plan in the recruitment strategies. The revised IRB protocol reflected the language and credential limitations I experienced with the X Clinic IRB requirements for distribution of recruitment flyers, which were more stringent than the medical school/hospital IRB at my home institution, which had already ruled my study exempt. For example, if I wanted to enroll Spanish speaking participants, the X Clinic required that I complete a training course in Spanish, even though I am Dominican, Spanish is my first language, and I learned English as a teenager after

coming to the United States. Another option was to have the Primary Investigator, who was not involved at my research site. Unfortunately, due to these irrelevant and insensitive IRB constraints I was unable to recruit Spanish-speaking participants for base field notes. Thus, I wasn't able to include Spanish-speakers' experiences in my quantitative analysis of syndemic risk factors.

*Revised Recruitment and Enrollment Strategy: Version 2*

Although the X Clinic's parent hospital's IRB would not allow me to directly recruit participants, under the protocol they finally approved staff at the X Clinic introduced me to willing participants who were 18 years old or older, and met the criteria of living with either HIV, HCV or both. The social worker who acted as my key informant ensured awareness of my study among clinic staff by speaking with other providers. This endorsed recruitment method, along with my volunteering and availability as a translator within the site, made my presence more tangible and my research more approachable. Reminding the staff of my research interests and daily approaching them to ask if I might shadow their appointments with patients connected me to physicians, case managers, and other staff who became interested in my research and whom I eventually asked to interview. Nevertheless, it all depended on if the patient was willing to allow me to observe their appointment. At times, the providers' perceptions, complicated by a patient's mental illness status or disclosures about sexual practices, prevented my observation during those appointments, despite my IRB-approved status as a researcher, as well as being a confidential volunteer and medical translator in the clinic. At all times, I deferred to provider or patient preference about my

presence or absence in each clinical encounter. The providers at the clinic also awaited my dual IRB approval before referring me to patients for semi-structured interviews.

### **Preview of Outcomes – Emerging Themes**

For my data analysis, I used modified grounded theory (mGT) data collection and syndemic analysis. I used a quantitative syndemic analysis of factors gleaned from the qualitative data that I gathered from or about all 35 participants living with HIV, HCV, or both. I conducted fourteen in-depth, semi-structured interviews with women living with HIV, HCV or both (no men volunteered for an interview), and eight interviews with providers who serve the population. Thus, this combination of data sources yielded the biological, structural factors, and contextual information, described by participants about their lived experiences with HIV/HCV syndemics, HIV/mental health syndemics, HCV/mental health syndemics (see Table 2), and the role of substance use in interactions between HIV and HCV, and for increasing risks for both. These structures of risk, the disease interactions they produce, and how people experienced them, are the themes and pathways I will present and describe in the following chapters.

**Table 2. Descriptive statistics, biological conditions, and structural contexts of people living with HIV, HCV, or both.**

	Women (17)	Men (18)	Total (35)
<b>Ethnicity/ Race</b>			
African-American	6	5	11
African Immigrant	1	2	3
White, Caucasian	4	4	8
Haitian	1		1
Latino(a)		5	5
Other ( <i>includes self-identification as “mixed race,” and “Brown American”</i> )	5	2	7
<b>Biological Condition</b>			
Living with HIV but not HCV	13	12	25
Living with HCV but not HIV		4	4
Living with HIV and HCV	4	2	6
Mental health conditions/ history of	9	6	15
<b>Social, Structural Context</b>			
Substance use/ history of	10	12	22
Food insecurity	7	4	11
Unstable housing/ homelessness/ history of	8	6	14

### **Qualitative Data Analysis**

My qualitative data analysis plan included an analysis of emerging or apparent syndemic interactions, and modified grounded theory. I hoped to enrich my data quality by using different research tools and methods to collect and triangulate the data at the analysis stage. I had planned to analyze the experiences of patients as reported in interviews, triangulating the results with my participant-observation field notes, de-identified transcripts of open-ended semi-structured interviews with the X Clinic staff, and pre-existing de-identified intake forms and HDAP applications from of HIV, hepatitis C, and HIV/C infected patients from the X Clinic. My interest in the effect of social and political-economic factors on the relationship and interactions between two biological factors, in this case HIV and HCV, pointed my study toward the field of

syndemics. I planned to use a syndemic and modified Grounded Theory (mGT) approach to gather data, and modified grounded theory and descriptive statistical analysis to analyze it. I wanted to employ methodological approaches from modified Grounded Theory (mGT) and syndemic theory to expand an understanding of HIV/HCV syndemics, in this case through the experiences of marginalized individuals in the Boston area. I hoped to ethnographically explore perceptions of vulnerability and susceptibility to these syndemic interactions, and elicit people's experiences of living with these diseases and of being at-risk for them. Unfortunately, despite arrangements and discussions from the beginning of the project, the staff members at the X Clinic never shared de-identified intake and HDAP documents with me, and so I was not able to triangulate my interview and field notes data with these sources.

#### *Modified Grounded Theory (mGT)*

I designed this study using an mGT approach to data analysis; as described earlier the de-identified data that emerged from my participant-observation field notes influenced the open-ended questions in the Interview Guides for both the X Clinic patients with HIV, HCV or both and for the X Clinic staff members. I constantly compared the different types of data I gathered. I used open-ended questions to gather lived experiences from both patients and staff members during semi-structured interviews. When I transcribed the interviews, all interview notes and transcriptions were de-identified. I manually coded my documents and then used Nvivo software to keep track of all my documents. Dr. Bayla Ostrach, my faculty advisor and the PI on the B.U. Medical School IRB protocol graciously assisted me to develop a list of codes to



categorize and organize the findings emerging from the study's de-identified data gathered via mixed-methods approaches described earlier in this section. I coded in 1) initial coding; 2) memo-writing. I used hand-coding because it allowed me to color code, annotate, shorthand, simplify, and learn/get a deeper understanding by processing the information as I wrote it down (Charmaz 2014).

I coded my participant-observation field notes from the on-going internship and then fieldwork, multiplied times. This helped me focus the research aims when I coded it for the second time, a process in modified Grounded Theory meant to ground the evidence in data from the research project (Charmaz 2014). I typed extended memo entries to correspond with the participant-observation field notes in my physical notebook, the night of the event or situation.

### *Syndemics Theory*

I planned to explore how, in the context of social disparity, structural risk factors such as homelessness, unemployment, substance use, lack of health insurance, immigration status, history of domestic abuse, etc. produce or exacerbate interactions between and risks for HIV and HCV. Therefore, my data analysis heavily depended on the data emerging from my field notes and interviews. I analyzed the social, political, economic and biological conditions emerging in the various data sources not only through modified Grounded Theory analysis of interview and field notes transcripts, but also using syndemics analysis, under the guidance of my advisor, a recognized expert in syndemics (Singer et al. 2017). We created an Excel spreadsheet to track and quantify the frequency with which the 35 participants living with HIV, HCV, or both, had reported

specific disease or structural factors, and in which combinations of lived experiences, to quantitatively evaluate the apparent syndemic interactions between the qualitative experiences they described to me or to their providers. Throughout the data analysis period, we met regularly to analyze my data and discuss the relationships between the disease, biological, behavioral, social, and structural factors that participants reported, in relation to known syndemic models and published literature. This quantitative analysis of qualitative data (Creswell 2013), and iterative, modified Grounded Theory analysis process, allowed me to develop a conceptual schema of the emerging syndemic relationships in my participants' lived experiences of HIV/HCV syndemics (Chapter Three), with syndemic clustering (Chapter Four), and with substance use syndemogenesis (Chapter Five). I thus used syndemic frameworks and analysis to identify the social, political, economic factors that appeared to have the greatest influence on either the risk of acquiring an HIV/HCV co-infection, or exacerbating the damaging health and structural conditions of a person who is living with HIV, HCV, or both, within the Boston area (Gonzalez-Guarda et al. 2011a).

Adding to the current HIV/HCV syndemics literature, my data documents ethnographic accounts of syndemic interrelationships between sufferers' experiences with HIV and HCV in the Boston area. Investigating these syndemic interrelationships drew attention to the production and exacerbation of the factors that shape how people who are at-risk for, or infected with, HIV, HCV, or both, experience these diseases. Ultimately, syndemic quantitative analysis of qualitative data revealed pathways of interaction, contextualized by ethnographic fieldwork and interviews that draw attention

to biological, social, psychological, behavioral, and structural factors. For instance, a major theme of unstable housing demonstrated how this larger structural form of precarity reinforces social instability, increasing risks for substance use, reduced medication adherence, and driving HIV/HCV syndemic interactions within this population. Furthermore, the combination of unstable housing, food insecurity, and lack of access to health insurance access also drove additional syndemic pathways of interactions associated with HIV, HCV, and mental health condition syndemics discussed in later chapters.

## CHAPTER THREE: HIV/HCV SYNDEMICS

*Patients don't die of HIV; they die of other causes, mostly overdose— “MCM,” a male health provider at the X Clinic (Interview, July 07, 2016).*

### **A Syndemic Analysis of Lived Experiences**

MCM's somber statement highlights the core elements of my argument: structures of risk (e.g., substance use, food insecurity and unstable housing) promote syndemic pathways of interaction associated with the production of HIV and HCV syndemics. In this qualitative sample, only six of the 35 individuals living with HIV had also lived with Hepatitis C; these participants shared with me a series of ethnographic accounts that depicted their perceptions of their risks for these interactions. Table 3 represents this marginalized group of people living with HIV and a current or past HCV co-infection, in the greater Boston area, and the structural risk factors that produced syndemic pathways of interaction for them. All six participants dually diagnosed with HIV and HCV reported a history of substance use; five experienced food insecurity (making them eligible for a free food pantry associated with the X Clinic); four reported unstable housing; and two suffered from mental health conditions that would meet criteria for psychiatric or psychological diagnosis in the Diagnostic and Statistical Manual of Mental Disorders (DSM) (Hauser and Kern 2015; Loftis et al. 2006).

**Table 3. An overview of participants’ experiences with structures of risk and HIV/HCV diagnosis.** *(Color-coding for specific themes used throughout analytical chapters)*

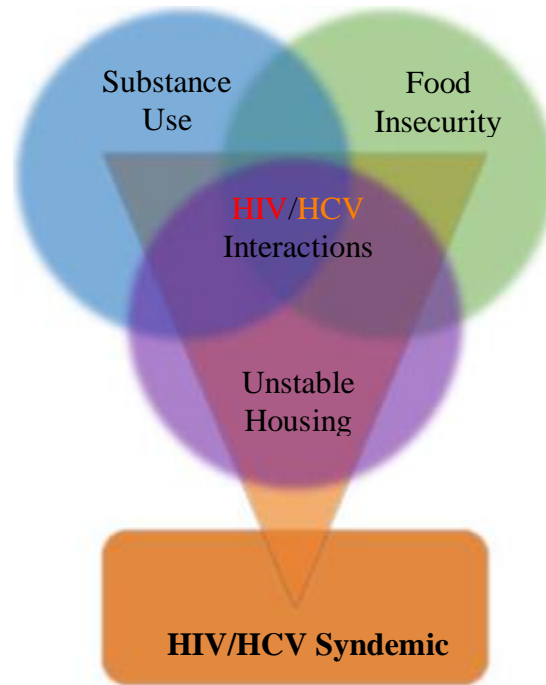
	<b>Women</b>	<b>Men</b>	<b>Total</b>
<b>Participants living with HIV reporting current or past HCV infection; structural risk factors reported</b>	(5/6)	(1/6)	(6/35)
Substance use/ history of substance use	(5/6)	(1/6)	(6/6)
Food insecurity	(4/6)	(1/6)	(5/6)
Unstable housing or history of	(3/6)	(1/6)	(4/6)
Mental health conditions or history of	(1/6)	(1/6)	(2/6)

In this chapter I analyze ethnographic descriptions each of the three structures of risks mentioned by participants living with both HIV and HCV; I discuss the two remaining structural risk factors, food insecurity (see Figure 6) and unstable housing (see Figure 8) later in the chapter. I use the compounded experiences of participants’ social suffering to explore syndemic pathways of interaction between HIV, HCV, substance use, food insecurity and unstable housing.<sup>10</sup> Thus, in this this chapter I argue individuals living with HIV, HCV or both, in the greater Boston area, encounter specific structures of risk for HIV/HCV syndemics (Figure 3), confirming the presence and danger of this known syndemic.

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<sup>10</sup> See Figure 3 for the complete HIV/HCV syndemic model.

*The HIV/HCV Syndemic Model*



**Figure 3. HIV/HCV syndemic model: substance use, food insecurity and unstable housing. (Cabral and Ostrach 2016)**

The conditions facilitating syndemic pathways of disease interaction are color coded and illustrated in Figure 3 as overlapping figures. I envisioned this syndemic model as three dimensional with rings instead of the circles held together by an upside-down pyramid structure instead of triangle facing the HIV/HCV syndemic. The triangle symbolizes possible biological interactions between two biological conditions affecting individuals at-risk for and who lived with an HIV/HCV co-infection (e.g., HIV and HCV or HIV/mental health conditions<sup>11</sup> or HCV/ mental health conditions). The square at the

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<sup>11</sup> I chose the term mental health conditions because the participants did not use the term *mental illness* in their descriptions of the mental health conditions they suffer from. See Table 4 for a list of the mental health conditions participants reported in interviews and de-identified informal conversations documented as participant-observation field notes.

bottom represents the HIV/HCV syndemic, which is one of the three HIV/AIDS and HCV syndemics<sup>12</sup> affecting the lives of the people most at-risk for an HIV/HCV co-infection. The idea for the model being that if looked from above; the randomly overlapping rings will have sections intersection with the structure in the middle. The sections of overlap symbolize the factors facilitating pathways of disease interaction, and the subsequent suffering. For instance, the spaces where the rings overlap with the center structure indicate the environmental conditions (be them social or physical) in which structures of risk such as substance use facilitate syndemic pathways of disease interaction between HIV and HCV that produce a known HIV/HCV syndemic.

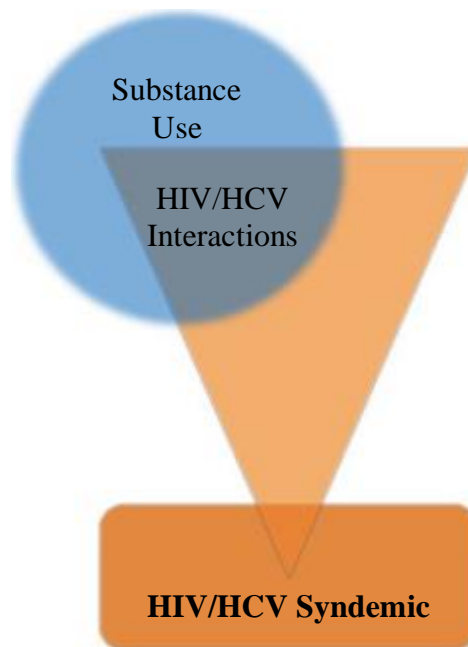
The empty spaces in the rings suggest that substance use (blue), food insecurity (green), and unstable housing (purple) are factors of risks experienced to different degrees by those diagnosed with HIV and HCV. The empty spaces symbolize situations where biological and social factors are not interacting in a syndemic manner. For instance, Singer argues that if only one disease is identified within adverse social conditions, then it's not a syndemic because a syndemic conceptualizes how multiple biological, behavioral or psychological factors interact to compound deleterious health outcomes (Singer 2009). Alternatively, if two or more biological, psychological, and behavioral conditions are interacting within a population yet no structural factors are identified, then it cannot be a syndemic because it does not consider the contexts facilitating and perpetuating these interactions (Singer 2009). Therefore, I chose to view

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<sup>12</sup> I identified three syndemics: HIV/HCV, HIV/mental health conditions, and HCV/mental health conditions syndemics. See Chapter Four: Syndemic Clustering for more information on the HIV/mental health conditions and HCV/mental health conditions syndemics.

the spaces of non-overlap as the physical and social environments where the processes needed to develop a syndemic, such as the risk factors, and larger social, cultural, political, and economic systems operating at the macro-level that reproduce conditions of poverty, injustice and suffering in a population. Conversely, the places where the risk factors, substance use, food insecurity and unstable housing overlap with each other and with HIV/HCV biological interactions further complicate the health outcomes and the disease experience among sufferers.

### **Substance Use: As a Risk Factor**



**Figure 4. HIV/HCV syndemic model part one: substance use.**

Coded blue throughout this document, substance use is a behavioral disease; the blurred edges of the Figure 4 above reflect the interwoven nature of social and biological pathways of syndemic interaction reflected in substance use as a structural factor. Figure 4 illustrates one of the three structures of risk that in my findings produced a known



HIV/HCV syndemic. The model reflects the role of substance use in pathways of disease interaction between HIV and HCV, for those at risk. The following vignette occurs during an interview, and it highlights the struggle substance use participants go through.

*“I am always down for the Good Fight,” Double-0-Seven says as she settles down in the only available seat in the private clinic office beside the examination bed, a metal chair adjacent to mine. For a long moment, there is silence except for the slight rustle of fabric as Double-0-Seven slides forward to the edge of her seat. I slowly cock my head to the side, prompting her to continue. “Most people can drink and go home. Some people can take medicine – painkillers – and stop when they are supposed...” her low wistful voice trails off.*

*Suddenly, she shrugs, and her light brown eyes lock with mine. “But some people cannot! In addition, if you play around and think you can? You can't!”<sup>13</sup> You can't win.” She leans back in the chair, arms resting on her thighs as her eyes scan the office. I follow her gaze, taking in the blue walls, the white cabinets and small sink on the left corner. She studies the bright spots dancing on the wooden desk between us as the rays of the morning sun peek through the gaps in the leaves of the tree outside the tall window, and into the room.*

*A sad smile twists her lips before she continues, “you have to recognize within yourself your limits.” She nods her head in a quick succession as if emphasizing the resilient nature needed to overcome substance use at the individual level. “Sometimes it takes 40 years!” She chuckles to herself.*

*“It took me about 35 years to figure it out; it's not too late, though. It's never too late. So, you just keep fighting the Good Fight” — “Double-0-Seven” (Interview, September 22, 2016).*

Double-0-Seven,<sup>14</sup> was a 55-year-old Caucasian woman who after struggling with substance use acquired HIV and later, HCV. Throughout the interview, she repeated the phrase “*just fighting the Good Fight*” as if it were a mantra, to remind herself that she had

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<sup>13</sup> Using punctuation (e.g., underlying) to reflect emphasized words and phrases. In this case, Double-0-Seven shakes her head vehemently, stressing the words, “you can't.”

<sup>14</sup> Double-0-Seven chose her pseudonym shortly after initiating a quick chat about Russia and espionage while inspecting the world map plastered to the opposite wall.

fought too hard in her struggle with substance use to yield. At the time, I was not familiar with the expression, so I asked her about it:

**[Interviewer]:** *How has fighting the good fight against substance use affected how you managed your diseases?*

**Double-0-Seven:** *I have HIV. I have had Hep C, but I got rid of it through treatment. I have no kids... I've been... a drug addict and an alcoholic since I was sixteen. So, in account of that, it brings me to this table with the HIV and the Hep C... It was a direct result of my drug use. It was, you know, from um, that lifestyle, that gave me these wonderful<sup>15</sup> little diseases (Interview, September 22, 2016).*

### *Being At-Risk: Sharing Drugs and Syringe Paraphernalia*

Double-0-Seven is clearly aware that her history of substance use increased her vulnerability for not just HIV and HCV, but additional opportunistic diseases as well. For example, in the following ethnographic excerpt she describes how her substance use increased her risk for HIV and HCV co-infection:

*HIV and Hep C go hand-in-hand. See, no matter what you do, if you are infecting yourself with one, and that is what addicts do when they go messing around with needles, you know? .... But I think Hepatitis C goes hand-in-hand with HIV because, I for one, got them [both] intravenously [by injecting illicit IV drugs] — “Double-0-Seven” (Interview, September 22, 2016).*

Her quote sets the stage for substance use as a structure of risk in HIV/HCV syndemics, as it increases HIV and HCV susceptibility, transmissibility, and disease progression.

Double-0-Seven alludes to needle sharing as a risky behavior practice among addicts; as described in Chapter One, sharing paraphernalia for injection drug use increases the risk of acquiring both HIV and HCV because the syringe acts as a vector for

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<sup>15</sup> Double-0-Seven’s voice squeaks in excitement as she stresses the word ‘wonderful’ but her cheery tone is too exaggerated and sudden to be genuine happiness. If I hadn’t already known she was being sarcastic, her exaggerated eye-roll and grunt would have clued in. It was as if she had no patience left to deal with the diseases that plague her daily life.

infectious agents. Upon removal from the body, a syringe generates a negative air pressure that can trap infectious agents, promoting blood-borne infections such as HIV and Hepatitis C (Bulled and Singer 2011). Once the HIV or HCV pathogen is in the syringe, transmission depends on the pathogen's ability to survive outside the human body (Bulled and Singer 2011). Levels of transmission also depend on how long an infectious agent can survive outside the body – HIV can survive for up to 30 days, while HCV can last for eight months at room temperature (Thompson et al. 2003). Thus, the substance use practice of sharing drugs through contaminated syringe paraphernalia is a risky behavior that increases the likelihood of transmitting HIV and HCV.

Double-0-Seven knew she was at a high risk for acquiring an HIV/HCV co-infection because she continued to do heroin and share meals with a woman living with Hepatitis C. During the interview, she states, "*I know that it was from her because she had Hep C and she was yellow as a banana!* [Indicating jaundice, a common symptom]" (Interview, September 22, 2016). Despite knowing she was at risk for acquiring HCV from her friend, Double-0-Seven continued to share syringes and other injection drug use paraphernalia with her: "*She had her own works, and I had my own works and needles, but sometimes, when we did not, we would share,*" (Interview, September 22, 2016).

The practice of drug and needle sharing behavior and the social dimensions perpetuating this risky behavior could be explained using the concept of *social lubricants*, within a *moral economy* of drug use (Bourgois and Schonberg 2009) shaped by structural violence, criminalization, and stigma. Grund et al. (1996) use the term social lubricants to conceptualize how the pharmacological effects of drugs result in altered

states of consciousness which then facilitate social interaction and feelings of camaraderie. Within a moral economy of needle sharing (discussed below), social lubricants also act to facilitate the conscious or unconscious overlooking of known risks. Double-O-Seven's following quote points out how substance use itself increases the likelihood of sharing drugs and paraphilia, framed by the concept of social lubricants:

*There is just one thing in common and that is just the common denominator, which is to get high. I'll help you if you don't feel good – that is the, camaraderie. I'll help you because I know that you don't feel good, if I can, but I'm not going to go out of my way to help you because of the take care of my own sickness—*  
“Double-0-Seven” (Interview, September 22, 2016).

She describes the social dimensions of substance use that produce syndemic interactions between HIV and HCV. Her description links this behavior to Bourgois (1998) *moral economy* concept. As Bourgois and Schonberg (2009) write,

*[The moral economy serves as] protection from full-blown heroin withdrawal symptoms.... [Since] it's considered unethical to leave a person stranded when he or she is dopesick unless one is openly feuding with that person. The best protection from withdrawal symptoms is to maintain a generous reputation, because everyone is eager to help someone who will reciprocate in the future* (Bourgois and Schonberg 2009:82).

Applying a moral economy of sharing to an HIV/HCV syndemic could explain why Double-0-Seven believes that addicts will persist to share drugs and syringes:

*I am not saying it to be bold and crude, but addicts will share because they are sick. Their bodies are sick and their minds are sick. They are not thinking about, right at that moment, of what they might catch. They will clean the [needles], but they may not have bleach that day. They will clean them as good as they can with water... Your body is craving something and you aren't thinking – you're worried about feeling better. You are not worried about catching a disease* (Interview, September 22, 2016).

Double-0-Seven, continues, “*There are things that can do prevent yourself from catching anything! Sometimes an addict just doesn't have that stuff. If they do not have it, then shame on them—they had a chance!*” (Interview, September 22, 2016).

Before we our interview ends, Double-0-Seven admits that she would rather use water to rinse her works than nothing at all. Unfortunately, water does not get rid of the HCV and HIV that can live in the reservoir of a syringe, thus increasing the likelihood of acquiring an HIV, and HCV infection (Hernandez and Sherman 2011; Lin et al. 2013). For this reason, her reaction to someone who does not even attempt to care about HIV or HCV transmission was much more jarring:

*I know people that are completely off-the-rocker-crazy! These people do not even attempt to worry about nothing. They just say, "I don't care."*

*At that moment, her demeanor changed: she sits up straight on her chair, palm flat on her chest as she leans back, recoiling and appalled. "Oh, you don't care? No? As a matter of fact, I do care, so I am not going to let you use my works, so how's that?!" She turns to me and says, "And I wouldn't. I never ran with people though. I ran with one person. I didn't run with a group of people. Nobody – no addict has a bunch of friends anyway" (Interview, September 22, 2016).*

Shortly after she says this, she hints at the reason why an addict would not have that many friends:

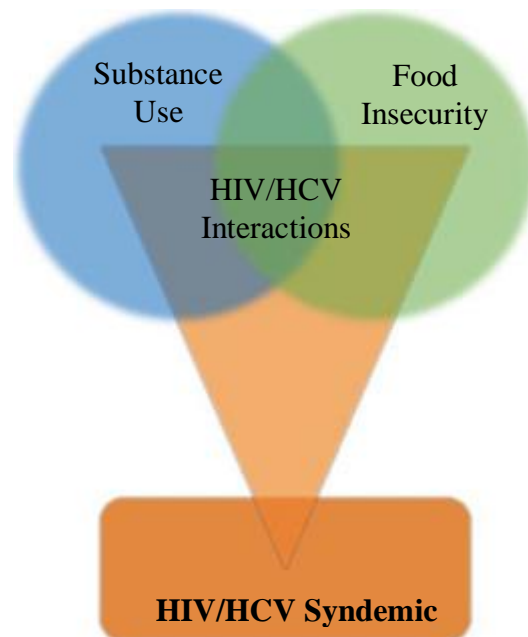
*"In my pocketbook, I have NARCAN [a medication used to reverse dangerous overdoses], just in case one of my friends decides to overdose or something. God forbid it happens, but this is it!" Double-0-Seven pulls out the nasal NARCAN box from her bag. "And if anything ever happened, I would have to stop and read the fucking directions," she guffaws while she mimics herself putting her reading glasses on to read the instructions. "I got you. I got you. Just give me a minute," she says, while hurriedly pretending to read the instructions. "Wait a minute, he's breathing? Oh, okay." She places the NARCAN right back to its spot in her purse (Interview, September 22, 2016).*

Double-0-Seven believes she acquired HCV and HIV from her friend after these reciprocal social interactions, when they shared drugs and syringe paraphernalia, demonstrating her own understanding of the structural contexts of risk for HIV/HCV syndemics. She concludes: "*it is all risky behavior and it is up to you to protect yourself*

and to just be aware of what you're doing. And if you mess around and Use<sup>\*16</sup> [drugs], your viral [load] goes up.... Addiction is very bad. You think you can control it, but you can't. You can't control it (Interview, September 22, 2016). Thus, self-reported experiences of sharing drugs and syringe paraphernalia highlight perceptions of risk, in the context of needle sharing, causing both social and biological interactions among syndemic sufferers (Bulled and Singer 2011; Singer 2014b).

#### *Substance Use and Food Insecurity*

*It's bad enough to do the drugs, but it is even worse when you put yourself in these "high risk situations" where you can catch [HIV/] AIDS. I already have the virus, but I didn't think... back then, I wasn't thinking about anything; I was just thinking about doing drugs— "Double-0-Seven" (Interview, September 22, 2016).*



**Figure 5. HIV/HCV syndemic: substance use and food insecurity.**

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<sup>16</sup> The word “Use” is capitalized because Double-0-Seven uses two fingers to tap the crook of her arm, suggesting injection drug use (IDU).

Participants' lived experiences of syndemic interactions fell under what I call *environments of risk* or *structures of risk*, echoing Singer's description of *HIV risk environments* (Singer 2014b). Structural violence shapes and maintains these high-risk settings<sup>17</sup> (Singer 2009). Poverty is a pervasive form of structural violence that perpetuates unequal access to services, and disproportionate social suffering (Farmer 2003b). Conditions of poverty therefore produce multiple environments of risk (Sarang et al. 2010). Many people in poverty and suffering from substance use disorders may spend money on drugs instead of food (Anema et al. 2015). Double-0-Seven explains that she buys pot to get an appetite,<sup>18</sup> but unfortunately, both cost money that she does not have:

*It's bad enough to do the drugs, but it is even worse when you put yourself in these "high risk situations" where you can catch [HIV/] AIDS. I already have the virus, but I didn't think... back then, I wasn't thinking about anything; I was just thinking about doing drugs (Interview, September 22, 2016).*

Additionally, there are also people who would rather spend money on drugs instead of food (Anema et al. 2015). Conversely, Double-0-Seven explains that she buys pot to get an appetite, but unfortunately, both cost money that she does not have:

*Yeah... I don't usually um, have an appetite these days, but I smoke pot though. I smoke pot a lot, and when I do, I eat, and I don't get in trouble with my doctor. [For having poor nutrition that makes her medications less effective]. The thing is, that [pot] is expensive; they [sic] costs money, just like everything else, and that's it. I can't... (Trails off) — "Double-0-Seven" (Interview, September 22, 2016).*

Double-0-Seven thus described some of the structural conditions in which she and others with both HIV and HCV live, produced by and compounding daily poverty, in which

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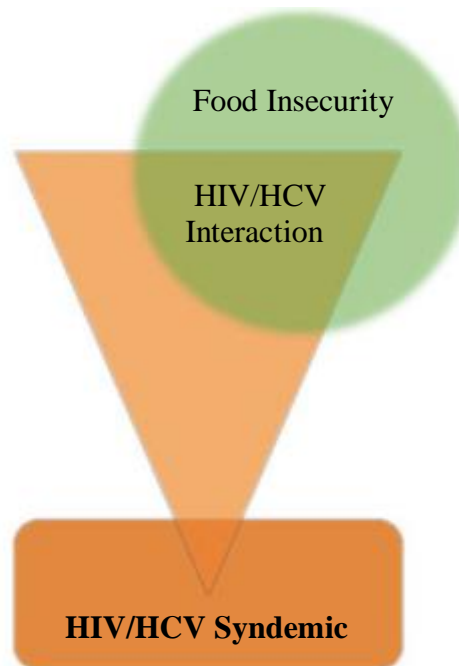
<sup>17</sup> See Chapter One: Background.

<sup>18</sup> Double-0-Seven's HIV and HCV medications are associated with side effects including nausea and appetite suppression.

substance use increases risks, and influences her appetite and wellbeing. She uses pot to stimulate her appetite because is aware that other drugs she consumed to suppressed her appetite. Importantly, the literature supports her experiences with drugs and a loss of appetite (Brooks 2015).

### **HIV/HCV Syndemic: Food Insecurity**

*It doesn't hurt to bring [food] back home. If I bring some food, at least I'm contributing by bringing food, you know? I'm not working... But [the landlady] can't complain and say I am staying at the house for free if I [bring food]—* “Ronnie,” a former substance user diagnosed with HIV and HCV, living in a situation of housing and food insecurity (Field note, April 4, 2016).



**Figure 6. HIV/HCV syndemic model part two: food insecurity.**

This quote from Ronnie, said while packing a few bags of rice, cans of beans and juice from the X Clinic food pantry into a book-bag after a session with his mental health counselor, illustrates the interplay between all the structural factors that my participants described producing structures of risk for. Ronnie is a Puerto Rican man who frequently



visited the clinic on a drop-in basis, without an appointment. While I assisted all six HIV/HCV co-infected participants as a volunteer in the food pantry at the X Clinic, there were only 11 out of the 35 participants who indicated a need for access to the food pantry.

The partial Figure 6 above illustrates how food insecurity as one structure of risk promotes HIV and HCV syndemic interactions among participants who experienced economic marginalization in the Boston area. Himmelgreen et al. (2009:404) defines food insecurity as “*a risk factor for both HIV transmission and worse HIV clinical outcomes... [And] HIV increases the risk and severity of food insecurity for HIV-infected individuals and the members of their households.*” The same dynamics increase risks for HCV infection and for exacerbating mutual interactions between HIV and HCV.

Niecy, a 62-year-old African-American woman living with HIV and previously diagnosed with an HCV infection, like Double-O-Seven also reported a history of substance use. She explained that her struggles with substance use hindered her ability to afford food and housing. At the time of the interview, she was unemployed, with Social Security checks as her only source of income. She mentioned she tried to save money through food-stamps, a federal program officially known as Supplemental Nutrition Assistance Program (SNAP), geared towards financially assisting low-income individuals to access food. Below, she highlights how she experienced the link between food insecurity, financial instability and substance use:

*When I was struggling with my drugs and alcohol, they had this guy tell me I could go and sign up for food stamps, and back then, well, back in the day –they still do it, but they are trying to cut down. Back in the day, you can sign up for food stamps and they might give you a little cash, and that was the case with me—*

“Niecy,” a woman living with HIV who also experienced an HCV co-infection (Interview, October 21, 2016).

The health providers at the X Clinic also note the connection between food access and ability to generate an income. For example, during an interview with Michonne, a health provider at X Clinic, she discussed food insecurity as a component of unemployment and financial precarity, which also affects the patient’s ability to adhere to the HIV or HCV treatments:

*Another thing that can interfere with being compliant to their treatment is that many of our patients have troubles in their personal life... Sometimes they don’t have enough food, they don’t have a job, or they can’t find a job... Many of our patients struggle financially—* “Michonne,” a health provider at the X Clinic (Interview, July 28, 2016).

Michonne’s statement hints at the political-economic systems operating at the macro-level, restricting access to employment opportunities or financial assistance programs.

After meeting with Ronnie, Sam, a female mental health counselor at the X Clinic and I discussed barriers to treatment that affect his ability to access quality foods. She explained:

*Finding affordable housing might be difficult for [Ronnie], particularly since he has a history of incarceration. [Ronnie’s] history of incarceration hinders his ability to be employed in a more stable job occupation to improve his financial, home and food insecurity—* “Sam,” a mental health counselor at the X Clinic (Field note, April 4, 2016).

In Ronnie’s case, he uses the food pantry as a source of food, which intersects with the uncertainty of his housing and financial situation – forms of precarity which in turn exacerbate negative health outcomes for people living with both HIV and HCV, as I found in this study. During the beginning of a therapy session for which Ronnie allowed me to sit in, he referred to his perceptions of the biological interactions between food, and

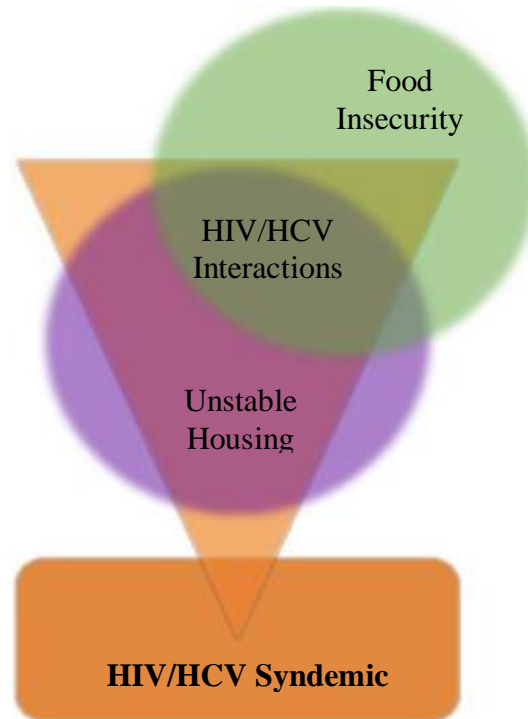
the effectiveness of treatments for his HIV and HCV, as his counselor shared in his excitement over Ronnie gaining his strength back due to being on regular medication for HIV and HCV. Ronnie acknowledged this was true, especially since he had the strength to ride his motorcycle: *“I can't wait to take it out for a spin and not just work on it...”* Ronnie flashed me a crooked smile, *“Yeah, it's good I'm eating and taking my medication and I'm feeling better now; that's why it's good I'm stronger now,”* (Field note, April 4, 2016).

By comparison, a structural risk environment that emerged for my participants was the inability to afford quality food over time, as an element of the HIV/HCV syndemic -- compounding suffering and increasing the interacting disease burden within a population. When Ronnie mentions his weight, he echoes a component of the syndemic interactions between access to food, and health outcomes discussed in literature: 1) food insecurity is associated with malnutrition and lower body weight, which in turn, affects susceptibility to HIV and opportunistic infections<sup>19</sup> (Himmelgreen et al. 2009; Ostrach and Singer 2012b); 2) lack of access to food influences ability to adhere to HIV and HCV treatment (Kalichman et al. 2014), and the effectiveness of these medications. Especially in the context of substance use, where the pharmacological effects from the drugs (e.g., methamphetamine) reduce appetite and with no energy from food, the immune system becomes weak (Hendricks and Gorbach 2009); worsened health conditions may limit employment options, which in turn, perpetuates conditions of poverty (Anema et al. 2015; Brooks 2015).

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<sup>19</sup> See Chapter One: Background for additional information regarding HIV and nutrition.

*Food Insecurity and Unstable Housing*

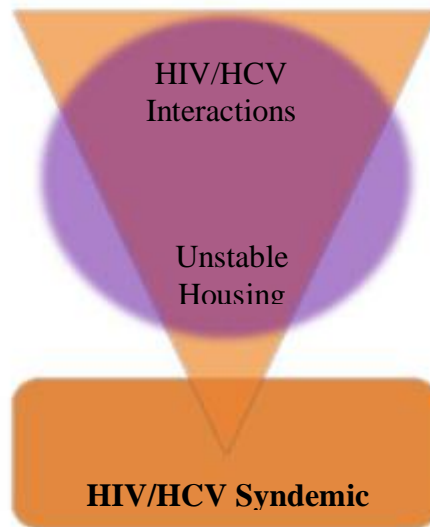


**Figure 7. HIV/HCV syndemic: food insecurity and unstable housing.**

*Ronnie explained that he is currently living with a person who he works for as someone who fixes things around the house. He tells me about the time he fixed the heater to the house he was staying in and that instead of being paid for his services, the landlady who owned the house let him live in the basement, free of charge. However, Ronnie notes that recently, the property owner has been complaining more, saying he isn't doing his job. Ronnie tells me that he thinks the property owner is complaining about his lack of contribution to the household as an excuse to kick him out. Although he is looking for cheap places to live in Massachusetts, he is also bringing in food to help save money on grocery shopping and not to rely on the landlady for food— Excerpt from the field note entry, “Meeting Ronnie,” (Field note, April 4, 2016).*

Indeed, Ronnie’s access to food at the X Clinic food pantry helps him manage financially when he cannot afford to pay rent nor food expenses. Consequently, Figure 7 illustrates the interconnected linkages between food insecurity and experiences of unstable housing.

## Unstable Housing



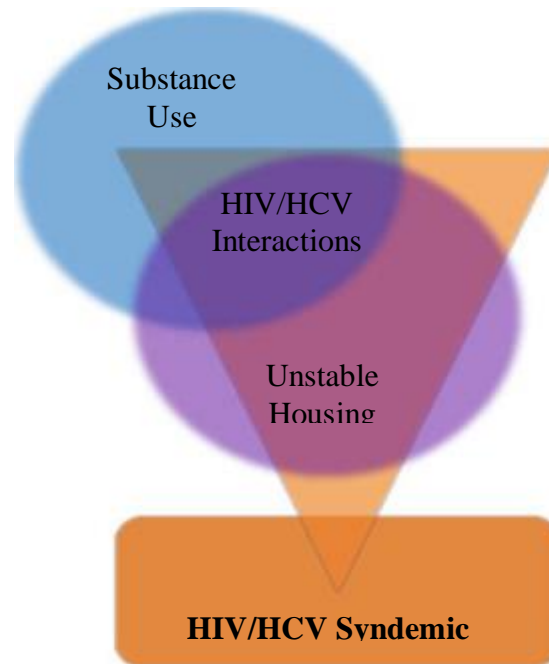
**Figure 8. HIV/HCV syndemic model part three: unstable housing.**

Double-0-Seven recounted how her history with substance use and, or, as she called it, the *lifestyle*, increased her chances of living in the streets. Intrigued by Double-0-Seven's use of the emic term 'lifestyle' to hint at substance use, unstable housing, and more, I asked her to describe what she meant. "*Yeah, the streets,*" she replied expectantly, "*You know... The Street*" she repeats (Interview, September 22, 2016). In doing so, she gives a name to the amorphous place where substance use and other high-risk behaviors were part of the "lifestyle," implying that as if by using the term "The Street," I should be able to picture a certain type of person (e.g., an addict). For instance, Erich Goode (1984:218) describes an *addict* as "...a criminal, a willful degenerate, a hedonistic thrill-seeker in need of imprisonment and stiff punishment."

Lastly, she describes how she managed to change her living conditions, from the streets, to a friend’s or family member’s house:

*I chased down my housing. I chased down everything that I got. Nobody came up to me and said “here, I know that you don’t feel good, so we got you housing.” Nobody did that. You have to go after it. You have to chase it down. And I did! I stayed at my friend’s couch, I stated my sisters. I was staying on the sidewalk; I was living in the, you know, street. I had no way to live— “Double-0-Seven” (Interview, September 22, 2016).*

### *Unstable Housing and Substance Use*



**Figure 9. HIV/HCV syndemic: unstable housing and substance use.**

JJ, a 63-year-old African-American woman living with HIV who was undergoing INF-free HCV 18-week treatment, and was the only participant living with HIV and HCV and actively homeless at the time of the interview. Two of the six HIV and HCV dually diagnosed participants reported a history of experiencing homelessness and the remaining two were living in unstable housing conditions. JJ describes her experience

with homelessness and how it affected adherence to her medication, by describing the shelter she where she was staying at and who oversees her medication:

*Right now, I am homeless and I am staying at the [name of organization]. There are only 12 women there. You do your own cooking, do your own laundry. You get a chore when you get there. You must call for a bed; you can stay there for 90 days – three months. They<sup>20</sup> do a screening. You got to pee in a cup, and there can't be any drugs – because the woman that is the head staff there, she's a nurse, so she takes care of our meds— “JJ” (Interview, September 29, 2016).*

JJ must follow these requirements and regulations if she wants to continue living in the shelter. By contrast, Ronnie who was also experiencing unstable housing conditions, despite fearing that his property owner would kick him out, refused to go to a shelter: “*I don't want to live in a shelter. They are too constricting, you know? Living under someone else's rules? No. I don't want that,*” (Field note, April 4, 2016).

Health providers at the X Clinic expressed that unstable housing and substance use hinder the ability to engage successfully in HIV and HCV treatment medication regimens. For instance, Dee, a health provider who works on the homeless team at the X Clinic notes that,

*When a person ends up homeless... [They] have gone through a lot of loss... a lot of things must fall apart for that to happen, typically. So, the daily needs for survival are prioritized over daily needs for health, unless it is an emergency... Some people might not be housed yet... or might still be drinking... and might just not be ready for treatment (Interview, July 26, 2016).*

JJ echoes Dee's description of what she went through, and continues to go through, as someone experiencing homelessness, “*I have lived through a lot of a lot of loss—a lot of stuff! Meeting people... seeing things,*” (Interview, September 29, 2016). To meet what

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<sup>20</sup> JJ refers to the health professionals who volunteer at the shelter as the ones who conduct the test, but to continue to stay in the shelter, the organization requires a substance use screening.

Dee calls the “*daily needs of survival*” (Interview, July 26, 2016), JJ sought out alternative methods to earning money for daily expenses.

For instance, she would sometimes do a little panhandling in the streets where JJ lived in; JJ is surrounded by what Double-0-Seven described as “*high risk situations*,” (Interview, September 29, 2016). In other words, JJ’s experience of homelessness increases her risk because she has people engaging in risky behaviors all around her:

*You got a mixture of everybody. You got the homeless, you got the students... You got weeders, pill poppers... Some that stare at you. I stare back! I don't say anything smart or nothing... you get people that drink, exchange money for drugs, and this and that... People that sleep up there... Pee out there. It's a mess there! They steal! Constantly stealing. My stuff [was] stolen and my meds were in it!—* “JJ” (Interview, September 29, 2016).

Ultimately, ethnographic accounts demonstrate the structures of risk producing syndemic pathways of interactions within a known HIV/HCV syndemic, in the Boston area.

### **Identified Pathways of Disease Interaction**

Based on both my participants’ accounts and the supporting literature on HIV/HCV syndemics, the triangle in Figures 3-9 represented the bio-behavioral links between HIV and Hepatitis C, while the overlapping circles represented the biosocial and political-economic interactions between substance use, food insecurity, and unstable housing. For example, substance use will increase the viral load of HIV and Hepatitis C, and interactions between them, through syndemics pathway of interactions. Double-0-Seven illustrates the socioeconomic and other structures of risk that drive this, as she describes what she went through to get money for drugs (substance use) when she was unemployed (financial precarity) and living on the streets of Boston (unstable housing):



*To get your drugs, you must do certain things. To get your money, you must go to places where you don't want to go to. You know, like hallways or whatever! Whatever you must do to get your money, you know? From A-Z, whatever it takes to get your money! So, you do this \*<sup>21</sup> and that is The Street — “Double-0-Seven” (Interview, September 22, 2016).*

Double-0-Seven suggests that the ability to afford drugs was at the forefront of her worries. Thus, economic instability exacerbated her suffering and drove her to seek out alternative means of generating income to pay for drugs, such as stealing. During the time she was living in the streets, struggling with her addiction, with no job prospects, she ended up doing “*whatever it takes*” to get money to spend on drugs (Interview, September 22, 2016). This simultaneously constrained access to safer injecting practices and increased the likelihood of engaging in alternate— and dangerous— ways of earning money. Double-0-Seven follows up by saying,

*When you are under the influence of drugs, there is no difference. You will get beat up by a man, even if you have high heels and lipstick, you know? You still get beat down.... However, that's life, you know? You must figure out how to get out of it and you must reach your bottom to get back up again. And sometimes it takes a lot of beatings, a lot of Street to get to the bottom— “Double-0-Seven” (Interview, September 22, 2016).*

Double-0-Seven later says the gender-based violence affected her self-esteem, which in turn affected her ability to negotiate safe sex or injection drug use (IDU) practices while she continued to live in the street. Risky sex practices increased her vulnerability for acquiring an HIV infection (Armstrong et al. 2011; CDC 2016; Friedman et al. 2009; Kerr and Jackson 2016; Loeliger et al. 2016). Although sexual transmission of HCV is possible, the chances are low (Terrault et al. 2013). Furthermore, the adverse health

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<sup>21</sup> I use an asterisk before the footnote number, to indicate a behavior or gesture. In this case Double-0-Seven makes a swiping motion with her hand, gesturing the act of stealing.

outcomes also depend on the type of substance use. For instance, at the individual level, high quantities of alcohol consumption affect autoimmune responses, increasing susceptibility for additional opportunistic infections (Anema et al. 2015).

On the other hand, drugs suppress appetite (Anema et al. 2015). This is because substance use addiction changes dietary intake patterns, one may assume that drugs affect one's appetite (Brooks 2015). Consequently, the effects of drugs could result in skipping meals for a day or more (Campa et al. 2007). Furthermore, over time, weight loss and malnutrition weaken the autoimmune system, which may accelerate HIV disease progression into AIDS (Duong et al. 2001; Fioravante et al. 2012). On top of that, HCV has also been known to reduce appetite levels among its sufferers (Hendricks and Gorbach 2009). Not to mention that an inability to afford or lack access to food can produce adverse conditions of food instability. At this point, one may be suffering not just from HIV/HCV co-infection, but also food insecurity and conditions of poverty and unstable housing. Under these compounded conditions, the likelihood of prioritizing financial stressors over medical appointments is high (Batchelder et al. 2015a; Mendenhall et al. 2012; Olsen et al. 2013).

Dee described this phenomenon in other patients who experienced homelessness. She says, "*they were not ready for treatment*" because at that point their living circumstances become a priority, unless it is a medical emergency (Interview, July 26, 2016). Missing medical appointments either because of work, or because of experiences with financial precocity, jeopardizes one's health. Especially among people living with HIV and HCV. This is even more when the person who experienced conditions of food

insecurity in addition to having problems with HCV treatment medication side effects.

For example, Double-0-Seven shares that her HCV treatment was truly awful:

*I took the Interferon— I tried to take it and I got sick. After two weeks, I was like Eugh! \*<sup>22</sup> But I am a big baby too, so... I'm like: \*<sup>23</sup> “My stomach hurts, you want to go home.” I tell them, but that is just the way it is. But yeah, the interferon with the shots? And then, the taking it? Eugh God, I couldn't deal with it! ... At the time, I think I had a cold, and I wasn't supposed to be taking it. It just got very... Not good — “Double-0-Seven” (Interview, September 22, 2016).*

She admits that she should not have been taking the medication since at the time, she was sick. When she began her treatment, her suffering worsened to include HCV treatment side-effects. The pain she pressed earlier in this chapter made it impossible for her to attend her medical appointments, much less can manage her HIV. Her primary care physician recommended that she stop taking her ART for HIV management for the duration of the HCV treatment since HCV reduces the effectiveness of ART (Miyamura et al. 2016; Treloar et al. 2016). If not careful, HIV may become resistant to ART cocktail combinations. During the time, Double-0-Seven underwent treatment for HCV, experiences with medication side-effects, food insecurity, financial instability and HIV/HCV co-infection, exacerbated her health and her health; she reported having a slightly higher viral load by the time the medicine cured her HCV.

## **Conclusion**

Quantitative syndemic analysis of the qualitative data from and about people living with both HIV and HCV in the greater Boston area thus confirms a known

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<sup>22</sup> Double-0-Seven re-enacted the side effects for me, doubling-over in her chair, holding her sides and groaning, as she shared her experiences with HCV treatment.

<sup>23</sup> At this point, Double-0-Seven bends over in feigned pain once more, making sure I understand it was a painful experience for her through her exaggerated movements.

HIV/HCV syndemic, and illustrates the structural environments that sufferers described produce it, in their lives. I used ethnographic data to demonstrate and contextualize this HIV/HCV syndemic. In so doing, I showed what drives it in this population and what it is like for people to live with these additive risks and their health consequences. I analyzed ethnographic data from participants<sup>24</sup> who describe how substance use, food insecurity, and unstable housing facilitated pathways of interactions between HIV and Hepatitis C (HCV), culminating in an HIV/HCV co-infection. To support my argument, I established that participants living with HIV and experiencing HCV infections typically had a history of substance use and experienced conditions of economic precarity including food insecurity and/or unstable housing.

In participants' accounts, substance use, food insecurity, and unstable housing interacted bio-socially to produce HIV/HCV syndemics. This is evident in the experiences of six former substance users diagnosed with both HIV and HCV. Their accounts of economic precarity demonstrate the difficulties of accessing HIV and HCV services, which in turn, worsened their suffering. Lastly, I analyzed participants' experiences to confirm how unstable housing, coupled with food insecurity and substance use, produced higher levels of suffering and disease clustering associated with a known HIV/HCV syndemic.

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<sup>24</sup> See Table 3 for descriptive statistics of the six participants affected by an HIV/HCV co-infection.

## CHAPTER FOUR: SYNDEMIC CLUSTERING

*I had to be ready to do this [get treatment for HIV]; I was too depressed. Too much stress. I was not ready— “Darryl,” living with HIV/mental health conditions (Field note, April 12, 2016)*

### Why Syndemic Clustering?

Globally, deleterious social, political, and economic factors reproducing structures of inequality influenced the rapid spread of HIV and other infectious diseases among vulnerable populations (Baer et al. 2013; Bourgois and Schonberg 2009; Farmer 2003c; Singer 2005). Mark Nichter (2008:157) notes, “[syndemics] is a useful conceptual framework for social science investigations into global health inequality that are sensitive to environments of risk and agents promoting risk, groups at-risk and risky behaviors.” Impoverished groups, subject to structural violence, and marginalization, are at increased risk for acquiring or developing adverse health conditions, which also raises the prospect and threat of supersyndemics. *Supersyndemics*<sup>25</sup> refers to “synergistic interactions among two or more previously independent syndemics” (Singer 2009), within a population:

It is evident that impoverished populations suffering from numerous structural disadvantages and resulting interconnected breakdowns of social infrastructures, interpersonal relationships, and immune defenses are vulnerable to multiple simultaneous syndemics, which, over time, can merge to form a supersyndemic (Singer 2011:13).

When there is an identified HIV/STI syndemic within a population, there may also be other factors that interact in a syndemic manner with HIV, STIs and the bio-political

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<sup>25</sup> While multiple syndemic interactions associated with multiple syndemic productions hint at the possibility of a supersyndemics among HIV, HCV and HIV/HCV co-infected individuals in Boston, I would need a larger population sample to confirm a supersyndemics.

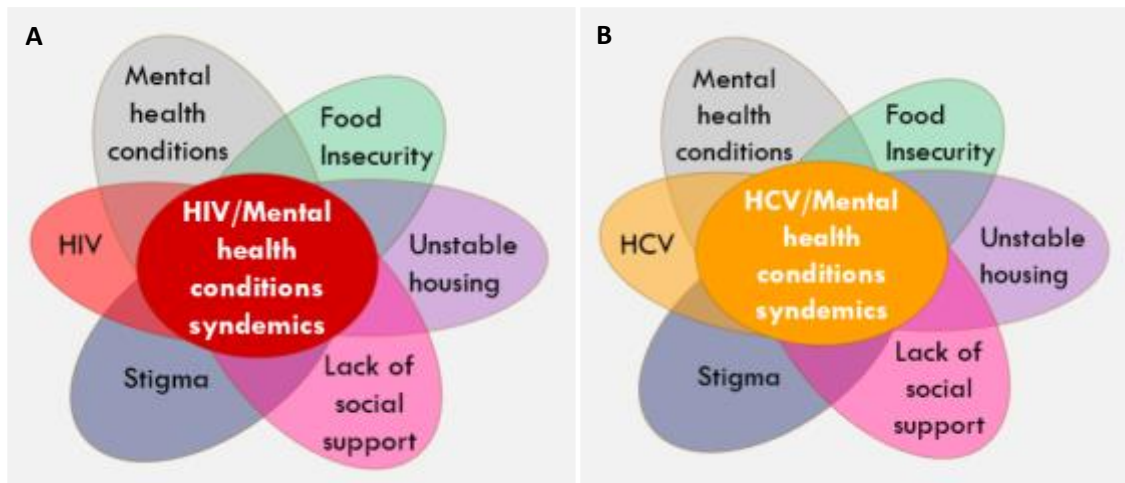
structural contexts in which they occur (Ostrach and Singer 2012a). In another example under conditions of structural inequality, a history of war, or a history of colonization, more than one syndemic may develop over time (Singer 2013), and consequently interact. To investigate supersyndemics, it is necessary to observe how a known syndemic or syndemics interact with other possible syndemics within a population. To do so, researchers would have to determine each of the individual relationships between syndemic factors, and how these together compound health and suffering outcomes.

In this chapter, I signal the potential for HIV and HCV supersyndemics by exploring *syndemic clustering*. Though my mixed-methods data with a total sample of 35 participants did not necessarily fully support an argument for HIV/HCV supersyndemics (though, in speaking with Singer, he suggested I might be able to identify one or more, in this data), I instead employ the concept of syndemic clustering, to demonstrate how my research population experiences multiple interacting and overlapping syndemics. I ethnographically describe and analyze their perceptions of the structures of risk driving the syndemic interactions that affect them daily. Singer used the idea of *syndemic clustering* (Singer 2014b) to describe multiple risk factors for crack-cocaine syndemics, whereas I use it to illuminate the interacting effects of participants' experiences with, and structural risks for, HIV and mental health interactions and Hepatitis C and mental health interactions, amid clusters of known risk factors for both HIV and HCV syndemics.

I also echoed Singer's (2005; 2011) theoretical framework of *social suffering*, and Mendenhall (2012a) extension of it, *syndemic suffering*, to analyze participant's day-to-day experiences of structural violence and syndemics. I use the terms *syndemic clustering*

or *multi-syndemics* to argue that, in the greater Boston area, marginalized people living with HIV, Hepatitis C, or both, are affected by structures of risk that drive the development of not only interactions between HIV and HCV as a known syndemic, but other HIV and Hepatitis C-linked syndemics as well – in particular pathways of interaction between HIV/mental health conditions (MHC), HCV/MHC, with negative health consequences amid disadvantageous social conditions.

*The Syndemic Cluster*



**Figure 10. Syndemic Cluster: A) HIV/MHC B) HCV/MHC syndemics.**

As I analyzed the qualitative data in interview transcripts and field notes to compare with the syndemic potential emerging in the quantitative analysis of the full qualitative sample, I noted participants’ experiences with HIV, HCV and MHC.<sup>26</sup> Fifteen of the individuals I interviewed and interacted with shared their experiences regarding the contexts promoting HIV/MHC and HCV/MHC syndemics (see Table 4). Table 4 shows

<sup>26</sup> For some people, some of the MHC listed in Table 5 overlapped, suggesting interactions between these two syndemics. For other people, there was only one set of MHC overlap, while the last group experienced different set of conditions from the first two.

that nine of the 15 participants described food insecurity; eight of the 15 participants reported unstable housing; six of the 15 participants described situations where they experienced a lack of positive social support; and lastly, five of the 15 participants described HIV- or substance use-related stigma as the driving factor for these syndemics.

**Table 4. Participants’ experiences with structures of risk and HIV/MHC and HCV/MHC.**

<b>Contextualized experiences of HIV/MHC and HCV/MHC syndemics</b>	<b>(15/35)</b>
Food insecurity	(9/15)
Unstable housing/ homelessness/ history of	(8/15)
Lack of social support	(6/15)
Stigma (related to HIV and/or Substance use)	(5/15)

Consequently, Table 5 is a list of MHC reported by participants affected by either HCV or HIV such as, depression, history of trauma, anxiety, PTSD and a history of addiction. Thus, participants’ accounts revealed how disease interactions contributed to the syndemics field, and how vulnerable populations experienced the consequences of interacting HIV/MHC (Altice et al. 2010; Batchelder et al. 2015a; Eisenberg and Blank 2014; Illangasekare et al. 2014; Mustanski et al. 2007), and HCV/MHC (Bulled and Singer 2011; Chasser et al. 2017; Craxi et al. 2016; Doyle et al. 2016).

**Table 5. Mental health conditions (MHC) reported by participants living with HIV (PLHIV) or HCV.**

<b>MHC mentioned</b>	<b>By PLHIV (10)</b>	<b>By people living with HCV (5)</b>
Depression	6	1
History of Trauma	5	1
Anxiety	2	2
PTSD	1	
History of Addiction	8	5



## Food Insecurity Promotes Syndemic Interactions

*At the time that I found out that I was HIV-positive [in 2006], I had stopped using drugs and stuff. The only drugs that were coming into my system was what [were] prescribed [to] me — “Niecy” (Interview, October 21, 2016).*

Mental Health Conditions (MHC) include the common mental disorders (CMD), which manifest as mood disorders such as anxiety and depression (Weaver and Hadley 2009). This section discusses how food insecurity worsens experiences of CMD symptoms among individuals living with MHC, such that inability to access food resources causes negative feelings that adversely affect an individual’s experience of anxiety or depression. Importantly, participants don’t talk about something as “mental illness,” but they interact within a clinical setting where those categories are used. The social worker/patient never used those terms; referred to a “condition.”

Food insecurity drives MHC that promotes uncertainty, which in turn, influences anxiety and depression engendered by conditions of inequality (Weaver and Hadley 2009). For example, Niecy, a 58-year-old African-American woman suffering from depression and anxiety. She lived in conditions characterized by poverty because the HDAP program, which is funded by the Ryan White foundation, covers the co-pays for her medication and only low-income people living with HIV<sup>27</sup> are eligible for HDAP.

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<sup>27</sup> See Chapter One: Background for additional information on HDAP and the Ryan White Foundation.

### *Financial Precarity*

During our interview, Niecy recalled conditions when she didn't have enough money to go grocery shopping and did not have any snacks or treats for her young nieces and nephews who dropped by her home unexpectedly.

*My niece and nephew come over sometimes and I would usually have something for them to snack or something, like their parents give them at home. But I hadn't done it [grocery shopping] ... it's tough. I should have had something [to eat]—*“Niecy,” African-American woman living with HIV and HCV, and suffering from anxiety and depression (Interview, October 21, 2016).

Her low voice and slumped posture hinted at embarrassment, or shame because she did not provide her nieces and nephews with anything to eat during their visit. To avoid experiencing conditions of food insecurity in the future, Niecy tried to enroll on Food Stamps. However, she encountered various issues that delayed her access to financial assistance programs.

*Back in the day, you can sign up for food stamps and they might give you a little cash, and that was the case with me—in the end. So, I applied for [health insurance] but the [health insurance company] were always denying me... I mailed the application several times but it was either denied, needed other paperwork, or was simply returned to my address and they wouldn't explain why! I stopped trying for a while—*“Niecy,” (Interview, October 21, 2016).

It was weeks later when she finally enrolled on Food Stamps. After sighing, Niecy continues, *“Sometimes, something happens and it makes you depressed and stuff, but it helps you to know how to deal with all of that, so you can move on,”* (Interview, October 21, 2016). Financial precarity shaped the social and structural dimensions where Niecy's food insecurity drove interactions between MHC and HIV. These interactions yielded stress-inducing conditions that resulted in higher levels of suffering due to feelings of shame and resignation. Individual experiences of inequality, food insecurity thus

promoted negative feelings, which could impact Niecy's mood, thereby exacerbating her symptoms of anxiety and depression.

## **HIV and Mental Health Conditions**

*On a Tuesday afternoon in March: while restocking the X Clinic food pantry Raquel, a petite, dark-skinned woman in faded jeans and a pink shirt walks up. I smile and reach out to her, letting her know I have yet to finish pulling the canned chicken from the boxes. She nods slowly and opens a medium-sized grocery paper bag. I use that moment to open the cabinets and wait for her to decide on the food items she wants to take home. I anticipate her usual selection of four juices and milk, as I reach for the items after her slightest of head nods. Three small bags of rice, four juice boxes, one box of milk, one of frozen chicken, four cans of black beans, two bags of spaghetti, a bottle of peanut butter, two boxes of raisin bran cereal, and a thank you later, Raquel left through the X Clinic back door...*

*By September: Raquel has eyes at half-mast, her speech barely above a whisper, and her walk more a sluggish dragging of feet; there was no room to engage in small talk with someone who seems this tired without inconveniencing her. She is a single parent of two young boys, she works full-time as a nurse, and she goes to school for a nurse practitioner certification. Raquel's hectic schedule combined with her post-traumatic stress disorder (PTSD) and anxiety makes it near impossible for her to have a full night's sleep. At the X Clinic, Raquel has an assigned mental health counselor to help her overcome her struggles to with MHC that affect her ability to adhere to her HIV medication regimen — Excerpts from field note entries (March - September, 2016).*

These field note excerpts concerning Raquel depict the complex experiences of someone in the greater Boston area who lives with HIV, manages MHC, and faces adverse structural conditions. The combination of medical and social conditions contributed to the stress that plagues Raquel's, and others similarly affected, daily lives and to their experiences with syndemic clustering and suffering (Mendenhall 2012a). Therefore, those conditions contributed to the syndemic clustering affecting people similarly affected by HCV/MHC and HIV/MHC interactions in risky structural environments.

### *Food Insecurity and HIV/MHC*

Conditions of food insecurity further compound interactions between MHC and HIV. Under conditions of poverty, lack of access to high quality and adequate food increased susceptibility to all infectious diseases, through immunosuppression (Farmer 2003b; 2004; Himmelgreen et al. 2009; Ostrach and Singer 2012b; Singer 2014a). Such was the case for my Spanish-speaking HIV-positive participant Paul, who was unemployed, had no medical insurance, suffered from depression, and had not picked up his HIV medication from the X Clinic for the past three months.

*I outreach via phone to Paul and I speak with him in Spanish. He tells me that he didn't know he had the previous' month HIV medication supply paid for, since he is currently uninsured and without HDAP. He does let me know that he come to pick up his medications, although he does not state exactly when he will be by the office to pick them up. At his hesitancy, I informed him that he doesn't have to pay for the medications that are already ready for pickup since his previous insurance already paid for it in advance.*

*At this point, he seems more willing to coordinate a date and we schedule his meeting later that day. He tells me that he first must drop of his child at school before he can make his way to the office. He tells me that he hasn't had the change to go to fill out his application at the health insurance building because he doesn't have the money for the travel expenses. I begin to wonder if he can't make it to the health care office so that he can get access to his medications, due to lack of funds, how likely would it be for him to come in to the X Clinic to pick up is medication after spending money on getting his child to school. I think back at how Sam will, more than likely provide him with the Charlie cards again. Once he arrives, he requests to use the food pantry and take some bags of rice, juice boxes and canned beans (Field note, May 10, 2016).*

In Paul's case, his financial precarity not only affected his nutritional intake because he could not afford to make the commute to the X Clinic, but also his HIV viral load which increased during the time he was not taking his HIV medication.

## HCV and Mental Health Conditions

*I lost my job due to a psych incident at work. I was on my HCV medication and I was the only person doing work—* “Pat” a patient living with HCV and undergoing IFN-free treatment for an HCV infection at the X Clinic, and he was affected by HCV/MHC (Field note, September 24, 2016).

As for HCV/MHC syndemic interactions, the following excerpt from a field notes entry titled “Meeting Ada,” highlights an interaction where Ada allowed me to join her appointment with a physician at the X Clinic, because we had previously met at the X Clinic food pantry:

*Ada often went by the food pantry at the X Clinic to pick up several juice boxes for her baby. At the food pantry, she told me: “Instead of spending a lot of money on food, I can use the bit of extra money to pay for things for my baby, transportation, doctor co-pays, and whatnot.”*

*...Later, during the appointment with her primary care provider (PCP), she would explain that her job was in a precarious situation because she was having problems with her coworker. With an unstable job position, accessing the food pantry helped Ada with the groceries for her daughter—* Excerpt from field note entry, “Meeting Ada” (Field note, May 26, 2016).

Ada, a tall woman with dark hair, visited the X Clinic for a monthly check-up with her physician. She reported engaging in the practice of cocaine use and a history of high alcohol consumption. Cocaine use increased the production of and the consequential reduction of a major neurotransmitter group categorized as Catecholamines, (e.g., dopamine, epinephrine and norepinephrine) (Brooks 2015). After extensive use of cocaine, Catecholamines were depleted, producing depressive effects (Kuhn et al. 2008).

Furthermore, Ada noted during an appointment with her PCP that “*her HCV infection was not treated because her depression and low-income status restricted her*

*enrollment to [INF (interferon) based (e.g., Ribavirin)<sup>28</sup>] HCV therapies”* (Field note, May 26, 2016). The costly INF-based therapies for HCV infections had a severe neuro-psychological side effect that exacerbated depression and mood disorders (Goossens et al. 2016; Hauser and Kern 2015; Ware et al. 2015). This process helped explain the biological-behavioral-psychological interaction between HCV infection, substance use, and MHC (e.g., depression).

#### *Food Insecurity and HCV/MHC*

To return to the notion that mental health conditions (MHC) increase of vulnerability for HCV infection, MHC or common mental disorders (CMD) affect one's ability to partake in sex and drug use practices.<sup>29</sup> The aspects that come up in this chapter highlight food insecurity as a structural factor driving MHC/HCV behavioral pathways of interaction. JJ notes that to be able to take her medication for anxiety, HCV and HIV she needs food: *“I take my HIV meds. It's three in one. I take it with food every day, once a day. Same with anxiety [meds.]”* (Interview, September 29, 2016).

JJ needs food to take her medications although at times, she does not have the appetite to eat the food from the shelter, much less the money to afford food outside of the shelter. She continues, *“I cook sometimes for the shelter. Not now though. [The shelter has] certain foods here that I don't eat... but I can't get my own [food] outside the shelter. It is uncertain,”* (Interview, September 29, 2016). Having limited choices for food resources and not being able to afford certain foods, may cause JJ's anxiety

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<sup>28</sup> Refer to Chapter One: Background for more information regarding treatment for HCV.

<sup>29</sup> Refer to Chapter One: Background, and Chapter Three: HIV/HCV Syndemics.

symptoms to become worse because she now faces a level of uncertainty regarding the future meals she needs. Uncertainty generates stress that influence an individual's mood or experience of MHC (Weaver and Hadley 2009).

Additionally, Double-0-Seven's following quote hints at a connection between accessible food services, MHC, and the effect of medication for HCV, which may cause loss of appetite:

*I don't feel as though I must chase down food services and stuff like that, because I'm not sick, \*<sup>30</sup> and I am not deathly sick where I can't cook for myself. They already cook the food, [the organization]. They may not be the greatest, but it is something to put in the stomach because people will lose their appetite with the meds, you know? (Interview, September 22, 2016).*

Double-0-Seven makes a distinction between first her MHC, and being too physically sick when she points to her head, suggesting MHC can impede appetite for food. Another factor that she points out, that reduces appetite is the medication taken for HCV.

Consequently, both Double-0-Seven, and JJ describe experiences of interactions between food accessibility, HCV and MHC. They both point out different behavioral pathways of syndemic interaction using the same structures of risks (e.g., food insecurity). In doing so, Double-0-Seven and JJ shared accounts of different syndemics whereby food insecurity promoted multiple syndemic interactions.

I classified syndemic interactions based on how participants talked about the role of food insecurity a structural risk factor in which MHC, HIV, HCV interactions exacerbate MHC symptoms and/or weaken the immune system due to a lack of nutrients from loss of appetite (Aibibula et al. 2016; Fioravante et al. 2012). Double-0-Seven

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<sup>30</sup> Double-0-Seven emphasized the word sick as she points to her noggin, to indicate the possible adverse mental health condition.

focused on food insecurity promoting interactions associated with HCV/MHC syndemics that result in worsened HCV medication side-effects. Alternatively, JJ oriented her narrative within financial precarity, food insecurity, and experiences with uncertainty regarding her ability to afford future meals to ingest with her HIV medications. Thus, JJ described conditions associated with HIV/MHC syndemics.

### **Structural Violence and Mental Health Conditions**

*Many people among the homeless population do have mental illness and access to mental health care is not great. Especially for people who can't keep appointments. The people that most need it [health care] ... need support getting to their appointments; if they missed three in a row usually, they are taken off and their health only gets worse— “Dee” (Interview, July 26, 2016).*

In the quote above, Dee described the effect of these additional interactions between adverse social, psychological and behavioral factors. Thus, Dee suggested a form of structural violence, in which people are experiencing homelessness who also suffered from MHC, and living with either HIV or HCV are removed from mental health care and treatment services if they missed three consecutive appointments. Dee's account underscored the exacerbated interaction between MHC and either HIV or HCV infection because a person who experienced homelessness may lose contact with the X Clinic and did not have any means for follow-up. Without a fixed address or other contact information, it was difficult for case managers and social workers to perform outreach attempts. Dee also suggested that the patient's health deteriorated without financial assistance and aid to navigate the bureaucratic process because he or she no longer had access to the HIV or HCV treatment medication.



Providers echoed their concern regarding their patients' adherence to HIV and HCV medication among individuals who experience financial and housing instability, and food insecurity: JayC, a health professional at the X Clinic notes "*the [patient's] socioeconomic situation is... Quite chaotic, so sometimes, it's a challenge for them to commit to an eight week or 12-week course of Treatment for Hepatitis C [Treatment]*" (Interview, August 02, 2016). Especially since these structural risk factors exacerbates vulnerability to infectious agents among socially, politically, and economically marginalized HIV and HCV populations.

*"A Loss of Opportunity"*

Particularly, unstable housing conditions further promoted syndemic interactions because they hindered communication between health providers and patients living with either HIV or HCV who suffered from mental health conditions. These, in turn, further restricted a sufferer's access to medication and treatment services due to what Sam described as "a loss of opportunity" during our interview.

*A loss of opportunity is the conditions patients living with HIV [and a mental health condition] or HCV [and a mental health condition] experience because, many of them were using drugs. Many of them were living in poverty, and many of them did not come from a place of opportunity* (Interview, May 24, 2016).

"A place of opportunity," in turn, affected access to housing and food services from a very early age. People most affected by Sam's "*a loss of opportunity*" (Interview, May 24, 2016) were the following vulnerable populations: PLHIV, HCV and HIV/HCV who live in environments of risks and experience syndemic interactions engender by structures of risk (i.e., unstable housing, substance use and food insecurity). The compounded health outcomes of these interactions consequently worsen deleterious

biological and psychological interactions and its subsequent suffering within this population. “A loss of opportunity,” increased the likelihood of malnutrition, food insecurity and unstable housing.

#### *Lack of Resources and Unstable Housing*

Sam further discussed malnutrition, food insecurity and unstable housing as, “*issues of lack of resources*” (Interview, May 24, 2016). The “issues of lack of resources” are akin to the structures of risks that influence the ability to access healthcare and social services. However, Sam’s “issues of lack of resources” as its name aptly suggests, are the social and political-economic consequences of structural violence, which are individually experienced. Throughout our interview, Sam elaborated on the term “issues of lack of resources,” by explaining:

*Those suffering from issues of lack of resources conditions are people who are on Social Security, on disability, and on those payments to people that are living on between 15% and 70% below the Poverty level* (Interview, May 24, 2016).

Poverty is a form of structural violence, which in turn, operates at the macro-level whereby societal, cultural, political-economic systems shape and reproduce conditions of inequality within a population (Baer et al. 2013). Under those conditions, the ten participants with HIV/MHC and the five participants who experienced an HCV/MHC reported living in unstable housing due to financial precarity. Thus, limited access to resources expose the power dynamics reproducing disparities within a population.

#### *Comparing to Syndemic Concepts*

From the participants’ accounts, I posit that the place where individuals suffer from “a loss of opportunity,” is akin to an environment of risk, the difference being that

“a loss of opportunity” regards the individual behavior, not the social or structural environmental conditions that increase the risk for acquiring a disease cluster.

Consequently, within a syndemic, a person affected by “a loss of opportunity” and the resulting “issues of lack of resources,” may individually experience multiple syndemics, depending on how they perceive syndemic interactions from their lived experiences. As such, these multiple intrapersonal-level interactions do not reflect a supersyndemic which includes multiple syndemics interacting within a population.

### **Navigating Resources**

*Our patients who need help with their SNAP [food stamps] applications, we can't offer those services unless they are living with HIV. HIV-specific federal grants fund case managers... only provide services to HIV-positive patients. So, if an HIV-positive patient has a problem with their Hepatitis C, we can totally help them. But for someone who only has Hepatitis C, but needs help, we must direct them to another case manager — “Sam” (Interview, May 24, 2016).*

I found that upon navigating access for HIV, HCV and mental health services, the health providers at the X Clinic provided a support system for the patients. Django suggests that that patients living with HIV and who need case management services earn a gross annual income that does not exceed 500% of the federal poverty level, \$60,300, meaning that these individuals are indeed living in conditions of financial precarity (HDAP 2016). The following is a quote from Django, a case manager for patients living with HIV at the X Clinic covered by the Ryan White Program and HIV Drug Assistance Program (HDAP):

*Case management is designed to be a support system to navigate health care and social services. To teach the patients the steps to take medication, and to educate them on how medications affect their body.... There are many things that are very hard to deal with, just imagine when we call [health insurance company] on*

*behalf of a sick patient and we stay on phone for three hours? It happened last year — “Django” (Interview, September 15, 2016).*

Django’s case management services are only for individuals living with HIV. Django’s services as a case manager are offered to low income patients living with HIV who require assistance navigating the bureaucratic process of pursuing a health insurance coverage. Such institutional and political-economic barriers to health care can function as a form of structural violence. Often, when structural factors hinder marginalized groups (e.g., people living with HIV, or HCV) ability to afford health care coverage, the institutionalized aspect of income disparities and social inequality are imbedded in people’s daily lives and physical bodies.

Without access to health care insurance, and no education on medication management, the patient may experience ineffective antiretroviral therapy (ART) and HAART (Choopanya et al. 2013; Mandorfer et al. 2016; Sayles et al. 2009; Surratt et al. 2015). People living with HIV who perceive the disease differently are taught by health professionals at the X Clinic how to properly manage their condition and prevent HIV viral load from rising or developing a resistance to the medications.

#### *Lack of Social Support*

*Multiple providers at the X Clinic expressed concern over the health and well-being of a patient with HIV with a history of trauma who was engaging in the practice of substance use. The providers particularly spoke of his history of childhood trauma, unemployment, lack of a social support network. The providers did not go into detail about the structural factors that kept this from attending a rehab program he had planned to join in Florida. The providers described that the sufferer, didn’t understand the bureaucracy process; the sufferer was unable to attend the rehab program in Florida because he couldn’t afford the move (Field note, March 15, 2016).*

The field note above describes the intersection between lack of support network outside of the X Clinic and HIV/MHC. The sufferer, in this case, was enrolled into substance use treatment program, which was not available locally, but did not have the financial resources to pay for his own traveling. His inability to afford treatments caused him to stay in the city, living with a friend, who engages in the practice of substance use.

The biomedical support was available, but getting to where the clinical help awaited them – whether it was a nearby pharmacy, or Florida, was a challenge some sufferers couldn't overcome. As a consequence, another provider at the X Clinic suspected the sufferer “*fell back on to substance use and didn't get his addiction treated since he was surrounded by people who Used,*” (Field note, March 15, 2016).

### **Adherence to Medication**

*The most adherent patients are going to be the one to have a stable place to live, stable access to food... [And to] have a steady income. Those patients are rare. Those people who aren't being abused or exploited or lacking resources in any way, are rare—* “Sam” (Interview, May 24, 2016).

Niecy, a 58-year-old African-American woman narrates a nightly routine that describes how she takes her medication for HIV, anxiety, and depression. Niecy begins by explaining that she hasn't forgotten or missed a dosage since June 2016:

*I've been on that track since June, and so far, I've been doing good. When I take my night meds – I take medicine for anxiety and depression, and I take them only at night. When I take those, and make sure I take my HIV meds—* “Niecy” (Interview, October 21, 2016).

In doing so, she suggests that between 2006 and June 2016, she may not have always taken her medication as directed. MHC are associated with low adherence to HIV medication, which results in worsened health outcomes among people living with HIV,

such as disease progression to AIDS, and increased suffering from MHC. For instance, a substantial body of literature documents the interrelationship between emotional and mental health, and HIV progression (DiStefano 2016; Eisenberg and Blank 2014; Gonzalez-Guarda et al. 2011a; Martin 2013; Walkup et al. 2008; Wang et al. 2016).

During the interview, Niecy admits she doesn't take her medication as directed for two main reasons: one, she would like to lower the dosage of her antidepressant, Trazodone and two, she usually falls asleep, forgetting to take her medication.

*A year ago, I was taking 300 milligrams (mg) of Trazodone, but I am trying to wean myself down, so I cut my dose down from 300 mg to 100 mg. Originally, my doctor didn't want to lower – my doctor wanted me on 400 mg, but I said no—*“Niecy” (Interview, October 21, 2016).

Niecy expressed a resilient agency when she changed doctors. She sought a different doctor because the first one she visited wanted her to have a higher dosage than she wanted to have, because she only used that drug to fall asleep. She explains, *“I wake up in the middle of the night and I go to the bathroom and I go back to sleep. That means I don't need more medicine”* (Interview, October 21, 2016). Instead, she searched for a different doctor, one willing to at least keep her Trazadone dose at 300 mg before lowering it: *“I had to go to another doctor –he left me at 300 mg [of Trazodone]. To sleep good at night, I take my medicine at night... sometimes I forget [to take] the medicines because I fall asleep watching TV,”* (Interview, October 21, 2016). If she doesn't take the medication for HIV, depression and anxiety that night, she would then have to ingest them the following morning, throwing off her routine.

Curious, I asked: *“Do you take your medication immediately in the morning or wait until that night to start your nightly routine over?”* (Interview, October 21, 2016).

*Niecy: I take them like... \*<sup>31</sup> when I watch TV, it is 9- 9:30 PM, but sometimes, I fall asleep, so, when I wake up and go to the bathroom around 12 AM-ish, and if I remember it's like, oh shit! I didn't take my medicine! So I have to take it now (Interview, October 21, 2016).*

When Niecy takes her medication, she knows she will be drowsy afterwards, and those feelings could spill over to the following day: “*when I wake up at 5 or 6 AM, I sometimes get up and start my day, but often, I just lay there and sleep all day*” (Interview, October 21, 2016). Her behavior hints at the association between MHC and the ability to perform a social function due to a lack of motivation (Weaver and Hadley 2009). The drug effects of the antidepressant medication hindered her ability to adhere to the HIV regimen because it disrupted her nightly routine.

By continuing to sleep, Niecy runs the risk of missing another dose of her HIV medicine. The HIV treatment therapy will become less effective, and there is a chance HIV may become resistant to antiretroviral (ARV) drugs (Eisenberg and Blank 2014). Non-adherence to HIV medication compromises autoimmune systems' response against diseases because the virus may develop a resistance to HIV treatment medications (Arends et al. 2015).

Another participant who had difficulty with her adherence was Raquel, who said:

*HIV, I am positive and... It is a struggle with adherence. And, possibly staying alive, I guess. It is so much to summarize 10 years of hard work.... but that is because of my ongoing battle with depression.... I hate to say it, I think it's the trauma. I think when I was being diagnosed, it's a little bit of PTSD, which I am being treated for, through therapy (Interview, September 01, 2016).*

Her quote illustrates the syndemic clustering that I argue produces multiple, potentially overlapping, HIV/mental health conditions and HCV/mental health conditions

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<sup>31</sup> Niecy taps her chin with a manicured index finger as she hums thoughtfully for a few seconds.

syndemics. Keeping in mind that non-adherence to HIV medications, increases HIV resistance to HAART (highly active Antiretroviral Therapy), which refers to combinations of different classes of HIV and AIDS treatment medications. Consequently, the increase in viral load accelerates disease progression towards AIDS, which further compromises the human autoimmune system's ability to defend against opportunistic infections (Arends et al. 2015; Beste et al. 2015; Fierer et al. 2013). Thus, Raquel describes how she uses therapy to treat her multiple mental health conditions, conditions which she perceives as intertwined with her history of addiction, and the traumatic experience of being diagnosed as HIV-positive, all of which ultimately lower her motivation (and hinder her ability to) adhere to HIV medication.

#### *“Old” Interferon and Ribavirin HCV Treatment*

*A lot of our patients have been co-infected for a very long time. And it's the Hep C – they've done well on HIV – some of them cannot tolerate the treatment with interferon a long time ago and then we were able to tell them, 'there are new medications; it's well-tolerated' there was some skepticism for a lot of them. Patients would say, "Are you really sure? Because I really suffered when I tried interferon" — “JayC” (Interview, August 02, 2016).*

Double-0-Seven underwent the “old” and rigorous Interferon and Ribavirin HCV Treatment regimen to treat her chronic HCV. Her story highlights how despite being cured of the physical virus, the “six to a year” check-ups and the memory of how the HCV medication made her feel HCV persists in affecting her life:

*“I was treated last year with it. I was treated and I got rid of it. The results, after two weeks, the viral load was out of me...and the genotype was in my corner to say... I got rid of the virus in two weeks.” Double-0-Seven beams up at me and just as quickly frowns. She scoffs as she says with what I assume to be a twinge of disbelief and outrage, “But still go to see the woman! Every six months to a year.” Anticipating my inquiry, she sighs and slumps on her chair in resignation.*



*“Because it was a community research initiative,” she explains. “It was called [name of the initiative], and at that time it wasn’t FDA approved— for the medicine, but I knew the medicine is going to help me because [Doctor’s name], my doctor here, she referred to be and it was up to me to take this, you know? And I said ‘sure.’ She [the doctor] wouldn’t lead me down the wrong road, right?” She nods in my direction, an eyebrow raised, as if expecting me to agree with her, when I nod, she asks once more “ri::ight?”<sup>32</sup>*

*The question hangs in the air. “And I took it and it’s now... two months later? They had to come out with Harvoni!” dropping her hand on the desk in exasperation. “Which is really what I” – she stops herself and shrugs. “It is just different long names, but I took them up in their research, so I had to jump on it.”*

*I am left to wonder about how her HCV medication affected her adherence to her HIV medication, her social support system, if she could afford her medical expenses, trips to the doctor, rent, food and daily expenses during this turbulent time, because she waves her hand in the air in front of her. Akin to the sigh of relief of someone taking off shoes two-sizes too-small after being on your feet all day at work, Double-0-Seven took a deep breath, let it out and stated, “But it’s out of me,” (Interview, September 22, 2016).*

She dismissed the idea that her doctor and the organization that treated her HCV might have conspired to start her on a dangerous treatment regimen a few days prior to having a safer, new, HCV treatment regimen, such as INF-free regimens as an option. Interferon-free (INF-free) regimen is a Hepatitis C treatment advance developed in 2015 (Goossens et al. 2016); however, interferon-free regimens is an exorbitantly costly became are available in 2015 (Harper 2015; Stahmeyer et al. 2016) – at least to the individuals who could afford the costly fees and co-pays – access to safer treatment options were woefully out of reach for individual such as Double-0-Seven who rely on Social Security as their source of income.

#### *IFN-free Treatment Regimen*

*A nurse practitioner invited me to observe one of her sessions for the day with a patient who had HCV, anxiety and a history of trauma and was at-risk for an*

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<sup>32</sup> The “Ri::ight” has two colons to indicate that Double-0-Seven stretched the word when she spoke in the interview.

*HIV/HCV co-infection. After a short greeting, the patient walks in and takes a seat next to me, both of us facing the nurse practitioner. She begins by explaining to me that [name of patient] the patient was referred to the clinic by his PCP years ago because his [previous] primary care physician [did not accept] his health insurance regarding HCV treatment.*

*He shares how he had an HIV-positive significant other "who died so very young—23 years old," he informs us in a somber tone, his eyes down cast, looking at the floor tiles. After a few seconds, he looks up and states that he did not know she was HIV-positive until she died. When he did find out, he [said he] panicked... He was very scared of acquiring an HIV infection because he used to share needles with her and that is how he acquired HCV from her... He shakes his head as he tells us that all his friends Use[d]... [and] use[ed] his spare bedroom to do drugs [and] to get clean, he had to get rid of them (Field note, July 17, 2016).*

This vignette illustrates the same pattern of behavior among individuals living with HCV who were undergoing treatment or were about to enroll on an IFN-free treatment regimen. Distancing oneself from substance use and those who participate in substance use seemed to be a defense mechanism for individuals to maintain their sobriety or their clean status. For example, in the following field note entry excerpt, Ellie makes clear the associations she perceives between how substance use increased her risks for, and subsequent acquisition, of Hepatitis C. Interferon-free (INF-free) regimen is a Hepatitis C treatment advance developed in 2015 (Goossens et al. 2016):

*A burly man walked in and sat on the closest chair, and the "Ellie," the health provider asks him about his medical history. He shares that he got Hepatitis C in the 1980s when he was engaging in substance abuse – cocaine was his drug of choice; he stopped using cocaine six years ago and stopped drinking two years ago. Ellie then why did he decide to be treated now, after knowing his status for so long? He says that his primary care physician referred him to the X Clinic, suggesting that he gets treatment.*

*When Ellie prompted if he knew of the new medication and how it doesn't have as many side effects as the previous regimen, and it may be his decision to get treated was based on that, he said no, that it was because his doctor suggested it.*

*Ellie nods and begins to check his palms and his stomach, lungs and neck; his palms were red in color, which she later tells me might indicate scarring of the*

*liver. She informs me that he might have scarring on his liver because of his history with substance abuse. She explains to him that he needs to get blood drawn for her to understand what type of Hepatitis C he was living infected with. Ellie lets him know that they will also do an Electrography – using sound ways to test liver elasticity and that he should come back in a month – the amount of time it takes to get all the laboratory results is usually about a month.*

*Before he leaves, Ellie smiles up at him and says. “There has been a proposed change in health insurance coverage for Hepatitis C treatment. Particularly, in August, or after August, Hepatitis C will be treated regardless of cirrhosis level”*— Excerpt from field note entry, “Ellie” (Field note, July 21, 2016).

Here, also begin to see a pattern between eligibility for the HCV treatment to hinder on the stage of cirrhosis, dating back to Mehta et al. (2005) who proposed a framework to understand the low rate of adherence to HCV treatment among HIV/HCV co-infected people who inject drugs (PWID). They analyze the data from multiple studies to note that some of the individuals chosen for HCV treatment have a high risk of mortality and as such, treatment eligibility should be monitored because previously rejected individuals might become eligible for HCV treatment at a future date (Mehta et al. 2005). They also note that the measurement for liver disease is not uniform and can be too costly.

## **Stigma**

Mental health conditions increase the risk of acquiring HIV because mental health adversely affect decision-making processes and risk-taking (Agnieszka et al. 2012; Singer et al. 2006; Turan et al. 2017). For example, Ann, a mental health counselor at the X Clinic further illustrates how individuals who acquired HIV by a sexual transmission react to an HIV-positive diagnosis. She brings up one exchange she had with a patient, who contracted HIV from her significant other after having unprotected sex:

*I had one African-American woman say, “It was my fault. It was my fault. I opened my legs, it was this thing.”<sup>\*33</sup> This thing wanted me to have sex, and that's why I...” and I'm like “that is not why you got infected, you got infected because... You got a virus... Let go of the history of HIV, and what it means... It doesn't mean what you think it means”— “Ann” (Interview, July 07, 2016).*

Ann states what she remembered the same patient telling her during a therapy session, “*I did this to myself; I shouldn't have sex,*” (Interview, July 07, 2016). Ann recalls her reply:

*I'm like... that would've been one way not to ever get HIV... [But] how likely do you think that is? As a 23-year-old male? Because... I don't know any 23-year-old male who is not going to have sex his whole life because he doesn't want to get AIDS. I'm sorry, it is just not going to happen! ...Like, you had sex, you did the normal, appropriate developmental behavior that you would expect of a 23-year-old man... same with women (Interview, July 07, 2016).*

Ann describes a patient who blamed himself for his current health condition, and internalized HIV-related stigma, which affected his self-esteem. Ann proceeds to inform the patient that his perception of HIV does not reflect the biomedical understanding of HIV as an infectious agent.

Sly comments on some of the biological stereotypes associated with HIV and how she wishes she could spend some time with people outside of the X Clinic who stigmatize people living with HIV (PLHIV):

*They talk negative! And stigma! ...I've heard [people say], “oh, they are such nasty people! You can tell they have HIV because their face is all sucked up!”<sup>\*34</sup> I would like [to say] “excuse me, that's not it! ... Let me tell you something, I am HIV-positive. How you doing? ... Look at me, do I look like I have a sucked in face?” I could just see the room gasping for air!<sup>\*35</sup> I would just love to say that, and then leave... but I don't – won't [disclose HIV diagnosis status] ... [because] I don't make HIV the topic of conversation... My children don't want to talk about*

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<sup>33</sup> Ann points with one hand to her groin, suggesting that her patient might have also made the same gesture when explaining why she had unprotected sex that lead to contracting HIV.

<sup>34</sup> Sly's voice changes into a mocking nasal voice, to differentiate between herself and those who believe and promote negative stereotypes of PLHIV in the community outside of the field of HIV.

<sup>35</sup> Sly gasps for air, demonstrating how she envisions people's reactions to be.

*it and neither do I. I haven't found that comfortability to sit and let others know what I live with—“Sly” (Interview, October 21, 2016).*

Despite her desire to speak against stigma, she won't disclose her HIV diagnosis status to strangers, much less her family members. Furthermore, Sly is not the only one who is aware of how she is perceived just because she is living with HIV, she would also like to meet with those who are spreading negative stereotypes, which then lead to PLHIV being overly cautious with who knows about their status. Sly continues,

*At another hospital, it was time for me to do a checkup, and a young lady asked me if I was on any medication, and of course I had to be honest and tell her the truth about my HIV, because I was going in to talk to my liver doctor. So, I told her what I was taking and a few minutes later she comes back in with a gown on, gloves and a mask. And I wondered if she was dressed like that because of what I told her I had HIV... She didn't have to dress up like that to come here dressed like that... That day hurt my feelings so bad! I was so embarrassed... but I let it go because I still I had to go on with my checkup and I wanted to get it over with... Later, I thought about it, and I was heated! It was the first time that I was discriminated against because I live with HIV — “Sly” (Interview, October 21, 2016).*

In the quote above, Sly describes a moment when she felt stigmatized by a medical health provider, the emotional distress that she felt while having to endure it for the sake of completing her check-up, and the anger she felt afterwards. Sly, a 62-year-old woman living with HIV, anxiety, diabetes, and asthma. Sly underwent a year of interferon-based treatment to cure her HCV and is a breast cancer survivor. Sly describes how within HIV/MHC syndemics, stigma promotes and perpetuates the social structures driving biological pathways of interaction between HIV and mental health conditions (e.g., low self-esteem, depression, and anxiety) (Emard 2016; Singer 2014a; Turan et al. 2014).

Sly perceives that her HIV-positive status is the cause for the nurse stigmatizing her when she came back to treat Sly with multiple protective layers. Sly comments, “*She harmed me. She hurt me, hurt my feelings. She disrespected me because she had a mask on, gloves on and a gown on. Honey, I am not going to give you nothing. All she was supposed to do was the paperwork. She didn't have to touch me or nothing,*” (Interview, October 21, 2016). Importantly, HIV-related stigma refers to the interpersonal process by which sufferers and assumed sufferers face social marginalization, which in turn, affects the sufferer at an intrapersonal level (i.e., cognitive, emotional, and behavioral repercussions) (Earnshaw et al. 2013c; Goffman 1963; Kalichman 2013; Turan et al. 2017).

Similarly, to Double-0-Sevem, Sly acknowledges that some of the stigma is partly because HIV used to be a death sentence. For instance, Double-0-Seven describes her behavioral and emotional experience with HIV-related stigmatization:

*Back then... People didn't want to talk about it... if you were on medicine – AZT, you couldn't say that because people would say, “Oh no, she's got AIDS. Oh, [she'll die] soon!” But, back then they were ignorant to the fact that... there is HIV and AIDS. So, they are two different things, but people don't get that, and in prison, they really don't get it and they can be mean and make you feel like a leper! I used to go to the window to get my meds and I would say the long name, so the girls behind me didn't know what it was (Interview, September 22, 2016).*

Sly, however, is all too aware that HIV is no longer a death sentence, “*It is just disease, honey. It is medicated, it is maintained and I do very well, thank you!*” (Interview, October 21, 2016). This form of enacted stigma affected not just Sly's perception of HIV-related stigma, but also Double-0-Seven's perceived stigma, which ties back into HIV/MHC syndemics because these negative experiences affect how PLHIV feel towards

themselves and about their HIV diagnosis. As such, Sly comments on the distinction between herself and HIV within the context of HIV-related stigma: “*It isn't what we live with, it is the fear of the name that bothers them. It ain't me!” (Interview, September 22, 2016).*

Furthermore, individuals suffering from mental health conditions are at an increased risk of disease acquisition and progression because illnesses may impair judgment, increasing the likelihood of engaging in risky behaviors (e.g., missing medical appointments, substance use, needle sharing, and unprotected sex) (Agnieszka et al. 2012; Compton et al. 2000; Graham et al. 2015; Rivera et al. 2014; Singer 2014a; Zickmund et al. 2003). Consequently, facing discrimination from health providers is associated with missed medical appointments and loss of physician trust (Graham et al. 2015; Turan et al. 2017). Thereby, Double-0-Seven's feelings of shame and Sly's embarrassment, coupled with her desire to leave the hospital as quickly as possible, risking ineffective treatment, might stem from the enacted and perceived stigma or the personal experiences of stereotyping or discrimination participants encountered in a medical setting that affected their trust in their HIV health providers, affecting PLHIV's ability to access health care services (Emard 2016; Lekas et al. 2011; Turan et al. 2017).

Within the behavioral and structural pathways of disease interaction, Singer (2004b) uses the term “oppression illness” to describe the process whereby, after experiencing constant stigma or discrimination for a long period, sufferers accept and internalize negative perceptions, negatively affecting their mental health (Earnshaw et al. 2013a; Earnshaw et al. 2013b; Rivera et al. 2014; Smith et al. 2016; Turan et al. 2017),

which may consequently manifest within the sufferer in the form of self-blame (Turan et al. 2017), further exacerbating risk-increasing behaviors (Chidrawi et al. 2016; Emard 2016; Rance et al. 2017).

### *Discrimination and Lack of Social Support*

People who anticipate stigma shy away from social relationships to reduce experiences of discrimination, which then result in social isolation that limits social support opportunities (Berger et al. 2001; Parker and Aggleton 2003). Importantly, Sly's experiences of discrimination for living with HIV in the health care field lowered her trust in providers. While managing her HIV and HCV, Sly got sick with Kidney stones during the time she was supposed to go to the amusement park with her children and grandchildren. Nevertheless, she couldn't go because she was in too much pain, and her support system did not accompany her to a hospital:

*I was supposed to go the amusement park, but the kidney stone stopped me from going to the amusement park so of course, that arrangement was not canceled. They still went! They left me at the hospital when they left they kept saying "you'll be alright, you'll be alright." \*<sup>36</sup> I am laughing now, but at the time heated! Because they left me. I had nobody and I was stuck with these morons and at that hospital, I had a nurse, and when my daughter found out about what happened, she wanted to slap the nurse for me! For real. He got rude, talking loudly about my HIV. He kept walking by me, telling he was going to be right there. But there he went doing something for somebody else. Somebody else called him and he Gowned-up \*<sup>37</sup> I did some swearing and eventually, I got admitted. It wasn't a long time, but I wanted to go home right away! (Interview, September 22, 2016).*

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<sup>36</sup> Sly laughs.

<sup>37</sup> Sly inhales deeply, holds it, and then exhales to calm her down, since she was getting agitated talking about it.



Being in pain, and feelings of disrespect and marginalization became worse because Sly did not have her support system to help her alleviate feelings of marginalization. Indeed, Sly's feelings of isolation coupled with her perception of HIV-related stigma resulted in a loss of positive expectations concerning her behavior and feelings towards herself. For instance, Sly's mood became erratic the longer she was stigmatized and she wanted to go home because wanted to avoid feeling unimportant despite being sick:

*Yeah, I was irritated. I was swearing because it was really ostracizing. It was like it was put in this bubble where nobody knew I was there but I was in plain sight, on the hallway... everybody was ignoring me... and then came the doctor, trying to smooth things out and I'm like, she can't Smooth things out now— it's too late. I had already been stigmatized! I had already been disrespected! So, what you say now, ain't going to mean me no difference. So, do what you do, say what you say, but I want to go home. Now! You can't fix what they made me feel. Tell me what she are going to do, because then I was getting a little aggressive and being there was giving me anxiety! (Interview, September 22, 2016).*

Indeed, losing her positive support network on a day she needed them the most exacerbated her anxiety because she had to manage being in pain from her kidney stone while being ignored by the medical health providers at the hospital in a Southern state. Sly continues to talk about how experiencing discrimination worsened the interpersonal expectations she held towards her medical care:

*First off, the hospital knew me because of my history with drinking and drugging... I [also] had no one to help me out and they had me in this hall way for almost 2-3 hours. I understand they may have worse patients than me – I get it – but give me my respect if you want me to give you yours... Do what you got to do but don't do this again because it hurts my feelings. I didn't ask to get HIV or the kidney stones, but to be disrespected on top of it all? It's too much. I felt worthless. I ended up just saying, "Go ahead ma'am and do what you need to do, please, because I am ready to go home. I get off this bed and I am out of here. The IV doesn't faze me. I pull it off and I keep it moving! You can believe that!" (Interview, September 22, 2016).*

Feelings of worthlessness result in erratic behavior that affects how one reacts to health care providers, treatment and perceived stigma (Earnshaw et al. 2013a; Edwards 2006; Holmes 2002; Jang and Bakken 2017; Zickmund et al. 2003). For instance, Sly tried to cut all her appointments short, even when the doctors would advise against it.

*I was hospitalized once because of my liver, and my doctor told me I will need to stay for 2-3 days and I told him, 'good, because 4-5 days from now, you will come back and you won't find me in this room. I would call my children so that they can come get me, because I don't want to stay here (Interview, September 22, 2016).*

Feelings of embarrassment, shame and worthlessness can be internalized, eventually affecting health outcomes by increasing the likelihood of being unable to access proper health care services for fear of being discriminated against (Birtel et al. 2017; Graham et al. 2015; Padam et al. 2016; Robinson et al. 2016).

## **Conclusion**

In this chapter I presented the pathways of syndemic interaction between HIV and mental health conditions, and HCV and mental health conditions, and the structures of risk in which they are produced, to expand on Singer's initial mention of syndemic clustering. I illustrated how the 15 out of 35 affected participants experienced this syndemic clustering by sharing their accounts that illustrate the HIV/MHC and HCV/MHC syndemics. Participants' narratives demonstrate pathways of interactions between mental health factors, HIV and/or HCV, food insecurity, stigma, and unstable housing that interact synergistically to produce clusters of syndemic risk factors, and social suffering. Anthropological literature has long documented the adverse health outcomes of synergistically interacting conditions such as HIV/AIDS, mental health, and HIV stigma (Emard 2016; Gideonse 2013; Gonzalez-Guarda et al. 2011a). Participants'

experiences illustrate how structures of risk produce disease interactions, and what these are like for people, depicting the structural factors that drove interactions between HIV, HCV, and other illnesses and social conditions, producing worsened life circumstances and health outcomes.

## CHAPTER FIVE: SUBSTANCE USE SYNDEMOGENESIS

*The risks for acquiring a dual HIV and HCV infection left a young African-American man, whose visit I sat in on, spooked. His significant other had passed away and he was not aware of her HIV-positive status during the time they shared needles and had unprotected sex... During an explanation of HCV and what it does to the liver, the female nurse practitioner treating him explains they need to do an elasticity test of the liver. She then [told me] that he has been a patient of hers for a long time and that he used to have Hepatitis B, but that he was one of the lucky ones that cleared it on his own. He cuts her off to let me know that he has always been lucky; he was lucky not to have acquired HIV even though he shared needles with his deceased significant other and he is lucky to have gotten rid of Hepatitis B (HBV) and is looking forward to getting rid of HCV.*

*The nurse practitioner takes this time to talk about how there is no need for an invasive biopsy if he does the elasticity ultrasound. She goes into detail about what it means to live with HCV now that it is curable and the things he should avoid, such as excessive drinking. He agrees, saying that the people who used to make him drink are no longer people who he associates with, so to him, that will not be a problem. She then tells him, the elasticity ultrasound will be enough proof for the insurance company that his liver is in bad shape and that he needs HCV treatment as soon as possible— Excerpt from field note, “Lucky” (Field note, June 17, 2016).*

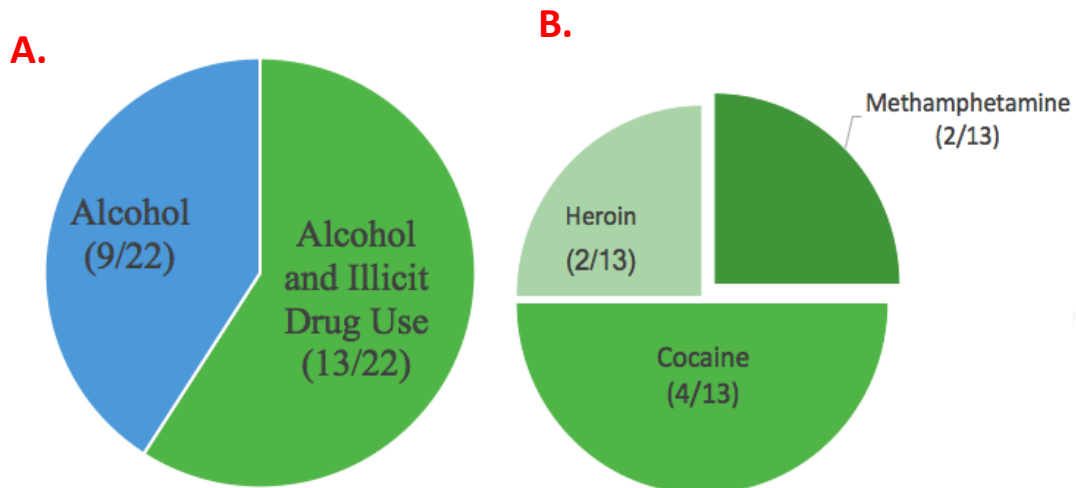
HIV, HCV, and substance use each and all are particularly likely to contribute to syndemics, through both biological and social pathways – in other words, they are all syndemogenic (Singer 2009). HIV/AIDS is implicated in the emergence of many syndemic interactions (Bulled and Singer 2011; Eisenberg and Blank 2014; Emard 2016; Gonzalez-Guarda et al. 2011a; Himmelgreen et al. 2009; Illangasekare et al. 2014; Mendenhall 2014; Morano et al. 2013; Ostrach and Singer 2012a; Wilson et al. 2014). They bi-directionally promote disease acquisition, acceleration, and social suffering (Singer et al. 2006) in the form of stigma and discrimination that results from and contributes to HIV susceptibility (Bichell 2016; Donnelly et al. 2016; Emard 2016; Larney et al. 2015; Rhodes et al. 2005).

In this chapter I devote greatest attention to the HIV and HCV syndemogenesis triggered by substance use, but I will first discuss the biological/disease and behavioral dimensions of substance use and its potential consequences. The behavioral consequences of substance use as a biological factor can take various forms, particularly through risky sex; a behavior constructed as risky can promote transmission of HIV, and/or Hepatitis C, and accelerate liver disease progression (Loftis et al. 2006). Substance use interacts with other biological conditions, further driving syndemic interactions. For example, alcohol intoxication and other substance use impairs cognitive reasoning, increasing vulnerability to needle sharing, and unprotected sex (de Souza et al. 2002). Such risk-increasing behavior can also be a coping mechanism for dealing with HIV stigma, in a vicious syndemic feedback loop (Emard 2016; Olsen et al. 2013; Turan et al. 2017; Ware et al. 2015; Wenger et al. 2016).

Furthermore, within HIV and HCV syndemics (Bulled and Singer 2011; Eisenberg and Blank 2014; Gross et al. 2016; Morano et al. 2013), and MHC-related syndemics (Eisenberg and Blank 2014; Gonzalez-Guarda et al. 2011a; Martin 2013; Mendenhall 2012b; Meyer et al. 2011), substance use both promotes and is the result of interactions between biological, behavioral, psychological, and structural factors (Altice et al. 2010; Bourgois et al. 2004; Brown et al. 2016; Chen et al. 2015; Eisenberg and Blank 2014; Illangasekare et al. 2014; Johnson 2003; Loeliger et al. 2016; Padilla et al. 2012; Robinson et al. 2016; Rogal et al. 2016; Smith et al. 2016; Wilson et al. 2014). For instance, given that HIV infection disproportionately affects those who face social inequality and are subject to social marginalization (Bulled and Singer 2011; Farmer

2003c; Gonzalez-Guarda et al. 2011b; Mendenhall 2012b; Singer 2013; Singer and Page 2013), in the context of substance use, marginalized people living with HIV (PLHIV) have very limited employment opportunities. Therefore, inequalities shape these environments in such a way that the individuals are driven to engage in alternate economic survival strategies that further increase their syndemic risks. Consequently, these economic strategies are linked to increased vulnerability for disease acquisition, progression and MHC symptom development, as I discuss later.

Not only is substance use an important structural risk factor for facilitating syndemic interactions between HIV, Hepatitis C (HCV), and mental health conditions (MHC), but participants' experiences illuminate substance use as a syndemogenic factor promoting multiple pathways of interaction affecting those who participate in substance use practices. Figure 11 below illustrates the number of participants who reported engaging in substance use and some of their preferred substances.



**Figure 11. Reported forms of substance use: A) alcohol only B) alcohol and illicit drug use.**

Importantly, Figure 11A illustrates the self-reported substance use of 22 of the 35 people in this study diagnosed with HIV and/or HCV. Nine of these 22 reported only consuming high quantities of alcohol, while the remaining 13 of the 22 reported high alcohol consumption together with illicit drug use. Figure 11B depicts participants who reported drug use: only eight participants of the 13 who reported both alcohol and drug use specified the type of illicit drugs they used. Therefore, Figure 11B shows the four participants who reported cocaine use; two participants who reported heroin use; the remaining two participants reported a history of methamphetamine use.

In this chapter, I present the various pathways of interaction through which my participants described the ways their different forms of substance use, as illustrated in Figure 11, contributed to their experiences and perceptions of vulnerability for HIV/HCV syndemic interactions. Of note, participants used the phrase “suffering from drug addiction” to refer to their practice of drug use and drinking to excess. These excessive behaviors are regarded as pathological and syndemogenic because they not only worsen biological and psychological conditions, but also because people at-risk for HIV/HCV syndemics who are actively using drugs, suffering from a history of substance use disorders, or drinking alcohol to an excess, tend also to be in social and structural conditions in which they experience unstable housing, food insecurity, and lack of access to resources or services.

### **Structures of Risk**

It is generally believed that drugs of abuse usurp neural circuitry in the brain that normally controls responses to natural rewards such as food, sex, and social interactions— Chao and Nestler (2004:114).

Singer (2014a) explains that a behavioral syndemic interaction may involve MHC as the driving factor for syndemic interactions because a mental illness, like or in interaction with substance use, also may impair judgement. The psychotropic effects of substances such as alcohol (Addicott et al. 2017; Fritz et al. 2010), crack, cocaine and heroin (Buchanan et al. 2006; Michel et al. 2016; Singer 2014b; Somlai et al. 2003), impair judgment and increase risks for HIV and HCV transmission through a multiplicity of identified pathways. Impaired judgement may lead to participating in risky behaviors or more difficulty negotiating risk reduction in a high-risk situation (e.g., unprotected sex with different partners and needle-sharing) (Bulled and Singer 2011; Lejuez et al. 2005; Woerner et al. 2016), thereby increasing the risk of acquiring HIV (Kalichman et al. 2002; Lansky et al. 2000; McLellan-Lemal et al. 2012; Ostrach and Singer 2012a; Padilla et al. 2012), and Hepatitis C (Terrault et al. 2013).

### *Risky Sex Practices*

Unprotected sex with multiple partners is constructed as a particularly risky behavior because it operates at both the biological and social dimensions to facilitate multiple syndemic interactions. Moreover, pathways of interactions engendered by high-risk sexual behaviors are compounded by mental health conditions (MHC) such as anxiety, depression, and suffering from substance use disorders. Substance use practices among the 22 individuals<sup>38</sup> in my study were shaped by experiences of structural violence, poverty, and inability to access resources. Conditions categorized by these

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<sup>38</sup> See Figure 11.



examples of structural violence facilitate interactions that worsen a population's vulnerability for disease acquisition, and illness development.

Earlier, I discussed needle sharing as a risk factor operating within the biological and social dimensions of substance use that increases vulnerability to HIV/HCV syndemic interactions. I described substance use producing environments of risk, within larger structural systems that shape conditions experienced by the individual when participating in substance use (e.g., limited access to HCV treatment, food insecurity, and unstable housing). Here I use ethnographic data to explore the syndemic interactions produced and facilitated by substance use, to increase understanding of substance use as a syndemogenic factor in HIV/HCV syndemics, through a multiplicity of pathways.

Little Flower is a 60-year-old Caucasian women living with HIV and diabetes, who suffers from depression and has history of substance use. Little Flower chose her pseudonym because it was what her father used to call her when she was young. During the interview, she shared that she acquired HIV through a heterosexual exposure from having unprotected sex after consuming large quantities of alcohol. What she did not know at the time was that her partner, whom she lived with, also participated in the practice of injection drug use (IDU): "*I resent him for getting HIV and for everything,*" (Interview, September 23, 2016).

While intoxicated, she had unprotected sex with her partner, resulting in a pregnancy in addition to her new HIV-positive diagnosis. Ultimately, she didn't want to give custody of her newborn son to the father, because of his drug addiction, Little Flower tried to fight for custody of the child. This process resulted in what Little Flower

summarizes as. *“The courts got involved”* (Interview, September 23, 2016). To treat her drug and alcohol addictions, she completed a five-week court mandated rehab program.

However,

*Even though I completed my program – I did what they asked – I was too sick [with HIV and diabetes] to take care of a baby... To give my son a good life, I gave him up for adoption... I don't even know if he still alive... It makes me sad thinking about it—* “Little Flower” (Interview, September 23, 2016).

At the time of the interview, Little Flower admitted that she missed some appointments at the X Clinic, but that was because she did not have the money to pay for the transportation. She reported she is engaging mental health services to treat her depression, with which she was diagnosed shortly after her HIV-positive diagnosis: *“the nurse told me, ma’am, you have HIV in the mid-1990s... At the time, they didn't offer any counseling... Later, I was officially diagnosed with depression,”* (Interview, September 23, 2016) – further illustrating the relationship between HIV and mental health conditions described in the previous chapter. Furthermore, Little Flower’s mental health condition symptoms worsened when her ex-husband moved to another state after getting remarried, taking her two older sons with him during the time she was still in rehab.

As discussed in Chapter Four, “Syndemic Clustering,” social isolation may increase the likelihood of substance use, which in turn could hinder the ability to manage other diseases. For instance, Little Flower’s perception of risk was and potentially is also affected by her interacting substance use behavior and MHC. Even now, she smokes cigarettes to cope with stress despite being aware that it increases the likelihood of developing lung cancer. Little Flower states, *“I am waiting for the lab results to tell me if*

*I have lung cancer. It comes back positive, I'll stop, otherwise I won't,*" (Interview, September 23, 2016).

Another participant reported being infected with HIV through heterosexual exposure, and suffers from childhood trauma and multiple MHC. During our interview, Raquel shared that when she was younger, she drank to excess (Interview, September 01, 2016). During one of those instances, she had unprotected sex, also became pregnant, and was later diagnosed with HIV. Raquel stated she *"had to undergo an abortion because her body was too weak to carry the pregnancy to full term,"* and she could not afford to take care of a child when she was first diagnosed (Interview, September 01, 2016). The sexual behaviors constructed as high-risk and associated with increased likelihood of HIV acquisition mentioned by participants included Sly, Little Flower, and Raquel carry very real biological risks for HIV (and HCV) acquisition, but are also socially stigmatizing. Furthermore, individuals living with HIV and/or HCV, stigmatized for these diagnoses, or suffering from addiction, are also more likely to be socially and economically marginalized (Bulled and Singer 2011; Donnelly et al. 2016; Kerr and Jackson 2016; Singer and Page 2013; Stall et al. 2009).

### *Suffering and Substance Use*

*"The immune system is a hell of thing!" Sly's raspy voice bounces off the walls of the enclosed space of the private office.*

*"For real. It fights, and it fights. Everyday. I get sick? It's fighting. I get tired? It's fighting." She stresses the word 'fighting,' and the echo intensifies into a chorus of 'fighting.' Frowning at the walls, she waits for the echo to fade, "I get so worn out at times, but I persist and keep going." As she speaks, she quickly rolls up the sleeves of her hoodie akin to someone who is revving up for an impromptu fight and needs to have her hands free to defend herself.*

*“I am a recovering addict on top of it all. That's how I caught them.” Sly nods towards her copy of the Interview Guide, as if to indicate she has experienced the biological conditions mentioned in the Interview guide, such as HIV and HCV.*

*“Doing everything that I had no business doing, but I did it. I did them all and I had a ball. I did! I am not going to sit here and tell you that I didn't. I loved to Use. It took me places that I had no business going, but I went. And I did it! I smiled going, and I smiled going out. Even when I stole from my daughter so I can Use again” — “Sly” (Interview, October 21, 2016)*

In this telling, Sly perceives her immune system as a perpetual fighter against disease acquisition and progression even as she struggled financially in her pursuit of the neuropharmacological effects of psychotropic drugs. Sly's preferred illegal substance was crack cocaine -- she suffers from a history of substance use. Sly's quote draws attention to how she is all too aware of how her addiction is perceived, and that she had to steal as a means of generating an alternative income. Double-0-Seven and JJ signaled the same connection to financial precarity as a structural precursor to syndemogenic substance use earlier in chapter three, “HIV/HCV Syndemics,” when they suggested that people who engage in substance use often also experience unstable housing or homelessness because of their addiction. Sly connects financial precarity and substance use, where the need to feel the effects of illegal substances overwhelms the need for anything else, resulting in risky alternative means of generating an income to buy drugs (e.g., stealing).

#### *Drug Use and Alcohol Consumption*

Alcohol intake and drug use are perceived by my participants to be equally risky in relation to syndemogenesis, as I noted during one of the mid-day meetings with the staff at the X Clinic. As depicted in this discussion of how excessive alcohol

consumption promotes adverse health outcomes and suffering within a group of individuals living with HIV, HCV, or both:

*During the meeting, which was held in the conference room on the first floor, a provider brought up an African-American MSM man who claimed to drink excessive alcohol every day. Another health provider then added, “the man’s [HIV+] partner also drinks with him.”*

*Upon hearing this, the health provider talked about how the individual drinking to excess was not concerned about his own excessive drinking, but rather, he was more concerned with other health conditions experienced by his partner, such as HIV and maintaining a low/undetectable viral load. The African-American MSM was believed to be adhering to his HIV medication regime.*

*However, when they brought up the subject of drinking, they mentioned that the African-American patient first discussed had previously disclosed to his health provider that he would drink up to a liter of malt liquor a day and smoke marijuana with his partner after work. The providers mentioned the African-American patient had expressed his excitement over an invitation to an upcoming celebration – a day after the celebration, he was admitted to the hospital with seizures.*

*During the afternoon meeting, his health provider shares that the African-American man disclosed a use of an illicit drug known as K2 and the health providers in the room wonder if fentanyl mixed with K2 might be the cause of his seizures. When they tested him for substances, one that came up in his system was fentanyl (Field note, March 01, 2016).*

This fieldnote illustrates the social networks existing between HIV+ individuals who engage in substance use, especially when participants are an intimate couple. The social obligation to attend a celebration, as in the above case, may further facilitate substance use, as an extension of moral economies and social lubrication which in turn, can affect risks for of acquiring HIV and HCV through needle sharing or via unprotected sex within a tight-knit social network intensified by social marginalization and stigma (Martin 2013).

## Known Syndemogenic Interactions and Substance Use

*Some days it's hard... to manage my HIV and HCV... and some days it is mellow. I used to try to keep my head calm – avoid [thinking about] drugs. Still, I get that stinking thinking, and when that stinking thinking start setting in... I go back down memory lane a lot when I am sitting in the house by myself about what I used to do when I Used [drugs]— “Sly” (Interview, October 21, 2016).*

HIV's syndemogenic nature is crucial for understanding the structures of risk that promote HIV acquisition within vulnerable populations (Singer 2009). To return to the pathways within which biological-behavioral-psychological interactions such as HCV or HIV interacting with MHC under conditions of substance use, mental health conditions and substance use each increase the risk of sexual transmission of HIV (Beadnell et al. 2000; Dolcini and Catania 2000; Ehrhardt and Exner 2000; Gonzalez-Guarda et al. 2011a; Hallfors et al. 2007; Johnson 2003; Martin-Subero and Diez-Quevedo 2016; Mustanski et al. 2007; Robinson et al. 2016; Singer 2009; Thanh et al. 2009), or of HCV (Terrault et al. 2013). In one syndemic pathway of interaction between structural risk environments and biological or disease factors, the pharmacological effect of excessive alcohol consumption can hinder the ability to negotiate condom use (Fritz et al. 2010; Leach-Lemens 2014; Padilla et al. 2012), increase the likelihood of sexual risk-taking, and affect medication adherence (Anema et al. 2015; Surratt et al. 2015).

The practice of substance use shapes risk environments that affect individuals differently. Substance use is a structural risk factor with unique syndemogenic qualities because it facilitates interactions between HIV and Hepatitis C, and between these and MHC. Substance use as a structural risk factor promotes more than one syndemic

pathway of interaction, in the context of alcohol consumption or drug use that produce syndemic clustering.

As a syndemogenic factor, substance use and its socially stigmatized “drug addict” label further exacerbate health outcomes by promoting interactions between biological, behavioral, and structural factors within the context of stigma and self-blame. Double-0-Seven’s story held echoes of self-blame: “*I knew had to stop, but I kept doing them [drugs]*” (Interview, September 22, 2016). Double-0-Seven, living with HIV and having lived with HCV, is also a breast cancer survivor, diagnosed with diabetes, and asthma. She underwent a Hepatitis C regimen of Ribavirin (RBV) and PEGylated interferon-alpha (Peg-INF-alpha) to treat her HCV. Her discussion of her illness experiences reflects recognition in the scholarly literature that addiction has adverse effects on both mental health and biological conditions, increasing a substance user’s susceptibility for acquiring HIV and HCV (Elliott et al. 2016; Martin-Subero and Diez-Quevedo 2016; Michel et al. 2016; Padgett et al. 2008).

Knowingly or not, in my interview with Double-0-Seven, she also spoke to women’s uniquely increased biological and structural risks for HIV/STI syndemics (Ostrach and Singer 2012a), through gender inequality and biopolitical vulnerability. Double-0-Seven describes situations where substance use put her in harm’s way, and negatively affected adherence to HIV and HCV medication treatments, resulting in her own and potentially others’ increased suffering and disease burden among the population.

## *Social Networks*

Risk-increasing social networks among people who use substances were cause for concern among health providers at the X Clinic. For instance, during one mid-day staff meeting, PCPs and mental health providers discussed a patient living with HIV whose substance use issues continuously hindered his ability to keep his appointments and get his HIV medication on time. Earlier that day the patient had told Ann, a mental health counselor, during their appointment: *“I don't know a single person who doesn't use [substances].”* His statement worried Ann, who sought advice during the group staff meeting. She explained, *“I am afraid he is circling the drain,”* (Field note, March 01, 2016).

### **Niecy's story**

*Without the knowledge of how to manage an HIV or HCV as a chronic condition, levels of mental health conditions (e.g., depression) are likely to increase... These adverse mood disorders and biosocial conditions are exacerbated if [someone is] also experiencing barriers to health care insurance... depression is associated with nonadherence to ART because it negatively affects motivation—* Excerpt from field note entry, “Managing HIV/HCV” (Field note, July 28, 2916).

Niecy, a soft-spoken 58-year-old African-American woman living with HIV, who in 2016 celebrated 11 years of sobriety, shared with me how her experiences with substance use, HIV stigma, and complicated/inadequate social support networks, compounded her risk for, acquisition of, and subsequent progression of, both HIV and HCV. When we met, Niecy described situations where substance use, as both a behavioral factor and disease (addiction), and a structural factor (substance use as a coping mechanism in stigmatized and impoverished communities) drove interactions



between HIV, Hepatitis C, social stigma, and depression. Her lived experiences are a significant demonstration of substance use syndemogenesis. She began:

*Sometimes I struggled.... with my addiction... Sometimes it comes to my head to get high, but I don't act on it. I've been trying to do many positive things to be a good role model for my niece and nephew when they grow up. Therefore, they don't have to go through the stuff that I went through or deal with stuff that I had to.... I got it [HIV] with a guy I had sex with, and he didn't tell me that he had it until afterward. I was mad and hurt, [but] then again; I can't be mad and upset... I can't hold him accountable because I played a part in it too. I didn't have to stay with him— “Niecey,” woman living with HIV and HCV, (Interview 13, October 21, 2016).*

At times throughout our interview, Niecey seemed to feel gratitude towards her family; at times, she described being mistreated by them for her struggles with addiction to freebasing cocaine and drinking alcohol, and her subsequent HIV diagnosis in 2006. “*I have two sisters who were struggling with their disease,*” she told me, “*and they were more out there, and they were the ones that got me started*” (Interview, October 21, 2016). However, just as her relationship with her family drove her to substance use, her family also became her tether to sobriety:

*I struggled with drugs and alcohol for a part of my life. A stage of my life, as I was growing up, I was getting in trouble all the time. Getting locked up. Fighting and stuff. And then, like, about 15 years ago, before I got my life together, I lost my mother to breast cancer. On her deathbed, she was trying to get me to get my life together, you know? But for some reason I couldn't back then (Interview, October 21, 2016).*

Niecey describes the structural connections between substance use, mental health conditions, social support networks, and risks for HIV and HCV:

*I have a niece that is struggling with the same disease that I am struggling with... And [her mother] wish[es] that she would get her life together... But every time [my niece] gets to a certain point, her mother intervenes, and I don't know what happens, but [my niece] goes back out and starts using again (Interview, October 21, 2016).*

Niecy implies that despite having a support network, within the context of substance use, the interactions become more complicated, and the risk of developing mental health conditions and acquiring HIV is exacerbated. Niecy tries to support her niece who faces similar issues by talking to her sister, her niece's mother. Niecy describes how the stigma associated with substance use, and HIV, affects family support networks:

*[My sister] had me sectioned [forcibly committed] to a program, and I used to call her. I used to call her and tell her that I need money and stuff, and she wouldn't – [my sister] wouldn't send me some money in the mail, or she would get one of my other sisters to bring it to me. She would not come be with me. And I told her that, "you couldn't do those things for me, when I needed you. And I know that I'm different from your daughter, but I am still your blood. Therefore, I feel you should give her the same benefit of the doubt that you gave me. And if you keep, every time your daughter goes in the program, and you find out, now you want to say you want to help her, but when she is out there using and with HIV, you didn't want anything to do with her, but now you do! And I think that is kind of backwards. I do... (Interview, October 21, 2016).*

Niecy related her substance use to her stigmatized HIV status, in the context of a complicated, often un-supportive family context. Even though Niecy is aware of the negative dynamic she has with her sister, she places familial bonds above all else, potentially internalizing HIV-related stigma. She may also be perpetuating the stigma that is part of difficult family dynamics that exacerbate syndemic interactions in her own HIV/substance use experience:

*When [my sister] wants to talk to her daughter [Niecy's niece], she calls me. Moreover, I tell my niece, I say, "I know that sometimes your mother makes you mad. Sometimes she says hurtful things she might not mean, but that is just her... but you must love her from a distance, you know? Try to work around because you only have one mother. When she is gone, you have nobody else"— "Niecy" (Interview, October 21, 2016).*

Niecy's experiences of being perceived as an "addict" by close family members on whom she relied, yet who stigmatized her behavior, reinforced her substance use, which in turn,

exacerbated her suffering and risk of disease acquisition. Substance use, and her family's stigmatization of it, increased Niecy's risks for acquiring HIV, within larger structures of risk.

As hinted at in her previous quote in this chapter, Double-0-Seven's experiences with substance use illustrate a long and hard-fought struggle with drugs and alcohol, which was a common risk factor for all individuals living with both HIV and Hepatitis C. In our interview, upon comparing her perceptions of needle sharing and substance use as risk factors, Double-0-Seven's narrative strongly coincides with that of her biomedical health providers at the X Clinic. During an interview with JayC, a mental health provider, he noted that although a person may be actively using, that does not mean they are neglecting HIV treatment adherence:

*The difference is that if they are actively... Using, it's like – you know, let's say they have Hepatitis C, HIV and they have substance abuse, so you have three diseases to take care of.*

*You have a discussion of whether – assess whether the substance abuse is going to get in the way of treating the other two. Now, you can have people who are actively... You know, using and abusing drugs and still be very adherent.*

*I've had people who are actively shooting up Heroin who never missed their dose of antiretroviral... You can't assume that a person that – that a person who is using is not going to take their antiretroviral. Therefore, you must make that assessment with the patient, to figure out whether they are going to take their medication or not. If you think that the substance abuse is going to get in the way, just concentrate on the substance abuse and try to... Try to get it to a sustainable recovery— “JayC” male health provider (Interview, August 02, 2016).*

Substance use, HCV, and HIV, function as three diseases or conditions for the provider to focus on if the patient is “actively using”/ “actively” engaging in the practice of substance abuse, since “substance use” is a known risk factor for both HIV and HCV.

Although substance use seemed to carry increased risks for acquiring both HIV and HCV for all substance users in my study, not all participants experienced HIV/HCV syndemics solely in the context of substance use. When I was with Ronnie helping him get food from the X Clinic food pantry after a meeting with his mental health counselor the day he explained that bringing food home helped to temporarily stabilize his tenuous housing situation, his tale made clear that while he might have acquired both HIV and HCV in the context of poverty and substance use, the greatest threat for disease acceleration, and his health now, is food insecurity, compounded by a mental health condition, and substance use stigma.

## **Conclusion**

Participants described substance use as a key structure of risk promoting syndemic interactions within all three syndemics (HIV/HCV, HIV/mental health conditions (MHC), and HCV/MHC – I have argued and demonstrated that substance use acts as a syndemogenic factor in HIV/HCV syndemics. It acts to drive the production of multi-syndemic clustering among people living with a combination of HIV and/or HCV, and many of them with MHC, in the Boston area.

## CHAPTER SIX: CONCLUSION

This ethnographic, prospective, mixed-methods research on the experiences of marginalized people living with HIV, HCV, or both in the Boston area yielded original and revealing data on multiple overlapping syndemics. I confirmed a known HIV/HCV syndemic, and illuminated the structures of risk that produced it, for my participants, six out of 35 participants living with both conditions promoted in conditions of food insecurity, housing instability and substance use. These conditions also emerged as structures of risk for syndemic clustering related to HIV and mental health conditions, HCV and mental health conditions, or the confluence of all of these. These structural risk factors, as described by my participants, demonstrated what drove multiple syndemics in this population. Substance use emerged as a key syndemogenic factor.

Participants perceived their risk environments for HIV and HCV interactions within the context of substance use, and compounded this by their experiences with lack of access to resources (in particular, food, housing, and healthcare). Substance use created situations that increased their likelihood of excessive drinking, sharing needles and having unprotected sex with people who, unbeknownst to them, were living with HIV. Participants also talked about how they experience poor living conditions because of unemployment or limited income generating opportunities. Participants with a history of substance use talked about their struggles to afford food and housing. They relied on food pantry services at the X Clinic, federal financial assistance programs (e.g., HDAP and food stamps), and their social networks, for access to food, housing, medical services

and substances. Under these conditions, they relied on their social networks for temporary housing conditions, or were forced to live in the streets due to an inability to afford food and housing. Shaped by structural violence, these structures of risk increased their risks for syndemic interactions between HIV and HCV. Therefore, participants' lived experiences under these structures of risks highlighted their vulnerability for HIV/HCV syndemics.

Participants described experiences with inadequate social networks and stigma that further reduced their ability to access and navigate resources. Moreover, mental health conditions (MHC) affect how participants perceive and manage their diseases. Participants also noted the risks for HIV/MHC and HCV/MHC interactions stem from their history of substance use and stigma. Individual experiences and perceptions of interactions between these factors illuminated and contextualized multiple syndemics affecting participants living with HIV, HCV, or both. Similar to participants who faced HIV/HCV syndemics, while suffering from the adverse health effects of drinking and using drugs, and conditions characterized by food insecurity and unstable housing, many participants with HIV and/or HCV, also suffered from MHC such as depression and anxiety. It is for this reason that I use the term “syndemic clustering” to argue that structures of risk produced the syndemics I here identify (e.g., HIV/MHC and HCV/MHC syndemics) in addition to the known HIV/HCV syndemic. This expands on existing syndemic literature on the intersecting social and biological dimensions in which substance use and other structures of risks such as mental health conditions, food insecurity, and unstable housing, drive various syndemic pathways of interactions.

Analyzing my participants' experiences of what it is like to live with additive risks, I also confirmed substance use as a particular structure of risk with syndemogenic properties for HIV/HCV syndemics, as well as other syndemics, in this marginalized population in the greater Boston area. I knew that there was a known HIV/HCV syndemic, and I identified the risk factors that produced the syndemic among people living with HIV, HCV, or both in the greater Boston area. I illustrate how substance use facilitates syndemic interactions in each of the three identified syndemics affecting this population. Consequently, substance use, as a structure of risk, shaped by structures of inequality (e.g., poverty) and as a syndemogenic factor, produced experiences of syndemic clustering among my participants.

### **Limitations**

Given my participants' socially and economically vulnerable status, the process of gaining access to the research site, building rapport with people living with HIV, HCV, or both, and the providers that treat them, was lengthy and complicated; time constraints resulted in eight months of field work but only a short period of IRB-approved formal recruitment and data collection. While ethnographically rich as a mixed-method study, and an important contribution to syndemics research, the quantitative analysis is not statistically significant. Syndemic analysis of syndemic interactions may be critiqued by epidemiologists, but is recognized as a strength within critical medical anthropology, and more broadly. Qualitative and ethnographic data analysis draws attention to perceptions of risk, and the structural factors hindering access to health care services and social services, thereby increasing the suffering among a vulnerable population.

## **Contributions**

Rooted within Critical Medical Anthropology (CMA) (Baer et al. 2013; Ostrach and AbiSamra 2017; Ostrach and Cheyney 2014; Ostrach and Singer 2012a; b; Singer 1986; 1995; 2004a; b; Singer et al. 2013; Singer and Clair 2003), syndemics theory (Singer 2009, Singer et al. 2017) examines the power dynamics involving social, structural, economic and political conditions that contribute to disease interactions and an exacerbated disease burden within vulnerable populations. My goal was to increase social science, medical anthropology, ethnographic, and syndemic understandings of the structural factors and lived experiences that shape disease interactions and risks for HIV and HCV syndemics, among marginalized individuals in the Boston area. I contributed to the body of existing research on HIV/HCV syndemics, illuminated understandings of the structural risk factors that cause these syndemics for different populations, and identified a new set of syndemics clusters demonstrating additional syndemic risks resulting from the same environments of risk and factors. It is also likely that my participants experience supersyndemics, but more research would be needed to fully articulate this argument.

## **Recommendations**

I recommend further research be conducted to identify the various structures of risks for HIV/HCV and mental health supersyndemics for diverse populations. Importantly, more ethnographic accounts are needed to further illustrate daily situations endured by individuals and communities, to identify the pathways of interactions conceptualized within HIV/HCV, HIV/MHC and HCV/MHC syndemics (Bulled and Singer 2011; Grund et al. 1996; 2009; 2010). Specially for vulnerable groups (e.g., the



impoverished, targets of systemic oppression, those who engage in the practice of risky behaviors due to lack of resources or other options, people living with HIV, HCV or suffering from MHC) often face health inequities, such as limited access to social and health resources, which promote worsened social and health outcomes (Aidala et al. 2016; Bichell 2016; Bourgois and Schonberg 2009).

Ultimately, this thesis explored syndemic clustering to argue the same structural risk factors produce a known HIV/HCV syndemic in addition to HIV/MHC syndemics and HCV/MHC syndemics. I focused on the structural risk factors (e.g., food insecurity, unstable housing, stigma, lack of social networks) and how they shape interaction between overlapping syndemics. To do so, I analyzed the lived experiences of people affected by HIV, HCV and MHC interactions produced and intensified in structurally unequal environments – conditions of syndemic risk. The presence of HIV/HCV, HIV/MHC and HCV/MHC syndemic interactions suggest how macro-level social structures (i.e., structural risk factors) and environments of risk produced by and caused by experiences of structural violence and social suffering perpetuate additional syndemic interactions within this population in the greater Boston area.

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**CURRICULUM VITAE**

